

Connexions

March 2024
Bulletin No.3

Essex
Neurology
Network



Website: [Essex Neurology Network | University of Essex](https://www.essexneuronetwork.com) email: essexneuronetwork@gmail.com

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

New Health, Wellbeing and Care Hub at the University of Essex

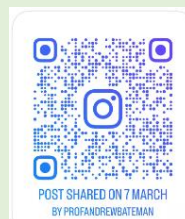
An exciting new state-of-the-art Hub is being created at the University of Essex's Colchester Campus, as part of their latest £10.7m phase of Parkside at the Knowledge Gateway research and technology park. It is being established with the support of NHS England and in collaboration with our regional NHS Integrated Care Boards, as a centre of excellence in health and care-related research and workforce development.



Clingoe House is the new building to be seen at the entrance to the University on Clingoe Hill, Colchester.

The ground floor of this new building is to be a new clinical facility open to the public, with staffing of qualified senior clinicians and students training at the University. There are plans well in place to offer a falls and frailty service, a neurorehab service and much more besides.

A virtual hub student placement has just finished. Five fabulous speech and language therapy students were the first to see inside, and, although there was



no furniture in place, they got into the spirit of the vision of the place and created a short video that can be seen by following this link https://instagram.com/p/C4N452YM76W/?utm_source=qr or QR code.

Among the exciting things we hope to be able to offer in the neurorehab service there, will be specialist splinting facilities, upper limb rehabilitation equipment, and augmented reality. The picture here shows Andrew reaching to touch a "virtual object" that appears to be in the room, as he looks through the HoloLens goggles (an image is projected into his eye!). This is an interesting way of motivating exercise or helping people by using visual cues to overcome various challenges - for example those living with Parkinson's will be familiar with the fact that it is easier to move toward something than through an open space.



The Hub opening on the March 21st is an invite-only affair but some of our network members will be there. (Do let Andrew know if you'd like an invite! a.bateman@essex.ac.uk) At our next ENN meeting Prof Andrew Bateman will share more updates about the work with training students and how the University is looking to contribute to neurorehabilitation services across Essex.

**Next Essex Neurology Open Network Meeting
an Introduction to the Health, Wellbeing and Care Hub
by Professor Andrew Bateman**

Thursday April 11th at 4pm at the University or via Zoom

**Join us to hear about this amazing new facility and how it will improve NHS services in Essex
Please contact essexneuronetwork@gmail.com for details of this event and/or the zoom link.**

The Brain & Spine Foundation is a national charity that supports anyone affected by any neurological condition, patients, family members, friends, carers and colleagues.

Our work is made up of 3 distinct areas:

- **Professional Neuro Services:** Free, expert help and support for any condition, and for anyone affected through our [Helpline](#), [peer support groups](#) and [health information](#).
- **Research:** We conduct social research in collaboration with The Neurological Alliance to influence change based on first-person insight into the reality of living with a neuro condition and trying to access treatment, care and support. We deliver results in real time. Find out more about our research project, [NeuroLifeNow](#).
- **Campaigning:** We build community & self-help structures through our campaign, [Neuro Changemakers](#).



A workshop hosted in February 2024 by Prof Majdzadeh and Ahang Kareem of the University of Essex, with expert facilitation from Speech and Language Therapy Lecturer Katie Chadd, provided an opportunity to look in detail at a **“Health System Performance Assessment”**

The meeting brought together representatives from ESNEFT stroke services, Healthwatch Essex, Tendring Specialist Stroke Service and Council representatives, along with academic staff and Masters students, to discuss inequalities in stroke service provision. Life after stroke is challenging enough but there are parts of our region where it is hard to access information and services and the research group are seeking to make a difference and help solve this problem.



There are more people in the UK living with a neurological condition than cancer, heart disease or diabetes. Change is needed urgently because the current system is under-funded, inadequately resourced, and fails individuals and families too often.

Report the challenges you face every day in accessing treatment, care and support. Your lived experience is shared with NHS commissioners, UK Governments and clinicians to influence how neurological services are delivered and to drive positive change.

A new survey can be found online every couple of months. Do take part if you are a patient or care for someone.

[NeuroLifeNow | Share Your Story - NeuroLifeNow](#)

‘ME/CFS Implications for Anaesthesia’.

The Royal College of Anaesthetists launched a new leaflet on ME/CFS at their 2024 conference. The ME Association and patients with ME/CFS have been working with the RCA to produce a patient information leaflet that has recently been launched by Professor Anton Krige and Dr Charles Shepherd: It is hoped this ongoing work with the College will raise awareness and understanding of ME/CFS among anaesthetists and help people with the condition when they need surgery in hospital.

Dr Shepherd is the Honorary Medical Adviser to the ME Association and has completely revised and brought up to date ‘The Purple Book’ - the comprehensive, evidence-based summary currently available, containing everything that health professionals and patients need to know about myalgic encephalomyelitis/chronic fatigue syndrome.



Heads Together is a National Institute for Health and Care Excellence funded research collaboration across universities in the UK, exploring brain injury social work education. The project is a collaboration led by Professor Andrew Bateman (University of Essex). Head Injury affects thousands of people in the UK. Heads Together aims to identify the knowledge and understanding social workers have of brain injury; ascertain the training currently available and develop a central resource point for social work practice around brain injury.

Brain Tumour Awareness Month

A month of activities to highlight one of the most dangerous forms of cancer. One in three people know someone affected by this devastating disease.



The month culminates with the return of one of the UK's most popular annual fundraisers on Friday March 31st **Wear A Hat Day** is back! Join in, look super for science and help research breakthroughs happen! Your support for Brain Tumour Awareness Month will help bring hope to brain tumour patients and their loved ones.



World Happiness Day: Wednesday March 20th

International Day of Happiness is a global event arranged by the United Nations annually. It serves to remind us that being happy is a

human right and worth celebrating — and if you're not already happy on this day, the celebrations may change that! Here's a day to cheer you up and appreciate the good things and silver linings in life.



NeuroPong Program

Dr Antonio Barbera, a keen ping pong player in the United States, was diagnosed with MS a few years ago, and has been running ping pong clinics for MS and Parkinson's patients ever since. 'Ping Pong has worked wonders for me and many others' he said. He believes that it could revolutionise treatment for these conditions, improving co-ordination and movement.



Carers and Personal Assistants

Barbara Carr, founder of **Care4Carers**, recently spoke to ENN members about the importance of supporting carers. She runs **Care4carers** - an online support community for both

professional and unpaid Carers in the UK. Carers are also invited to join **PA Place** - a private Facebook page for them. [Home | Care4Carers Club](#)

If you are interested in finding out more, please contact: Barbara@care4carersclub.co.uk

Hot off the Press!

For information about and for all carers - see our Carer's Pack coming soon on our webpage at: [Essex Neurology Network | University of Essex](#)

Stress Awareness Month has been held every April since 1992 to raise awareness of the causes and cures for our modern-day stress epidemic. It is the time when we have an opportunity for an open conversation on the impact of stress. Dedicated time to removing the guilt, shame, and stigma around mental health. To talk about stress, and its effects and open up about our mental and emotional state with friends, families, colleagues, and professionals.

Neuro-diversity Celebration Week March 18th - 24th 2024



Our purpose is to help the world to understand that when it comes to inclusion, neurodiversity refers to a world where neurological differences are recognised and respected as all other human variations.

<https://www.neurodiversityweek.com>



Huntington's Disease Association

provides support to individuals and families affected by Huntington's disease. Offering advice, education, and support to those affected by the disease,

they provide a helpline for anyone seeking advice and support, as well as running webinars and training sessions for professionals this month.

See <https://www.hda.org.uk>

University of Essex Cross-departmental Brown Bag Series

All are invited to our new Brown Bag Series for 2024



An informal opportunity to meet others interested in all aspects of neurorehab research.

21 March 9.30am - 4.00pm: [Mental health and Huntington's disease - A study day for professionals](#)

27 March 2.00pm - 3.30pm: [Overview of Huntington's disease for care staff](#) Contact: katie.chadd@essex.ac.uk

True stories

As a nurse, one has to deal with some pretty tough things and the days are long and exhausting. One evening, as I ended my shift, a seriously ill lady called me by my name. She held my hand and thanked me for everything I was doing for her! Those few kind words meant so much to me. It works both ways!



Claire Wright

If you have a story about how someone who went out of their way to do something special to help you, or someone with a neurological condition then please send it to:

essexneuronetwork@gmail.com

Short articles about your service or charity, or from people with neurological conditions, their families and carers, are welcome for inclusion in one of these *Connexions* bulletins.

