How the EU could help more children survive cancer

May 24 2013

A leading expert in childhood cancer at The University of Nottingham is spearheading a Europe-wide lobby of the European Parliament to try to make it easier for doctors to develop and test new treatments on children and young people with rare cancers.

Every year around 1,500 children are diagnosed with cancer in the UK, and around 15,000 across the whole of the European Union. Most are brain tumours or bone cancers, but every childhood cancer is a rare cancer, which makes them especially difficult to treat. Although treatment has improved greatly, tragically around 25 per cent of children with cancer will die.

Professor David Walker of the University's Childrens' Brain Tumour Research Centre, has campaigned for public awareness of brain tumour symptoms and better research funding for brain cancer, notably in the national HeadSmart campaign launched in 2011. He has been working closely with two East Midlands MEPs to lobby for changes to planned Clinical Trials Regulations currently being discussed in the European Parliament.

One size does not fit all

Professor Walker said: "At the moment the existing EU Clinical Trials Directive is a 'one-size-fits-all' piece of EU legislation, making some academic research particularly difficult. EU countries are still using

different standards for clinical trials depending on their interpretation of the law, and this lack of homogeneity makes it very difficult to set up cross-border clinical trials in children with rare cancers which are large enough to be effective in pioneering new treatments and procedures.

"Paediatric oncologists and clinical researchers across Europe welcome the key changes in the new regulation, including a single portal to make applying for clinical trials simpler; allowing co-sponsorship to encourage academic participation in trials; establishing national indemnity schemes to lower insurance costs and differentiating between trials that do not pose additional risks to patients compared to normal clinical practice, and those that do. But more detailed amendments should be included to encourage academia-driven clinical trials, such as clearer definition of 'low intervention trials' involving the experimental use of new combinations and doses of standard clinical practice drugs (off-label use) and other investigational medical products as well as more proportionate Annual Safety Reporting."

Beating the odds

Jane Redman, a press officer at Cancer Research UK whose daughter Amy has been successfully treated for a brain tumour by Professor Walker's team at Nottingham said: "Some of the most exciting developments in cancer research have come from the paediatric community. They were the first to develop combination chemotherapies, they are experts in complex international studies, and their patients cope with treatment regimes of an intensity that would kill an adult. There is so much to be learnt, and so much to be built on so that more children can beat the odds." Jane has written a powerful blog on her experience available on the Cancer Research UK website here.

MEP support

East Midlands MEPs Glenis Willmott and Emma McClarkin have visited Professor Walker's Children's Brain Tumour Research Centre. Glenis Willmott is a long term supporter and advocate for the pioneering work of the University's Children's Brain Tumour Research Centre. She is also the EU rapporteur charged with taking the Clinical Trials Regulation through the European Parliament and negotiating the final legislation with EU governments.

Glenis Willmott MEP said: "Because there are so few patients with certain types of cancer we need to be able to carry out cross border trials with other EU countries. That's why we have the Clinical Trials Directive, but at the moment it isn't working. EU countries are still using different standards which means researchers have to apply multiple times for a clinical trial, with different applications. Some countries might approve the trial, others might reject it. This makes the whole process time-consuming, expensive, and sometimes futile. That's why we want to make sure all EU countries are playing by the same rules. We also need to reduce unnecessary bureaucracy and delays in authorising this life-saving research, and reduce astronomical insurance costs. I am steering all of these proposals through the European Parliament, and will negotiate the final law with EU governments.

"There is no known treatment to save a child with some types of brain tumour. We need new research to provide hope to these children and their families. We also need more expertise and awareness of childhood cancers, because the earlier the cancer is diagnosed, the higher the chances are that the child can survive. I am lucky to have the excellent Nottingham Children's Brain Tumour Research Centre in my constituency which is an example of the best way to care for children with cancer."

Emma McClarkin MEP has also visited the Children's Brain Tumour Research Centre in Nottingham and is using her influence in relevant

European Parliament committees to push for amendments in forthcoming legislation. She said: "Removing EU administrative burdens will increase the number of clinical trials in the UK and throughout the EU so that we can continue our research to deliver more and better treatments. I am so proud of the work Professor Walker and his team do and we should listen to those who are carrying out these clinical trials to see what we can do to improve and help the process."

Revisions to the new Clinical Trials Directive are due to be voted on by the European Parliament over the next few months and may become EU law by this autumn.

Provided by University of Nottingham

Citation: How the EU could help more children survive cancer (2013, May 24) retrieved 11 May 2024 from https://medicalxpress.com/news/2013-05-eu-children-survive-cancer.html

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.