

BRAIN TUMOUR INFORMATION & SUPPORT
BRAINWAVES NI
WWW.BRAINWAVES-NI.ORG



Brainwaves NI Annual General Meeting

Report by Sandra McKillop, Chairperson Brainwaves NI
on behalf of Brainwaves NI Committee

9th October 2013

Brainwaves NI Committee 2012-13

The 2012-2013 Committee, elected at AGM 10th October 2012

Chair	Sandra McKillop	
Vice-Chair	Maggi Whyte	
Honorary Secretary	Kate Ferguson	
Treasurer	Elaine Hayes	
Committee Members	Ethna O'Kane	Kay McKenna
	Evelyn McNeice	Neil Megahey
	Marie O'Neill	Jackie McCaw (2 months)

Committee members:

- give freely of their time;
- balance personal, carer, work, family and other commitments & responsibilities;
- do not receive any financial remuneration.



Committee Business

- Committee met 2012: Nov, Dec, 2013: Jan, Feb, March, April, May, June, July*, Sept, Oct (*exceptional meeting)
- Meetings mostly held in RVH for approx 2-2½ hours. All meetings are recorded/minutes
- Each meeting had quorum to ratify decisions
- Work areas & priorities for 2012-2013 were agreed at November 2013 meeting



Charity Identity / Logo

✓ Review & redesign of Charity logo



Purpose:

- To maintain branding of Charity – similar colour & image
- Create softer image of the 'heads'
- Make the purpose of Charity clearer by including 'Brain Tumour'



Branding & Merchandise

- ✓ Design & purchase of charity merchandise including wristbands, pens, pencils & t-shirts
- ✓ Reprint of Charity Information Leaflets
- ✓ Display Stands (leaflets)
- ✓ Penguin/Banner & 1m x 3m vinyl banners



Brainwaves NI Services

The Charity provides a range of services for children and adults affected by a brain tumour and their families and carers. Services include:

- providing information and signposting to appropriate and accurate quality materials;
- raising awareness of the needs of those recently diagnosed or living with a brain tumour;
- organising and running social activities for members; and
- raising vital funds for research.



Following is a summary of how Brainwaves NI delivered its Services in 2012-2013 & some of the Charity's Key Achievements

Evidence of the Positive Impact of Brainwaves NI on those affected by a Brain Tumour in NI



Working at a Regional Level

- ✓ Brainwaves NI is a member of the Regional Patient/Support Group Forum (previously NiCaN Patient and Public Involvement Forum).
- ✓ Brainwaves NI is a member of NI Neurological Charities Alliance (NINCA).
- ✓ Brainwaves NI continues to form closer working relationships with the key health care professionals involved in the pathway of care and management of the NI Neuro-Oncology Service.
- ✓ Brainwaves NI is further strengthening efforts to support local brain tumour research at CCRCB, QUB.



Working at a National Level

- Proud member of Brain Tumour Research (BTR)
- BTR mission is to raise at least £7M per annum to support seven centre's of dedicated brain tumour research across the UK
- Comprises over 20 member charities
- ✓ Previously provided funding for national BTR Research
- ✓ Supported strategy & process for selection of next Centre(s) of Excellence



Brainwaves NI Committee attend annual BTR Workshop

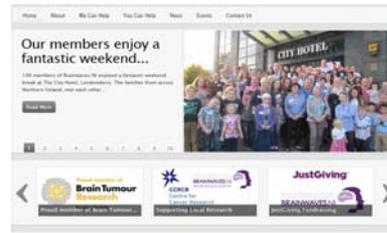


Kate Ferguson: Recipient of 'You Inspire Me Award'



Information & Support

- ✓ Review of design & content of website
- ✓ Regular updating – dynamic website
- ✓ Social media – Facebook postings



Hosting Information Events



May 2013 & June 2013

Both events were well supported – over 70 delegates

Positive Feedback



Social / Support

106 members attended weekend break at The City Hotel, Derry/Londonderry.



Purpose:

- provide members with a well earned break and to spend quality time with family and friends;
- give members the opportunity to meet others affected by a brain tumour and to share experiences and lend encouragement and hope.

Overwhelming positive feedback



We all want to thank you all for our wonderful weekend, we also want to thank everyone for all they did for us. We very much look forward to hearing from you all and meeting up with you again. Many many thanks, yours faithfully P.s. Keep in contact. x

Grimes Family, Cookstown

Thanks for the invite this weekend. We all thoroughly enjoyed. It was really relaxing and great to spend time as a family out of the house. We also met some great people and spent a lot of time just having a laugh. Everything was perfect, well organised and a great location. Thanks again for allowing us this time.

Tumelty Family, Ardglass



To all the hard working committee of Brainwaves NI my family and myself would like to thank you for the wonderful weekend away at the City Hotel, Londonderry. It was a brilliant weekend and thoroughly enjoyed by us all. It was very thoughtful with everything catered for. We met many new friends and seen many old ones! These outings always seem to come at a time when we need it most and it really does make a difference to speak to people in the same position with ourselves, invaluable! Thank you all again x

William's Family, Newtownards



I would like to say a big thank you to Brainwaves NI for such an enjoyable weekend in Derry. It was great meeting up with other people who have brain tumours. My husband and I found that chatting to other people was a great help. It's also a small world. My husband got talking to an old school friend whose wife has a brain tumour. It also turned out that she had just had the Gamma knife surgery which is something that the Consultant had suggested that ~~she~~ might get. We got really close with this couple and we learnt so much more about what was involved in this type of surgery. It is also great to hear stories of those who have went years without their tumour growing. It gives you hope. All in all it was a really eventful weekend and I thank all the Committee for making it happen.

McDowell Family, Ballyclare



We want to thank you very much for affording us such a lovely time in Derry last weekend. We were very touched at such a warm welcome and were made feel we were valuable contributors to the good of Brainwaves NI. The charity should be congratulated on many levels. To organise such a wonderful occasion with what I imagine has limited manpower and even more limited financial resources is quite remarkable! The feeling of warmth and camaraderie from the large group of members and their families was evident. It was hard to remember, except perhaps in obvious presentations, that a lot of the folk were actually very ill - a truth I found humbling if not a little unnerving given my own possible prognosis. My personal need to be brave about the future was not to be avoided and at times I forced my self to put it all aside in 'the box' and ignore it again - for a while! The courageous folk I met were to be commended for remaining sociable despite their personal health struggles. Again, Brainwaves NI is to be highly commended for uniting such a diverse group of people in such a cohesive way and with such a considered mix of empathy and sympathy. It's fair to say then the objectives of the weekend were well and truly met!

McMillan Family, Bangor



We just wanted to thank the charity for allowing ~~name~~ and I to have a much needed break. Also thanks to those who organised it which took amazing skills. During the weekend we were able to meet up with a wonderful family we had contacted via Facebook. ~~name, name~~ and ~~name~~ have now become great friends. We both understood what we each were going through and were able to offer each other support. Thank you for giving us the time and facilities to relax and to forget our worries for the weekend.

Ramsey Family, Newtownards



I just want to thank the committee for arranging such a brilliant event in Londonderry. It allowed me to have a break without the children and to reflect on what has been a very difficult year so far. I was able to enjoy the company of other Brainwaves NI members in an environment that was both relaxing and entertaining. I met some wonderful people and was able to share my journey and experiences of living with someone who had suffered from a brain tumour. Whilst I try to attend the various meetings throughout the year, a weekend like this gives much more of an opportunity to engage with other people and get to know them on a deeper level. I found it very therapeutic as I haven't laughed so much for ages. Thank you.

Mrs Burns, Dundonald



Thank you for an amazing weekend. We had a lovely time, and really enjoyed meeting other beautiful people who have either been on this hard journey themselves or supported those who have gone through it. It is so nice not having to explain things to people who have no understanding of what it means to live with or recover from a brain tumour, so to be in the company of people who have walked the walk, means so much. It's an honour to be associated with such brave, compassionate people. The whole weekend was really relaxed with no pressure being put on anyone to step outside of their comfort zone, if they weren't ready to do so. It is a weekend that will become a precious memory for the years to come.

Kearns Family, Dunloy



Funding Local Brain Tumour Research



16,000 people in UK diagnosed with a brain tumour each year
 Brain tumours kill more children than leukaemia or any other cancer

- Brain tumours receive less than 1% of the national spend on cancer research.
- Brainwaves NI is a member charity of Brain Tumour Research
- Brainwaves NI is working in partnership with the Centre for Cancer Research and Cell Biology (CCRCB), QUB to fund local brain tumour research.
 - Glioma Tissue Collection
 - post-doctoral research fellow for Glioma Research Programme



BTR National Research Funding Report, July 2013



Other Services

- 1:1 telephone support provided by Kate Ferguson – an invaluable and empathetic service of listening and offering appropriate advice and support
- Support & attendance at fund raising events / receiving donations / speaking at events
- Financial Assistance – 9 approved grants to individuals/families; average £400 provided



So, how does Brainwaves NI deliver its services and continue to make a Positive Impact on those affected by a Brain Tumour in NI ?

by ...

the Brainwaves NI Committee working with its members, the 'family' of supporters and fabulous fundraisers



Our Fabulous Members & Fundraisers

Sample of activities...

- Collections Boxes: local shops, workplace, ..
- Being 'adopted': Mayor of Craigavon, Edenmore & C'Reagh Golf Clubs, ...
- Sales : jewellery, books, ...
- Sporting: marathon, abseiling, cycling
- Events: Summer Jam, BBQs, coffee mornings, corn threshing, Wear a Hat events, School Events (eg non uniform,...)
- Donations in lieu of (wedding, party, flowers)



Brainwaves NI 2013 – 2014: Next 12 months

- Continue to deliver our core services
- 2014 is Brainwaves NI 20th year !
 - Celebrate significant achievements to date
 - Increase our awareness raising, lobbying and fund raising efforts
- Garner MP & Political Support
- Continue to foster closer working relationships with local key clinicians and researchers



Support and Skill Set Brainwaves NI would value

- Administrative Support to Committee:
- Increasing value of donations – managing Brainwaves NI Just Giving website / Gift Aid reclaim
 - Exploring potential funding opportunities/grants available
 - Creating Marketing Materials, e.g. NI Brain Tumour Statistics & Facts
 - Design of pack/packaging for Patient Info Pack (with Medb Bradley, Clinical Nurse Specialist)



- Support at Events:
- Omagh Half Marathon, March 2014
 - Mid Ulster Vintage Tractor Trek, July 2014
 - ..

- Raising Awareness & Fund Raising:
- Lobbying, garnering local politician support
 - Corporate sponsorship / adoption
 - ..



We would be delighted to hear from you if you could offer any support: 028 9335 3995; info@brainwaves-ni.org



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Please get in contact should you wish to discuss any of the items within this Report.

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