

# **Brainwaves NI**

## **2022 – 2023 Trustee Annual Report (1/9/22 – 31/8/23)**

The volunteer charity committee of Brainwaves NI met to discuss and plan the work for the charity during 2022/23 attending eleven committee meetings held during the year.

During the year we established what we regard as the four pillars of Brainwaves NI.

Awareness  
Fundraising  
Research  
Members' Outings.

This is what we focus on.

All committee members are affected in some way by a brain tumour and give freely of their time to manage the charity, attend members' outings, and meet fundraisers for cheque presentations.

During the year to 31 August 2023, we applied to become one of two charities selected annually by Queen's University RAG (Raise and Give) Committee. We were delighted to be successful in our application thereby raising awareness and growing fundraising.

### **RESEARCH**

Brainwaves NI continues its long-term relationship with the Patrick G Johnston Centre for Cancer Research (PGJCCR), Queen's University. In the last number of years, we have provided funding of almost £600,000. In the year being reported, funding of £39,631 was provided to the PGJCCR.

In October 2022 we agreed to fund a PhD student to carry out research for three years into finding a cure for brain cancer. Sadly, for personal reasons, the student had to leave the programme in June 2023, which was very disappointing for all parties. Payments are made on a phased basis meaning there was no financial implication.

Discussions started immediately with the PGJCCR to establish a way forward. An advertisement was placed within QUB seeking a suitable student. While this was on-going, we were made aware that the Department for the Economy had provided research funding to QUB, which was available to the PGJCCR. Suitable students were sourced, and we agreed to fully fund the student replacing the departed student and part fund two other students. They started in October 2023.

We are pleased to report that subsequent feedback is very favourable.

### **SUPPORT FOR FAMILIES AFFECTED BY A BRAIN TUMOUR**

We have 300 members who have been affected by a brain tumour in some form or other.

Our mission continues to be two-fold. We provide significant funding to the PGJCCR, as above, and we support our members by way of outings/events. Members are either affected by a brain tumour themselves or are a carer for someone. Connecting people who are on a similar journey gives a period of respite and someone else to talk to.

Committee members continue to be touched by the gratitude expressed on outings. We see it as a fundamental part of what we do. Research is vital in finding a cure but taking people out provides an immediate benefit.

We had a number of social gatherings during the year. There was a members' bowling trip followed by lunch, a visit to the annual Pantomime in the Grand Opera House. We arranged a 12 Days of Christmas Draw December 2022 and trips to Killymoon Castle and Belfast Zoo.

Members were invited to a PGJCCR Open Day and Brainwaves NI Information Evening.

On occasions Committee members maintain contact on an individual basis.

We continue to offer emotional support to members. This is provided externally by an appropriately trained psychotherapist, paid for by Brainwaves NI, and is available promptly.

It is humbling to meet families who are challenged by the impact of a brain tumour and the isolation that often comes with it.

## **FUNDRAISING**

Thank you to all our members and supporters for giving up their time to fundraise during 2022/23. We are indebted to all those who worked hard to raise funds to support the work of the charity and fund research.

Brainwaves NI relies solely on fundraisers. It is not widely known that brain cancer claims the lives of more people under 40 than any other type of cancer. Of the national spend on cancer research 1% is allocated to brain cancer. We have a small number of members with young children, where the prognosis is not good.

Funds raised in the year 1 September 2022 to 31 August 2023 were £128,088 (£121,859 in previous year). We are pleased with this outcome at a time when peoples' budgets were and are stretched.

The charity stresses to all fundraisers that all funds are used in Northern Ireland and all committee members are volunteers.

As awareness of brain cancer and in particular Brainwaves NI increases, we are seeing the benefits. During year to August 2023 several golf club Captains/Lady Captains selected Brainwaves NI as their charity for the year. One that stands out is Donaghadee Golf Club. The Lady Captain lost her niece to brain cancer at the age of 32. Fundraising amounted to over £11,000.

Each golf club, however, tends to be for one year as the incoming team, as expected, choses a different charity.

One fundraiser ran 6k every day for a year and raised £16,000. His brother-in-law died from brain cancer. Another ran 100k overnight and raised over £7,000. In memory of his father who died at the age of 46 one fundraiser climbed the five peaks across the UK and Ireland in five days and raised £8,600. It would have been his father's 60<sup>th</sup> birthday.

Two committee members did a skydive and raised over £5,000.

Committee members are glad to have been able to meet fundraisers and arrange our normal cheque presentations for social media purposes.

The decision to employ a social media company in 2022 undoubtedly increased awareness of Brainwaves NI as a local volunteer led brain tumour charity.

We continue to be inspired by all those who give of their time to fundraise for us.

## FINANCIAL SUPPORT

This year five families applied and received a one-off grant as part of the Financial Support service offered by the charity for brain tumour patients in difficulty. The total paid out was £3,500. This grant is only awarded on completion of a Financial Assistance Form and countersigned & validation stamped by a Consultant, GP or Social Worker. The amount of the maximum one-off grant is £750.

## ALLIANCES

- **Brain Tumour Research** - As a member charity we share experience, successes and plan future campaigns. We engage with other charities from all over the UK based under the Brain Tumour Research umbrella and hear about what is going on in the area of research etc.
- **All Party Parliamentary Group for Brain Tumours** – As a result of pressure from brain tumour charities to increase the funding into research, MP's are undertaking an inquiry into the costs involved which should hopefully lead to an increase in funding. Northern Ireland are represented by one of our local MP's.
- **International Brain Tumour Alliance Summit in London** – This is another super opportunity for Brainwaves NI to network with other charities & medical professionals from all over the world.
- **NI Neurological Charities Alliance** - We have been involved with NINCA since its formation and are represented on this Alliance by a charity member who is the voice for brain tumour patients and represents the views and issues affecting the brain tumour community.

## BRAINWAVES NI ELECTED CHARITY COMMITTEE 2022/23

Hon Chair: Colin McMillan  
Hon Vice Chair: Sylvia Watt  
Hon Treasurer: Steve Harris

Committee: Carol Harris, Yvonne Monaghan, Lauren Monaghan, Jennifer Arbuthnot, Kimberley Carvill, Aimee Alderdice and Fiona Alderdice, Alan Coates.

Secretary: Michaela Chambers

# **Brainwaves NI Constitution**

This constitution was formally adopted on the 10 day of October 2012 by the members of the association in [an Inaugural Meeting] [an Annual General Meeting [a Special General Meeting].

SIGNED: Sandra McKillop (Chairperson) Kate Ferguson (Secretary)

## 1. NAME

The name of the Association is Brainwaves NI (hereinafter called "the Association").

## 2. ADMINISTRATION

Subject to the matters set out below the Association and its property shall be administered and managed in accordance with this constitution by the members of the Management Committee, constituted by clause 5 of this constitution ("the Committee").

## 3. OBJECTS

3.1 The Association is established to support children and adults who are suffering or have suffered from brain tumours, and their families and carers (hereinafter called "the beneficiaries) in Northern Ireland (hereinafter called "the area of benefit") without distinction of age, gender, disability, sexual orientation, nationality, ethnic identity, political or religious opinion and in particular to:

- a) provide or assist in the provision of resources or facilities for the beneficiaries in the area of benefit not normally provided by the statutory authorities;
- b) provide relief for the beneficiaries in the area of benefit by the provision of support services to them and by linking to appropriate networks of self-help groups;
- c) provide recreational facilities for the beneficiaries in the interest of social welfare with the objects of improving the quality of life for the beneficiaries;
- d) fund or carry out research into the causes, treatment and cure of brain tumours and where appropriate ensure that the results of the such research are disseminated.

## 3.2 POWERS

In furtherance of the above objects, but not further or otherwise, the Association may:

- a) Provide, assist in providing or secure the provision of educational and recreational facilities;
- b) provide, maintain and equip or assist in the provision, maintenance and equipment of premises and facilities designed to carry out the objects of the Association;
- c) promote and carry out, or assist in promoting and carrying out research, surveys and investigations and publish the useful results thereof;
- d) organise or assist in organising meetings, lectures, classes and exhibitions, and publish or assist in publishing reports, periodicals, recordings, books or other documents or information;

- e) obtain collect and receive money by way of grants, donations, bequests, legacies or other lawful method PROVIDED that the Association shall not undertake any permanent trading activities and shall conform to any relevant requirements of the law;
- f) purchase take on lease or in exchange, hire or otherwise acquire any real or personal property and any rights and privileges necessary for the promotion of the above objects and construct, maintain and alter any buildings or erections which the Association may think necessary for the promotion of its objects;
- g) make any regulations for any property which may be so acquired;
- h) subject to any consents as may be required by law, sell, let, mortgage, dispose of or turn to account all or any of the property or assets of the Association with a view to the furtherance of its objects;
- i) subject to such consents as may be required by law receive money on deposit or loan and borrow or raise money in such a manner as the Association shall think fit and to charge all or any part of the property of the Association with repayment of money so borrowed;
- j) invest the moneys of the Association not immediately required for the furtherance of the said objects in or upon such investments, securities or property as may be thought fit, subject nevertheless to such conditions (if any) as may for the time being be imposed or required by law;
- k) recruit and train volunteers with relevant skills to carry out the objects of the Association;
- l) employ and pay any person or persons, NOT being a member of Committee to supervise, organise and carry on the work of the Association and make all reasonable and necessary provision for the payment of remuneration to employees;
- m) promote and organise co-operation in the achievement of the above objects and to that end to work in association with local authorities and voluntary organisations engaged in the furtherance of the above objects in the area of benefit;
- n) establish and support, co-operate with, join or amalgamate with any charitable trusts, associations or institutions formed for all or any of the above objects;
- o) do all such other lawful things as may be necessary for the attainment of the above objects or any of them;

#### 4. MEMBERSHIP

- 4.1 Membership of the Association shall be open to the following, irrespective of [ethnic identity, disability, age, gender, political party, nationality, sexual orientation, marital status, or religion]:
- a) People aged 18 years or over in the area of benefit who support the objects of the Association and whose applications for membership are accepted by the Committee; such members shall be called Individual Members and shall be entitled to vote at meetings of the Association.
  - b) Organisations within the area of benefit, whether voluntary or statutory may upon application to and with the approval of the Committee be admitted as Affiliated Members, and such approval shall not be unreasonably withheld;

c) Well-wishers anywhere or persons who, in the opinion of the Committee, have special knowledge or experience to offer to the Association; such members shall be called Associate Members and shall have the right to vote at meetings of the Association;

4.2 Affiliated Members shall each be entitled to be represented at meetings of the Association by a duly authorised representative with power to vote on behalf of the Affiliated Member.

4.3 The Committee shall fix the rate of annual subscription appropriate to each category of membership, shall issue membership cards and shall have the right for good and sufficient reason to terminate the membership of any member provided that the member concerned shall have the right to be heard by the Association in a General Meeting before a decision is made.

## 5. MANAGEMENT COMMITTEE

5.1 The Committee shall meet not less than 6 times a year and shall consist of not less than 6 people elected at an Annual General Meeting. Management committee members will automatically become individual members of the association upon election to the committee if they were not individual members before their election onto the committee.

a) Nominations from full members of the Association for members of the Committee must be in writing, and must be in the hands of the Honorary Secretary of the Association at least 7 days before the Annual General Meeting hereinafter mentioned.

b) If the number of nominations exceeds the number of vacancies, election shall be by secret ballot of the members of the Association present and voting at an Annual General Meeting.

c) If the number of nominations is less than the number of vacancies, further oral nominations may with the approval of the Annual General Meeting be invited from members present and voting at the said Annual General Meeting.

5.2 The Committee elected at an Annual General Meeting shall have the power to co-opt further members to fill any casual vacancy arising on the Committee, who shall be Individual Members or representatives of Affiliated Members and who shall serve until the conclusion of the next following Annual General Meeting PROVIDED that the number of co-opted members shall not exceed one-third of the total membership of the Committee. Co-opted members shall have the right to vote.

5.3 The Chairperson, Secretary and Treasurer, who shall be the Honorary Officers of the Association, shall be full Individual Members or representatives of Affiliated Members of the Association, and shall be elected annually by and from the members of the Committee at their first meeting following the Annual General Meeting. The office of Chairperson shall not be held by any one person for more than nine consecutive years.

5.4 Any member of the Committee who fails to attend 4 consecutive Committee meetings without reasonable excuse shall lose her/his place on the Committee which may be filled by co-option in accordance with Clause 5.2 above.

5.5 The Trustees (if appointed for the purpose of holding property in their own names on behalf of the Association) shall be notified of and shall be entitled to attend all meetings of the Committee but without the power to vote.

## 6. FUNCTIONS OF THE COMMITTEE

- 6.1 The Committee may make such regulations as they consider appropriate for the efficient conduct of the business of the Committee and the Association.
- 6.2 The Committee may appoint such staff NOT being members of the Committee as they consider necessary on such terms and conditions as they may determine.
- 6.3 The Committee may appoint such sub-committees, advisory groups or working parties of their own members and other persons as they may from time to time decide necessary for the carrying out of their work, and may determine their terms of reference, duration and composition. All such subcommittees shall report back fully and promptly.
- 6.4 The proceedings of the Committee shall not be invalidated by any failure to elect or any defect in the election, appointment, co-options or qualification of any member.

## 7. CHAIRING MEETINGS

All meetings of the Association or of the Committee or of any of its subcommittees shall be presided over by its Chairperson failing whom its Vice-Chairperson, if one has been appointed. If neither the Chairperson or Vice-Chairperson are present, those present may elect one of their number to take the Chair. The Chairperson of any meeting shall have a second or casting vote.

## 8. FINANCE

- 8.1 All moneys raised by or on behalf of the Association shall be applied to further the objects of the Association and for no other purpose PROVIDED THAT nothing herein contained shall prevent the payment of legitimate outof-pocket expenses to members of the Association engaged upon the approved business of the Association.
- 8.2 The Honorary Treasurer shall keep proper accounts of the finances of the Association.
- 8.3 The financial year of the Association shall run from 1 September to 31 August.
- 8.4 The accounts shall be audited by an auditor or auditors appointed by the Annual General Meeting OR examined by any independent person who shall be appointed at the Annual General Meeting.
- 8.5 An annual statement of accounts for the last financial year shall be submitted by the Committee to the Annual General Meeting.
- 8.6 A bank account shall continue to be in the name of the Association with Bank of Ireland Ltd, or with such other bank as the Committee shall from time to time decide. The Committee shall authorise in writing the Honorary Treasurer and 2 members of the Committee to sign cheques on behalf of the Association. All cheques must be signed by not less than 2 of the 3 authorised signatories.

## 9. TRUST PROPERTY

The Association may appoint and may terminate the appointment of not less than 3 people to act as Trustees for the purpose of holding any moneys or property belonging to the Association. The title to all or any such real and/or personal property which may be required by or for the purposes of the Association shall be vested in the Trustees who shall hold such property in trust for the Association. The Trustees shall act under the instructions

of the Committee who shall, subject to the approval and consent of the Association as determined by a General Meeting, have power to fill vacancies among the Trustees.

#### 10. ANNUAL GENERAL MEETING

10.1 An Annual General Meeting of the Association shall be held at such place and time (not being more than 15 months after the holding of the preceding Annual General Meeting) as the Committee shall determine.

10.2 At such Annual General Meeting the business shall include the following:

- a) the election of members to serve on the Committee;
- b) the appointment of an auditor or auditors OR an independent person to examine the annual accounts;
- c) the consideration of an Annual Report of the work done by or under the auspices of the Committee;
- d) the consideration of the annual accounts;
- e) the transaction of such other matters as may from time to time be considered necessary.

#### 11. SPECIAL GENERAL MEETINGS

The Committee may at any time at its discretion and shall upon a requisition signed by not less than 4 members having the power to vote and giving reasons for the request, call a Special General Meeting of the Association for the purpose of altering the constitution in accordance with Clause 13 hereof or of considering any matter which may be referred to them by the Committee or for any other purpose.

#### 12. RULES OF PROCEDURE AT ALL MEETINGS

##### Voting

12.1 Subject to the provisions of Clause 13 hereof all questions arising at any meeting shall be decided by a simple majority of those present and entitled to vote thereat. In case of an equality of votes the Chairperson shall have a second or casting vote.

##### Minutes

12.2 Minute books shall be kept by the Committee and all other subcommittees and the appropriate Secretary shall enter therein a record of all proceedings and resolutions.

##### Quorum

12.3 The quorum at General Meetings of the Association shall be 6 and at meetings of the Committee shall be 6 or such other number as the Committee may from time to time determine.

##### Standing Orders

12.4 The Committee shall have power to adopt and issue Standing Orders and/or Rules for the Association. Such Standing Orders and/or Rules shall come into operation immediately PROVIDED ALWAYS THAT they shall be subject to review by the Association in General Meeting and shall not be inconsistent with this constitution.

### 13. ALTERATIONS TO THE CONSTITUTION

- 13.1 Any alterations to this Constitution shall receive the assent of not less than two-thirds of the members of the Association present and voting at the Annual General Meeting or a meeting specially called for the purpose PROVIDED THAT notice of any such alteration shall have been received by the Honorary Secretary in writing not less than 21 clear days before the meeting at which the alteration is to be brought forward.
- 13.2 At least 14 clear days notice in writing of the meeting setting forth the terms of the alteration to be proposed shall be sent by the Honorary Secretary to each member of the Association PROVIDED FURTHER THAT no alteration shall be made which would cause the Association to cease to be a charity at law.

### 14. DISSOLUTION

- 14.1 If the Committee by a simple majority decide at any time that on the grounds of expense or otherwise it is necessary or advisable to dissolve the Association they shall call a meeting of all members of the Association who have the power to vote of which meeting not less than 21 days notice (stating the terms of the Resolution to be proposed thereat) shall be given.
- 14.2 If such decision shall be confirmed by a simple majority of those present and voting at such meeting the Committee shall have power to dispose of any assets held by or in the name of the Association.
- 14.3 Any assets remaining after the satisfaction of any proper debts and liabilities shall be given or transferred to such other charitable institution or institutions having objects similar to the objects of the Association as the Committee may decide.

### 15. INDEMNITY AND INSURANCE

- 15.1 The Association must insure to their full value against any foreseeable risk all the property of the Association (except those buildings that are required to be insured by a tenant). The Association must also insure suitably in respect of public liability and employer's liability and take out other insurance policies to protect the Association when required.
- 15.2 The Association may purchase indemnity insurance for the Management Committee members against any liability that by virtue of any rule of law would otherwise attach to a Management Committee Member or other officer in respect of any negligence, default breach of duty or breach of trust of which he or she may be guilty in relation to the Association but excluding:
- i) fines;
  - ii) costs of unsuccessfully defending criminal prosecutions for offences arising out of the fraud, dishonesty or wilful or reckless misconduct of the Management Committee Members or other officer;
  - iii) liabilities to the Association that result from conduct that the Management Committee Members or other officer knew or must be assumed to have known was not in the best interests of the Association or about which the person concerned did not care whether it was in the best interests of the Association or not.