Connexions

September 2025
Newsletter No.15

Essex Neurology Network

Member of the Neurological Alliance
THE NEUROLOGICAL ALLIANCE

Welcome to you all for this early autumn edition of our newsletter, which as usual is packed with lots of information for you to share with colleagues at work or members of your family.

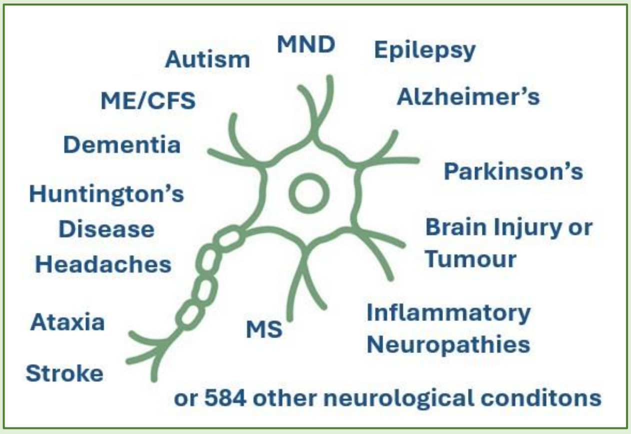
Date for your Diary

Thursday October 16th 4pm:
ENN Annual General Meeting

Followed by our speaker:
Dr Alex Street
Senior Research Fellow
Cambridge Institute for Music Therapy Research (CIMTR)

'Music-based interventions in neurorehabilitation, an overview of evidence and accessibility'

This meeting will be by Zoom only
Please pre-register by clicking this link.



Essex Neurology Network

is the only organisation in Essex that covers all neurological conditions. 1 in 6 people in England suffer from one or more of these conditions, of which there are over 600, many life-limiting, some life-threatening and certainly all life-changing.

We are delighted that our mailing list now numbers over 360 individuals. Some of these are people who have neuro-conditions themselves, as well as their families or carers; others work in NHS neurology services or in one of the many charities that support people with these conditions, whilst in addition, members of the University of Essex are also involved.

We welcome anyone who would like to join us and look forward to sharing ideas with you. For more information contact us via our secretary on **essexneuronetwork@gmail.com**

Funding for Essex Neurology Network

We now have our own bank account and need to raise funds for our big publicity campaign next Spring, so we can reach more people with neuro-conditions through a new website, publicity materials and a special event.

We are also registered with **easyfundraising**, which means you can help us raise funds for FREE. Over 8,000 retailers will donate to us when you use easyfundraising to shop with them – at no extra cost to yourself! All you need to do is sign up and remember to use easyfundraising whenever you shop online. It's easy and completely FREE! These donations really mount up, so please sign up to support us at **https://www.easyfundraising.org.uk/causes/essex-neurology-network/**

We were delighted to hear recently from Dr Matthew Sweeting, Executive Medical Director for Mid and South Essex Integrated Care Board.

He tells us he is passionate about neurological conditions and intends to bring a more detailed response to a future ICB Board meeting, outlining how these priorities will specifically support residents living with or managing a neurological condition

We shall look forward to hearing further details at the next (or a future) Board meeting

ICB Board Meeting – 18 September 2025 - Mid and South Essex Integrated Care System
2:00pm to 3:30pm
Southend Civic Centre, Victoria Avenue, Southend-on-Sea, Essex SS2 6ER

You can book your place to attend or go online to watch the link to this meeting – see above link

New study may help treat post-stroke fatigue

Fatigue is one of the most common effects of stroke. It can make you feel unwell and like you're not in control of your recovery. Unlike regular tiredness, this kind of fatigue doesn't go away with rest, and many people notice that their tiredness doesn't always relate to how active they were that day. The signs of fatigue aren't always clear to others, so they might not understand what you're going through.

Currently, there are no effective treatments for PSF. Dr. Ali Ali and Professor Arshad Majid are leading a research project to **investigate whether remote ischaemic conditioning (RIC), which involves altering blood supply to one arm, can treat PSF**. A pilot study indicated promising results, with participants reporting reduced fatigue, allowing survivors to get back to activities like running and socialising.

With funding from the Stroke Association, a **larger trial with 60 participants aims to further understand RIC's effectiveness in treating PSF and its mechanism at a cellular level**. RIC research offers potential long-term benefits for stroke survivors. It provides a low-cost, solution that survivors can administer themselves. If successful it could significantly enhance wellbeing and recovery.

For more information: **New study may help treat post-stroke fatigue | Stroke Association**

The DecodeME team are delighted to share an important update on their study.

The initial DNA analysis is now complete, and we have made some exciting discoveries. Our results show that people with an ME/CFS diagnosis have significant genetic differences compared to the general population. These findings confirm that genes contribute to someone's chances of developing ME/CFS.

Eight genetic signals have been identified that are much more common in people with ME/CFS than the general population. The signals discovered are involved in the immune and the nervous systems, indicating immunological and neurological causes to this poorly understood disease.

The discoveries open the door for scientists to explore what's going wrong in ME/CFS at a molecular level and are a major step forward in ME/CFS research.

Find out more about the results:

- Read more about our findings in our **announcement blog**
- Read our **FAQs on the initial results**
- **Register for our upcoming webinar,** where you will hear more about the results from the DecodeME management team, and will have the opportunity to ask questions
- Find the **scientific preprint paper here**
- Learn the **science behind the findings**

This progress has only been possible thanks to everyone who took part in DecodeME. We are extremely grateful for your continued support.


Choices
MS-UK
Supporting your MS journey
Pain

Our **useful information Choices booklet** covers what pain is, the different types of pain, alternative and complementary ways to manage it. Plus, practical self-management tips and even how to describe pain clearly when speaking with healthcare professionals. It's designed to help you feel more informed, supported, and confident in managing pain day to day. **Click here to find out more**

Ellie Goldstein to join Strictly Come Dancing

Carol Boys OBE, Chief Executive of the Down's Syndrome Association, said: 'We are absolutely thrilled that Ellie has been chosen for this year's show.

Ellie's had huge success over the last couple of years, as a model, author, actress and advocate, and this is a wonderful recognition of her hard work. 'It's so important for other people who have Down's syndrome, as well as the wider community, to see representatives in big shows like Strictly. I know we all loved seeing George in the Christmas special a couple of years ago.'

'We will be cheering Ellie on every week and can't wait to see her on the dance floor!'

The Leukodystrophy Charity (Alex)

Established in 2004, Alex TLC provides invaluable support and information to people affected by leukodystrophy. There are more than **100 different** known types of leukodystrophy, including some so rare they only affect one or two individuals. We are the **only charity in the UK** that provides support and information to people affected by any of the leukodystrophy conditions **worldwide**.

Hundreds of thousands of people diagnosed with long-term health conditions will receive extra help and support from expert charities, under a new service announced by the government.

Diagnosis Connect to launch next year

Leukodystrophies are genetic disorders primarily affecting the white matter of the central nervous system (ie. the brain or spinal cord), affecting impaired mobility, vision, speech and hearing, incontinence, inability to swallow and loss of cognitive skills.

Alex continues to support valuable research, as well as working with government. The recent July announcement of Diagnosis Connect will ensure patients are referred directly to trusted charities and support organisations as soon as they are diagnosed - providing personalised advice, information and guidance to help them manage their condition and feel more in control. This support is designed to complement, not replace, their usual NHS care. It recognises the vital role that civil society plays in helping repair the health of the nation. Diagnosis Connect is due to be launched in early 2026.

Future of Essex ICBs

The Darzi report concluded that the responsibilities of ICBs needed to be clarified to provide more consistency and better enable the strategic objectives of redistributing resource and integrating care. In line with every ICB moving to focus on strategic commissioning, the NHS England Chief Executive wrote to NHS leaders on 1 April highlighting the critical role ICB will play in the future system architecture. A Model ICB Blueprint was created, which affirms that ICBs are essential to the future success of the NHS, delivering the Government's priorities. It commits to building the capabilities of ICBs and the strategic commissioning skills of their staff through a national commissioning development programme which will be scoped over the summer.

The Blueprint makes clear that as strategic commissioners, ICBs will focus on providing system leadership for population health, setting evidence based and long-term population heath strategy and working as healthcare payers to deliver this, maximising the value that can be created from available resources.

According to NHS England this week, there are to be changes ahead, with some ICBs clustering. However, Mid & South Essex ICB will remain the same and will work closely with West Essex and North East Essex geographies from relevant ICBs; i.e. to remain linked to West Herts & Suffolk respectively.

Waddle-on-Sea – Southend's Quirkiest Summer Trail!

A fun-raising event has been taking place this summer to raise funds for Havens Hospices. The event has featured 31 large penguin sculptures and 72 baby penguins, each uniquely designed and placed around Southend and Leigh on Sea. The large penguins, each sponsored by a business, will be auctioned off at the end of the trail to raise vital funds for Havens Hospices' specialist care.

Visit Waddle HQ to find out more about the trail and chat to our volunteers or enter our Waddle-on-Sea Raffle to take home your very own baby penguin sculpture! See: **The Trail — Waddle on Sea**

Carers Supporting Carers Through Gardens

Carers give so much every day – that's why we wanted to share the story of Jane, who's giving back to carers as a former carer herself.

At Downton House in Gloucestershire, Jane Kilpatrick opens her garden to the public – not just to share its beauty, but to create a space where everyone can pause, exhale, and feel the healing power of nature.

Jane knows what this means. As a former carer herself, she understands the weight so many carers carry and how gardens can offer something rare: calm, connection, and a moment to breathe.

National Garden Scheme visits are a special experience – you can wander through beautiful gardens on a guided tour, enjoy tea and homemade cakes, and connect with like-minded people.

Behind each open garden day are incredible volunteers like Rachael and Caroline, who support Jane in welcoming visitors to Downton House. They know that what they're doing is about more than flowers and lawns – it's about giving something back to carers who give so much. Discover the incredible support Rachael and Caroline provide. Like many volunteers across the UK, they give so much to help make National Garden Scheme visits a lovely experience for everyone.

Watch the video to see what a visit is really like and Jane's story as a carer.
Downton House, Painswick supporting carers through the National Garden Scheme
For information about the Carers' Trust: Carers Trust | Transforming the lives of carers

University of East Anglia

The University of East Anglia study into how smell loss / change impacts the brain

Researchers Tabitha James, Dr Louis Renoult and Professor Carl Philpott are working on a project to explore how smell activity may be linked to various aspects of brain functioning. This research will be used to help improve the understanding of how smell loss / change impacts the brain.

They are looking to recruit people with smell impairment to take part in an online experiment that will take 45 minutes to complete. If you would like to know more about this study, then please contact: **memoryandageing@uea.ac.uk**

SmellTaste
Support, Education, Research

SmeeSmellTaste 2025 National Conference

Date: Saturday 8 November 2025
Time: 9.30 am to 5:00 pm
Place: **University of Nottingham,** Trent Building, University Park Campus
Tickets: **In person: £20**, including lunch and refreshments | **Online: £15**
A landmark event dedicated to raising awareness, providing support and information, and driving progress for people living with smell and taste impairments. For deails & to book a place see: **SmellTaste 2025 National Conference - SmellTaste**

Huntington's Disease Association

Community Conference and AGM

Nov 1st 2025 - Nov 2nd 2025 10:00am - 4:30pm
Crewe Hall Hotel, Crewe, CW1 6UZ

This event is for everyone affected by Huntington's disease, whether family, friends, individuals or professional to come together to understand more about the disease.

Huntington's disease is an inherited neurodegenerative disorder that causes the progressive degeneration of nerve cells in the brain.

Hear from acclaimed speakers and connect with and learn from other members of the Huntington community. For details and to book a place:

Huntington's Disease Association - Huntington's disease Community Conference and AGM 2025

Encephalitis International

CALL FOR ACTION!

We are looking for people affected by;
Encephalitis associated with MOG antibodies.
Influenza (flu) encephalitis
Measles encephalitis
Tick-borne encephalitis
Japanese encephalitis
If you have   can help us, please get in touch: -
peersupport@encephalitis.info

And for those of you interested:
Encephalitis Conference
3rd - 4th December 2025!
8am – 6pm
Royal College of Physicians, London & Virtual

Encephalitis International is a non-profit organization dedicated to providing support, raising awareness, and funding research related to encephalitis, and inflammation of the brain

ALZHEIMER'S RESEARCH UK FOR A CURE

Hope rises as more Alzheimer's drugs enter clinical trials

CAN YOU HELP FIND NEW TREATMENTS?

While **scientists are working hard to test more potential medicines**, they need our support. Without people volunteering to take part in research, finding a cure will be impossible.

More than 50,000 volunteers are needed to run Alzheimer's trials across the globe

In the UK, it is estimated that over 10,000 more people could benefit from participating in clinical trials for dementia, if the UK enrolled people onto trials at a comparable rate to the rest of the world.

People with dementia, their carers, and people without dementia can all help by signing up to take part in research &**make a real difference!**

Brain Research UK

London Marathon 2025 - they did it!

In April, our incredible team of almost 300 runners completed this year's TCS London Marathon to raise vital funds for research. We are delighted to share that, to date, **the team has raised an outstanding total of £980,000** to help people with a neurological condition live better, longer.

A huge thank you and well done to all our #TeamBrainResearchUK runners for accomplishing this major milestone – we hope you are deservedly very proud of yourselves!

Excitingly, fundraising and training have already begun for the 2026 TCS London Marathon with the ballot results released last week. A reminder that, if you have secured your own place in next year's race via the organiser's ballot, you are still able to be part of our team… we would love to hear from you! Please get in touch with **events@brainresearchuk.org.uk** if this opportunity interests you.

The importance of research into migraine and headaches

Headaches are the most common type of pain with **190,000 migraine attacks** occurring every day in the UK. Many people with migraine, other headache and facial pain disorders remain insufficiently treated, unable to get effective relief from the pain and other associated symptoms.

New, improved treatments are desperately needed. We are working towards this by funding research that aims to better understand these disorders. **Brain Research UK | Funding world-class brain research**

ATAXIA

Gene therapy survey – your help is needed

Gene therapy is a potential treatment for genetic ataxias, and as such the views of people with the condition are invaluable in the design of future research and clinical trials. The results of this research will provide information to the ataxia research community about opinions on gene therapy, which will help when designing future treatment trials.

People diagnosed with a genetic ataxia, or their family members, are eligible to complete the survey. Minors are required to complete the survey with a parent or guardian. We expect the survey will take roughly 30 minutes to complete, and the data collected will be anonymous.

If you have any questions about this research, contact Ataxia UK's research department at research@ataxia.org.uk. For more information and to take part, click here

September is Dystonia Awareness Month

Every September, Dystonia UK and the dystonia community come together to help raise awareness of the condiion - a neurological movement disorder thought to affect around 100,000 people in the UK. Each year, we celebrate with our fabulous festival vibe and host a variety of events across the UK from landmark light ups, webinars, podcasts, and picnics.

Unfortunately, little if anything, is known about e condition and many medical professionals have not heard of it. It is usually a lifelong condition, however in most cases it is not life limiting. It is the third most common movement disorder behind Parkinson's and Essential Tremor.

Dystonia can affect any region of the body, eyelids, face, jaw, vocal cords, neck, torso, limbs, hands, and feet. It presents differently depending on the region of the body affected, and each type has its own clinical name. Dystonia can affect people at different times in their lives. When it starts in adult life, it usually presents in one or two parts of the body, whilst if symptoms start in childhood, it tends to spread across multiple parts of the body and be more generalised.

Whilst currently there is no cure for dystonia, there are several treatments available that can help alleviate the symptoms. These are injections of Botulinum toxin, given every 3 months, medicines to relax the muscles, given as tablets, or surgery known as Deep Brain Stimulation. Support is valuable, and talking to someone who has Dystonia is a lifeline. **https://www.dystonia.org.uk/**

September webinar

'Deep Brain Stimulation (DBS) for Parkinson's: The next steps' is taking place on Wednesday September 24th at 5pm. Professor Tilo Kunath from Edinburgh University will be joined by an expert panel to discuss what DBS is, how the therapy works and interacts with the brain. The panel will also be considering whether DBS, especially adaptive DBS, could have a disease-modifying effect. Reserve your place here:

Deep Brain Stimulation (DBS) for Parkinson's: The next steps Registration, Wed 24 Sep 2025 at 17:00 | Eventbrite

Gig of a lifetime! On Saturday July 5th, fans descended on Villa Park in Birmingham for 'Back to the Beginning' – Black Sabbath's epic farewell concert. The event featured the original members of Black Sabbath , including Ozzy Osbourne, reunited for the first time in 20 years, to play in their hometown of Birmingham. For Ozzy, who had Parkinson's, the show marked his final performance on stage before his passing on July 22nd.

CEO of Cure Parkinsons, Helen Matthews, said 'All of us at **Cure Parkinson's** are thinking of Ozzy's family and friends. Since he sadly passed away, we have seen an increase in fundraising from fans wishing to celebrate his life. From tribute nights to dedicated jewellery and NFTs (Non-Fungible Tokens) – we have been taken aback by the generosity and creativity of everyone wishing to honour Ozzy's memory. Thank you!' Cure Parkinson's | UK charity working to end Parkinson's

Do you ever feel that your brain isn't coping with the unusually hot temperatures that we are frequently seeing?

It's not your imagination. As humans, we function best at between 20-26C and at humidities of between 20-80%. When we find ourselves outside our comfort zone, everyday activities can become more of a challenge. Our brains struggle to regulate temperature, and we notice the difference in our ability to function and think straight. This can be a particular challenge for people with epilepsy, not least because heatwaves can also disturb sleep patterns which in turn can mean seizure control deteriorates.

Which is why we need your help. Our researchers are carrying out a survey to collect information about the impact that adverse weather conditions, including heatwaves, are having on people with epilepsy. The survey takes just 10-15 minutes to complete but could provide vital information to help us improve safety for those with epilepsy as we face the challenges of climate change.

Fill in our survey: epilepsy and extreme weather events

3 Million Steps

No one chooses brain injury but with help, people can choose how to improve their new life. We understand that everyone is different and everyone's brain injury is different. That's what makes 3 Million Steps different. We help to provide the equipment and services needed by brain injury survivors and their carers, so they can concentrate on their recovery after discharge and once again live with dignity, self-worth and return to being a valued member of society & their families. **https://3millionsteps.org/**

Shaftesbury chef's passion wins award

If you're wondering what to have for dinner tonight, you're probably not alone. Many people with disabilities don't always get much choice in what they eat.

That's why Marie, chef at **Shaftesbury Brookside** works closely with the people we support to understand what they like and what they want. Her dedication has transformed mealtimes for residents and won her an award.

Deputy Manager Shukri said Marie's passion and commitment shone out from the start: 'Marie came to our residents' meetings and listened to what people wanted.' Shukri was so impressed by the huge difference Marie's approach had made to the people who live there, both in what she cooked and the dining experience itself, that she nominated Marie for a local council catering award – and she won!

Engaging patients to understand their experiences and expectations of rewards, recognition and remuneration for patient involvement.

This report presents the findings of a project commissioned by NHS England – East of England to support them in developing guidance for the reward, recognition and remuneration of patients who share their personal experiences to improve health and care services. **Download the report**

Based on these findings, the report makes five recommendations:

1. Ensure guidance on reward, recognition and remuneration is holistic
2. Prioritise inclusivity and accessibility in patient involvement to tackle health inequalities
3. Emphasise the creation of safe and empowering environments for patient feedback
4. Strengthen patient partnership in practice and champion its adaptation across systems
5. Simplify processes and minimise barriers to patient involvement

The report concludes that while fair reward, recognition, and remuneration is vital for meaningful patient engagement, they represent only one part of a broader approach that is needed. Any guidance must reflect a holistic perspective that values the intrinsic motivations of patients and diversifies participation with a particular focus on those from marginalised and underrepresented communities to drive genuine improvements in health and care services.

September is Alzheimer's Awareness Month

Join us in Mid-Essex this autumn at community groups for people with dementia and their carers. Get information, make friends and have fun! All events are free! For details ask at **essexgroups@alzheimers.org.uk Tel: 0333 150 3456**

Saturday September 20th 2025

Join us between 10am and 2pm for our special Alzheimer's day at the Museum as part of Alzheimer's Awareness Month. We will be joined by a range of local organisations that can provide information about support, health and groups you can join in the area. The event is free to attend & forms part of the Heritage Open Days free weekend. **Tel: 01245 605700**

Be First in Line for the New Volunteering Platform

Something big is coming! This autumn, we are launching a new digital volunteering platform to help connect people with flexible one-off and long-term volunteering opportunities. Be among the first involved & register today ahead of our autumn launch.

Virtual Village Hall volunteers – needed soon! Would you like to support health and wellbeing in your local communities? We'll soon be recruiting Online Community Engagement Volunteers to help raise awareness of the Virtual Village Hall and share its benefits. Full details on how to apply coming soon! **https://royalvoluntaryservice-online.org.uk/**

Par-Con 2025

Friday & Saturday October 24th & 25th
The Vox Conference Venue, Resort World, Birmingham B40 1PU

Find out more including the draft agenda and how to register on our website: **parkinsons.org.uk/get-involved/par-con**

Parky Charter: The Movers and Shakers are a group of public figures who all have Parkinson's and host a podcast about Parkinson's, 'Movers and Shakers'. They have published a charter, 'The Parky Charter', describing 5 things that people with Parkinson's need from the government but are not getting. Parkinson's UK, Cure Parkinson's and Spotlight YOPD support the principles of the Charter and are partnering with the Movers and Shakers to bring it to the attention of politicians. Their petition has now exceeded 100,000 signatures, so Parliament will consider debating it in the Commons.

Thank you to everyone who has been part of this achievement! However, a debate is not guaranteed, so we urge everyone to continue signing and sharing the petition to show the strength of support for the charter. The petition will be open until September, unless a debate is called before then. Please continue to sign and share the petition far and wide: **http://petition.parliament.uk/petitions/713714**

The summer edition of our newsletter contains lots of interesting information about services Parkinson's UK provides, plus local information which may interest other groups and people with neuro-conditions. **The latest from Parkinson's UK in Essex - essexneuronetwork@gmail.com - Gmail**

Groups at the Health, Well-being & Care Hub, University of Essex, Colchester

- **On-line Fatigue Management Group**

Are you living with a long-term condition? Do you feel fatigued after small tasks? We are running an online workshop for fatigue management which are led by healthcare students supported by an Occupational Therapist.

For details see: **Online Fatigue Management Group | University of Essex**

- **Living with Parkinson's**

A series of in-person weekly workshops aimed at those with a diagnosis of Parkinson's Disease, who are looking for education and support to live well. See: **Living well with Parkinsons | University of Essex**

Walk with us – we need you!

A research study to help us understand how the way we walk changes as we get older or live with Parkinson's? We need volunteers over 65 years old or with Parkinson's, who are able to walk comfortably (with no aids) and have had no leg injuries in the past year.
Enquiries please contact Mahbi Razavi on **sr23233@essex.ac.uk**

Inspiring stories from people with neurological conditions

Inspire Others is an innovative project between people living with neurological injury 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.

This website shares personal stories (words/pictures/video) of people doing what matters after injury. Inspiring others to do what matters to them after their injury. We hope to offer hope and a breath of fresh air. **Inspire Others – Inspiring stories from people with neurological conditions**

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

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