INTERNATIONAL BRAIN TUMOUR ALLIANCE

Report of the

5th Biennial World Summit of Brain Tumour Patient Advocates

Bridging our communities across the globe... building progress... building hope



25th - 28th June 2023

THE INTERCONTINENTAL WIEN HOTEL, VIENNA, AUSTRIA

Report written by Jacqueline Partarrieu

Acknowledgements and sponsors

The International Brain Tumour Alliance (IBTA) is grateful to the following companies/organisations for their support of the Fifth World Summit of Brain Tumour Patient Advocates.

In addition…

We are very appreciative of the wise advice, help and support provided by the IBTA's Senior Advisors on this project: Jean Arzbaecher, Jenny Baker, Rosemary Cashman, Maureen Daniels, Stuart Farrimond, Anita Granero, Carol Kruchko, Sharon Lamb, Mary Lovely, Mary Ellen Maher, Christine Mungoshi, Sally Payne and Chris Tse.

We were delighted to welcome to the 2023 World Summit of Brain Tumour Patient Advocates in Vienna representatives of leading patient advocacy, support and information from around the world. Thank you all so much for your presence at this Summit.

A big thank-you to the oncology professionals, research specialists and medical society representatives who made time in their hectic work schedules to join us in Vienna as plenary speakers, workshop leaders and panel participants.

Thanks and appreciation go to Ms Christine Quah, Manager, Global Accounts, HelmsBriscoe for her invaluable help in finding and securing our Summit venue at the InterContinental Wien Hotel.

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Special thanks to our report writer, Jackie Partarrieu. We were delighted she can join us in Vienna to take detailed notes and then produce the text for this report.

We are very grateful for the talents of our photographer, Martin Hormandinger (www.mh-photography.at), whose wonderful pictures appear in this Summit report.

Last but by no means least, heartfelt thanks for IBTA Co-Director Gordon Oliver's unfailing support and patience over the months of planning that have gone into this year's Summit, starting back in the depths of the pandemic in 2020/2021.

The IBTA World Summit of Brain Tumour Patient Advocates is a project of the International Brain Tumour Alliance (IBTA) and is a wholly independent activity conceived, planned and carried out by the IBTA. For details of the IBTA's sponsorship and transparency policies, please see www.theibta.org.

5th Biennial World Summit of Brain Tumour Patient Advocates

25th - 28 June 2023, in Vienna, Austria - The InterContinental Wien Hotel

Bridging our communities across the globe, building progress, building hope.

The Programme

DAY 1 - SUNDAY 25TH JUNE 2023

Throughout the day	**REGISTRATION** ARRIVALS at the Intercontinental Hotel, Johannesgasse 28, 1030 Vienna, Austria. Check in.	**All Summit participants**	The InterContinental Hotel, ground floor hotel reception desk
2:00pm to 7:00pm (5 hrs)	**REGISTRATION FOR PARTICIPANTS** attending the Fifth Biennial World Summit of Brain Tumour Patient Advocates.	**All Summit participants** Jean Arzbaecher (USA) and Mary Ellen Maher (USA) in charge of registration	The IBTA Hospitality Desk on the ground floor, lobby area of the InterContinental Hotel
Evening	EVENING AT LEISURE IN VIENNA	**All Summit Participants**	

DAY 2 - MONDAY 26TH JUNE 2023

	SESSION 1 - PLENARY		**LOCATION**
		Chair: **Kathy Oliver** (UK)	Ballroom (Ballsaal), InterContinental Hotel
9:00am to 10:00am (60 mins)	**WORLD SUMMIT OF BRAIN TUMOUR PATIENT ADVOCATES OPENING SESSION -** welcome and introductions of participants	Speaker: **Kathy Oliver** (UK), All Summit participants	Ballroom (Ballsaal), InterContinental Hotel
10:00am to 10.15am (15 mins)	**INNOVATIVE SURGICAL APPROACHES TO BRAIN AND CNS TUMOURS**	Speaker: **Friedrich Erhart** (Austria)	Ballroom (Ballsaal), InterContinental Hotel
10:15am to 10:30am (15 mins)	**UPDATE ON RADIOTHERAPY FOR BRAIN AND CNS TUMOURS (INCLUDING STEREOTACTIC RADIOSURGERY, PROTON BEAM, ULTRA-HIGH DOSE RATE (FLASH) RADIOTHERAPY, ETC)**	Speaker: **Carola Lutgendorf- Caucig** (Austria)	Ballroom (Ballsaal), InterContinental Hotel
10:30am to 11:00am (30 mins)	**COFFEE/TEA BREAK AND NETWORKING**	**All Summit Participants**	Ballroom (Ballsaal) Foyer
	PLENARY SESSION 2		**LOCATION**
		Chair: **Kathy Oliver** (UK), Chair and Founding Co-Director,	Ballroom (Ballsaal), InterContinental Hotel
11:00am to 11:15am 15 mins	**THE MOLECULAR ERA - UPDATE ON THE WHO 2021 CLASSIFICATION OF BRAIN AND CNS TUMOURS**	Speaker: **Susan Chang** (US)	Ballroom (Ballsaal), InterContinental Hotel

11:15am to 11:30am (15 mins)	**UPDATE ON CURRENTLY AVAILABLE SYSTEMIC TREATMENT APPROACHES FOR LOW GRADE HIGH-GRADE BRAIN TUMOURS**	Speaker: **Matthias Preusser** (Austria)	Ballroom (Ballsaal), InterContinental Hotel
11:30am to 11:45am (15 mins)	**NOVEL THERAPEUTICS FOR PRIMARY MALIGNANT BRAIN TUMOURS (INCLUDING IMMUNOTHERAPY AND TARGETED THERAPEUTICS IN MOLECULARLY DEFINED SUBSETS OF GLIOBLASTOMA)**	Speaker: **Tracy Batchelor** (US)	Ballroom (Ballsaal), InterContinental Hotel
11:45am to 12:00 noon (15 mins)	**THE WORLD OF PATHOLOGY FOR BRAIN AND CNS TUMOURS: A NEURO-PATHOLOGIST'S PERSPECTIVE**	Speaker: **Adelheid Woehrer** (Austria)	Ballroom (Ballsaal), InterContinental Hotel
12:00 noon to 12:15pm (15 mins)	**METASTATIC BRAIN TUMOURS (CLINICAL PERSPECTIVE – FEEDBACK FROM THE INTERNATIONAL PATIENT ADVOCACY SYMPOSIUM ON BRAIN METASTASES HELD ON SUNDAY, 25 JUNE)**	Speaker: **Manmeet Ahluwalia**	Ballroom (Ballsaal), InterContinental Hotel
12:15pm to 12:30pm (15 mins)	**METASTATIC BRAIN TUMOURS (PATIENT ADVOCACY PERSPECTIVE – FEEDBACK FROM THE INTERNATIONAL PATIENT ADVOCACY SYMPOSIUM ON BRAIN METASTASES HELD ON SUNDAY, 25 JUNE)**	Speakers: **Nicole Wilmarth** (US) and **Ralph DeVitto** (US)	Ballroom (Ballsaal), InterContinental Hotel
12:30pm to 1:00pm (30 mins)	**ASK THE EXPERT PANEL SESSION**	**PANEL MEMBERS:** **Georg Widhalm** (Austria) **Carola Lutgendorf-Caucig** (Austria) **Susan Chang** (US) **Matthias Preusser** (Austria) **Tracy Batchelor** (US) **Adelheid Woehrer (Austria)** **Manmeet Ahluwalia** (US) **Nicole Willmarth** (US) **Ralph DeVitto** (US)	Ballroom (Ballsaal), InterContinental Hotel
1:00pm to 2:30pm (90 mins)	**LUNCH BREAK AND NETWORKING**	**All Summit participants**	The Parlor Restaurant InterContinental Hotel
	SESSION 3 – MASTERCLASSES (Concurrent)		**LOCATION**
2:30pm to 4:00pm (90 mins)	**THE ESSENTIALS OF CREATING A SUPPORT GROUP FOR BRAIN TUMOUR PATIENTS**	Facilitators: **Maureen Daniels** (Canada) Interactive learning session	Breakout Room: Main Ballroom Ballsaal, Section 1, InterContinental Hotel
2:30pm to 4:00pm Masterclass 2 (90 mins)	**POLICY RECOMMENDATIONS FOR CANCER CARE BASED ON MULTI-DISCIPLINARITY**	Facilitators: **Eskil Degsell** (Sweden) Speaker: **Richard Price** (Belgium) Interactive learning session	Breakout Room: Ballroom Ballsaal Johann Strauss Section 5, InterContinental Hotel
2:30pm to 4:00pm Masterclass 3 (90 mins)	**BRAIN TUMOUR CLINICAL TRIALS - ARE WE DOING IT RIGHT?**	Facilitators: **Chris Tse** (New Zealand) Speaker: **Manmeet Ahluwalia** (US) Interactive learning session	Breakout Room: Ballroom Ballsaal Johann Strauss Section 6, InterContinental Hotel

2:30pm to 4:00pm Masterclass 4 (90 mins)	**HOW TO REACH UNDERSERVED/DISADVANTAGED POPULATIONS IN THE BRAIN TUMOUR COMMUNITY: IMPROVING HEALTH LITERACY AND INEQUALITIES IN CARE**	Facilitator: **Komal Syed** (Pakistan) Speakers: **Brijesh Deshpande** (India) **Irene Ngong** (Cameroon), **Christine Mungoshi** (Zimbabwe) **and Alexandra Diaz Alba** (Mexico) Interactive learning session	Breakout Room: Main Ballroom (Ballsaal), Section 3 InterContinental Hotel
2:30pm to 4:00pm Masterclass 5 (90 mins)	**A DEEPER DIVE INTO MOLECULAR PROFILING OF BRAIN TUMOURS**	Facilitators: **Carol Kruchko** (US) Speaker: **Tracy Batchelor** (US) Interactive learning session	Breakout Room: Main Ballroom (Ballsaal) InterContinental Hotel
4:00pm to 4:30pm	**COFFEE/TEA BREAK AND NETWORKING**	**All Summit Participants**	Ballroom (Ballsaal) Foyer, InterContinental Hotel
	SESSION 4 - PLENARY		**LOCATION**
		Chair: **Mary Ellen Maher** (US)	Ballroom (Ballsaal), InterContinental Hotel
4:30pm to 4:50pm (20 mins inc 5 mins Q&A)	**BRAIN TUMOUR-RELATED EPILEPSY: CHALLENGES AND SOLUTIONS**	Speaker: **Martin Glas** (Germany)	Ballroom (Ballsaal), InterContinental Hotel
4:50pm to 5:10pm (20 mins inc 5 mins Q&A)	**CLASSIFYING BRAIN TUMOURS: A SOCIAL SCIENCE PERSPECTIVE**	Speaker: **Henry Llewellyn** (UK)	Ballroom (Ballsaal), InterContinental Hotel
5:10pm to 5:30pm (20 mins inc 5 mins Q&A)	**BACK TO SCHOOL WITH A BRAIN TUMOUR - AN INTRODUCTION TO BRAIN TUMOUR SUPPORT NEW ZEALAND'S EDUCATION GUIDE**	Speaker: **Chris Tse** (New Zealand)	Ballroom (Ballsaal), InterContinental Hotel
5:30pm to 5:50pm (20 mins inc 5 mins Q&A)	**MEDICAL EXPERTS AND PATIENT ADVOCATES COMING TOGETHER WITH ONE MISSION -** the Pakistan Society of Neuro-Oncology and the Brain Tumour Foundation of Pakistan	Speakers: **Komal Syed** (Pakistan) and **Ather Enam** (Pakistan)	Ballroom (Ballsaal), InterContinental Hotel
5:55pm to 6:15pm (20 mins inc 5 mins Q&A)	**CHALLENGES OF A BRAIN TUMOUR DIAGNOSIS IN MONGOLIA**	Speaker: **Batchimeg Batchuluun** (Mongolia)	Ballroom (Ballsaal), InterContinental Hotel
	EVENING AT LEISURE		

DAY 3 - TUESDAY, 27TH JUNE 2023

	SESSION 5 - PLENARY		**LOCATION**
		Chair: **Rosemary Cashman** (Canada)	Ballroom (Ballsaal), InterContinental Hotel
9:00am to 9:20am (20 mins inc 5 mins Q&A)	**REDUCING STRESS IN BRAIN TUMOUR PATIENTS**	Speaker: **Noa Faaij** (The Netherlands)	Ballroom (Ballsaal), InterContinental Hotel

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9:20am to 9:40am (20 mins inc 5 mins Q&A)	**THE UKRAINE CRISIS AND BRAIN TUMOUR PATIENTS**	Speaker: **Anna Uzlova** (Ukraine)	Ballroom (Ballsaal), InterContinental Hotel
9:40am to 10:00am (20 mins inc 5 mins Q&A)	**RAISING AWARENESS OF THE CHALLENGES OF BRAIN TUMOURS THROUGH COMMUNITY ENGAGEMENT**	Speaker: **Hugh Adams** (UK)	Ballroom (Ballsaal), InterContinental Hotel
10:00am to 10:20am (20 mins inc 5 mins Q&A)	**CREATING A WEEKEND RETREAT FOR BRAIN TUMOUR PATIENTS AND THEIR FAMILIES**	Speaker: **Bec Mallett** (Australia)	Ballroom (Ballsaal), InterContinental Hotel
10:20am to 10:40am (20 mins inc 5 mins Q&A)	**WHAT CAN YOU DO FOR NEURO-ONCOLOGY MEDICAL SOCIETIES AND WHAT CAN THEY DO FOR YOU?**	Speaker: **Chas Haynes** (US)	Ballroom (Ballsaal), InterContinental Hotel
10:40am to 11:00am (20 mins inc 5 mins Q&A)	**BRAIN TUMOUR PATIENT SUPPORT IN CHINA**	Speaker: **Chengcheng Guo** (China - pre-recorded)	Ballroom (Ballsaal), InterContinental Hotel
11:00am to 11:30am (30 mins)	**COFFEE/TEA AND NETWORKING**	**All Summit participants**	Ballroom (Ballsaal), Foyer, InterContinental Hotel
	SESSION 6 - WORKSHOPS (CONCURRENT)		**LOCATION**
11:30am to 1:00pm Workshop 1 (90 mins)	**BUILDING SURVIVORSHIP PLANS FOR BRAIN TUMOUR PATIENTS AND FAMILIES**	Facilitator: **Jean Arzbaecher** (US), Speakers: **Susan Chang** (US), and **Jack Latteur** (Belgium)	Breakout Room: Ballroom Ballsaal Johann Strauss Section 4, InterContinental Hotel
11:30am to 1:00pm Workshop 2 (90 mins)	**NEURO-REHABILITATION FOR BRAIN TUMOUR PATIENTS**	Facilitator: **Tina Mitchell Skinner** (UK), Speaker: **Andreia Capela Marques** (Portugal),	Breakout Room: Ballroom Ballsaal Johann Strauss Section 5, InterContinental Hotel
11:30am to 1:00pm Workshop 3 (90 mins)	**PALLIATIVE AND END-OF-LIFE CARE FOR ADULT AND PEDIATRIC BRAIN TUMOUR PATIENTS**	Facilitators: **Mary Lovely** (US) and and **Anita Granero** (Italy/France) Speakers: **Christine Marosi** (Austria) and **Ulrike Leiss** (Austria)	Breakout Room: Ballroom Ballsaal Johann Strauss Section 6, InterContinental Hotel
11:30am to 1:00pm Workshop 4 (60 mins)	**DOCTOR/PATIENT COMMUNICATION INCLUDING MASTERING THE ART OF SHARED DECISION-MAKING AND SEEKING A SECOND OPINION**	Facilitator: **Fiona Keegan** (Ireland) Speakers: **Guy Buyens** (Belgium) and **Ana Arnaut** (Croatia)	Breakout Room: Main Ballroom (Ballsaal) InterContinental Hotel
1:00pm to 2:10pm (70 mins)	**LUNCH BREAK AND NETWORKING**	**All Summit Participants**	The Parlor Restaurant InterContinental Hotel

	SESSION 7 - PLENARY		LOCATION
		Co-Chair: **Anita Granero** (Italy/France)	Ballroom (Ballsaal), InterContinental Hotel
2:10pm to 2:30pm (20 mins inc Q&A)	**GETTING BACK TO WORK WITH A BRAIN TUMOUR**	Speaker: **Veronica Foote** (UK),	Ballroom (Ballsaal), InterContinental Hotel
2:30pm to 2:50pm (20 mins inc Q&A)	**THE RAYMOND A WOOD FOUNDATION: A NOVEL APPROACH TO SUPPORTING YOUNG PATIENTS WITH HYPOTHALAMIC PITUITARY BRAIN TUMOURS**	Speaker: **Amy Wood** (USA)	Ballroom (Ballsaal), InterContinental Hotel
2:50pm to 3:10pm (20 mins inc Q&A)	**PEDIATRIC BRAIN TUMOURS AND THE WORK OF CHILDHOOD CANCER INTERNATIONAL**	Speaker: **Anita Kienesberger** (Austria)	Ballroom (Ballsaal), InterContinental Hotel
3:10pm to 3:30pm (20 mins inc Q&A)	**GEMEINSAM GEGEN GLIOBLASTOM (TOGETHER AGAINST GLIOBLASTOMA)**	Speaker: **Martin Glas** (Germany)	Ballroom (Ballsaal), InterContinental Hotel
3:30pm to 3:50pm (20 mins inc Q&A)	**THE WORK OF THE BRAIN TUMOUR ASSOCIATION OF KENYA**	Speaker: **Dr Minda Okemwa** (Kenya)	Ballroom (Ballsaal), InterContinental Hotel
4:00pm to 4:30pm (30 mins)	**COFFEE/TEA BREAK AND NETWORKING**	**All Summit Participants**	Ballroom (Balsaal) Foyer InterContinental Hotel
	SESSION 8 - PLENARY		**LOCATION**
		Chairs: **Kathy Oliver** (UK)	Ballroom (Balsaal) InterContinental Hotel
4:30pm to 4:50pm (20 mins inc Q&A)	**AN INTRODUCTION TO THE WORK OF THE EUROPEAN REFERENCE NETWORK (ERN EURACAN)** for brain tumours and how cross-border collaboration is reshaping neuro-oncology care in Europe	Speaker: **Ahmed Idbaih** (France)	Ballroom (Balsaal) InterContinental Hotel
4:50pm to 5:10pm (20 mins inc Q&A)	**A BIRD'S EYE VIEW OF THE INTERNATIONAL BRAIN TUMOUR PATIENT ADVOCACY COMMUNITY** and building pragmatic, impactful international collaboration between brain tumour patient organisations and others	Speaker: **Kathy Oliver** (UK)	Ballroom (Balsaal) InterContinental Hotel
7:30pm to 10:00pm	**OFFICIAL IBTA WORLD SUMMIT PHOTOGRAPH** (meet in hotel lobby at 7:30 pm) **AND SUMMIT DINNER** (starting at 8:00 pm)	**All Summit Participants**	Salons Vier, Jahreszeiten and Kaunitz, InterContinental Hotel

DAY 4 - WEDNESDAY, 28TH JUNE 2023

	SESSION 9 - PLENARY		LOCATION
		Chairs: **Melissa Lim** (Singapore)	Ballroom (Balsaal) InterContinental Hotel

9:00am to 9:20am (20 mins inc 5 min Q&A)	**THE OCEAN AND SKY CHILDREN'S HOSPICE IN YOKOHAMA, JAPAN**	Speaker: **Hisato Tagawa** (Japan – pre-recorded)	Ballroom (Balsaal) InterContinental Hotel
9:20am to 9:40am (20 mins inc 5 min Q&A)	**TOP TIPS ON STARTING A BRAIN TUMOUR PATIENT REGISTRY IN YOUR COUNTRY - LEARNINGS FROM THE CENTRAL BRAIN TUMOR REGISTRY OF THE UNITED STATES (CBTRUS)**	Speaker: **Carol Kruchko** (US)	Ballroom (Balsaal) InterContinental Hotel
	SESSION 10 - PLENARY		**LOCATION**
		Moderator: **Maureen Daniels** (Canada)	Ballroom (Balsaal) InterContinental Hotel
9:50am to 10:10am (20 mins inc 5 min Q&A)	**ETHICAL CHALLENGES IN TREATING BRAIN TUMOUR PATIENTS**	Speaker: **Christine Marosi** (Austria)	Ballroom (Balsaal) InterContinental Hotel
10:15am to 10:35am (20 mins inc 5 min Q&A)	**IMPROVING CARE AND OUTCOMES FOR PEOPLE WITH EPENDYMOMA: A CASE STUDY ABOUT THE IMPORTANCE OF LEVERAGE IN NONPROFIT STRATEGY**	Speaker: **Kimberly Wallgren** (US)	Ballroom (Balsaal) InterContinental Hotel
10:40am to 11:10am (30 mins)	**COFFEE/TEA BREAK AND NETWORKING**	**All Summit participants**	Ballroom (Ballsaal) Foyer, InterContinental Hotel
	SESSION 11 - PANEL/AUDIENCE DISCUSSION:		**LOCATION**
		Moderator: **Helen Bulbeck** (UK)	Ballroom (Balsaal) InterContinental Hotel
11:15am to 12:15pm (60 mins)	**BRAIN TUMOUR RESEARCH: BARRIERS AND SOLUTIONS**	**PANELLISTS:** **Matthias Preusser** (Austria) **Gaetano Finocchiaro** (Italy) **David Jenkinson** (United Kingdom) **Eskil Degsell** (Sweden)	Ballroom (Ballsaal) InterContinental Hotel
12:15pm to 12:30pm (15 mins)	**CLOSING REMARKS**	**Kathy Oliver** (UK)	Ballroom (Ballsaal) InterContinental Hotel
12:30pm to 1:30pm (60 mins)	**LUNCH PROVIDED AT THE INTERCONTINENTAL HOTEL FOR ALL SUMMIT PARTICIPANTS**	**All Summit participants**	The Parlor Restaurant, InterContinental Hotel
2:00pm	**END OF IBTA SUMMIT AND DEPARTURES**		
	SIDE MEETING (for IBTA Advisors only)		**LOCATION**
			IBTA Summit Office, InterContinental Hotel
12:30pm to 1:30pm (60 mins)	IBTA Advisors Meeting (working lunch)	**All IBTA Advisors**	



Members of the IBTA's senior advisory board were present at the World Summit of Brain Tumour Patient Advocates in Vienna in June 2023.

Executive Summary

The fifth biennial World Summit of Brain Tumour Patient Advocates, organised by the International Brain Tumour Alliance (IBTA) convened in June 2023 in Vienna, Austria to address the critical and unmet needs of brain tumour patients and their families. Brain tumours are a subset of rare cancers that face significant research and development challenges due to a range of scientific and commercial reasons. The Summit served as a platform where brain tumour patient advocates, healthcare professionals, patients, caregivers, industry representatives, medical societies and others came together to seek solutions and foster advancements in the field.

The overarching message conveyed was that each brain tumour diagnosis encompasses not only a medical battle but also a deeply personal narrative. Families and patients faced with a life-changing diagnosis and the realisation that there are not enough resources dedicated to brain tumours, are driven to become advocates for research, treatment, and support, despite the multifaceted impact of the disease on their lives.

The Summit's focus areas included the urgent quest for improved screening, diagnosis techniques, expanded treatment options, more effective and less toxic therapies, and enhanced psychosocial support.

These areas of unmet need span across disciplines such as epidemiology, pathology, diagnostics, treatments and pharmaceutical innovations. However, notable strides in medical science were also highlighted during the discussions, including advances in neurosurgery, radiotherapy, devices, and systemic therapies. Surgical techniques showcased breakthroughs in precision and minimally invasive procedures, while radiotherapy innovations promised targeted treatment with reduced side effects. The encouraging developments in systemic therapies, particularly the advent of targeted therapies, were underscored with specific examples. Molecular classification techniques were showcased as pivotal in tailoring treatments to individual patients, resulting in higher treatment efficacy and fewer adverse effects.



Personal stories shared during the Summit provided poignant insights into the challenges faced by brain tumour patients and their families. Amid the isolation and emotional upheaval, these stories served as inspirations of resilience, prompting many to transform their struggles into initiatives that empower fellow patients and caregivers. The determination and dedication of healthcare professionals to advance research and foster collaboration were evident throughout the Summit, emphasising the critical role of a comprehensive, multidisciplinary support system for those affected by brain tumours.

A central theme at the Summit was the influential role of patient advocates, transcending age barriers. Patient experts and advocates, including children, emerged as pivotal drivers of change. Their voices not only influence research priorities but also infuse a sense of hope into the community. The Summit's discussions laid a robust groundwork for future collaborative endeavours, underscoring the significance of international cooperation in advancing research, prioritising patient-centred studies, and expanding global support networks.



Melissa Lim (left) from Brain Tumour Society (Singapore) and Anita Granero (right) from Oscar's Angels which is based in France and Italy attended the IBTA Summit.



Participants at the IBTA's fifth Biennial World Summit of Brain Tumour Patient Advocates, Vienna, 2023, came from 33 countries.

DAY ONE

Monday 26 June 2023

PLENARY SESSION 1

Chair: Kathy Oliver, International Brain Tumour Alliance (IBTA), United Kingdom

Welcome Address

Speaker: Kathy Oliver - International Brain Tumour Alliance (IBTA), United Kingdom



Kathy Oliver, Chair and Co-Director of the International Brain Tumour Alliance (IBTA) welcomes everyone to the Summit on Day One.



Simone Silenzi from Gruppo Italia Glioblastoma Multiforme cancro al cervello in Italy capturing a moment in the Summit for posterity.

Introduction

The 5th Biennial World Summit of Brain Tumour Patient Advocates commenced with a warm welcome from Kathy Oliver, Chair of the International Brain Tumour Alliance. The Summit, held in the beautiful city of Vienna, Austria, aimed to bring together individuals from various countries and backgrounds to collaborate, share knowledge, and work towards significantly improving outcomes for brain tumour patients. Kathy Oliver's opening address emphasised the importance of collaboration, inclusivity, and fostering a spirit of hope in the field of brain tumour research and patient advocacy.

Attendees and diversity

Kathy Oliver acknowledged the over 100 attendees representing 33 countries and five continents, consisting of a diverse group of professionals and patient advocates dedicated to the cause. She stressed the significance of in-person introductions in Vienna: putting faces to names would help foster a deeper understanding and better collaboration among the participants. The Summit showcased an exceptional global representation, with a delegate from Mongolia participating for the first time and others from Ukraine attending, who had overcome challenging journeys from their home country to attend.

Collaboration and hope

The IBTA Chair expressed her optimism about the current state of brain tumour research and neuro-oncology, citing that there is more hope than ever before, due to the recent advancements in treatments and surgical approaches. She highlighted the collective dream shared by all attendees - to enhance the lives of brain tumour patients through collaboration, knowledge sharing, and maintaining a sense of hope. By cultivating unity and encouraging joint efforts, attendees aim to improve the lives of those affected by brain tumours and their caregivers.

Networking and professional engagement

Kathy Oliver encouraged all attendees to take full advantage of the networking opportunities offered during the Summit. She emphasised the diverse array of professionals present, including neurosurgeons, pathologists, radiation oncologists, neuro-oncologists, and nurses, among others. Attendees were encouraged to exchange contact information and materials, fostering new connections that would prove beneficial in their respective fields and patient advocacy efforts.





IBTA Chair Kathy Oliver encouraged all Summit participants to interact with speakers by asking questions, networking and exchanging information.

Inclusivity and language

She reassured non-English speakers that language barriers should not hinder active participation in the Summit. She highlighted the understanding and acceptance among participants, emphasising that there were no "stupid questions." Attendees were encouraged to ask for clarifications and engage actively in discussions, regardless of language proficiency.

Empowerment of advocates

The Chair acknowledged the presence of fantastic advocates who had already made significant contributions in the field of brain tumour patient advocacy. She urged these experienced advocates to share their insights with those who were just beginning their journey in advocacy. Attendees were encouraged to seek out countries where patients faced significant difficulties in diagnosis and treatment, offering support and materials to improve these challenging situations.

Conclusion

Kathy Oliver's welcome address set the tone for the 5th Biennial World Summit of Brain Tumour Patient Advocates, emphasising the importance of collaboration, inclusivity, and hope in achieving positive outcomes for brain tumour patients worldwide. The Summit provided a unique platform for diverse professionals and advocates to exchange knowledge, ideas, and experiences, ultimately working together towards a better future for those affected by brain tumours. The commitment and passion displayed by all attendees were a testament to the dedication of the brain tumour community in making a difference in the lives of patients, their families, and caregivers.

Innovative surgical approaches to brain and CNS tumours

Speaker: Mag. Dr Friedrich Erhart,
Department of Neurosurgery,
Medical University of Vienna, Austria



Mag Dr Friedrich Erhart is a neurosurgeon from the Medical University of Vienna.

Key points

- The presentation emphasised advancements in tumour visualisation, resection margin optimisation, and surgical precision for improved results.
- Diverse brain tumour entities were discussed, with histological research playing a crucial role in determining appropriate treatment strategies.
- Fluorescence-guided surgery (FGS) using 5-ALA (5-aminolevulinic acid) was introduced. This fluorescent dye enhances tumour tissue visibility during brain surgery, aiding neurosurgeons in more precise resection while preserving brain function.
- 5-ALA technology correlates with tumour density, vessel density, and histological characteristics, providing insights into tumour biology and improving patient survival.
- Intraoperative MRI was discussed as a tool for real-time evaluation and optimisation of resection margins, leading to improved patient survival outcomes compared to conventional surgery.
- A case study exemplified the application of various imaging technologies, including functional MRI, DTI imaging, and 3D model MRI, for precise localisation of brain functions before surgery.
- Raman histology provides real-time tissue analysis during surgery, aiding in distinguishing tumour tissue from healthy brain tissue.
- The potential of artificial intelligence (AI) in surgical decision-making was highlighted, as AI algorithms can differentiate between tumour and healthy tissue, enhancing surgical precision.

Friedrich Erhart, from the Medical University of Vienna, delivered a comprehensive presentation on the latest innovative surgical approaches for brain tumour operations. The presentation highlighted cutting-edge technologies that improve patient outcomes through enhanced tumour visualisation, optimised resection margins, and increased precision during surgery. He emphasised the importance of combining advanced surgical techniques with other diagnostic tools, and multidisciplinary collaboration to achieve successful outcomes for brain tumour patients.

Friedrich Erhart began by discussing the diversity of brain tumour entities, with the majority being non-malignant, and approximately 25% to 33% being malignant. Histological research plays a crucial role in confirming the nature of brain tumours, making it essential in determining the appropriate course of action for each patient.
The presenter introduced the audience to fluorescence-guided surgery (FGS) using 5-ALA (5-aminolevulinic acid) a fluorescent dye swallowed by patients prior to neurosurgery that highlights tumour tissue, making it more distinguishable from normal brain tissue. By using this technology, neurosurgeons can visualise tumour boundaries more clearly during surgery, aiding in achieving maximum resection while preserving essential brain functions.
Studies have shown that 5-ALA technology improves patient survival, and it correlates with tumour density, vessel density, and histological characteristics, providing valuable insights into tumour biology.

Friedrich Erhart presented a case illustrating the application of 5-ALA in a patient with a suspected left temporal glioma. The surgical video showed the significance of 5-ALA in distinguishing tumour tissue from healthy brain tissue, ultimately leading to the accurate diagnosis of a WHO grade 3 high-grade glioma.
The use of intraoperative MRI during neurosurgery was discussed, aiming to evaluate and optimise resection margins. This advanced technology allows for real-time assessment of the surgical site, ensuring a more precise resection. Friedrich Erhart emphasised that using intraoperative MRI has shown to improve patient survival compared to conventional surgery.

The speaker presented a case of a patient with a recurrent left frontal insular lesion. He demonstrated the use of various imaging technologies, including functional MRI, DTI imaging, and 3D model MRI, to ensure precise localisation of critical brain functions before surgery. The intraoperative MRI allowed for immediate assessment and refinement of resection margins, ultimately contributing to better surgical outcomes.

He introduced Raman histology as an emerging technology that provides additional information about tissue composition during surgery. By measuring the scattering of light, Raman imaging allows for real-time tissue analysis, closely correlating with conventional

histology. This new tool promises to enhance the ability to distinguish tumour tissue from normal brain tissue, guiding surgical decisions for better patient outcomes.

The potential of artificial intelligence (AI) in aiding surgical decision-making was highlighted. AI algorithms can automatically interpret tissue samples and assist neurosurgeons in differentiating between tumour and healthy tissue. Implementing AI in future surgical procedures can significantly enhance surgical precision and outcomes.

Dr Friedrich Erhart's presentation showcased the latest innovations in surgical approaches for brain and CNS tumours. The integration of technologies such as fluorescence-guided surgery using 5-ALA, intraoperative MRI, and Raman histology demonstrated their potential to improve surgical outcomes and enhance patient survival. The importance of multidisciplinary collaboration and the ongoing research on AI highlighted the promising future of brain tumour surgery. These advancements pave the way for better treatment strategies, ultimately improving the lives of brain tumour patients worldwide.



Dr Erhart, speaking to a packed house, delivered a comprehensive presentation on the latest innovative surgical approaches for brain tumours.

Update on radiotherapy for brain and CNS tumours

Speaker: Dr Carola Lutgendorf-Caucig, MedAustron, Vienna, Austria



Dr Carola Lutgendorf-Caucig from Med Austron in Vienna gave a fascinating overview of current radiation practice for brain tumours.

Key points

- Radiotherapy employs radiation to control or destroy malignant cancer cells while minimising damage to healthy tissue and by damaging DNA through ionising radiation.
- Current standards of care include X-ray or photon-based radiation, together with newer technologies like proton-based radiotherapy, 3D conformal stereotactic radiosurgery, gamma knife, and ion therapy.
- Photons and X-rays induce cell damage through an indirect ionisation process involving oxygen and free radical production. Protons share a similar biological mechanism but behave differently.
- Protons stop at a specific depth, enabling better dose distribution within the tumour, unlike photons that can pass beyond a tumour and continue through the body.
- Treatment planning relies on surgeon reports, pathology data, imaging, and clinical information to define target volume and plan treatment.
- Pathology reports guide the delineation of the clinical target volume (CTV) around the visible tumour, expanded to account for potential microscopic disease.
- CT scans aid treatment planning for photon-based radiotherapy, while proton therapy is preferred in paediatric patients to minimise radiation exposure to normal (still growing) tissues.

- Treatments include photon-based 3D conformal techniques and advanced volumetric modulated therapy (VMAT), which offers highly conformal dose distribution.
- Proton therapy shows promise, particularly in paediatrics, reducing radiation exposure to normal tissues and potentially improving long-term outcomes.
- Carbon ion therapy is used for challenging macroscopic diseases, and research.
- Emerging technology, flash radiotherapy, delivers ultra-high radiation doses per second, potentially reducing tissue toxicity while maintaining tumour control.
- Treatment modality choice is patient and situation-dependent, considering factors such as tumour characteristics and patient status.

Radiotherapy has been a crucial component of cancer care for brain tumours and other malignancies. While the history of cancer surgery dates back many centuries, radiation oncology emerged in the late 19th century. Chemotherapy was introduced during World War II, and in the 1990s, targeted therapies and immunotherapies showed promise in cancer treatment, including for brain tumours.

Radiotherapy involves the medical use of radiation to control or kill malignant cancer cells while minimising damage to surrounding healthy tissue. Ionising radiation damages DNA, leading to cell death or other cellular changes. The standard of care currently includes X-ray or photon-based radiation. Newer technologies like proton-based radiotherapy, 3D conformal stereotactic radiosurgery, gamma knife, and ion therapy with protons are also utilised.

The key difference between photons and X-rays lies in their indirect ionisation process, where oxygen in the tissue leads to cell damage via free radical production. Protons have a similar biological mechanism, but the main difference is their physical behaviour. Photons pass through the body, while protons stop at a specific depth, allowing for a better dose distribution within the tumour and less risk of collateral effect. Radiotherapy treatment planning is essential since radiation oncologists do not directly see the tumour. They rely on surgical and pathology reports, along with imaging and clinical information, to define the target volume and plan the treatment.

Pathology reports provide critical information about the tumour's location and characteristics, allowing for the delineation of the clinical target volume (CTV) around the visible tumour. The CTV must be expanded to account for potential microscopic disease and to ensure comprehensive treatment.

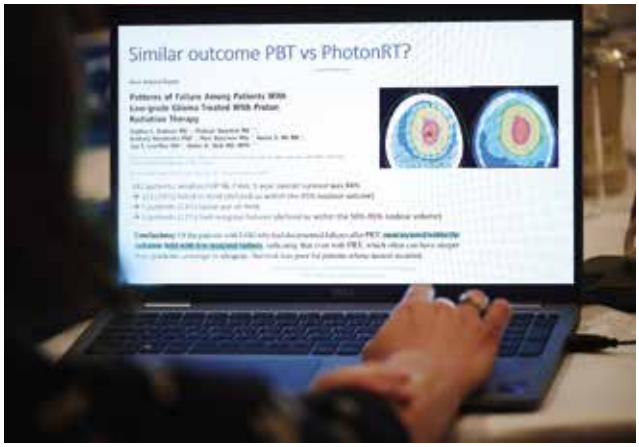
The treatment plannin Sg typically involves a CT scan for photon-based radiotherapy due to its X-ray-based nature, which helps determine optimal energy and dose distribution. Proton therapy is also used, especially in paediatric cancer patients, as it can spare normal tissue from unnecessary radiation exposure.

External beam radiotherapy using photon-based 3D conformal techniques has been the standard treatment, shaping the radiation beam to match the target profile. Volumetric modulated therapy (VMAT) is a more advanced technique that rotates the radiotherapy machine gantry around the patient, allowing for highly conformal dose distribution.

Carbon ion therapy is another form of charged particle therapy, larger than protons, and can be used for research and treatment of macroscopic diseases with difficult-to-achieve local control.

A cutting-edge emerging technology is flash radiotherapy, which delivers ultra-high doses of radiation per second, reducing normal tissue toxicity while maintaining tumour control. Its underlying mechanism is not fully understood, and extensive research is ongoing to explore its potential benefits.

In conclusion, radiotherapy has evolved significantly since the 1990s, moving from 2D and 3D conformal techniques to more sophisticated modalities like proton therapy and flash radiotherapy. The choice of treatment modality should always be patient-dependent and situation-dependent, considering factors such as tumour location, size, and patient status. With continuous advancements in radiation technologies, the goal remains to achieve better conformality, improved tumour control, and reduced long-term side effects for cancer patients.



PLENARY SESSION 2

Chair: Kathy Oliver,
International Brain Tumour Alliance (IBTA),
United Kingdom

The molecular era – update on the WHO 2021 Classification of Brain and CNS Tumours

Speaker: Dr Susan Chang, MD, University of California, San Francisco (UCSF), United States



Dr Susan Chang gave a clear, high-level overview of the WHO 2021 update on the Classification of Brain and CNS tumours.

Key points

- Overview of the *2021 WHO Classification of Brain and Central Nervous System (CNS) Tumours.*
- The 2021 WHO Classification improves tumour characterisation by incorporating molecular and genomic features.
- Classification is crucial for appropriate patient care and management.
- Historical evolution of tumour classification.
- Role of genetic and molecular markers
- IDH mutation revolutionised glioma classification, influencing prognosis and treatment approach.
- Differentiation between astrocytic tumour grades (e.g., grade 3 and grade 4) based on genetic markers.
- Implications for clinical trials and treatment selection.
- Targeted therapies and personalised treatment: understanding specific genetic abnormalities in tumours (e.g. IDH mutation and BRAF mutation) allowed for the development of inhibitors that target these mutations.

Dr Susan Chang's presentation provided a high-level overview of the *2021 WHO Classification of Brain and Central Nervous System (CNS) Tumours.* She pointed out that other presentations would delve into the molecular and genetic characteristics in more detail, including insights from neuropathologists.

Brain and CNS tumours constitute a highly diverse group, arising from various cell types within the brain. The classification and diagnosis of these tumours are essential for appropriate patient care and management. Susan Chang presented the case of a 50-year-old patient with a large brain mass and emphasised the importance of tissue confirmation to distinguish between different causes of brain masses, such as tumours, abscesses, and inflammation.

She discussed the historical evolution of tumour classification systems, with the 2021 WHO Classification being the most recent and comprehensive version. Traditionally, tumour diagnosis relied heavily on histology, which could be subjective and led to varying interpretations among pathologists. Moreover, some tumours exhibited mixed features, making accurate classification challenging.

However, the understanding of brain tumour biology has significantly advanced, and the importance of genetic and molecular markers in tumour diagnosis has become evident. One of the critical discoveries is the IDH mutation, which has revolutionised the classification of gliomas. The presence or absence of this mutation significantly influences the prognosis and treatment approach.

The update also highlights the differentiation between different grades of astrocytic tumours, such as grade 3 and grade 4 gliomas. The presence of certain genetic markers may define a tumour as a glioblastoma, even if it lacks classic histological features. This differentiation has implications for clinical trials and treatment selection.

Susan Chang emphasised the importance of understanding the specific genetic abnormalities in tumours, as this knowledge allows for targeted therapy. For example, IDH inhibitors have shown promise in low-grade gliomas with IDH mutations. Similarly, targeting BRAF mutations in certain tumours, (for example, melanoma), has proven effective.

In conclusion, the 2021 WHO Classification of Brain and CNS Tumours has improved tumour characterisation, incorporating molecular and genomic features to better define them. This advancement provides more reliable information on clinical outcomes, aids in personalised drug development, and facilitates the enrolment of patients with uniform diagnoses in clinical trials, to assess treatment effectiveness more accurately. The understanding of tumour biology and genetics is transforming brain tumour

diagnosis and treatment, offering hope for improved patient outcomes in the molecular era.



Dr Susan Chang confers with Chris Tse of Brain Tumour Support NZ.

Update on currently available systemic treatment approaches for low-grade and high-grade brain tumours

Speaker: Univ.-Prof. Dr Matthias Preusser, Clinical Division of Oncology, University of Vienna, Austria



Professor Dr Matthias Preusser of the University of Vienna has been a wonderful supporter of the IBTA's work and, at the IBTA Summit, gave a talk on currently available systemic treatments for low-grade and high-grade brain tumours.

Key points

- Overview of the guidelines of the European Association of Neuro-Oncology (EANO).
- Low-grade gliomas:
  - Need for chemotherapy or radiation therapy in most cases of low-grade gliomas.
  - Significance of the IDH mutation found in these tumours.
  - Exciting results from a global study of the IDH inhibitor vorasidenib demonstrating a 61% reduction in tumour recurrence risk, and increased progression-free survival for low-risk patients.
- Glioblastoma treatment approach:
  - Current treatment approach involves surgery, radiotherapy, and chemotherapy.
  - Potential use of IDH inhibitors for glioblastoma, although not routine yet.
  - Recurrence management lacks defined protocols.
  - LEGATO trial aims to define a new therapeutic standard for glioblastoma treatment.
- Challenges and clinical trials:
  - Treating glioblastoma remains challenging.
  - Patients are often offered participation in clinical trials to explore new treatments.
  - Potential of immunotherapy for glioblastoma, citing ongoing research.
  - Complexity of glioblastoma, difficulty in finding effective immune-boosting strategies.
  - Combination treatments and research:
  - Glioma presents unique challenges for combining older chemotherapy drugs with newer targeted treatments.
  - Ongoing research to discover more effective systemic treatment approaches for both low-grade and high-grade brain tumours.

Univ.-Prof. Dr Matthias Preusser delivered an informative presentation on systemic treatment approaches for brain tumours, with a focus on low-grade glioma and glioblastoma. He referred to the guidelines of the European Association of Neuro-Oncology (EANO).

Low-grade gliomas were discussed first, emphasising the need for chemotherapy or radiation therapy in most cases, either immediately after surgery or later. Matthias Preusser highlighted the significance of the IDH mutation found in every cell of these tumours. Targeting this mutation could allow selective treatment of tumour cells while sparing healthy cells, a crucial goal in oncology. Exciting results were presented from a global study of an IDH inhibitor drug called vorasidenib, demonstrating a 61% reduction in tumour recurrence risk and a significant increase in progression-free survival for low-risk patients.

However, some questions remain about the drug's effectiveness in grade 3 and grade 4 brain tumours and its potential interaction with other treatments like radiation and chemotherapy. Despite these uncertainties, the results are promising, and regulatory authorities are likely to review the drug for approval in the near future.

Moving on to glioblastoma, the most common and malignant brain tumour, Matthias Preusser discussed the current treatment

approach involving surgery, radiotherapy, and concomitant chemotherapy. He also mentioned the potential use of IDH inhibitors for glioblastoma, although it is not yet routine practice. Regarding recurrence, current evidence does not yet allow us to define a protocol. He mentioned the LEGATO trial (lomustine with or without re-irradiation for first progression of glioblastoma: a randomised phase III study) that hopes to define a new therapeutic standard for the treatment of glioblastoma.



Two of the focus points of Professor Preusser's presentation at the IBTA Summit were on IDH inhibitors for low-grade gliomas and ongoing research into immunotherapies for glioblastoma.

Professor Preusser acknowledged that treating glioblastoma remains challenging, and patients are often offered participation in clinical trials to explore new treatments and advance knowledge in the field.

Matthias Preusser touched on the potential of immunotherapy for glioblastoma, citing ongoing research in the area. However, he also emphasised the complexity of glioblastoma and the difficulty in finding effective immune-boosting strategies.

Regarding the combination of older chemotherapy drugs with newer targeted treatments, it was acknowledged that glioma presents unique challenges. Nevertheless, research continues to discover more effective systemic treatment approaches for both low-grade and high-grade brain tumours.

In conclusion, Matthias Preusser's presentation provided valuable insights into the evolving landscape of systemic treatments for brain tumours, with a particular focus on the exciting prospects of IDH inhibitors for low-grade gliomas, and ongoing research into immunotherapies for glioblastoma. As research progresses, it is hoped that these systemic therapies will lead to improved outcomes and quality of life for patients with brain tumours.



Pia Riis Olson (left) of the Danish Brain Tumour Association and Amber Barbach (right), of the Glioblastoma Research Organisation in the United States.

Novel therapeutics for primary malignant brain tumours

Speaker: Professor Tracy Batchelor, Harvard Medical School, and Brigham and Women's Hospital, Boston, United States



Professor Tracy Batchelor spoke about novel therapies for malignant brain tumours focussing on targeted therapies, immunotherapies, and molecularly defined subsets of glioblastoma.

Key points

- There is significant progress in novel therapeutics for brain tumours, especially in targeted therapies.
- There are six approved targeted therapies in neuro-oncology, with more in the pipeline.
- Tovorafenib is promising for paediatric astrocytoma, showing tumour shrinkage in trials.

- IDH1 inhibitors have been identified through immunohistochemical staining.
- Cancer neuroscience is exploring neuron-cancer cell interactions, with the potential for targeting neurotransmitters.
- Immunotherapies for nervous system tumours, include CAR T cells for CNS lymphomas.
- There is an emphasis on drug design, combination therapies, overcoming resistance, and blood-brain barrier challenges.



The audience at the IBTA World Summit listened intently as Professor Batchelor confirmed that there is significant progress in novel therapeutics for brain tumours, especially in targeted therapies.

The presentation by Professor Tracy Batchelor focused on novel therapeutics for primary malignant brain tumours, with an emphasis on targeted therapies, immunotherapies, and molecularly defined subsets of glioblastoma.

Tracy Batchelor began by highlighting the significant progress made in developing novel therapeutics for malignant brain tumours, especially in targeted therapies. He shared a diagram illustrating the complexity of cancer cell pathways, which have now become legitimate targets for drug development. He informed the Summit participants about six approved targeted therapies in neuro-oncology, with five approvals since 2018, and four additional targeted oral drugs currently undergoing FDA registration studies.

The presentation delved into specific targeted therapies for paediatric low-grade astrocytoma, highlighting tovorafenib as a promising drug that specifically targets RAF in paediatric astrocytoma. Clinical trials have shown encouraging results with tumour shrinkage in a significant number of patients.

IDH1 inhibitors, another significant area of research, were discussed briefly. Tracy Batchelor emphasised the importance of detecting IDH mutations using a simple immunohistochemical staining, making it a practical screening method for initial assessments.

A novel area of interest presented in the talk was cancer neuroscience, which explores the relationship between neuronal inputs and brain cancers. It was demonstrated that cancer cells cluster around neurons, and the electrical interactions between them play a crucial role in tumour growth and survival. Targeting neurotransmitters like glutamate is a potential therapeutic avenue to slow or stop tumour growth.

The presentation also touched upon immunotherapies for nervous system tumours. While some FDA-approved immunotherapies exist for rare conditions, more research is needed to improve their effectiveness for primary brain tumours. CAR-T cells show promise in CNS lymphomas, offering a potential avenue for effective treatment.

In conclusion, Professor Tracy Batchelor highlighted the significant advancements in understanding oncogenic pathways driving nervous system tumours, and the improved design of drugs facilitated by modern medicinal chemistry and artificial intelligence. He emphasised the growing list of approved and pipeline oral targeted drugs, the need for combination therapies, and overcoming resistance and the blood-brain barrier. Tracy Batchelor also underscored the challenges in immunotherapy for primary brain tumours but expressed optimism regarding the potential of CAR-T cells for CNS lymphomas.

Overall, the presentation provided a comprehensive and hopeful overview of novel therapeutics for primary malignant brain tumours, illustrating the progress made in targeted therapies and the promise of immunotherapies and molecularly defined subsets of glioblastoma.

Advancements in brain and CNS tumour pathology: a neuro-pathologist's perspective

Speaker: Dr Adelheid Woehrer, Institute of Neurology, Medical University of Vienna, Austria



Dr Adelheid Woehrer is a neuro-pathologist at the Medical University of Vienna.

Key points

- Brain tumours are relatively rare compared to other cancer types.
- The brain's complexity results in over 120 different types of brain tumours.
- Classification of brain tumours has shifted from morphology to molecular markers.
- DNA methylation profiling is crucial for accurate classification.
- IDH mutation serves as a treatment target for gliomas.
- AI-driven algorithms aid pathologists in diagnosis and treatment decisions.
- Nanopore sequencing offers rapid and comprehensive molecular diagnosis.
- Understanding molecular characteristics improves patient care and outcomes.

Adelheid Woehrer covered various aspects of brain tumour pathology in her presentation, including the incidence rates of brain tumours and their significance in comparison to other cancer types. She highlighted the unique challenges faced in classifying brain tumours and the ground-breaking advancements in molecular diagnostics and technological tools that have revolutionised the field.

Brain tumours are relatively rare in comparison to other cancer types, such as lung, prostate, breast, and colorectal cancers, which have higher incidence rates. Developed countries experience higher rates of brain tumours due to factors like aging populations. However, the diverse and complex nature of the brain, with its vast number of neurons and glial cells, contributes to the existence of over 120 different types of brain tumours. This diversity presents significant challenges in accurately diagnosing and characterising these tumours.

Over the years, brain tumour classification has evolved from a morphological approach to one that integrates molecular markers, becoming a cornerstone of cancer diagnostics. These advancements have been driven by technological breakthroughs in gene sequencing and DNA methylation profiling.

Gene sequencing techniques have progressed beyond single-gene analysis to simultaneous examination of multiple genes. However, Adelheid Woehrer highlighted the significance of DNA methylation profiling, an epigenetic marker that remains stable and heritable across cell generations. DNA methylation profiles provide insights into tumour cell origins, facilitating more accurate and reliable classification. Advanced platforms for DNA methylation profiling have simplified the process and improved neuropathologists' diagnostic capabilities.

Dr Woehrer emphasises the importance of screening for treatment targets in brain tumours. For instance, the IDH mutation serves as an exciting treatment opportunity for gliomas. Although some tumours have limited treatment targets today, the identification of these targets is crucial, as they may provide a lifeline for patients with limited options. The report suggests that beyond genomic screening, examining different molecular layers (DNA, gene expression, and epigenetics) and observing cell response to treatment are potential avenues for future research.

The advent of artificial intelligence (AI) has opened new possibilities in pathology. AI-based algorithms can support pathologists in making diagnoses, suggesting potential classifications, and detecting complex patterns in medical images. By identifying predictive markers that alter cell phenotypes, AI can guide treatment decisions, ultimately improving patient outcomes.

Adelheid Woehrer introduced an emerging technology known as nanopore sequencing. This handheld device uses membranes and pores to rapidly sequence DNA fragments, providing a comprehensive molecular integrated diagnosis within hours. Nanopore sequencing shows promise for analysing copy number alterations, mutations, and DNA methylation patterns, making it an attractive option for smaller laboratories and developing countries.

In conclusion, this presentation provided a comprehensive overview of the current state of brain and CNS tumour pathology. Understanding the molecular and genetic characteristics of brain tumours will continue to drive progress in the field and contribute to improved patient care and treatment outcomes.



Day One of the morning session of the IBTA Summit was packed with patient advocates, healthcare professionals, representatives of industry and others, listening to the clinical lectures about brain tumours.

Report on metastatic brain tumours: clinical perspective

Summary and feedback from the International Patient Advocacy Symposium on Brain Metastases 25 June 2023 (run by the International Brain Tumour Alliance in collaboration with the American Brain Tumor Association)

Speaker: Dr Manmeet Alhuwalia,
Miami Cancer Institute, United States



Joining the IBTA Summit in Vienna was Dr Manmeet Alhuwalia who provided a summary and feedback from previous day's special think tank meeting on brain metastases for which the IBTA collaborated with the American Brain Tumor Association.

Key points

- Brain metastases are more common than primary malignant brain tumours.
- Lung, breast, and melanoma cancers commonly metastasise to the brain.
- Recent advancements in medical interventions have improved survival rates in primary cancers. In turn, longer patient survival contributes to the increased incidence of brain metastases.
- Improved diagnostic techniques, like brain MRIs, aid in detection of brain metastases.
- Advocacy is important for appropriate screening measures.
- Treatment options have expanded to include targeted therapies and immunotherapies.
- Collaboration among specialists is key for comprehensive treatment.
- Combination therapies, including radiosurgery and immunotherapy, show promise.
- Genomic profiling predicts the likelihood of brain metastases.
- Non-invasive methods to disrupt the blood-brain barrier enhance drug delivery.
- Clinical trials, multidisciplinary care, and neurocognitive testing are vital.
- Global initiatives and collaboration advance research and treatment strategies.



Dr Manmeet Ahluwalia is an expert on brain metastases and is based at the Miami Cancer Institute in the United States.

Dr Manmeet Ahluwalia presented a summary on the *International Patient Advocacy Symposium on Brain Metastases* that took place on 25 June 2023 in Vienna (the day before the Summit), with a focus on the clinical perspective of managing brain metastases. He provided insights into the current landscape and advancements in the understanding and treatment of brain metastases.

Brain metastases, which are cancers originating in other parts of the body and spreading to the brain, were the central theme of the Symposium. Dr Ahluwalia emphasised that brain metastases are ten times more common than primary malignant brain tumours. The most common cancers that tend to metastasise to the brain include lung cancer, breast cancer, and melanoma.

Approximately 200,000 patients are diagnosed with brain metastases each year in the United States. Historically, the prognosis for these patients was poor, with an average survival of only nine to twelve months. However, recent developments in medical interventions have transformed this landscape, offering new hope for extended survival and improved quality of life.

A key reason for the increasing incidence of brain metastases is the overall improvement in cancer care of a person's primary tumour, leading to longer survival of patients with systemic cancers. As patients live longer, their likelihood of developing brain metastases increases. Additionally, advancements in diagnostic techniques, such as the requirement for brain MRIs in stage 4 cancer trials, have contributed to better detection rates.

Manmeet Ahluwalia emphasised the importance of advocacy in ensuring availability of appropriate screening measures, particularly in European countries where brain MRIs are not yet a standard part of staging workups. It was highlighted that different types of cancers have varying tendencies to develop brain metastases.

Traditionally, brain metastases were primarily managed through neurosurgery, radiosurgery, and whole-brain radiation. However, advancements in drug development have expanded treatment options, with targeted therapies and immunotherapies demonstrating promising outcomes.

The Symposium showcased that treatment strategies often depend on the medical professionals involved, whether medical oncologists or neurooncologists and indicated a shift from a sole reliance on surgical and radiation interventions. First-generation targeted therapies were less effective, with response rates of around 20-30%. However, newer generation drugs have shown much higher response rates, reaching 50-70%, particularly in ALK-driven tumours.

The Symposium underscored the significance of combination therapies, highlighting that the treatment of brain metastases is a collaborative effort involving multiple specialists, including neurosurgeons, radiation oncologists, neuropathologists, and neurooncologists. Dr Ahluwalia presented data indicating that combining radiosurgery with targeted therapies and immunotherapies can lead to more complete responses, with immediate or concurrent immunotherapy showing better outcomes.

He explained that the Symposium also delved into future directions and challenges in the field of brain metastases. Genomic profiling and signatures are being developed to predict the likelihood of brain metastases. Additionally, emerging technologies, such as non-invasive methods to disrupt the blood-brain barrier, hold promise in drug delivery and enhanced treatment efficacy.

It was emphasised that clinical trials are essential for guiding



the management of complex brain metastases. The need for multidisciplinary care, neurocognitive testing, and the importance of treating brain metastases in tertiary care centres was highlighted.

The Symposium concluded by highlighting the importance of global initiatives and collaboration. The establishment of the Miami Cancer Institute as the coordinating site for the International Radiosurgery Research Foundation was a notable example. The collaboration among leading cancer centres aims to advance research and treatment strategies for brain metastases.

In conclusion, Dr Alhuwalia provided a comprehensive overview of the current state of understanding, diagnosis, and treatment of brain metastases from a clinical perspective. The symposium highlighted the rapid transformation of the landscape due to advancements in targeted therapies, immunotherapies, and multidisciplinary approaches. The collaborative efforts of patient advocacy groups and global initiatives were showcased as critical in advancing the field and improving patient outcomes.

Report on metastatic brain tumours: patient advocate perspective

Feedback from the International Patient Advocacy Symposium on Brain Metastases - June 25, 2023 (run by the International Brain Tumour Alliance/IBTA in collaboration with the American Brain Tumor Association/ABTA)

Speaker: Ralph DeVitto and Nicole Willmarth, American Brain Tumor Association (ABTA), Chicago, United States



Nicole Willmarth (left) and Ralph Devitto (right) of the American Brain Tumor Association (ABTA) provided feedback to Summit participants on the previous day's First International Patient Advocacy Symposium on Brain Metastases organised by the IBTA in collaboration with the ABTA.

Key points

- Brain metastases in the United States is estimated between 50,000 to 500,000 cases yearly.
- Primary cancer representatives discussed origins and collaborative solutions.
- Four priority areas were identified: research, patients and caregivers, treatment access, diagnosis.
- There were proposed initiatives in each area to address challenges and gaps.
- Collaboration was stressed as key to impactful solutions.
- Research challenges include prevention, biomarkers, clinical trial inclusion and global surveys.
- The patients' and caregivers' focus includes education, support, multidisciplinary care and symptom management.
- Access to treatment focusses on overcoming barriers (including participation in clinical trials), biomarker testing, cost and education.
- Diagnosis challenges include early detection, studies, efficient screening, better communication.
- Next steps for patient advocacy groups regarding the challenges of brain metastases include regular international meetings, working groups, mapping resources and fundraising.

The Symposium, convened jointly by the International Brain Tumour Alliance (IBTA) and the American Brain Tumor Association (ABTA), focused on collaborative efforts to improve research, patient care, access to treatment, and diagnosis for people with brain metastases.

Ralph DeVitto, CEO of ABTA, highlighted the ongoing efforts of that organisation, initiated in 2018, to address brain metastases in the United States through a collaborative approach. Under the leadership of Nicole Willmarth, Chief Mission Officer of ABTA, the initiative gained momentum and attracted scientific advisors and partners. Recognising the lack of accurate data on the incidence of brain metastases in the United States, the ABTA works towards data collection and collaboration.



Ralph DeVitto - President and Chief Executive Officer, American Brain Tumor Association (ABTA) highlighted some of the brain metastases Symposium's key takeways.

Key Symposium Takeaways

Ralph DeVitto, revealed that the estimated incidence of brain metastases in the United States ranges between 50,000 and 500,000 cases annually. The exact incidence is unknown. Thus, unmet needs begin with basic data collection.

The Symposium drew participation from representatives of primary cancer disciplines, such as lung, breast, kidney, and melanoma, which commonly metastasise to the brain.

The interactive and collaborative nature of the event facilitated the emergence of targeted projects intended to enhance the well-being of patients and caregivers affected by brain metastases. Furthermore, a commitment to establishing regular meetings among various brain tumour and other primary cancer organisations reflects the ongoing dedication to collaborative efforts and shared goals.

The Symposium emerged as a dynamic platform fostering extensive discussions and partnerships. Within this environment, the identification of four pivotal priority domains – research; patients and caregivers; access to treatment, and diagnosis and treatment – underscored the focus on comprehensive problem-solving.

In a bid to bridge existing gaps and challenges, distinct initiatives were proposed within each priority area (see below). Notably, the Symposium emphasised collaboration as a potent strategy for consolidating resources and orchestrating more impactful solutions to tackle the multifaceted challenges at hand.

Priority areas and discussion points

1. Research:

- Investigating brain metastases prevention and early diagnosis through research.
- Developing biomarkers to identify patients at higher risk of brain metastases.
- Collecting accurate incidence and mortality data to better understand the scope of the problem.
- Inclusion of brain metastases patients in clinical trials, especially those with progressive disease.
- Updating and expanding the ABTA patient, caregiver, and physician survey initiated in 2018.

2. Patients and caregivers:

- Mapping existing patient education materials and addressing gaps.
- Raising public awareness about brain metastases and its symptoms.
- Providing individualised support through connections with patients who have similar experiences.
- Developing checklists for multidisciplinary care teams to im prove patient management.
- Offering practical resources for symptom management, including transportation assistance.

3. Access to treatment:

- Addressing barriers to inclusion of brain metastases patients in clinical trials
- Mapping barriers to access and developing strategies to overcome them
- Expanding access to biomarker testing for targeted therapies
- Identifying and addressing cost, education, and awareness-related barriers

4. Diagnosis and treatment:

- Advancing early diagnosis through targeted screening and higher-risk patient identification
- Conducting prospective studies for brain metastases patients
- Educating healthcare professionals about the importance of contrast MRI for accurate detection
- Exploring more cost-effective and efficient MRI screening methods
- Enhancing communication between healthcare professionals and patients regarding treatment options

Next steps:

- Regular virtual meetings will be convened to maintain momentum and collaboration.
- Bi-annual in-person meetings are proposed to accommodate the busy schedules of participants.
- Working groups will be formed to address immediate priorities and actionable items.
- Existing resources will be mapped to identify gaps and overlaps.
- ABTA has committed to raising funds for research and data collection.

Conclusion:

The International Patient Advocacy Symposium on Brain Metastases marked a significant step in the collaborative efforts to improve the lives of individuals affected by brain metastases. With key priorities identified and specific projects outlined, the Symposium provided a blueprint for further action and collaboration among primary cancer and brain tumour organisations.

The commitment to regular meetings, ongoing collaboration, and targeted initiatives demonstrates the dedication of the Symposium participants to making tangible advancements in research, care, and treatment options for brain metastases patients and their caregivers.



Amber Barbach, whose organization specializes in supporting glioblastoma research in the United States, asks a question.



Left to right: Susan Chang (University of California San Francisco), Nicole Willmarth and Ralph DeVitto (both of the American Brain Tumor Association/ABTA).

"Ask the Expert" panel session: a summary

Introduction

The "Ask the Expert" panel session at the IBTA Summit provided an insightful platform for discussing various aspects of brain tumour management, diagnostics, and therapies. Experts from diverse fields, including neurosurgery, oncology, radiation oncology and pathology, convened to answer pertinent questions and share their knowledge on current trends, challenges, and innovations in the field.

Here are some summarised excerpts from the panel discussions with the audience.

On brain metastases

Brain metastases, also known as metastatic brain tumours, are secondary malignancies that spread to the brain from other parts of the body. In contrast, glioblastoma (GBM) is classified as a primary brain tumour, originating within the brain itself. GBM rarely metastasises outside the brain.

Typically, brain metastases originate from cancers such as lung, breast, melanoma, kidney, and others capable of spreading to various body parts. This contrasts with primary brain tumours that arise and remain in the brain due to their locally infiltrative nature.

The concept of "secondary glioblastoma" previously referred to the progression of a tumour from a lower grade, such as grade 2 astrocytoma, to a higher grade, culminating in grade 4 astrocytoma, or GBM. This delineation between primary and secondary GBM has become obsolete due to the understanding of the IDH mutation, which characterises lower grade tumours, while IDH wildtype is indicative of glioblastoma. The use of "secondary GBM" terminology has been phased out in favour of more current genetic-based classifications.

On CAR-T treatments

CAR-T cell therapy, a form of immunotherapy targeting specific genetic markers, has shown promise in treating various diseases. It is already approved for several haematological malignancies. However, its application in treating gliomas, particularly brain tumours, is still in the early stages and presents numerous challenges.

Initial trials indicate that CAR-T cells can reach and impact tumours locally, yet this has not translated into significant clinical benefits. Progress appears more promising in rare tumours like CNS lymphoma, where CAR-T therapies, originally developed for lymphoma, are being tested. This approach is logical, given the therapy's background, but full approval for such treatments in CNS lymphoma is still pending.

In paediatric oncology, CAR-T cell therapy shows potential, especially for diffuse midline gliomas (DMG), previously known as diffuse intrinsic pontine glioma (DIPG). Despite these hopeful signs, it remains a nascent area of research, underscoring the need for further investigation and development to fully harness CAR-T cell therapy's potential in these challenging cases.

On neuro-oncology as a specialty

Neuro-oncology as a specialty varies significantly across countries and hospitals, with some countries recognising it as a distinct field, while others do not. For instance, in Austria, there is no separate specialty for neuro-oncology, and care for patients with brain tumours can differ widely from one city or hospital to another. Treatment might be administered by medical oncologists within internal medicine or by neurologists without neuro-oncology board certification, depending on the institution.

In some countries, clinical oncologists are responsible for both chemotherapy and radiotherapy, highlighting the diverse approaches to treatment. Despite the lack of a formal specialty board approval for neuro-oncology in many regions, efforts are ongoing at a European level to gain recognition, although it is expected to be a lengthy process.

The quality of care for brain tumour patients does not necessarily suffer due to the absence of a neuro-oncology specialty. The level of care often depends on the setting, with a potential disparity in expertise between community settings and larger, specialised centres like university hospitals or large cancer centres. Specialists who deal with brain tumours daily, including neurosurgeons focused exclusively on brain tumours, are likely to be more up to date with research and treatment methods compared to those who encounter these cases less frequently.



Members of Ask the Expert Panel are (left to right): neuro-pathologist Dr Adelheid Woehrer, radiation oncologist Dr Carola Lutgendorf-Caucig, neurosurgeon Professor Dr Georg Widhalm and oncologist Professor Dr Matthias Preusser.



Anita Granero founder and president of Oscar's Angels Italia and Oscar's Angels France poses a question.

Identifying and supporting neurologists or oncologists with a keen interest in brain tumour care is crucial. Encouraging these physicians to undergo mentoring and gain hands-on experience from experts in the field can enhance their proficiency, even without specific board certification.

The importance of multidisciplinary teams (MDTs) in the treatment of brain tumour patients cannot be overstated. To address the educational gap, initiatives in Europe and the United States, such as the European Association of Neuro-Oncology's (EANO) "The School of Neuro-oncology" and the Society for Neuro-Oncology's (SNO) similar programme, offer training and webinars for healthcare professionals interested in specialising in neuro-oncology. These educational opportunities are vital for fostering expertise in the care and treatment of patients with brain tumours.

On the importance of healthcare professional – patient communication

Communicating with patients, especially during their initial visit, presents significant challenges for healthcare professionals. The initial consultation is crucial for establishing rapport, assessing the patient's understanding of their diagnosis, and discussing treatment options, including potential long-term side effects. For example, patients need to be informed about immediate side effects of treatments like radiation, such as temporary hair loss, as well as possible long-term impacts, which could affect their quality of life in the years to come. This is particularly complex when explaining these issues to children, who may not grasp the concept of late effects.

It's essential for patients to feel encouraged to ask questions and seek support for side effects, even a long time after treatment is finished, as many of these effects can be managed with appropriate care. The process of creating a treatment plan, while complex, is a critical aspect of patient care, with the quality of the doctor-patient relationship being paramount.

From a surgical standpoint, managing patient expectations is also challenging. Patients often seek a prognosis early on, but healthcare providers must emphasise the importance of a step-by-step approach, beginning with detailed investigations like imaging and functional MRI, before proceeding to surgery and treatment decisions.

Pathologists play a unique role in patient communication, especially in the United States where pathology reports are accessible to patients via electronic medical records. This transparency offers an opportunity to improve how complex information, including molecular markers, is communicated to patients. Simplifying these reports could help patients better understand their condition and treatment options.

Challenges in doctor-patient communication are not only due to the complexity of the information but also to infrastructural and time constraints. The healthcare system often faces pressures from a high patient-to-physician ratio and the administrative burdens of clinical trials, underscoring the need for improvements that would allow more time for patient care.

Diverse opinions from different doctors highlight the importance of seeking care from specialised centres experienced in treating brain tumours. These centres have access to advanced imaging and surgical techniques, providing patients with the best possible care. Operating on gliomas regularly, for example, greatly enhances a surgeon's expertise.

Overall, despite the challenges, interacting with patients is deeply rewarding. Improving communication, streamlining administrative processes, and ensuring patients have access to specialised care are key to enhancing patient experiences and outcomes.



Members of the Ask the Expert Panel session at the IBTA World Summit included (left to right): Nicole Willmarth (Chief Mission Officer, American Brain Tumor Association), neurologist Dr Tracy Batchelor (Harvard Medical School) and Dr Manmeet Ahluwalia (medical oncologist at Baptist Health).



Brain tumour patient advocate Roberto Pugliese from the Italian organisation Glioblastoma.IT ODV makes a point.

On clinical trials in glioblastoma

Clinical trials in glioblastoma present a multifaceted challenge due to the tumour's heterogeneity, its infiltration properties, resistance to therapies, and the complexities surrounding genomics and drug delivery.

One promising area of research focuses on gene fusions in glioblastoma, considered a significant target. However, the rarity of the tumour complicates the execution of trials based on genomic subtypes. For instance, studies on FGFR tag gene fusions, which are relevant to only a small percentage of glioblastoma patients, illustrate the struggle to recruit enough participants for these highly specific trials. Despite the potential benefits of clinical trials, many patients either are unaware of them or view them as a last resort, not realising they could participate in a trial immediately following diagnosis.

The National Comprehensive Cancer Network (NCCN) guidelines prioritise enrolment in clinical trials for glioblastoma patients above standard care, a unique recommendation underscoring the importance of research in advancing treatment options. This approach reflects an understanding that treatments must be as diverse as the tumour itself, considering factors like IDH mutation status and MGMT methylation, which influence chemotherapy's effectiveness.

In the United States there is an increased focus on ensuring that drugs not only reach the tumour but also achieve their intended effect. This scrutiny extends to evaluating whether a drug merits progression to phase 3 trials, advocating for a more informed and strategic approach to trial selection. The tendency to rush into phase 3 trials without solid evidence of effectiveness is being reconsidered, with efforts to improve understanding of drug delivery, particularly across the blood-brain barrier, and to select candidates for phase 3 trials more judiciously.

While phase 3 trials, especially randomised ones, remain crucial, maintaining high-quality standards and adhering to well-established trial designs is essential. The goal is to refine the selection process for drugs entering these trials, ensuring that only those with a realistic chance of benefiting patients advance to this critical stage of research.

Conclusion

The "Ask the Expert" panel session underscored the complexities and advancements in brain tumour research and treatment. It highlighted the importance of ongoing research, technological integration, and the need for specialised care in neuro-oncology.

PLENARY SESSION 3

Summit Masterclass 1 The essentials of creating a support group for brain tumour patients

Facilitator: Maureen Daniels, The Gerry and Nancy Pencer Brain Tumor Center, Canada

Speaker: Jean Arzbaecher, University of Illinois, United States



Jean Arzbaecher, RN, an advance practice nure and an IBTA senior advisor leads a workshop on creating a support group for brain tumour patients and caregivers.

Key points

- Challenges and rewards of impactful support groups for patients and caregivers.
- Scarcity of tailored brain tumour support resources.
- Adaptations due to Covid-19 pandemic highlighted by existing support groups.
- Key considerations for establishing support groups: who, why, when, where and what.

■ Importance of diversity: survivors, caregivers, facilitators, various diagnoses.

■ Location options: community centres, hospitals, private residences, online platforms.

■ Initiation steps: forming core group, setting date and venue, promoting the group.

■ Structuring meetings: ground rules, milestones, setbacks, time constraints discussed.

■ Managing sensitive discussions: handling member loss, ongoing evaluation emphasised.

■ Emotional dimension of facilitation acknowledged.

■ Diversity in diagnoses fosters connections, shared experiences create bonds.

■ Caregivers returning post-loss; unique insights and support noted.

Jean Arzbaecher, with over two decades of experience as a nurse in neuro-oncology and more than ten years of facilitating support groups for brain tumour survivors and caregivers, brought a wealth of expertise to this masterclass. Her presentation was enriched by poignant quotes from her own support group participants, providing the backdrop for a dynamic and interactive discussion on the challenges and rewards of creating support groups for brain tumour patients and caregivers. Engaging the audience, the session resonated particularly with those who already participate in community support groups or were keen to establish their own successful initiatives.

In response to the lack of support resources tailored to the brain tumour community (compared to more prevalent cancers) participants reflected on the potential advantages of this scarcity, as it could enhance the focus on support group attendance in the absence of numerous competing resources. The session started with participants sharing their experiences regarding their existing support groups, reflecting on the profound impact of the Covid-19 pandemic and how they innovatively adapted their group models to navigate pandemic-induced constraints.

Jean Arzbaecher initiated a clear and concise exploration of the essence of support groups by delving into the fundamental considerations of "Who, Why, When, Where & What." She outlined pivotal considerations for establishing new support groups, encompassing different aspects:

- The significance of brain tumour support groups.
- The variety of participants: survivors, caregivers, facilitators, and those with various brain tumour diagnoses.
- Exploration of the merits and challenges of separate groups for survivors and caregivers.
- Location options: community centres, hospitals, private residences, and online platforms.



Jean Arzbaecher has over two decades of experience as a nurse in neuro-oncology and more than ten years of facilitating support groups for brain tumour survivors and caregivers.

- The challenge of determining the optimal meeting time and place.
- Initiation steps: forming a core group, setting a date and venue, and promoting the group.
- Formulating the format for the first group meeting, including introductions and ongoing format input.
- Continuing structure: establishing respectful ground rules, celebrating milestones and setbacks, adhering to time constraints, and potentially inviting speakers or setting discussion themes.
- Addressing challenges and potential pitfalls, such as managing dominant contributors or reticent participants.
- Managing sensitive discussions, such as when participants face setbacks or recurrence.
- Navigating the unfortunate scenario of a group member passing away, involving approaches like a "grey notice" or a candle-lighting ceremony.
- The recommendation for ongoing evaluation of the group's dynamics.
- Fostering a welcoming atmosphere, nurturing a safe space for information exchange, inspiring hope, and incorporating appropriate "tumour humour."

Throughout the masterclass, diverse topics emerged organically as participants shared their own facilitation experiences. Particularly noteworthy was the emotional dimension of leading a support group. Practical strategies were discussed, including acknowledging the facilitator's role, debriefing with colleagues, and embracing moments of shared emotion. Participants widely agreed that displaying emotion as a facilitator resonates with support group members.

The significance of incorporating a diverse range of brain tumour diagnoses within a group was highlighted, as connections often form in unexpected ways. Similar symptoms or experiences can forge bonds, even without identical diagnoses. Encouraging the natural evolution of connections was collectively endorsed.

An in-depth exploration of managing caregivers who wish to return to the group following the loss of a loved one also ensued. The complexities of this scenario were acknowledged, as the presence of bereaved individuals could impact first-time attendees. However, it was recognised that surviving caregivers possess unique insights and



Summit participants enjoying one of the sessions.



Richard Price (at the table left), Head of Policy at the European Cancer Organisation (ESO) and Anita Kienesberger (right at the table), Chair, Childhood Cancer International-Europe led a Masterclass on cancer care policy.

are instrumental in supporting newcomers facing similar challenges.

The masterclass fostered an insightful and collegial discussion, ultimately underscoring the intricacies of brain tumour support groups and leaving participants with a greater understanding of how to effectively navigate their challenges and maximise their benefits.

Summit Masterclass 2 Policy recommendations for cancer care based on multi-disciplinarity

Facilitator: Anita Kienesberger,
Childhood Cancer International, Austria

Speaker: Richard Price,
European Cancer Organisation, Belgium

Key points

- The presentation outlined key strategies for achieving advocacy objectives, including setting clear goals, supporting requests with data, and fostering collaboration.
- It also provided an overview of the historical evolution of policy and advocacy, highlighting the increasingly competitive environment in this field.

The masterclass began with introductions, where participants shared their backgrounds and interests related to the topic of the masterclass.

The talk included policy recommendations for cancer care based on the principles of multi-disciplinarity. The objectives of the masterclass were:

1. To address the key needs for effectively advocating policy recommendations for the brain tumour community.

2. To explore ethical considerations in deploying advocacy activities, considering broader health and societal concerns.

3. To apply these principles to specific brain tumour advocacy examples discussed during the masterclass.

Richard Price, from the European Cancer Organisation, explained that policy and advocacy are interconnected concepts crucial for driving societal change. Policy involves creating rules and principles by governments and organisations to guide decision-making. Advocacy, on the other hand, focuses on promoting causes or ideas, often with the aim of influencing policy decisions. The report acknowledges the historical evolution of policy and advocacy and notes the increasing competition in this field.

To achieve advocacy objectives effectively, Richard Price provided several strategies:

1. Set clear objectives: Advocacy campaigns should have specific, well-defined goals. Communicating priorities to decision-makers is essential.

2. Support requests with data: Providing robust and compelling data about the problem being addressed strengthens the advocacy effort.

3. Identify decision-making allies: Building relationships with individuals who can support your cause is crucial.

4. Be Timely and Adaptive: Recognise the changing priorities of legislators and decision-makers and be prepared to adapt your strategy accordingly.

5. Persistence and collaboration: Persistence and collaboration with other advocacy groups can amplify your impact and build trust among different communities.

6. Amend policy messaging: If the initial policy messaging is not resonating, be flexible in adjusting the approach to find solutions.

7. Ethical considerations: The masterclass emphasises ethical lobbying and advocacy, including honesty in representation and refraining from obtaining information or decisions dishonestly or through undue pressure.

Richard Price also highlighted the responsibility to consider broader societal agendas, beyond specific advocacy goals. These include:

1. Efficient healthcare systems: Ensuring healthcare systems can meet the evolving needs of aging societies and workforce pressures.

2. Environmental impact: Reducing the environmental impact of policy areas, such as cancer medicines.

3. Democracy and trust: Building democratic societies where citizens trust the basis of policy decisions and addressing the influence of the loudest voices.

In conclusion, this presentation outlined key strategies and ethical considerations for effective policy advocacy in cancer care, emphasising the importance of collaboration and a broader societal perspective in achieving meaningful change.

Summit Masterclass 3
Brain tumour clinical trials – are we doing it right?

Facilitator: Chris Tse,
Brain Tumour Support New Zealand

Speaker: Dr Manmeet Alhuwalia,
Miami Cancer Institute, United States

Key points

- Importance of pre-clinical research and phases of clinical trials (phase 0 to phase 4) highlighted.
- Low participation rate in brain tumour clinical trials, especially for glioblastoma (GBM).
- Efforts needed to relax eligibility criteria for better patient access to trials.
- Discussion on access challenges: age criteria, international participation barriers, trial design.
- Financial burden, lack of uniform availability, patient-centricity concerns addressed.
- Telehealth proposed to bridge logistics gap for trial participation.
- Efficacy concern in glioblastoma trials discussed; need for top-down approach in drug development.
- Drug delivery into the brain, relevant endpoints, and combination treatments importance.
- Session emphasised complexity of brain tumour trials, leaving questions on funding, quality, and participation.



Dr Manmeet Ahluwalia spoke to a masterclass about drug development and the crucial role of clinical trials for brain tumour treatments.

During this interactive learning session, Dr Manmeet Ahluwalia provided a comprehensive overview of the drug development process and the pivotal role of clinical trials. He underscored the significance of pre-clinical research and subsequently outlined the distinct phases of clinical trials, ranging from phase 0 to phase 4.

Addressing challenges inherent to brain tumour clinical research, Dr Ahluwalia highlighted a concerning low participation rate, with just 21% of brain tumour patients enrolling in clinical trials. He described reasons cited by patients for their non-participation, which included their doctors not recommending clinical trials, ineligibility for participation, and a lack of knowledge about clinical trial resources.

The situation was even more dire for glioblastoma (GBM) clinical trials, with a meagre enrolment of less than 11% of patients. To improve patient access, efforts were being made to relax the eligibility criteria. Subsequently, the session transitioned to a lively floor discussion, initially centring on access challenges. Pertinent issues included age criteria restrictions, international participation barriers, and the design of clinical trials. The imposition of age criteria by various jurisdictions was highlighted, with Dr Ahluwalia noting the FDA's requirement for a paediatric arm in many clinical trials and the agency's discouragement of upper age limits, advocating instead for criteria based on functional status.

The financial burden of participation in randomised clinical trials, where standard-of-care treatment often incurs costs, was identified as a barrier to international participation. The lack of uniform availability of clinical trials across countries was emphasised, and the frustration stemming from incongruities with



Noa Faaij (left), Klaske Hofstee (centre) and Charles LaHaye (right) – all are brain tumour patient advocates from organisations in The Netherlands.

international guidelines was acknowledged. Concerns surrounding patient-centricity of trial designs were raised, particularly when the possibility of being randomised into a placebo arm is high. The potential of multi-arm trials to mitigate this concern was proposed, potentially leading to increased patient engagement.

Practical logistics, such as travel times, were recognised as potential impediments. A suggestion emerged to bridge this gap by adopting telehealth and similar measures to facilitate trial participation. Dr Ahluwalia underscored the persisting concern regarding efficacy in glioblastoma clinical trials, noting the absence of FDA-approved drugs showing survival benefit in recurrent GBM. The need for a top-down approach in drug development was advocated, involving genomic profiling to comprehensively understand the driving factors of the tumour. Dr Ahluwalia cited the INDIGO study and the INSIGhT platform trial as examples of such an approach.



Melissa Lim, Founder and President of the Brain Tumour Society (Singapore).

Importantly, the session highlighted the critical issue of drug delivery into the brain. The masterclass also addressed the importance of selecting relevant endpoints in clinical trials, especially in scenarios involving combination treatments. The potential of seemingly negative trial outcomes to yield valuable insights based on specific patient subsets with distinct genomic profiles was underscored.

In conclusion, the session proved to be a vibrant and participatory exchange of ideas, shedding light on the intricacies of brain tumour clinical trials. The breadth of topics discussed emphasised the complexity of this field and revealed that the Summit's discussion only scratched the surface. Participants were left contemplating three questions:

- How to fund non-pharma sponsored brain tumour clinical trials.
- How to improve the quality of brain tumour clinical trials.
- How to increase participation rates in brain tumour clinical trials.

Summit Masterclass 4
How to reach disadvantaged populations in the brain tumour community: improving health literacy and inequalities in care

Facilitator: Komal Syed, Brain Tumor Foundation of Pakistan

Speaker: Brijesh Deshpande, Brain Tumor Support Group Awareness Foundation, India; Irene Ngong (Jacob's Hope Foundation, Cameroon; Christine Mungoshi, Zimbabwe Brain Tumour Association/ZBTA; Dr Alexandra Diaz Alba, Instituto Neurológico de Guadalajara, Mexico



Komal Syed from Pakistan facilitated a well-attended Masterclass on improving health literacy and care in underserved countries.

In a world where healthcare is a fundamental human right, it is disheartening to witness the significant disparities in access to quality care faced by thousands of brain tumour patients in



Dr Alexandra Diaz Alba is a neuro-oncologist from Mexico.



Irene Ngong Azong-Wara of Jacob's Hope Foundation in Cameroon spoke at the IBTA Summit session on helping brain tumour patients in her country.

developing nations. The imbalances in healthcare resources, infrastructure, and expertise have far-reaching consequences, leading to preventable suffering, compromised well-being, and ultimately, the loss of countless lives.

This masterclass covered the topic of "How to reach underserved/disadvantaged populations in the brain tumour community: improving health literacy and inequalities in care" with speakers from four underserved countries, across three regions. Some of the brightest minds and compassionate hearts in the field, each of whom has dedicated their lives to the pursuit of healing and improving the quality of life of brain tumour patients in their countries, were part of the masterclass.

From the Americas, Dr Alexandra Diaz Alba (Mexico), a neuro-oncologist in Guadalajara, Jalisco working at the Instituto Neurológico de Guadalajara spoke about the challenges to kick-start a support group in Mexico. She addressed the difficulty of convincing patients and caregivers to join support groups in regions where patients rely heavily on family bonds. She also highlighted the importance of training doctors to be more empathetic within the limited training they receive in Mexico. For example, training in neuro-oncology is limited in Mexico, so Alexandra Diaz Alba applied for a scholarship to study in France, which helped expose her to the network of brain tumour patient advocates across the world. She is currently trying to start a support group in Mexico.



Christine Mungoshi helped establish the Zimbabwe Brain Tumour Association (ZBTA) after the lost her young daughter to a brain tumour.

From the African region, Christine Mungoshi (Zimbabwe Brain Tumour Association – ZBTA) spoke about the current challenges and the future role of patient advocacy in driving change for underserved brain tumour communities in Zimbabwe and Sub-Sharan Africa. Christine helped found the Zimbabwe Brain Tumour Association after losing her daughter to a brain tumour in 2005. She inspired attendees to challenge themselves and remember that even small change is a change and that every step taken in the right direction will help improve the quality of life of those impacted by a brain tumour.

From Central Africa, Irene Ngong Azong-Wara (Jacob's Hope Foundation in Cameroon) shared a moving, personal story about her first encounter with a brain tumour diagnosis through her father, and how her journey to become a brain tumour patient advocate started there. Irene addressed the different ways by which patients in underserved communities are reached, with a focus on the challenges and opportunities that come with current civil war. Irene also brought into perspective Maslows hierarchy of needs in underserved populations, and how it is critical to meet the patient and families where they are, with targeted outreach efforts. Finally, Irene stressed the importance of taking care of oneself as a patient advocate, since the support that patient advocates need to provide for underserved populations can become overwhelming. In honour of her father, Irene established Jacob's Hope Foundation, with a focus on awareness creation within the Cameroon community of cancer patients.

Finally, Brijesh Deshpande (a volunteer with the Brain Tumour Support Group and Awareness Organisation, India) represented South Asia. Brijesh was diagnosed with a brain tumour and is passionate about helping those currently suffering from this condition. Brijesh spoke at the masterclass about:

1. How healthcare systems, both public and private, can help brain tumour patients
2. How we can leverage government support towards brain tumour patients with schemes like Ayushman Bharat in India
3. How neurosurgeons and neuropsychologists can work in tandem, benefitting brain tumour patients and caregivers



Brijesh Deshpande volunteers with the Brain Tumour Support Group and Awareness Organisation in India.



Carol Kruchko (left) and Dr Tracy Batchelor (right) led a Summit masterclass on molecular profiling.

4. The potential of leveraging the power of social media, crowd funding and corporate social responsibility (CSR) to raise awareness and support for treatments. Brijesh also reminded us that in most cases, healthcare professionals in the neuro-oncology field are extremely supportive and that patient advocates should leverage the support of these healthcare professionals to gain momentum with their efforts in underserved countries.

Discussions also focused on the IBTA "Brain Tumour Patients' Charter of Rights." Participants agreed that the Charter can be used as a starting point for new patient advocates in underserved countries. The charter defines the benchmark brain tumour patient advocates in all should strive towards.

The road ahead may be challenging, but it is through collective efforts that we can bring about tangible improvements, making quality healthcare a reality for all, irrespective of their geographic location or socioeconomic status.

Summit Masterclass 5
A deeper dive into molecular profiling of brain tumours

Facilitator: Carol Kruchko, Central Brain Tumor Registry of the United States (CBTRUS)

Speaker: Dr Tracy Batchelor, Brigham and Women's Hospital, United States

Carol Kruchko, IBTA Board member and President of the Central Brain Tumor Registry of the United States (CBTRUS) and senior advisor for the International Brain Tumour Alliance (IBTA) facilitated this session on "A Deeper Dive Into Molecular Profiling of Brain Tumours". Dr Tracy Batchelor, Professor of Neurology at the Harvard Medical School and Neurologist-in-Chief at Brigham and Women's Hospital in Boston, Massachusetts was the speaker in this session. At the time of this presentation Dr Batchelor was the President of the Society for Neuro-Oncology (SNO).

Tracy Batchelor opened his presentation with a slide adapted from CBTRUS data, which showed the overall distribution of common brain tumour types. He then led the masterclass through a series of slides starting with the history of the World Health Organisation (WHO) Classifications of Central Nervous System (CNS) Tumours. He spoke about the meetings held in Haarlem, The Netherlands, which resulted in the 2016 WHO Classification of CNS Tumours and the c-IMPACT-NOW meetings held in Utrecht, The Netherlands, which resulted in the 2021 WHO Classification of CNS Tumours.

Teams of neuropathologists reviewed the many types of brain tumours linking verified molecular markers with appropriate histopathologies. Both the 2016 and 2021 WHO Classifications included biomarkers for the first time in histology labels and are required for the molecular profiling currently used in diagnosis. A slide in Dr Batchelor's presentation titled "Updates for 2016 WHO" included: oligoastrocytoma discontinued, 1p-19q co-deletion identified oligodendroglioma, while 1p-19q non-co-deletion identified astrocytoma further divided into astrocytoma, IDH1 mutation and astrocytoma, IDH1 wild type.

The same slide also included the updates for the 2021 WHO Classification including the addition of astrocytoma, IDH-mutant, homozygous CDKN2A/B deletion elevating diffuse astrocytoma, IDH-mutant to Grade 4, and the more refined identification of glioblastoma, IDH-wild type. In an overview of 2021 WHO Dr Batchelor pointed out that 2021 WHO recognized the differences between adult and paediatric low and high-grade gliomas.

Carol Kruchko added that the 2016 WHO molecular markers are currently collected by cancer registries in the United States since 2018, but that the 2021 WHO molecular markers have only recently become required starting January 1, 2024. She said that this delay in reporting has been disappointing to CBTRUS and the clinical and research community as these data provide important statistical information.

Dr. Batchelor showed a slide listing the various molecular tests along with their timeframes. Broad-DFCI Whole Exome testing took the longest time to conduct at 21 days while MGMT testing took between five to seven days.





Professor Martin Glas (Germany) spoke to participants at the IBTA Summit about the challenges and solutions of brain-tumour related epilepsy.

The importance of having molecular profiling conducted was highlighted in the case histories that Dr Batchelor presented. While providing a "deeper dive into molecular profiling", he demonstrated how molecular profiling provides an important refinement in diagnostic accuracy directly affecting the patient's treatment plan and contributes to investigations of therapeutic targets.

PLENARY SESSION 4

Brain tumour related epilepsy: challenges and solutions

Chair: Mary Ellen Maher, Lou and Jean Malnati Brain Tumor Institute, United States

Speaker: Professor Martin Glas, Neuro-oncologist, Essen University Hospital, Germany

Key points

- Treating brain tumour patients is complex due to various factors and conditions.
- Epilepsy's role is significant regarding clinical definitions, diagnostic criteria, and differentiation from other conditions.
- Continued antiepileptic medication, as appropriate, was emphasised for brain tumour patients
- Epilepsy is a common symptom in brain tumour patients affecting quality of life and survival.
- There is a distinction between focal and generalised seizures based on brain areas involved.
- A single seizure presence is enough for an epilepsy diagnosis in brain tumour patients due to chronic disposing condition.
- Antiepileptic therapy initiation is recommended even without electroencephalogram (EEG) abnormalities.
- There can be an interaction between antiepileptic drugs (AEDs) and chemotherapy highlighting the challenges of enzyme-inducing AEDs (EIADs).
- Alternatives to EIADs exist such as levetiracetam, lacosamide, brivaracetam, and valproic acid were discussed.
- There is a selection of AEDs for brain tumour-related epilepsy which are effective and tolerable.

The presentation by Professor Martin Glas focused on the challenges and solutions related to epilepsy in brain tumour patients. Professor Glas highlighted the complexity of treating brain tumour patients due to the wide range of contributing factors and conditions. The presentation primarily discussed the significance of epilepsy in brain tumour patients, its clinical definitions, diagnostic criteria, differentiation from other conditions, and the importance of continued antiepileptic medication if required.

Professor Glas emphasised that treating brain tumour patients goes beyond finding the right therapeutic approach, as these patients sometimes present with various concomitant diseases that must be considered in their treatment plan. Epilepsy is identified as a common symptom in brain tumour patients, with significant implications for their quality of life and even survival.

Martin Glas defined epilepsy as a disease of the brain characterised by specific conditions. These conditions include at least two unprovoked seizures occurring more than 24 hours apart, or one unprovoked seizure along with a probability of further seizures similar to the general recurrence risk after two unprovoked seizures within the next ten years. The term "unprovoked" is crucial



in this definition, referring to the absence of temporary or reversible factors triggering a seizure.

Martin Glas distinguished between focal seizures that occur in localised brain areas (and may generalise) and generalised seizures that occur in both hemispheres, often resulting in loss of consciousness. The clinical presentation of seizures varies based on the anatomic location, and seizures can manifest as both motoric and non-motoric symptoms.

The presentation emphasised that in brain tumour patients, the presence of a single seizure is sufficient for diagnosing epilepsy due to the chronic disposing condition of brain tumours. Electroencephalogram (EEG) alterations also play a role in determining recurrence risk. Therefore, the recommendation is to initiate antiepileptic therapy, even without EEG abnormalities.

The interaction between antiepileptic drugs (AEDs) and chemotherapy was discussed, particularly enzyme-inducing antiepileptic drugs (EIADs) that affect the metabolism of chemotherapeutic agents. It was mentioned that some EIADs can impact patient survival time. Non-enzyme inducing antiepileptic drugs (NEIADs) like levetiracetam, lacosamide, brivaracetam, and valproic acid are considered alternatives.

Professor Glas provided insights into the selection of antiepileptic drugs for brain tumour-related epilepsy. Levetiracetam and lacosamide were highlighted for their effectiveness and tolerability in brain tumour patients. Valproic acid was also discussed, with a focus on its potential to reduce seizure frequency and its effects on thrombocytopenia and leukopenia.

The presentation concluded with a summary of key points. Martin Glas reiterated the importance of treating epilepsy in brain tumour patients, especially in cases of malignant gliomas where epilepsy should be considered chronic and treated accordingly. He emphasised that despite potential side effects, continued medication is crucial for reducing seizures and the harm they can cause to the brain.

Overall, the presentation provided valuable insights into the challenges and solutions surrounding epilepsy in brain tumour patients, helping to guide healthcare professionals in their treatment decisions.



Bec Mallett is the Founder and Chief Executive at the Peace of Mind Foundation in Australia.

Classifying brain tumours: a social science perspective

Speaker: Dr Henry Llewellyn, Department of Global Health and Social Medicine, King's College London, United Kingdom



Dr Henry Llewellyn emphasised that anthropology, as a social science, has a valuable role to play in understanding the social and ethical dimensions of classifying brain tumours, beyond the biological aspects.

Key points

- Classification of brain tumour is important for diagnosis, treatment, and research.
- The transition to the molecular era in neuro-oncology is expected to lead to more accurate tumour subtypes and tailored treatments.
- There are challenges of access to molecular technologies in resource-limited settings.

- Anthropology's role in mapping transnational knowledge space of cancer classification is important.
- Collaboration with pathologists, clinicians, and advocates in Uganda, Nigeria, and South Africa is planned.
- Dr Llewellyn's project objective is to understand stakeholder interests, and bridge gaps between resource-rich and resource-limited settings.
- Ethnographic methods involving qualitative interviews and deep observation will be employed.
- Collaboration with the International Brain Tumour Alliance (IBTA) will be helpful to include advocacy knowledge and perspectives



In his presentation, Henry Llewellyn, discussed the role of anthropology in the context of brain tumour classification. He addressed the challenges and considerations associated with classifying brain tumours, particularly from a social science perspective. Henry Llewellyn highlighted the importance of understanding the implications of classification on a global scale, particularly in resource-limited settings.

He acknowledged the unusual presence of an anthropologist in the field of brain tumour classification. He emphasised that anthropology, as a social science, has a valuable role to play in understanding the social and ethical dimensions of classifying brain tumours, beyond the biological aspects.

His presentation outlined the significance of classifying cancer types and subtypes for effective diagnosis, treatment, and research. The standardisation of clinical and biological data into shared terms is essential to ensure consistency in communication and to facilitate disease management. Classifications underpin epidemiological studies, healthcare policies, and treatment decisions.

Henry Llewellyn noted that the field of neuro-oncology has transitioned into the molecular era, with a focus on molecular understandings of brain tumours. This transition is expected to lead to more accurate tumour subtypes, consistent diagnoses, and tailored treatments. However, he also explained that this transition presents challenges related to access to technologies and expertise, especially in resource-limited settings.

He pointed out that classifications are not static; they evolve in response to changes in the field. With the advancement of molecular technologies, the question arises as to whether international classifications should prioritise cutting-edge technologies or be representative of the diagnostic capacities available globally. He highlighted the disparity in access to molecular technologies, particularly in the global South, and emphasised the ethical implications of such discrepancies.

Henry Llewellyn proposed that anthropology can contribute by mapping the transnational knowledge space of cancer classification. He presented his current project that aims to understand how ideas and knowledge are produced, standardised, and circulated between cancer classifiers mainly in the global North and countries in the global South. He will collaborate with pathologists, clinicians, and patient advocates from Uganda, Nigeria, and South Africa to explore brain tumour diagnosis and care in these distinct contexts.

The main objective of the project is to gain a deeper understanding of the interests of various stakeholders involved in brain tumour classification. This involves critically examining and interrogating current standards of classification and standardisation. The project aims to engage with diverse perspectives, bridge gaps between resource-rich and resource-limited settings and contribute to the improvement of brain tumour care.

Henry Llewellyn explained that the project employs ethnographic methods, which involve qualitative interviews and deep observation. The research will involve spending up to three months in laboratories and hospitals across Uganda, Nigeria, and South Africa, observing diagnosis and care processes, documenting available diagnostic technologies, and understanding the challenges faced in resource-limited settings. The project also involves collaboration with the International Brain Tumour Alliance (IBTA) to include expert knowledge from patient advocates.

The presentation concluded by underscoring the critical importance of considering global disparities in brain tumour classification and care. Henry Llewellyn's interdisciplinary approach, combining anthropology with medical research, aims to shed light on the social, ethical, and contextual dimensions of brain tumour classification. Through collaboration with stakeholders in diverse settings, the project aspires to contribute to more inclusive and equitable brain tumour care on a global scale.

Back to school with a brain tumour: an introduction to Brain Tumour Support New Zealand's education guide

Speaker: Chris Tse, Brain Tumour Support New Zealand, and Senior Advisor - International Brain Tumour Alliance (IBTA), New Zealand



An education guide to support New Zealand school children with a brain tumour was the focus of Chris Tse's presentation a the IBTA World Summit.

Key points

- Brain Tumour Support NZ was formed in 2019 to provide information, support, and advocacy for brain tumour patients.
- The organisation has produced an education guide for children with brain tumours returning to school.
- They collaborated and consulted with the New Zealand Ministry of Education and Regional Health schools.
- The guide is tailored to the New Zealand context, avoiding medical jargon, with practical advice for parents.
- Lessons learned by working on the project include doing thorough research, avoiding duplication, focussing on goals, leveraging expertise, seeking advice, maintaining a positive tone.
- The education guide and "Brain Box 4 Kidz" programme were launched successfully in August 2022.
- A Facebook group for parents of children with brain tumours was launched in January 2023.

Chris Tse presented the experience of creating an education guide to support families and children with brain tumours when they return to school in New Zealand. The presentation showcased the power of a small charity to make a meaningful impact on its community through targeted efforts.

Chris Tse began by providing context about New Zealand, a South Pacific nation with a population of just over five million people. The country is known for its multicultural society, influenced by indigenous Māori culture. The Māori health model emphasises holistic wellbeing, incorporating spiritual, mental, emotional, physical, and family/social aspects.

He shared statistics about brain tumours in New Zealand, with around 357 cases of malignant primary brain tumours diagnosed annually and approximately 278 related deaths. He emphasised that behind every statistic is a person, showing a picture of Tyla-Jaz (TJ) Inia-McGarvey and her grandmother Madeleine, who passed away from glioblastoma when TJ was only nine years old.

Chris introduced Brain Tumour Support NZ, a charity formed in 2019 to provide information, support, and advocacy for brain tumour patients in that country. He mentioned their various initiatives, including a website, the "Brain Boxes 4 Kidz" programme, support friends programme, online support groups, and more.

The focus of Chris Tse's presentation was the creation of an education guide to support New Zealand children with brain tumours in returning to school. He explained the process of identifying the unmet need for such a resource. He also emphasised the importance of collaboration and consultation with various stakeholders, including the New Zealand Ministry of Education, Regional Health schools, Starship Children's Hospital, and the parents advisory group. He also highlighted the importance of creating resources relevant to local patients (not just translating material created in other countries).

Chris Tse discussed the target audience of the education guide, which aims to help parents of school-age children aged three to seventeen. The guide's content is specifically tailored to the New Zealand context, avoiding medical and educational jargon, and focusing on practical advice for parents. It also includes a Māori language summary and incorporates quotes from parents and children for relatability.

According to Chris Tse, several valuable lessons were learned during the process of creating the education guide:

- Thorough research and collaboration are crucial.
- It is also vital to avoid duplicating existing resources and to identify gaps and unmet needs.



- It's best to focus on specific goals and stay within that scope.
- It's important to leverage expertise and play to strengths.
- It's also crucial to seek expert advice and foster collaboration with various stakeholders.
- Maintain a positive and inclusive tone in the guide's content.

Chris presented images of children benefiting from Brain Tumour Support NZ's initiatives. He mentioned the successful launch of the guide and the "Brain Box 4 Kidz" programme in August 2022. Chris also shared that a Facebook group for parents was launched in January 2023.

Chris concluded by emphasising the importance of collaboration, targeted efforts, and addressing unmet needs in supporting children with brain tumours and their families.

- BTFPAK's mission is to provide information, education, advocacy, and research.
- BTFPAK's initiatives include support groups, a patient navigator program and collaboration with hospitals.
- There is also a focus in Pakistan on collaboration between medical professionals and patient organisations.
- Future initiatives include a national Patient Navigator programme, partnerships and fundraising.

Medical experts and patient advocates coming together with one mission

Speaker: Dr Ather Enam,
Pakistan Society of Neuro-Oncology (PASNO)
Speaker: Komal Syed,
Brain Tumour Foundation Pakistan (BTFPAK)



Komal Syed (left) and Dr Ather Enam, both from Pakistan explained how they joined forces to provide better care and support to brain tumour patients in their country.

Key points

- Brain tumour patients in Pakistan have a range of critical unmet needs
- Financial constraints, geographic challenges and lack of insurance impact care in LMICs.
- BTFPAK and PASNO collaborate for patient advocacy and improved care.

The stories of Komal Syed, Founder of the Brain Tumour Foundation of Pakistan (BTFPAK), and Dr Ather Enam, President of the Pakistan Society of Neuro-Oncology (PASNO), highlight the critical need for comprehensive support and advocacy for brain tumour patients in Pakistan.

Their presentations delved into their personal journeys, the challenges faced by brain tumour patients and caregivers, the initiatives taken by BTFPAK and PASNO, and the collaborative efforts to improve the quality of life for brain tumour patients in Pakistan.

Komal Syed established the BTFPAK in memory of her late husband, Mohammed Taha Rafi, who succumbed to a glioblastoma in 2015. Taha's three-year battle with a brain tumour highlighted the lack of support mechanisms for patients and their families in Pakistan. Despite having a strong family network and dedicated medical professionals like Dr Enam, Komal and Taha felt isolated in navigating treatment options, obtaining second opinions, and coping with the daily impacts of the disease. This isolation intensified as Taha's condition worsened, particularly with memory loss.

After Taha's passing, Komal moved to Canada in 2016 to be close to her parents. In Toronto, she volunteered with the Brain Tumour Foundation of Canada and was inspired to make a difference for brain tumour patients in Pakistan. On a return visit to Pakistan in 2020 Komal worked alongside Dr Enam exploring ways to improve the quality of life and care for brain tumour patients and their families.



Komal Syed's parents from Pakistan were also in the audience at the IBTA World Summit.





Dr Ather Enam, a neurosurgeon, is Chair of the Department of Surgery at the Aga Khan University in Karachi, Pakistan.



Dr Enam, Taha's neurosurgeon and President of PASNO, expressed his frustration in providing comprehensive care to patients like Taha. Despite his medical expertise, he recognised the limitations in addressing patients' holistic needs due to financial constraints and geographic challenges in Pakistan. Dr Enam emphasised the high prevalence of catastrophic expenditure (the burden of health care expenditure - that is, out-of-pocket costs - on a household's available resources) associated with cancer treatment in low- and middle-income countries (LMICs) like Pakistan, where many individuals lack medical insurance coverage.

He underscored the importance of focusing on essential techniques and innovative approaches to bridge the gap in access to treatment. Dr Enam acknowledged the need for collaboration, research, and customised solutions that consider the local context and socioeconomic challenges of LMICs.

Dr Enam highlighted the financial burden of cancer treatment in LMICs and the disproportionate impact on families' economic well-being. He discussed the lack of insurance coverage and the catastrophic healthcare expenditure faced by a significant portion of the population. Additionally, the absence of comprehensive follow-up care and distance-related challenges hindered patients' ability to access treatment and support.

He shared two poignant cases that illustrated the struggles patients and families encounter due to financial constraints and distance-related barriers. These cases emphasised the urgent need for practical solutions that consider both medical and non-medical support for brain tumour patients in LMICs.

Komal Syed outlined BTFPAK's mission to provide brain tumour patients and their families in Pakistan with access to information, education, patient advocacy, and research. The Foundation seeks to improve the quality of life for brain tumour patients and aims to make their journey easier than Taha's was. BTFPAK focuses on creating awareness, offering non-medical support, and collaborating with medical professionals and organisations. The first steps included creating awareness about the existence of the Foundation so that professionals and families could refer patients to BTFPAK for support. It also entailed explaining how the Foundation could improve quality of life for patients and caregivers.

She emphasised the interconnectedness and importance of collaboration between medical professionals and patient organisations in supporting patients comprehensively. BTFPAK's initiatives include running support groups, establishing a patient navigator programme, and working closely with hospitals and medical experts to address patients' needs across the patient journey.

BTFPAK's future initiatives include building partnerships with hospitals, launching a national Patient Navigator programme, offering customised support in partnering hospitals, and engaging in fundraising efforts to scale their impact. Dr Enam focuses on essential techniques, disruptive innovations, and local solutions to improve access to care in LMICs.

The stories of Komal Syed and Dr Ather Enam underscore the challenges faced by brain tumour patients and caregivers in Pakistan and similar LMICs. Their collaborative efforts through the Brain Tumour Foundation of Pakistan and the Pakistan Society of Neuro-Oncology reflect a commitment to addressing these challenges comprehensively.

By focusing on medical and non-medical support, research, awareness, and advocacy, they aim to provide brain tumour patients and their families with a more supportive and empowered journey. This collaborative approach holds promise for enhancing brain tumour patient care and quality of life in Pakistan and beyond.

Challenges of a brain tumour diagnosis in Mongolia

Speaker: Batchimeg Batchuluun,
Nomax Publishing, Mongolia



Batchimeg Batchuluun travelled all the way from Mongolia to join the IBTA World Summit and share her experience of caring for her mother who had brain metastases.

Key points

- Mongolia's cancer statistics are alarming; it ranks first in liver and stomach cancers.
- Mongolia ranks 97th in brain tumour cases, lack of treatment and support.
- Brain tumours are categorised as incurable in Mongolia; patients seek treatment abroad.
- Batchimeg's mother was diagnosed with brain metastases in 2021.
- Lack of accessible information in the Mongolian language compounds challenges.
- Batchimeg's discovery of the "End of Life Care for Brain Tumor Patients" manual from the University of California San Francisco (UCSF) was an invaluable resource.
- Batchimeg translates critical materials regarding brain tumours into Mongolian.
- She issued a call to action for caregivers and advocates to join translation efforts.
- There is a pressing need for peer support networks and brain tumour support groups in Mongolia.

Batchimeg Batchuluun, a caregiver and founder at Nomax Publishing, shared the significant obstacles encountered in her journey as a caregiver to her mother who was diagnosed with a brain metastasis in 2021. Her presentation highlighted the unique challenges faced in Mongolia, the current state of brain tumour diagnosis and treatment in her country and the efforts being undertaken to improve the situation for patients and caregivers there.

Batchimeg Batchuluun's personal journey as a caregiver for her mother, serves as a poignant backdrop to the challenges faced in Mongolia's healthcare system. Mongolia is a country located between Russia and China, with a population of approximately 3.4 million and Mongolian is the official language.

Cancer statistics in Mongolia are alarming, with the country ranked highest for incidence of liver and stomach cancers globally. Furthermore, brain tumours are categorised as incurable diseases in Mongolia, leading to patients having to seek treatment abroad.

Batchimeg Batchuluun's mother Enkhtuya Palamdorj (1960 - 2022), an economist who worked in the Tax Department of Mongolia, was diagnosed and treated for breast cancer in 2005. Breast cancer recurred in 2014 and then in 2020 spread to the lung and pancreas. She was treated at the time with surgery, chemotherapy, and radiotherapy.

In 2021, after being found lying unconscious on the floor, Enkhtuya was diagnosed with a metastasis to the brain. This marked the beginning of Batchimeg's journey as a caregiver.

Brain tumours are included in a list of conditions requiring overseas treatment in Mongolia, due to their categorisation as incurable. However, only a small portion of expenses, around 5%, can be reimbursed by relevant Mongolian authorities, leaving patients with substantial financial burdens.

Mongolia's brain tumour statistics indicate that it ranks 97th globally for incidence, with 150 registered cases in 2021. Despite the relatively low incidence, the challenges lie in the lack of available treatments and support within the country. While Mongolia does have MRI facilities, they are not fully covered by social health insurance. The introduction of PET scan tests in secondary hospitals in July 2021 was a significant development; the absence of PET scans previously meant that patients had to travel overseas for this test. Moreover, the lack of accessible information and resources in the Mongolian language exacerbates the challenges faced by caregivers and patients.

Batchimeg Batchuluun shared her personal challenges as a caregiver, particularly during the end-of-life phase of her mother's



journey. During the final weeks, brain tumour patients experience increasing motor and sensory problems, may lose control of bowel and bladder, have problems with eating and drinking and experience headaches. All of these can be very distressing to caregivers and family members, especially if they don't know what to expect and are not prepared to support the patient and understand symptom relief during this phase.

The lack of accessible information in the Mongolian language in her country and on the internet compounded Batchimeg Batchuluun's struggles. However, her discovery of the "End of Life Care for Brain Tumor Patients" manual for healthcare providers (available online) from the University of California San Francisco (UCSF) became an invaluable resource, offering comprehensive insights into symptoms, challenges, and expectations during this critical phase.

Inspired by her experience and the need for accessible resources in her language, Batchimeg embarked on a journey to translate critical materials into Mongolian. She chose to translate the "Transitions in Care for Patients with Brain Tumours: Palliative and Hospice Care" manual (also available online in English from the UCSF website) ensuring that families facing similar circumstances could benefit from the expertise of professionals. Batchimeg submitted her translation to medical professionals to review terminology and then to a university translation service for their review and approval.

Batchimeg Batchuluun's initiative underscores the importance of bridging language barriers and making essential information available to those who do not have proficiency in English.

Her call to action resonates with caregivers and advocates, urging them to join her initiative in translating crucial materials for patients and caregivers. The absence of a brain tumour support group in Mongolia highlights the need for peer support networks to facilitate knowledge-sharing, emotional support, and guidance for caregivers and patients alike.

Her dual role as a caregiver for her mother and mother-in-law Doljin (who was also diagnosed with a brain metastasis in 2022, from a primary tumour of the sinus treated in 1996) underscores the extent of the challenge and the urgent need for systemic improvement.

In Mongolia, the challenges faced by caregivers and patients dealing with a brain tumour diagnosis and their subsequent care needs underscore the importance of access to treatment and resources, language-sensitive information, and peer support networks. Batchimeg Batchuluun's journey serves as a testament to the resilience and creativity of caregivers in finding ways to fill in gaps, as well as the urgent need for collaborative efforts between caregivers, medical professionals, and advocacy organisations to improve the quality of life for those affected by brain tumours in Mongolia.































DAY TWO

Tuesday 27 June 2023

PLENARY SESSION 5

Chair: Rosemary Cashman, Senior Advisor - International Brain Tumour Alliance, Canada

Reducing stress in brain tumour patients

Speaker: Noa Faaij,
University of Amsterdam, The Netherlands

Key points

- Stress in brain tumour patients can be short-term or long-term, affecting well-being.
- Noa Faaij's research involved a study with 57 brain tumour patients to assess stress levels, awareness, and coping mechanisms.
- Results show 50% of patients reported unacceptable stress levels.
- MRI scans emerged as a significant stressor, leading to "Post Traumatic Brain Tumour Disorder."
- Interventions to reduce stress include cognitive behavioural therapy, support groups, pharmacological options, exercise, music, and mindfulness.
- In Noa Faaij's study, guided interventions with exercise, music, and mindfulness led to a 33% stress reduction in three weeks.
- Stress reduction can improve patients' quality of life and treatment outcomes.
- Stress reduction efforts should also involve caregivers and consider their stress as well.

The presentation by Noa Faaij, a board member of the Stichting STOPhersentumoren.nl foundation in The Netherlands and a double bachelor student of medicine and biomedical sciences at the University of Amsterdam, focused on the critical issue of reducing stress in brain tumour patients. Drawing from personal experience, research findings, and a deep passion for improving the lives of those affected, she highlighted the profound impact of stress on brain tumour patients and proposed interventions to alleviate this burden.



Noa Faaij from STOPhersentumoren.nl gave a masterful presentation on reducing stress in brain tumour patients.

Noa Faaij's personal journey into this topic began with her father's diagnosis of oligodendroglioma when she was only three years old. She recounted her father's struggles with, not just the disease itself, but also the immense stress it brought. The lack of support for brain tumour patients compared to other victims of trauma, like crime victims, motivated Noa to delve into the connection between stress and brain tumours.

Noa explored the dual nature of stress experienced by brain tumour patients. Stress can be short-term, triggered by specific events like diagnoses or treatment, or it could be long-term, resulting from the ongoing challenges patients face, such as cognitive decline and post-treatment recovery. This stress can manifest both physically and psychologically, affecting patients' overall well-being.

To address the lack of knowledge on stress and brain tumours, Noa Faaij designed a randomised controlled trial involving 57 patients from the University Medical Centre in the Dutch city of Utrecht and brain tumour support groups. Her research aimed to determine if brain tumour patients experienced stress, how aware they were of their stress levels, their coping mechanisms, and whether interventions could reduce stress.

The results of Noa's study (published in Brain Tumour Magazine) revealed that 50% of brain tumour patients reported unacceptable levels of stress. Surprisingly, 98% of loved ones recognised stress





Enircling the globe, from left to right are: Noa Faaij (STOPhersentumoren.nl), Klaske Hofstee (STOPhersentumoren.nl), and co-directors of the IBTA Kathy Oliver and Gordon Oliver.



From left to right: Roberto Pugliese (President, Glioblastoma.it ODV, Italy), Noa Faaij and Klaske Hofstee (both from The Netherlands).

experienced by the patients, highlighting a disparity between patients' self-awareness and external observations.

Notably, events like diagnosis and new tumour growth were identified as highly stressful, but the MRI scan emerged as a consistent stressor, evoking a phenomenon Noa termed "Post Traumatic Brain Tumour Disorder" (PTBTD). It was not so much the act of undergoing the MRI as the thought processes it triggers in patients (facing their mortality, fear that the MRI will show a new growth, fear for loved ones if the diagnosis is bad and worry about how the family will cope if they die).

Noa explained that current treatments prioritise quantity of life. She urged health professionals to prioritise quality of life because of its possible effect on prognosis and the success of treatments themselves. She emphasised the urgent need to address stress due to its potential adverse effects on tumour growth and metastasis, as well as the overall well-being of patients. Stress compromises immunity, creating opportunities for further tumour invasion and the development of other health problems, such as cardiovascular disease. The relationship between stress and brain cancer, while not fully understood, necessitates further investigation.

Noa Faaij explained that a range of interventions can reduce stress among brain tumour patients. These include cognitive behavioural therapy, support groups, pharmacological options (including natural remedies such as CBD), and simple interventions such as spending time with pets or having a bath.

Her intervention group experienced the use of exercise, music, and mindfulness for eight weeks. Noa's research demonstrated that guided interventions with these three tools led to a 33% reduction in stress within three weeks, indicating the potential for improving patients' quality of life. Patients in the intervention group felt more at ease and educated to cope with stressful events. They also thought that music and physical exercise were the most effective interventions.

Her presentation underscored the urgent need to address stress in brain tumour patients. Her personal connection, rigorous research, and innovative interventions shed light on the profound impact of stress on patients' well-being and on treatment prognosis. She pointed out that more research is needed, and that Maastricht University in The Netherlands has started research on the connection between stress and treatment outcome.

During the question-and-answer session following her presentation, Noa Faaij addressed inquiries about measuring the impact of interventions, considering caregivers' stress, and the role of MRI scans in evoking stress. She highlighted the importance of both objective and subjective measurements of stress; of tailoring interventions to individual needs and involving caregivers in stress reduction efforts since their stress sometimes surpasses that of patients. Caregiver's stress also affects patients, so it would be important to reduce their stress to create an environment of stress reduction.

In summary, Noa Faaij's presentation shed light on the critical intersection of stress and brain tumours, offering insights into patients' experiences, possible interventions, and the potential for improving patients' quality of life, thereby impacting treatment and outcomes. Her dedication and passion inspired attendees and provided hope for a future where stress reduction becomes an integral part of brain tumour patient care.

The Ukraine crisis and brain tumour patients

Speaker: Anna Uzlova,
Inspiration Family, Ukraine



Anna Uzlova, one of the founders of the Ukrainian cancer organisation, Inspiration Family, gave a moving and powerful presentation on the situation for brain tumour patients in her war-torn country.

Key points

- Inspiration Family was founded in 2020 by cancer survivors to transform Ukraine's cancer treatment landscape.
- The charity focusses on systemic changes, support projects, and educational initiatives for cancer patients.
- The war in Ukraine disrupted cancer centres, treatment procedures, and medication supplies.
- The charity provides accurate information through Messenger and social media to help patients amidst the chaos of war.
- The charity collaborated with EU institutions to facilitate temporary treatment relocation for Ukrainian cancer patients.
- Inspiration Family continues to drive systemic changes in the Ukrainian healthcare system.
- Brain tumour patients in Ukraine face financial barriers due to lack of insurance coverage.
- The charity aims to bridge the gap between brain tumour patients and available resources.
- International community support will be crucial for rebuilding healthcare infrastructure in post-war Ukraine.



Gordon and Kathy Oliver (left, IBTA), and Anna Uzlova and Inessa Matiushenko, Co-Founders, Inspiration Family, Ukraine, proudly hold the Ukrainian flag aloft at the IBTA World Summit.

Anna Uzlova presented the challenges faced by the Inspiration Family charity in Ukraine due to the war with Russia and its impact on cancer patients, specifically those suffering from brain tumours. The charity's efforts to provide support, access to treatment, and improve the healthcare system were highlighted.

The Inspiration Family charity was founded in September 2020 by five women who are cancer survivors themselves. Their collective goal is to transform Ukraine into a country where cancer is treatable. The organisation focuses on systemic changes, collaborates with government institutions, and offers educational and emotional support for cancer patients.

Before the outbreak of the war, the charity had several ongoing projects aimed at helping cancer patients, including the "Goodbye Hair" project, entertainment programmes, cancer survivors' forums, and races for cancer cure. They had also planned to launch a peer-to-peer support program in oncology.

With the invasion of Ukraine by Russia on 24 February 2022, the situation drastically changed. Cancer centres were disrupted, medication warehouses were blocked, and treatment procedures were halted due to the danger posed by the conflict. Despite the confusion and challenges, the Inspiration Family charity continued to work to support cancer patients amidst the chaos.

The charity recognised the urgent need to provide accurate information to cancer patients in wartime, as official channels





Pictured centre above is Erik Ramos from Northwest Biotherapeutics.

were not providing sufficient communication. They undertook the task of gathering information from cancer centres and medical professionals across Ukraine, compiling it into Messenger (a popular messaging application in Ukraine) and social media platforms. This provided patients with a reliable source of information about available treatments and resources in Ukraine and abroad.

To address the situation, the charity collaborated with European Union institutions to facilitate the temporary relocation of Ukrainian cancer patients for treatment. They partnered with European organisations and patient organisations like the International Brain Tumour Alliance to support patients' needs, including accommodation and treatment. Additionally, the charity maintained communication with the global community to raise awareness about the plight of cancer patients in Ukraine.

The charity's focus remains on driving systemic changes in the Ukrainian healthcare system. They continue to collaborate with government institutions and international organisations to ensure patients' rights and access to treatment. The charity also works to coordinate medical evacuations, secure humanitarian aid, and provide psychological and social support for patients.

Anna Uzlova's presentation highlighted the specific challenges faced by brain tumour patients in Ukraine. Inspiration Family carried out a survey that revealed that a significant portion of brain tumour patients were not covered by medical insurance. Patients had to personally fund their surgeries, radiotherapy, and medications. Additionally, the survey pointed out the need for psychological, social, and legal support for these patients.

Financial barriers were a significant concern for brain tumour patients, as nearly 70% of them were unable to cover the cost of treatment despite government promises of coverage. Surgical expenses proved to be a major challenge for patients, with the current economic situation exacerbating this issue.

The presentation underscored the essential support needed for brain tumour patients in Ukraine, including access to treatment, insurance coverage, psychological assistance, social support, legal guidance, and assistance in acquiring necessary medications. The charity aims to bridge the gap between patients and the resources available to them.

Anna Uzlova recounted the inspiring story of Julia, a 28-year-old brain tumour patient from Kherson who has an autistic daughter. Julia has faced numerous challenges while seeking treatment amidst the crisis in war-torn Ukraine. Despite having to flee her hometown and experiencing her house flooded after Russians destroyed the Khakovska power station, she is persevering and continues her fight against cancer.

The ongoing crisis in Ukraine has posed unprecedented challenges for cancer patients, particularly those with brain tumours. The Inspiration Family charity's relentless efforts to provide information, access to treatment, and emotional support demonstrate the need for non-governmental organisations (NGOs) that can step in during times of crisis to alleviate the suffering of cancer patients. Through collaboration with government bodies, international organisations, and the global community, the charity continues to advocate for systemic changes and access to treatment, ultimately aiming to transform Ukraine into a country where cancer is treatable.

When the war is over, the Ukrainian healthcare infrastructure will need to be rebuilt. This effort will require substantial support from the international community.

Raising awareness of the challenges of brain tumours through community engagement

Speaker: Hugh Adams,
Brain Tumour Research, United Kingdom

Key points

- There needs to be an emphasis on engaging community beyond brain tumour-affected individuals.
- The "Wear a Hat Day" event symbolises outreach efforts, attracts diverse participants, and generates funds.
- Empowerment is a core theme, encouraging patients to voice concerns and advocate for change.
- The work of Brain Tumour Research focusses on structured messaging with three key points: the issue, organisation's action, call to action.
- Social media has a crucial role in building community, sharing content, and increasing awareness.
- Collaboration with other organisations in cancer and neuroscience is vital to pool resources and efforts.
- Building trust and maintaining visibility through consistency and reliability is key.



Hugh Adams of Brain Tumour Research explains how to raise awareness of brain tumours through community engagement.

Hugh Adams' presentation highlighted the impactful work of the Brain Tumour Research charity in raising awareness and funds for brain tumour research in the United Kingdom. Hugh Adams has over 13 years of experience with Brain Tumour Research and emphasised the importance of engaging the community beyond those affected by brain tumours and empowering patients to drive change and increase awareness.

He said that this is essential because people cannot support a cause they are unaware of. To reach beyond traditional audiences, the charity organises events such as the "Wear a Hat Day," which encourages people to wear hats of any kind to symbolise their support of brain tumour research and has become synonymous with the organisation in the UK.

By collaborating with milliners and engaging with the horse racing community (among others), they have attracted individuals who wouldn't typically engage with their cause. Hugh Adams also revealed that the "Wear a Hat Day" event alone brings in a significant amount of funds, demonstrating the impact of visually engaging activities that can be easily shared on social media.

Empowerment emerged as a core theme in his presentation. He emphasised that providing a sense of hope and empowerment to those affected by brain tumours is crucial for encouraging proactive engagement. Empowering individuals with the belief that they can make a difference and bring about change is vital. The charity strives to empower patients to voice their concerns and challenges.



By challenging the status quo and advocating for change, they provide hope to individuals facing the daunting diagnosis of a brain tumour. Hugh Adams also stressed the importance of speaking truth to power, taking campaigns to Westminster, and interacting with politicians (ministers, local representatives) to bring about policy changes.

His presentation highlighted the significance of structured messaging (beginning, middle and end) to effectively convey the cause to different stakeholders. The importance of structuring messages around three key points was emphasised:

- what the issue is
- what the organisation is doing about it, and
- how others can help (a clear call to action)

This structure aids politicians, media, and the public to engage with and act upon messages. This strategy enhances the ability to convey complex issues like brain tumours in a concise and understandable manner. Additionally, Hugh Adams highlighted the necessity of offering a clear call to action to drive engagement and support.

He stressed the role of social media in amplifying awareness efforts. He emphasised that social media engagement is essential for building a community, sharing content, and increasing awareness. He shared insights from a social media expert who compared not engaging on platforms to standing in a room full of people facing the wall. Regular engagement, posting relevant content, and actively participating in conversations are essential for maximising the reach of awareness campaigns. There has never been an easier time to be known and get a message across, thanks to social media.

Hugh Adams also discussed the importance of collaborating with other organisations in the cancer and neuroscience fields to pool resources, knowledge, and efforts. Collaborations can help address common challenges and advance research and advocacy initiatives. He highlighted the potential for collaboration on topics such as the impact of stress, loss of driving licenses, and insurance costs that impact brain tumour patients and were discussed previously at the Summit. By participating in conversations surrounding these topics on social media, organisations can elevate their profile and contribute meaningfully to the conversation.

The presentation concluded by emphasising the importance of building trust and maintaining visibility. Consistency and reliability were highlighted as key attributes in gaining trust and support. By keeping promises and being a consistent, reliable, and timely source of valuable information, organisations can establish themselves as trusted sources. Hugh Adams urged organisations to be visible and value people, encouraging them to embody the qualities that generate loyalty and support.

The presentation highlighted Brain Tumour Research's successful approach to raising funds and awareness of brain tumours through community engagement. By reaching beyond their immediate community, empowering individuals, advocating for change, structuring messages effectively, leveraging social media, collaborating with other organisations, and building trust, the charity has effectively raised awareness and funds for brain tumour research.

The Insights shared In the presentation provided valuable guidance for other organisations seeking to engage their communities and drive positive change.

Creating weekend retreats for brain tumour patients and their families

Speaker: Bec Mallett,
Peace of Mind Foundation, Australia

Key points

- Retreats play a crucial role in reducing isolation, providing respite, fostering community, and offering distraction from challenges.
- Types of retreats include men's, women's, caregivers', and family retreats.
- Activities include movie nights, scavenger hunts, reptile shows, driving adventures, pampering sessions, mindfulness, photography, and more.
- Practical insights into planning and organising retreats, including recruiting volunteers with relevant skills, collaborating with medical professionals, collecting participant information, training volunteers, aligning the venue with demographics, and logistics were also highlighted.
- Promotion strategies involve email, direct messaging, social media and partnerships with hospitals and clinicians.
- Budget considerations encompass accommodation, catering, activities, entertainment, and essential supplies.
- Involvement of volunteers is key; they contribute time and funds, and seek discounts, donations, and support from local businesses.
- Testimonials showcase the profound impact of retreats on participants' lives.

Bec Mallet, Founder and CEO of the Peace of Mind Foundation in Australia. shared insights on how to successfully organise and host retreats for brain cancer patients, their caregivers, and families. The presentation highlighted the Foundation's mission, services, and the transformative impact on the lives of those affected by brain cancer when they can take time away for a break from their daily lives.

Bec Mallet introduced Peace of Mind Foundation as Australia's largest brain cancer support charity, dedicated to providing comprehensive support to brain cancer patients and their families. Their vision is to ensure that every family in Australia impacted by brain cancer receives the necessary support. The Foundation offers a range of services, including advocacy, resources, financial assistance, counselling, support groups, and retreats.



Bec Mallet of the Peace of Mind Foundation in Australia.

Examples of services include:

- the Brain Cancer Navigator Programme that sees a nurse visit people at home helping them to deal with their diagnosis, from the beginning through to bereavement.
- a national advocacy service that provides information on accessing support services such as the National Disability Insurance Scheme; funds to help keep patients at home for as long as possible; and access to social welfare payments.
- the Survivorship Diary that helps keep track of appointments, treatments and suggests questions to ask health professionals.

Bec Mallett emphasised the transformative experience of retreats for patients. Retreats play a vital role in reducing isolation, offering respite for caregivers, fostering a sense of understanding and acceptance, and building a strong, supportive community. These events serve as distraction and relief from the challenges of treatment and prognosis for brain cancer patients and their families. Different types of retreats were highlighted, including men's, women's, caregivers', and family retreats, each catering to specific needs and creating an inclusive environment.

Her presentation showcased the variety of activities that form the backbone of these retreats, from movie nights and scavenger hunts to reptile shows, driving adventures, and pampering sessions. The retreats also include sessions on mindfulness, photography, makeup and hair sessions, and thematic dinners, all designed to provide relaxation, joy, and a sense of connection. The itinerary of each retreat is structured to accommodate various interests, needs, and energy levels, ensuring an inclusive experience.

Bec Mallett provided practical insights into planning and organising brain cancer retreats. Key considerations included recruiting sufficient volunteers, ensuring they possess relevant skills, collaborating with doctors and nurses for medical support, securing photographers and videographers to capture moments.

She stressed the significance of collecting vital participant information, including contact details, medical history, specific needs, and emergency contacts. Training for volunteers and staff, focusing on brain cancer understanding, mental health first aid, and organisational policies, was deemed essential to create a supportive and knowledgeable team. The importance of aligning the venue with the demographics of participants and the logistics of public transport was also highlighted.



Bec Mallet organises special retreats for people with brain tumours and spoke of the profound impact of these events which offer respite, camaraderie and joy to patients, their caregivers and families.

Promotion strategies included leveraging email, direct messaging, social media, and partnerships with local hospitals and clinicians to disseminate information about the retreats.

Also important is to have a defined budget that covers accommodation, catering, activities, entertainment, and essential supplies like first aid kits. She suggested the involvement of volunteers who could contribute both time and a financial component to cover their participation. She also encouraged seeking discounts, donation of services, and support from local businesses to make the retreat affordable. The "pay it forward" policy was introduced, allowing donors to contribute funds for families to attend the retreats, fostering a sense of community engagement and generosity. Sponsors are invited to participate or visit the retreat.

Bec Mallett concluded her presentation by sharing the profound impact of these retreats through heart-warming testimonials. Examples were provided where families and patients expressed gratitude for the transformative experiences and connections made thanks to the retreats. Bec herself met her husband at one of Peace of Mind Foundation's retreats, further illustrating the impact of the initiative.



Bec Mallett (right) along with fellow-Australians Catherine Hindson, centre, (Brain Tumour Alliance Australia, BTAA) and Peter Ramstadius, left, also from BTAA.

The presentation highlighted the invaluable role of brain cancer retreats in offering respite, camaraderie, and joy to brain cancer patients, their families, and caregivers. The practical insights, including planning, budgeting, recruitment, and organisation tips, provided a comprehensive approach to hosting successful events. The stories of personal growth, connection, and transformation underscored the profound difference such retreats can make in the lives of those affected by brain cancer.

What can you do for neuro-oncology medical societies and what can they do for you?

Speaker: Chas Haynes,
Society for Neuro-Oncology (SNO), United States

Key points

- SNO's membership includes over 3000 healthcare professionals from 44 countries, covering diverse subspecialties in neuro-oncology.
- SNO facilitates communication among neuro-oncology researchers, promoting knowledge exchange and advancement.
- SNO hosts conferences and events, including the *Biennial Pediatric Neuro-Oncology Research Conference* and the *SNO Annual Meeting*, to foster collaboration and knowledge sharing.
- SNO collaborates with partners to publish academic journals: *Neuro-Oncology*, *Neuro-Oncology Practice*, and *Neuro-Oncology Advances*.
- The *Neuro-Oncology Academy* is SNO's e-learning platform, offering free access to education modules in neuro-oncology.
- SNO engages in outreach efforts, offering travel scholarships, webinars, and support for professionals in low-middle-income countries (LMICs) and community settings.
- SNO collaborates with advocacy partners like IBTA to address critical issues and provide support.
- *The Quadrennial World Federation of Neuro-Oncology Meeting* in November 2025 will bring experts together in Honolulu, Hawaii.



The Society for Neuro-Oncology's Chief Executive Chas Haynes.

The Society for Neuro-Oncology (SNO), based in the United States, is a professional organisation dedicated to advancing multi-disciplinary brain tumour research, education, collaboration, and improving patient care. Chas Haynes, Executive Director of SNO, highlighted its mission, membership composition, key activities, conferences and events, publishing initiatives, education platforms, outreach efforts, partnerships, and upcoming plans.

He began by introducing SNO and emphasising their collaborative approach to working with advocacy partners, policy partners, industry partners, and within the organisation itself. The guiding principle: "If you want to go fast, go alone. If you want to go far, go together," underscores their commitment to collaboration.

SNO's membership consists of healthcare professionals dedicated to developing new therapies and improving outcomes for brain tumour patients. As of 2022, SNO had over 3000 members from 44 countries worldwide. The organisation covers a wide range of subspecialties within neuro-oncology, including neuro oncologists, neurosurgeons, radiation oncologists, pathologists, medical oncologists, allied healthcare professionals, and basic scientists. The diversity statement on the SNO website reflects their commitment to inclusivity and welcoming professionals from various backgrounds.

SNO facilitates communication among researchers in neuro-oncology to drive discoveries and advances in the field. Their primary role includes providing education through conferences and events, academic publishing, and e-learning platforms.

SNO hosts various conferences and events to foster knowledge exchange and collaboration within the field. These events include the *Biennial Pediatric Neuro-Oncology Research Conference*, the *Conference on CNS Clinical Trials and Brain Metastases* in partnership with the American Society of Clinical Oncology (ASCO), and the *SNO Annual Meeting* where researchers, clinicians and scientists from around the world gather to share the latest findings.

SNO collaborates with partners to publish academic journals that contribute significantly to the brain tumour field:

- *Neuro-Oncology*, their leading journal launched in 1996, was created in partnership with the Pediatric Brain Tumor Foundation.
- *Neuro-Oncology Practice*, focusing on practical aspects of neurology, was launched in collaboration with the National Brain Tumor Society and the European Association of Neuro-Oncology (EANO)
- *Neuro-Oncology Advances*, a fully Open Access journal, offers free and immediate access to articles and is developed in partnership with EANO.

The Neuro-Oncology Academy is an e-learning platform on the SNO website. It offers fourteen content areas and many modules to provide education in neuro-oncology. The Academy is accessible to all, offering free access to enrich the knowledge of professionals and the broader community.

SNO actively engages in outreach efforts to support professionals in low-middle-income countries (LMICs) and those providing care in community settings. SNO provides travel scholarships, webinars, and faculty support to neuro-oncologists in LMICs.

SNO collaborates closely with advocacy partners like the International Brain Tumour Alliance (IBTA) to address critical issues, such as the impact of the COVID-19 pandemic on brain tumour patients. They have jointly issued statements (for example on the situation in Ukraine), hosted meetings, and conducted surveys to provide support and guidance to patients and caregivers.

SNO is preparing for the Quadrennial World Federation of Neuro-Oncology Meeting in November 2025, which will take place in Honolulu, Hawaii. This special event will bring together experts and professionals from around the world to share and advance the field of neuro-oncology. Chas Haynes invites everyone to join.

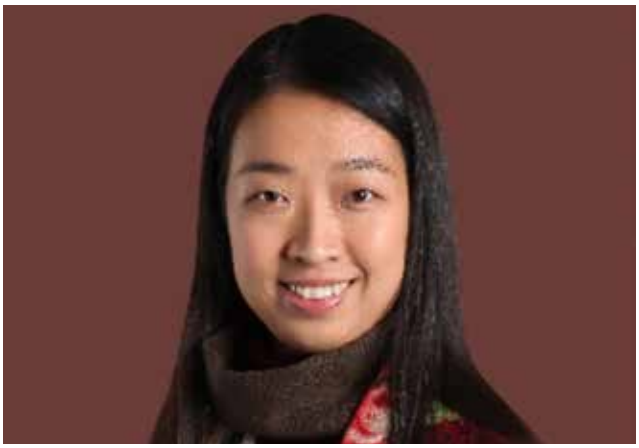
His presentation showcased SNO's dedication to collaboration, education, and advancing brain tumour research and patient care. SNO's conferences, publishing initiatives, and educational platforms, combined with their advocacy and non-profit partnerships, contribute to their mission of driving discovery and improving patient outcomes in the field of neuro-oncology.



Chas Haynes from the Society for Neuro-Oncology (SNO) explained that the Society is dedicated to collaboration, education and advancing brain tumour research and patient care.

Brain tumour patient support in China (pre-recorded)

Speaker: Dr Chengcheng Guo and Dr Xiaoqun Chen, Department of Neurosurgery and Neuro-Oncology, Sun Yat-sen University Cancer Centre, China



Chengcheng Guo is from the Sun Yat-sen University Cancer Centre in China.

Key points

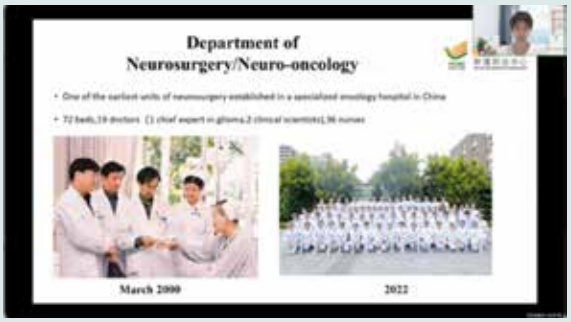
- Sun Yat-sen University Cancer Centre in China is the largest integrated cancer centre in the region, focusing on care, research, education, and prevention.
- The Department of Neurosurgery and Neuro-Oncology offers a comprehensive approach to patient care, including physiological care, psychological support, family assistance, and social support.
- Initiatives like a dedicated patient activity room for children, cultural and festival activities, professional psychological nurses, and events like "Every Second Counts" and "Brain Trekking" enhance patient well-being and community support.
- The department developed the Glioma Science Education Manual to enhance patients' understanding of their condition, improving their quality of life and survival prospects.
- Challenges remain, such as increasing social organisation involvement, addressing cognitive impairments, providing comprehensive psychosocial support, and facilitating patient reintegration into society.











These are a series of frames from Dr Guo's and Dr Chen's video which was played at the World Summit in Vienna.

Dr Chengcheng Guo, representing the Department of Neurosurgery and Neuro-Oncology at Sun Yat-sen University Cancer Centre in China, presented a comprehensive overview of their hospital, department, and initiatives aimed at enhancing the care and well-being of brain tumour patients.

Sun Yat-sen University Cancer Centre, which opened in March 1964 as a small tumour hospital in southern China, has since transformed into the largest integrated cancer centre in the region, focusing on care, research, education, and prevention. The presenter highlighted the growth of the centre from its modest beginnings to its current status, featuring 2100 beds, 26 operating rooms, and 15 radiotherapy units across two campuses with plans for a third cancer campus. The centre's dedication to international exchange and partnerships with renowned hospitals was also emphasised.

The Department of Neurosurgery and Neuro-Oncology is noted for being one of the earliest specialised oncology units with a focus on neurosurgery in China. It currently consists of 72 beds, 90 doctors, and 36 nurses dedicated to the treatment of brain tumour patients. The department's ethos revolves around the principles of cooperation and comprehensive patient management.

Brain tumour patients present complex treatment needs, and their incidence is steadily increasing. Despite this, the social awareness of brain tumours remains relatively low. Patients and their families experience a range of physical and psychological challenges during the extended treatment process. Additionally, many of their needs remain unmet due to limited medical resources. The department's primary concern is to help patients manage their condition effectively, alongside their families and society.

The department offers a holistic approach to patient care, encompassing professional physiological care, psychological support, family assistance, and social support. These services are rooted in medical humanistic care, incorporating various forms of expression such as art, music, and video to provide comprehensive assistance to patients.

A dedicated patient activity room was created for children with brain tumours, featuring activities like paper cutting and games. These initiatives are designed to alleviate children's fear of hospitals and provide a positive and engaging environment.

The department actively engages in various cultural and traditional festival activities to improve patients' emotional well-being and foster a good relationship between health professionals and patients. Traditional Chinese cultural activities like paper cutting, making lanterns, and dyeing flowers are incorporated during festivals to infuse a sense of celebration and provide patients an avenue to express their blessings to their loved ones and medical staff.

Recognising the psychological challenges patients face, the department employs professional psychological nurses to introduce positive thinking and meditation techniques to alleviate anxiety.

In a heart-warming endeavour, the department initiated the "Every Second Counts" event, where patients and families come together in unity. This event fosters communication, sharing of achievements, and identification of individual needs, facilitating a sense of community and mutual support.

The "Brain Trekking" activity seeks to raise public awareness about brain tumours while encouraging patients to face their challenges with courage. This initiative aims to replace stress with exercise and showcases success stories, like that of Mrs. Fong, a patient who found strength through medical care, family support, and nurse encouragement.

In May 2023, the department developed the Glioma Science Education Manual, aimed at enhancing patients' understanding of their condition, thus improving their survival prospects and overall quality of life.

Despite the progress, challenges persist, including finding ways to increase involvement of social organisations in these activities, addressing cognitive impairment through rehabilitation, providing comprehensive psychosocial support to patients and caregivers, and facilitating reintegration into society.

In summary, Dr Guo's presentation provided a comprehensive overview of the Department of Neurosurgery and Neuro-Oncology's dedication to holistic patient care, psychological support, patient empowerment, and the advancement of brain tumour understanding. The department's multifaceted initiatives serve to improve the lives of patients and their families while fostering a sense of community and hope.

PLENARY SESSION 6

Summit Workshop 1 Building survivorship plans for brain tumour patients and families

Facilitator: Jean Arzbaecher,
University of Illinois and Senior Advisor – International Brain Tumour Alliance,
United States

Speaker: Susan Chang,
UCSF Weill Institute for Neurosciences, and Sheri Sobrato Brisson Brain Cancer Survivorship Program,
United States

Speaker: Richard Price,
European Cancer Organisation (ECO), Belgium

Speaker: Jack Latteur,
European Cancer Organisation (ECO), Belgium

The workshop on survivorship care plans for individuals with brain tumours, shed light on the essential components of these plans and introduced innovative tools designed to improve patient well-being. The workshop featured presentations by Dr Susan Chang a neuro-oncologist from the University of California San Francisco (UCSF) and representatives from the European Cancer Organisation (ECO), Jack Latteur and Richard Price.



Dr Susan Chang spoke at the Summit workshop on building survivorship plans for brain tumour patients and families.



Richard Price, Director of Policy at the European Cancer Organisation (ECO) was one of the speakers at the survivorship workshop.

Developing survivorship care plans for brain tumour patients

Susan Chang's presentation focused on the crucial steps involved in creating survivorship care plans tailored to the needs of individuals with brain tumours. The workshop highlighted seven key pillars of brain tumour survivorship: cognitive care, physical exercise, nutrition and integrative health, community, access to information and resources, peer support, and finding meaning and purpose in life.

Survivorship care plans were outlined to encompass various aspects, such as addressing physical effects, recurrence risks, health promotion, disease prevention, psychosocial effects, and medical concerns management. Susan Chang discussed the comprehensive survivorship plan endorsed by the National Cancer Institute (NCI) in the United States, covering components like diagnosis, treatment summary, symptom management, medications, fertility considerations, healthcare provider information, supportive care referrals, genetics, and follow-up plans involving imaging, side effects, and health maintenance.

Particularly pertinent to brain tumour patients, survivorship care plans must encompass life-altering and life-limiting effects, as well as cognitive, emotional, physical, and neurological impacts. The workshop emphasised that brain tumour patients often experience a substantial symptom burden, placing a significant demand on caregivers. Notable lessons learned from the presentation included the importance of intentionality, having an advocate, active patient listening, leveraging existing resources, building a supportive community, and using technology and staff expertise to enhance patient care.

European initiatives for survivorship care planning

Jack Latteur and Richard Price from the European Cancer Organisation (ECO) shared insights into European survivorship care plans. Their presentation underscored the recognition of distinct core needs in survivorship care planning. They introduced the smartCARE app an ongoing development project aimed at enhancing survivorship care for patients. The app will be designed to provide treatment summaries, resource functions, and symptom management.

The development of the smartCARE app was informed by patient workshops and surveys, ensuring its alignment with patient needs. The app envisions incorporating features such as a personal library, community information, a "My Health" section, life goals tracking, telehealth capabilities, cancer information and support resources, as well as a user profile.

Feedback from workshop participants indicated a desire for app integration with other tools and emphasised the need for accessibility features catered to individuals with brain tumours.

The workshop fostered a vibrant exchange between presenters and attendees, exploring the potential and usefulness of survivorship care planning for individuals with brain tumours. It demonstrated the collective commitment to enhancing the lives of brain tumour survivors through holistic and patient-centred care approaches.



The survivorship workshop was facilitated by the IBTA's senior advisor Jean Arzbaecher.



Summit Workshop 2 Neurorehabilitation for brain tumour patients

Facilitator: Tina Mitchell Skinner,
Brain Tumour Support, United Kingdom

Speaker: Andreia Capela Marques,
Centro Hospitalar de Vila Nova de Gaia/Espinho,
Portugal

The purpose of this workshop facilitated by Tina Mitchell Skinner (CEO of Brain Tumour Support in the United Kingdom) was to provide participants with an understanding of neurorehabilitation and its advantages in the context of brain tumour diagnoses.



Tina Mitchell Skinner, Founder and CEO of Brain Tumour Support in the UK facilitated a workshop on neurorehabilitation for people with brain tumours.



Dr Andreia Capela Marques was the speaker in this workshop. She is a medical oncologist from Portugal.







Dr Capela Marques led workshop participants in a series of physical and mental exercises so people could experience the type of support given to people with brain tumours at Dr Capela Marques' hospital who require rehabilitation.

Dr Andreia Capela Marques, a medical oncologist from Portugal, conducted the workshop through a combination of presentations, interactive exercises, brain games, and Q&A sessions. Her presentation highlighted the significance of assessing patients' neurological status and needs from the beginning of the rehabilitation process.

Andreia Ca spela Marques discussed the challenges faced by patients undergoing oncology rehabilitation. She underscored the importance of tailoring rehabilitation programs to address patient dysfunctions and engage the appropriate professionals. Cancer rehabilitation was defined as a supportive healthcare programme administered by trained experts. The approach involves a multi-disciplinary team (MDT) continually assessing and reassessing the patient, while keeping the patient and their family central to decision-making. The rehabilitation journey starts from diagnosis and extends to neuro-palliative support, aiming to enhance safety, function, and quality of life.

Andreia highlighted the significance of guiding patients, setting goals, and adhering to the neuro-oncology and rehabilitation model, which comprises preventative, restorative, supportive, and palliative categories. This approach guides patients through various phases of rehabilitation, considering their unique needs.

To translate theory into practice, Anabela Amarelo, a rehabilitation and oncology nurse from Portugal, was introduced to the workshop participants via Zoom. Anabela led participants through a brief physical rehabilitation programme involving stretches and movements, to replicate the exercises she conducts with her patients. This exercise evoked participants' empathy toward patients facing cognitive impairment due to brain tumours. It illuminated the challenges of following instructions and provided insight into the caregiver's supportive role. The workshop facilitated laughter, reflection, and personal story sharing.

Brain games followed, involving puzzles and drawings to challenge participants' thinking. An example exercise encouraged participants to complete an outline of an object on paper, taking a different approach than expected. This exercise mirrored the essence of rehabilitation -achieving a goal through novel pathways. A participant shared a poignant story of her daughter's adaptive drawing technique due to impaired vision.

The workshop was enlightening, creative, and thought-provoking. It encouraged participants to reconsider aspects of life often taken for granted. Attendees were appreciative of the insights gained, and the experience underscored the Latin phrase "Mens sana in corpore sano" ("a sound mind in a sound body"), emphasising the importance of physical exercise for mental and psychological well-being.

In conclusion, the workshop succeeded in conveying the importance of neurorehabilitation for brain tumour patients. This highly interactive session and the sharing of personal stories helped participants empathise with the challenges patients face and helped them appreciate the multifaceted benefits of comprehensive rehabilitation programmes.

Summit Workshop 3 Palliative and end-of-life care for adult and paediatric brain tumour patients

Facilitator: Mary Lovely, International Brain Tumour Alliance, United States and Anita Granero, Oscar's Angels, Italy/France

Speaker: Christine Marosi, Medical University of Vienna, Austria

Speaker: Ulrike Leiss, Medical University of Vienna, Austria



Dr Christine Marosi highlights some of the challenges in palliative care for adults with brain tumours.



Dr Ulrike Leiss talked about palliative care challenges for the pediatric brain tumour population.





Representatives from eleven countries attended this workshop, facilitated by Anita Granero and Mary Lovely (both IBTA senior advisors) and led by neuro-oncologist, Professor Dr Christine Marosi and clinical psychologist specialising in the field of paediatric psycho-oncology Dr Ulrike Leiss, both based in Austria at the Medical University of Vienna.

This workshop consisted of a varying range of participants:
- Family members of brain tumour patients: 14 attendees
- Representatives from associations: 14 attendees
- Focused on adult brain tumours: 11 attendees
- Focused on paediatric brain tumours: 3 attendees
- Focused on both adult and paediatric cases: 3 attendees

During the workshop, several important topics were discussed including:

- Addressing the cultural challenges surrounding discussions about advanced care planning and end-of-life decisions. These conversations are essential to enable patients to express their preferences for future healthcare and personal care choices, particularly if they become unable to consent to or decline treatment.
- Recognising that advanced care planning is influenced by individual priorities, beliefs, and values. Participants emphasised the significance of understanding a person's end-of-life care options, wishes, and services before a health crisis emerges.
- Acknowledging that cultural barriers often hinder conversations about end-of-life care. Family members and patients may avoid such discussions due to emotional discomfort and fear of upsetting one another. The emotional nature of these discussions was emphasised.
- Recognising that patients should be given the opportunity to voice their beliefs, values, and preferences. The importance of respecting patients' wishes and providing compassionate and empathetic care was highlighted.
- Noting the growing awareness and availability of resources, but also highlighting the ongoing need for discussions about palliative care, advanced care planning, and end-of-life planning. It was pointed out that even healthcare professionals may lack awareness of relevant guidelines from organisations like the National Institutes of Health (NIH in the United States), the European Society for Medical Oncology (ESMO) and the American Society of Clinical Oncology (ASCO).
- Emphasising the role of effective communication between patients, families, and healthcare providers. A multidisciplinary team approach is vital to ensure a seamless transition from living to dying. Coordinating necessary resources for timely interventions was also underscored.
- Recognising that palliative care discussions should begin at the time of diagnosis, differentiating between palliative care and end-of-life care. Palliative and supportive care aims to manage symptoms and pain throughout treatment, while end-of-life care pertains to the transition from life to death.
- End-of-life discussions should address all the patient and family's concerns such as what to expect, fear of dying, understanding prognosis, achieving important end-of-life goals, confronting difficult questions and attending to physical needs.
- Highlighting common challenges, including the predominant focus on treatments and the lack of available resources (or lack of awareness of existing resources).

Throughout the workshop discussions, the following words were frequently brought up:
complicated, awareness, communication, empowerment, emotionally moved, love, understanding, soul, passion, death, compassion, acceptance, optimism, hope.

The workshop provided a valuable platform for participants to share insights, experiences, and knowledge surrounding palliative and end-of-life care for patients with brain tumours. It highlighted the importance of breaking down cultural barriers and fostering effective communication to ensure that patients' wishes are respected, and their quality of life is maximised during their journey from diagnosis to end-of-life care.

Summit Workshop 4 Doctor/patient communication including mastering the art of shared decision-making and seeking a second opinion

Facilitator: Fiona Keegan, Brain Tumour Ireland

Speaker: Guy Buyens, Anticancer Fund, Belgium and

Speaker: Ana Arnaut, GLIA, Croatia



This workshop on doctor/patient communication was facilitated by Fiona Keegan from Brain Tumour Ireland.



Dr Guy Buyens from the Anticancer Fund, based in Belgium, was one of the two speakers in this session.

This workshop aimed to tackle obstacles hindering shared decision-making and the pursuit of second opinions among patients. The session began with a presentation by Dr Guy Buyens, Medical Director at the Anticancer Fund based in Belgium, and advocate for patient information and shared decision-making. He elaborated on the work of the Anticancer Fund, particularly its "My Cancer Navigator" service, which empowers cancer patients to obtain second opinions and guidance in decision-making.

Following Dr Buyens' presentation, participants were divided into three groups to discuss barriers patients face and potential solutions.



Anna Arnaut was also a speaker in this session. Anna is from the Croatian brain tumour advocacy organisation, GLIA

Group 1: Patient and healthcare provider communication

Barriers identified:

- Lack of time with medical professionals
- Patients' lack of preparedness to ask questions
- Perceived lack of empathy from doctors
- Difficulty understanding medical terminology

Solutions proposed:

- Involvement of neuro-oncology nurses/social workers to facilitate conversations and provide support
- Educational materials from advocacy groups guiding patients on formulating questions
- Doctor participation in events organised by patient advocacy groups.

Group 2: Seeking a Second Opinion

Barriers identified:

- Fear of offending current doctors
- Delays in sharing patient records
- Uncertainty in choosing between differing second opinions

Solutions proposed:

- Embed seeking second opinions into standard healthcare procedures
- Training for doctors on facilitating second opinions as part of comprehensive patient care

Group 3: Shared Decision Making

Barriers identified:

- Knowledge disparity between patients and physicians






The session on doctor/patient communication was a lively combination of a presentation, group exercises and discussion.

- Clinicians emphasising 'gold standard of care'
- Imbalanced doctor-patient power dynamics
- Challenges in delaying treatment decisions

Solutions proposed:

- Adopt Australian model of encouraging patient questions
- Doctors' awareness of patients' desire for active participation in decisions
- Recognition of neuro-oncology nurse's role in shared decision-making

Following extensive discussions, participants viewed a concise video on shared decision-making from the Centre for Shared Decision Making in Denmark. The workshop concluded with co-presenter Ana Arnaut (brain tumour survivor, patient advocate, and President of the Croatian Brain Tumour Patients' Association, GLIA) sharing her personal experience as a brain tumour patient navigating the medical system while maintaining her central role in treatment and care decisions.

The workshop was a poignant exploration of the challenges faced by patients in their communication with medical professionals and their pursuit of comprehensive care. It underscored the significance of shared decision-making and second opinions in improving patient experiences and outcomes. Participants left with a deeper understanding and appreciation of the intricate nature of doctor/patient interactions.

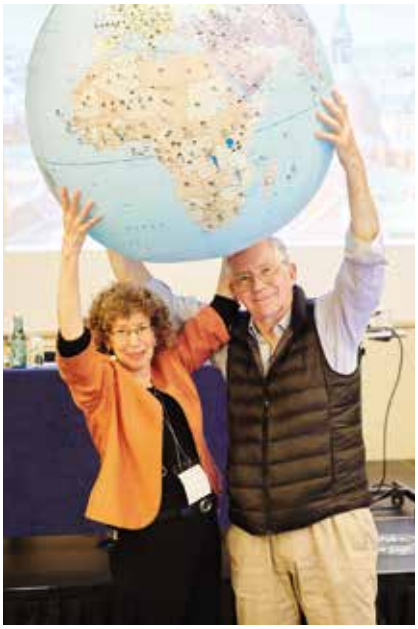

























IBTA
Fifth Biennial
World Summit of
Brain Tumour
Patient Advocates







PLENARY SESSION 7

Chair: Anita Granero,
Oscar's Angels Italy and France

Getting back to work with a brain tumour

Speaker: Veronica Foote,
Working with Cancer, United Kingdom



Anita Granero of Oscar's Angels in Italy and France welcomes participants to the workshop on getting back to work with a brain tumour.

Key points

- "Working with Cancer" in the UK supports individuals, employers, and caregivers dealing with work-related challenges during and after cancer treatment.
- Early workplace support is crucial for smooth reintegration.
- Human resources (HR) professionals, managers, and colleagues need training to provide effective support.
- Cancer survivors face complex challenges including physical, emotional, and identity-related issues.
- Stigma, misunderstandings, and unpredictability complicate return-to-work.
- The UK's Equality Act protects cancer patients and mandates workplace adjustments.
- Global legislation variation calls for advocacy.
- "Working with Cancer Pledge" aims to reduce stigma.
- Recommendations include integrating return-to-work plans in treatment and considering it in clinical trials.



Working when you are diagnosed with cancer is a very important topic and Veronica Foote gave an excellent presentation on this subject at the Summit.

Veronica Foote is a former corporate professional with a background in pharmaceuticals and oncology. She was diagnosed and treated for two meningiomas in 2017. While still recovering, she became a caregiver for her husband who was diagnosed with prostate cancer. This personal experience led her to leave corporate life and join "Working with Cancer," a non-profit organisation dedicated to training employers and supporting employees, freelancers, job seekers, and caregivers in their work-related challenges during and after cancer treatment.

Veronica Foote's presentation was centred around the challenges faced by individuals diagnosed with cancer, specifically focusing on brain tumours, and their return to work. The presentation emphasised the importance of support, awareness, and policies to facilitate a smoother transition for cancer survivors into the workplace.

By providing coaching, training, masterclasses, and policy development, "Working with Cancer" aims to bridge the gap between the challenges posed by cancer and the need for a productive and accommodating work environment.

She emphasised the critical role of early support from the workplace for individuals diagnosed with cancer. She suggested that the support should begin from the moment of diagnosis and continue throughout the treatment and recovery journey. By providing this consistent support, individuals can maintain a connection to their work and have a smoother transition back into their roles when they are ready.

The presentation highlighted the crucial roles played by HR professionals, line managers, and colleagues in a cancer survivor's journey. Veronica stressed the importance of proper training and education for these stakeholders, enabling them to provide empathetic and effective support to cancer survivors. Line managers can significantly impact an individual's experience with cancer, work-related challenges, and the return-to-work journey.

Veronica Foote discussed the multifaceted challenges that cancer survivors encounter. Beyond physical side effects, cancer treatment can lead to psychological impact, financial burdens, and identity-related concerns tied to work. The presentation emphasised the unpredictability of fatigue, of emotions and having good and bad days, as well as the stigma and misunderstandings associated with cancer, both from colleagues and society at large. The "Working





with Cancer" website offers recommendations for both employers and employees on dealing with difficult and honest conversations. Veronica shared the results of a survey conducted together with the Institute for Employment Studies in the United Kingdom that shed light on the return-to-work experience of patients in the UK.

She also spoke about the often overlooked and yet profoundly significant challenges faced by caregivers of individuals with cancer. Those who support their loved ones through the complex journey of cancer diagnosis, treatment, and recovery, contend with a unique set of emotional, practical, and work-related struggles. Balancing the demands of caring for a family member or friend with their own work responsibilities can be overwhelming. The presentation underscored that caregivers may be hesitant to share their situation with employers due to concerns about how their role as a caregiver might be perceived. Additionally, the emotional toll and the juggling of responsibilities can lead to fatigue and burnout. Veronica shone a light on the essential need for organisations to recognise and support caregivers with flexible work arrangements if needed.

The presentation shared thought-provoking statistics, such as the high likelihood of a cancer diagnosis during one's lifetime and the significant global number of new cancer diagnoses annually. The impact on both individuals and the economy was underscored, highlighting the need for efficient support mechanisms to facilitate return to work after cancer treatment. Some of the statistics presented were:

- Half of those born after 1960 will experience a cancer diagnosis at some point in their lives.
- Worldwide, over 25 million new cancer cases are diagnosed annually.
- In the UK, nearly one million people of working age are living with cancer.
- In the UK, the economic burden of individuals not returning to work after cancer treatment is around £8 billion.
- In the European Union, it's estimated that there are almost two million people of working age with cancer that are not working fully, contributing to an economic burden of around €9.5 billion.
- Although cancer survival rates are improving, return-to-work numbers within the first year of completing treatment are still relatively low, with only 60% attempting to work again.

Veronica described the UK's Equality Act of 2010, which classifies individuals with cancer as disabled, providing them with legal protection against discrimination. This legislation mandates that employers make reasonable adjustments (time for appointments, more breaks, flexible working hours, reduced duties, working from home) to accommodate the needs of individuals undergoing cancer treatment. She highlighted the significance of this legislation in ensuring fair treatment and support for cancer survivors in the workplace.

The presentation acknowledged the global variation in legislation protecting cancer patients in the workplace. Some countries have provisions that safeguard the rights of cancer survivors, while others lack comprehensive protection. Foote called for advocacy to fill gaps in legislation, thereby providing better support to individuals dealing with cancer worldwide.

Veronica introduced the "Working with Cancer Pledge" (a campaign launched by the owner of Publicis after he was diagnosed with cancer) that aims to raise awareness about cancer stigma in the workplace. This initiative, supported by various major global organisations, seeks to change perceptions, and foster a more supportive work environment for cancer survivors. The video can be found here.

Veronica proposed actionable recommendations for various stakeholders:

- For patient advocates, she suggested focusing on understanding and improving legislation in their respective countries to make sure appropriate employment rights exist for patients
- Healthcare professionals were encouraged to integrate return-to-work plans into treatment journeys, ensuring a holistic approach to patient care and recommending reasonable adjustments for those patients who wish to return to work (even while undergoing treatment)
- Furthermore, Veronica proposed that return to work should be considered an endpoint in clinical trials (patient reported outcomes measures), thereby underscoring its importance in the survivorship journey.

She concluded: life is more than just surviving; you want to thrive!

The Raymond A Wood Foundation: a novel approach to supporting young patients with hypothalamic pituitary brain tumours

Speaker: Amy Wood, Raymond A Wood Foundation, United States



Amy Wood is the founder and Executive Director of the Raymond A Wood Foundation in the United States.

Key points

- The Raymond A Wood Foundation (RAWF) empowers patients with hypothalamic pituitary brain tumours through education, technology, and evolving treatments.
- Craniopharyngioma is a rare tumour affecting the hypothalamus, leading to various debilitating symptoms.
- The presentation shared the personal journey of Amy Wood's son Alex, showcasing the profound impact of craniopharyngioma on his life and that of his family.
- Caregiver burden is high, with approximately 80% at risk for depression.
- RAWF addresses challenges through technology, including a handheld blood analyser, a sodium meter and the "ins and outs" app for fluid monitoring.
- Research, education, and community-building are central to RAWF's mission, with initiatives like patient registries, education programmes, and support groups.
- Early diagnosis challenges and the need for awareness among medical professionals were emphasised.



This presentation by Amy Wood, the Executive Director of the Raymond A Wood Foundation (RAWF) based in the United States, shed light on the Foundation's ground breaking efforts to provide support and improve the quality of life for patients dealing with hypothalamic pituitary brain tumours, with a special focus on craniopharyngioma. The RAWF is a rare disease patient advocacy organisation founded in 2017. Its mission is to empower survivors of these rare brain tumours with an improved quality of life by providing access to education, technology, and evolving treatments. Amy Wood's son Alex was diagnosed with craniopharyngioma at age four, inspiring the creation of the RAWF.

Craniopharyngioma is a rare tumour (620 adult and paediatric new cases every year in the United States) that affects the hypothalamic-pituitary region of the brain. It is classified as a "benign" tumour, but the tumour and/or treatment can come with complexities and lifelong challenges for patients and their caregivers. Families are often told at diagnosis that "this is the best brain tumour you could get," because these tumours are largely survivable. But when the post-treatment challenges begin to emerge, patients and families find themselves struggling to manage these issues daily.

The tumour's impact on the hypothalamus, which controls vital bodily functions, leads to a wide array of debilitating symptoms, including arginine vasopressin deficiency (AVP-D), hormonal imbalances, obesity, cognitive decline, sensory issues, temperature dysregulation, and more. The presentation vividly describes the transformation of a once neurotypical and healthy child into an individual dealing with a multitude of physical, cognitive, and emotional struggles.

Amy Wood highlighted the stark reality of the condition's impact on both patients and their caregivers. Caregiver burden for craniopharyngioma patients is found to be higher than caregivers of those with dementia, Alzheimer's, and chronic pain, with approximately 80% of caregivers at risk for depression. This insight underscores the profound toll this condition takes on families and emphasises the urgent need for comprehensive support.

To provide the audience with insight into the journey of survivorship, Amy Wood introduced us to her son Alex, a craniopharyngioma patient who has been profoundly affected by hypothalamic complications. Prior to his diagnosis, Alex was leading a neurotypical life, achieving his developmental milestones, enjoying an active social circle, displaying verbal proficiency, and maintaining his overall health.



Caroline Kane Montague (centre) from Brain Tumour Ireland asks a question at one of the plenary sessions at the Summit.



The Brain Tumour Charity's Catherine Fraher takes the microphone.

However, the day his tumour was diagnosed, circumstances swiftly changed for all the family. Alex had to undergo emergency surgery for removal of the tumour due to hydrocephalus (a neurological condition caused by an abnormal build-up of cerebrospinal fluid deep within the brain). Initially, they received reassuring news – during the surgery, the parents were informed that the tumour was "benign", and they were hopeful that he would be back home within a matter of days. The sense of relief was palpable; they believed they were fortunate to have the best possible outcome.

But the reality that followed was a whirlwind of challenges. Mere hours after the surgery, unfamiliar terms began cropping up: diabetes insipidus, hyper/hyponatremia (abnormal blood sodium levels), loss of endocrine function, and insatiable hunger leading to rapid weight gain. Behavioural shifts emerged – Alex became increasingly aggressive and experienced overwhelming fatigue. Learning difficulties emerged, coupled with sensitivities to noise, light, and tactile sensations. Orthopaedic issues surfaced, accompanied by the development of eczema and psoriasis.

As time progressed, a new set of complications arose. Alex's temperature regulation became erratic; although he was diagnosed in the summer, he began experiencing hypothermia during the winter months, leading to seizures and extended hospital stays. His ability to socialise deteriorated; making friends became a challenge, compounded by speech problems that made him difficult to comprehend. The loss of adrenal function became evident, resulting in adrenal insufficiency and the potential for adrenal crises.

This snapshot into Alex's experience underscores the intricate and profound impact that craniopharyngioma can have on a survivor's life. Beyond the immediate medical concerns, these complications have reshaped his day-to-day existence (and his family's), altering his relationships, his ability to communicate, and his overall quality of life. It serves as a reminder of the multifaceted and often unanticipated challenges with which individuals and families grapple.

The RAWF has embarked on a multifaceted approach to address the challenges faced by patients and caregivers. Leveraging technology, the Foundation is developing innovative solutions to manage the condition's symptoms such as sodium imbalance and adipsia (the complete absence of thirst). A handheld blood analyser, typically used in hospital emergency rooms and urgent care settings, has been adapted to provide rapid at-home testing of blood sodium levels. This innovation significantly reduces the need for frequent lab visits and helps prevent life-threatening complications associated with sodium imbalance. The Foundation is now working on a sodium meter akin to a glucometer for at-home sodium testing.

The RAWF's commitment to innovation and practical solutions is further exemplified by the development of the "ins and outs" app. This app monitors fluid intake and output. Patients are required to meticulously track these metrics and share them with their healthcare providers. The app streamlines this process, allowing patients and caregivers to easily log fluid measurements, while also providing clinicians access to this data for more informed decision-making.

Research and education are at the forefront of the RAWF's mission. By collaborating with experts and patients, the Foundation is building an international network to drive research, prioritise treatment strategies, and fill gaps in knowledge. Patient registries are being developed to document the natural history of the disease and its sub-conditions, aiming to identify treatment priorities and inform benefit-risk evaluations.

Education initiatives, including virtual conferences, webinars, videos and a comprehensive online hub of medical information including a clinical trial and a physician finder, empower patients and caregivers with knowledge to navigate the complex medical landscape. The Foundation's efforts extend to creating a sense of community, with caregiver and patient support groups, buddy programs, and creative outlets like an online art competition.

During the question-and-answer time following her presentation, Amy Wood explained that early diagnosis is a significant challenge. Patients tell stories of going to the doctor when their child was walking unsteadily or gained a lot of weight suddenly. However, doctors often dismiss these symptoms, attributing them to overeating, headaches, or even gluten sensitivity. Subsequently, the situation escalates, and the child ends up in the emergency room undergoing an MRI, when a brain tumour is discovered. This pattern presents an opportunity to raise awareness among general practitioners (GPs) and paediatricians. It is crucial that medical professionals recognise red flags like sudden weight gain, headaches or unexplained vomiting and pursue further



investigations instead of brushing off parents' concerns. One key plea is for doctors not to disregard parents or undermine their worries. Amy says they consistently hear about dismissive attitudes which is disheartening; the only recourse is to continue advocating for awareness.

She also referred to the matter of craniopharyngioma patients feeling like outliers. They aren't certain whether they fall under the cancer category (patients don't undergo chemotherapy) and perspectives can differ based on geographical location or medical approach. The critical distinction to grasp is that whether patients have overcome the tumour long ago or dealt with recurrence, they still grapple with significant challenges that lack understanding and effective treatment. Hypothalamic obesity is particularly devastating and there's no treatment currently available. Its impact on patients and families' social lives is profound – often, children can't go to gatherings, parties, or events due to the complexities around food. Parents find themselves constantly monitoring their child's actions, as they may attempt to eat non-edible items or pilfer food while at the grocery store. This predicament has led RAWF to initiate specific support groups.

Despite the strides made by the RAWF, Amy Wood acknowledges the ongoing challenges faced by patients, caregivers, and the Foundation itself. As she eloquently puts it, the quest for answers continues. Collaboration, innovation, and community involvement remain essential to address the unmet needs of those affected by hypothalamic pituitary brain tumours and ensure a better quality of life for these patients and their families. The presenter invited the audience to contribute ideas and solutions to this ongoing journey of innovation, support, and advocacy.

Paediatric brain tumours and the work of Childhood Cancer International Europe

Speaker: Anita Kiesenberger,
Childhood Cancer International Europe, Austria



Anita Kienesberger is an enthusiastic and dedicated patient advocate representing Childhood Cancer International Europe.

Key points

- Childhood Cancer International Europe (CCI Europe) has 63 member organisations in 34 European countries, aiming to support children, adolescents, and families facing cancer.
- Five pillars guide CCI Europe's work: research, diagnosis and care, psychosocial care, survivorship, and capacity development.
- Paediatric brain tumours are the second most common childhood cancer; CCI Europe focuses on empowering member organisations to assist families.
- Prevalence statistics show the need for improved support; one in 300 new-borns develop cancer before age 20, with over 6,000 young people with cancer dying annually in Europe.
- Patient Public Involvement and Engagement (PPIE) brings patient expertise to research and healthcare decisions.
- Patient experts provide valuable insights due to their direct experiences and education.
- There are three levels of PPIE involvement: participation, engagement, and involvement.
- CCI Europe's projects include increasing PPIE awareness and the Junior Research Academy to train young brain tumour survivors as advocates.





Anita Kienesberger explains the five pillars that guide the work of CCI Europe.

Anita Kienesberger, Chair of Childhood Cancer International Europe, delivered a presentation focusing on paediatric brain tumours and the initiatives undertaken by Childhood Cancer International (CCI) to support patients, survivors, and their families. CCI Europe serves as the continental branch of Childhood Cancer International and is the largest umbrella organisation for patient groups in the field of childhood cancer in Europe. The presentation aimed to highlight CCI's efforts, particularly in the context of paediatric brain tumours, and shed light on their strategies, challenges, and ongoing projects.

Anita began by introducing CCI Europe, encompassing 63 member organisations spread across 34 European countries. CCI Europe's mission is to ensure that children, adolescents, and their families facing a cancer diagnosis receive support, regardless of their geographical location. This includes not only patients but also their parents, siblings, and childhood cancer survivors.

She outlined the five pillars that guide CCI Europe's efforts:

1. Research and innovation: clinical trials, new therapies, and regulatory aspects to advance research and treatment
2. Diagnosis, treatment, and care: the organisation emphasises European standards, cross-border care, essential medicines, and effective pain management
3. Psychosocial care: providing care during and after treatment, addressing bereavement, and setting standards for psychological support
4. Survivorship: ensuring follow-up care, addressing late side effects, and advocating for socio-economic rights of survivors including adolescents and young adults (AYAs)
5. Capacity development: this involves educational initiatives and networking efforts to enhance support services

While CCI Europe is involved in all childhood cancers, the focus of the presentation was on their efforts related to paediatric brain tumours. Anita emphasised that CCI Europe does not offer direct support programmes. Instead, it empowers member organisations to better assist families in need.

The presentation provided statistical insights into the prevalence of paediatric cancers, with brain tumours being the second most common type of tumour after leukaemia. Anita highlighted that paediatric cancers are the leading cause of disease-related death in children over one year old. She emphasised that around one in 300 new-borns will develop cancer before reaching 20 years of age, and approximately 6,000 young people succumb to cancer annually in Europe. Furthermore, two out of three survivors experience severe, long-term side effects. Currently, the number of childhood cancer survivors in Europe exceeds 500,000.

The presentation introduced the concept of Patient Public Involvement and Engagement (PPIE) to incorporate patient expertise into research and healthcare decision-making processes. A video explained that patient experts possess invaluable insights into the reality of illness and treatment, providing a perspective from which researchers, healthcare professionals, and policymakers can benefit. The presentation emphasised the importance of patient experts who bring first-hand experiences and expertise to the table.

Anita discussed the three fields of patient expertise: individual patients and caregivers, patient advocates, and patient experts. She highlighted that patient experts possess significant knowledge due to further education and exposure to research, development, and health policy.

The presentation explained the three levels of PPIE involvement: participation, engagement, and involvement. Participation involves patients contributing to clinical trials through various means. Engagement focuses on sharing research and care information with relevant stakeholders. Finally, involvement entails patient experts playing a substantial role in the research process, including designing studies, data collection, analysis, and result dissemination.

Anita Kienesberger discussed two projects undertaken by CCI Europe. The first project aimed to increase awareness and understanding of PPIE. A survey revealed that there was a lack of awareness about PPIE among survivors, parents, and healthcare professionals. To address this, CCI Europe produced a video to explain the concept.

The second project, the Junior Research Academy, aims to train young brain tumour survivors between the ages of 8 and 14 to become patient advocates and experts in PPIE. The academy comprises several modules, and participants are educated on various aspects of the research process. During the workshops, participants establish unmet needs in the community and then focus on one issue. A complete study design is decided on to prepare a finished research proposal. The project highlighted the specific needs of brain tumour survivors, leading to the development of tools and resources for conducting similar academies, soon to be

available on the CCI Europe website.

Anita stressed the importance of collaboration between various childhood cancer subgroups, including those focused on brain tumours, haematology, and sarcomas. She discussed the need to map services and programmes for long-term brain tumour survivors ("it's not over when it's over") and called for increased awareness about the specific needs of adolescents and young adults (AYAs). The presentation concluded with the acknowledgment that much work remains to be done, but collaborative efforts are crucial for driving progress in the field of childhood cancer research and support.

In summary, Anita Kienesberger's presentation showcased CCI Europe's commitment to enhancing the lives of children and adolescents diagnosed with cancer, and their families. The organisation's efforts in the field of paediatric brain tumours, PPIE, and survivorship, highlight its dedication to improving care, treatment, and support for those affected by childhood cancers across Europe.

Gemeinsam gegen glioblastom (Together against glioblastoma)

Speaker: Professor Martin Glas,
Department of Clinical Neuro-Oncology,
Essen University Hospital Neurology Clinic, Germany

Speaker: Jolijn Boer, Patient Expert and Doctoral Student, Charité Hospital, Germany



Professor Martin Glass from Essen University Hospital introduces Jolijn Boer who lost her father to a glioblastoma.

Key points

- The German Innovation Alliance for Cancer & Brain seeks to collaborate on brain tumour patient improvements.
- Collaboration enhances transparency, cooperation, and advancements in diagnostics and therapy.
- The "Yes We Cancer" app connects cancer patients for information exchange, strength-building, and support.
- The movement hosts an in-person cancer convention "Yes!Con."
- The "Together Against Glioblastoma" campaign launched in 2020, and offers resources, insights, and community.
- The campaign's website serves as an information hub, featuring expert answers and patient experiences.
- Digitisation allows access to virtual events for patients facing travel restrictions.
- Collaboration with the International Brain Tumour Alliance (IBTA) amplifies efforts.

Professor Martin Glas, Chairman of the German Innovation Alliance Cancer & Brain introduced Jolijn Boer, a doctoral student at Charité Berlin and Clinical Trial Manager who presented the "Gemeinsam gegen Glioblastoma" (Together Against Glioblastoma) initiative.

Jolijn Boer began by sharing her personal connection to the cause, highlighting her father's war with glioblastoma: "A war out of the blue. A war with very unequally distributed forces and with an inadequate arsenal of weapons for life and without strategic partners."

She introduced the audience to her father's journey, from the early stages of diagnosis to the challenges he faced due to the lack of adequate information, support, and connection with others facing the same disease. Boer emphasised the need for strategic partners to guide patients through their battle against glioblastoma.

The presentation highlighted the significance of raising awareness about brain tumours, particularly glioblastoma, and placing patients at the centre of society. The German Innovation Alliance for Cancer and Brain, led by Professor Martin Glas, aims to bring together various stakeholders, including scientists, doctors, industry representatives, self-help groups, and public figures, to collaborate on improving diagnostics and therapy for brain tumour patients. The guiding principle of "change for good" (C4G) underpins their efforts to enhance patients' lives sustainably.

By combining the expertise and efforts of various stakeholders, the Alliance seeks to achieve transparency, cooperation, and advancements in diagnostics and therapy. With a sevenfold increase in two-year survival rates for brain tumour patients over the past 12 years, the Alliance's collaborative approach aims to further improve outcomes through increased awareness, patient participation, and the integration of digital technologies and artificial intelligence.

Jolijn Boer then introduced the "Yes We Cancer" app, which serves as Germany's largest digital self-help group for cancer patients. With half a million people diagnosed with cancer annually in Germany, the movement aims to address the fear, stigma, helplessness, and poverty often associated with cancer. The "Yes We Cancer" app acts as a platform for connecting cancer patients





Professor Martin Glass from Essen University Hospital introduces Jolijn Boer who lost her father to a glioblastoma.

and relatives who are navigating similar experiences. Jolijn Boer described the app as a safe digital space that facilitates information exchange, strength-building, resilience, empowerment, and support among cancer patients.

Expert groups within the app provide patients with direct access to specialists, allowing them to ask questions and receive guidance in real-time. The movement also organises events, including Germany's largest in-person cancer convention for patients, called "Yes!Con." The conference covers various topics related to cancer, including rare tumours, nutrition, clinical studies, and digitisation.

The "Together Against Glioblastoma" campaign was jointly launched by the "Yes We Cancer" platform and the German Innovation Alliance for Cancer and Brain in June 2020. It focuses on creating awareness, enabling support, fostering community, and disseminating information to glioblastoma patients and their relatives. By collaborating with experts from Germany, Austria, Switzerland, and the United Kingdom, the campaign aims to offer comprehensive resources and insights to those affected by glioblastoma.

The core of the campaign is the website, which serves as an information hub for patients and relatives. Patients can submit questions that are answered by experts. Short video clips offer insights into living with glioblastoma from those who have first-hand experience. Given the aggressive nature and limited life expectancy of glioblastoma patients, they begin treatment soon after diagnosis. Most suffer from side effects and neurological restrictions that make travel challenging. Since the campaign employs digitisation, it allows patients to access virtual events, where experts, patients, and caregivers come together to share information and ask questions.

The presentation concluded by highlighting the international collaboration between "Together Against Glioblastoma" and the International Brain Tumour Alliance (IBTA). Joint efforts include translating the Brain Tumour Patients Charter of Rights into German and raising awareness through publications in the IBTA magazine. Jolijn Boer emphasised their dedication to being strategic partners for glioblastoma patients, aiming to provide guidance, support, and information to improve the quality of life for those battling this aggressive disease. Their aspiration is to expand their initiatives to other German-speaking regions and continue making a positive impact on the lives of glioblastoma patients and their families.

In summary, Jolijn Boer's presentation on "Gemeinsam gegen Glioblastoma" illuminated the challenges faced by glioblastoma patients and their families. The presentation highlighted the importance of collaboration among various stakeholders, of using digital platforms and campaigns to provide patients with information, support, and a sense of community during their battle against this aggressive form of brain cancer. Through the German Innovation Alliance for Cancer and Brain, the "Yes We Cancer" movement, and the "Together Against Glioblastoma" campaign, the presenters showcased efforts to improve the lives and outcomes of those affected by glioblastoma in German speaking regions.

PLENARY SESSION 8

Chair: Kathy Oliver,
International Brain Tumour Alliance (IBTA),
United Kingdom

The Milton Marks Neuro-Oncology Family Camp

Speaker: Mary Lovely,
University of California San Francisco and International Brain Tumour Alliance (IBTA), United States



Mary Lovely gave a moving presentation about the Milton Mark Family Camp for brain tumour patients and their families.

Key points

- The Milton Marks Family Camp provides holistic support to brain tumour patients and their families through therapy, activities, and connections.
- The camp addresses the needs of families beyond medical treatment, aiming to alleviate isolation, role changes, uncertainties, and tensions post-diagnosis.
- Established by Abigail Marks, whose husband had glioblastoma, the camp offers a safe environment for networking, therapy, and sharing experiences.
- The camp has operated for eight years in partnership with the University of California San Francisco (UCSF), hosting 11-15 families at a time, tailoring programmes to unique needs.
- Over 60 volunteers provide personalised care, including medical professionals, therapists, and counsellors.
- Daily routine involves structured activities, support groups, networking, family projects, couples therapy, and nature-related activities.
- Funding sources include a UCSF grant, donations, and volunteer contributions.
- The camp has a profound impact on families facing brain tumour challenges (video with testimonials).

Mary Lovely, PhD, nurse, advocate, professor at the UCSF and IBTA special advisor, presented the significant positive impact of the Milton Marks Neuro-Oncology Family Camp on brain tumour patients and their families. The presentation revolved around the origin, objectives, structure, and benefits of the camp, highlighting its vital role in addressing the needs of families beyond medical treatment.

The Milton Marks Family Camp was established by Abigail Marks, a PhD psychologist, whose husband Milton was diagnosed with glioblastoma at age 50. They had three young boys. As Milton's condition worsened, Abigail felt helpless and isolated. She recognised the lack of support for families facing the challenges of caring for a brain tumour patient. After Milton passed away, Abigail Marks embarked on a mission to create a camp that would offer families a safe environment to network, receive therapy, and share their experiences.

The camp has been operating for eight years and is a partnership between UCSF and Abigail Marks. It provides a respite and an immersive experience for families dealing with brain tumours and the changes they bring in family dynamics. Based on existing literature about the main challenges faced by patients, the camp aims to alleviate the isolation, family role changes, many uncertainties (outcome, work and financial issues, neurological symptoms such as falls and seizures) and tensions often experienced within families after a brain tumour diagnosis.

The camp hosts 11 to 15 families, each comprising a patient being treated at the UCSF clinic with a malignant brain tumour and children still living at home. Families range from those with babies to those with children up to 20 years old. The camp tailors programmes to each family's unique needs. Candidates are



Mary Lovely described how the Milton Marks camp involves over 60 volunteers, including medical professionals, logistics experts, massage therapists, and counsellors.



interviewed before selection, ensuring their health status allows them to actively participate in the camp's activities.

The camp involves over 60 volunteers, including medical professionals, logistics experts, massage therapists, and counsellors. The volunteers provide personalised care and supervision, categorised into three levels based on the patient's health status. The camp's offerings include yoga, exercise, support groups, art therapy, yummy meals, nature walks, swimming, developmentally appropriate activities for children, and interactive sessions.

Mary Lovely explained that the daily routine involves structured activities, support groups, networking sessions, and family-oriented projects. Families can share experiences, receive therapy, and engage in rejuvenating activities. The popular couples therapy sessions help them rediscover their identities amidst the challenges of a brain tumour diagnosis.

Participants have described the camp (that takes place in a beautiful natural environment) as a "magical place" that addresses their needs and allows them to connect with others facing similar challenges. The camp becomes a place of singing, laughter, tears, and bonding. The camp forms a close-knit community, and when a camper passes away, the camp honours their memory by sending tributes and maintaining a sense of connection.

Mary Lovely explained that the camp is free for participants. It is designed to offer concierge care and full support. Funding for the camp's operations comes from a combination of sources, primarily a generous grant from the University of California San Francisco (UCSF). In addition, the camp receives donations from various sources including friends of Milton Marks, as well as individuals who believe in the camp's mission and its positive impact on families facing brain tumour diagnoses.

The camp's success is also attributed to the dedicated volunteers and staff members who contribute their time, expertise, and passion to make the camp a meaningful experience for participants. These individuals come from diverse backgrounds, including medical professionals, logistics experts, therapists, counsellors, and more. Their commitment to creating a supportive and enriching environment for families adds to the camp's positive impact.

Mary Lovely concluded her presentation by emphasising the emotional significance and the profound impact the camp has on families facing the challenges of brain tumours. She mentioned that the campers often become like family, and even when individuals pass away, their presence and memories remain with the camp community. She expressed the deep sense of unity, healing, and renewal that the Milton Marks Family Camp brings to the lives of those affected by brain tumours.

In the concluding part of the presentation, a video with testimonials from camp participants was shown to the audience.

In essence, Mary Lovely's presentation highlighted the remarkable efforts of Abigail Marks and the Milton Marks Family Camp in providing comprehensive support to brain tumour patients and their families. Through a holistic approach that includes therapy, activities, support groups, and connections, the camp contributes to improving the quality of life for families navigating the challenges of a brain tumour diagnosis.

A bird's eye view of the international brain tumour patient advocacy community: building pragmatic, impactful, international collaboration between brain tumour patient organisations and other stakeholders

Speaker: Kathy Oliver, International Brain Tumour Alliance (IBTA), United Kingdom



The IBTA Chair and Co-Director Kathy Oliver focused in her presentation on the crucial role of collaboration and patient engagement within the international brain tumour patient advocacy community.

Key points

- Kathy Oliver shared the personal story of her son Colin's brain tumour diagnosis that revealed the need for improved resources and understanding.
- Collaborative efforts involving patient organisations, research bodies, healthcare professionals, and more are crucial.
- The rarity of primary brain tumours adds complexity, requiring collaboration across stakeholders and countries.
- The International Brain Tumour Alliance (IBTA) facilitates collaboration, transcending cancer types.
- "Nothing about us without us" emphasises patient engagement in treatment, research, and decision-making.
- The key attributes of patient engagement are intentionality, clear strategy, mutual learning, and timely involvement.
- Patients' experiences guide research and enrich advocacy efforts.
- Brain tumour patient advocacy includes patients, caregivers, and expert advocates.
- Innovative patient-centric solutions emerge from collaboration, like the Swedish yarn connection during radiation.
- Building collaboration requires dispelling misconceptions, identifying shared goals, and building trust.
- Regular communication between key players fosters strong working relationships.

Kathy Oliver (IBTA Chair and Co Director) focused on the crucial role of collaboration and patient engagement within the international brain tumour patient advocacy community. Kathy, a passionate advocate herself, highlighted the importance of involving patients in various aspects of the brain tumour journey and research processes. The deeply personal story of her son Colin's brain tumour diagnosis served as a poignant backdrop for her insights.

She began by emphasising the significance of collaborative efforts between brain tumour patient organisations, research bodies, healthcare professionals, industry stakeholders, and regulatory bodies to address the challenges faced by brain tumour patients. She recounted the emotional journey of receiving her son Colin's brain tumour diagnosis. This life-changing moment revealed the lack of support and information resources for patients and caregivers which the family faced and spurred her determination to contribute to the brain tumour patient community.

The rarity of primary brain tumours presents unique challenges due to their low incidence rate. Kathy Oliver stressed the need for collaboration across various stakeholders and countries. She recognised the complexities associated with primary brain tumour research and treatment, as well as the disparities in access to care and support globally.

She emphasised that collaboration is essential in the journey of brain tumour patients. She discussed the IBTA and its role in facilitating collaboration among patient organisations, research entities, and international organisations. This cooperative approach allows for shared insights and solutions.

The phrase "nothing about us without us" encapsulates the concept of patient engagement. She stressed that patients' perspectives should be at the heart of decisions regarding treatments, reimbursement, and research directions. Patients can provide meaningful insights into their experiences, preferences, and priorities, driving the research agenda.

During her presentation, Kathy Oliver discussed the key attributes of meaningful patient engagement, which include intentionality, clear strategy, mutual learning, and timely involvement. She



Kathy Oliver demonstrates a simple but effective method of using inexpensive innovation – a simple ball of yarn – to provide comfort and security to children undergoing radiation therapy.

underscored the value of patients' personal experiences in guiding research design and planning. Additionally, she discussed the importance of underserved communities and the role they play in enriching the patient advocacy community.

The brain tumour patient advocacy community encompasses diverse participants, including individual patients, caregivers, and expert advocates. Kathy Oliver highlighted the collective value they bring to research projects, regulatory discussions, and post-marketing activities. Their varied insights enrich the understanding of brain tumour journeys and challenges.

To illustrate how patients can contribute to better patient and family support with clever, inexpensive solutions, Kathy Oliver shared the example of Swedish parents who creatively addressed the emotional challenge of children undergoing radiation treatment. Parents cannot accompany children into the radiotherapy room which is distressing to both parents and young patients. The use of a simple yarn connection between parents and children during the radiotherapy session provided comfort and a sense of security. This case illustrated the potential of innovative and patient-centric solutions that emerge from collaboration and engagement.

Practical strategies for building collaboration were presented. Kathy stressed the importance of dispelling misconceptions, identifying shared goals, and building trust among patient advocacy organisations. She encouraged regular communication between key players from various groups to establish strong working relationships.

In conclusion, Kathy reinforced the central themes of collaboration and patient engagement. The presentation encouraged attendees to recognise the transformative power of shared knowledge, connections, and collaborative efforts. By collectively addressing challenges, the brain tumour patient advocacy community can drive positive change and improve patient outcomes.

Nothing about us without us.


















Fifth Biennial World Summit
of Brain Tumour
Patient Advocates











DAY THREE

Wednesday 28 June 2023

PLENARY SESSION 9

Chair: Melissa Lim,
Brain Tumour Society Singapore

The Ocean and Sky Children's Hospice in Yokohama, Japan (pre-recorded presentation)

Speaker: Hisato Tagawa,
Representative Director of the
Yokohama Children's Hospice, Japan

Key points

- Despite Japan's medical prowess, palliative care for children with life-threatening conditions was underdeveloped in the country.
- Hisato Tagawa's personal experience with his daughter's incurable brain tumour diagnosis motivated his mission.
- In 2003, he established a non-profit, providing non-medical support for hospitalised children and families.
- His vision expanded to creating a children's hospice, inspired by international experiences.
- Generous bequest of ¥105 million in 2014 catalysed the Yokohama Children's Hospice Project.
- The hospice's architecture prioritises inclusivity, comfort, and collaboration.
- The hospice offers a nurturing environment for family activities and community networking.
- The project aims to initiate a network of children's hospices across Japan.
- "The National Children's Hospice Summit 2022" united organisations to establish a cooperative network.



Melissa Lim of Brain Tumour Support Singapore introduces a virtual presentation by Hisato Tagawa of Japan who was the dynamic force behind the establishment of the ground-breaking Ocean and Sky Children's Hospice in Yokohama.

This presentation shed light on the creation and evolution of The Ocean and Sky Children's Hospice in Yokohama, Japan. Hisato Tagawa, the Representative Director of the Yokohama Children's Hospice Project and Vice-President of the Japan Brain Tumour Alliance, passionately shared the journey of establishing a haven for children with life-threatening conditions (LTCs) and for their families, emphasising the significance of quality palliative care.

Hisato Tagawa commenced by acknowledging Japan's prominent medical technology and low perinatal mortality rate. However, he delved into the reality that around 20,000 children grapple with life-threatening conditions like childhood cancer, genetic, metabolic, or neurological diseases. Despite Japan's medical prowess, the realm of children's supportive care focusing on quality of life for both the child and the family was underdeveloped.

Motivated by personal experience, Hisato Tagawa shared how his daughter's diagnosis of an incurable brain tumour in 1997 when she was six years' old, ignited his mission. Haruka's passing, five months after her diagnosis, unearthed the deficiencies in palliative care for children and their families. In 2003, he established a non-profit organisation offering non-medical support for families of hospitalised children. Despite this step, Hisato Tagawa believed there was much more to be done, culminating in the vision of a children's hospice that could be a place of comfort, rest, fun and enjoyment.

Hisato Tagawa's dream took tangible form in 2014 with a generous bequest of ¥105 million from a former nurse who shared his vision. This windfall became the catalyst for establishing the Yokohama Children's Hospice Project. Through seminars, workshops, and cross-sectoral partnerships, he and his team raised awareness and funds. In 2019, they reached their ¥300 million goal, securing municipal land and support to build The Ocean and Sky Children's Hospice in Yokohama.

He acknowledged the pivotal role international experience played in shaping the hospice's design. Visits to children's hospices in the United Kingdom, Germany, and the Netherlands exposed Hisato Tagawa to warm and welcoming atmospheres. Collaborations between doctors, nurses, specialists, therapists, families, and architects were pivotal in shaping an inclusive space catering to individuals of all abilities.

The hospice's architecture reflects its commitment to inclusivity



Hisato Tagawa, Vice-President of the Japan Brain Tumour Alliance, passionately shared the journey of establishing a haven for children with life-threatening conditions.

and comfort. The ground floor, resiliently constructed for disaster protection, features a public area with a multi-purpose hall, dining and kitchen spaces with varied counters, and counselling and sitting rooms. Warm colours painted by volunteers and supporters envelope the hospice. The upper floor boasts wooden structures, housing family bedrooms, a big family bathroom (a family bath is an important part of Japanese culture), and facilities following examples from other hospices.

The Yokohama Children's Hospice is characterised by two primary aims. The hospice itself provides a nurturing environment for families to engage in activities such as camping, baking, or bathing together, once deemed impossible. The hospice currently operates for day use but is preparing for future accommodations. The second aim focuses on fostering a community network through seminars, workshops, and social events to create a supportive environment for families facing life-threatening conditions.

The creation of The Ocean and Sky Children's Hospice represents the initiation of a network of such facilities across Japan. While freestanding hospices are a rarity, the growing movement seeks to establish them in various regions. A symposium titled "The National Children's Hospice Summit 2022" united these organisations to build a cooperative network, exchange knowledge, and advocate for more children's hospices in Japan.

Hisato Tagawa's dream is a society that doesn't allow life-threatening conditions to limit children and families. His presentation closed with a heartfelt belief that children should be able to live "in the moment" and that his daughter, Haruka, symbolises the call for a supportive society where no child or family is left isolated.

Top tips on starting a brain tumour patient registry in your country – learning from the Central Brain Tumor Registry of the United States (CBTRUS)

Speaker: Carol Kruchko,
Central Brain Tumor Registry of the United States



Carol Kruchko is the founder and president of the Central Brain Tumor Registry of the United States (CBTRUS).

Key points

■ The key steps to starting CBTRUS included: a feasibility study, CBTRUS establishment, collaborations, data collection and reporting, publication of annual reports.

■ Major government bills in the United States supported data collection and cancer registries.

■ Advice for starting a registry includes:
- Commitment
- Form a committee
- Use existing infrastructure
- Conduct feasibility studies
- Raise funds
- Publish results in peer-reviewed journals
- Collaborate with government programmes
- Engage with clinicians
- Strive for continuous improvement
- Collaborate and share

■ CBTRUS supports other organisations by sharing resources and templates.



Carol Kruchko offered valuable advice at the IBTA World Summit for those interested in establishing brain tumour patient registries in their own countries.

Carol Kruchko, the Chief Mission Officer of the Central Brain Tumour Registry of the United States (CBTRUS) shared the journey and insights gained from establishing the registry and offered advice to others interested in initiating patient registries for brain tumours in their respective countries.

Her personal motivation for founding the CBTRUS was deeply rooted in her own experience. She shared the heart-wrenching story of her son Willie's battle with a brain tumour, diagnosed when he was 22 months, that ultimately led to his passing aged three. The emotional impact of this experience compelled her to act and make a positive impact on the field of brain tumour data collecting. She highlighted the collaborative efforts that went into establishing the CBTRUS and emphasised the importance of perseverance.

Carol Kruchko started volunteering at the American Brain Tumor Association (ABTA), who had helped her family navigate Willie's disease. They had identified the lack of comprehensive brain tumour data in the United States. The existing incidence data were extrapolated and not sufficient to understand the prevalence of brain tumours accurately. Inspired by the breast cancer patients' advocacy movement, they saw an opportunity to collect more comprehensive data on brain tumours.

So, key initial steps were then taken:

1. Feasibility study: a feasibility study was carried out with an epidemiologist, exploring the possibility of collecting comprehensive brain tumour data.

2. Establishment of CBTRUS: positive results from the feasibility study led to the establishment of CBTRUS in 1992. Carol noted that this step required engagement with various stakeholders and organisations who committed to sharing data with CBTRUS.

3. Collaborations: CBTRUS also collaborated with neuropathologists and used the central nervous system (CNS) histology groupings for brain tumours published by the World Health Organization (WHO) and with the International Agency for Research on Cancer (IARC).

4. Data collection and reporting: CBTRUS collaborated with cancer registries and established protocols for data collection. Their reporting followed a clinical definition focusing on what clinicians observed in their practices. The data were coded using the ICD-O coding book, which became the global language for cancer registration.

5. Annual reports: CBTRUS published annual reports and supplements to the journal Neuro-oncology of the Society for Neuro-Oncology (SNO). They continued to improve the accuracy and completeness of brain tumour data over the years.

At the same time, in the United States, three major government bills laid the groundwork to collect the data that CBTRUS now uses:

- The National Cancer Act of 1971 mandated collection of data used for prevention, diagnosis, and treatment of cancer and led to the establishment of the US National Cancer Institute's (NCI) Surveillance, Epidemiology and End Results (SEER) programme.
- The Cancer Registries Amendment Act of 1992 established the US Centers for Disease Control and Prevention's (CDC) National Program of Cancer Registries, expanding cancer registration to the entire US.
- The Benign Brain Tumor Cancer Registries Amendment Act of 2000 mandated collection of non-malignant brain and CNS tumours by these registries

Carol Kruchko offered valuable advice for those interested in establishing patient registries for brain tumours:

1. Commitment: make establishing a brain tumour registry a goal of your organisation and commit to it.

2. Form a committee: assemble a dedicated committee to lead the effort.

3. Build on existing infrastructure: use existing resources and collaborate with established organisations. 185 countries contributed data on 36 cancers to global cancer statistics in 2020. Search Globocan.

4. Conduct feasibility studies: determine the feasibility of collecting comprehensive data in your country. Use IARC resources.

5. Raise funds: secure funding to support the project. Today, around $40,000 would be needed.

6. Publish results: share your findings in peer-reviewed journals.

7. Collaborate with government programmes: partner with government-funded cancer surveillance organisations to promote your findings.

8. Engage and build alliances, especially with neuropathologists.

9. Continuous improvement: commit to regular publications and strive for accuracy and completeness.

10. Collaborate and share: use resources from established registries and collaborate with organisations with similar goals. CBTRUS is happy to support other organisations by sharing resources such as templates.

Carol Kruchko acknowledged the CBTRUS team and sponsors and thanked the IBTA for bridging brain cancer communities across the globe, building progress and hope.

PLENARY SESSION 10

Chair: Maureen Daniels,
Gerry and Nancy Pencer Brain Tumor Centre, Canada

Ethical challenges in treating brain tumour patients

Speaker: Professor Christine Marosi,
Division of Palliative Care and Neuro-oncology,
Medical University, Vienna, Austria

Key points

- Medical ethics involve defining right and wrong behaviour in healthcare.
- There are four principles in medical ethics: autonomy, non-maleficence, beneficence, justice.
- The historical development of medical ethics is based on the Hippocratic Oath, religious influence and modern codes.
- Medical ethics are applied in clinical practice, research ethics review boards, consultations.
- Respect for patient autonomy, informed consent, balancing patient autonomy with decision-making capacity are important elements of medical ethics.
- Medical ethics call for end-of-life conversations when patients are ready and integrating palliative care early.
- There are many challenges for brain tumour patients: they have an aggressive disease/cancer, a neurodegenerative illness, significant symptom burden, behavioural changes, and are subject to a rapid and often relentless course of their disease.
- Medical ethics encompasses encouraging palliative care, advanced care planning and enrolling in clinical trials.
- There is an emphasis on beneficence, providing optimal care and support.
- Medical ethics highlights caution against unproven treatments from "Google medical experts."
- There is also the justice principle for equitable access to state-of-the-art care and allocation of research funds for orphan indications.



Maureen Daniels of the Gerry and Nancy Pencer Brain Tumor Centre, Canada introduces Professor Christine Marosi who spoke to the Summit about ethical challenges in treating brain tumour patients

Professor Christine Marosi, a senior staff physician in the Clinical Division of Palliative Care and Neuro-oncology at the Medical University of Vienna, presented a talk on ethical challenges in treating brain tumour (BT) patients.

She began by defining ethics as a branch of philosophy that involves defining concepts of right and wrong behaviour. She emphasised that medical ethics, an application of these principles, is essential in the medical and healthcare professions.

The four principles of medical ethics were outlined:
- respect for autonomy
- non-maleficence
- beneficence
- justice

Christine Marosi stressed the importance of maintaining a balance among these principles to ensure fair and moral medical care for all.

Her presentation described the historical development of medical ethics, starting with the Hippocratic Oath ("First, do no harm") and the Formula Comitis Archiatrorum. Christine Marosi noted the influence of religious beliefs in the Middle Ages, followed by



Professor Christine Marosi spoke on the ethical challenges of treating brain tumour patients.





In her presentation on ethical challenges in treating brain tumour patients, Professor Christine Marosi - from the Division of Palliative Care and Neuro-oncology at the Medical University of Vienna - emphasised the need for patient-centred care, informed consent, and equitable access to quality care for all patients.

the modern codes of medical ethics. The Declaration of Helsinki on Medical Research (1964) and Beauchamp and Childress' "The Principles of Biomedical Ethics" (1979) played crucial roles in shaping modern medical ethics.

Christine Marosi emphasised the daily application of medical ethics in clinical practice. She discussed ethical review boards for medical research and ethical consultations for difficult clinical cases.

The need for professionals to respect patient autonomy, provide adequate information, and offer informed consent for treatments was highlighted. The challenge of balancing patient autonomy with their ability to make decisions was also addressed. Autonomy implies that patients are adequately informed about their disease, in a way they can understand, and when they are ready to receive this information. Christine Marosi gave the example of immigrants in Austria. She explained that doctors often call upon professional translators to get the message across. She recommended avoiding using family members for translation because they may not give full information or be overwhelmed by emotions preventing them from finding the right tone and words.

She said end-of-life conversations should be had when the patient is ready for them, citing La Rochefoucauld: "Le soleil ni la mort ne se regardant fixement" ("Neither the sun nor death can be stared into directly for a long time").

The unique ethical challenges facing brain tumour patients and their physicians were discussed by Christine Marosi. She talked about patients' simultaneous battle against an aggressive cancer and neurodegenerative illness. She mentioned the high burden of symptoms, possible behavioural changes, and the rapid, unpredictable course of these diseases. She encouraged the early integration of palliative care, and discussions about advanced care planning and end-of-life wishes.

The importance of beneficence was underscored by encouraging enrolment in clinical trials and providing palliative care to alleviate symptoms. Christine Marosi emphasised that while healthcare professionals may not cure brain tumour patients, they can offer optimal care and support. She cautioned about "Google medical experts" in the patients' entourage who recommend unproven treatments such as strict regimens and emphasised the significance of non-maleficence in protecting patients from potentially harmful interventions.

The ethical principle of justice and the need for equitable access to state-of-the-art care for all patients, including those with orphan indications like brain tumours, was highlighted. Christine Marosi stressed that research funds should be allocated for orphan indications, and the unique needs of brain tumour patients should be considered when designing healthcare systems.

Christine Marosi's thought provoking presentation on ethical challenges in treating brain tumour patients provided a comprehensive exploration of the principles of medical ethics and their practical application in the context of brain tumours. Her insights emphasised the need for patient-centred care, informed consent, and equitable access to quality care for all patients. Her presentation underscores the importance of integrating ethical considerations into medical practice to ensure the well-being of brain tumour patients facing complex healthcare challenges.

Improving care and outcomes for people with Ependymoma: a case study about the importance of leverage in nonprofit strategy

Speaker: Kimberly Wallgren,
National Brain Tumor Society, United States

Key points

- Ependymoma is a rare tumour affecting both brain and spine in adults and children.
- CERN, founded in 2006, aims to enhance ependymoma patients' lives through research coordination and community support.
- CERN's focus is on leveraging education, awareness, and research support to drive change.

- With respect to education: CERN developed the Ependymoma Key Issues Document to address education, clinical coordination, transparency, and survivorship.
- Regarding increasing awareness: CERN organises the "Ependymoma Awareness Day" and integrates this to coincide with the annual "Head to the Hill" advocacy event.
- With respect to research support: CERN collaborates with institutions for research efforts, aligning with established initiatives.



Kimberly Wallgren of the National Brain Tumor Society in the United States presented on ependymoma and the special challenges associated with this type of brain tumour.

Kimberly Wallgren, Executive Director of the Collaborative Ependymoma Research Network (CERN) Foundation, a programme of the National Brain Tumor Society (NBTS) shared insights into enhancing care and outcomes for individuals with ependymoma by leveraging advocacy and collaboration.

Ependymoma is a rare tumour that affects both the brain and spine, and both adults and children. Kimberly Wallgren's journey as a caregiver for her father, who survived nearly 20 years after an ependymoma diagnosis, led her to spearhead the CERN Foundation's advocacy efforts.

CERN, established in 2006, is dedicated to improving the lives of people with ependymoma through research coordination and community support. The Foundation initially invested in basic science research that identified the first nine subtypes of ependymoma. Kim Wallgren's marketing background helped the Foundation create a framework for rare disease community engagement, leading to the successful accrual of patients for the first prospective study for recurrent adults with ependymoma. This publication played a crucial role in gaining National Comprehensive Cancer Network (NCCN) guideline approval for recurrent ependymoma in the United States.

Kim Wallgren explained that to leverage is to "use a quality or advantage to obtain a desired effect or result." It entails having clear objectives, understanding one's strengths and capacities, and relying on collaboration to achieve results that can't be reached alone. Key leverage categories for CERN are education, awareness, and research support.



Kimberly Wallgren explained that leveraging education, awareness, and research through collaboration, has enabled the CERN programme to amplify its impact and drive change.

1. Education: CERN capitalises on existing initiatives to create targeted advocacy efforts. They adapted the IBTA-co-produced Brain Tumour Patients' Charter of Rights to establish the Ependymoma Key Issues document. This document was collaboratively developed by ependymoma leaders, aiming to address crucial aspects like education, clinical coordination, transparency, and survivorship. Grassroots groups have become significant contributors to advocacy efforts, amplifying the patient community's voice.
2. Awareness: "Ependymoma Awareness Day" is an annual event that brings together, patients, care partners and researchers to raise awareness and highlight the urgent need for more clinical studies and better targeted treatments. This day is held in coordination with the National Brain Tumor Society's (NBTS) annual "Head to the Hill" advocacy event, engaging brain tumour advocates who travel to Capitol Hill in Washington DC to ask lawmakers for their support of more research and help for brain tumour patients. The programme's approach to awareness includes the use of infographics, real stories, and data from CBTRUS reports to expand understanding of ependymoma subtypes and challenges.
3. Research support: CERN navigates the challenges of funding for rare diseases by collaborating with institutions like like St Jude Children's Research Hospital in the United States, and the Robert Connor Dawes Foundation in Australia. In addition, a focused project within the NBTS DNA Damage Response Consortium allows further possibilities for research collaboration. Kimberly Wallgren emphasised the importance of aligning with established efforts and leveraging resources to stimulate focused research..

She concluded by underscoring the importance of passion, perseverance, tenacity, and grit in advocacy work. She emphasised that even small efforts can make a meaningful difference within the community. Her personal connection to ependymoma, marked by her father's journey, further fuelled her commitment to advocating for better care, research, and awareness. Kimberly Wallgren's presentation shed light on the significant strides made in improving care and outcomes for individuals with ependymoma and empowered others to thinking creatively when focusing on rare disease strategies. Leveraging education, awareness, and research through collaboration, the CERN programme has been able to amplify its impact and drive change.






Fifth Biennial World Summit
of Brain Tumour
Patient Advocates




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PLENARY SESSION 11

Panel and audience discussion Brain tumour research: barriers and solutions

Moderater: Susan Chang,
University of California San Francisco, United States

Panel participants: Professor Matthias Preusser,
Medical University of Vienna, Austria
Dr Gaetano Finocchiaro,
IRCCS Ospedale San Raffaele, Milan, Italy
David Jenkinson,
The Brain Tumour Charity, United Kingdom
Melissa Lim, Brain Tumour Society (Singapore)
Chris Tse, Brain Tumour Support New Zealand

Dr Susan Chang introduced the last session of the Summit, a panel on "Brain Tumour Research - Barriers and Solutions". She highlighted the crucial role that research plays in unravelling the intricacies of brain tumour biology and in developing innovative therapies that can improve patient outcomes.

Her presentation set the scene by describing the different types of clinical research and the clinical trial roadmap.

Clinical research takes on various forms. Often, we think primarily of therapeutic research, where the aim is to treat patients and thereby enhance their outcomes, whether it's the time it takes for cognitive function to recover or the extension of a patient's lifespan.

Yet, there are other equally important forms of research, including prevention and non-therapeutic studies. These types of research depend on the active involvement of patients, making the partnership between researchers and patients a cornerstone of success. The advocacy groups and foundations that push boundaries are at the forefront of nurturing this partnership, fostering the development of improved therapies.

While prevention studies offer the potential of intervening to prevent brain metastases and primary brain tumours, research is still in the early stages of realising this vision.

Non-therapeutic research spans a diverse array of approaches that Dr Chang explained and illustrated with examples:

- Epidemiology and genetic studies
- Natural history and registry studies
- Diagnostic studies
- Screening studies
- Survivorship/caregiving and quality of life (QoL) studies
- Non-tumour-related treatment studies



Dr Susan Chang from the University of California in San Francisco, moderated a lively panel of experts who discussed "Brain tumour research – barriers and solutions.

· Medical record & database studies

For example, an epidemiological and genetic study is being carried out in collaboration with firefighters in the United States. Reaching out to the community is a remarkable way to unlock non-therapeutic insights. The study examines the elevated cancer risk among firefighters due to their exposure to specific chemicals, like haloalkanes. Investigators have reached out to the California firefighting community, collecting blood samples, and studying the risk of brain tumour development.

A noteworthy natural history study, the ETERNITY study, also epitomises collaboration. Jointly undertaken with advocacy groups and the European Organisation for Research and Treatment of Cancer (EORTC), it comprehensively examined the factors contributing to the long-term survival of glioblastoma patients, shining light on why some people diagnosed with this type of brain tumour surpass the average survival period.

Diagnostic and correlation studies also play a pivotal role. By repeatedly assessing patients' conditions through non-invasive methods like imaging and liquid biopsies, invaluable insights into disease progression can be gained, to improve diagnosis and outcomes.

Quality of life studies encompass a broad scope, involving patients, caregivers, and healthcare providers in efforts to enhance well-being. An example is an international study using surveys to assess QoL for patients and caregivers.

Moving on to treatment interventional trials that aren't focused solely on tumours, they test new therapies to improve care. An example is a trial to evaluate the feasibility of cognitive rehabilitation strategies for stable patients with low grade glioma.

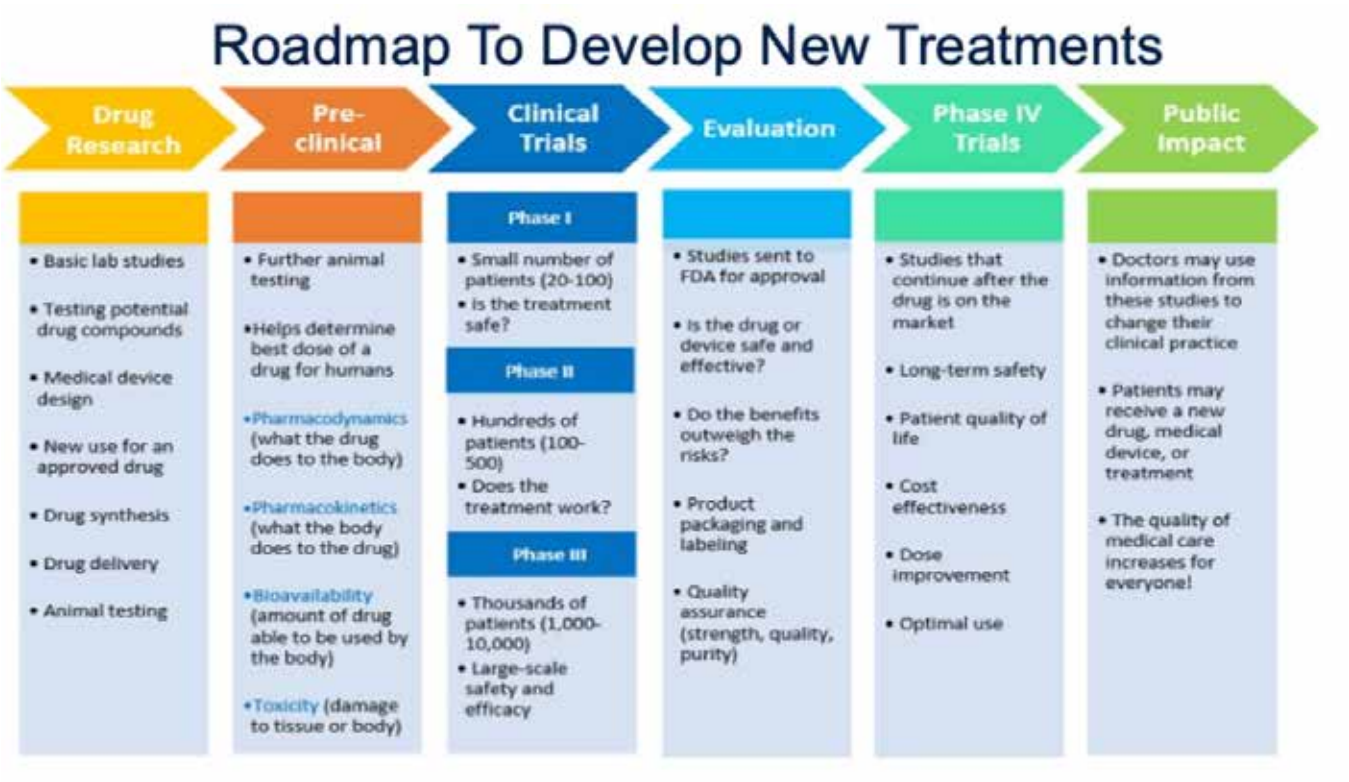
The realm of medical records and database studies allows researchers to review information from large groups of patients from diverse institutions. This collective information generates hypotheses for future testing. An example is a study exploring the effect of the extent of resection on survival in a cohort of over 1000 glioblastoma patients.

On the other side of the spectrum are therapeutic research studies, which can be classified based on their approach: surgical, radiation, chemotherapy, targeted therapies, and the recent frontiers of immunotherapy and cell therapy.

Developing new treatments is a journey marked by distinct stages, spanning from drug research and preclinical testing to clinical trials of varying phases (I, II, III and sometimes phase 0 or phase IV trials). The goal is to evaluate treatment safety, benefits, and risks in patient populations, leading to regulatory approval.

Phase 0 trials, which include a very small number of patients testing very limited drug exposure, can help determine whether a drug behaves the way it is expected to behave. After FDA approval, Phase IV trials provide insights into long-term safety and patient quality of life. As approved treatments become part of clinical practice, medical care continually advances.

In summary, Susan Chang explained that the experts on the IBTA Summit panel (Professor Matthias Preusser, Professor Gaetano Finocchiaro, Dr David Jenkinson, Melissa Lim and Chris Tse) encompass a wide spectrum of research and advocacy endeavours that are pivotal to the outcomes and well-being of brain tumour patients. These efforts reflect the collaboration between researchers, patients, and advocacy groups, as they strive to transform scientific knowledge into tangible improvements in patient care.



The brain tumour clinical perspective

Speaker: Professor Matthias Preusser, Medical University of Vienna, Austria



Professor Matthias Preusser shared his thoughts on brain tumour research with colleagues on the panel and particpants at the World Summit.

Professor Matthias Preusser, Head of Medical Oncology and Clinical Division of Oncology at the Medical University of Vienna offered a glimpse into his role and insights. Matthias Preusser cares for patients directly and concurrently manages clinical trials. In his view, clinical trials are paramount to propel the field of brain tumours forward.

Over the past 15 years, his experience in conducting clinical research has brought to light certain inefficiencies, particularly within neurology and brain tumour research. To advance, these shortcomings should be rectified.

Matthias Preusser said that, regrettably, errors have been made in the past, such as rushing into phase III trials prematurely. These substantial trials encompassing global patient populations and huge investments have often led to disheartening outcomes. It is discouraging to witness a multitude of unsuccessful endeavours, each costing significant resources and time. Despite these efforts, the brain tumour field remains rife with unanswered questions. A glimmer of hope, said Matthias Preusser, is the recent INDIGO trial, yet the larger narrative has been one of repeated disappointments.

The contrast with progress in other tumour types benefiting from immunotherapies and targeted treatments, makes it clear the brain tumour research approach needs revising. The central challenge lies in transitioning from taking modest data gleaned from limited studies to conducting comprehensive early-stage investigations. The drug's behaviour needs to be assessed within the brain and tumour environment before embarking on massive phase III trials. The exemplary INDIGO trial was meticulously planned with a thorough comprehension of the biology, solid assessment of tumour response and confirmation of drug penetration in the brain before finalising the chosen drug candidate.

On the regulatory front, researchers also face mounting complexities. Navigating the process from study design, approvals, quality control, and ethical considerations has become an intricate undertaking. This complexity becomes problematic when conveying trial details to patients for their consent. In such situations, instead of medical professionals and facilitators, doctors more resemble lawyers inundating the patient with a binder of intricate documents and overwhelming the vulnerable patient in an already challenging time, by having to communicate technicalities about what may go wrong.

While solutions to these challenges aren't apparent, Matthias Preusser highlighted the urgent need for improvement. He concluded by saying that the current situation is disconcerting, and the energy spent, and opportunities lost in this pursuit are substantial.

The brain tumour translational research perspective

Speaker: Dr Gaetano Finocchiaro, IRCCS Ospedale San Raffaele, Milan, Italy



Dr Gaetano Finocchiaro provides his perspectives.

Dr Gaetano Finocchiaro, neuro-oncologist at IRCCS Ospedale San Raffaele in Milan, Italy expressed his gratitude to Kathy Oliver and the IBTA for organising such an inspiring and moving event. He also thanked them for endorsing "Brainy", the Italian association dedicated to advancing brain tumour research, an initiative born during the COVID-19 pandemic.

To illustrate the journey of translational research, Gaetano Finocchiaro presented checkpoint inhibitors. Checkpoint inhibitors intercept the suppressive mechanisms in T cells, bolstering the immune response against tumours. The strategy involves blocking these inhibitory checkpoints, often employing antibodies like PD1. While this approach showed promise in various cancers, including melanoma, its application to glioblastoma was not as straightforward.

Gaetano Finnocchiaro showed experiments where mice implanted with glioblastoma tumour cells were treated with anti-PD-1 antibodies where more than 50% of the treated mice exhibited positive responses.



Dr Gaetano Finocchiaro said: "…The focus of translational research needs to shift from animal models to human patients…"

However, the clinical reality turned out to be different and rather disappointing. The outcomes from large-scale phase III trials involving glioblastoma patients receiving either anti-PD-1 antibodies or a placebo after standard treatment (surgery, radiation, chemotherapy) showed no discernible difference.

He explained that, to begin with, we must recognise that glioblastoma differs significantly from melanoma. Unlike melanoma, glioblastoma is immunologically "cold" and does not naturally attract immune cells like T cells. This can be attributed to the limited number of DNA mutations found in glioblastoma.

In the experiment shown, the glioblastoma cells used had an unusually high mutation count, which does not reflect real-world glioblastomas. In contrast, other glioblastoma cells have far fewer mutations, mirroring the situation in patients.

An analogous experiment using these cells exhibited results that aligned with clinical experiences: survival rates weren't improved with checkpoint inhibitor antibodies. However, the model with the high-mutation cells displayed promising survival rates, unlike the patient scenario.

This underscores the significance of the model in research, although it's not the sole determinant. The number of mutations in tumour cells is just one factor among many. Gaetano Finocchiaro lamented that many clinical trials lack specific tissue requirements, making it difficult to understand treatment responses.

This brought him to the notion of the "valley of death," a term coined by the journal Nature. In his opinion, the gap between laboratory and clinical efforts should have been bridged by now. The key lesson here is that if researchers and clinicians do not work closely, more disappointments await.

In his perspective, a more patient-centric approach to translational research is imperative.

Gaetano Finocchiaro echoed a recent commentary in Cancer Cell that proposes shifting the focus from animal models to human patients: "the model-centric approach has not yielded the expected abundance of treatment advances. We propose that the focus of translational research needs to shift from animal models to human patients, and the goal should be to understand why tumor responses and outcomes are so variable between patients and how it can be predicted at the individual level and thus to generate hypotheses that are more relevant to people than to atypically sensitive animal models."

The brain tumour patient advocacy organisation perspective

Speaker: David Jenkinson,
The Brain Tumour Charity, United Kingdom



David Jenkinson, the then-head of research at The Brain Tumour Charity, stressed that a collaborative approach in brain tumour research is crucial.

David Jenkinson, (former) Chief Scientific Officer of The Brain Tumour Charity in the United Kingdom explained that his PhD was rooted in molecular biology so this academic bias has shaped his research-oriented perspective.

The Brain Tumour Charity advocates for clinical research into brain tumours. As treatments emerge and brain tumour approvals slowly materialise, David Jenkinson envisions the forthcoming years as an exciting time in neuro-oncology.

However, he acknowledges the imperative to deepen our comprehension of these tumours. He said that given there are over 130 orphan diseases, each affecting a limited number of individuals, collaboration is paramount. Acknowledging the financial constraints within this sphere, David underlined the necessity for collective action and harmonised efforts to drive meaningful change for brain tumour patients.

He concurs with the sentiment previously voiced — clinical trials, while crucial, require an understanding of the biology to avoid failure. David identified a burgeoning interest from pharmaceutical companies, primarily in metastatic diseases stemming from breast and lung cancers. This new interest in brain metastases could lead to the development of drugs that penetrate the blood-brain barrier and that could be repurposed for brain tumours

He also emphasised that, until those advances come to fruition, the brain tumour community must face its challenges collectively. The metaphorical "valley of death" is deeper for brain tumours, exacerbated by the complexity of the blood-brain barrier and the limited number of patients, making it economically challenging for pharmaceutical companies to develop brain tumour treatments.

David Jenkinson called for unified support to unravel the biology underpinning tumours, that can lead to clinical trials and eventual

cures. He also explained that the brain tumour community needs to move into drug discovery itself to press things forward and make changes. That will require extensive funding that can only be obtained with wide support from the entire community.

David stressed that a collaborative approach is vital for progress.

The brain tumour patient perspective

Speaker: Melissa Lim, Brain Tumour Society (Singapore)



Melissa Lim from Brain Tumour Society Singapore provided the patient perspective of brain tumour research.

Melissa Lim, the founder and president of the Brain Tumour Society (Singapore) and a brain tumour patient herself, shared her perspective on the challenges faced by brain tumour patients in Singapore and their involvement in research. Her presentation highlighted the need for improved patient advocacy, increased patient involvement in research, and more equitable partnership between patients and researchers in the region.

She stressed that patients should play a pivotal role in driving research efforts that directly impact their lives. Often patients only become interested in brain tumour research when their lives are at stake, making it difficult to sustain engagement due to the limitations imposed by their conditions. She noted that as patients transition to palliative care or lose their lives, the momentum for advocating for brain tumour research dwindles.

Melissa Lim highlighted the passive role patients play during clinical trials in Singapore. Patients are only involved when they qualify for a clinical trial, and even then, there is a lack of empowerment and engagement in the research process. She expressed the desire for local clinical trials, as patients often exhaust all available options and see clinical trials as their last hope. However, the stringent criteria required for participation often force patients to compromise their comfort, rights, and preferences to meet trial requirements.

She shared two examples to underscore her points. In one case, a ten-year-old patient with diffuse intrinsic pontine glioma (DIPG) had to undergo a biopsy to qualify for a study. The procedure resulted in facial palsy and diminished quality of life. Even though her parents had expressed their reluctance, they gave their approval for the biopsy as this was the only chance for their daughter to access the trial.

In another instance, a patient was unable to access a promising lung cancer therapy that genetic sequencing had shown he was responsive to. The tumour size requirement that impeded his participation in a trial for this therapy seemed arbitrary.

Melissa Lim expressed the need for patients to be treated as equal partners in the research process, rather than being approached only when their participation is needed. She cited the example of Australia, where patients have a significant presence in every stage of a new study, from conception to final approval. This approach empowers patients, ensuring their needs and perspectives are considered throughout.

She also shared encouraging developments, such as researchers now proactively reaching out to patient groups in Singapore for participation in studies. While this is a step in the right direction, she emphasised the importance of not only involving patients when needed, but rather fostering an ongoing partnership.

In her presentation, Melissa Lim effectively conveyed the challenges brain tumour patients in Singapore face in terms of patient advocacy, limited engagement in research, and unequal partnerships with researchers. Her examples and insights shed light on the urgency of creating a collaborative research environment where patients are empowered, actively engaged, and valued as equal stakeholders.

The brain tumour caregiver's perspective

Speaker: Chris Tse, Brain Tumour Support New Zealand



Chris Tse, Brain Tumour Support New Zealand

Chris Tse, caregiver to his wife (a long term glioblastoma survivor), founder of Brain Tumour Support NZ and senior advisor at the

International Brain Tumour Alliance (IBTA) offered a valuable caregiver perspective during the panel discussion. His presentation shed light on the unique journey of caregivers, their relationship with research, and the challenges they face. Chris emphasised the significance of hope in research and discussed various frustrations caregivers encounter in their role.

He opened by acknowledging the diverse nature of both patient and caregiver journeys, emphasising that each experience is unique. Addressing the audience, he inquired how many were caregivers, recognising that he was "preaching to the converted." He welcomed alternate viewpoints and encouraged attendees to share their experiences.

Chris Tse described research as the tangible embodiment of hope. His awareness of the importance of hope was heightened through his involvement with IBTA. Brain tumour research (spanning from basic science to clinical and caregiver research) has been important to him ever since his wife Lynda was diagnosed with a glioblastoma in 2006. As a caregiver/researcher, he undertook the task of searching for high-quality information and scientifically validated treatment options to understand and support his wife's treatment journey. He recounted advising his wife not to search Google since the first information that came up were dire survival statistics.

The significance of open access journals in caretaker research was highlighted by Chris Tse. He noted that finding relevant open access articles was like receiving a Christmas present. Otherwise, he had to write directly to authors asking them individually for access to their papers.

He outlined several key frustrations that caregivers encounter. He echoed Christine Marosi's annoyance with well-intentioned individuals suggesting miracle cures. He emphasised the importance of evidence-based discussions and scientific backing. Poor scientific journalism and sensationalised media reporting compound this issue for the non-scientist caregiver researching for reliable information. He acknowledged the need for more skilled science communicators to bridge the gap between scientific research and public understanding.

The long development cycle for new therapies is a matter of concern to patients and caregivers. Chris Tse posed the question as to whether artificial intelligence (AI) could expedite the research process by converting clinical data into valuable insights for regulatory approvals. He underscored the importance of efficient use of research efforts, lamenting instances of duplicate research due to lack of collaboration and information-sharing among researchers working in isolation.

He highlighted the importance of global awareness in research efforts. He noted the lack of representation from New Zealand researchers at international conferences such as the Society for Neuro-Oncology (SNO) annual meetings and advocated for increased collaboration and sharing of insights across borders to hasten progress.

Upcoming technologies in brain tumour research that hold promise include liquid biopsies, improved drug delivery methods, and immunotherapies. He also expressed the need for greater integration of research into standard care, particularly in New Zealand.

Chris Tse's presentation provided a heartfelt and comprehensive insight into the world of caregivers. His observations on hope, key frustrations, the need for global collaboration, and the role of research in caregivers' lives served as a poignant reminder of the crucial role caregivers can play in the journey toward improved brain tumour treatments and care.

Panel discussion



The panel of experts at the World Summit provided a comprehensive overview of challenges and opportunities in brain tumour research.

The panel discussion following the brief interventions above revolved around international collaboration in brain tumour research, addressing challenges, opportunities, and strategies to enhance cooperation among researchers, funding organisations, and other stakeholders. The insights and perspectives shared during the discussion shed light on the complexities of research funding, the need for prioritisation, overcoming barriers to collaboration, and the importance of patient involvement in the research process.

Collaboration and funding:
The panel discussion underscored the importance of collaboration in research funding, urging the breakdown of borders to pool resources for trials that might be overlooked by the pharmaceutical industry. Collaboration was highlighted as vital to overcoming regulatory hurdles, particularly for international trials, and addressing concerns about research duplication.

Patient perspectives and prioritisation:
Acknowledging patient interests aligned with research goals, panel members asked for a show of hands as to which of the organisations represented at the IBTA World Summit were involved in research funding and if they would increase funding if the process was made more accessible. This inquiry to the audience at the Summit revealed substantial interest in funding research and indicated the significance of collaborative endeavours.

Facilitating international research funding:
The panel explored ways to collectively facilitate international research funding collectives. Strategies discussed included streamlining administrative procedures, data and resource sharing, transparency in funding priorities and outcomes, and creating centralised structures to coordinate trials.

Challenges of collaboration and duplication:
Challenges regarding research duplication were emphasised, with a call to prevent wastage of resources. Transparency in research funding was stressed to avoid unnecessary overlap. Balancing competition with collaboration and addressing researchers' fears of being overtaken by competitors were considered important.

Focused ultrasound trials and technical solutions:
The potential of focused ultrasound to deliver drugs directly to the brain and its use for detecting cell-free DNA through liquid biopsy was acknowledged. Current trials were discussed, considering benefits and challenges. However, concerns about limited data and the pace of research advancement prompted calls for cautious, informed trial design.

The role of the Focused Ultrasound Foundation in steering trials across regions was highlighted, urging focus on tumour types to avoid redundancy. Challenges in rare tumour trials were addressed, emphasising efficient trial design for maximum impact.

Collaborative funding success stories:
Ralph deVitto from the American Brain Tumor Association (ABTA) shared the example of the Brain Tumour Funders' Collaborative, involving five organisations from the United States and Canada plus one anonymous funder that pooled their resources to create a substantial fund for brain tumour research. This model demonstrated the potential of collaboration to leverage funding and generate more impact collectively than any organisation could achieve individually.

Balancing research areas:
The importance of balancing basic science research and translational research was discussed. Summit participants also commented that, while basic science research is fundamental, other research areas with immediate impacts on patients' quality of life also need to be investigated.

Challenges faced by researchers:
Challenges faced by researchers, especially clinical researchers, including growing funding struggles and publication pressures, were acknowledged. Researchers' shift from academia to industry for better prospects and less administrative burden was mentioned. Considerations to ease administrative burdens and support researchers were suggested.

Patient-centric research and participation in clinical trials:
The panel discussants stressed the role of patient involvement in research decisions, from prioritising research areas to clinical trial design. Addressing misconceptions about clinical trials and increasing brain tumour patient participation in clinical trials were seen as crucial.

Conclusion:
The panel discussions provided a comprehensive overview of challenges and opportunities in brain tumour research, with a focus on international collaboration, patient engagement, and funding strategies.

Collaboration, transparency, patient involvement, and prioritisation emerged as recurring themes. Insights shared during the discussions can serve as a foundation for future projects to improve brain tumour research and patient outcomes.

Closing remarks

Speaker: Kathy Oliver, International Brain Tumour Alliance (IBTA), United Kingdom



Pictured left to right: Dr Susan Chang, Kathy Oliver and Professor Matthias Preusser at the end of the fifth Biennial Summit of Brain Tumour Patient Advocates.

Kathy Oliver, IBTA Chair and Co-Director, thanked all Summit participants and called Batchimeg Batchuluun (representing Mongolia for the first time at a Summit) and Professor Matthias Preusser from Vienna (whose invaluable assistance helped make the meeting possible) to the stage. She presented both with a world globe, a symbol of patient advocates coming together to "shrink" the world and make it a more compact place where the community can reach out to each other and collaborate to improve life for brain tumour patients.

The theme of the 2023 IBTA World Summit of Brain Tumour Patient Advocates in Vienna was "bridging our communities across the globe, building progress, building hope." Thanks to the much-appreciated presence of so many enthusiastic, committed and determined healthcare professionals and patient advocates at the Summit in Vienna, the dream of a more collaborative international brain tumour community across the world may fast become a reality.






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5th Biennial World Summit of Brain Tumour Patient Advocates

25th - 28 June 2023, in Vienna, Austria - The InterContinental Wien Hotel

Bridging our communities across the globe, building progress, building hope.

List of participants (alphabetical order, by first names)

The International Brain Tumour Alliance (IBTA) extends its heartfelt thanks to all the participants and contributors who played an invaluable role in shaping the 5th Biennial World Summit of Brain Tumour Patient Advocates in Vienna in June 2023.

Your insights and dedication were instrumental in shedding light on the barriers and solutions for brain tumour research. Thank you for your unwavering support.

- **Adelheid Wöhrer**, Neuropathologist, Medical University of Vienna, Austria
- **Alexandra Diaz Alba**, Neurologist, Instituto Neurologica de Guadalajara, Mexico
- **Akinpelumi Toheeb Salami**, Nigeria
- **Amber Barbach**, Founder and Director, Glioblastoma Research Organisation, United States
- **Amy Wood**, Executive Director, Raymond A Wood Foundation, United States
- **Ana Arnaut**, President, GLIA, Croatia
- **Andreia Capela**, Medical Oncologist, Centro Hospitalar Vila Nova de Gaia-Espinho, Portugal
- **Anna Berankova**, Founder, BrainCzech, Czech Republic
- **Anna Uzlova**, Founder and Chief Executive, Inspiration Family, Ukraine
- **Anita Granero**, Founder and President, Oscar's Angels, and Senior Advisor, International Brain Tumour Alliance (IBTA), Italy and France
- **Anita Kienesberger**, Chair, Childhood Cancer International-Europe, Austria
- **Ather Enam**, Founding President, Pakistan Society of Neuro-Oncology (PASNO)
- **Batchimeg Batchuluun**, Founder, Nomax Publishing, Mongolia
- **Bec Mallett**, Founder and Chief Executive, Peace of Mind Foundation, Australia
- **Bernard Leon**, Chairman, Oligocyte, France
- **Brijesh Deshpandi**, Bengaluru Chapter Coordinator, Brain Tumour Support Group and Awareness Organisation, India
- **Caline Montfort**, Association pour la Recherche sur les Tumeurs Cerebrales (ARTC), France
- **Carol Kruchko**, President and Chief Mission Officer, Central Brain Tumour Registry of the United States (CBTRUS) and Senior Advisor, International Brain Tumour Alliance (IBTA), United States
- **Carola Lütgendorf-Caucig**, Clinical Director Radiooncology, Director o Pediatric and CNS Particle Therapy, MedAustron, Austria
- **Caroline Kane Montague**, Board Member, Brain Tumour Ireland
- **Catherine Fraher**, Director of Services and Digital Health, The Brain Tumour Charity, United Kingdom
- **Catherine Hindson**, Vice-Chair, Brain Tumour Alliance Australia (BTAA) Australia
- **Charline Geant**, Treasurer, Plus Cerebrale qui nous tumeur!, France
- **Chas Haynes**, Executive Director, Society for Neuro-Oncology (SNO), United States
- **Charles LaHaye**, President, Sterk en Positief, The Netherlands
- **Chengcheng Guo**, Associate Professor, Department of Neuro-Oncology, Sun Yat-sen University, China
- **Chris Tse**, Chair, Brain Tumour Support NZ and Senior Advisor, International Brain Tumour Alliance (IBTA), New Zealand
- **Christine Marosi**, Neuro-oncologist, Medical University of Vienna, Austria
- **Christine Mungoshi**, Director, Zimbabwe Brain Tumour Association (ZBTA) and Senior Advisor, International Brain Tumour Alliance (IBTA), Zimbabwe
- **Claudine Nogarede**, Board Member, Sterk en Positief, The Netherlands

- **Courtney Davies**, President and Chief Executive Officer, Pediatric Brain Tumor Foundation, United States
- **David Jenkinson**, formerly Chief Scientific Officer, The Brain Tumour Charity, United Kingdom
- **Eloise Cowie**, Board Member, Brain Tumour Ireland
- **Emilie Jochymek-Schaer**, President, Association Plus Cerebrale que Nous Tumeur!, France
- **Erik Ramos**, Manager, Northwest Biotherapeutics
- **Eskil Degsell**, Vice-Chairman, Svenskahjarntumorforeningen, Sweden
- **Fiona Keegan**, Chief Executive Officer, Brain Tumour Ireland
- **Friedrich Erhart**, Professor of Neurosurgery, Medical University of Vienna, Austria
- **Gaetano Finocchiaro**, MD Consultant, San Raffaele Scientific Institute and Founder, Brainy, Italy
- **Georg Widhalm**, Professor of Neurosurgery, Medical University of Vienna, Austria
- **Gordon Oliver**, Co-Director, International Brain Tumour Alliance (IBTA), United Kingdom
- **Guy Buyens**, Medical Director, Anticancer Foundation, Belgium
- **Heike McClellan**, Secretary to the Board, Svenskahjarntumorforeningen, Sweden
- **Henry Llewellyn**, Research Fellow, Department of Global Health and Social Medicine, King's College London, United Kingdom
- **Hisato Tagawa**, Representative Director, Yokohama Children's Hospice Project, and Japan Brain Tumour Alliance (JBTA)
- **Hugh Adams**, Head of Stakeholder Relations, Brain Tumour Research, United Kingdom
- **Inna Kucherenko**, Administrative Executive, International Brain Tumour Alliance (IBTA), Ukraine
- **Inessa Matiushenko**, Co-Founder, Inspiration Family, Ukraine
- **Irene Ngong**, Co-Founder, Jacob's Hope Foundation, Cameroon
- **Isabelle Sokolow**, Board Member, Association pour la Recherche sur les Tumeurs Cerebrales (ARTC), France
- **Jack Latteur**, EU Projects Officer, European Cancer Organisation (ECO), Belgium
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- **Jean Arzbaecher**, Advance Practice Nurse/Clinical Nurse Specialist, University of Illinois Brain Tumor Center and Senior Advisor, International Brain Tumour Alliance (IBTA), United States
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- **Jenny Baker**, IBTA Senior Advisor, United Kingdom
- **Johan de Graaf**, Chair, Dutch Pituitary Association, The Netherlands
- **John de Bruin**, Executive Board Member, Hersentumor Contact Group, The Netherlands
- **Jolijn Dirksje Boer**, Patient Expert, Gemeinsam gegen Glioblastom (GGG), Germany
- **Kathy Oliver**, Co-Founder, Chair and Co-Director, International Brain Tumour Alliance (IBTA), United Kingdom
- **Kelli Duprey**, Executive Director, Our Brain Bank, United States
- **Keren Gonen**, Chief Executive Officer, ILAM, Israel
- **Kimberly Wallgren**, Executive Director, CERN Foundation, a designated program of the National Brain Tumor Society, United States
- **Klaske Hofstee**, Chairwoman and Founder, Stichting STOPhersentumoren.nl, The Netherlands
- **Komal Syed**, Founder, Brain Tumour Foundation of Pakistan
- **Laura Appleton**, Support Specialist, brainstrust, United Kingdom
- **Lia LeRoy**, President, Werkgroep Hersentumoren (WGHT), Belgium
- **Lina Piliciauskiene**, Chair, The Lithuanian Brain Tumour Patients and Caregivers Society
- **Lucy Wilkinson**, Support Services Manager, Brain Tumour Support, United Kingdom
- **Magda Magiera**, Chairman, Glioma Foundation, Poland
- **Manmeet Ahluwalia**, Chief of Medical Oncology, Chief Scientific Officer and Deputy Director Fernandez Family Endowed Chair in Cancer Research, Baptist Health - Miami Cancer Institute, United States
- **Maria Solomou**, President and Founder, Cyprus Brain Tumour Association (CBTA)
- **Marjolaine Fazilleau**, Global Evidence Generation Manager, Servier
- **Mary Lovely**, Senior Advisor, International Brain Tumour Alliance (IBTA), United States
- **Mary Ellen Maher**, Advance Practice Nurse, Lou and Jean Malnati Brain Tumor Institute United States
- **Martin Glas**, Professor and Head, Division of Clinical Neuro-Oncology and Brain Tumor Center, University Hospital, Essen, Germany
- **Matthias Preusser**, Professor of Medical Oncology and Head, Clinical Division of Oncology, Medical University of Vienna, Austria
- Maureen Daniels, Registered Nurse, Coordinator, Gerry and Nancy Pencer Brain Tumor Centre, Prince Margarte Cancer Centre, and Senior Advisor, International Brain Tumour Alliance (IBTA), Canada
- **Melissa Lim**, Founder and President, Brain Tumour Society Singapore
- **Naina Chauhan**, Chair/Founder/Trustee, Jay C Trust, United Kingdom
- **Nicole Willmarth**, Chief Mission Officer, American Brain Tumor Association (ABTA), United States
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- **Olga Sapoznikov**, International Accrediation Manager, Masaryk Memorial Cancer Institute, Czech Republic
- **Patricia Berkelaar**, Volunteer, Hersentumor Contact Group, The Netherlands
- **Peter Ramstadius**, Committee Member and Website Coordinator, Brain Tumour Alliance Australia (BTAA), Australia
- **Pia Riis Olson**, Board Secretary, Danish Brain Tumor Association, Denmark

- **Rahul Chauhan**, Trustee, Jay C Trust, United Kingdom
- **Ralph DeVitto**, President and Chief Executive Officer, American Brain Tumor Association (ABTA), United States
- **Richard Price**, Head of Policy, European Cancer Organisation, Belgium
- **Roberto Pugliese**, President, Glioblastoma.it ODV, Italy
- **Rolf Ledal**, Secretary General, Norwegian Brain tumor Association, Norway
- **Rosie Cashman**, Senior Advisor, International Brain Tumour Alliance (IBTA), Canada
- **Shannon LaHay**, Chief Executive Officer, Brain Tumor Foundation of Canada
- **Simone Silenzi**, Founder and Coordinator, Gruppo Italia Glioblastoma Multiforme cancro al cervello, Italy
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- **Stu Farrimond**, Senior Advisor, International Brain Tumour Alliance (IBTA), United Kingdom
- **Susan Chang**, Director of Neuro-Oncology, University of California San Francisco (UCSF) United States
- **Tina Mitchell Skinner**, Founder and Chief Executive Officer, Brain Tumour Support, United Kingdom
- **Tracy Batchelor**, Chair, Department of Neurology, Brigham and Women's Hospital, United States
- **Veronica Foote**, Head of Policy and Consulting, Working with Cancer, United Kingdom



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