

Q3277Connexions

March 2026
Newsletter No.19



Essex
Neurology
Network



Hosted by the University of Essex

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



Happy Easter ... Be a good ENN EGG!

ENN is a successful and growing organisation,
but we need some help!

We are looking for people to join our Committee:

A Chairman to champion our vision and help shape our future

A Treasurer to help us raise some funds

Someone to keep an eye on Social media

Trustees and volunteers

We need enthusiastic people like you!

If you are willing to give up a small amount of your time each month to help promote our aims and to attend our on-line committee meetings, perhaps helping with an aspect of the committee's work, then please contact Rosie for more details:

Essexneuronetwork@gmail.com



Next ENN Open Meeting



A talk by Essex Respite and Care Association

We believe everyone deserves compassionate mental health support. Our services are designed to empower individuals facing mental health challenges, including dementia and brain injuries. Together, we can enhance your quality of life.

Thursday May 7th at 4pm by Zoom

[Book a place here](#)



Essex Respite and Care Association

Living with a neurological condition can be a challenge, but you do not have to face it alone. At ERCA, we believe that everyone deserves to live a fulfilling, supported life, no matter the challenge they face. If you, or someone you care for is living with a neurological condition such as

dementia, brain injury or stroke, neuro-diversity or other long-term neurological needs, ERCA can help.

We provide person-centred practical day-to-day support for adults with neurological conditions, helping them to build independence, confidence & a better quality of life, whilst providing vital respite for carers.

Whether you are navigating the effects of a neurological condition, or supporting someone else who is, ERCA's compassionate team is here to walk beside you every step of the way.

Call us today on 01245 353 855 or visit www.erca.org.uk to see how we can support you.

Join us at **Essex Neurology Network for the talk on May 7th**



The Health, Well-being and Care Hub

is a state-of-the-art facility is the University of Essex's Colchester Campus Parkside at the Knowledge Gateway research and technology park on the University of Essex's Colchester Campus.

Within the Hub we have a range of multidisciplinary spaces from meeting rooms, consultations rooms, a gym, a fitness room, and a seminar space. This purpose-built environment supports health services, wellbeing initiatives, research, & education, all under one roof.

Hub services are accessible to all. Referrals can be made either by an individual, their care giver, a social prescriber, a health, social care or education professional.

For further details see: [Our services | University of Essex](#)



The King's Fund Report on Public views of NHS

"Concerningly, analysis of the 2025 British Social Attitudes survey by The King's Fund and the Nuffield Trust finds that confidence in the future of NHS care has fallen to its lowest level, with fewer than one in six people believing standards will improve over the next five years. This lack of optimism really matters. The government's 10-Year Health Plan places a strong emphasis on patient power and partnership, but that ambition will be difficult to realise if patients do not feel confident that the system will meet their needs."

"Access remains a defining issue for patients. Difficulties getting a GP appointment, long waits in A&E, and ongoing problems with NHS dentistry continue to shape how people experience care. Too many patients still feel stuck: unable to get timely support or left waiting in uncertainty. Behind these statistics are real people trying to access care they need."

Rachel Power, Chief Executive of the Patients Association
[public_satisfaction_nhs_bsa2025_march2026.pdf](#)



The Daisy Garland

*'A journey of hope...
for children with epilepsy'*

Epilepsy Awareness Day

March 26th was Epilepsy Awareness Day, when millions of people across the globe came together to raise epilepsy awareness.

This year, to mark our 21st year as a charity, we're asking you to join forces with The Daisy Garland putting epilepsy in the spotlight helping raise lots of awareness about this much-misunderstood condition. We can't do this without your support! Please ask your friends, family, schools, clubs, pubs, shops and businesses to get on board and join our Purple Day Crusade! A mindfulness course available for families, professionals and other support agencies – next one due in the autumn.

Over 1,000 people die each year from SUDEP, most deaths happen in bed. Our Reducing the Risk of SUDEP (sudden unexpected death in epilepsy) Programme funds life-saving, night-time breathing (SATs/epilepsy) monitors for use in the home keeping children safe while they sleep. These monitors are not available on the NHS for home use. It costs £880 to fund a SATs monitor and £455 to fund an epilepsy monitor. If you'd like to help the next child on our waiting list, please get in touch.

[The Daisy Garland](#)



Department
of Health &
Social Care



NHS Rare Diseases Action Plan 2026

The fifth action plan shows how the Department of Health and Social Care and delivery partners are implementing the UK Rare Diseases Framework in England.

Rare conditions can affect different parts of the body and so patients may need to see many different doctors and nurses. It is important that doctors and nurses understand rare conditions so they can recognise the signs, make the right diagnosis, and work together to give the best care and treatment.

The 4 priorities of the framework are:

- helping patients get a final diagnosis faster
- increased awareness of rare diseases among healthcare professionals
- better co-ordination of care
- improved access to specialist care, treatment and drugs

These priorities have remained at the core of the England rare diseases action plans. They are supported by the following underpinning themes:

- inclusion of patient voice
- national and international collaboration
- pioneering research
- digital, data and technology
- wider policy alignment
- health equity

There are more than 7,000 rare conditions. That is a very large number for anyone to remember or learn about. No doctor can know everything about every rare condition. The NHS in England created an online library called GeNotes. This will help doctors and nurses and other people who work in healthcare to learn about rare conditions. GeNotes has grown and now contains clear and helpful information about more than 150 rare conditions. It is linked directly to every GP's computer system. This means family doctors can quickly look up trusted information about these rare conditions.

[England Rare Diseases Action Plan 2026 - GOV.UK](#)



Listening to patients, speaking up for change.

The King's Fund Report on Healthwatch

"...findings reinforce many of the concerns we raised at the government's decision to close Healthwatch England and its local network ... In particular, the report highlights the critical importance of independence, strong local relationships, and the ability to gather rich insight from diverse and often underrepresented communities; strengths that we have seen first-hand in our work alongside Healthwatch ... the voices of patients must remain at the heart of the journey towards a fairer, safer, and more responsive NHS."

Rachel Power, Chief Executive of the Patients Association

['The future of patient voice: learning from the Healthwatch model'](#)

Headway Suffolk's 11th Neuro Conference - May 20th 2026

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



Speakers include:

- Johnson Beharry VC , sharing his personal experience of brain injury sustained during the Iraq War
- Professor Roger Blake – Brain Stem Therapy for Parkinson's Disease
- Dr. Anirban Chowdhury – Advances in Stroke Treatment
- Chris Palmer – Former Headway Suffolk client and now Senior Social Worker

Special discounted price for Veterans £40 (includes lunch)

Tickets – £55.00, Information Stands £200, large banners £300, Poster presentation £100, Sponsorship opportunities are available.

For more information and to book your place please email:

helenmfairweather@headwaysuffolk.org.uk or Call: 01473 712225



EastEnders tackles epilepsy story

We all know about the stigma that surrounds epilepsy and why many people with epilepsy only share their condition with close friends and family. We do our best to increase awareness here at the Epilepsy Society, and sometimes the best way is via a soap opera! So, we would like to share with you that we have been working with the BBC's EastEnders research team these past few months on an epilepsy storyline featuring a young character, Davinder Gulati, known as Nugget.

EastEnders has such an amazing reputation for tackling issues that other programmes fear to discuss. The researchers were keen that the programme should be strictly accurate and kept us on our toes, asking lots of questions and making sure that, while there are lots of dramatic moments, they reflected the reality of living with epilepsy. The actor who plays Nugget, Juhaim Rasul Choudhury, was keen to ensure that he gave a truthful representation of the condition.

We hope that conversations about Nugget's story and the impact on his family will make it that bit easier for someone with epilepsy to tell their friends; and bring epilepsy out of the shadows. EastEnders reaches parts of our national conversation that others can't, and that means more openness and less stigma, and a better life for people with epilepsy.

We know it isn't always easy to talk about epilepsy, but we hope that the more visibility we can gain, the easier it will become. [Epilepsy Society | Transforming lives through advocacy, research and care](#)

P.S. EastEnders is also tackling the Menopause currently.



Down's Syndrome Research Foundation (DSRF UK)

The Response to the UK Government's Draft Statutory Guidance for the Down's Syndrome Act 2022.

Down's Syndrome
RESEARCH FOUNDATION UK

The DSRK commends the government's efforts to gather momentum with the Draft Statutory Guidance accompanying the Down Syndrome Act 2022, bringing us a step closer to Guidance that will fulfil the hopes of the DS community for this legislation. The recognition of the need for improved support across health, education, and social care represents an important step forward.

DSRF UK is the UK's only Down syndrome research charity, and was involved in the drafting of the Down Syndrome Act. As the consultation on the latest iteration of the Guidance comes to a close, we find it necessary to highlight areas where it currently does not match with the needs. We find that the current draft remains largely aspirational, and lacks the specificity, accountability, and clinical clarity required to meaningfully improve outcomes for people with Down syndrome.

If approached with focus and clarity, the Down Syndrome Act has high potential to act as a forerunner and exemplar of better policy and practices for people with similar needs ... We strongly recommend the approach of making the Down Syndrome Act focused primarily on the needs of people with Down syndrome: not to exclude others, but to pave the way for more robust processes to include every need.

[Down's Syndrome Research Foundation UK Response to the UK Government's Draft Statutory Guidance for the Down Syndrome Act 2022 | Down's Syndrome Research Foundation](#)

Down Syndrome and Sleep Research Network

The DSSRN (Down Syndrome and Sleep Research Network) held its first ever online meeting recently, bringing together researchers and practitioners focused on sleep and Down syndrome. A recording of the presentation is available [here](#).

The Network aims to accelerate sleep research by bringing the right experts together, acting as a catalyst for creating better resources and practices. One of our aims is to foster centres of excellence where people with Down syndrome have a real voice in the process of research.

Before we launch this pack, we need a panel of experts by experience who have Down syndrome, and also carers, to help us review the materials. We are looking for 10 participants to take part in this focus group, to review and discuss the material. Do you know anyone who would like to be involved? You can also bring someone to support you to this meeting.

[Request to Families in the Down Syndrome Community – get involved to help us improve sleep research resources](#)



British Acoustic Neuroma Association

BANA provides support and information for people affected by Acoustic Neuroma and the related conditions, symptoms and effects.

Our support services are based on community interaction, linking patients throughout the UK who might not otherwise have contact. Because of the rarity of Acoustic Neuroma, patients often feel a sense of isolation when diagnosed and find great support in communicating with others in a similar place, who understand the impact and challenges faced.

BANA's Vision is a world in which an Acoustic Neuroma is no longer a life-changing diagnosis and those affected have access to appropriate support by having opportunities to connect, share experiences, have access to up-to-date information and timely opportunities for support.

BANA has links with Treatment Centres and medical professionals across the UK who make up our Medical Advisory Panel. They kindly provide advisory assistance for the information we offer. Ensuring it is up-to-date and the most reliable from the UK perspective. Members of MAP will, if appropriate, answer questions from BANA members relating to their diagnosis.

Call Today: 01246 550011 or email admin@bana-uk.com

[About BANA - BANA UK | British Acoustic Neuroma Association](#)

A Million Acts of



A Million Acts of Hope: the untold story of Britain

A joint initiative to counter hate and division

A national campaign celebrating

the everyday acts of hope and kindness that truly define Britain

Watching the news or looking at your social media feed, it's easy to believe that the UK is more divided than ever. The voices of those who seek to spread hate, harm our communities & separate us are loud. But the reality is millions of people across the UK show up for each other, their neighbours and their communities every single day. From litter picking in parks to donating stuff to food banks, coaching our kids' football teams to working together to make our streets safer - acts of hope and kindness happen all the time.

These stories are too often left untold. So, in May 2026, community and faith groups, plus charities big and small, will come together to celebrate and inspire A Million Acts of Hope across Britain. From May 13th to 20th, A million Acts of Hope will amplify these stories locally and nationally, reaffirming shared civic values and creating space for positive, inclusive action. There is far more that connects us than divides us.

Civil society, including charities and voluntary groups like yours, sit at the forefront of our communities. Your work supports countless people. These everyday acts of kindness, volunteering and neighbourliness are at the heart of what Britain stands for, and we want to spotlight them against a backdrop of growing pessimism and division.

[A Million Acts of Hope](#) and info@millionactsofhope.org



Deep Brain Stimulation

Deep brain stimulation (DBS) is a revolutionary advancement in the treatment of movement disorders, such as Parkinson disease, essential tremor, and dystonia.

Its potential applications extend to a broad spectrum of neurological and psychiatric conditions.

Cureus Journal of Medical Sciences provides supports the publication and dissemination of research across various medical disciplines.

[Cureus Collection | Deep Brain Stimulation for Movement Disorders and Other Indications | Cureus](#)



Towards a Sociology of Neurology

Imbrications with the Sociologies of Ageing, Disability, Science and Mental Health

Tuesday May 5th 2026 9.30am – 3.30pm at the University of Essex

Despite medical and technological advances, neurological conditions remain the leading cause of illness and disability. This event should be of interest to colleagues working across health, social care, disability, mental health, ageing, STS, and related areas. There are bursaries available for students towards travel expenses.

If you would like to attend, email tara.mahfoud@essex.ac.uk indicating your interest by April 17th.

TIME FOR CHANGE SUMMIT 2026

MONDAY 9TH
NOVEMBER 2026

The Lowry, Pier 8,
The Quays, Salford,
M50 3AZ



UKABIF's primary role

is to raise awareness of acquired brain injury. To fulfil our objective we have a campaigning function. UKABIF provides the secretariat for the **All Party Parliamentary Group for Acquired Brain Injury** and steered the course to develop a report designed to drive change for brain injury survivors.

The UKABIF Summit promises to be a day to educate, enlighten and connect!

For further information contact: [UKABIF Summit 2024 - ited Kingdom Acquired Brain Injury Forum](#)



240 people wake up
to the impact of a
stroke every day.

Stroke Information Programme

for people affected by stroke who may benefit from one or more of the sessions.



Our full programme calendar is attached for you and your teams to share with stroke survivors, families, and carers. Programme details:

- Delivery: Online via Zoom
- Schedule: Every Wednesday for 7 weeks
- Time: 11:00am – 12:00pm

Participants can register by emailing strokeinformationeast@stroke.org.uk or by using this QR code.

Rail Delivery Group



Major rule change gets train users a third off rail tickets

More people will be able to buy a railcard for disabled train passengers from Sunday. Industry body the Rail Delivery Group (RDG) said the eligibility criteria of the Disabled Persons Railcard is being extended to

include a broader range of visible and non-visible disabilities.

Among the people who will become able to purchase it are those who have a Blue Badge, hold a disabled person's bus pass, are unable to drive on medical grounds or are unable to talk. About 390,000 of the railcards are currently in circulation. They cost £20 for one year or £54 for three years, and provide a 33% discount on train fares for the named card holder and an adult companion. This provides average annual savings of £126 per card.

For further details see:

<https://raildeliverygroup.com/our-services/putting-customers-first/accessibility-and-inclusion.html>



Hospital Visiting Rights – a review of Regulation 9A

The response from John's Campaign offers a balanced and powerful reflection of what the review of Regulation 9A of the Health and Social Care Act 2008 Regulations will mean in practice for patients in hospital and their loved ones. The response recognises the intent behind the work led by the Department of Health and Social Care, while also setting out clearly why many of the proposed measures risk falling short of the meaningful change, for which people have been waiting.

Review of Regulation 9A report: what it means for visiting rights

John's Campaign: It's Time for the Secretary of State to Take Action | John's Campaign

Meningitis

There has been much concern about the recent outbreak of meningitis in Kent. This particular strain was bacterial meningitis, which is more serious than either viral or fungal varieties. This form develops very rapidly and needs to be treated urgently with antibiotics. It is also prevented through vaccination. The infection can pass through the brain's natural barrier and infect the meninges and the cerebrospinal fluid (CSF), leading to a rise in inflammation and intracranial pressure around the brain. Most people with meningitis will make a full recovery, however it can cause hearing or vision loss, seizures, memory problems, balance and coordination problems; and in some rare cases, amputation of affected limbs or even death. (*Editor: I have personal experience of this devastating illness.*)

For more information see: [Meningitis Now](#) | [Meningitis charity](#) | [Research and awareness](#)



**Encephalitis
International**
The brain inflammation non-profit

Encephalitis International Conference
December 7th and 8th 2026
Location: Royal College of Physicians
(RCP), London, UK & virtual

The conference is dedicated exclusively to encephalitis (infectious and autoimmune) and covers

epidemiology, pathogenesis, diagnosis, treatment and rehabilitation in both children and adults.

There will be cutting-edge insights from global leaders in the field of brain inflammation covering hot topics, critical research questions, and approaches to the key clinical challenges informed by the latest research.

Professional Members of Encephalitis International - 20% discount on tickets with code ENCEPH26.

To become a Professional Member, please register here for free: www.encephalitis.info/professional-membership/ or use the code above and we will register you as a Professional Member.

Discounted student tickets available, please see our registration page for ticket criteria: www.encephalitis.info/encephalitis-2026-registration/ **Book your ticket by clicking [here!](#)**

The call for abstracts will open later in the Spring.

NICE

National Institute for
Health and Care Excellence

NICE Rare diseases quality standard(QS214)

Just before Rare Disease Day, NICE (National Institute for Health and Care Excellence) launched a new Quality

Standard for Rare Diseases. Quality Standards are designed to improve the quality of care and services delivered and commissioned by the NHS and other providers.

The Quality Standard for Rare Diseases is made up of eight statements that lay out what people with a Rare Disease (which includes all Inflammatory Neuropathies) should expect in terms of services. These cover things like referrals, diagnosis, information, and access to services. It also states that everyone should have a named healthcare professional who coordinates or leads on their care and support.

This is a great step forward in ensuring that people with a Rare Disease know what to expect in terms of care and support, and to what standard they should expect. It doesn't mean instant change and improvement but does give us something to build on and use to hold services to account. Inflammatory Neuropathies UK are delighted to see this standard in place and are happy to endorse and support it.

To find out more head to [Overview | Rare diseases | Quality standards | NICE](#)



From April 2026, National Voices – working with Innovation Unit and Collaborate CIC as the Voices for Health Equity Partnership – will lead the next phase of the Care Quality Commission's Public Engagement Network.

The Network brings together over 200 equality VCSE organisations across England, sharing insight from people experiencing health inequalities to help shape how services are assessed and improved.

In this next phase of the Network, we are determined to do things in a way that drives real change – turning insights into action, evidence into improvement and feedback into tangible changes that make a difference in people's lives.

And above all, we want this to feel personal, not abstract. Just as the gaps in care, the indignities, and the fears are real for communities experiencing health inequalities, they must be real for the staff and systems that make decisions about their care.

If you're a VCSE organisation working with people experiencing health inequalities and you're interested in registering to join the network, you can fill out an expression of interest form [here](#).



Department
of Health &
Social Care

Neighbourhood Health Framework

Most people and communities want to access health and care as close to home as possible, in a way that is most convenient for them and that gives them what they need when they need it.

Similarly, our staff want to support patients and service users without being constrained by organisational boundaries, and often echo the frustrations voiced in

their communities when the design and delivery of local services fall short of what the NHS could - and should - be delivering

Despite these 2 things being persistently true, for too long the NHS and wider health and care system has struggled to create the environment in which local services can work together, be co-ordinated, funded and delivered in a consistent way that enables what is often described as the 'left shift' to happen in an industrialised way while still meeting local needs and circumstances.

This government and ministerial team are determined to change that.

The Neighbourhood Health Framework framework is designed to support ICBs and local authorities, including health and wellbeing boards (HWBs) and their local voluntary, community and social enterprise organisations (VCSEs) and wider system partners to deliver the vision that the 10 Year Health Plan offers, the truly modern service that people, communities and staff are crying out for.

For more information: [Neighbourhood health framework - GOV.UK](#)

New NHS Essex

Essex Integrated Care Board

The Essex Joint Committee has been established as part of the transition towards creating a single Essex Integrated Care Board from Wednesday April 1st. The Committee is focused on transitional governance arrangements and preparing for the proposed establishment of a new ICB.

The development of a single ICB for Essex follows national policy direction. The change will simplify care commissioning and delivery across the county, enabling a sharper focus on prevention, early intervention, and reducing health inequalities.

Local healthcare leader Tom Abell has been appointed as Chief Executive Designate of the new Essex Integrated Care Board (ICB) cluster.

Members of the public are invited to observe the **Inaugural meeting of the NHS Essex Integrated Care Board on Wednesday April 1st from 10.10am o 10.45am**. This is the first formal meeting of the new organisation, where the Board will come together to set direction, confirm key arrangements, and begin its work to improve health and care services for people across Essex.

The first full meeting of the new ICB Board will be held on April 23rd.

True stories: A Note of Hope

Read Ellie Howes' story about her experiences with a devastating condition, the attitudes she had to endure and the glimmer of hope she had, from which she has developed her amazing project called a 'Note of Hope'.



"Ellie is doing such incredible work, making people feel heard when sometimes all they've been is ignored."

[More than a patient | The Patients Association](#)

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

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

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