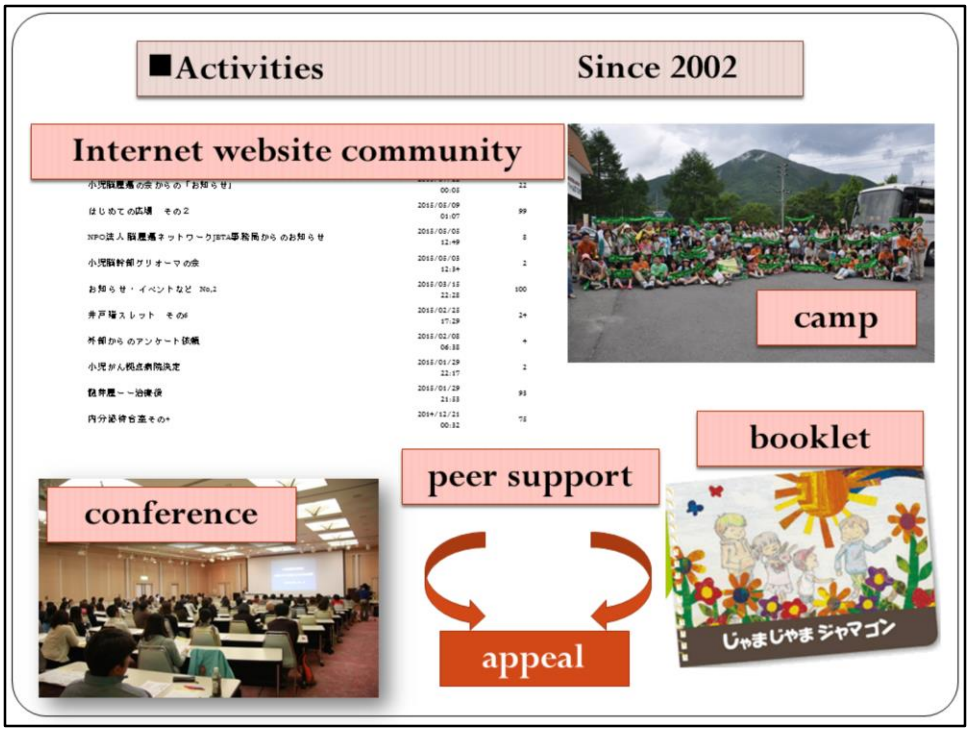
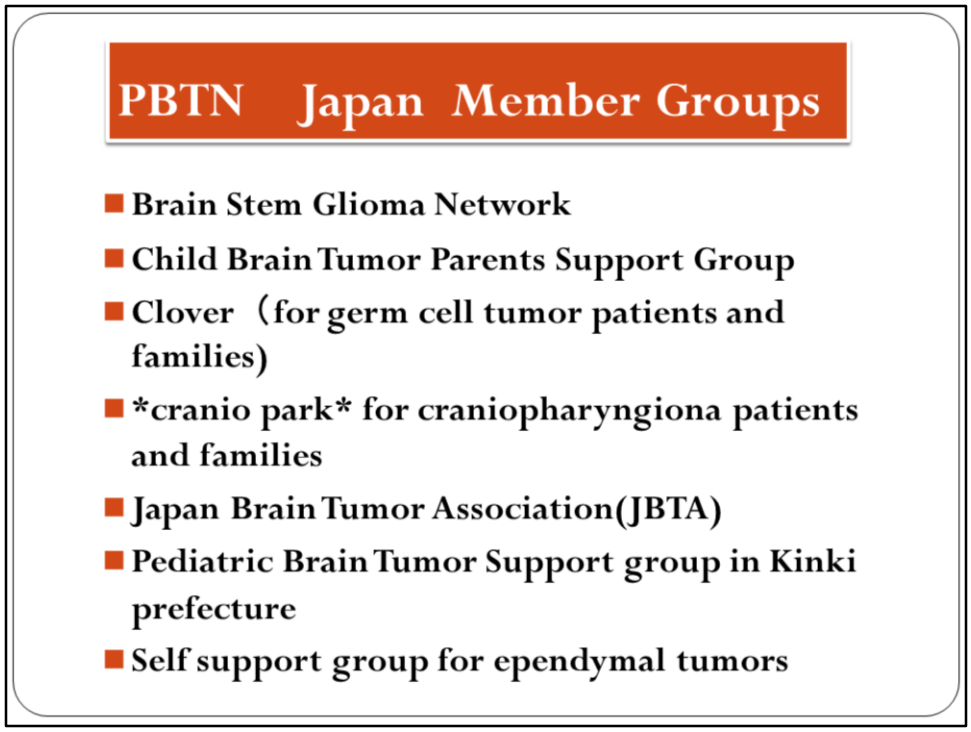
It was seventeen years ago. When my one year old daughter began to vomit. She was diagnosed with common cold but this “cold” persisted. It was three months later that a 4cm (1.6 inches) tumor was detected in her cerebellum. In those days, there was no hospital specialized in pediatric brain tumor in Japan. So we went to a major university hospital, hoping to receive a better treatment. However, even there, they had treated only one case of pediatric brain tumor. My daughter underwent an emergency operation and diagnosed with grade IV medulloblastoma. The doctors, although they lacked the experience, tried their best to treat my daughter by following the examples of the latest treatments in US and Europe. Since then, my daughter underwent many kinds of treatments to cope with various problems.



In 2003, I joined the support group and started to help organizing camps and lectures. Here is the outline of our activity. As you know, Pediatric brain tumor is very rare. It is really hard to find someone who has the same problem. So the support group started to organize an internet forum where the families of patients can exchange information about treatments and QOL. The number of visitors to this website now exceeds hundred and fifty thousand. Pediatric brain tumor has so many different kinds

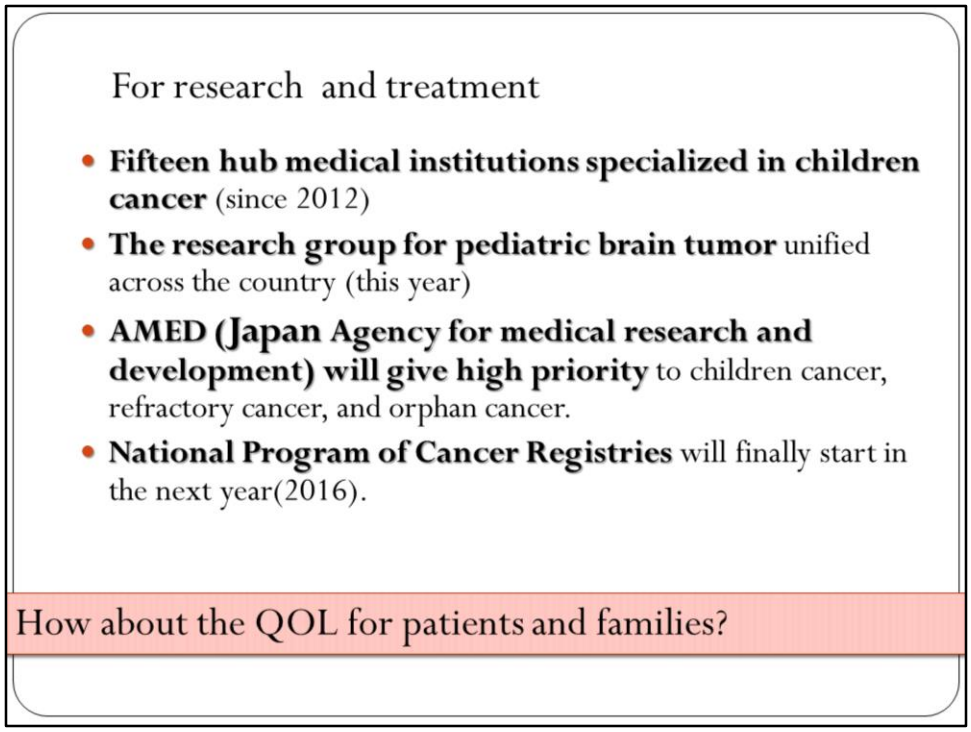


Today, people suffering from the same type of tumor organize the groups specifically discuss certain tumors. As members of Pediatric Brain Tumor Network, we actively exchange information and engage in lobbying.

From our information exchange, we learned that many hospitals treat rare pediatric brain tumors, providing different treatments to the same type of tumor, thus creating therapeutic divide. Due to this, some patients have poor prognoses. Whether adult or child, patients of a rare illness have difficulty to find necessary information and experts who can treat their case. So we collaborated with other similar groups across the country to make petitions to the government. Finally in 2012, fifteen hub medical institutions specialized in children cancer were established by the government to cope with this illness.

In Japan, we have medical insurance system for the whole nation. Therefore, the medicines from other countries are tested in Japan to ensure patients' safety and only the drugs which passed the test are introduced. This creates medical drug lag, which inhibits us to immediately introduce good medicines from foreign countries.

Also, since the population of Japan is aging faster than that of any other country, medical and welfare policies put much emphasis on elder generation. For example, government budget available for pediatric medical research was a sixteenth part of that for adult medical research. Therefore, the research on pediatric brain tumor has been very slow.



But newly created hub medical institutions allowed to gather patients at one place for clinical test. This autumn, the nationwide research group for pediatric brain tumor will be formed. For cancers in general, National Program of Cancer Registries will finally start in the next year. Also, a group named AMED (Japan Agency for medical research and development) has been established to specially enforce clinical testing in the treatments. Seeing these moves, I expect that the new medicines and treatments will be quickly introduced. We hope also global clinical trials.

Speaking of QOL, Japanese people tend to think that children should be taken care of by their parents rather than the entire society. Once you leave hospital after treatment, you will hardly find social or psychological support for patients and their families. Some have difficulties to accept unexpected illness or handicap, some children refuse to go to school due to the lack of understanding by teachers and classmates. Terminal care for children is also hard to find. Patients and their families are living with a lot of stress and they need hearty QOL support. Currently, our support group organize workshops on peer support and we have listened to the families of patients. Also Mr. Tagawa of JBTA is now working on the project, aiming to realize such warm supports.

Unfortunately, Mr. Tagawa could not make it here today as planned, so I will explain the details of the activities in his place.

Greetings participants of the World Summit, Our NPO JAPAN BRAIN TUMOUR ALLIANCE NPO) SMILE OF KIDS support families and children with diseases and disabilities. It was back when my daughter, Haruka, developed DIPG and passed away 5 months after the doctor told us how much longer she had to live. It was during her struggle against the disease that I began to think that it was my mission to establish a children's hospice, and now I am working toward making that dream come true.

- approximately 20000 children in Japan that still has no concrete treatment

Yokohama Children's Hospice Establishment Preparatory Committee

- More places where children could productively use the remaining time that they have and places where they could enjoy themselves are needed.

There are approximately 20000 children in Japan that have a fatal disease that still has no concrete treatment such as child cancer and other chronic diseases. Together with families and support staff, I wanted to have a place where children could productively use the remaining time that they have and a place where they could enjoy themselves rather than just going back and forth between their home and the hospital. A transitional facility (a children's hospice), based around home assistance where families can stay together, is needed, but there is only one in Japan in Osaka known as "TSURUMI Children's Hospice," which is based on the Helen & Douglas House.

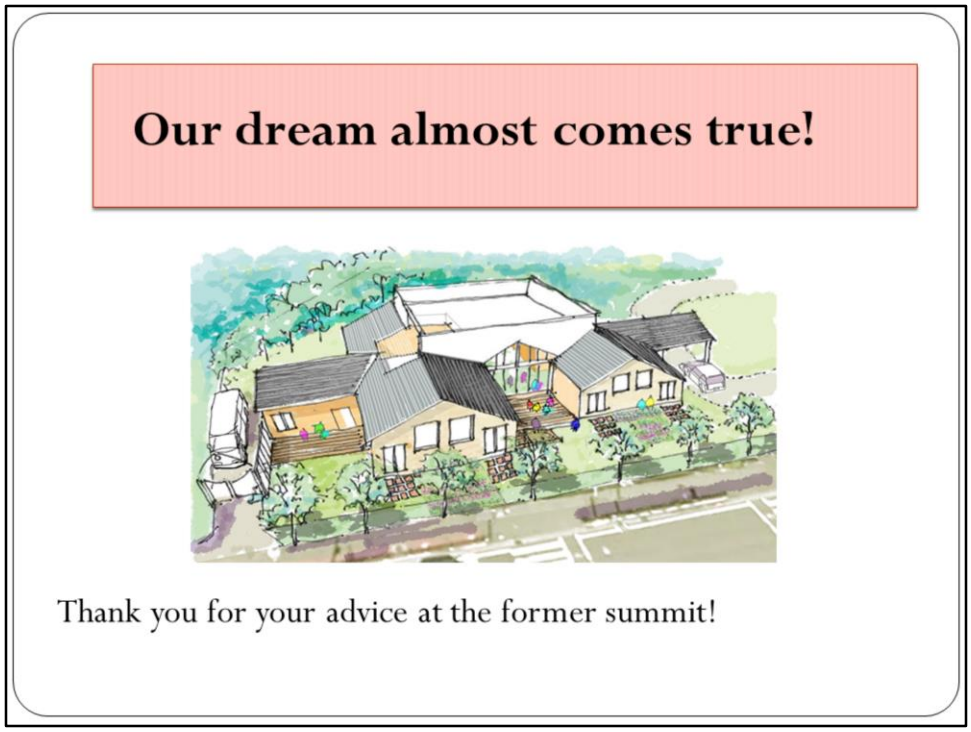
If I can help the children, who do not have much time left on this earth, create wonderful memories with their families, and if I can help them get one step closer to their dreams, then I believe that their immune strength will increase and their precious time on this earth will grow. This is a warm, caring facility which can be thought of like a second home away from home where everyone thinks and works together in order to make the best of life. In Japan, children that cannot get the necessary treatment only have their home and the hospital to go to. A home assistance facility that will always be there for the children is essential.

A former nurse in Fujisawa near Yokohama who had the same dream as us.

Her dream was to use the inheritance left to her for building a children's hospice.

Our NPO received support the year before last. It was from the request of a former nurse in Fujisawa near Yokohama who had the same dream as us-building a children's hospice. Our fate brought us together and we received 105 million yen in inheritance money from her to bring us one step closer to getting the necessary funding.

On August 15 of last year, we were able to set up a Yokohama Children's Hospice Establishment Preparatory Committee.



This is the rough buiding design of our hospice.We plan on establishing our children's hospice 5 years from now (2020). We have gathered 240 million yen in donations as of August of this year. We have not decided upon the exact location yet, but we are in discussion with Yokohama city as of now.
There are 52 locations in England and many in Germany, US, Australia, and other Christian cultural spheres, but Japan is still late when it comes to child support systems. I can only hope that these facilities only continue to increase within Japan.

From Japan, I am wishing you all good health and success. HISATO TAGAWA Japan Brain Tumour Association