

**A Race Across the Premier League  
Jacob's Rare Condition  
The Power Football Play Offs**

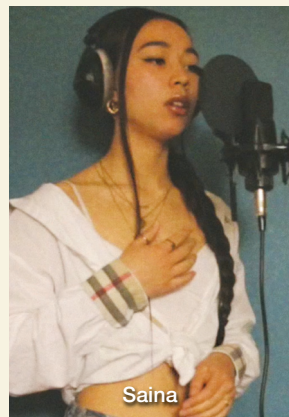
# Musician's new song cherishes memories of grandpa with dementia

**"I hope Strangers strikes a chord with other people who are going through the same kind of experience"**

Saina, 23, is cherishing memories of her grandpa after his diagnosis of Alzheimer's.

She said: "This song was an expression of the sadness and frustration I felt in coming to terms with the changes I've seen in him, while also cherishing my best memories with him. I hope Strangers strikes a chord with other people who are going through the same kind of experience, with loved ones who are living with dementia and Alzheimer's."

Listen to Strangers here: [www.bit.ly/Nerve05241](http://www.bit.ly/Nerve05241)



## Neuro Gym members turn Power Football pros

### Fundraising officer Esme joined members on the visit to Greenbank Academy

As part of our Access to Exercise and Wellbeing partnership we joined Greenbank Academy for their open day in March.

The partnership promotes emotional and physical therapies available in Liverpool, Chester and online for people living with neurological conditions.

At the open day, Neuro Gym members took part in a game of Power Football, which takes place in specialist electric wheelchairs that allow chair contact. Well done to gym manager Scott for scoring the winning goal!

We then played a game of boccia with the Greenbank Giants Boccia Team. It got very competitive, with the round ending in a draw, forcing a tie break. Congrats to Team Red who were the eventual winners! There was also the chance to try table tennis and disability cycling with the Wheels 4 All Project and a tour of Greenbank Academy's accessible gym.

The Brain Charity will be hosting the next Access to Exercise and Wellbeing open day at the Neuro Gym on Friday, 17 May between 10am and 4pm.





# People of The Brain Charity – Meet Diane

**“What we do is we make lives easier”**

## **Tell us about yourself and your role!**

“My name is Diane Green, I am an Information and Advice Officer and I’ve worked here for just under 12 months, since April 2023.

“My job is working in the hospitals in the Wirral, Clatterbridge and Arrowe Park.”

## **What do you wish people knew about The Brain Charity?**

“For everybody to know about it and what we do, especially those on the Wirral. What we do is we make lives easier.

“I can’t change your diagnosis and I can’t change your past, but I can make your future life easier for you. Whether that’s helping you to fill out a PIP form, putting somebody in touch with other organisations that can help them. Whether it’s coming here for social support or if it’s somebody that you want to talk to.”



Diane Green,  
Information and Advice Officer

## **Who do you want to shine a light on at The Brain Charity?**

“It’s our Reception. They are the first person that everybody sees from the minute they come in through the door. They are so patient with everybody and make everybody feel so welcome.”

## **The Brain Charity is Liverpool’s best kept secret, yes or no?**

“Yes. And I only wish it was far more known. The amount of people that have driven past the building and say, ‘Oh we recognise the building’. They need to know what goes on behind the doors as well.

“It’s a whole different world here. And it’s a nice world where we care for people. Nobody is going to judge them, we’re going to be friendly and happy with everybody, we’re going to help everybody that comes through that front door as well and more people need to know that.”

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## Head Matters 2024

**Join The Brain Charity on Wednesday, 22 May, between 10.30am and 3.30pm for our annual open day, Head Matters.**

We’ll hear from Emeritus Prof Gus Baker, former trustee and current Patron of The Brain Charity, sharing insights on understanding and caring for the brain.

More than 19,000 people signed a petition urging all UK governments to create a UK-wide Neuro Taskforce for change. Miranda Lloyd, from The Neurological Alliance, will discuss the national campaign’s significance.

Attendees will have the opportunity to meet The Brain Charity’s Trustees in informal sessions at the beginning and end of the day. They can also visit stalls from The Brain Charity and local organizations supporting individuals with neurological conditions.

**Present this copy of The Nerve at Head Matters 2024  
and get a free cake and coffee!**

# Jacob, 5, lives with rare genetic condition UBE2A

## His parents were able to buy medical equipment thanks to help from The Brain Charity

Jacob was 20 months old when he experienced myoclonic epilepsy, which causes sudden jerking seizures.

After an MRI scan, he was diagnosed with UBE2A, an intellectual disability syndrome characterised by dysmorphic features, impaired speech and often epilepsy.

**Jacob's mum Suvi said: "It affects everything, including his development, his gross motor skills and fine motor skills and his speech. He needs a significant amount of support day to day. He's now 5 and a half but presents as a 2-year-old and his behaviour is quite challenging."**

Jacob requires care and special medical equipment to help manage his condition, which comes at a cost. Mum Suvi, 39, from Gateacre, explained her and her husband struggled with the payments after their mobility allowance application was disputed because Jacob could walk. They came to The Brain Charity for help through our Carer's Advocacy service.

She said: "He gets tired after he's only just started walking. Even now he gets tired much more quickly. Jacob's condition is demanding on him physically. The support he needs is life-long, and it will only get more difficult.

"John [from The Brain Charity] helped us in presenting the case at a tribunal. The allowance was being disputed and he helped us present evidence. He was really helpful."



Jacob meeting Woody from Toy Story



Jacob with his mum and dad



# Triumph amid adversity: A story of courage and compassion

**In the face of fierce winds, relentless rain, and biting cold, a determined group of individuals embarked on a daring adventure up the formidable slopes of Yr Wyddfa (Mt Snowdon). Their mission? To raise funds for The Brain Charity during Brain Awareness Week.**

The group conquered the summit and raised an impressive total of more than £2,500. The organiser and inspiration behind the hike was Lauren Stoney.

She said: "Yes, we bloody well did it! When it came to the day itself, we were faced with 49 mph winds, constant rain and -3°C weather. In all honesty, if it had been any harder, we may not have continued. But I'm glad it was a challenge as it meant all the donations and sponsorship weren't for nothing!"

Driven by her mission to empower others as a health and performance coach and advanced lightening practitioner, Lauren rallied a team of like-minded individuals to join her.

She said: "It was undoubtedly one of the toughest challenges we've faced but knowing that our efforts were making a real difference kept us going."



Lauren Stoney sums up the dreary weather conditions!

## Art for Wellbeing Exhibition: A Journey Through Healing

In the heart of Liverpool, an extraordinary exhibition is set to unfold, inviting you into the realm of art as a tool for healing. The Brain Charity's Art for Wellbeing group is getting ready to showcase their remarkable creations at Cass Art on School Lane, from 10–23 June.

At the helm of this creative voyage is Jens, a person-centred creative arts practitioner with a passion for unlocking the therapeutic potential of artistic expression. Through weekly gatherings, Jens guides participants in exploring the profound connection between artmaking and mental wellbeing.

Jens said: "It's like taking a walk in the fog. You're not quite sure where you're headed, but as the mist clears, revelations emerge. We're not setting goals here; success is self-defined. People leave feeling lighter, more positive, having glimpsed new aspects of themselves."

Each artwork tells a unique story, offering insights into the subconscious and fostering a sense of community among participants.

Jens said: "It's process-based. We're not just creating art; we're creating space for healing and self-discovery."

As the curtains rise on this remarkable exhibition, it's an invitation to witness the beauty that emerges when creativity meets compassion. Join us on this journey through the labyrinth of the mind, where every stroke of the brush is a step towards healing.



# The Value of You

**Motivation**  
**Upskilling**  
**Self-esteem**  
**Progression**

**Confidence-building**  
**Positivity**  
**Wellbeing**  
**Prosperity**

**Do you want to see personal progress and move forward in your goals in life?**

Register now for our latest **FREE** personal development programme designed to improve your skills and self-confidence.

**The Value of You** is a series of one-to-one coaching and group workshops for people with neurological conditions to access support, develop skills and build confidence and help you change your employment situation.

**What support do YOU need to express YOUR value?**

To register, contact: [valueofyou@thebraincharity.org.uk](mailto:valueofyou@thebraincharity.org.uk)

Mandy: **07888 301 735**

Karen: **07360 205 156**

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— UP —**



**LIVERPOOL  
CITY REGION**  
COMBINED AUTHORITY

**METRO MAYOR**  
LIVERPOOL CITY REGION



# “My wheelchair became the best thing”

## Rupak shares his story of living with primary progressive multiple sclerosis (PPMS)

“In the 5 years since my diagnosis, I’ve gone to being homeless, not living with my partner and my children and being fully wheelchair bound. It has been a long and difficult road, but things are starting to look up. These are some of the things I didn’t know before my diagnosis.

“Multiple Sclerosis is called a brain disease. I see it as a spinal cord disease. Although my brain is working, the signals from my brain are not going through to my body, thanks to my spinal cord and lesions on it. Although my brain thinks ‘walk here’ my body is telling me I can’t.

“My wheelchair would become the best thing for my independence. It took only 6 months for me to go from a manual wheelchair to an electric wheelchair and now I can’t imagine life without it.

“What I once thought was simple is now no longer so. Things such as my eyesight, hand-to-eye coordination and speech are all deteriorating. The muscles on one side of my head weren’t working, affecting my eyes and causing double vision. After 3 years on a waiting list, my children could spend their Christmas with a dad who had two working eyes. This gives me hope that everything else not working will either be fixed or can be managed.

“Accepting is difficult. It was only when I accepted my condition and was willing to go in a wheelchair that I found a home adapted to my needs. My partner once said to me when I start accepting my condition and start accepting the help I am due, my life will get better. She was right.

“Having a social network is important. I’m from London and last weekend 2 schoolfriends came to see me. It’s a 30-year friendship and spending time with them meant so much. It helped me remember who I used to be, not what I am now.”



# Running for Dad: Archie's Premier League Marathon

**Archie Whitfield, a 22-year-old from Thirsk, North Yorkshire, is embarking on a remarkable journey next year to run between all 20 Premier League stadiums in less than a month – to honour his late father while raising funds for The Brain Charity.**

Starting from Newcastle's St James's Park and ending at Arsenal's Emirates Stadium, Archie aims to cover around 680 mile - the distance depending on this season's promotion and relegation.

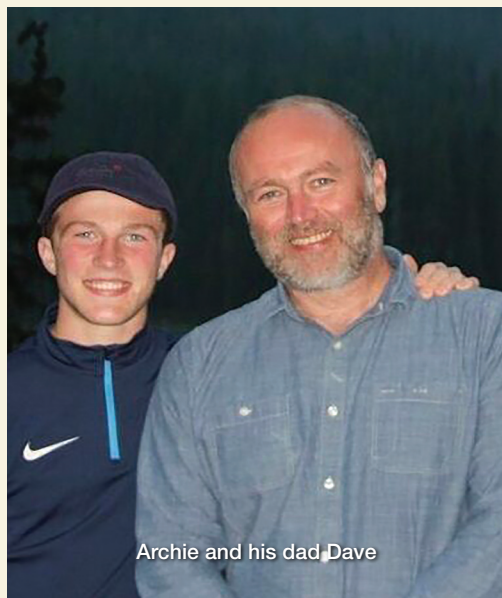
Inspired by his father's resilience and love for football, Archie has already raised over £4,000, a year before the marathon fundraiser takes place.

The quest, scheduled from 2 to 30 April, 2025, holds profound significance for Archie, whose father was a devoted Arsenal fan. Dave Whitfield, a former Geography teacher and community leader, tragically passed away due to complications from Cushing's syndrome.

Archie invites supporters to join him on various legs of his journey, fostering unity and solidarity. To support Archie's mission and The Brain Charity, donations can be made through his dedicated fundraising page: [www.justgiving.com/page/archie-whitfield](https://www.justgiving.com/page/archie-whitfield)

Archie's determination to turn grief into positive action resonates deeply with his family. He emphasises the importance of The Brain Charity's work, stating, "We liked The Brain Charity very much; what they do to help people with so many conditions."

Follow Archie's journey and stay updated on his progress through Instagram, Facebook and his website [archiewhitfield.org.uk](https://archiewhitfield.org.uk)



Archie and his dad Dave







# SPOTLIGHT ON...

## Murmuration Community

### Mum Poppy created a charity to support parents of children with complex needs.

Poppy is the mum of a child with complex needs, brought on by a rare genetic disorder. Her daughter has had regular hospital stays, corrective spinal surgery and mental and behavioural tendencies associated with autism.

Poppy said: "It has been a deeply worrying and exhausting process, often lonely, and at times downright terrifying."

Together with her therapist friend, Poppy founded Murmuration Community, which helps the overlooked and usually quite traumatised parents of children with complex needs looking after their own mental health. Participants attend weekly workshops that include peer support and de-stressing exercises such as yoga and meditation.



Poppy and her daughter

## The Neuro Euros

Get ready to embark on an incredible journey with our Neuro Euros fundraiser, set to ignite passion and purpose during the Euro 2024 football tournament.

From 1 June to 14 July, The Brain Charity invites you to merge the thrill of sports with the noble cause of supporting individuals affected by neurological conditions.

More than just a fundraising effort, the Neuro Euros campaign symbolises solidarity and empowerment.

Participation is easy and makes a difference! Whether you're a football enthusiast eager to highlight your skills in sponsored challenges like keepy-up or penalty shootouts, or a compassionate supporter looking to contribute through fantasy football leagues, or charity matches, there's a way for everyone to get involved.

Look out for the downloadable Neuro Euros fundraising pack on our website at the start of June. Join us as we harness the power of football to kickstart change, one goal at a time. Together, we can create a lasting impact, so no one faces neurological challenges alone. Join the Neuro Euros campaign today and let's score for a cause.



**NEURO EUROS**  
— 2024 —

"The head talks to the heart and the heart talks to the feet." Pelé

### A note on safety

While we celebrate the joy of football, we also prioritize safety. The Brain Charity does not endorse heading the ball due to potential risks of brain injury. We encourage all participants to engage in football activities responsibly and in line with relevant guidelines.

# What's on at the Neuro Gym



DAY	AM	PM	Virtual Sessions
<b>Monday</b>	Open gym access 9.30am – 12.30pm	Boccia (1) 1 – 2pm Boccia (2) 2 – 3pm Open gym access 3 – 4.30pm	Seated gym 1pm
<b>Tuesday</b>	Open gym access 10.30am – 1.30pm	Tai chi session: 2.30pm	Boxing 9.30am
<b>Wednesday</b>	Open gym access 10.30am – 12.30pm Circuit classes 11am – 12pm	Women's only workout 1 – 3pm Open gym access 3 – 4.30pm	Seated exercise 10.30am
<b>Thursday</b>	Open gym access 9.30am – 12.30pm	New age kurling 1 – 2pm Men only Thursday 2 – 4pm	Weekly support groups 11.30am
<b>Friday</b>	Open gym access 9.30am – 12.30pm Circuit classes 11am – 12pm	Yoga 'move it or lose it' session 1 – 2pm Gym inductions 2 – 3.30pm 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](mailto:gym@thebraincharity.org.uk) or call our reception **0151 298 2999**.

Congratulations to our latest Neuro Gym award winners: Brian Molyneux, Margaret Scott and Alan Sykes.

Brian cycled over 200km in the month on our recumbent cardio cycle and also regularly attended the gym and exercise classes at least 3 times per week which have had a huge impact on his personal fitness and wellbeing.

Margaret had an amazing month in the gym, but also regular weekly attendance and amazing results in her 3-month review.

Alan has consistently attended the gym 3 times per week and continues to improve in his personal times and distances on our TheraBike.

We invite you to join Brian, Margaret and Alan on their fitness journeys at our gym. Sign up and begin to achieve your fitness goals today: [www.bit.ly/Nerve05242](http://www.bit.ly/Nerve05242)



Award winners. Brian Molyneux - Alan Sykes  
- Margaret Scott

## Neuro Gym open day: 17 May

Guest speakers, activities and rolling 30-minute taster sessions.  
Drop in any time between 10am – 4pm on the day.



# Social Activities May - June

	Monday	Wednesday	Thursday
Mornings	Art for wellbeing 10am – 12.15pm*	Knit and natter 10am – 12pm	
		Crafters club 10am – 12.15pm	Ukulele for all 11am – 12pm
Afternoons	Maths 1.30pm – 3pm	Drawing group 1.30pm – 3pm	
		Aphasia social 2pm – 3pm	
	Shared reading 3pm – 4pm	Sing and a social 4pm – 5pm	

\*waiting list only

To register for any activity, or for more information, head to our website calendar at [www.thebraincharity.org.uk/events](http://www.thebraincharity.org.uk/events) or call us on **0151 298 2999** and choose activities from our menu.

## Featured activity: Shared reading

Shared reading is an inclusive activity where people come together to appreciate novels and poetry. We discuss our readings without any pressure to read aloud or speak. The goal is to create a comfortable space where everyone can enjoy literature.

## The Brain Charity’s Theatre Club

We have discounted tickets available for the following shows, including a limited number of wheelchair spaces:

Hairspray on Wednesday 21 August at 7.30pm. Payment to be made by 19 July 2024.

Hamilton on Wednesday 21 May 2025 at 7.30pm. Payment due by 27 May 2024.

For further information or to make reservations, contact Moira Warburton-Smith [moira@thebraincharity.org.uk](mailto:moira@thebraincharity.org.uk) or **0151 207 8530**.

## 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 quick questionnaire to help shape the future of The Nerve!

[www.bit.ly/NerveSurvey24](http://www.bit.ly/NerveSurvey24)



# 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](http://www.thebraincharity.org.uk/donate)**

to give an amount of your choice today!



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](http://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](http://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](http://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](http://www.bit.ly/signupTBC)** or ask our information team (on the number and email address below) to add you to the list.

## The Brain Charity

Norton Street,  
Liverpool  
L3 8LR

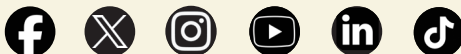
Tel: **0151 298 2999**

Email: **[info@thebraincharity.org.uk](mailto: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](http://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 (No: 05741930)



Responsibly sourced paper

