



British Neuro-Oncology Society

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# British Neuro-oncology Society Newsletter

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Number 04/11, March 2011

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**Proton Radiotherapy - The NHS Specialised Services Proton Overseas Programme**  
By Dr Adrian Crellin (Leeds)



There is now sufficient confidence in the safety and outcomes of proton radiotherapy for treatment in highly selected indications, that the Cancer Reform Strategy (2007) recommended that the NHS National Commissioning Group set up a mechanism to centrally approve and manage the referral of patients for treatment abroad.

The diagnostic and clinical criteria are very tight (evidence base, limited capacity available abroad, limitations on acceptance criteria by centres) so be sure to read the guidance carefully before thinking about referral.

There is a range of paediatric diagnostic indications. The adult indications are skull base Chordoma and Chondrosarcoma and selected Spinal and Paraspinal Sarcomas. Patients should be assessed through specialist local MDTs. All details of surgery,

histology and imaging on CD need to be available (post op scans within 8 weeks of referral) in addition to a referral form. It is very strongly recommended that a Clinical Oncologist sees and refers all patients. A National Clinical Reference Panel assesses the cases before approval is given. Funding for travel and accommodation abroad are covered for the patient.

The referral guidance document and referral forms are available at:

<http://www.specialisedservices.nhs.uk/service/proton-beam-therapy>

The current programme has had 178 referrals and 102 patients have had approval for treatment in Villigen, Paris and Jacksonville. A business case is being prepared by the DH for the commissioning of at least one centre in the UK by 2015.

Dr Adrian Crellin  
Consultant Clinical Oncologist  
DH National Clinical Lead Proton Beam Therapy  
Chairman Clinical Reference Panel

## Liverpool Neuro-Oncology Research Group (LNRG)

By Dr Barry Pizer (Liverpool)



LNRG is a group formed as a collaboration between scientists at the University of Liverpool including Violaine See, Diana Moss and Carol Walker (Astro Fund Brain Tumour Northwest Research Coordinator) and a multidisciplinary team of clinicians based at the Walton Centre, Clatterbridge Centre for Oncology and Alder Hey Children's Hospital.

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The group aims to conduct basic science, translational and clinical research covering both adult and paediatric neuro-oncology. The research group is predicated on the excellent adult and paediatric neuro-oncology clinical services, a very good grounding in previous and current research activity and excellent collaborative links between individual group members and national and international neuro-oncology groups.

Areas of particular interest include advanced and intra-operative neuroimaging, imaging and molecular correlates in gliomas, the biology of low grade gliomas, drug sensitivity and intracellular signalling activation in medulloblastoma, glioblastoma and Atypical Teratoid/Rhabdoid Tumour, the effects of hypoxia in glioblastoma and the biology and treatment of brain metastases.

The group will conduct collaborative research, particularly within the Brain Tumour North West consortium and other basic science, translational and clinical trials groups, including those of BNOS members.

For further information please contact Dr Barry Pizer, Consultant Paediatric Oncologist, Alder Hey Children's Hospital: [barry.pizer@alderhey.nhs.uk](mailto:barry.pizer@alderhey.nhs.uk) or Dr Carol Walker: [carolw@liverpool.ac.uk](mailto:carolw@liverpool.ac.uk).

### Major Depressive Disorder in adults with supratentorial glioma

By Dr Ally Rooney (Edinburgh)

Studying how people react emotionally to the diagnosis of glioma should help clinicians improve their supportive care. Although nearly everyone feels sad immediately after being diagnosed, the emotional reaction can be severe and prolonged enough to amount to clinical depression, or Major Depressive Disorder (MDD). Because most previous studies of this topic are of relatively low quality, however, our basic knowledge is incomplete regarding MDD in glioma.



Between 2007 and 2010 Dr. Ally Rooney was funded by the ECNO Endowment Fund to design and conduct a prospective observational cohort study of clinically relevant aspects of MDD in adults with supratentorial glioma. He recruited 155 patients from the catchment areas of the tertiary neuro-oncology services in Edinburgh (P.I. Dr. Robin Grant) and Glasgow (P.I. Prof. Roy Rampling). In serial interviews, he studied the frequency of MDD, its independent predictors, and its clinical course over a six-month period. The study is now closed and data analysis is complete.

This is one of the largest and most methodologically

robust studies of depression in glioma conducted to date. Data suggest that while MDD is a common complication of glioma (affecting one in five people over a six-month period), most patients cope relatively well with the diagnosis. This supports the case for actively seeking and managing disordered low mood when it occurs. In particular, people with previous depression, or physical functional impairment, were at increased risk of suffering clinical depression. MDD lasted for a median of 3 months, and being one of the strongest predictors of impaired quality of life, is clearly important to treat where possible. Research papers detailing the study and results will be drafted and submitted to peer-reviewed journals over the coming year.

### RCPCH: raising awareness of paediatric brain tumours

By Lucie Clough (London)



**Clinical Champions to raise awareness of brain tumour symptoms in children**

The Brain Pathways Team are thrilled that 21 UK neuro oncology units have provided lead 'Clinical Champions' to be ambassadors for their raising awareness campaign. Our new Clinical Champions have agreed to submit symptom interval data for audit purposes to help measure the success of the Brain Pathways campaign.

The 'Brain Pathways: Promoting Earlier Diagnosis of Brain Tumours in Children' is a two year project, which aims to enhance the awareness of symptoms indicative of brain tumours to both the public and healthcare professionals. Children in the UK wait up to three times longer for diagnosis than children in Canada and the United States.

The Brain Pathways Team held their first 'Brain Pathways Working Group Meeting' in Bristol in January 2011. This meeting set the foundations for effective collaboration to reduce the length of time it takes to diagnose brain tumours in children. The meeting was superbly attended by clinicians from several neuro oncology units, and managers and policy leads from across the country.

The meeting consisted of a number of short presentations by the Brain Pathways Team on the importance of symptom interval data collection and the value of the campaign. Dr Peter Lachman, Consultant Paediatrician and Health Foundation Fellow, delivered an interesting session on quality improvement. Jennifer Benjamin, Head of the National Awareness and Early Diagnosis Initiative, Cancer Waiting Times and Informatics (Department of Health) delivered an informative presentation explaining how the Brain Pathways project fits with the new government strategy, 'Improving

Outcomes: A strategy for Cancer', published on the same day.

Symptom interval data collection has already begun and each of the neuro oncology units will continue to provide selected data throughout the project. Standardized dissemination guidelines will be available to each unit to help disseminate information and raise awareness of the project amongst our colleagues in primary and secondary care.

The Brain Pathways Campaign will be launched in late May / early June 2011, consisting of a new website, symptom cards and an ongoing national promotion. Baseline symptom interval results will be published prior to the campaign launch.

If you would like to learn more about this important project you'll find the team at the RCPCH Annual Conference in April 2011. Professor David Walker and Dr Sophie Wilne will be presenting a Personal Practice Session on the 'Diagnosis of Brain Tumours in Children' guidelines. We hope you can join us!



We wish to thank the neuro oncology units that have joined our campaign for their enthusiasm and future support.

The Brain Pathways Project is a partnership between the University of Nottingham, Royal College of Paediatrics & Child Health and the Samantha Dickson Brain Tumour Trust, and sponsored by Health Foundation.

For further information about the project please visit <http://www.rcpch.ac.uk/Education/Projects-and-Programmes/BrainPathwaysProject>.

Contact Lucie Clough, Project Manager for the Brain Pathways Project [lucie.clough@rcpch.ac.uk](mailto:lucie.clough@rcpch.ac.uk) or 020 7092 6156.

For further information on symptom interval data collection or to volunteer a Clinical Champion, please contact Dr Sophie Wilne on [Sophie.Wilne@nuh.nhs.uk](mailto:Sophie.Wilne@nuh.nhs.uk).



## BNOS2011 – Targeting Heterogeneity and Individualising Therapy

Online abstract submissions and registration is now open: [www.neurooncology.org.uk/bnos2011](http://www.neurooncology.org.uk/bnos2011)  
Deadline for abstract submissions: **28 March 2011**.  
Deadline for early bird registration: **30 April 2011**.

## Meet our new Communications Officer!



BNOS is delighted to announce that Elizabeth Tudball has joined us as Communications Officer in a voluntary capacity.

It is very encouraging that the innovative and diverse areas relating to brain tumours are steadily adopting a higher profile both within the UK and internationally. BNOS constantly aspires to keep abreast of current developments and to communicate clearly with professionals and the public alike.

Substantial progress is being made in many areas: brain tumour research, clinical trials, active involvement with the All Party Parliamentary Group for Brain Tumours, Government led national cancer initiatives, and brain tumour charities who are often the driving force behind bringing about positive changes in Parliamentary legislation, as well as being staunch supporters behind new research.

Likewise, national and international brain tumour meetings and societies, journal articles, technology and the media all offer us a wealth of new information. Collating this information and making it available as a national information resource for patients, carers, scientists and clinicians is our aim.

Elizabeth's role will help our society to stay at the cutting edge and she will be a valuable point of contact for society communications in these areas. She brings substantial experience of working in a communications capacity, media relations and public affairs. Welcome Elizabeth, it's good to have you on board.

Elizabeth's email: [communications@bnos.org.uk](mailto:communications@bnos.org.uk).

## 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).