



Brainwaves NI
INFORMATION • SUPPORT

For Children and Adults with Brain Tumours,
their Families and Carers

**Brain
Tumour
UK**

PRESS RELEASE, March 2009

MORE THAN 900 PEOPLE AFFECTED BY BRAIN TUMOURS ARE MISSING FROM NORTHERN IRELAND'S OFFICIAL STATISTICS EACH YEAR

Brain Tumour UK and Northern Ireland's support group for brain tumour patients, Brainwaves NI, and their loved ones are calling on Northern Ireland's Assembly and Health Boards to ensure that all brain tumours are recorded in the official statistics by the end of 2009, so that effective care can be planned and delivered.

"Brain tumours, by virtue of their dangerous location, can impact on every characteristic that defines us as human beings," says the Brain Tumour UK's chief executive, Jenny Baker OBE. "It is scandalous that thousands of people, many of them suffering very substantial cognitive and physical impairments as a result of their tumour, are largely overlooked because health services have not recognised their existence and complex needs."

"Strategies to deliver effective care to patients with many serious diseases are being developed now in Northern Ireland," says Maggi Whyte, chair of Brainwaves. "We want Health Boards to gather robust data on brain tumour patients and their needs so that a healthcare strategy can also be planned and delivered for them."

Dr Jacqui Harney, Consultant Oncologist at Belfast City Hospital, commented: "In order to deal effectively with a disease that has such a devastating effect not only on patients but also on those around them, the very least we need is accurate recording of numbers. I congratulate Brain Tumour UK on this report. It is about time that this patient population received the same level of understanding, support and investment as other cancers."

Brain Tumour UK's report – Register my tumour, recognise me – estimates that 48,000 people develop a primary or secondary brain tumour in the UK every year.

In Northern Ireland, the charity calculates that around 1,127 people are affected by tumours each year. But only 188 are included in official statistics.

Of affected patients, 376 will have primary brain tumours whilst a further 751 have secondary cancer in the brain arising from cancer elsewhere in the body. Brain Tumour UK reveals that studies have shown that half of all primary brain tumours are missing from the official statistics. And secondary brain cancer is rarely recorded, even though for many cancer patients brain cancer may be the actual cause of death.

Brain Tumour UK's review of post mortem studies leads it to conclude that around 32,000 people affected by secondary brain tumours are not properly recorded in the UK's official statistics each year.

Secondary cancer in the brain is becoming increasingly common as advances are made in treating other primary cancers. "In future, the brain is likely to be the primary battle ground against cancer because other cancers can hide from chemotherapy behind the blood- brain barrier," says Mrs Baker. "It is essential that our health services monitor this growing danger and prepare to fight it."

Please see the attached report: Register my tumour, recognise me, Brain Tumour UK, 2009. Data for patient numbers is taken from reports for 2005.

ENDS

For further information please contact Kate Ferguson, Brainwaves NI

For more information about Brain Tumour Research please contact Vanessa Dury,
Communications Advisor on: 07879 648 957

About Brainwaves NI

Brainwaves NI is a Northern Ireland based charity dedicated to providing support and information to those people affected by a brain tumour. Over the years the Charity has supported children and adults diagnosed, or living with a brain tumour and their families and carers.

The services provided by the Charity include: providing information and signposting to appropriate and accurate quality materials; raising awareness of the needs of those just recently diagnosed or living with a brain tumour, and the needs of their families and carers; organising and running social activities for members and making donations towards research. Brainwaves NI has formed strategic alliances with local and national charities and has joined forces with 14 other brain tumour charities as part of a national brain tumour campaign to raise awareness and increase funding for vital research.

Key Contacts: Maggi Whyte, Chairperson; Sandra McKillop; Vice Chairperson; Kate Ferguson: Secretary: brainwavesni@hotmail.com; 028 9335 3995.