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We are 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.

greater collaboration ► greater knowledge ► greater hope



MEDIA RELEASE (Embargoed until Midnight Saturday 20 October 2007)

200,000 PEOPLE WORLDWIDE AFFECTED EACH YEAR BY HIGHLY MALIGNANT BRAIN TUMOURS

Research commissioned by the International Brain Tumour Alliance (IBTA) has identified that annually at least 200,000 people worldwide develop a primary malignant brain tumour, which is one of the most lethal of all cancers. (IBTA website: www.theibta.org)

It further identified that the incidence of primary malignant brain tumours is 3.7 per 100,000 each year for males and 2.6 per 100,000 per annum for females.

No one has yet established why men are more susceptible to developing these brain tumours.

(Further statistical information is available at this page on the IBTA website:

<http://www.theibta.org/uploads/file/Statistics.htm>)

The research was released at the commencement of the inaugural **International Brain Tumour Awareness Week** which is being held during **21-27 October**.

The IBTA is an advocacy group that brings together brain tumour patients, their caregivers, scientists, clinicians, and commercial companies, with an interest in brain tumours.

IBTA Chair Denis Strangman from Canberra, Australia, who lost his wife several years ago to a glioblastoma brain tumour, said that the statistical estimates while invaluable, were very conservative and probably an underestimation because of inadequate cancer statistical collection resources in some countries.

“There are also many thousands of people who develop so-called ‘benign brain tumours’ that can also be lethal, and there are also hundreds of thousands of people who develop brain metastases as a result of a cancer elsewhere in the body. The overall impact and cost is almost incalculable but it is a very devastating disease” he said.

Meanwhile, one of the world's leading specialists in brain tumour research has called for greater attention to be given to brain tumours.

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The IBTA is a not-for-profit, limited liability company incorporated in England and Wales, Company Number: 6031485. Registered address: c/o Roxburghe House, 273-287 Regent Street, London W1B 2AD, UK. Address for correspondence: The Secretary, IBTA, PO Box 244, Tadworth, Surrey, KT20 5WQ, United Kingdom.

Professor M.J. van den Bent of the Netherlands, who was a member of the international team that identified the advantages of combining radiation therapy with the drug temozolomide for glioblastoma brain tumours, says that better treatments for brain tumours are urgently needed and also an increased awareness of the effects of this cancer on the person and their relatives.

"Most primary brain tumours have a very poor prognosis, and many of the affected patients are young. Apart from the shortened life, these patients suffer from a variety of signs and symptoms that have an enormous impact on their quality of life.

"In particular, the presence of cognitive deficits, memory disturbances, personality changes and other neurological deficits, often interfere with daily functioning and prevent these patients from leading a normal active life; and because of these cognitive deficits and personality changes the relatives of these patients suffer as well.

"Better treatments are urgently needed and also an increased awareness of what these tumours cause for patients that look healthy but who nonetheless often suffer from a dramatic loss of function, and what consequences this has for their relatives.

"I sincerely hope that the International Brain Tumour Awareness Week increases the attention given to this horrible disease. Despite recent advances, a lot has still to be done. Only joint efforts will help us to improve the outcome for this gruesome disease," Professor van den Bent said.

NOTES

Background to the Awareness Week: The inaugural **International Brain Tumour Awareness Week** is being held during 21-27 October 2007 and has been supported by almost 100 patient, professional, scientific and commercial organisations from 23 different countries. The main activity has been the **Walk Around the World For Brain Tumours** whereby people undertake sponsored walks for local brain tumour research and support purposes and donate the mileage to the IBTA to achieve a target of 40,000 kms – representing once around the Earth at the Equator. 32 such walks have already taken place and the target is likely to be greatly exceeded, with a further 30 walks planned during the Awareness Week. A media release about the World Walk will be issued during the Week. Scientific meetings, picnics and outings for patients and caregivers, and patient information meetings will also take place during the Week. The project has been supported by undirected grants from Schering-Plough, Lilly Oncology, Ark Therapeutics, NovoCure, Antisense Pharma, and Neuroendoscopy.

CONTACTS

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Statistical research: This was commissioned from the Central Brain Tumor Registry of the United States (CBTRUS), Illinois, USA. Contact: Ms Carol Kruchko, President and Administrator. Email: Ckcbrtus@aol.com Telephone +1 - 630-655-4786

Brain tumour patient support organisations: There are hyper-links to 49 national and local brain tumour organisations on the right-hand column of the homepage for the IBTA at www.theibta.org These organisations can provide information and comment about local situations.

National expert comment: The following people, in addition to Professor van den Bent, support the **International Brain Tumour Awareness Week** and are available for comment (please be considerate of time zones if telephoning). **North America:** Professor Abhijit Guha MD, Professor of Neurosurgery, University of Toronto and Chair of the Society of Neuro Oncology, Telephone +1- 416-603-5740 Email: Abhijit.Guha@uhn.on.ca **Europe:** Dr Francesc Graus (Spain), President, European Association for Neuro-Oncology Telephone +34-932275414 Email fgraus@clinic.ub.es **United Kingdom:** Professor Roy Rampling, Professor of Neuro-Oncology, Beatson West of Scotland Cancer Centre Glasgow. Telephone: +44 0141 301 7092 Email: r.rampling@udcf.gla.ac.uk **Germany:** Professor Wolfgang Wick, MD, Chairman, Department of Neurooncology, University of Heidelberg. Email: wolfgang.wick@med.uni-heidelberg.de Tel.: + 49 (0) 6221/56-7075 **Italy:** Dr Alba A Brandes, Chairman, Medical Oncology Department, Bellaria Maggiore Hospital, Azienda USL di Bologna, Italy, and President of Gruppo Italiano Cooperativo di Neuro-Oncologia (GICNO). Telephone: +39 051 6225697. Email: alba.brandes@yahoo.it **Australia:** Dr Elizabeth Hovey, Chair, Neuro-oncology Group, Clinical Oncological Society of Australia. Telephone: +61 -2-9382 2577 during working hours and via hospital switchboard after hours on +61-2-9382 2222 Email: liz_hovey@yahoo.com **Professor David A Walker** from the University of Nottingham (UK) (website: <http://www.cbtrc.org/>), who is an expert on **paediatric brain tumours**, is also available for comment and is currently visiting Royal Children's Hospital (Melbourne, Australia). Contact details are: David A Walker, TCT Visiting Professor, Royal Children's Hospital / Peter MacCallum Hospital, Melbourne, Victoria. Email david.walker40@gmail.com Telephone: +61 3 93455656 / 5690 (office), +61 402575812 (mobile).

BACKGROUND ABOUT BRAIN TUMOURS:

- There are over 120 different types of brain tumour.
- There are two main categories of brain tumours: primary and metastatic. Primary brain tumours can either be malignant (of varying degrees of aggressiveness) or non-malignant (so-called "benign").
- Tumours are diagnosed and then classified according to the World Health Organisation (WHO) grading system which ranges from Grade I brain tumours (slow growing, least malignant) to Grade IV brain tumours (rapidly growing and highly malignant)
- The causes of brain tumours are, as yet, largely unknown.
- Brain tumours know no boundaries. They occur in people of all ages, from very tiny babies to the elderly, male and female, and across all cultural groups around the world.
- The cancers that most commonly metastasize to the brain are lung and breast.
- **What is needed:** Research into the causes of, and treatments for, brain tumours is seriously under-funded. Better support is needed for sufferers. Equitable access to promising new therapies is another area which needs much work. Understanding the signs and symptoms of brain tumours, and improved availability to a wider range of vital support services including psycho-social support, rehabilitation and palliative care, and

access to neuro-oncology care coordinators, are additional goals which most people in the brain tumour community campaign for.