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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



## First European Rare Disease Day – Friday, 29 February, 2008 – Brain tumours

Media Release.

27 February 2008

Friday 29 February has been chosen by Eurordis (European Organisation for Rare Diseases) and the National Rare Disease Alliances as the inaugural **European Rare Disease Day**.

Not only are brain tumours a cancer but they are also a rare disease, which are defined in Europe as affecting less than 1 in 2,000 people, but among the more than 100 different types of brain tumours there are even rarer instances of the disease.

Brain tumours are one of the most devastating of all cancers, yet relatively little is known about them or their possible causes. Despite the continuing controversy there is no firm evidence yet that cell (mobile) phones cause brain tumours.

Brain tumours are not a major cancer in terms of numbers but when you evaluate them for their financial and mortality impact they jump high in the list to among the top four. They are one of the most lethal and devastating tumours in adults with one British study ranking the glioblastoma multiforme tumour as the highest of 17 malignancies based on its impact and average years of life lost.

In fact, among children under 15 years of age brain tumours compete with all leukaemia cancers as being responsible for the most deaths caused by cancer.

Brain tumours do not discriminate by sex, race, geography, age, religion, or class. Famous people who have had brain tumours include actress Elizabeth Taylor, investment banker Dan Case, film maker François Truffaut, churchman John Cardinal O'Connor, educator Marshall McLuhan, composer George Gershwin, UK parliamentarian Mo Mowlam, Kon-Tiki explorer Thor Heyerdahl, Olympic gold medallist Eric Liddell ("Chariots of Fire"), and many others.

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According to research commissioned by the International Brain Tumour Alliance ([www.theibta.org](http://www.theibta.org)) approximately 200,000 people worldwide will develop a malignant primary brain tumour each year.

Thousands more will develop so-called benign brain tumours or metastatic brain tumours (from a cancer elsewhere in the body).

There has been only one significant treatment breakthrough in thirty years when in 2005 the combination of the chemotherapy temozolomide (Temodal/Temodar) and radiation therapy was shown to increase two-year survival in the highest grade malignant glioma brain tumours.

In recent years there have been further promising treatment avenues opened up but according to Denis Strangman, Chair of the International Brain Tumour Alliance, much more needs to be done and “brain tumours need a focus of attention equivalent to that placed on the AIDS/HIV scourge that led to the treatment breakthrough of the anti retroviral drugs”.

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