

Connexions

September 2024
Bulletin No.6

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 membership continues to grow steadily, now reaching over 250 people and organisations in Essex and the surrounding area. We are a member of the Neurological Alliance and support their work in lobbying for improved services.

Please help us to promote the following survey, which will provide us with important information specifically about neuro-conditions and Essex!

We need your help with #MyNeuroSurvey

People living with neurological conditions across the UK and Ireland are being asked to take part in the largest neurological survey to help improve vital services and support.

The Neurological Alliance – the leading coalition of over 90 charities working to transform quality of life for people with neurological conditions – runs the survey every two years to gain invaluable insights into care, treatment and support across the country. This year the survey is not only looking at the experiences of adults and children affected by neurological conditions, but their informal carers as well.

The **survey aims** to:

- understand the experiences of people affected by neurological conditions** in the UK and Republic of Ireland,
- provide insights to inform future advocacy, influencing, and service improvement** at national and local levels.

1 in 6 people in the UK & the Republic of Ireland suffer from a neurological condition, which means that, with over 1.2 million residents in Essex, there could be over 200,000 people currently living with a neurological condition in the county. There are over 600 neuro-conditions ranging from migraines, epilepsy, strokes, MS, MD, MND and FND to brain injury and tumours, dementia, Alzheimers, Parkinson's disease, a range of neuropathies and many very rare conditions.

Last time the Alliance ran a similar survey, **8,500 people responded!** Hopefully, we can inspire even more people to respond this time. The facts and figures produced will clearly assess diagnosis, treatment and care needs, and the commissioning of appropriate services. **As an NA member, ENN will receive valuable feedback details specifically about Essex, as well as the rest of UK.**

So, **please encourage everyone who has contact with anyone with a neurological condition** to share their experiences and celebrate excellent care or highlight areas for improvement. The survey lasts until November 15th and there is a form for adults, one for children & young people and one for carers.

Details about the survey can be found **via this QR code or link:**

<https://revealingreality.welcomesyourfeedback.net/a84.vvg>

A poster is also attached for you to print off and display at your venue.

1 in 6 people in the UK and the Republic of Ireland has a neurological condition. Help reach them all.



#MyNeuroSurvey



Suffolk & North East Essex NHS Incorporated Care System Event

An opportunity to connect with stakeholders across Suffolk and North East Essex

www.sneeics.org.uk/Expo-2024



NEW EVENT DATE...


Friday 13 September 2024
9:30am to 3:30pm
Colchester Rugby Club,
Raven Park, Cuckoo Farm Way,
Colchester, CO4 5YX



THE POWER OF KINDNESS

Programme includes:

- Keynote Speakers
- Presentations and Demonstrations
- ICS Awards Ceremony
- Compassionate Leadership Masterclass
- Communities Exhibition Zone
- Lived Experience Exhibition Zone
- Wellbeing Exhibition Zone
- Innovation Exhibition Zone
- Quality Exhibition Zone
- Opportunities Exhibition Zone
- Central Exhibition Zone




Our next Essex Neurology Network Open Meeting

Everyone welcome!

'Fifth Sense' is the charity for people affected by smell and taste disorders. Based in the UK, the charity was set up in 2012 with the sole aim of transforming the lives of those affected by smell and taste disorders. They provide information and direct support to individuals and their families affected by these conditions and work to improve knowledge and understanding amongst professionals through education and training.

Join us at **Essex Neurology Network on Zoom on Thursday September 19th at 4pm** for this interesting talk from Helen Rhodes, Education & Engagement Officer for Fifth Sense, with our **brief AGM** beforehand. Please register your interest by responding to this registration link:
[ENN Meeting Thursday 19th September at 4pm \(google.com\)](#)



Essex County Council


Adults with Disabilities

Essex County Council Adult Social Care Adults with Disabilities Commissioning team, specifically from the Physical Sensory Impairment and Acquired Brain Injury commissioning group, invite people with firsthand experience, to embark on a collaborative journey with us.

We aim to connect with people, including frontline service delivery staff, patients, family carers, friends, and anyone touched by our services. We are looking for people who might like to join our steering groups, helping us co-produce solutions and monitor contracts, but also to meet and engage with people giving us their lived experiences. Your experiences - be they positive, challenging, or revealing unmet needs - are crucial for us to understand the broader picture of the day-to-day challenges.

We hope to build a network of people that we can learn from but that can support each other as well. If this sounds like something you, and/or your organisation would like to be part of we would be delighted to hear from you. Please contact: Rhona Gilder - Senior Commissioning Officer
rhona.gilder@essex.gov.uk

A Collection of Quarterly Parkinson's Webinars



NEXT WEBINAR

INNOVATIONS IN GENE THERAPIES FOR PARKINSON'S

5:00-6:00 p.m. BST | 12:00-1:00 p.m. ET
Wednesday 4th September, 2024

Cure Parkinson's

Webinar: **Innovations in gene therapies for Parkinson's**
Wednesday 4 September at 5pm for a webinar discussing gene therapies for Parkinson's, presented in partnership with the Journal of Parkinson's Disease and chaired by the University of Edinburgh's Professor Tilo Kunath. Contact: <https://cureparkinsons.org.uk>



Alex, The Leukodystrophy Charity (Alex TLC) provides invaluable support and information to people affected by leukodystrophy. Leukodystrophies are genetic disorders that mainly affect the white matter of the central nervous system (i.e. the brain or spinal cord). There are more than 100 different known types of leukodystrophy, including some so rare they only affect one or two individuals.

Established in 2004, we are an internationally recognised centre of excellence and the only UK charity providing support and information to people affected by any of the leukodystrophy conditions worldwide.

The Alex Community Weekend will be taking place from **October 11th - 13th** at Park Regis Birmingham hotel and will focus on bringing our community together, therefore the event is free to attend, with both accommodation and food being provided. To find out more about our Community Weekends, visit our website: [Community Weekends](https://www.alex-tlc.org/community-weekends). For questions, please contact info@alex-tlc.org
Home - Alex - The Leukodystrophy Charity (alex-tlc.org)

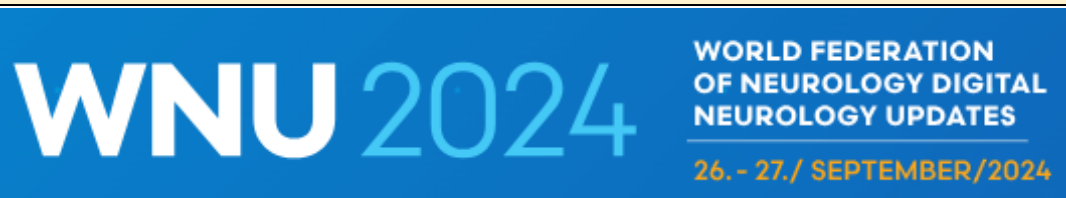
Rare Barometer, the global survey initiative of EURORDIS – Rare Diseases Europe, has launched a new survey on the impact of rare diseases on everyday life. The survey will be open from 10 July to 8 September. to all people living with any rare disease and their family members worldwide and will be available in 25 languages.

The results of the upcoming survey will be used by EURORDIS and its members to measure the social vulnerability of people living with a rare disease and design advocacy and actions to reduce it. By gathering insights from the rare disease community, this survey aims to:

- Assess the level of social participation and identify factors that facilitate or hinder involvement in various social activities, such as education, leisure, and employment.
- Understand preferences and needs related to independent living.
- Collect experiences with disability assessments.
- Identify the main barriers and facilitators to accessing social and disability rights.

The objective is to transform the opinions and experiences of people living with a rare disease and their close family members into facts and figures that can be shared with a wider public and with decision-makers.

[Rare Barometer to launch a new survey on the impact of rare diseases on daily life - EURORDIS](https://www.eurordis.europa.eu/en/news/rare-barometer-launches-new-survey)

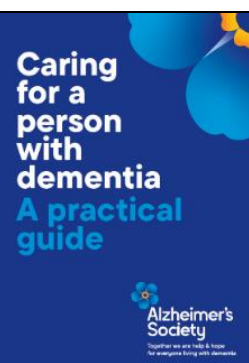


On behalf of the World Federation of Neurology (WFN), a warm welcome is extended to each of you to the inaugural edition of the World Federation of

Neurology Digital Neurology Updates (WNU 2024), scheduled to take place on September 26th to 27th. This online event marks a significant milestone in our continuous journey towards fostering global medical education.

The decision to host WNU 2024 as a fully online event was made with a clear vision in mind - to transcend geographical and logistical barriers, thus enabling a more inclusive and far-reaching platform for neurologists, researchers, and healthcare professionals from around the world. This digital format not only allows participants to engage from the comfort of their own settings but also significantly reduces the carbon footprint associated with traditional conferences, aligning with our commitment to sustainability.

[World Federation of Neurology Digital Neurology Updates \(WNU 2024\) \(wfneurology.org\)](https://www.wfneurology.org/)



Alzheimers World Alzheimers Day – Saturday September 21st

1 in 3 people born in the UK today will develop dementia. On September 21st, the world concentrates its efforts on creating awareness of Alzheimer's Disease, which is amongst the most prevalent forms of dementia. Globally, dementia is one of the biggest challenges we face, with nearly 50 million people living with dementia worldwide. To tackle this international challenge, we need to work together and share learning, best practice and experience with one another.

To download this guide go to:

[Caring-for-a-person-with-dementia-a-practical-guide.pdf \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/caring-for-a-person-with-dementia-a-practical-guide.pdf)



British Association of Neuroscience Nurses (BANN)

provides a voice for neuro-science nurses working within various clinical and community settings. They aim to promote the highest standard for care within the speciality, to encourage and give the opportunity for exchange of ideas within this country and abroad and to encourage interest and awareness of the special needs of neuroscience patients.

Autumn Conference 4th & 5th October 2024

Hosted by the Neuroscience Unit at Newcastle upon Tyne Hospital Foundation Trust
and in collaboration with Northumbria University

Venue: Copthorne Hotel, The Close, Quayside, Newcastle upon Tyne NE1 3R

For details see: [BANN Autumn 2024 Conference – BANN](#)

British Neuroscience Association Award for Outstanding Contribution to Neuroscience

The BNA community wish to announce and congratulate Professor Julie Williams, Director of the UK Dementia Research Institute at Cardiff University as the recipient of this award. Professor Williams has been recognised for her contributions to the field of genetics, in particular to dementia and Alzheimer's research, but also her commitment to EDI and nurturing the researchers of the future.



We believe Professor Williams exemplifies the qualities we value at the BNA and thoroughly deserves to receive our most prestigious prize. Her groundbreaking work in dementia and Alzheimer's research, alongside her dedication to fostering diversity, equity, and inclusion within the scientific community, is truly inspiring. Professor Williams embodies the excellence and commitment that we strive to promote at the BNA. We are eagerly looking forward to her plenary session at the BNA Festival of Neuroscience in Liverpool, where she will undoubtedly inspire attendees with her remarkable journey and contributions to neuroscience."

Professor Williams will be a plenary speaker at the forthcoming BNA Festival of Neuroscience in Liverpool in April 2025 where she will present an overview of her career path to date and her research.



A major new study released by *The Lancet Neurology* shows that, in 2021, more than 3 billion people worldwide were living with a neurological condition. The World Health Organization (WHO) contributed to the analysis of the Global Burden of Disease, Injuries, and Risk Factor Study (GBD) 2021 data.

Neurological conditions are now the leading cause of ill health and disability worldwide. The overall amount of disability, illness and premature death (known as disability-adjusted life years or DALYs) caused by neurological conditions has increased by 18% since 1990.

"Neurological conditions cause great suffering to the individuals and families they affect, and rob communities and economies of human capital," said Dr Tedros Adhanom Ghebreyesus, WHO Director-General. "This study should serve as an urgent call to action to scale up targeted interventions to allow the growing number of people living with neurological conditions to access the quality care, treatment and rehabilitation they need. It is more important than ever to ensure brain health is better understood, valued and protected, from early childhood to later life."

[Over 1 in 3 people affected by neurological conditions, the leading cause of illness and disability worldwide \(who.int\)](#)



World Stroke Day: Tuesday October 29th aims to raise awareness, discuss prevention, and improve care and treatment for stroke survivors. There are over 1.2 million stroke survivors living in the UK – many of whom are reliant on their friends and family for help with daily living for example, or support with their emotional and mental health needs. A lack of awareness about stroke leaves survivors feeling isolated and misunderstood.

[World Stroke Day 2024 | World Stroke Organization \(world-stroke.org\)](#)

UK Stroke Forum 2024 Conference

Tuesday December 3rd – Thursday December 5th

at the Arena and Conference Centre, Liverpool

Join us for the UK's largest multidisciplinary conference for stroke care professionals

[About UK Stroke Forum | Stroke Association](#)



Epilepsy Action

Mark your calendar on **Friday 27th September**, to celebrate the 20th anniversary of **Epilepsy Action's** most colourful and creative annual fundraising campaign - **National Doodle Day!**

As always, the most important part of the **doodle-tastic festivities**, is our eBay auction - which features A5 original artworks from a range of your favourite artists, illustrators and celebrities. We are super excited to have some incredible doodlers taking part this year including **Heartstopper creator Alice Oseman**, **Paddington illustrator R.W. Alley** and **Academy Award winner Oliva Colman CBE!**

Last year was our biggest year to-date, **raising more than £30,000** across the three day auction period ... so to make it even **BIGGER** for 2024, we have extended the auction to **TEN days**, from **20th to 29th September!!!**

If you are an artist, illustrator, school or university who would like to create an artwork for this year's auction, it isn't too late to get involved. Send an email to doodle@epilepsy.org.uk for more information.

Beware! Dementia patient targeted by scammers

The Alzheimer's Society has reported an incident where Peter, a retired policeman & ex-IT worker, who has dementia, was rung by a scammer and his bank account was cleared of £2,500. Luckily, he was suspicious and rang Action Fraud, who told him to ring his bank, who confirmed he had been a victim. Action Fraud were great. They explained the next steps to him and how he might get his money back. Barclays reimbursed him in full and as soon as he told them that he was living with dementia, they put a flag on his account and took extra care to look after him. So, if you or one of your patients is rung by someone they don't know, tell them to be alert!

For help in spotting a scam or to report a fraud, contact **Action Fraud** [Action Fraud](#)

or **Friends Against Scams** <https://www.friendsagainstscams.org.uk> which welcomes people from all walks of life to take a stand against scams. Don't worry if you think you don't know much about scams, that is exactly what the session is for!



Walk4Daisy 2024

The Daisy Garland is a charity set up in memory of our daughter Daisy who died in her sleep at the age of six from SUDEP (sudden unexpected death in epilepsy). The work we do relies 100% on the support of kind people like you.

To celebrate our 20th Anniversary, and in an attempt to boost much needed charity funds, we are desperately seeking kind-hearted people to take part in this year's WALK4DAISY, our annual fundraising daisy-themed sponsored walk, taking place in the month of August (or September) at a date to suit you.

Click below and find about our Walk4Daisy 2024

<https://www.thedaisygarland.org.uk/Appeal/team-daisy-walk4daisy>

Dance Therapy

Scientists are trying to learn more about how dance impacts the brain with a new field of study, dance neuroscience. Dancer and neuroscientist Julia Basso, PhD, wants us all to dance -- together or separately, it's all good. Dancing with a partner creates a synchrony that's remarkably like that between a mother and infant, and even dancing alone benefits body and brain alike. Find out how dance produces new neurons and engages brain processes, and why it is that joyful movement optimizes brain function.

[Will dancing help with my Parkinson's? | Parkinson's UK \(parkinsons.org.uk\)](#)



Why do we have two ears and only one mouth?
So we can listen twice as much as we speak!
Epictetus



Effective two-way communication is not just a matter of good manners; it is a fundamental part of a well-functioning healthcare system. By prioritising open dialogue, active listening, and seamless information

sharing, the system can empower patients, ease the pressure on NHS staff, and play an important role in restoring the public's level of satisfaction in the NHS.

Support our demand to put two-way communication at the forefront of healthcare reform. Together, we can build a system that truly listens to and serves the needs of its patients, paving the way for better outcomes and increased satisfaction.



[The importance for two-way communication \(patients-association.org.uk\)](https://patients-association.org.uk)



Join us for **Patient Partnership Week - September 2nd to 6th**
Plus Patient Safety Commissioner, Dr Henrietta Hughes, will be in conversation with our Chief Executive Rachel Power, during the week in our free webinars:

- * Implementing shared decision making in practice
- * Empowering patients as equal partners in care
- * The role of data in joining services around patients

Their August webinar now available to watch on line, with the Chair of Trustees Julie Thallon and Trustee Prof Alf Collins, discussing [Active involvement in shared decision making \(youtube.com\)](https://www.youtube.com/watch?v=...)



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 [online form](#) or email Katie Chadd: katie.chadd@essex.ac.uk



Ataxia UK Virtual Annual Conference 2024

Friday 27th & Saturday 28th September

Tickets cost £15.00 per screen

[Ataxia UK Annual Virtual Conference 2024 - Ataxia UK](https://ataxia.org.uk)

'Ataxia' is an umbrella term for a group of neurological disorders that affect balance, coordination and speech. There are many different types of ataxia that affect people in different ways'

If you would like to find out more, or talk to a member of the team

call 0800 995 6037 or email

help@ataxia.org.uk

Helpline open:

Monday to Thursday 10.30am - 2.30pm



Community Conference and AGM

Saturday, 26th October and Sunday, 27th October

Crewe Hall Hotel & Spa, Crewe, Cheshire

This year's conference will be held in person over two days: the AGM and community conference on Saturday and interactive workshops on Sunday. Don't miss this

amazing opportunity to attend this year's conference. The first in person event since 2019! For more information & to book a place: [Huntington's Disease Association - Huntington's disease Community Conference and AGM 2024 \(hda.org.uk\)](https://huntingtons-disease-association.org.uk)



The Brain Charity provides practical help, emotional support & social activities for anyone with a neurological condition. A diagnosis can be devastating; people can lose control of their lives and many face unemployment, poverty & social isolation as a result.

The charity was set up out of the recognition that not enough [practical help](#) was being provided for people with neurological conditions, outside of treating their physical symptoms in hospital. Our information officers give advice to people based anywhere in the UK. This could be around living with their condition, understanding their financial rights and applying for benefits, housing and aids and adaptations as well as free legal advice referrals and support with employment.

Statistics suggest at least 50% of people with neurological conditions also have mental health problems. Being affected by a neurological condition can be a frightening experience which can impact greatly on the emotional well-being not just of the person diagnosed, but on their family members, carers and friends too.

If you or someone you know someone who needs support in any of the ways above or could benefit from our services, please call the **free helpline on 0800 008 6417** or see [Home - The Brain Charity](#)

Are you caring for somebody towards the end of life?

Our free website is designed by palliative care experts for patients, carers and clinicians.

A new resource is launching in Mid and South Essex to help navigate the complex health and care needs around end of life and palliative care.

The HPAL website is a palliative and end of life care information resource for clinicians, patients, carers and loved ones in mid and south Essex. The website's

content will help clinicians develop their palliative care knowledge, as well as help patients and carers support their own care needs, whether in a hospice, care home or in their own home.

The comprehensive and user-friendly platform provides information in bite-sized and easy to read snippets. You can try out some of the articles now by visiting the HPAL Mid and South Essex (MSE) website. Clinicians can easily use it during their consultations with patients. [Medindex: HPAL MSE](#)

True stories

At the start of a then-undiagnosed neuro-condition, I was taken into ICU and faced having an urgent tracheotomy. I learned afterwards that it was touch and go whether I would survive the night ahead!



Despite being so ill, I asked to see a chaplain, even though I am not a practicing church goer. She came to me that night and listened and reassured me with her calm words. After that, she came back to my bedside every day or two for the next month, always bringing a smile, kind words and two listening ears.

Somehow we managed to communicate – I could not speak as I was ventilated, but we gradually got to know one another. It was during COVID, so I was not allowed many visitors – just my husband and my special 'angel'. One day she brought me a small wooden heart and a poem called 'Hope'. She helped me through some of my darkest days. I often think of her and this quote from Hebrews comes to mind: 'Be not forgetful to entertain strangers, for thereby some have entertained angels unawares.'

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

INSIGHT scheme for new researchers

The University of Essex has been selected as the lead organisation in the East of England to offer 90 research training masters places across three years alongside partner institution, the University of Hertfordshire. They will work together to help students and those at early career stages to access the full range of research careers, from research delivery to academic.

[Essex to train up next generation of health and social care researchers | University of Essex](#)

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