The Nerve

The Brain Charity

National support for all neurological conditions

March/April 2024



Memorial bench honours Janet's legacy

Louis shares his NF1 story

Pippa's first 6 months as CEO

Pippa's first 6 months at The Brain Charity

We sat down with CEO Pippa Sargent to hear how she's found her first few months with us.

Tell us about your work before you joined The Brain Charity.



"My career has been focused on improving iives through leading public health, mental health and wellbeing programmes, as well as behaviour change and strategic communications initiatives that have brought about health policy improvements."

Tell us about your achievements over the last 6 months.

One of the highlights has been the publication of our It's all in your head report and travelling to Parliament for its launch. The opening of our Neuro Gym at our annual celebration event was a fantastic achievement; I'm so proud we're able to offer physical rehabilitation in a safe setting for free.

"In broader terms, one of the greatest achievements has been keeping the charity focused on being the best it can be for all our staff, volunteers and clients. This has included seeking out new opportunities and consolidating what we do best to continue providing support that has a real impact."

What can we look ahead to in 2024?

"We have several major targets for the year ahead, including more work to support people into employment including confidence coaching, expanding our counselling services, a focus on championing neurodiversity and using AI to help us work smarter.

I also want to ensure we measure, celebrate and shout about our success so everyone can hear about the fantastic work our wonderful team does."



HONOURING A LEGACY: **JANET'S MEMORIAL BENCH**

A beautiful addition to our charity's outdoor space has caught the eyes of recent visitors.

The skilfully crafted wooden bench was created by Free Range Designs in memory of our late team member Janet Ireland. As a fitting tribute, the back of the bench is adorned with two owls – a symbol that held special significance for Janet. Not only did her office house some of her own collection of owls, Janet was also 'snowy owl' to her Brownie troop.

Janet was a huge part of The Brain Charity family and devoted her life to helping our community. She was one of the most caring, compassionate and dedicated individuals we have ever met and her absence is felt deeply by everyone who had the privilege of knowing her.



Be more Janet

When we asked people how they remember Janet certain words kept appearing, words like: friendly, kind and supportive. With this in mind, we have started a campaign to '**Be more Janet**' which encourages us all to try to embody these qualities in our daily lives.

We'll be using the hashtag **#BeMoreJanet** on relevant social media posts and we invite you to join us. Use this hashtag to let us know on social media your memories of Janet and the qualities that made an impact on you.

Gear up for our **3D virtual tour!**

You'll soon be able to swoop through The Brain Charity's centre ahead of your visit in our 3D virtual tour.

The immersive experience will show what to expect when you step into the centre, helping reduce some of the anxieties clients may face in new surroundings.

Thanks to an exciting partnership with the University of Liverpool Innovation Department and the Virtual Engineering Centre (VEC) the virtual tour will be available to view on our website soon.



Staff and volunteers get moving for our annual away day

In February, The Brain Charity's staff and volunteers got together for our annual away day.

We reviewed The Brain Charity's strategy and explored how to create the best workplace with activities about styles of working from Peter Waller of Flynn Privilege HR. We also discussed what we value most about The Brain Charity.

Our Neuro Gym team broke up the day with gentle exercise sessions before Alex Keyter from Generative Minds delivered a fascinating workshop introducing us to AI and ChatGPT. We ended the day with breathwork and body scan exercises with our Confidence Coach Mandy.

Thank you to all staff and volunteers who came to our away day!



Karla Rimaitis took visual notes throughout the staff and volunteer away day–

What our volunteers said about the away day...

"It was a really fun day! I learned a lot about different things such as AI and we learned a lot about ourselves. We did team trust exercises which I thought was really fun. It was good to get to know people I had never really spoken to. It was an experience I haven't really done before."
- Shawn, volunteer at The Brain Charity

"It was an enjoyable experience. I liked talking to a lot of people – listening to the things they had to say was enjoyable. But I talk to everyone anyway!" ***– Rose, volunteer at The Brain Food Café***

Louis' Neurofibromatosis 1 (NF1) story

"Coming to The Brain Charity is one of the best things I've ever done"

When Louis was just 3 years old, doctors found a tumour wrapped around the main artery to his brain, which was closing his airway. He was given emergency surgery and diagnosed with NF1.

NF1 is a genetic condition which causes tumours to grow along the nerves. The tumours are usually benign, but can cause pain and other symptoms.

In 2016 Louis was diagnosed with two more life-threatening tumours on his spine.



"They said if I hadn't pursued a diagnosis, I would have been paralysed, or even died. I didn't have a choice other than to do surgery, although the risk was high."

During his recovery, Louis struggled with his mental health and *"locked himself away"* as he *"didn't like going out at all at the time".*

"I was in a really dark place and didn't think I was getting anywhere."

His family encouraged him to get in touch with The Brain Charity.

He said: *"I was nervous at first as I felt I'd been labelled as someone with a 'disability' and had been made to feel different. I was scared about coming here but it was the best thing I've ever done.*

"Everyone is treated normally, no one is treated any different. Coming here was one of the best things I've done, I wish I'd done it earlier. I've made good friends, everyone is really approachable – everyone has got their own story.

"It's nice to speak to someone and to know that you're not on your own, you're not the only one. Counselling was really good. It was good for me to have someone to speak to and it helped me through problems I was dealing with at that time."

Legal experts discuss the law on disability at Brain Charity panel event

We work closely with several legal firms and in February we hosted a panel day with them.

The aim was to ensure that all Brain Charity information staff coming across legal questions would be able to refer clients confidently to the appropriate specialist and address perceptions or concerns clients might have about specific legal practices.

While the individual areas of focus of each firm can often overlap, each member brings unique skills and expertise to the table which they showcased through case studies.

Highlighting our collaborations with solicitors should reinforce our commitment to ethical, client-centred practices and dispel misconceptions. This event underscored our dedication to providing top-notch legal support while fostering trust and professionalism within our community.

Brighton hoves into view


Dave Honeywell

We're pleased to announce our team of 6 runners for this year's Brighton Marathon. Team TBC includes Dave Honeywell, Helen Coe, Paul Willimott and Tom Jackson, as well as husband and wife, Graeme and Alison Carpenter. It's one of the most anticipated events of the year, with its picturesque finish line on the city's seafront.

"This is my first marathon," says Alison. *"I was never sure about doing one, but a friend convinced me that I might regret it later in life, so here I go – and running for a good cause".*

For Dave Honeywell, Brighton is just one of 60 marathons he is running to celebrate his 60th birthday. *"I approach each marathon differently,"* admits Dave, whose training regime is already underway.

Our Brighton heroes will be flying the flag for The Brain Charity on Sunday 7th April.

Staying in Brighton...


Lauren Stoney

Local business owner Lauren Stoney is all set for her exciting challenge to climb Snowdon at sunset. A qualified wellbeing practitioner, Lauren is leading a team of fifteen hikers up the Welsh mountain on Tuesday 16th March as part of Brain Awareness Week.

"I strongly believe in the power of brain training and the mind body connection," says Lauren, who has recovered from an auto-immune condition herself.

"I feel incredibly passionately about bringing hope back to those struggling with invisible issues, particularly those with fatigue," she continues. *"Snowdon is a new challenge for me personally too, and since regaining my health from illness, it will be the biggest I have set for myself. So I'm excited and honoured to be doing this for The Brain Charity and to be sharing this milestone with some of my lovely clients and friends."*

You can support Lauren's fundraising by visiting: **www.bit.ly/TBCSnow24**

Medal guru



We would like to thank Lisa Hayes for her continued fundraising in memory of her late husband, Mike, who died three years ago from a brain aneurysm. Her tireless work has raised over £7,000 so far and forthcoming events include marathons, psychic nights and climbing Snowdonia.

***"Mike was a gold standard husband and his legacy will live on,"* says Lisa, whom we've awarded one of our special fundraiser medals.**



Pay-it-forward and couples counselling available

The Brain Charity's services have recently expanded to include both pay-it-forward and couples counselling.

Our qualified professional counsellors are dedicated to supporting those with neurological conditions, helping more people navigate emotional challenges. Through our pay-it-forward service, this is now available for the general public too.

Sharon, Counselling Service Manager, said: ***"We're so pleased to be able to offer the pay-it-forward service as part of our counselling support. Every contribution goes towards continuing to provide free sessions for the 1 in 6 with a neurological condition. "In addition, we now offer couples counselling for those navigating the challenges of being diagnosed with a neurological condition. We understand the complexities that neurological conditions can bring to relationships. We provide tailored therapy sessions, designed for one or both partners, which address the unique needs that arise."***

If you would like to learn more about The Brain Charity's couples counselling service, or our pay-it-forward service, you can email **counselling@thebraincharity.org.uk** or ask reception.

Harin's campaign for fully accessible hotels and accommodation

"I believe everyone should be included no matter your disability."

Campaigner Harin is a full-time wheelchair user with cerebral palsy who loves to attend concerts and shows around the UK. He's been to more than 100!

Over the years, he has been faced with the barrier of struggling to find suitable accommodation for his needs that is also affordable. Harin has launched a petition to change this.

On his petition page he says: *"I have started this petition as I believe everyone should be included no matter your disability or ability. This would really change my life and others around me that have the same issues with finding accommodation. It would reduce a whole lot of stress for us and would give us more freedom to travel the country."*



If you would like to support Harin's calls for action, you can sign his petition here: www.bit.ly/HotelCampaign24

What we learnt about **'Leading Neurodiversity in the Workplace'**

The Brain Charity recently attended a three-day training course entitled Leading Neurodiversity in the Workplace by In Professional Development, and it was truly enlightening!

Diversity and inclusion are key components of success in modern workplaces. Neurodiversity, which celebrates the unique wiring of human brains and minds, is now getting its well-deserved spotlight.

The course was aimed at equipping leaders with the knowledge and ability to create inclusive environments where everyone feels valued and empowered.

Neurodiversity is not about seeing differences as deficits, but rather as natural variations that offer unique perspectives and talents. The Brain Charity champions this approach, and it's catching on fast elsewhere too.

Traditional workplace structures often inadvertently exclude neurodivergent individuals, missing out on their incredible potential.

That's where inclusive leadership comes in, ensuring everyone's strengths are recognised and utilised to their maximum.

The course looked at the strengths and challenges of various neurodivergent profiles, so workplaces can master the art of adapting their communication styles. It focused on creating those inclusive work environments from scratch.

The course covered how to accommodate and support in a way that helps neurodivergent individuals thrive: to prioritize empathy, flexibility, and collaboration. By equipping leaders with the tools to embrace neurodiversity, this course aimed to spark transformative change within organisations, one inclusive step at a time.

Embracing neurodiversity isn't just the right thing to do – it's a strategic advantage.



Pippa (left) and Jane (right) after the training in London in January

Jane Cullen, Training Manager at The Brain Charity, said: ***"If we were all the same, we'd all make the same decisions and come to the same conclusions. I value working with people who think differently and can question how we all work together. This course has helped shape how we can best support everyone to thrive."***

If you'd like to learn more about our Neurodiversity in the Workplace training, visit our website: **www.bit.ly/WPNDT24**

Complete this survey, carried out by Birkbeck University, for Neurodiversity in Business, to share your experiences of neurodiversity in the workplace. It is fully accessible and data is anonymised.

www.bit.ly/NiB2024researchsurvey

What's on at the NEURO GYM

DAY	AM	PM	Virtual Sessions
Monday	Gym inductions	Open gym access 1- 4pm	Seated gym 1pm
Tuesday	Open gym access 10.30am - 1.30pm	Tai chi session 1: 2.30pm Tai chi session 2: 3.30pm	Boxing 9.30am
Wednesday	Open gym access 9.30am - 12.30pm and 2.30pm - 4.30pm Circuit classes 10am - 12pm	Boccia (1) 12.30 - 1.30pm Boccia (2) 1.30 - 2.30pm Gym inductions	Seated exercise 10.30am
Thursday	Open gym access 9.30am - 12.30pm	New age kurling 1 - 2pm Gym tours / inductions	Weekly support groups 11.30am
Friday	Open gym access 9.30am - 12.30pm Circuit classes 10am - 12pm	Yoga 'move it or lose it' session 1 - 2pm Gym tours / induction Table Tennis 3.30pm	Mindfulness 10.30am Strength & balance 11.30am High intensity training 12pm

To find out more about any of these activities or to join our gym please email Scott at **gym@thebraincharity.org.uk**



Since opening the Neuro Gym 60 people have taken part in inductions and in our first month clients have cycled a total of 345km (214 miles) over 75 different cycle sessions – the equivalent of going by bike from Liverpool to Dundee or Liverpool to Plymouth!

That's a pretty impressive total, but we'd love you to join the team and get pedaling towards our next goal.

Other activities in the centre

Knit & natter

Our friendly knitting group meets each Wednesday at 10am.

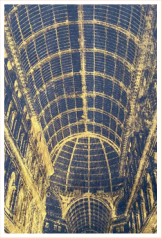
They have an ongoing project to knit squares for a quilt, so it's ideal for beginners. Accomplished knitters may bring along their current projects, and maybe share some of their skills too.


Andrew at Knit & natter

Screen printing with Jello

Come and join Suze, the latest artist to join The Brain Charity. You will learn how to make unique and vibrant designs using a simple Jello print base and some plain paper. The creative opportunities are endless!

Sessions take place between 10.30am-12pm on the following Tuesdays: 19th March, 26th March, 2nd April, 9th April and 16th April.



Coffee morning

Takes place at The Brain Charity from 10.30am on Monday 4th March and 8th April.



See our full diary of events online here: **www.thebraincharity.org.uk**

Head Matters to take place in May

Our annual Head Matters event will be held on Wednesday, 22nd May.
Don't worry, your vouchers from last months' edition will still be eligible for coffee and cake! We will hear all about the technology revolutionising treatment of neurological conditions.

Shape the future of your newsletter

Take our reader survey now

We want to hear what you think about our newsletter. What do you enjoy reading? Is there anything you would like to see more of?

Scan the QR code and fill in our 2 minute questionnaire to help shape the future of The Nerve! **www.bit.ly/NerveSurvey24**

SPOTLIGHT ON...
JOL ILLUSTRATIONS

Holly is an abstract artist with Friedrich's Ataxia (FA) – a neurodegenerative condition affecting her motor skills. She has faced numerous challenges since her diagnosis, including limited mobility in her arms and legs and deterioration of her eyesight.

This has led to difficulties in drawing fine details, so Holly has had to adapt her style continually.

She has built a strong muscle memory and relies on her fingers' ingrained familiarity to create her images. Together with her partner Josh, she has started a new venture, JOL Illustrations. Josh uses his skills in graphic design, web design and coding to digitise Holly's creations.



Josh and Holly are the team behind JOL Illustrations

Holly says JOL Illustrations is a celebration of making the most of her limitations, embracing change and using it as a springboard for creative evolution. It also highlights the creativity that emerges when people collaborate and combine their unique skills.

Holly said: ***"Yesterday, I compared my current illustrations with the ones I created two years ago for my niece's book. I noticed a distinct difference between them. The older drawings were very precise, whilst the new ones have a lot more character and charm. It was challenging for me to compare and contrast the two, but it's also a reminder of how much I've grown as an artist."***

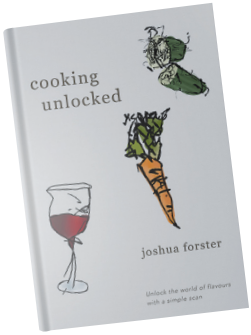


FA has given Holly various challenges, but it didn't limit her creativity. It acted as a catalyst for growth, innovation, and reinvention.









Ways you can support us

We are very grateful for any support during these challenging times. Here are some of the ways you can help:

Donate online

Making a regular or a one-off donation will help The Brain Charity continue to do the amazing work it does on a daily basis. Donating couldn't be simpler. Just visit: **www.thebraincharity.org.uk/donate** to give an amount of your choice today!

Give as you live

Give as you Live is a simple way for you to support The Brain Charity every time you shop with any of the major brands – at no extra cost to yourself.

Getting involved is easy – just register at **www.bit.ly/GAYLTBC** to start raising money for The Brain Charity today.

Donate by text

Give just £3 now by texting **BRAIN** to **70460**. Texts cost £3 plus one standard rate message. If you'd like to give £3 but do not wish to receive any marketing communications, text **BRAINNOINFO** to **70460**.

Website shop

We offer all our charity-branded items for sale through our online store: **www.thebraincharity.org.uk/shop**

Donate via QR code

Scan the QR code (right) on your mobile phone camera now to donate:

About The Brain Charity

The Brain Charity offers emotional support, practical help and social activities to anyone with a neurological condition and to their family, friends and carers.

For more information, contact the centre or visit our website: **www.thebraincharity.org.uk**

If you wish to be added to our mailing list, to receive news and fundraising updates including The Nerve, please go to **www.bit.ly/signupTBC** or ask our information team (on the number and email address below) to add you to the list.

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The Nerve is available in large text on request and as a PDF on The Brain Charity website: **www.thebraincharity.org.uk**

Connect with us: @thebraincharity

The Brain Charity is registered as a charity (No: 1114999) and a company limited by guarantee in England and Wales

The Brain Charity

Responsibly sourced paper
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