

Summer 2024 newsletter

MND Association invests £5 million

The MND Association is investing up to £5 million in developing a new network of MND Association Research Nurses across England, Wales and Northern Ireland, with the aim of giving everyone diagnosed with the disease opportunity to take part in vital research.

The charity has committed to a five year investment to build a first-of-its-kind co-ordinated network of MND Association Research Nurses. The first nurses will be in post by the end of 2024.

Currently, access to trials depends on a number of factors. This can include a person's proactivity in seeking opportunities, the knowledge their health and social care team has of research trials and where they live, as many clinical trials only take

place in a small number of locations. The MND Association Research Nurse Network will bring equitable access, with the opportunity to take part in clinical research and trials part of each person's holistic care.

The specialist nurses will help people with MND navigate the research trial process – providing information, identifying trials and research opportunities patients are eligible for, explaining what's involved, and supporting their ongoing involvement. Collaboration across the Network will support the sharing of outcomes, so successful research can be put into practice quickly.

WE ARE ONLINE!

Visit the East Sussex MND Association East Sussex branch website at www.mndaeastsussex.org.uk.

You can also find us on Facebook @MNDAEastSussex and Twitter @MNDAEastSussex



Therapy improves quality of life

A study funded by the MND Association and National Institute for Health and Care Research has found that a form of psychological therapy can significantly improve overall quality of life for people with MND when delivered alongside existing care. The COMMEND study into the impact of Acceptance and Commitment Therapy (ACT) was conducted by researchers at the University of Sheffield and University College London.

ACT is a form of psychological therapy that helps people to learn new ways of handling distressing thoughts and feelings. It also helps people to develop ways of taking part in activities that are important and meaningful to them.

Chris Bennett, our Head of Regional Services and Partnerships, said: "We know many people with MND seek help to cope with the psychological impact of the disease but often this isn't available or, if it is, not in a timely way. The COMMEND study shows psychological support can be effective in improving quality of life and that there is clear clinical benefit in Acceptance Commitment Therapy specifically. We are committed to taking forward these findings and

to investing in ACT training so this type of psychological support can be offered within the standard care package to all those who may benefit from it."

The results of the study have been highlighted in the media including on BBC Breakfast and in The Independent newspaper.

Thank you to all branches and groups who supported this study financially through our 2019 CEO appeal. Around £26,000 of funding was donated.

To find out more about the study, you can watch an Q&A session and interview with members of the COMMEND team and a participant called, Jennie, on the MND Association Research Blog. Visit the homepage at <https://mndresearch.blog>, then type 'COMMEND' into the search box at the top right of the screen.

We hope you find our quarterly newsletter interesting. It is costly to produce and we are grateful to members who receive this by email which helps save vital funds. If you receive a hard copy and would like to it emailed to you in future, please email Secretary, Sharon Bass, to let her know at sharonbass2023@gmail.com



Above: The retiring President of the Seafood and Peacehaven Canteenians presents a cheque for £2,700 to our Chair, Sharon Bass.

Thank you so much for such a wonderful donation to MND Association East Sussex Branch. We are extremely thankful for it.

Meet our new committee member, Morag

I am delighted to announce that we have a new member on our MND Association East Sussex Branch committee – Morag Hockin.

Morag's husband, Steven, sadly lost his fight with MND at the end of 2023.

Since he was diagnosed with MND, both Morag and Steven have organised many different fundraising events, which have generated a huge £40,000 for the MND Association!

Their business, Rapkyns Nursery (www.rapkynsnursery.co.uk) near Heathfield in East Sussex is now run by Morag with the support of some wonderful volunteers.

Her latest fundraising venture is "The Rapkyns Nursery Chelsea Flower Show (in a seed tray)!" which will take place during the week of the Chelsea Flower Show.

You may have seen on Facebook that Morag helped at the Rob Burrow Leeds Marathon. And she's now in training to run the marathon next year!

Well done, Morag and welcome onto the committee.



If you have any comments, stories or articles for our quarterly newsletter, please email them to newsletter editor, Ellie Seymour, at hello@wordsbyellieseymour.com

Thanks for reading!



www.mndassociation.org

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