BREXIT AND BRAIN TUMOURS

A statement from DOMAIN 10 OF EURACAN

the European Reference Network (ERN) for
Brain and Central Nervous System 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.

Brain tumours are a unique cancer as the tumour and treatment can directly alter the sense of self in the person affected. Brain tumours are not just one disease – there are over 150 different types. They can affect people of any age, from tiny babies to the elderly in any geographic locality. There are few treatment options and changes in quality of life can be radical and permanent, including substantial cognitive deficits and personality change. Yet brain tumours remain one of the least well-understood and one of the most intransigent cancers. Tragically, around 60% of people diagnosed with a brain tumour will die within one year.

We are experts in brain tumours from across the EU. On behalf of Domain 10 - the brain and central nervous system (CNS) tumours subgroup of EURACAN, the European Reference Network (ERN) for adult rare solid tumours - we are concerned about cross border access to treatment, care and support for people with this terrible disease after the UK leaves the EU.

1 http://www.cancerresearchuk.org/cancer-info/cancerstats/types/brain/survival
Patients, knowledge, expertise and capacity are dispersed across Europe. In reality, it is difficult, if not impossible, to make any real progress in research in this area as a single country. The engagement of sufficient cohorts of both brain tumour researchers and widely-scattered patient populations, such as those with a specific, very rare type of brain tumour, requires collaboration. Consequently, pan-European co-operation and collaboration is now inherent in the field of brain tumours as a result of open borders.

EURACAN is a direct result of these values, pragmatic thinking and collaborative efforts. EURACAN 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. The brain and CNS domain is one of ten rare cancer site-specific subgroups.

Patients’ cross border access to treatment is central to EURACAN. Patients physically cross borders to access healthcare in a limited number of cases and it is envisioned that, in practice, under the EURACAN umbrella, patients’ data will travel instead of the need for them physically to do so. But the uninterrupted exchange of information and data is crucial to the treatment of patients with rare cancers like a brain tumour. An example of where EURACAN adds value is the secure sharing of patient data between healthcare professionals through the Clinical Patient Management System (CPMS). The CPMS can enable clinicians to provide a second opinion or seek suggestions for treatment protocols where relevant expertise does not exist within their own country or contacts².

For the sake of brain tumour patients in the UK and Europe now and in the future, we urge the UK Government and EU Member States to provide clarity and commitment that the European Reference Networks such as Domain 10 will be able to operate as designed following BREXIT.

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