

## Newsletter – April 2011

### WELCOME READERS!

Welcome to the Spring edition of our Newsletter.

In this edition, we bring you an update on the campaign to reverse the decision to reduce the number of neurology beds at the Royal Victoria Hospital. You can also read about the activities our committee members are involved in which are changing things for the better for those affected by a brain tumour in Northern Ireland.

As always, you too have a chance to have your say. Please read our article below on how you can determine the priority areas for the newly established Neurology Network in Northern Ireland.

**Maggi Whyte**  
Chairperson Brainwaves NI



### SHAPING YOUR NETWORK: WE NEED YOU TO SPEAK OUT AGAIN !

The Minister for Health has requested the development of a neurological network. This is to ensure the best possible outcomes for those diagnosed and living with a brain tumour and those with other long-term neurological conditions.

***Your Network is being established and your help is needed.***

Firstly though, what is a 'Network'? It is recognised that those with a brain tumour have complex needs requiring intervention or support from a wide range of professionals. A 'network' will promote joined up services that make the best use of resources to deliver appropriate treatment and support in all settings.

Those with responsibility for the Neurology Network are now undertaking an exercise to identify the priority areas and ultimately where funding shall be allocated.

The Committee of Brainwaves NI want to ensure there is a comprehensive response to this important exercise. We are currently capturing 'stories' from our members and have also arranged a facilitated session at our open meeting in April.

If you haven't already responded and would like to get involved – please contact us ASAP!

See contact details on back page.

### GETTING RESULTS ... YOU SAID NO TO BED CLOSURES AT RVH

In our last newsletter, we brought to you the plans and the potential impact, of the decision by the Royal Victoria Hospital to cut the number of specialist neurology beds, a facility for all in Northern Ireland.

We are pleased to report progress. At a debate in Stormont late last year, Mr. Jim Wells, Chairperson, of the Committee for Health, Social Services and Public Safety, asked the Minister to go back to the drawing board and totally review the decision on bed closures. The question was put and agreed to.

Maggi Whyte, Chairperson, was present in the Public Gallery with representatives of other charities in the NI Neurological Charities Alliance. She commented that it was reassuring to listen to the support from the MLA's speaking on behalf of the motion and their understanding of the wide range of neurological conditions affecting 35,000 patients in NI.

**Thank you .....** We thank all of you for voicing your support on Facebook and, in response to our plea, writing to your local MP. This undoubtedly helped to raise the issue prior to the debate and garner further support for the motion.

We also thank our colleagues within the NI Neurological Charities Alliance, chaired by Patricia Gordon, for liaising with the Committee for Health, Social Services and Public Safety at Stormont and finally, all those MLA's who supported the motion.

## WORKING FOR YOU: SUCCESSFUL SUPPORT AND INFORMATION DAY

A support and information day for those affected by a brain tumour took place in October at the Holiday Inn, Belfast.

The event was organised by Samantha Dickson Brain Tumour Trust, in partnership with Brainwaves NI.

*Really glad I went to the Information Day. Thank you*

*An excellent opportunity to breakdown barriers between patients and the professionals caring for them. This must be the way forward!*

The day was exceptionally informative and supportive with many key Northern Ireland consultants and medical experts hosting sessions on both adult and paediatric brain tumours as well as offering advice and guidance to all attendee's.

Everyone was impressed by the presentations, many of which were accompanied by excellent illustrations to help with visualising diagnosis & treatment options.

*Lots of information for new patients which I think I would have found helpful when my husband was told he had a brain tumour in 2005. I think it's a good idea to give patients an information pack, great day.*

The clinicians had evidently invested time preparing for the event to help inform patients, carers and their families. We would like to express our appreciation and thanks for their hard work. Very positive feedback has been received and we look forward to hosting similar events in the future.

The Brainwaves NI Committee acknowledge the support and diligence of the Samantha Dickson Brain Tumour Trust in making this event a success.

## FABULOUS FUNDRAISERS!

Brainwaves NI extend a huge thank you to the Williams family who held a charity fundraising night in the 'Dry Spout' in Ballywalter. Donations were received from local businesses with gifts donated from friends and supporters.

Alan Williams and family and friends raised a massive £2,477 for Brainwaves NI. This shall help the charity continue its work to support those diagnosed and living with a brain tumour, and their families, across Northern Ireland.

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In memory of his parents, both of whom died from a brain tumour, Kenneth Gannon organised and hosted a fantastic fundraiser for his friends, colleagues and supporters in Westport, Co Mayo.

The focus of the fundraising activities was a quiz night held in Westport and attended by Kate and Maggi from the Charity. Kate was delighted to be invited to address the audience and provided information on how the funding would be used to support the vital services of the Charity.

Brainwaves NI offer personal thanks to Kenneth for his efforts and to his family, friends and colleagues and staff of Supervalu for raising a staggering £5,850.



Michelle & Alan Williams (seated far right & left, 2<sup>nd</sup> row present Kate Ferguson (centre) with a cheque for Brainwaves NI.



Kenneth Gannon speaking at the fund raising event in Westport, Co Mayo

See back page for further details of sponsorship kindly received.

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

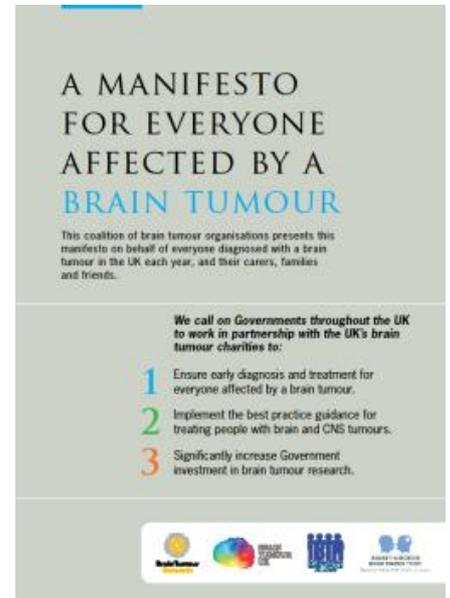
## BRAIN TUMOURS ON THE POLITICAL AGENDA

Brainwaves NI are part of a UK strong coalition of brain tumour charities which have produced a Manifesto for everyone affected by a brain tumour.

Our Manifesto calls on Governments throughout the UK to work in partnership with the UK's brain tumour charities to:

1. Ensure early diagnosis and treatment for everyone affected by a brain tumour.
2. Implement the best practice guidance for treating people with brain and CNS tumours.
3. Significantly increase Government investment in brain tumour research

The Manifesto was first launched at the House of Commons and presented to James Arbuthnot MP, head of the All Party Parliamentary Group for Brain Tumours.



Brainwaves NI Vice-Chair, Sandra McKillop (right) with guests at the House of Commons

Commenting on the occasion, Sandra McKillop said it was a privilege to attend such a fantastic event and really uplifting to see so many people gathered together in a common cause right across the UK.

Being part of this national alliance is excellent for our Charity as it gives our members a stronger unified voice for the purposes of lobbying, sharing information, support and representation. As a Committee, we continue to build local and national alliances to increase our effectiveness in exercising influence and leverage.

Our efforts shall continue with the goal of changing things for the better for those affected by a brain tumour in Northern Ireland.

## WORKING FOR YOU ON A NATIONAL FORUM



Brainwaves NI representatives, Kate Ferguson and Maggi Whyte, attend a recent Brain Tumour Research Workshop in Southampton



Further funding is desperately needed for Research.

Brainwaves NI are actively working to raise funds.

In the last number of months, Brainwaves NI have contributed **£5,000.00** to Brain Tumour Research.

Maggi and Kate travelled to Southampton to join over 15 other charities across the UK to 'put their heads together' to further examine ways to raise awareness and increase funding for vital research.

## 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:

- Alan Williams
- Charities Trust
- In memory of Deborah Ellen Neill
- Kay McKenna Collection Box
- Kenneth Gannon & Supervalu, Westport
- Lorraine Cartmill, in memory of her husband
- Medicare, Carrickfergus
- Oddball Golfing Society
- Ozzy's Sandwich Bar, Belfast
- School of Dentistry, Royal Victoria Hospital

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**THANKS &  
GOOD LUCK**  
**JANIS &  
DANNY!**

The Brainwaves NI Committee extend their warmest thanks and sincere appreciation to Janis McCulla and Danny Sinclair as they leave their posts in the Northern Ireland Cancer Network (NICaN).

The Patient and Public Involvement Forum, established by Janis, has been a highly effective forum in enabling our members to shape cancer services; while the work initiated by Danny will contribute to the availability of quality assured patient information and materials.

We thank Janis and Danny for their professionalism over the years and particularly their resilience and cheerfulness in working tirelessly for those affected by cancer. It is reassuring that there are plans to take this work forward.

Finally, we sincerely wish them every success in their new posts within the HPSS.

## WORKING FOR YOU

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>	Elaine Hayes
<b>Communications &amp; PR</b>	Siobhán McKenna

### Committee Members

Maureen Kane	Evelyn McNeice
Tracey McAuley	Ethna O'Kane
Nathena McCloy	Kay McKenna

**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.

## FIND US ON FACEBOOK!



The Brainwaves NI Facebook page 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 ....:

[www.facebook.com/brainwavesni](http://www.facebook.com/brainwavesni)

## 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.

The Charity hosts a number of *'information and networking'* meetings. **The next meeting is in June 2011.**

Details will posted on Facebook and on our website.