



Brain & Spine  
Foundation

# Annual Review

2017-2018

# A note from our CEO

At the Brain & Spine Foundation, we understand how important it is for people affected by neurological problems to know they are not alone. We are also here for family members, carers and friends.

We are always striving to be there the first time, and every time, someone takes the step to ask for help.

We need your support to continue this important work so that we can be there for even more people.

We're so grateful to everyone who has helped us by fundraising, donating and raising awareness. Enjoy reading our review of the year and all about our exciting plans for the future.

*A. Doyle*

Alice Doyle  
CEO

This year we are proud to be able to say we:

**Supported  
over 2900  
individuals**

**Covered  
over 150  
different  
conditions and  
topics**

**Increased  
the number of  
calls answered  
first time from  
68% to 80%**



**Hosted 120  
delegates at  
our patient  
& carer  
conferences**



**Reached  
1047 people  
through our  
online support  
groups**



**95,000  
information  
resources were  
downloaded**

# Lauren's inspiring story

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Lauren Downie recently joined our team of Community Ambassadors and has been involved with the Brain & Spine Foundation for many years. Lauren first came into contact with our charity after suffering a subarachnoid haemorrhage (SAH) in 2004.



*'At last I was speaking to someone who understood SAH. Whilst my GP was very kind, understanding and supportive, due to lack of specialist training, few GPs really understand the long-term impact of SAH.'*

Lauren's consultant gave her one of our booklets and she went on to contact our helpline for further information. Over the years since, Lauren has worked tirelessly to raise awareness of neurological conditions and has become a valuable supporter.

After experiencing firsthand the lack of local community support for people affected by a neurological condition, Lauren made it her goal to change this. Through media coverage and countless fundraising events, Lauren has increased our profile and raised over £10,000 to support the work we do.

In 2015, Lauren received a first class honours degree in Health & Social Care. Lauren has also joined us at national events to speak about her experience and the importance of increased awareness and ongoing support.

We are proud that we were there to support Lauren during her journey and are delighted to see her achieving her goals!

## Supporting people at every step

For many people, the information and support they find through our services simply doesn't exist anywhere else.

Our helpline is a free and confidential service, available to anyone affected by a neurological problem, including carers, family, friends, and health professionals.

Our helpline team has specialist knowledge and experience of a range of neurological conditions and can take the time to listen to what people need.

**We know how hard it can be for someone to call us and ask for help, so we want to be there the first time, and every time.**

In early 2017 we extended the helpline opening hours. We wanted to increase the number of calls we were able to answer first time.

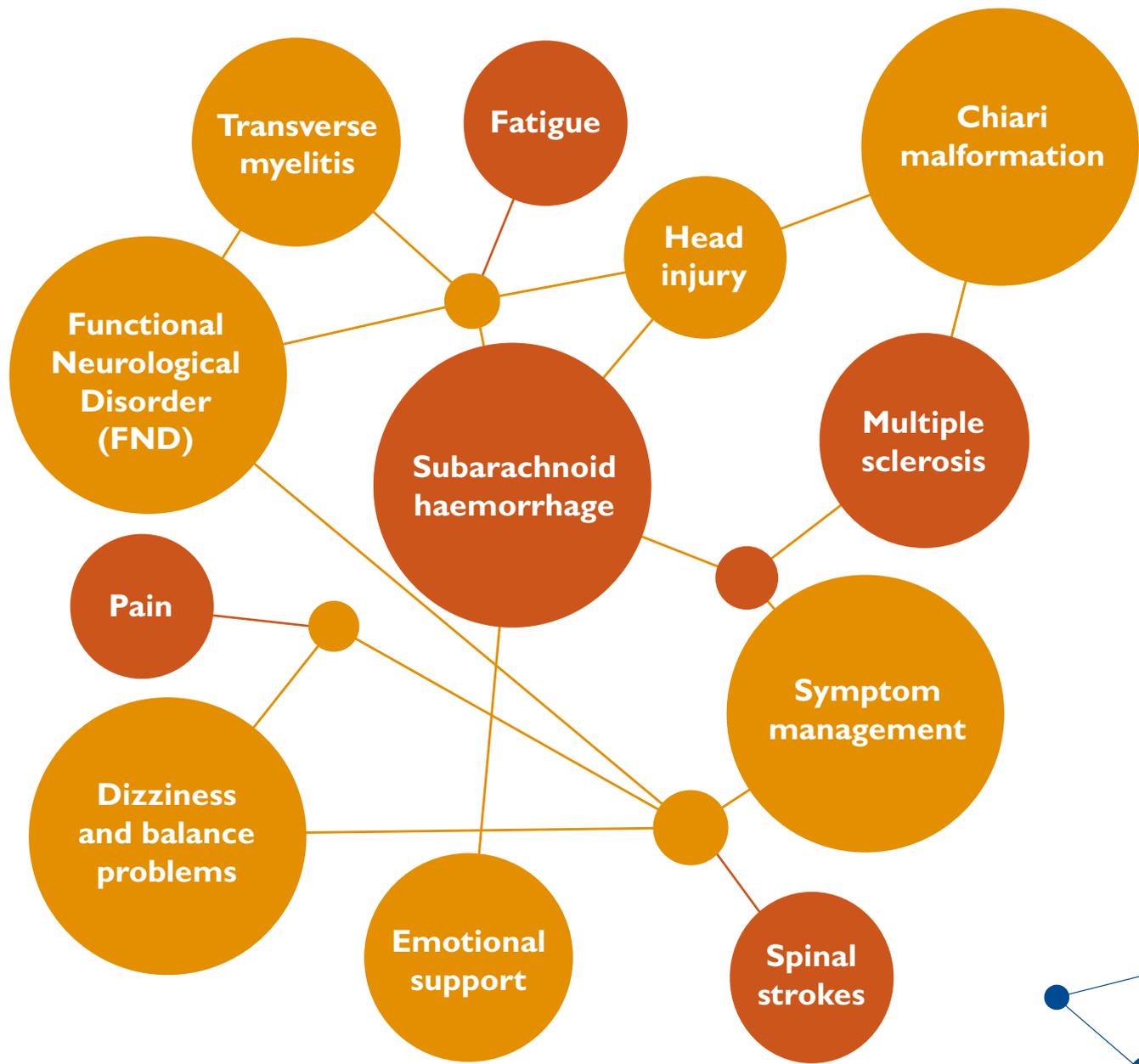
The result of the extended hours is that 80% of calls were answered first time in 2017/18, compared to only 68% during the previous year.



*'I am so pleased that I called you. I had a chance to speak to a human being, not to a computer. You do understand how I feel and you made me feel better by explaining my condition and discussing my worries. I have a big smile on my face now. Thank you.'*

**Feedback from one of our callers**

This year we supported people with **over 150 different conditions, symptoms and issues** relating to a neurological problem, including:



# Improving access to expertise and information

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A 2017 survey<sup>1</sup> showed that the experience of patients with neurological problems has not seen improvement in recent years, and in some areas has worsened.

Patients continued to struggle to get a diagnosis or expert advice on their condition, treatment and what to expect in the long-term. Furthermore, only about half of those who responded felt that their diagnosis had been communicated to them appropriately.

The Brain & Spine Foundation produces a range of evidence-based information and booklets that cover a number of neurological problems and conditions. These are available in hospitals and clinics across the U.K. and are free to download from our website.

**We believe it is important for people to be able to access accurate and up to date information. This empowers them to make shared and informed decisions alongside their healthcare team, and to be able to take an active role in managing the problems they face.**

Our resources provide people with easy to read, accurate information that can help them to understand and manage their condition or problem, and to know what to expect.

In March 2018, we launched our re-designed website which offers visitors a better user experience and improves the accessibility of our information.

We took this opportunity to also expand our A-Z to cover more topics and will continue to grow this in the future.

## Developing our information resources

This year we have developed new information including a fact sheet explaining lumbar puncture and booklet on Chiari malformation.

This booklet provides people with information on what a Chiari malformation is, what tests or investigations they may have, what treatment options may be available to them. It also answers questions they may have about how this condition might affect their quality of life.



## Our Subarachnoid haemorrhage booklet receives high praise

We are also proud to say that in 2017 our Subarachnoid haemorrhage booklet was highly commended by the British Medical Association (BMA) in its Patient Information Awards.

*'This resource seems to offer a comprehensive resource for patients and...it is clear that patients value it. It is balanced and strikes a good balance between honesty and being positive.'*

**BMA Patient Information Awards**



## Bringing people together

Social isolation and loneliness have been moving up on many organisations' agendas as research continues to show the negative impact these problems can have. A lack of social connections has been compared to smoking 15 cigarettes a day in terms of the risk it poses to your health <sup>2</sup>.

*'...it is not so much that social networks stop you from getting ill, but that they help you to recover when you get ill'*

**Marmot Review  
(2010)**

Following an injury or a diagnosis, some people may withdraw from their family and friends. Symptoms such as pain or fatigue may limit what a person is able to do. Even changes to a person's ability to drive or use transport can be a significant barrier to keeping in contact with their friends.

**We understand how important it can be for people with a neurological problem to know they are not alone, and how life changing it can be to connect with others who are going through a similar experience.**

We have now established two Facebook groups. The first for people affected by a rare form of stroke, 'Subarachnoid Haemorrhage Group – A Space for You.' We followed this with another for people who are affected by Chiari malformations.

*'The group has indeed been helpful to me, in fact it has been the most help I have received since I had my SAH in 2011.'*

**Facebook Group  
Member**

Our online support groups have continued to grow each year and we now have over 1000 members across both our Subarachnoid haemorrhage and Chiari malformation Facebook groups.



*'I just wanted to say a big thank you to all the team for Saturday's Chiari conference. It really was a very special day, hugely beneficial both for relatives and 'sufferers' alike.'*

**Chiari conference attendee**

We have also launched a new community on HealthUnlocked where people with any neurological condition or problem can support one another and connect.

### **Bringing people together for support and learning**

We held two events this year where people could come together in person to share their experiences, support each other and hear from a range of health professionals.

The first event was a workshop on Subarachnoid haemorrhage (SAH). Many of those who experience this form of stroke live with long term effects which can be

disabling, invisible and misunderstood. This workshop focused on managing fatigue, getting appropriate exercise, and the cognitive and emotional impacts of SAH.

Later in the year we had our first event for people affected by Chiari malformation. Sponsored by United Business Group, this event took place at the National Hospital for Neurology and Neurosurgery in Queen Square, London. 120 people attended to hear from expert patients and health professionals talking about different aspects of living with and managing Chiari, as well as associated conditions such as syringomyelia and hydrocephalus.

# Fundraising in 2017/18

As a charity, we are entirely funded by voluntary donations from our supporters; we receive no government funding. We take our commitment to ethical fundraising seriously.

We continue to be registered with the Fundraising Regulator, which requires our practices to reflect their principle of mutual respect between ourselves and the people who donate to us.

**We value the trust that people place in us when they donate or fundraise to support our work. We want them to be sure that their contribution will make a difference to people affected by a neurological problem, and that their personal data is handled respectfully.**

The introduction of GDPR\* has been an important focus across the charity this year. We've worked hard to ensure we are ready for the deadline, and will continue to handle people's data lawfully and with respect.



## David's Walk

David Chennells completed a walk around Harlow town centre raising **£4,000** for our work! This is a phenomenal achievement as 11 years ago David experienced a rupture of his arteriovenous malformation, which is a tangle of abnormally formed blood vessels in the brain, that left him immobile.

## 2017 London Marathon

Captained by Olympian Helen Glover MBE, our London Marathon team raised an incredible **£93,700**. Training alongside the team, Helen took on the challenge of running her first ever marathon, in aid of the Brain & Spine Foundation.



We would like to thank our media partners The Daily Telegraph and specialist physiotherapists Runningods, who support our runners every year with advice leading up to the day and much-needed post-race massages.



## Community art event

In Manchester, Community Ambassador Kavita Basi hosted an art auction featuring pieces kindly donated by artist Sue MacPherson. Fellow Ambassadors Paula and Charlie Pearson joined guests to help raise a fantastic total of **£5,000**. Thank you to all involved.



## Mongol Rally

Five friends, including two sons of our founder Peter Hamlyn, raised an amazing **£41,900** by driving 10,000 miles from Goodwood in England, to Ulaanbaatar in Mongolia. They travelled through 22 different countries over five and a half weeks in a 1.0L Nissan Micra built in 1996.



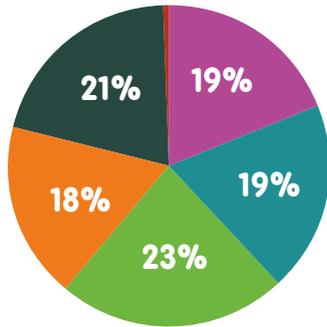
## United Business Group

United Business Group sponsored our 'Life with Chiari' conference. Over 100 delegates from across the UK attended to listen to specialist speakers. Terry Woods, Managing Director of United Business Group, attended the conference and has a Chiari malformation himself.



## Garfield Weston

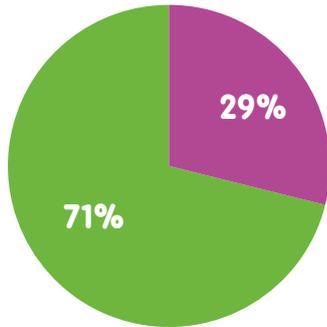
The Garfield Weston Foundation is a family funded grant making trust that supports charities of all sizes across the UK. We are delighted to have received a grant of **£25,000** from such a prestigious trust.



### Income breakdown

£132,276		legacies
£135,409		fundraising events
£161,515		gifts in kind
£125,033		charitable activities
£143,581		donations and appeals
£2,458		sponsorship / other earned (0.4%)

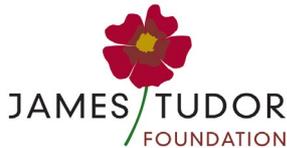
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 £700,272 | total income



### Expenditure breakdown

£244,041		raising funds
£592,909		charitable activities

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 £836,950 | total expenditure



The  
GOLDSMITHS'  
Company Charity



This year we were supported by **over 4,500** people through donations, fundraising events, volunteering, grants and sponsorship. We want to thank everyone who has supported us, including the above organisations, the G & K Boyes Charitable Trust and those who chose to remain anonymous.

# Our plans for 2018/19

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In the coming year we will:

- Expand the helpline team, to increase our capacity and support more people
- In partnership with the Royal Society of Medicine, hold a conference for health professionals on the latest treatments and best practice for neurovascular disorders
- Continue to develop our online information hub and improve accessibility, to support the health and wellbeing of people with neurological problems and conditions
- We will focus on developing information and practical help for those with emotional, cognitive and mental health needs. We know these are significant issues experienced by around 50% of those with neurological conditions, and support is under-resourced in many parts of the NHS <sup>3</sup>
- Increase service user involvement in developing our information resources and informing our work as a stakeholder with the National Institute for Health and Care Excellence
- Continue to build relationships with health professionals – to share information about our work and to ensure our service development meets the needs of their patients
- Host a Gala Dinner, building on the success of the Head Injury in Sport event in 2016 and aiming to raise over £100,000 once again
- Work with a wide range of supporters to raise the money needed to run and develop our services
- Conduct a strategy review to consider the next stage of the Brain & Spine Foundation's development.

3. Neurological Alliance (2017) *Parity of esteem for people affected by neurological conditions*

# Thank you from all of us at Brain & Spine Foundation

## Board of Trustees

Mark Luce (Chair), Peter Hamlyn BSc MB BS MD FRCS FISM (Vice Chair and Founder), Alistair Watkins, Chris Welch, Clive Holland, Colin Cosgrove, Ian Basden-Smith, James Lamont, Jo Garnham-Parks, Lizzie Printer

## Patrons

Mr Desmond Lynam OBE, Sir Michael Parkinson CBE, Mr Jeffrey Rose CBE, Ms Julia Somerville OBE, Mr Michael Watson MBE



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