



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

Happy New Year 2025

We should like to wish you all a very happy, healthy and successful New Year. Here at ENN, we have lots of exciting plans for the coming year, when we hope to reach even more people who are interested in or experience neurological conditions. We hope that you will help and support us and join with us in promoting better neurological services, resources and support locally.

Opportunities for volunteers in 2025

The ENN committee are seeking volunteers to help with the following jobs:

Social media: to set up Facebook and other social media links.

Web master: to set up and run a new website.

Publicity: to coordinate the design & production of publicity materials and their distribution

Occasional helpers (non-committee) to help distribute publicity materials in local areas of the county.

We are looking for people who will promote the aims of the Essex Neurology Network, who have relevant skills to develop these roles, who can be team players and preferably have some experience of neurological conditions. The roles could interest people who have neuro-conditions themselves or a family members or carer. The roles can be undertaken in people's own time, should only require a limited number of hours each month, plus a willingness to attend monthly committees by Zoom.

Professionals and charity staff, who work with people with neuro-conditions are asked to encourage anyone they know who might be suitable, to apply. Any of these roles could be a stepping stone for someone to get involved in the community, to use their skills or gain further experience.

Further details of the roles and information about ENN can be requested by emailing essexneuronetwork@gmail.com

Open Meetings via Zoom – Everyone welcome to join us!

PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

Thursday January 30th at 4pm: a talk by Parkinson's UK. The group offers friendship and support locally to people with Parkinson's, their families and carers. Join us by Zoom, or in person at the university, to hear about the special services, much appreciated by many who benefit from them. **If you wish to join the session please click here**

For information and advice on Parkinson's, or for emotional support, call the Parkinson's UK helpline on [0808 800 0303](tel:0808 800 0303)

the patients association
Listening to patients, speaking up for change.

Thursday March 27th at 4pm: a talk by The Patients' Association. Booking for this talk will take place at the start of March.

The Patients' Association is an independent patient charity campaigning for improvements in health and social care for patients. Uniquely for a charity with a remit covering all health and care issues, the group works with patients directly, providing information to thousands of people each year about the health and social care system. **Helpline 0800 345 7115**

New Neuro Forum

The UK government has launched the first ever Neuro Forum to address gaps in treatment care in neurology.

Parliamentary Under-Secretary of State at the Department of Health and Social Care (DHSC), Andrew Gwynne announced the new UK-wide forum in late November 2024. He said it will work to improve care and support for people affected by neurological conditions. The forum will hold formal biannual meetings, bringing together clinical leaders, organisations and people with lived experience of neurological conditions. The forum is expecting to hold its first meeting in early 2025.

The announcement follows the long-standing 'Back the 1 in 6' campaign by the Neurological Alliance organisations from the four UK nations. The campaign called on the UK government to establish a Neuro Taskforce to address challenges facing people affected by neurological conditions. "The campaign was informed by the experiences of over 9,500 people who responded to the Neurological Alliance's My Neuro Survey. More than 100 organisations, including Essex Neurology Network, and over 19,000 people supported the campaign", the Neurological Alliance said.

The forum will "aim to drive real progress in areas where UK-wide collaboration is most impactful", the Neurological Alliance spokesman said. It added that the forum will drive person-centred care and "address unwarranted variation in access to care across the country".

The campaign also wanted support with problems including treatment and care delays, lack of mental health and wellbeing support and insufficient information at the point of diagnosis.

The national clinical director for Neurology at NHS England, Dr Niran Nirmalanathan, said: "Neurological conditions are the leading cause of disability and affect over 10 million people in the UK. This initiative brings together key stakeholders from across the UK for the first time, and aims to share learning to ensure patients receive the equitable care and treatment they need, with the goal of improving lives."



RARE DISEASE DAY

28 FEBRUARY 2025

Rare Disease Day is an important international awareness day that takes place each year. This year, it falls on the rarest date in the calendar - Thursday February 29th. Rare Disease Day, represents nearly 300 million people living with a rare condition globally. More than 3.5 million people in the UK live with a rare disease; although rare conditions are individually rare, they are collectively common. Today is dedicated to raising awareness of the over 7000 rare conditions affecting people across the UK.

The Genetic Alliance UK will be publishing '[More than you can imagine: an anthology of rare experiences](#)' as part of our Rare Disease Day 2025 campaign.

[Rare Disease Day 2025 - Genetic Alliance](#)

Jayne Hughes, has been awarded a British Empire Medal (BEM) in the King's New Year Honours List 2025, for her services to children with DNA repair disorders and their families, through her work with Amy & Friends. [Amy and Friends](#)

No Neurologist in South Cumbria

NHS patients with neurological conditions have been left without a specialist doctor across an entire region in England. There is not a single NHS neurologist, specialising in brain, spine and conditions related to the nervous system, across the whole of South Cumbria.

Ninety NHS Trusts in England provide a specialist neurology service, but they are not evenly distributed, leaving patients with no support or delays in referrals. Nationally almost a quarter of a million people are waiting for a neurology appointment, which is the third biggest backlog by speciality.

Dorset entrepreneur receives recognition as a disability champion

Sam Everard with ME/CFS has been named as one of the most influential disabled individuals in the UK by being included in this year's Shaw Trust Disability Power 100 list in the Education and Research category.

Sam is the founder and CEO of the Bournemouth-based charity SAMEE (Support and Mentoring Enabling Entrepreneurship), which is committed to helping enable disabled people to start their own businesses. She founded SAMEE eight years ago, and in that time Sam and her small team have built up a respected one-stop support shop for disabled people, offering self-employment guidance and mentoring.

Speaking about her award, Sam said: "I'm really humbled to be included in the top one hundred, but I am most proud about the disabled community that I represent daily. I know that they are all able to succeed if given the right support." [_https://samee.co.uk](https://samee.co.uk)

URGENT PHARMACEUTICAL NEEDS ASSESSMENT PUBLIC SURVEY 2025

This survey is being carried out by Essex County Council as part of a wider partnership of organisations planning for future pharmaceutical services. Completion of the survey is voluntary and if you choose not to take part it will not affect the care you receive from the NHS or your pharmacy/GP in any way.

You are invited to take part in a survey about pharmaceutical services (provided by pharmacies, dispensing doctors, internet pharmacies and dispensing appliance contractors) in the Essex area. The results from this survey will help ECC to understand how local people use the services, how they rate their experience, and what they would like in the future. These views will contribute towards the production of a Pharmaceutical Needs Assessment for Essex and assist in determining what services are required to meet the needs of the local population.

The current Pharmaceutical Needs Assessment covering Essex is available on [Essex Open Data](#).

If you would like more information about the survey, alternative formats (such as a paper copy, translation or an easy read copy) or have questions on how to complete the questionnaire, you can contact PublicHealth2@essex.gov.uk **Closing date January 10th**

For more information on the survey and the link to complete it, [click here](#)

The results of this survey will be available on Essex Open Data where the Pharmaceutical Needs Assessment will be published in October 2025.

Exploring Stroke:

Perspectives from the University of Essex is running a series of conversations supported by the Stroke Association

Welcome to a series of webinars entitled "*Exploring Stroke*" led by Essex University. These important conversations are aimed and open to people living with the consequences of stroke, their carers and professionals supporting them.

The sessions are convened by Professor Andrew Bateman at the University of Essex, with the support of students and researchers. Professor Bateman has worked in research & rehabilitation since 1990 and is President of the Association of Chartered Physiotherapists in Neurology, Honorary Treasurer and a Past President of The Society for Research in Rehabilitation and Chair of the United Kingdom Acquired Brain Injury Forum.

The Tuesday morning sessions last over 6 weeks and can be followed online via Zoom. Please join us on the following dates:

January 22nd An introductory session about the sessions and The Health, Wellbeing & Care Hub

January 29th A holistic perspective on stroke – techniques to help you cope with after-stroke life

February 5th Stroke Inequalities – hear about why stroke affects different communities worldwide

February 12th Social Media and Apps – looking at exciting websites, as well as the pitfalls & risks too.

February 19th Stroke Research at the University of Essex & developments in stroke work

February 26th Let's be stroke activists and get political! Seek to challenge the status quo, and influence decision makers who can make things better.

To join the sessions, which are free, please join via:

<https://essex-university.zoom.us/j/92727584964?from=addon> Meeting ID: 927 2758 4964

For more information see sheet attached with this newsletter.



National Tremor Foundation

National Essential Tremor Awareness (NETA) month

The National Tremor Foundation (NTF) will continue to raise awareness of this little known condition called essential tremor (ET). March is a special NETA month, as they celebrate the NTF's 30th anniversary, and this year with your help it will be bigger than ever!

What is National Essential Tremor Awareness Month?

National Essential Tremor Awareness month, was started by the International Essential Tremor Foundation (IETF) in 2010 in the USA to raise awareness of essential tremor and has since been growing internationally from strength to strength. **Essential tremor:**

- * is considered as one of the most common neurological movement disorders.
- * affects over one million people in the UK, 10 million in the USA and millions more worldwide.
- * is a progressive neurological disorder. At least 5% of all cases of essential tremor occur in childhood.
- * is estimated that 60% of all cases are inherited.
- * is often confused with Parkinson's, although it is estimated to be 8 –10 times more common.

www.tremor.org.uk

01708 386399

enquiries@tremor.org.uk



NHS England will be hosting an online drop-in event for patient groups on **10th January 2025 from 1.30-3pm.**

The session will be an opportunity to learn more about the revised Specialised Adult Neurology Service Specification and ask any questions. The session will be led by Niran Nirmalanathan, National Clinical Director for Neurology and Carolyn Brennan, National Programme of Care Senior Manager - Trauma and Lead Commissioner for Neurology and Neurosurgery & Spinal Surgery Clinical Reference Groups (CRGs).

The Specialised Neurology Service Specification is important as it will aim to clearly define the standards of care expected from organisations funded by NHS England to provide specialised care.

You can find the previous specification here:

<https://www.england.nhs.uk/wp-content/uploads/2013/06/d04-neurosci-spec-neuro.pdf>

Please email england.npoc-trauma@nhs.net for an invitation, However, NHS England can offer one place per organisation.

National Neurology Transformation Meeting January 29th 2025

Effective delivery of integrated neurology care requires a whole system approach. This is particularly important from April 2025, when the commissioning of specialised neurology services will be delegated to Integrated Care Boards (ICBs) across England. There is currently widespread unwarranted variation in the provision of neurology services (Neurology GIRFT Report 2021) and widespread inequity of service delivery. **My Neuro Survey** has further demonstrated that people affected by neurological conditions are subject to widespread variation in both access and experience of services. The full delegation of neurology services to ICBs will be in place by April 2025 but there remain questions without clear answers at present.

This is the second annual meeting and will be delivered by a partnership between NHS England and The Neurological Alliance. The meeting will focus on practical aspects of transformation of ICB commissioned services, and how we can collectively effect change.

The meeting will cover:

- An overview of how the organisation of neurology services will change in the coming years
- Insights from the national ICB neurology dashboard, and how we can use data to improve pathways and performance
- How we can improve unplanned and emergency neurology care in ICBs
- The role and impact of community neurology services in transformation
- Leveraging the voluntary, community and social enterprise sector in supporting transformation of local neurology services
- Sharing examples of neurology transformation within ICBs

The event will be held at the Macdonald Burlington Hotel, Birmingham and is intended for everyone involved in neurology operational management and transformation. It is aimed at Neurology clinical leads & neuroscience clinical directors, Community neuro-team leads, Trust service or business managers and ICB & regional neurology commissioners.



neu health

Neu Health wins award for digitising patient care

Health Innovation East and East Suffolk and North Essex NHS Foundation Trust (ESNEFT) won the Digitising Patient Care Award at the 2024 HSJ Awards for their work supporting the adoption of Neu Health.

Neu Health are working to revolutionise care for people with Parkinson’s Disease. The Neu Platform combines a smart-phone app empowering patients and carers and feeds into a clinician dashboard which utilises AI and machine learning algorithms to provide insights for monitoring and managing Parkinson’s disease.

At **ESNEFT**, the Neu Platform innovation has:

- * Improved clinic efficiency in over 90% of consultations, reducing appointment times by an average of 6 minutes.
- * Led to care changes for 50% of patients, enhancing symptom management.
- * Increased patients’ knowledge and confidence in managing their condition.
- * Reduced in-person visits through remote monitoring, resulting in annual savings of £2,000 per patient.
- * Achieved 78.4% patient uptake with over 600 hours of at-home testing.

The partnership was facilitated by Health Innovation East and driven by adopters and advocates, clinicians and patients at ESNEFT. The collaboration demonstrates how digitising patient care can reshape healthcare delivery, providing better outcomes for patients and staff across the NHS.

“This award represents the culmination of a massive team effort and the unwavering support from our partners and patients. We are deeply honoured to receive this recognition and look forward to continuing to innovate and transform care for people with Parkinson’s disease and dementia.”

Caroline Cake, Co-Founder & CEO, Neu Health

Find out more about the Neu Health collaboration with ESNEFT.



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 94 year-old widow was alone at Christmas and unlikely to see anyone as her only daughter was far away and her carers didn’t plan to visit her. Nearly 100 years ago, she had spent several Christmases as a young child in hospital when presents were few and parents could not stay. She sadly thought that this Christmas might be similar and perhaps her last.



At teatime on Christmas Eve, a neighbour brought her a box of wrapped Christmas treats. She promised not to open them until Christmas Day! Then another neighbour popped in to see her and invited her to have Christmas lunch with her. She was amazed and touched by the kindness of people she hardly knew. Afterwards she rang them to thank them for making her Christmas such a special time.

**A Happy New Year to you all,
may 2025 be a year full of promise for better things to come neurologically!**

Short articles or adverts about neurological conditions, services or support organisations are welcome. The next deadline is February 1st. Please send to essexneuronetwork@gmail.com
