



**PRESS RELEASE**  
**29 February 2012**  
**For immediate release**

### **HeadSmart child brain tumour awareness initiative launched in Europe**

The new pan-European **HeadSmart** campaign has been launched today on Rare Disease Day, to raise awareness of the symptoms of brain tumours in children and young people. This formerly UK-based campaign is now set to be rolled out in other EU countries, through partnerships between patient groups and professionals.

'Solidarity' is the theme of this year's Rare Disease Day, 29 February 2012: international collaboration among professionals, patients, and all people active in the field of rare diseases is essential to access correct diagnosis, increase the availability of information, mitigate social consequences, and much more. Partnership is vital to address the challenges of rare disease patients, as rare diseases are "Rare but strong together".

For paediatric brain tumours, **early diagnosis can make a real difference in outcome and long-term effects**. With the increasing number of survivors of childhood cancer, ensuring the best quality treatment and standard-of-care needs to be a priority in European health systems. Late diagnosis of brain and bone tumours needs to be dealt with and is a problem in all European countries. SIOPE Europe, the European Society for Paediatric Oncology and ICCCPO, the International Confederation of Childhood Cancer Parent Organisations, are working together to raise awareness of the symptoms to watch out for in young people, including:

- Persistent / recurrent vomiting
- Persistent / recurrent headache
- Abnormal balance / walking / co-ordination
- Abnormal eye movements
- Blurred or double vision
- Behaviour change
- Fits or seizures
- Abnormal head position such as wry neck, head tilt or stiff neck

Several countries are devising strategies to roll-out a 'HeadSmart' campaign on the 'warning signs' for children. Groups in Denmark, Sweden, France, Germany, Austria, Poland and Spain are set to share best practice tools and techniques to target GPs and the public, encouraging them to think twice about certain symptoms. Member of the European Parliament Glenis Willmott hosted an event in Brussels on 07 February prompting the event. "The EU has funded a lot of research into childhood and adolescent cancers, and has legislation in place for paediatric medicines, clinical trials and treatment of rare diseases, all relevant for children with cancer. But whilst we have made a lot of progress, we must continue to improve the situation. The earlier the cancer is diagnosed, the higher the chances are that the child can survive", stated Willmott.

Prof. David Walker from the Children's Brain Tumour Centre in Nottingham, UK who is helping to co-ordinate the campaign said, "This meeting in the European Parliament



highlighted the widespread experience of significant diagnostic delays being experienced by children across European countries. There was universal agreement that not only was this extremely distressing for the children, young people and their families but that earlier diagnosis would offer the opportunity for better clinical outcomes and in some cases the saving of lives.”

The meeting precipitated an intention to form partnerships between health professionals and parents groups to promote a European-wide approach to accelerating diagnosis by promoting enhanced awareness amongst the public and profession of the range of red flag symptoms of childhood cancer but in particular brain tumours and bone tumours. The next step for this project is to set a new target for speed of diagnosis across the EU Member States as a trigger for a systemic change in this field.

### **Editor's Notes:**

#### SIOPE: The European Society of Paediatric Oncology

SIOPE Europe is a European organisation promoting research and optimal standards of care for children and young people with cancer. It is the only multidisciplinary, pan-European organisation dedicated to childhood cancer. A Founding Member of ECCO- the European Cancer Organisation and the continental branch of the International Society of Paediatric Oncology (SIOPE), SIOPE encourages close co-operation with all disciplines in the acquisition and diffusion of scientific knowledge throughout Europe.

[www.siope.eu](http://www.siope.eu)

#### Rare Disease Day

Rare Disease Day is an annual, awareness-raising event co-ordinated by [EURORDIS](http://eurordis.org) at the international level and the National Alliances of Patient Organisations at the national level.

February 29, 2012 marks the fifth international Rare Disease Day coordinated by EURORDIS and organised with rare disease national alliances in 25 European countries. The focus of this year's event is [Solidarity](http://solidarity.org). Hundreds of patient organisations from more than 40 countries worldwide are organising awareness-raising activities converging around the slogan “Rare but strong together”.

[www.rarediseaseday.org](http://www.rarediseaseday.org)

#### HeadSmart

The aim of the HeadSmart campaign is to reduce the time it takes to diagnose children and young people with brain tumours in the UK by educating healthcare professionals and the public about the symptoms of brain tumours in children and young people. Reducing the time to diagnosis should reduce the long term disability that many children and young people diagnosed with a brain tumour currently experience. The HeadSmart campaign is run by a partnership between the Children's Brain Tumour Research Centre (CBTRC) at the University of Nottingham, the Royal College of Paediatrics and Child Health (RCPCH) and Samantha Dickson Brain Tumour Trust (SDBTT), and has been funded by The Health Foundation and SDBTT. These diverse organisations have joined force to tackle the issue of brain tumour awareness in order to speed up diagnosis times. [www.headsmart.org.uk](http://www.headsmart.org.uk)

#### Media Contact:

Edel Fitzgerald, SIOPE Policy and Communication Coordinator

Edel.Fitzgerald@ecco-org.eu

Tel: +32 2 775 02 01

Fax: +32 2 775 02 00

Direct: +32 2 775 29 34

[www.siope.eu](http://www.siope.eu)