

# Sussex MND Care & Research Network News Autumn 2021

Sussex MND  
Care &  
Research  
Network

## MND Network grant

The MND Network is currently partially funded through a grant from the MND Association, which funds Rachel Thomson's role as Network Coordinator. We have secured another grant to run for three years from December 2021. We have a new set of objectives which focus on several key themes such as improving psychological support and access to research.

## Team changes

We are very sad to announce that Professor Nigel Leigh (right) is stepping back from clinical work at the end of September. Nigel set up the MND service in 2011 when he moved to Sussex having retired from King's. He was also the driving force behind establishing the MND Network. Luckily for us, he is continuing his involvement in clinical research, both through clinical trials at Royal Sussex County Hospital in Brighton and the evaluation of the MIROCALS study (see over). We wish Nigel best wishes for a long, happy (semi!) retirement.



Dr Andrew Barritt (left, with Rachel Thomson) has taken over as Director of the MND Network and MND service lead at University Hospitals Sussex NHS Foundation Trust. As well as being Honorary Senior Lecturer at Brighton and Sussex Medical School, he also somehow finds time for a spot of running!

We are delighted to welcome Hennie Sleeman to the community Specialist Practitioner team. Hennie is now in post covering the Horsham/Crawley/Mid Sussex areas.

## MND clinics

We continue to run the Motor movement disorder clinic at Hurstwood Park, Princess Royal Hospital. This clinic is mainly for second opinions where MND is suspected.

People often come to hear about local, national and international research and they may be offered the opportunity to participate in various studies where appropriate.

## Support for people with MND

We continue to run information sessions for people newly diagnosed with MND. These take place approximately every three months on Zoom. Please contact Becky Griffiths, area support coordinator for more details:

[becky.griffiths@mndassociation.org](mailto:becky.griffiths@mndassociation.org)

MND Association face to face support meetings are resuming. Please contact Becky Griffiths for details.

## Research news

Research is one of our core activities. Many people with MND/ALS rate research and participating in research as of high importance.

### Clinical research news

We hope to be able to open the MND-SMART study by the end of the year:

<https://mnd-smart.org/>

We are currently commencing recruitment to Meridian

<https://www.meridiantrial.com/>

Both the above are being run through the Clinical trials unit (CIRU) at Royal Sussex County Hospital, Brighton.

Results from the [MIROCALS](#) study are expected later this year.

The MND Register has moved to an opt out model, with data collected through routine clinical appointments. Online registration is no longer available.

The MND Specialist Practitioners in Brighton and West Sussex are also now participating in the project for Sussex Community NHS Foundation trust. You can find out more [here](#)



### Other local research:

**“Non-coding RNAs” as biomarkers in MND.** Led by Professor Majid Hafezparast and Professor Sarah Newbury.

**CordiALS study** is a small pilot study using newer forms of spinal cord MRI to understand mechanisms of disease in ALS/ MND. Led by Dr Andrew Barritt and Dr Samira Bouyacoub at Brighton and Sussex Medical School.

### Finding out about MND research

- You can find out about current research here: <https://www.mndassociation.org/research/get-involved-in-research/take-part-in-research/>
- The UK MND Clinical studies group is made up of leading MND researchers and representatives of MND care centres and networks. You can search here for research studies by locality: <https://www.mndcsg.org.uk/>
- ALS Untangled publishes systematic reviews of unlicensed or alternative treatments (US site) <https://www.alsuntangled.com/>
- Twitter is a really useful way of keeping up to date with research news. We like: @MNDResearch @ALSUntangled @kingsmnd

## Education for professionals

### 2021 Stephen Hawking RCN lecture

Palliative and end of life care in MND: What you need to know, and what you need to ask to deliver person centred care. 17/11/2021. Online. Free. Book [here](#)

### The South East MND Network study day

The network study day will take place on Tuesday 8 March 2022 at Holiday Inn Gatwick Airport. Topics to include: withdrawal of ventilation, supporting children and young people, research updates, psychological support.

Email [R.Thomson@bsms.ac.uk](mailto:R.Thomson@bsms.ac.uk) for more info.

### The MND Association Community of Practice

The MND Association Community of Practice is a peer-led forum for improving support and care. They run regular structured information and knowledge exchange events online.

Please sign up here to join: <https://www.mndassociation.org/professionals/community-of-practice/>