

## Newsletter – Autumn 2010

### WELCOME READERS!

Welcome to the Autumn edition. We hope you enjoy reading our latest update which includes some of the work and successes of our committee and dedicated supporters and members.

In this edition, you can read about the leading edge care and treatment that is now available to patients in Northern Ireland at a Leeds Centre. Whilst this is another excellent development for our neurology service, we have also the alarming news of potential neurology bed closures at the Royal Victoria Hospital, see below.

At time of going to press, we are working on the final details of the **Brain Tumour Support and Information Day** to be held on 1st October, in partnership with the Samantha Dickson Brain Tumour Trust. We're delighted that already over 80 patients and carers are registered and our next newsletter will provide a summary of the proceedings.

As always, we hope you enjoy this newsletter! With best wishes to you on behalf of the Brainwaves NI Committee.

**Maggi Whyte, Chairperson Brainwaves NI**

### BRAINWAVES NI WELCOMES JOSIE



Elaine Hayes, a member of Brainwaves NI meets Josie.

Josie Phillips and her husband, Roger, sailed into Bangor Marina in July this year as part of their fundraising and awareness campaign.

In 2004 Josie was diagnosed with a brain tumour, following five years of unexplained symptoms.

Josie, a doctor at Norfolk and Norwich University Hospital, set herself a challenge of sailing anti-clockwise around the coast of Britain and Ireland, raising awareness of brain tumours and, at the same time, collecting around £20,000 through sponsorship for Brain Tumour Research [www.braintumourresearch.org](http://www.braintumourresearch.org).

Committee members from Brainwaves NI took time out to welcome Josie to Northern Ireland. Maggi Whyte commented, *"We are truly inspired by Josie's bravery and strength. Her journey shows real strength of character and gives other patients and their families hope. I would encourage those interested to help Josie reach her fundraising target of £20,000 for Brain Tumour Research."*

### POTENTIAL 30% REDUCTION IN OUR SERVICE – VOICE YOUR CONCERNS

Brainwaves NI has learnt that the Belfast Health and Social Care Trust plan to reduce the number of neurology beds at the Royal Victoria Hospital (RVH) from 23 to 15.

In working with our members, we are acutely aware of the pressure the service is already under. With a potential 30% reduction, it is unlikely that the Unit will cope with demand. There is also an added concern that this move will further increase the ratio of mixed sex accommodation at the RVH, which most view as unsuitable.

Whilst we understand the pressures on our health service, this latest move has come about with what would appear, no consultation. We would urge you to register your opposition with your local Assembly Member and to make them aware of the immediate impact on patient care and the potential wider consequences of this development. Should you require more information, please contact us.

## BENEFITS MAZE – MADE CLEARER

Our last **open meeting** was again a great success. Over 35 members from across Northern Ireland met in Jury's Hotel, Belfast. Whilst there was time for catching up with friends, members also had a very informative talk from **Siobhan Muldoon, Welfare Rights Manager** (Macmillan Cancer Support/Citizens Advice Bureau).

Siobhan spent some time talking through the type of information and specialist advice available to patients on social security benefits, generalist advice, and housing, debt and employment issues advice.

Find out more at [www.macmillan.org.uk](http://www.macmillan.org.uk) or call Siobhan on 028 9069 9306/7.



Brainwaves NI members at recent open meeting in Jury's Hotel.



Lorraine Cartmill presents Kate Ferguson with a cheque for Brainwaves NI in memory of her husband Don.



Kate accepts a cheque from Bombardier Aerospace.

## THREE CHEERS FOR FUNDRAISERS!

Brainwaves NI would like to extend a huge thank you to Lorraine Cartmill and her friends in Markethill who have raised over £3,700 for the charity by holding a fundraising football match.

The match was held between Markethill Swifts and Laurelvale Football Club in memory of their old team mate Don Cartmill who sadly passed away last year.

The money will help Brainwaves NI continue their work to support those diagnosed and living with a brain tumour and their families across Northern Ireland.

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Brainwaves NI would also like to extend a huge thank you to the staff at Bombardier Aerospace who recently held a Coffee Morning in aid of the charity.

The fabulous fundraisers collected a hefty cheque for £605 which will be a great help to the charity during their work over the next few months.

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See back page for further details of sponsorship kindly received.

## ACCESS TO ADVANCED TREATMENT FOR PATIENTS FROM NORTHERN IRELAND

The Leeds Gamma Knife centre has cemented its position at the forefront of brain tumour care by recently treating its first patients from Northern Ireland.

Based in the £250m new cancer unit at St James's University Hospital, the centre is home to the Perfexion Gamma Knife – the most-advanced in the world. It offers a safer alternative to open brain surgery for the treatment of cerebral metastases, acoustic neuromas, pituitary tumours, meningiomas and other brain tumours. The Gamma Knife unit administers 192 beams of gamma radiation to target and destroy abnormalities with pinpoint accuracy, minimising the damage to healthy surrounding tissue.

The link with patients from across the Irish Sea comes as the Leeds Centre strengthens its team of specialists by appointing Belfast neurosurgeon, **Mr Tom Flannery**. Tom is to give an insight into the capabilities of the Gamma Knife at the Brain Tumour Information Day in October. Full details of the proceedings will be in our next newsletter.

## BRAIN TUMOUR RESEARCH

### BRAINWAVES NI ACTIVE IN A UK CAMPAIGN

The latest report from Brain Tumour Research highlights significant inequalities in funding and profile of brain tumours. Some of the headlines include:

- 16,000 people each year in the UK are diagnosed with a brain tumour
- 20% of all cancers now spread to the brain
- Primary tumours cannot be prevented because their cause is unknown
- More men under the age of 45 and women under the age of 35 die from a brain tumour than any other cancer
- While the five-year survival rate for many cancers is over 50% and rising to over 90% for some cancers, for brain tumours, the five year survival rate for men is 14.1% and women is now 13.8%
- Brain tumours are the most common solid tumour found in children and they have overtaken leukaemia as the biggest cancer killer of children in the UK
- Brain tumour research receives less than 1% (0.7%) of cancer research spending in the UK.

**Brainwaves NI, as part of the Brain Tumour Research Alliance, recommends:**

- All intrinsic tumours (grade 1-4) are included in cancer waiting time standards
- Cancer registries record secondary cancer in mortality statistics
- Further analysis is undertaken on the cancer burden in different age groups as well as gender
- National Cancer Research Institute partners give brain cancer a priority status and increase levels of funding
- The government significantly increases the proportion it spends on research related to brain tumours, at least to the levels of expenditure for other cancer.

**Brainwaves NI** is one of a group of 16 brain tumour charities 'putting their heads together' to raise awareness and increase funding for vital research.



As a member of the Brain Tumour Research Alliance, Brainwaves NI will be attending a **reception at the House of Commons** in October.

Following the General Election, the reception is an opportunity to ensure that brain tumours are high on the agenda in the new Parliament and to raise awareness of brain tumour issues amongst MP's and members of the House of Lords.

Coming together as a united front also highlights how our member charities are working together across the UK for a common cause.



## TIME TO UNWIND – DAY TRIP FOR BRAINWAVES NI MEMBERS

In early summer, Brainwaves NI took a group of patients and their families along to W5 at the Odyssey Arena, Belfast for a day of fun and games.

Again this day was a great success and your feedback was extremely positive.

If you haven't already been on these trips, please keep an eye on our website, Facebook page and in our next newsletter for details of future outings.

## BRAINWAVES NI SUPPORTERS - MAKING A DIFFERENCE

The Committee would like to acknowledge the ongoing support of the many friends and supporters who have joined in raising much needed funds. Some of those who have been active in the last few months include:

- Ballywalter Snooker Hall and Darren Williams
- Bombardier Aerospace staff
- Brian Courtney
- Deloras Spratt
- Family and friends, in memory of Deborah Ellen Neill
- Lorraine Cartmill, in memory of her husband
- Michelle and Alan Williams
- School of Dentistry, RVH
- Tower Inn, Newtownards

All donations received are used directly to fund, or further develop, the services provided by the Charity.

## BRAINWAVES NI - SERVICES

*The most important role of the Charity is providing information and support to patients and their families.*

In summary our services include: [HERE](#)

- 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.
- Providing financial support, where appropriate.
- Making donations towards research.

## CONTACT INFORMATION

If you would like to contact the Charity, please email [brainwavesni@hotmail.com](mailto:brainwavesni@hotmail.com). You can also call / leave a message on 028 9335 3995.

## FIND US ON FACEBOOK!

The family of supporters on Facebook is growing everyday and we are so grateful for your constant encouragement and support! Keep your ideas and opinions coming! If you haven't done so already, please take a second to sign up to our page: [www.facebook.com/brainwavesni](http://www.facebook.com/brainwavesni).

## AGM NOTICE - YOUR CHANCE TO MAKE A DIFFERENCE

You are cordially invited to the Annual General Meeting of the Brainwaves NI Charity:

**Wednesday 13<sup>th</sup> October 2010**

**7:00 – 9:00pm**

**Jury's Hotel, Great Victoria St, Belfast**

Refreshments will be served

The Charity has had a very productive year. At the AGM you will have a chance to hear about the many notable achievements as the Charity works to support those recently diagnosed or living with a brain tumour and their families and carers.

We are especially keen to welcome new committee members this year to play a role in shaping and delivering our ambitious plans over the next few years.

The current Committee Members **working on your behalf** are:

<b>Chair</b>	Maggi Whyte
<b>Vice-Chair</b>	Sandra McKillop
<b>Honorary Secretary</b>	Kate Ferguson
<b>Treasurer</b>	Nathena McCloy

### Committee Members

Elaine Hayes	Kay McKenna
Maureen Kane	Evelyn McNeice
Tracey McAuley	Ethna O'Kane

**Charity Patron:** Pamela Ballantine

Committee members act on a voluntary basis. They all share the same ambition which is to work together to support those affected by a brain tumour.

The Charity receives no statutory grant.

## NEXT NEWSLETTER

Check out our next newsletter for proceedings of our **Brain Tumour Support and Information Day** on 1st October 2010.

The event is being held in partnership with the Samantha Dickson Brain Tumour Trust.

