



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

VOLUNTEERS NEEDED

We at Essex Neurology Network, have come a long way in the last eighteen months but now, we need YOU to help us! With 300 members now on our mailing list, we are ready to roll!

We want to reach out to people in Essex and to hear about your experiences, so you can tell us what you need, whether support services work well for you or how they could be improved. Over the rest of this year we shall be championing people with neuro-conditions, with talks and presentations by relevant charities or covering specific topics such as the subject of 'Fatigue' - other events will follow during the year.

Whether you are someone with a neuro-condition, a member of their family or a carer, or are someone who works with patients, then you are just the person we are looking for!

YOU matter to us! So how can you help us? You can volunteer to help in many ways.

We are looking for **Volunteers** to help us grow and develop!

We need some **new committee members to join our friendly team**. who will be willing to give a little time to help us promote our aims:

- raising awareness and promoting understanding of neurological conditions;
- securing the highest standards of neurological service and care;
- building strong relationships between patients and professionals;
- facilitating & encouraging research.

We are also currently looking for:

- **someone with IT skills, to set up a new website and social media platforms for us.**
- **someone to design publicity materials and help organise their distribution.**
- **volunteers around the county to deliver publicity materials.**

You can **work from home**, occasionally joining our monthly committee meetings.

We'd love to hear from people who have a **link to any of the many neuro-conditions** or who would welcome a **step up role after being off work**, perhaps through injury or illness, or caring for someone.

Please do encourage anybody that you know, who might be interested! We are a **very friendly, welcoming group!** Our committee meetings are held monthly, by zoom, so you can join us from anywhere in the county!

If you or someone you know could be encouraged to join us, please get in touch for a friendly chat contact essexneuronetwork@gmail.com

Parliamentary Neuro Reception

The new year started with a bang. On January 16th, the Neurological Alliance organised a reception at the House of Commons, to which MPs were invited, as well as representatives of the Alliance's 90 member organisations.

Essex Neurology Network Committee member Barbara Carr (right), met with Georgina Carr (no relation) CEO of the Neurological Alliance, and joined with others to promote the need for the improvement of neurological services. It proved a very interesting and exciting meeting!

The event was the biggest event NA have ever held together to date.

- Over 1,400 people took the e-action inviting their MP to join us, an amazing result in just a week.
- 548 MPs received at least one email from a constituent about the event.
- A record-breaking 35 MPs or their representatives attended – the largest number of MPs to attend a Neurological Alliance event in its 30-year history.



This is a fantastic result that really represents the collective power of the Alliance and has helped us to establish a really strong base of support in Parliament. Thank you to everyone for your support!

Coming soon...



Brain Awareness Week 10th- 16th March: #InvestInNeuroResearch

We are collaborating with the Neurological Alliances across the UK to call for greater investment into neurological condition research.

Coming Soon: We are using the week to showcase the different voices, lives and work impacted by research and to call on the UK Government to **#InvestInNeuroResearch**.

Around one in six people in the UK have at least one neurological condition with an estimated 600,000 people diagnosed each year. A recent study found that neurological conditions are now the leading cause of ill health world wide. These conditions do not discriminate; they can affect anyone, at any age, at any time. It is likely that you or a loved one will be impacted by a neurological condition in your lifetime.

Yet despite touching so many lives, neurological research receives just 8.9% of the total health research expenditure in the UK. Researchers working in the field of neurological conditions face the prospect of losing their jobs due to insecure funding, and clinical trials are severely limited in their number. We believe this needs to change – and we need your help to make it happen.

**Join Us This Brain Awareness Week to raise awareness
about the critical need for more research on neurological conditions**



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[Get ready for National Essential Tremor Awareness Month](#)

Throughout March 2025 the National Tremor Foundation (NTF) will again raise awareness of this common, but little known condition called Essential Tremor (ET).

Essential Tremor is considered one of the most common neurological movement disorders and is estimated to be eight to 10 times more prevalent than Parkinson's disease. People exhibit a rhythmic trembling of the hands, head, legs, trunk and/or voice. It can afflict persons of any age, gender and race and in the vast majority of all cases it is inherited. While more commonly noticed in older individuals, essential tremor can begin as early as birth.

The National Tremor Foundation aims to provide help, support and advice to all those living with all forms of tremor irrespective of age. **Downloadable information:** [Essential Tremor Information Leaflet](#)
For more information contact: www.tremor.org.uk 01708 386 399 enquiries@tremor.org.uk

The Health Research Centre in Brain Injury is seeking people with lived experience of brain injury to assist in research projects by signing up to RHITE.

Since the launch of the new NIHR HRC in Brain Injury, RHITE has been updated. Through the new Orion Health Hub you will have more control over your registration preferences and can amend your registered details. The NIHR HealthTech Research Centres have replaced the MedTech and In Vitro Diagnostics Co-operatives (MICs), which came to an end on 31 March 2024.

RHITE is a public register for individuals interested in taking part in brain injury research. By joining RHITE, you can play an active role in medical research and improve health outcomes.

People who join the list might be invited to:

- Join an online focus group to share their thoughts on new innovations.
- Review the information given to patients about a new research project.
- Complete a short survey about the design and use of new innovations.
- Help to identify the unmet needs of patients and carers.

People are recompensed for their time and there is no obligation to say yes to any invitation .

By signing up to RHITE using the form below, you are helping researchers and innovators to understand more about neurological health and care conditions.

Register your interest to join the list at orion.net/rhite

RHITE has been supported by the [NIHR HealthTech Research Centre in Brain Injury](#) in partnership with [Orion MedTech](#), a not-for-profit Community Interest Company.



WEAR A HAT DAY – Friday March 28th

Join us by putting your hats on for hope on Friday 28th March to help find a cure for all types of brain tumours.

Wear A Hat Day is one of the UK's biggest and best-loved brain tumour awareness and fundraising days, bringing people together across the nation, as they put on their favourite

hats, make a donation, or attend a fundraising hat-themed event. Since its launch in 2010, Wear A Hat Day has raised more than £2.2 million to support our vision to find a cure for all types of brain tumours.

Brain Tumour Research has become synonymous with hats and hatting. A bespoke pink silk top hat created for us by Lock & Co. – the world's oldest hat shop – has been our emblem and is an instantly recognisable part of Wear A Hat Day every year. Wearing a hat reminds us of those who have been personally affected by this devastating disease and helps spread awareness of our cause. This year's Wear A Hat Day is supported by Novocure.

Bring your community together, gather round with your work mates, or get a fundraising event on your school timetable. The more people you can get involved, the more money you can raise to help support ground-breaking research. [Register now](#)



New research into the immunology of ME/CFS

Some important new research into immune system dysfunction in ME/CFS, which has been carried out using blood samples from the ME Biobank, has now been published as a pre-print.

The paper describes how people with mild/moderate ME/CFS have cells which are more “immunosenescent” (exhausted) and cytotoxic, which could imply that they are more frequently exposed to active virus infection.

Meanwhile the people with more severe ME/CFS have a more general pro-inflammatory response. Together, these results suggest that the symptoms in the two groups have different causes.

#ThereForME

Delivery Plan for ME

#ThereForME shares stories from people affected by ME and Long Covid, as well as those working to support them. They have been invited to contribute to the Department of

Health and Social Care (DHSC) cross-government delivery plan for ME/CFS, which aims to improve attitudes, bolster research & better lives.

Amongst many suggestions made, many of their readers would like to see the delivery plan framed as a clear step away from the psychiatry-led approaches that have dominated ME care and research for decades, framing ME as a primarily psychosomatic condition. It was suggested that the Delivery Plan should make a clear statement on this, articulating that it is putting forward a complete break from the past many people also emphasised the importance of educating healthcare workers.

The delivery plan for ME/CFS will be published by the DHSC in March 2025. [#ThereForME](#) | [Karen Hargrave](#) | [Substack](#)



Headway Suffolk's 10th Annual Neuro Conference

Wednesday May 21st 2025

at Kesgrave Conference Centre, Twelve Acre Approach, Ipswich IP5 1JF

Keynote Speaker:

Prof Sir Jonathan Van-Tam MBE

Other speakers:

Helen Fairweather: CEO Headway Suffolk

Lucy Maudlin: Consultant Obstetrician, Addenbrookes Hospital

Beth Cobbold: ex Headway Suffolk service user

Roger Blake: (RNLD) Learning Disability and Autism Specialist Nurse

Dr Norman Shreeve: When a doctor has a stroke

Prof Andrew Bateman: University of Essex

Tickets: £50, Information Stands £200

Sponsorship Opportunities Available

Further Information from: helenmfairweather@headwaysuffolk.org.uk

Sponsored by:  GadsbyWicks &  Ellisons Solicitors



Simple dementia-detecting blood test begins NHS trial

A simple blood test that could revolutionise dementia diagnosis has started trials in NHS clinics. The study of more than 3,000 patients will verify a diagnostic test suitable for routine use that can detect problems with memory and mental processing at an early stage.

Currently just 2% of people with Alzheimer's Disease have a proper diagnosis because the NHS doesn't have enough specialised PET (positron emission tomography) brain scanners or trained staff to take a sample of fluid from the spine. Scientists will analyse the blood for a series of proteins – biomarkers - that have been linked to different forms of dementia in previous research.

The research is funded by the Alzheimer's Society, Alzheimer's Research UK and the People's Postcode Lottery, among others. For more details see: [Alzheimer's Society](#)

Primark launches clothing range designed for people with disabilities



Primark is a go-to shop for cheap knickers and designer dupes, but now it hopes to become the top destination for clothing designed for those with a range of disabilities. The range includes mens and womenswear, with features including magnetic zips on trousers; hidden access points for stomas, insulin pumps or other medical equipment; and cropped jumpers that ensure clothes fit better on seated wearers. It also includes ultra-soft pyjamas, loungewear, formal shirts and trousers with hidden elastic waistbands. The new range follows the release of a so-called "adaptive" underwear range

last year.

Eliza Rain, a disabled activist and fashion vlogger, said it was an exciting time in the adaptive clothing space. "Disabled people deserve to look and feel good, and they deserve to be able to buy their clothes in regular stores at a regular price."



How a head injury caused epilepsy – but became Emma’s path to helping others

Thirty-five years ago, a family walk changed Emma’s life forever when she slipped on a disused railway track and sustained a severe head injury.

Emma remained determined to achieve her dreams. After losing her third job due to her condition, she decided to pursue her lifelong goal of becoming an author and went on to write a book called *Jo’s Hidden Secrets*.

[Read more about Emma's experiences here.](#)

The Brain Charity offers practical and emotional support to people with neurological conditions and to their families, friends and carers.

[Home - Support for neurological conditions | The Brain Charity](#)



Watch Autistica’s new film: *Our World, 2030*

To celebrate the beginning of 2025, Autistica are thrilled to share *Our World, 2030* with you - a compelling short film that envisions a future where autistic people can live happier, healthier, and longer lives.

This two-minute film highlights the challenges faced by autistic and neurodivergent people while showcasing how their ground-breaking autism research and campaign work is transforming lives. It features an incredible cast of neurodivergent actors.

Click the link to watch the film on You Tube: [Our World, 2030](#)

The film is an entrant in this year’s Smiley Charity Film Awards!

Autistica are the UK’s leading autism research and campaigning charity. Their mission is to create breakthroughs that enable all autistic people to live happier, healthier, longer lives. We do this by funding research, shaping policy, and working with autistic people to make more of a difference.



The Genetic Alliance UK are excited to be hosting a Joint Nation Online Event for Rare Disease Day 2025! Rare Disease Day is an annual international day aimed at raising awareness and highlighting the needs of people with rare conditions.

The community will be coming together to recognise the day with health professionals, policymakers, researchers, people affected by rare conditions and support organisations from across all four nations in the UK. Stories from people with rare conditions and leading policy-makers will be heard.

The event on **Thursday March 6th** will see the launch of **‘More than you can imagine: anthology of rare experiences’**, which will be published online and will share a wide range of experiences from the genetic, rare and undiagnosed communities through creative works such as poetry, stories, photos and drawings. The anthology will form a key part of their public awareness campaign, designed to raise the profile of genetic, rare and undiagnosed conditions in the UK.

People from across the UK are welcome to register for the event at:

[Rare Disease Day 2025 Joint Nation Online Event Tickets, Thu 6 Mar 2025 at 10:00 | Eventbrite](#)

If you have any queries, please email rachel.mceleny@geneticalliance.org.uk



Epilepsy Action wants 2025 to be the year they get epilepsy out of the shadows. This is why they have released **“A Place I’m Meant to Know”**, their new short film showing what it feels like to have a seizure. Even to the people that don’t know.

Epilepsy Action teamed up with composer, music producer, and drummer Alex Marchisone to collect real-life experiences from people with **epilepsy** and create an animated, immersive music video that depicts what it is like to have a seizure. (*Highly recommended – Ed.*)

If you have epilepsy, Epilepsy Action hope this short film resonates with you.

If you don’t have epilepsy, they hope it can help you understand more about what it can feel like to live with epilepsy. Please watch and share it to help us get epilepsy out of the shadows.

Watch the film: www.labocine.com/films/a-place-im-meant-to-know



East of England Neurosurgery Network (EoE NN)

Are you interested in helping shape the future of Neurosurgery in the East of England?



The EoE NN is a Clinical Network hosted by Cambridge University Hospitals NHS Foundation Trust (CUH) and was launched in October 2023. The team is made up of four members (left to right):

Kirsty Grieve - EoE NN Specialist Nurse

Naomi Deakin - Manager of the EoE NN

Ripa Begum - Neurosurgery Case Referral Management Coordinator

Daniela Caputo - Patient Engagement & Regional Clinical Research Strategy Lead

The triple aim of the EoE NN across the eastern region is to improve quality of care, reduce inequalities and improve value of neurosurgical management.

To achieve these goals, EoE NN has a dedicated Patient Community Voice. They are keen to hear from anyone who has experience with the regional Neurosurgical Service—whether as a patient, carer, family member, or guardian. Your experiences and insights are invaluable in helping to improve care across the entire region and beyond and can make a real impact on the future of neurosurgical care in the East of England.

You can get involved in a variety of flexible ways, depending on your availability and interests – for more details see: [The East of England Neurosurgery Network - opportunity for patients to get involved](#)

To get involved, please complete this [Expression of Interest Form](#)

To learn more or ask questions of the team, please email eoenn@nhs.net



The University of Essex Cross-departmental 'Brown Bag' meetings

3rd Wednesday of each month between 4 & 5pm

What is a Brown Bag meeting?

An informal and friendly opportunity to meet all sorts of people interested in neurorehabilitation research, from academic researchers to patients and the public, and health and social care professionals. Suggestions for session topics and agenda items are welcome. We collaborate on a Padlet to share information, contacts and opportunities: <https://padlet.com/katiechadd8/uo-neurorehab-research-brown-bags-b8sww61e47aa22a8>

Please register here on the [online form](#) or email Katie Chadd: katie.chadd@essex.ac.uk

True stories

A mother arrived at the GP's waiting room, looking hassled, with a three-year-old boy in tow and a baby in a buggy. The waiting room was hot and crowded and, as it was raining outdoors, it felt musty and there were damp umbrellas and waterproofs everywhere. The wait to see the doctor was long and as time passed by both of the children got more agitated - despite the mother and the other patients trying to keep them occupied, nothing seemed to help. At last the GP's door opened and she called the family's name. As soon as she saw the mother struggling, she came out of her room and smiling she said 'Do let me help you.' She immediately took the buggy, whilst telling the boy to sit on the special children's chair she had in her room. Both the children cheered up and mum certainly looked much relieved and less hassled. A Gold halo for a great GP!



If you have a story about how someone went out of their way to do something special to help you or someone with a neurological condition that you know, then please send it to: essexneuronetwork@gmail.com

'There is a crack, a crack in everything, That's how the light gets in'.

Leonard Cohen 1943 – 2025 based on a Hemingway quote.

Short articles or adverts about neurological conditions, services or support organisations are welcome. The next edition is due in May and the deadline is April 1st.

Please send to essexneuronetwork@gmail.com

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