

BRAIN TUMOUR
IRELAND



Brain Tumour Ireland
Strategy 2022-2024



Foreword...

Dear Community, I am so pleased and honoured to be writing to you as the new Chair of the Board of Directors of Brain Tumour Ireland (BTI). It's truly encouraging to see what an incredible success the charity has become. I am extremely grateful to our charity's impressive Board of Directors and our irreplaceable Head of Services. It has been humbling to observe their passion for finding ways to advocate and support for those affected by this disease. I am delighted to unveil our new strategic plan, we know there is still much more to do and we will continue to work towards our vision.

Peter Cosgrove
Chairperson

As a founding member and previous Chair of BTI I feel very proud of the work that has been done by so many people over the last number of years. I know my mother, Ronnie Fehily, after whom this charity was founded, would be thrilled to know that brain tumour patients and family members have somewhere they can go for information and support following a brain tumour diagnosis. This has only been possible due to the dedication of our Board members, health professionals, family members and the patients themselves. I am confident this strategy will help us make even more great strides in our battle against brain tumours.

Natasha Smith
Charity Founder





Mission, Vision & Values



About Us

The charity was founded in 2012 by a small group of people caring for a family member, Ronnie Fehily, who was sadly lost to a brain tumour in early 2012. As a national voluntary organisation our aim is to continue to fight the battle against the disease in her honour. Through Brain Tumour Ireland (The Ronnie Fehily Foundation), we hope to create a place where people can come for up-to-date information, guidance and support.

Mission

Brain Tumour Ireland's mission is to provide information and support to people with brain tumours, their carers/family/friends, as well as to medical and other relevant professionals. We aim to raise awareness of brain tumours, and advocate for Ireland to be a world leader in brain tumour research, diagnosis, treatment and care.

Vision

Brain Tumour Ireland envisions a society where all people affected by brain tumours are treated with dignity and respect, and have access to effective treatment, quality services and up-to-date information.

Goals

Long term goal

On the way to a cure for brain tumours, catch them earlier and give people a better quality of life

3-year goal

Provide Brain Tumour Support Services and contribute to Brain Tumour Research

Values

Inclusive and
non-discriminatory

Open and
transparent

Ambitious and
forward thinking

Client focused

Peer-led

Partnership-focused

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What We Do



In order to achieve our mission, we currently undertake a number of activities, upon which we plan to build over the coming years. Currently, these include:

Fundraising events

Our fundraising committee organises fundraising events annually. We also facilitate supporters of Brain Tumour Ireland around the country to host their own fundraisers and we do our utmost to support them.

Information provision

We have a website and email address which provides information and support for people affected by brain tumours, including patients/families and professionals. Our email service successfully signposts those who contact us to a range of relevant services throughout the country.

Wellness events

We have run a number of wellness events around the country. These events are for people living with brain tumours and those who care for them. At these events, people are given access to holistic therapies, information and support as well as an opportunity to meet with others in similar circumstances. People who have attended these events have reported experiencing a sense of solidarity with other participants and thereby reducing their feelings of isolation and stress.

Supporting research

Part of our fundraising goes towards supporting research into brain tumours. We are establishing links with a number of institutions involved in research.

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Strategic Priorities

1

Support
Services

2

Website & Communications
/ Reputation

3

Research

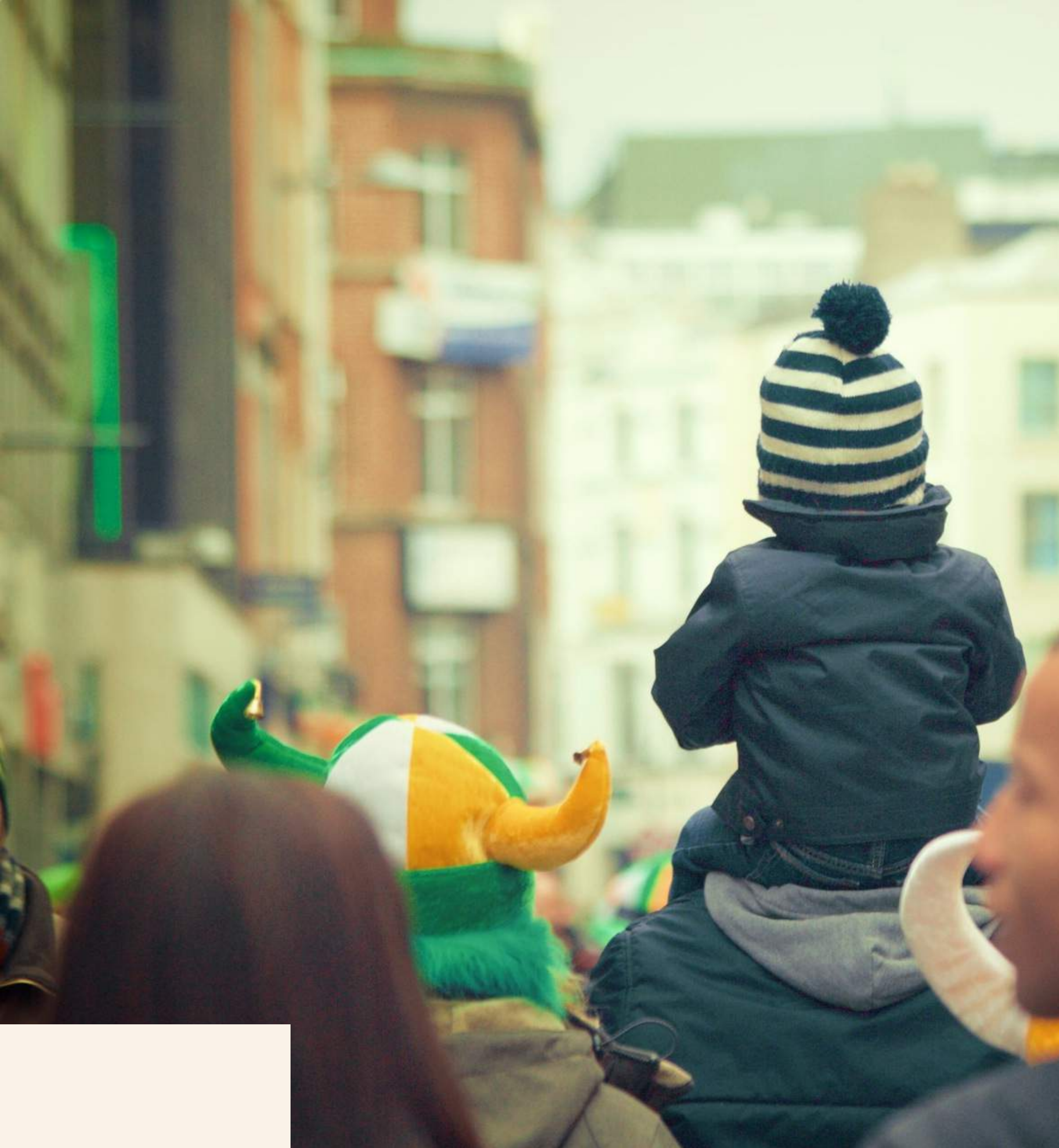
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External Expertise & Fundraising



1 Support Services

- New family support group fully operational
- Cork brain tumour support group to become BTI support group
- Develop a survey for parents and work with multiple stakeholders to capture the 'lived experience' for parents trying to access services following their child's diagnosis
- Systematise flagship events
- Provide support services & information for parents of children with a diagnosis
- Offer counselling to parents as part of our paediatric service and following trial period expand to adult services
- Provide bereavement support to BTI members



2

Website & Communications/ Reputation

- Identify a partner/staff to support on the brand/communication/website
- Develop brand and communication plan for BTI both online and offline
- Redesign the website so that it is easy to navigate
- Ensure website identifies the adherence to governance code
- Create an information pack that is given to patients and families in hospitals and other centres at time of diagnosis, and is also available to download from our website
- Create reports (impact, annual report, newsletter) to disseminate information on the charity to all stakeholders
- Build a digital / social media capability working with a partner
- Define our fit with other brain and cancer charities
- Identify an ambassador in Ireland or abroad to amplify the charity's messaging



- Continue to fund and develop a brain tumour biobank in Ireland to support research in Ireland and across Europe with the intention of having a seat at the table for the charity
- Continue to work with other medical / research bodies to promote brain tumour research and to be the voice for the patient
- Invite researchers to present updates on current research to our patients and families as part of their commitment to public patient involvement (PPI)

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Research



4

External Expertise & Fundraising

- Identify the key expertise needed to drive forward strategic initiatives and partners and experts we can identify to support us
- Identify any areas on the Board we need to strengthen
- Systemise how we interact with those who are supporting us through fundraising
- Identify better ways to develop fundraising through tender processes
- Identify ways to secure 'core funding' from HSE, Pobal and others
- Identify other fundraising opportunities



Jan/2022

Dec/2024



Y/E 2022

Y/E 2023

Y/E 2024

| | | | |
|--|---------------------|-------------|-------------|
| Revenue | Double 2021 Revenue | 2022 + 50% | 2023 +25% |
| Number of inbound contacts | +50% Y.O.Y. | +50% Y.O.Y. | +50% Y.O.Y. |
| Amount of people support us with Fundraising | +50% Y.O.Y. | +50% Y.O.Y. | +50% Y.O.Y. |

Results

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Implementation Plan
by Year



2022

Capabilities

Support Services

Website Communications/ Reputation

Research

External Expertise & Fundraising

Q1

- New family support group fully operational

Q2

- Cork brain tumour support group to become BTI support group

Q3

- Develop a survey for parents and work with multiple stakeholders to capture the 'lived experience' for parents trying to access services following their child's diagnosis

Q4

- Systematise flagship events

Q2

- Identify a partner/staff to support on the brand/communication/website

- Develop brand and communication plan for BTI both online and offline

Q3

- Redesign the website so that it is easy to navigate
- Ensure website identifies the adherence to governance code

Q4

- Create an information pack that is given to patients and families in hospitals and other centres at time of diagnosis, and is also available for download from our website

Q2

- Continue to fund and develop a brain tumour biobank in Ireland to support research in Ireland and across Europe with the intention of having a seat at the table for the charity

Q4

- Continue to work with other medical / research bodies to promote brain tumour research and to be the voice for the patient

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- Identify the key expertise needed to drive forward strategic initiatives and partners and experts we can identify to support us
- Identify any areas on the Board we need to strengthen

Q3

- Systematise how we interact with those who are supporting us through fundraising

2023

Capabilities

Support Services

Website Communications/
Reputation

Research

External Expertise
& Fundraising

Q1

- Provide support services & information for parents of children with a diagnosis

Q2

- Offer counselling to parents as part of our paediatric service and following trial period expand to adult services

Q3

- Provide bereavement support to BTI members

Q1

- Create reports (impact, annual report, newsletter) to disseminate information on the charity to all stakeholders

Q2

- Build a digital / social media capability working with a partner

Q3

- Define our fit with other brain and cancer charities

Q3

- Invite researchers to present updates on current research to our patients and families as part of their commitment to public patient involvement (PPI)

Q4

- Identify better ways to develop fundraising through tender processes

2024

Capabilities

Website
Communications/
Reputation

External Expertise
& Fundraising

Q4

- Identify an ambassador in Ireland or abroad to amplify the charity's messaging

Q1

- Identify ways to secure 'core funding' from HSE, Pobal and others

Q2

- Identify other fundraising opportunities



Lina Stein

Sydney born Westport based milliner Lina Stein was diagnosed with a meningioma in 2016.

She says of her diagnosis, “My old life felt like a boat that I could see sailing off without me. I was on a new boat, one that I could not control. I couldn’t fight it. Yet I had no sense of panic.

“I’d had no physical symptoms prior to the seizure, apart from every now and then there would be a tingling feeling and I would forget a word and be unable to get it out. I learned how to mumble my way around this. I was 49 and thought it was connected with menopause. I was going to get a brain scan done privately, but didn’t bother in the end — and then I had the seizure.” Quotes from Irish Independent, Health & Living, 01.11.21 The tumour was successfully removed and though recovery took time, Lina lives a full life working as a milliner in Westport Co Mayo.

In 2021 Lina was invited to be Brain Tumour Ireland’s official milliner for Wear a Hat Day, taking place during Brain Tumour Awareness Week.

During the awareness week, Lina also taught a fascinator making workshop we hosted for some front line heroes who look after the brain tumour community in Ireland so well.



BRAIN TUMOUR
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