

# Sussex MND Care & Research Network News Autumn 2020

Sussex MND  
Care &  
Research  
Network

## Network team news

We welcomed a new member to the MND network team in August. Dr Andrew Barritt is newly appointed as a consultant neurologist at Brighton and Sussex University Hospitals (BSUH) NHS Foundation Trust, having worked as a neurology registrar in the Trust for eight years. He has a special interest in MND having recently completed his PhD at Brighton and Sussex Medical School.

Andrew's research used detailed forms of MRI scanning to better understand causes of nerve cell damage within the brain in patients with the disease. He plans to continue his imaging research including with spinal cord MRI. He will be working alongside Professor Leigh in the Hurstwood Park clinic and is a co-Director of the MND Network.



Unfortunately, Dr Basil Ridha has now left BSUH for pastures new. We are very grateful for his dedication to the MND Network and he will be greatly missed.

## MND network grant

The MND Network is partially funded through a four-year grant from the MND Association, which funds Rachel Thomson's role as Network Coordinator. The initial four-year grant ends on 30/11/2020. Due to uncertainty as a result of COVID, we haven't applied for a four-year grant renewal as we had originally planned. We have secured a one-year extension to the grant and will apply for a three-year grant in 2021.

## MND specialist practitioners

We are very fortunate to have a team of MND specialist practitioners covering most of the Sussex areas. They ensure that all people with MND in their area are getting the care they need. They regularly review each person, provide advice and support and refer on to other services as necessary. Unfortunately, there is currently no funding for a specialist post for High Weald, Lewes, Havens area. We are working on this with the NHS and MND Association colleagues. Specialist practitioner contact details can be found on our website here >

## MND clinics

We resumed face-to-face appointments at the specialist neurology clinic at Hurstwood Park, Princess Royal Hospital in June. Both Professor Leigh and Dr Barritt are seeing patients. There are several mitigations in place in order to make the clinic COVID secure. Unfortunately, we are required to run at reduced capacity in order to avoid crowded waiting rooms. This clinic is mainly

for second opinions where MND or other unusual neurological conditions are 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.

## MND Association regional staff

The MND Association restructured their regional teams earlier this year and we are working closely with our two new colleagues.

Becky Griffiths is the Area Support Coordinator for Sussex, and ensures that people affected by MND are able to access all the support they need. She manages the Association visitors and works closely with local branches and groups and with local Health and Social Care Professionals.

Becky is based in Brighton but covers the whole of the Sussex region. You can contact her on [becky.griffiths@mndassociation.org](mailto:becky.griffiths@mndassociation.org) or 01604 800611.



Rob Wallis is Service Development Manager covering London and the South East, including Sussex. His role is to improve and develop health and care services to ensure better outcomes for people living with and affected by MND.

## Research news

Research is one of our core activities. As you know, people with MND/ALS rate research and participating in research as of high importance. To date we have recruited 162 people with MND into the Register. This is a really important contribution and we are working with Professor Ammar Al-Chalabi and colleagues at King's to understand factors that lead to delays in diagnosis. People can also sign up online here >



### “Non-coding RNAs” as biomarkers in MND

Led by Professor Majid Hafezparast and Professor Sarah Newbury. We have identified a range of RNA (ribonucleic acid) molecules that help to distinguish MND from other conditions. This work is funded by the MND Association, The Dunhill Medical Trust, and MyName5Doddie Foundation. View a video from one of our researchers, Dr Greig Joilin here >

### MIROCALS ([www.mirocals.eu](http://www.mirocals.eu))

This international clinical trial and scientific study, funded through the European Union H2020 programme, managed to complete recruitment and to obtain almost all the blood and spinal fluid (CSF) samples just before COVID-19 struck. Our patient volunteers have been fantastic – each having had many blood samples and three lumbar punctures to allow unique studies on molecular markers of disease and (we hope) response to the trial agent, low dose interleukin-2 (ld IL-2). We are on course to complete the study in July 2021.

### New trials

We have offered to take part in the MND-SMART study but COVID-19 has halted the start of this, and we are not sure when we will be able to start recruitment. We are also discussing taking part in a new Pharma-led trial – details will be circulated.

## Education events

### South East MND network study day

Originally scheduled for March 2020, the study has been rescheduled to Tuesday 16 March 2021. Given the current situation with distancing and meeting restrictions, we are planning for this to be held as a virtual event. If you registered for the March 2020 event, you will receive further information from the MND Association very soon. Any queries regarding cancellation or bookings, please contact: [conference@mndassociation.org](mailto:conference@mndassociation.org)



### Virtual International ALS Symposium

The symposium will take place from 9-11 December 2020, with a vastly reduced registration fee. This is your chance to attend the largest ALS meeting in the world from the comfort of your home! Find out more here >

### End of life care in MND masterclass

Sussex masterclass planned for May 2021 – details coming soon. Find out more here >

### The Virtual Allied Professionals Forum

The forum, hosted by the International Alliance of ALS/MND Associations, will be spread over two days to accommodate time zones on 3 – 4 December 2020. Join international healthcare professionals who will share information on good practice to enable health and social care professionals from all parts of the world to provide the highest quality care possible for people with ALS/MND through education and application. The forum is targeted to healthcare professionals who specialise in ALS/MND. This event is highly recommended. Register here for £30 >

### Annual Stephen Hawking Foundation MND Lecture

This annual free lecture, organised by the MND Association and Royal College of Nursing (RCN), and sponsored by The Stephen Hawking Foundation, will focus on effective respiratory care in MND. It will explore the relevant NICE recommendations, consider how these can be applied and share examples of good practice. The event will be live-streamed on 25 November from 6.15pm to 9pm. It is suitable for all health and social care professionals and members of the public with an interest in MND. Register here >

If you are a health or social care professional, and you would like to stay informed about upcoming education events, you can sign up to MND Association education updates here >

If you have any questions about this newsletter, please contact Rachel Thomson.  
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