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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



SOCIETY FOR NEURO ONCOLOGY SPEECH 17 NOVEMBER 2007

Kathy Oliver, Secretary, IBTA

Over the last months hundreds of thousands of people have had brain tumours on their minds.

And I'm not just talking about the 200,000 people around the globe who are diagnosed with a deadly glioblastoma multiforme each year or the somewhat similar number who develop so-called "benign" brain tumours, or the many, many more who develop metastatic brain tumours.

I'm talking about the thousands and thousands of additional people who, as part of the recent inaugural International Brain Tumour Awareness Week at the end of October took part in events on five continents in order to raise awareness of this devastating disease and raise funds – over \$1million – for research and support.

And I'm also talking about the 20,000 people who "Walked Around the World for Brain Tumours", amassing a staggering 100,000 kilometres which is two and a half times around the world, far surpassing our original target of 40,000 kilometres which is once around the world.

The International Brain Tumour Alliance very much hopes that 2008 will see further collaboration on a world scale, not just among patients, their families and caregivers, but among clinicians, neurosurgeons, researchers, nurse, allied healthcare professionals and commercial companies who have an interest in the disease.

We at the IBTA are determined in our aim of promoting access for *all* brain tumour patients to the most promising new therapies. But at the same time we recognise that in some areas of the world this just isn't possible.

We need to remember that thousands and thousands of brain tumours are diagnosed in the developing countries. The challenges for brain tumour patients in these places are often at the most basic level, such as access to morphine for pain control, anti-epilepsy drugs for seizures and corticosteroids for brain swelling.

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Desperate calls for help come to us from people in developing countries who have heard of promising new therapies but have no way of affording them.

And while it's important to have as a long-term objective the education of doctors and health care assistants in these countries, and the transfer of skills, we can't ignore the thousands who will suffer from a brain tumour before the situation changes.

Can you imagine that in one African country this year they completely ran out of anti-epilepsy medication? In 22 developing countries they don't even have radiation therapy facilities and in many others the supply is compromised or only available to a select few. How can we talk about the widespread implementation of the concomitant therapy for high grade glioma when faced with these scenarios?

The situation won't change overnight. Therefore we need to focus for a time on ensuring that maximum palliation is provided which, in some cases, falls to organisations such as Medecins Sans Frontieres.

Just as the Walk Around the World for Brain Tumours started with one single step, so we can perhaps start with one achievable project.

One practical way is to ensure that the World Health Organisation speedily endorses the IAHPIC List of Essential Medicines for Palliative Care that was drawn up by an expert body in Salzburg last year. Individual countries should also be encouraged to endorse the List because it contains the medicines that a brain tumour patient needs at the end stages of their disease.

We would also like to see a survey undertaken of a representative sample of developing countries to identify existing standards of care for brain tumour patients and the availability of essential medicines needed to treat this disease.

We invite SNO to join with us in these campaigns.

Finally, we would like to pay tribute to all the medical specialists and allied healthcare professionals who work in the field of brain tumours.

Your incredible efforts, combined with the indomitable courage and determination of brain tumour patients, their families and caregivers all over the world are a real force for change and a beacon of light and hope in what can be one of the darkest journeys on earth.

Thank you all.