



British Neuro-Oncology Society

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# British Neuro-oncology Society Newsletter

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## Welcome to BNOS2010 – Glasgow

BNOS would like to extend a very warm welcome to those of you attending this year's meeting in Glasgow.



## Special meeting events:

### Access to tissue – breakfast symposium

*Achieving greater access to tissue in neuro-oncology research*

**Breakfast symposium Thursday morning - Please attend!!**

This is an issue that affects every one of us involved in brain tumour management and is a 'Cinderella' subject. There is a pressing need for the increased and improved availability of brain tissue for research in the UK. It is estimated that only about 1% of surgical tissue is currently being stored for research purposes, the remaining 99% of surgical tissue surplus to diagnostic requirements is currently effectively wasted. Obtaining tissue for research needs to be made significantly easier and BNOS is actively working with the charities to help bring about a change to current practices and to advocate for a default position whereby unused surgical material is made available for research.

You are strongly encouraged to attend the Thursday morning breakfast symposium at **08:45 in the**

**Joseph Black Lecture Theatre**, chaired by Professor John Darling, and join us in a debate about this crucial issue. You are invited to actively participate so come along with your ideas and contributions. The press will be attending and issues raised in this session will go out into the public domain.

## Young Investigator Award

A new initiative has been introduced this year into our annual meetings and BNOS2010 marks the first occasion when a young person who is making an outstanding contribution in the field of British neuro-oncology (clinical or laboratory work) will be presented with this prestigious award and will also be invited to present their work at the conference. BNOS Council feel this is an important and encouraging milestone as BNOS' vision is to help promote the work of young investigators.

Full BNOS members were invited to nominate a young investigator working in any field of neuro-oncology in the UK. BNOS Council received several first class submissions, and the most impressive applicant's identity will be revealed during the conference! The winner has been invited to present his/her research work at **10:15 on Friday 25 June** at which time they will also receive a special award sponsored by Brain Tumour UK.

## Update from Brain Tumour Clinical Studies Group

By Dr Susan Short, Chair BTSG

During the last year activity in the Brain Tumour Clinical Studies Group (BTSG) portfolio has continued to increase and we have a broad range of studies open or in set up for the common treatment indications for adult patients with brain tumours. These include a number of studies testing the efficacy and toxicity of new agents in glioma treatment that we hope will significantly improve outcome for a significant proportion of patients.

In the past year we have also continued to address the long term issues underlying poor recruitment in

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rare tumour types, which has been helped by the recruitment of a project officer post which provides an important means of liaison between active centres.

I am also pleased to report that we have been successful in getting early phase studies funded through CRUK-SDBTT joint funding. We continue to recruit to several large international Phase III studies and continue to work with the EORTC brain group to ensure access to studies for patients with rarer tumour types.

In the immediate future we hope the UK will be a significant contributor to the CATNON and CoDEL studies which will address the important issue of the role of adjuvant temozolomide for patients with grade III tumours and provide more material for important translational studies linking tumour molecular genetics and epigenetics to outcome.

We have also built on our established links with the paediatric and teenage and young adult groups and will continue to work with them within the new CCLG framework. In the recent membership round it was very encouraging that we had many applications from motivated young clinicians and scientists working in neuro-oncology who will continue to support the work of this group.

### **Brain Tumour UK – working for and with the brain tumour community**

By Jenny Baker OBE, Chief Executive

Brain Tumour UK was set up in 1997 in response to the urgent need for research funding, better information and support for patients and families and to raise public awareness of brain tumours.

Brain Tumour UK is widely recognized today as the nation's caring charity working for and with people affected by a brain tumour. Our vision is for a world where brain tumours no longer limit lives and our original mission remains: to fight brain tumours on every front and change things for the better.



We're acutely aware of the need to expand carefully and sustainably whilst keeping pace with growing demand for our services from our stakeholders - patients and carers, health professionals, researchers and others.

Funding research remains fundamental to what we do. We are proud that we have recently committed £550,000 for Brain Tumour UK's Neuro-Oncology Research Centre at Wolverhampton University, also jointly funding with the Braintrust Charity, a project at Portsmouth University.

In the last two years we have provided confidential and personalised support to more than 4000 people affected by a brain tumour including the award of 200 grants, each up to £500. In adopting the use of new technology we are reaching out to another 5,000 people via Facebook and Twitter.

Our first Development Co-ordinator will work with patients and hospital teams across Scotland. Further country and regional development posts are planned.

Growing numbers of people are sharing their experiences to inform our campaigns which are designed to deliver real benefit for anyone affected by a brain tumour. We identify real problems and make the case for practical solutions. We work with other organizations too including BNOS and our community of fellow charities to present a strong and unified voice around the shared issues of research, support and the ever pressing need to drive up standards in care and treatments.



### **Rare Tumours Guidelines**

In joint collaboration with the National Cancer Action Team at the DOH, BNOS has been working over the past two years to produce a new set of national guidelines for rare brain and CNS tumours (CNS lymphoma, adult PNET, Pineal tumours and adult optic pathway gliomas). This follows a recommendation in the Improving Outcomes for People with Brain and other CNS Tumours (June 2006). The process was chaired by a representative of BNOS (initially David Levy, and subsequently by the BNOS secretary David Jellinek).

This has been a significant project to undertake and we are delighted to report that the consultation period has now been completed and we are in the final stages of peer review prior to the National launch.

### **Newsletter Submissions Welcomed**

Producing a regular newsletter is another BNOS initiative. We see the newsletter as an effective means of communicating widely with our members who are working in a variety of disciplines within the field of neuro-oncology and opening up networking opportunities between members. Whatever area you are working in we would love to hear from you.

Send us your content on anything that you feel would be of interest to your colleagues – report back after a conference, summarise a journal article, new technology, your own new initiatives. Articles should be no more than 250 words and will be credited to the author. Contact the newsletter editor at: [newsletter@bnos.org.uk](mailto:newsletter@bnos.org.uk).