# The Nerve



National support for all neurological conditions

July/August 2023



# In loving memory of Janet Ireland 1961 - 2023

#### We are deeply saddened to announce the death of our beloved colleague and friend Janet Ireland, who passed away peacefully in May.

Janet was one of The Brain Charity's longest serving staff members and had dedicated years of her life to helping our community's most vulnerable people. She was one of the kindest and most loving and gentle individuals we have ever known, and we are all devastated to have lost such a beautiful person from our lives.

We have created an online memorial page for The Brain Charity's clients, volunteers and staff, and anyone else who knew Janet, to share their memories and condolences.

We have been blown away by the volume of positive messages we have received from some of the many people whose lives Janet positively impacted. Here is just a small sample:

"Some individuals leave an enduring imprint on your life and profoundly influence it. Janet went above and beyond that; she brought light into people's lives and instilled hope for a better future. Her knowledge was unparalleled, her compassion and kindness unmatched."

"The void Janet leaves behind is immeasurable, and I will profoundly miss her presence. She was my rock, always there when I needed her."

"Janet was a constant source of guidance and compassion, a kind and lovely lady who will be sorely missed."

"Janet radiated warmth and made everyone feel welcome."

"A truly remarkable lady who touched the lives of countless people! Janet was an inspiration, her infectious energy captivating all."



# The Brain Charity appoints Pippa Sargent as new CEO

The Brain Charity is pleased to announce that it has appointed Pippa Sargent as its new CEO.

Pippa has 25 years' experience working in the health, voluntary, social, public and private sectors, leading programmes and campaigns to improve and save lives.

In a career focused on public health, mental health and wellbeing, she has also led behaviour change and strategic communications initiatives that have brought about health policy improvements, worked to ensure people have a say in change programmes, and led the development of new innovations that prevent ill-health. This includes senior roles in the NHS, local and national government, the third sector and in commercial settings.



Pippa said: "I am pleased and excited to be taking on this role and am very much looking forward to building on the inspirational work of The Brain Charity to date.

"The team at The Brain Charity have achieved so much, but there is more work to do to support people with neurological conditions and to change the environment they experience for the better.

"From the outset, it was clear that kindness is a value at the heart of The Brain Charity, and I was encouraged to apply for this role by that word alone.

"One of my strengths is bringing multiple and diverse people and organisations together and making things happen and I will be looking to collaborate with partners to achieve the charity's aims.

"My priority will be to build on The Brain Charity's many amazing successes, to grow the charity sensitively, leading the strong, capable and talented team to bring about positive change for people living with neurological conditions."

In addition to a career working to improve people's lives. Pippa has direct family experience of supporting relatives living with neurological conditions and who are neurodivergent.

Pippa's personal values include kindness, curiosity, gratitude, courage and laughter. She added: "I will be focused on leading The Brain Charity to a place where we see increased funding to provide more services, and higher visibility for the issues that are important to us, to reach more people living with neurological conditions who can benefit from our services."

Pippa will take up the post full time in August.

#### John's story:

## "The Brain Charity's Music Makes Us! sessions gave my 96-year-old dad a complete new lease of life"

Care home resident and music lover John, 96, is immobile due to osteoarthritis and was feeling lonely after three years of being confined to his room during the COVID-19 pandemic.

All his family live far away from his care home on the Wirral, and so can't visit as often as they'd like.

His daughter Caroline said taking part in The Brain Charity's Music Makes Us! Move physiotherapy through dance sessions since March had given the retired mechanical engineer a complete new lease of life.

Dad-of-three, grandfather and great-grandfather John is now looking forward to our Music Makes Us! Sing speech and language therapy through song workshops which will be starting at his care home. Hoylake Cottage. soon.



Caroline said: "Taking part in Music Makes Us! has made a world of difference - it gave him a new lease of life after being confined to his room for the past three years of the COVID-19 pandemic.

"It has given him something to talk about and look forward to with enthusiasm.

"The experience has been a total joy and something I can't recommend enough - it really has been life affirming for Dad."

Music Makes Us! is an innovative Brain Charity programme which uses music to improve the lives of people living with dementia, and other care home residents.

Caroline said the sessions helped her dad go from feeling lonely and isolated during the COVID-19 pandemic to rediscovering his zest for life by providing him with something exciting to look forward to, despite his limited physical mobility.



After dance sessions, she noticed he was also more willing to engage in movements and exercises, contributing to his physical wellbeing.

Caroline said: "Dad's enthusiasm for the sessions was infectious. They gave him a sense of purpose.

"Music Makes Us! has brought dad joy, connection and a renewed sense of life. My family and I are eternally grateful for this wonderful initiative from The Brain Charity."

## **Looking back over COVID19**

During COVID-19, our CEO Nanette and several other volunteers and trustees were some of the more than 550 people who took part in regular interviews with the NHS.

Now, the impact of the pandemic and lockdowns on The Brain Charity has been laid bare as part of the NHS Voices of COVID-19 study, produced in collaboration with the British Library.

#### Rapid response

One of the key priorities for The Brain Charity during the lockdowns was to work out how we could still support vulnerable clients who could no longer venture outside.

Services were quickly set up to ensure vulnerable clients would be kept safe and protected, with staff and volunteers collecting prescriptions, purchasing and delivering food and walking pets.





#### Social activities

Very shortly after the national lockdowns began, we moved many of our in-person social activities and workshops online to help combat feelings of isolation and loneliness for those required to isolate.

Online activities allowed clients to form a community, regardless of their distance from the centre. No longer were people who lived far away seeking The Brain Charity solely for information purposes, but they were able to access social and emotional support online too. Subsequently, the scale of outreach for the organisation rose exponentially.

#### **Emotional support**

Many clients were at a higher emotional risk at the outset of the pandemic, due to their living circumstances and pre-existing mental health conditions. A phone befriending service was established to help provide extra check-ins for these people and combat loneliness.

Another major source of emotional support was our counselling service, demand for which rose rapidly after the first few months of lockdown.

#### Long COVID

Many, many new clients came to us seeking help with neurological problems and symptoms caused by contracting coronavirus - a condition which became known as long COVID.

# Dyspraxic handbag designer so

Moray Luke, who has dyspraxia caused by cerebellitis, wants to shine a light on discrimination and hidden disabilities.



A neurodivergent fashion designer who was diagnosed with dyspraxia after a childhood brain injury says her disability makes her more creative.

Moray Luke launched her eco-friendly handbag brand in her bedroom just 18 months ago, and has since featured on the BBC's Dragons' Den, held a show at Paris Fashion Week and released 3 collections.

But aged just 16, teachers told Moray she 'shouldn't bother' applying to art school and she felt she never fitted into a neuro-typical world which wasn't made for her. The 26-year-old, from Porthcawl, South Wales, developed cerebellitis, a rare neurological condition where the lining of the brain becomes inflamed, after a bad bout of chicken pox aged 8. This caused damage to her brain which meant Moray was hospitalised for six months and had to learn to walk again. As a result, she was diagnosed with dyspraxia, a developmental condition which affects her coordination and movement.

Moray, who has a hundreds-strong waiting list for her sustainable handbag line, said: "The fashion world was an escape for me.

As a child recovering from brain injury, I daydreamed because people weren't taking me seriously and I felt I didn't fit into the 'normal' world."

For Moray, her dyspraxia causes problems with her vertigo and balance, meaning she struggles with tasks like taking escalators, tying her shoelaces and reading words or numbers written on graph paper. She also experiences panic attacks, heightened sensory perception and visual distortions.

But while Moray feels she has had to mask her invisible disability to fit into a neurotypical world, she feels it has given her unique attributes which have helped her excel in the fashion industry.

She said: "If I woke up tomorrow without a disability, I would be like everyone else and I wouldn't want that.

"As a neurodivergent adult my disability means I have better ideas and think outside the box - it's certainly been a strength for having my own fashion business.

"From a young age I became skilled at learning how to read people and I've had to learn how to pitch, convey my ideas



# ays disability inspires her ideas

and be charming and dynamic, because I couldn't get things down on paper. "I'm seen as an innovator, and it's not because I'm necessarily naturally that way, it's because I grew up in a system which was about ticking boxes and I wasn't able to follow normal rules or fit in."

Moray's environmentally-friendly handbags were influenced by her favourite childhood tale The Little Mermaid and are made from waste fish leather from the £618 million Scottish salmon industry. This provides a more durable and sustainable alternative to the unsustainable exotic leathers used by other fashion brands such as snakeskin. The bags are also made with soft curved edges and tactile, strokeable textures, something that is useful for neurodivergent people who experience sensory overwhelm.



As someone who feels she has been misunderstood for all of her adult life due to her dyspraxia, Moray now wants to use her platform to unmask her invisible disability. She is acting as an ambassador for The Brain Charity to raise awareness of the unique skills neurodivergent people possess. She said: "I want to stop masking and stop feeling like I have to hide my disability. I'm proud to be disabled.

"People say I don't 'look' like the typical face of disability, which is why I think it's



so important to share my story, because what does that even mean?

"I know many disabled people don't get to have the opportunities I've had, and this is something I'm passionate about changing. "Fundamentally, it is my dyspraxia which brings the creativity and mindfulness which helped me discover fish leather in the first place, as a sensory and engaging texture which I knew would be perfect for my handbags.

"I wanted to work with The Brain Charity because I never want anyone else to go through the discrimination I did. While my life may look glamorous, I want to show that disabilities are often hidden."

Moray Luke handbags are available in boutiques across the UK and online at: morayluke.com

Photography by Gigi Aleksieva

# Our 30 for 30 supporters are raising the bar on fundraising

From marathons and the MoD to neuro-bikers and nineties revivals, it's been an incredible first 6 months for The Brain Charity's 30 for 30 challenge.

Among the highlights was the Brighton Marathon, which attracted 7 runners taking part on behalf of The Brain Charity who raised a combined total of  $\mathfrak{L}2,000$ . Tom Carpenter - who ran with his dad and brother - achieved the best time of the group at 3 hours and 26 minutes.

Taking a more individual approach was former Brain Charity intern **Rafael Barbosa**. His international challenge began in Manchester, then onto Stockholm and will finish with a bike ride from Liverpool to Manchester. In total, he hopes to complete more than 100 miles.

Volunteers **Pamela and Andrew Wennell** powered up the 530 steps of Spinnaker Tower in Portsmouth in April, while **Viv Walker** took part in the Bryn Meadows Caerphilly 10k a month later. Viv, whose daughter Megan has recently been diagnosed with cerebellar atrophy, raised £2,370 in the process.

Merseyside Police CSO **James Bourne** was lured out of sporting retirement to take part in the Southport triathlon. Giving himself just 60 days to train, James puts his fitness down to the 10k military mud runs in which he has previously competed.

Meanwhile, the MoD itself donated more than £1,000 to The Brain Charity courtesy of the 208 (Liverpool) Field Hospital and Ian from Bikers for Neuro arrived at our centre to drop off the £700 they had raised from various fundraisers, including a naked calendar.

Fully dressed in nineties attire were the staff at Curry's Aintree where **Amanda Weall and her team** staged a retro fundraising weekend in late May, raising £420.

In the next few months, there will be lots more 30 for 30 challenges on the horizon. If you would like to get involved, you can sign up at

www.thebraincharity.org.uk/30-for-30



### **Neurodiversity** - my journey and my family

The Brain Charity's volunteer David reflects on his childhood, education and family and shares his experiences of living in a neurodiverse world.

The terms neurodiversity and neurodivergent make so much sense to me, especially as I look back at my own childhood, education and family. Three years ago we welcomed our niece into the family; she has since been diagnosed with non-verbal autism. Although she has yet to begin talking. she is clearly a very intelligent and happy child who sees the world around her differently from us. That is no bad thing it is a strength.





It is a strength I didn't fully understand until reading about neurodiversity. I have no doubt she will grow up to be an intelligent and independent person whose strengths are recognised. I count myself as lucky to have had the childhood and upbringing I had. However, I always struggled with words and spelling, As I grew up, I saw other children take to spelling and words like ducks to water, while I was flailing around in what felt like a turbulent ocean.

I was never diagnosed with dyslexia, but as I look back, I realise that my problems would probably now be classified as this. I now see how I learnt and took in information was different. My spelling and writing improved after a member of my family bought me Garfield comics. The pictures, words and laughter made me fall in love with reading and writing. With effort, my spelling improved and the worry disappeared.

Understanding that people have different strengths and learn differently is crucial. I wish this had been known when I was growing up, it was more of a struggle to find out how my own brain worked and took in new information.

Not everyone is the same and that is a beautiful thing. I may not have benefited from this greater understanding, but I know it will only benefit our niece as she grows up and starts school - and she can do anything.

# Carers felt like the cat that got the cream

In June we held a 'caring for the carer' event to celebrate National Carers' Week.

More than 30 quests enjoyed free head, neck, shoulder, and hand massages; a singing for wellbeing session and insightful presentations from other carers/experts.

One guest said: "As a carer sometimes the load can feel heavy, but I came out of the event feeling far less stressed than I did going in.

A fantastic event and it was clear from the positivity in the room how well the sessions were received."



#### Help us make an impact in Parliament

Our report into the frequent delayed and misdiagnosis of neurological conditions - titled 'It's all in your head' is launching with an event in the Houses of Parliament on Wednesday, September 6th at 1pm, hosted by Chris Bryant MP. We need your help! Would you like to come to the event in London, or can you send a letter to your MP asking them to take on board our recommendations?

Email campaigns@thebraincharity.org.uk if you would like to be part of our volunteer campaign team - the more voices we have talking about the issues affecting people with neurological conditions, the bigger difference we can make.

# Social activities July - August 2023

	Monday	Wednesday	Thursday
Mornings	Art for wellbeing 10am - 12.15pm* NEW! Music Mondays Mondays 1.00pm - 2.00pm From 10th July	Knit and natter 10am - 12pm Crafters club 10am - 12.15pm	<b>Ukulele for all</b> 11.00am - 12.00pm
Afternoons	<b>Chess club</b> 12.30pm - 1.30pm	Boccia (indoor bowls) 12.15pm - 1.30pm	
	<b>Maths</b> 1.45pm - 3.15pm*	Drawing class 1.30pm - 3.00pm	Bat & chat (table tennis) 1.00pm - 2.00pm
		Aphasia social 2.00pm - 3.00pm	New age kurling 2.00pm - 3.00pm
	Shared reading 3.15pm - 4.15pm	Sing and a social 4.00pm - 5.00pm	NEW! The Brain Charity quiz 4pm - 5pm (online and in person)

<sup>\*</sup>waiting list only

For more information, email activities@thebraincharity.org.uk or call us on 0151 298 2999 and choose activities from our menu.

Coffee mornings: 3rd July, 7th August, 4th September, 2nd October (first Monday of the month).

#### Chess club - Mondays 12.30pm

Chess is accessible to all who wish to learn, practice or perfect their strategy.

Playing chess can improve cognitive skills like memory, planning, and problem-solving. Or just be a fun way to spend an hour! All equipment provided, although you are welcome to bring your own board if preferred.

#### Free barbering

Miguel the 'Nomad Barber' will be offering his services free to The Brain Charity's clients on Wednesday 9th August for his new project 'StoryCuts'.

Please suggest your preferred treatment and time slot when you book: www.bit.ly/Nerve23062

#### Minds Re-imagined: an art in science exhibition

Between July 7th and 27th. The Brain Charity will host an art exhibition, which is a collaboration between artist Helen Lydon and neuroscientist Dr Josh Kearney.

The artworks will be on display in The Brain Charity for anyone to view during our opening hours (Monday to Friday, 9am to 5pm). On Friday, July 7th between 12pm and 2pm there will be an informal launch in The Brain Food Café - all are welcome



#### Fun sensory day for kids - 4th August from 10am to 1pm

At Jake's Sensory World and Soft Play Centre, Netherton Activity Centre, Glovers Lane, Bootle, L30 3TL. Session One, from 10am to 11.30am, is specifically tailored for children and young ones with complex needs or limited mobility, as well as children under the age of 4.

Session Two, from 11.30am to 1pm, is open to children with less complex needs and welcomes children up to the age of 12.

Siblings are also welcome to join in the fun!

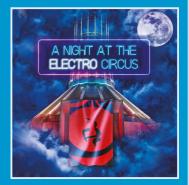
For more information and to sign up: www.bit.ly/Nerve2306

# The Brain Charity's Electro Circus is coming this December!

In our 30th anniversary year, we're pleased to announce that we are putting a new spin on our annual fundraiser.

On Friday 1st December, The Brain Charity will be hosting A Night at the Electro Circus at Liverpool's iconic Metropolitan Cathedral. Don't miss out! Tickets to this incredible musical event are now available from our website shop or The Brain Charity reception.

www.bit.ly/Nerve23061



EuroGrant funding helps us spread a little Eurovision magic

Recently, our Music Makes Us! and Brain Changer projects held Eurovision themed workshops across the region - thanks to funding from the National Lottery Heritage Fund.

Our Music Makes Us! project brings music-based therapy to people living with dementia, but this time it had a Eurovision twist!

Our workshop at Hoylake Cottage consisted of past Eurovision entries, with one resident stating, 'These songs make me feel young again!'

Our Brain Changer sessions visited the Royal School for the Blind for a Eurovision themed session that brought dance, music, and art together. The activities included recreating Norway's previous entry 'Give that wolf a banana' and creating wool and paper jellyfish plus a coral reef out of clay.

We'd like to thank the National Lottery and Culture Liverpool for enabling us to host these events to celebrate the spirit of Eurovision.



Arts Project

# 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 Give as you Live® 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

#### **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, from t-shirts to teas, through our online store: www.thebraincharity.org.uk/shop

#### **DONATE VIA QR CODE**

Scan the QR code below 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

Connect with us:



thebraincharity



thebraincharity



thebraincharity

You can also find us on:







by searching for The Brain Charity

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 numbers and email addresses below) to add you to the list

The Brain Charity, Norton Street, Liverpool L3 8LR Tel: 0151 298 2999 Helpline: 0800 008 6417

Email: info@thebraincharity.org.uk

The Nerve is available in large text on request and as a PDF on The Brain Charity website:

www.thebraincharity.org.uk

The Brain Charity is registered as a charity (No: 1114999) and a company limited by guarantee in England and Wales (No: 05741930)