



15 February 2009 – On International Childhood Cancer Day.

International call for greater attention to be given to childhood brain tumors

The International Union Against Cancer (UICC) and the International Brain Tumour Alliance (IBTA) have issued a joint statement to coincide with International Childhood Cancer Day (15 February) drawing attention to the fact that in a number of countries* brain tumours are now the greatest cause of childhood cancer mortality in the age group 0-14.

While today there are many childhood cancer survivors because of improvements in treatments brain tumours are lagging behind, principally because their causes are currently unknown, they cannot be screened for, and they cannot be detected early.

IBTA Chair **Denis Strangman** said that worldwide approximately 200,000 people each year develop a malignant primary brain tumour for which there is no cure and very little in the way of effective treatments.

“There is a real need to promote a wider public understanding of the challenges faced by brain tumour patients, their families and their caregivers,” says **Isabel Mortara**, Executive Director of the UICC.

Both organisations called for a greater effort to be made in combating brain tumours, particularly childhood brain tumours. They welcomed signs of increased activity, including moves in the USA Congress to establish a Childhood Brain Tumor Prevention Network and the decision of the European Rarecare Project (a European Commission-funded initiative) to construct a table of rare cancers which includes brain tumours.

In support of the call for greater attention to be given to brain tumours, **Dr Larry Kun**, Chair of the US Pediatric Brain Tumor Consortium, described childhood brain tumors as “perhaps the most vexing area of pediatric oncology”.

Mr Mike Traynor, who is Chair of the Pediatric Brain Tumor Foundation in the US, the world’s largest non-governmental funder of pediatric brain tumor research, said that “Childhood brain tumors are one of the most underserved areas of cancer research which requires the philanthropic community to provide significant funds to bring an understanding of the disease to save the children afflicted with brain tumors.”

Professor Martin van den Bent from the Daniel den Hoed Cancer Center/Erasmus University Hospital in the Netherlands and Chair of the EORTC Brain Tumor Group, said: “These children not only suffer from having a malignant disease. They also suffer from the consequences of having a severe neurological illness with many behavioural and cognitive problems, even if treatment has been successful. Because of this, these childhood brain tumors need to become a top priority in cancer research.”

Professor David Walker of Nottingham (UK) said that enhancing the timeliness of diagnosis in

children could reduce visual impairment “which is the most damaging neurological consequence of delayed diagnosis that is so common across the world.”

Professor Victor Levin of the MD Anderson Cancer Center in Texas, said that the major problem “is that we do not have new and unique drugs targeted to these (childhood brain) tumors. We expect that borrowing drugs effective against adenocarcinomas and leukemia will suffice, but it has not and will not ... It will require a special effort to develop new therapies”.

NOTES: In recent years brain tumours have been vying with leukaemias as the most prominent cause of childhood cancer mortality but in the latest available childhood (0-14 years) cancer statistics for several developed countries (USA 2005, Canada 2000-2004, UK 2007) brain tumours have now overtaken leukaemias. This is not necessarily because of a growing incidence of childhood brain tumours, although this has happened in some instances, but because of more effective treatments for leukaemia and insignificant improvements in the treatment of brain tumours.

***USA statistics:** Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Mortality - All COD, Aggregated With State, Total U.S. (1969-2005) , National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2008. Underlying mortality data provided by NCHS (www.cdc.gov/nchs).

***Canada:** Canadian Cancer Society/National Cancer Institute of Canada: Canadian Cancer Statistics 2008. Toronto, Canada, 2008.

***UK:** Mortality Statistics. Deaths Registered in 2007. DR 07. Review of the National Statistician on Deaths in England and Wales, 2007.

Legislation for the proposed US National Childhood Brain Tumor Prevention Network has been introduced by US Senators Charles E. Schumer (D-NY), David Vitter (R-LA) and Congresswoman Barbara Lee (D-CA).

Further information on the EU rare cancers project can be found at:
<http://www.rarecare.eu/aims/aims.asp>

The International Brain Tumour Alliance (IBTA) is an alliance of brain tumour support, advocacy and information groups around the world, including brain tumour patients and caregivers, researchers, scientists, clinicians and allied health professionals who work in the field. (www.theibta.org)

The International Union Against Cancer (UICC), based in Geneva, Switzerland, is the leading international NGO dedicated to global cancer control. It is a dynamic global community of cancer control organizations, professionals and volunteers, working together to eliminate cancer as a major life-threatening disease for future generations. (www.uicc.org)

The International Confederation of Childhood Cancer Parent Organisations (ICCCPO) initiated the International Childhood Cancer Day in 2002. The ICCCPO Mission is: “To share information and experience between parent groups around the world, and with all others involved in the treatment and care of children with cancer, in order to ensure the best possible access to treatment and care for children with cancer everywhere in the world.” (www.icccpo.org)



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