Connexions

December 2025
Newsletter No.17

Essex Neurology Network

This news bulletin brings together news and information about local Essex NHS Neurology services, support groups for patients, their families & carers, and local and national initiatives and research, which we hope you will share with colleagues, family and friends

Essex Neurology Network
wish you, your family, friends and colleagues
'A Very Happy Christmas!'

We'd like to thank you all
for everything you have done during the past year to support ENN and people with neuro-conditions and look forward to 2026 with hope and enthusiasm.

'ENNgage with Us - Together we are stronger!

Charities in Essex joined us for our pre-Christmas Open meeting recently to think about how we can work more closely together, and to enable us to plan the way ahead for the Network. We shall be asking other sectors to share their ideas too.

Meanwhile, we plan to launch our 'ENNgage with us!' publicity project after Christmas, despite our lack of funds. **If anyone could possibly sponsor the printing of some posters for us, that would be amazing!** Please contact us on **essexneuronetwork@gmail.com**

'Mind the Gaps'

Minds that Misfire, Rewire, and Inspire
Stories of Life-Journeys with Neuro-Conditions

We plan to create a book that will bring together the life-experiences of people in Essex who have neuro-conditions. We hope it will be a powerful read and inspiring insight into people's experiences, which will instigate understanding and change attitudes. .

We should like to invite people to share their own story of their neurological journey or that of someone they care for. It can be a written description, a poem, a photograph, or even some other creative way of telling your story. Whilst it is sometimes difficult to share situations and obstacles faced on these journeys, it is important to share how these were overcome, so others can benefit and learn from them.

Please help us find people of any age, who have experience of a neurological condition, and who are willing to share those experiences with others. A poster is attached – please display this and include it in your own newsletters.

Closing date February 28th. Form & details are available from: essexneuronetwork@gmail.com
Poster attached: If you could **please display** this anywhere where Neuro-Patients might see it.
And **please talk about this project** to everyone you can! Thank you!

Please help us raise some much needed funds.

Use 'easyfundraising' every time you shop online this Christmas

If you haven't signed up to support us yet, it's easy and completely FREE.

Over 8,000 retailers will donate to us, including all the big names like eBay, John Lewis & Partners, Argos, ASOS, Expedia, M&S, Just Eat, Uswitch and many more! This means you can raise FREE donations for us no matter what you're buying.
These donations really help us, so it would be great if you could get started & sign up before Christmas!
Thank you for your support. https://www.easyfundraising.org.uk/causes/essex-neurology-network/

Just a few weeks after her husband Phil's accident, one of **Headway's** team met Rachel. She explained to her that it was like the accident had caused Phil's brain to form a tightly-bound knot of Christmas tree lights that would need time to untangle.

For many of us, decorating the Christmas tree with our treasured decorations is one of the highlights of the festive season. For Rachel, the tree became a symbol of the immediate aftermath of Phil's brain injury. Her beautiful letter explains just what that Christmas tree meant to her.

You are invited you to leave a message and make a donation on Headway UK's virtual Christmas tree – perhaps to write your Christmas wish, fondest memory, or to remember a loved one, and you can even upload a photo!

However much you can donate alongside your message on Headway UK's virtual Christmas tree, please know you'll be making the biggest difference for families like Rachel, Phil and Sam.

Get access for:

- Helpful info and advice about living with the long-term effects of polio and post-polio syndrome
- Names of specialist consultants who understand polio
- Financial assistance for mobility equipment or respite holidays
- A supportive network of people who share similar experiences
- Social events and gatherings to foster connection and community

Contact us today and make a difference!

0800 043 1935
info@britishpolio.org.uk
britishpolio.org.uk

British Polio Fellowship
Empowering polio survivors and their families

Huntington's Disease Association

British Empire Medal

On Friday, November 21st, Cath Stanley was presented with her British Empire Medal (BEM) by the Lord Lieutenant of Merseyside in a ceremony held at Southport Town Hall.

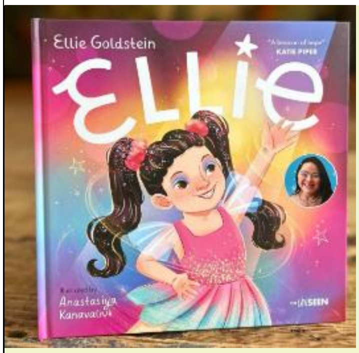
Cath has been dedicated to the Huntington's Disease Association for over 30 years, and has been Chief Executive for over 12 years. In that time, Cath has overseen the charity grow into a team of 51 people, all dedicated to making a difference to people affected by Huntington's disease.

Everyone at the Huntington's Disease Association is extremely proud of her and the work she does to make a difference to those affected by Huntington's disease.

DOWN'S SYNDROME ASSOCIATION

Strictly Come Dancing Ellie Goldstein

Many of you will have watched Ellie Goldstein dance in this year's Strictly Come Dancing show on BBC TV. She was a joy to watch!



The Down's Syndrome Association are running a prize draw for the chance to win a signed copy of Ellie Goldstein's book, Ellie. She is a powerful role model, who continues to inspire so many people who have Down's syndrome and their families. This signed copy is a wonderful keepsake and we are delighted to offer it as a way of raising vital funds for our work.

To take part, simply make a donation of any amount using the link below. Every donation helps us continue providing information, services and support for people who have Down's syndrome, their families, and the wider community.

For more information, see **ENTER HERE.** The draw ends on December 12th.

Also, a consultation seeks views on the draft statutory guidance issued under the Down Syndrome Act 2022, closes on Wednesday January 28th. **Down Syndrome Act 2022 draft statutory guidance**

The Brain Charity Annual Report

As we look back on another remarkable year, the Brain Charity are proud to share our Annual Report — a reflection of the incredible resilience, compassion, and progress that define our community.

We've continued to support thousands of people affected by neurological conditions, offering vital services, expert advice, and a welcoming space where no one faces their journey alone. Every achievement has been made possible thanks to the dedication of our staff, volunteers, and supporters.

This year's report highlights some truly powerful stories — from clients rebuilding their confidence after life-changing diagnoses to volunteers finding purpose and connection through their roles. It also celebrates major milestones such as the first-ever Neurodiversity Arts Festival, and the continued success of our Neuro Gym. **Read the full Annual Report 2024/2025**

The festive season is a wonderful time to come together with loved ones – sharing food, exchanging gifts, and enjoying quality time with one another. But it's also a time of reflection, when families may begin to notice the early signs of dementia.

This Christmas, nearly a million people in the UK will be living with dementia – but with your support, we can drive forward the research that will **bring hope home**. Every action we take moves us closer to a cure.

Whether it's hosting a festive event to taking on a Yuletide-themed challenge, there are many ways to get involved and fundraise this Christmas.
You'll find plenty of ideas in our **Christmas Fundraising Pack**.

Experience of living with an Inflammatory Neuropathy?

The NIHR is working with a commercial company to hold an on-line document review group, to gather public feedback on a clinical trial for inflammatory neuropathy. Will you share your experiences of living with inflammatory neuropathy? Who can take part? Do you:

- Live in the UK
- Aged 18 years or over
- Lived experience of CIDP or other inflammatory neuropathy
- Can access and use a word processing programme such as Microsoft Word
  You will be paid £50!

If you would like to take part in this opportunity, please complete this application form:
https://forms.office.com/e/25K2WkN7Se
If you have any questions about the PECD Service or the planned activity, or have any difficulties completing the application form, please contact the NIHR PECD Service Coordinator at:
pecd@leeds.ac.uk

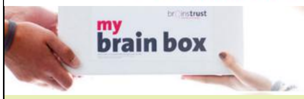
Jess's Rule introduced in NHS England

A new patient safety initiative, Jess's Rule, is being implemented across the NHS in England. Named after Jessica Brady, who died after a delayed cancer diagnosis, the rule is designed to ensure people with persistent symptoms are not overlooked.

The rule introduces a 'three strikes and rethink' approach. If a person presents with the same symptoms three times without a clear diagnosis or improvement, their GP is prompted to formally re-evaluate the case. This encourages doctors to reflect, review, and rethink. This could give GPs a crucial opportunity to consider a rare diagnosis.

The guidance also supports seeking second opinions and specialist referrals. For rare conditions, a specialist's expertise is often crucial for an accurate diagnosis. By standardising this process, Jess's Rule aims to prevent patients from getting stuck in a cycle of GP appointments and to facilitate earlier access to expert care.

s Patients are passive – People are engaged



Brainstrust was founded in 2006 and provides impactful support to thousands of people and their caregivers living with a brain tumour. Working with healthcare partners is an important part of our strategy, ensuring you have the support and resources from us that will allow you to best support your patients.

Our current strategy, ‘first, we are people’, launched in 2019, sees us work to eliminate isolation, grow involvement with care and the condition, reduce fear, and improve knowledge and understanding.
We do this through events, coaching, training, information & advocacy, collaborating wherever possible. Our support, rooted in coaching principles and practices, aligns seamlessly with the NHS 10 year plan and its commitment to patient centred care. We have a proven, evidential track record in helping patients to be confident and involve partners in their care.

How collaborative work is helping us secure the best outcomes for people with a brain tumour.

In partnership with the Patient Information Forum we can provide robust, trustworthy and understandable information for people with a brain tumour. Help your patient get a Brain Box here:
The Brain Box - Brainstrust, brain tumour charity

Inclusive accessibility app for disabled secures Dragon's Den £80k deal

An APP designed to make every day experiences more accessible for people with disabilities has won £80k investment in the Dragon’s Den.

Poole-based digital marketing and software agency b4b, is celebrating the success of one of its clients. The mobile app, built by b4b’s software team, achieved a major milestone by securing an £80,000 investment split between all five Dragons on Dragon’s Den.

“Over the past few years, their support has gone far beyond development - they’ve been part of the Snowball family, helping us make sure everyone, everywhere, can go anywhere.”

Jed Murray, head of software at b4b, said: “We are incredibly proud to have played a key role in bringing this project to life. Our software team worked tirelessly to develop an intuitive, high-performing mobile application, and to see it receive recognition from such high-profile business leaders is truly rewarding.”

Snowball app has been previously recognised by awards. Since its inception in 2023, it has won eleven awards most notably as winner of the Santander Global Award 2024 and most recently as a finalist in the Travel for All Awards 2025.

Research: New funding awarded to PhD project

We’re pleased to share news of a new PhD project that is being jointly funded by the MEA Ramsay Research fund and the UKRI (UK Research Institute) that aims to accelerate biomarker discovery in ME/CFS by identifying unknown metabolites and uncovering evidence of infection.

“Our research into ME/CFS is moving forward with the help of new technologies. The RFI metabolite discovery project, led by Dr Bela Paizs and Miss Aleyna Lumsden, plays a vital role in this progress. By identifying the molecules that may contribute to ME/CFS, this work will help us better understand what drives the illness—and ultimately support the development of new treatments.”

Mid-Essex Neighbourhood Teams

are pleased to announce the continuation of our weekly Neighbourhood drop-in schedule for the next 10 months.
The drop-ins have been designed to be a safe space, and when you are asking a question or presenting a case, please avoid using any personal identifiable data, but share contextual details.

Whilst there is no expectation for you to attend the drop-ins every week, we ask that you accept the invites, so you have them in your calendars for as and when you need them.

If you have colleagues who would like to attend the drop-ins or access other parts of our Community of Practice, please ask them to complete our One Page Bio here: **Partners One Page Profile**
Want to find out more about Neighbourhood Working in Mid Essex? click here

Compassionate Community Network North East Essex

A collaboration of people, places and projects who are building networks of support in the community, to help prevent isolation and loneliness, especially during times of health crisis or personal loss.

Everyone can have a role to play and can help make a difference. Showing empathy and listening to people's concerns can often be enough. Offering to help with specific tasks can be a relief to people when they are struggling to cope, or perhaps signposting community projects, groups and services that are able to offer direct support can be a help. Sometimes small gestures can make the biggest impact – and a friendly smile can often make somebody else's day more manageable.

CAN DO Health & Care - Awards 2025

Community Services and Discharge Processes: Insights from the State of Care Report

The Care Quality Commission (CQC) published its annual State of Care report in late October. The publication of this report has always marked an important moment for the health sector, offering a clear picture of what's working well and where things are falling short.

This year's report feels especially significant, coming in the wake of the many promises made in the Ten Year Health Plan. It serves as both a starting line and a warning, a reminder of the scale of the challenge ahead and a test of the Government's ability to deliver on its commitments.

The state of health care and adult social care in England 2024/25 - Care Quality Commission

In addition, the following important report was also published:

CQC-Final-report-Peoples-experience-of-care-after-hospital-discharge-.pdf

Could infrared light help beat childhood brain cancer?

An innovative project at our Centre of Excellence at the Institute of Cancer Research (ICR) is exploring whether a drug activated by infrared light could help target and destroy the deadliest of all childhood cancers. It's work that could lead to much-needed new treatments for paediatric-type diffuse high-grade glioma – a group of highly aggressive brain tumours which carry a stark average survival of just nine to eighteen months.

Jacob Reeves, a PhD student funded by Brain Tumour Research, is investigating photoimmunotherapy – a treatment approach that combines targeted therapy with light to destroy cancer cells. Having shown that a light-sensitive drug can successfully target the cancer cells in experimental models, he is now exploring whether it can improve survival and activate the immune system to attack the tumour.

Using infrared to kill brain cancer 🚨

Inspire Others is an innovative project between people living with neurological conditions and professionals working alongside. We have built this website together to share personal stories of steps towards doing what matters to us. We hope to inspire others living with neurological conditions to move towards what matters to them; offer hope and a breath of fresh air; and create a sense of community, encouragement and support.Read some inspiring stories! **Learn more**

Essex Neurology Network

welcomes articles from any of the organisations on our mailing list.
If you have an advert or a short article about an event, a neurological condition, services, or support organisation, please consider sending it in for inclusion in one of our coming newsletters.

The next deadline is January 9th. Please send to **essexneuronetwork@gmail.com**

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