

How a local boy with cancer helped to change European law

Ms Glenis Willmott
Member of the European Parliament

When Pam and Mike White's son Sam was diagnosed with a brain tumour at the age of 12, it was the start of a remarkable journey. Determined to improve the available treatment for other children and teenagers suffering from rare cancers, Sam began his advocacy work. Sadly Sam passed away last September 2013, but his parents and Ms Glenis Willmott, Member of the European Parliament, are determined to continue his work and change the EU legislation to improve treatments for young people with cancer.

From their home in Newark, Notts, Pam and Mike White found themselves travelling to the European Parliament in Brussels, watching Sam carry the Olympic torch and speaking in TV interviews about his illness. Sam met his local Labour Member of the European Parliament (MEP) Glenis Willmott at the Children's Brain Tumour Research Centre in Nottingham three years ago. After hearing his story Mrs Willmott began looking at how changes to EU legislation could help Sam and others in his position.

As all childhood cancers are rare cancers, the medicines used are often experimental and not designed for children. Clinical trials are needed to find better and more suitable treatments. Due to the small numbers of patients it is often not feasible to carry out research in the UK alone, and children and teenagers with cancer are denied the opportunity to try a new medicine. *'We need to boost the number of clinical trials carried out in the UK, and we need to facilitate cross-border trials with our European neighbours to find the solutions we urgently need for many rare diseases,'* said Mrs Willmott. *'For a child suffering from cancer a clinical trial can be their only hope of survival.'*



Over the last year Mrs Willmott has been leading the negotiations on the [Clinical Trials Regulation](#) in the European Parliament, and has now reached a deal with EU governments. Once the European Parliament gives its final approval in March, it will become law in the 28 EU countries. *'Currently a cross-border trial needs multiple applications in multiple countries, all with differing rules. The new law*

will mean that researchers need to submit just a single application for a cross-border trial, and the relevant countries will work together on the assessment. Organisations that carry out paediatric oncology trials are mainly non-commercial, such as Cancer Research, the NHS or universities, and this huge reduction in bureaucracy will support their life-saving research.'

'I'm also very proud of the transparency measures that we've put in place. All clinical trials will have to report results to a publicly accessible database, whether the outcome is positive or negative. This will greatly improve our understanding of medicines, and advance the development of new treatments.'

Sam's mother Pam White has welcomed the progress at European level. Sadly Sam passed away in September 2013, but Mrs White is determined to continue his work. *'Sam always said that should he leave us, we must continue his campaign to improve treatments for young people with cancer,'* said Mrs White. *'These new European rules will give hope to other families in our situation and I know that Sam would be delighted with what he has managed to achieve.'*

'If I had not met Sam I would not have become so involved in this legislation,' said Mrs Willmott. *'His courage and determination was an inspiration to everyone he met.'*

More information

[MEP Glenis Willmott website](#)

[Video story of Sam White](#)