BREXIT AND BRAIN TUMOURS

A statement from EURACAN
the European Reference Network for rare adult solid tumours
with support from
The Brain Tumour Charity, Brain Tumour Research, brainstrust, Brain Tumour Action,
Brain Tumour Support, Brain Tumour Research and Support Across Yorkshire and
the International Brain Tumour Alliance (IBTA)

We ask the UK Government to clarify their intentions on the status of European Reference Networks in the UK post-Brexit and what progress has been made in relation to this specifically since the publication of the “Collaboration on science and innovation: a future partnership paper”.

We also urge the European Commission to clarify their intentions on the status of European Reference Networks in the UK post-Brexit.

There are around four million people in the EU who are affected by a rare cancer. Collectively these represent around 22% of all cancers diagnosed in EU member states¹. Action on rare cancers has been prioritised by the EU and numerous member states but there remains a long way to go in terms of the knowledge, understanding and capacity required to diagnose, treat and care for people affected.

We are experts in rare cancers from across the EU and represent EURACAN, the European Reference Network (ERN) for adult rare solid tumours. We support continued cross border access to treatment for UK citizens affected by a rare cancer after the UK leaves the EU.

The principle of open, cross borders – in delivering world class care, access to clinical trials and improved patient outcomes - must remain intact to ensure that the interests of patients with rare cancers continue to come first. Patients, knowledge, expertise and capacity regarding rare cancers are dispersed across Europe. Consequently, pan-European co-operation and collaboration are now inherent in the field of rare cancers as a result of open borders.

¹ http://www.rarecancerseurope.org/About-Rare-Cancers/The-Burden-and-the-Challenges-of-Rare-Cancers
ERNs were established under the EU Directive on cross border healthcare. Each ERN aims to establish a world-leading, patient-centric and sustainable network of multidisciplinary research-intensive clinical centres. ERNs are virtual and connect existing centres of excellence from at least eight different member states.

In reality relatively few patients from the UK physically travel across borders to receive healthcare subsidised by the UK National Health Service (NHS). But collectively, EU member states harness a great wealth of information, experience and capacity in the field of rare cancers which can be used to help treat and research rare cases. The exchange of these assets is made easier by harmonized regulation, free movement and joint funding initiatives.

ERNs improve treatment and care in numerous ways. For example, clinicians can more easily seek counsel on patient data and get a second opinion or seek suggestions for treatment protocols where the relevant expertise does not exist in their own country. Patient advocacy organisations from across the EU can more easily disseminate educational tools to advance clinicians’ understanding of the patient journey. And clinical practice guidelines can be continually reviewed and developed to better reflect best practice in the continent.

Researchers conducting pre-clinical and clinical trials also benefit from access to reliable patient data through commonly established procedures between ERNs and members states that can reduce delay, bureaucracy and maximise the impact of research and funding grants. The engagement of sufficient cohorts of both brain tumour researchers and disparate patient groups such as those with a specific type of brain tumour or children, teenagers and young adults (CTYA) is vital to progress. The UK Government recognises that ERNs are integral to the delivery of its commitments in the UK Strategy for Rare Diseases but has failed to offer a definitive assurance to UK patients that ERNs will be able to continue to operate as designed across UK and EU member state borders. We also urge the EU to provide clarity on this point.

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