

## **SOUTH HERTS BRANCH NEWSLETTER**

**AUGUST 2020**

### **CHAIR'S MESSAGE**

Another newsletter from us – we have been sending these out more frequently as we are keen to keep in touch with you during these unprecedented times.

I am delighted to report that we have another new committee member – they seem to be joining us thick and fast! Thanks to the efforts, again, of Carmen Brown, our Area Support Coordinator, I am delighted to welcome Samantha Arter to our committee. Sam has joined us as another Association Visitor supporting people living with MND in the South Herts area. Sam is a clinical dietician and professionally works with PwMND as well as patients with other illnesses so, I am sure, her expertise will be of great benefit to our PwMND. Welcome on board, Sam.

We continue to contact all PwMND living in our area to check on them and offer help and assistance. We have got to know many of these people quite well over the last few months.

If you are a PwMND or carer/family member who would like our support, please do not hesitate to call me and I will be very happy to arrange this for you.

### **FUNDRAISING**

Head Shave for MND – one of our relatively new members, Diana Colville, arranged a fundraising event to have her own head shaved in support of MND. Diana has raised just over £14000 to date – this is a magnificent achievement and we thank Diana from the bottom of our hearts. Diana has agreed that £3000 will come to the branch – the remaining £11,000+ will go to national office to help fund research into this terrible disease.



BEFORE

DURING

AFTER

We think you look magnificent, Diana! Thank you again for such a fantastic achievement.



The MND Association is on a mission, and we need you to join us. Together we want to cover 5,000 miles, that's a mile for every person living with MND in the UK today. Take part and run, walk, swim, cycle or even scoot however far you can.



## **Covid Advice and Help**



As I mentioned in my last newsletter, there is a lot of information and advice available on the main MND Association website which is updated regularly. Please click on the links below if you have any queries. If you are still not able to find the answers/advice you need, please let me know and I will forward your queries to the relevant people at National Office to get the information you need. It is very important we all remain cautious and follow the recommendations from the Association and government guidance for people in the extremely vulnerable group, whilst also respecting people's own decisions and choices.

<https://www.mndassociation.org/about-mnd/coronavirus-and-mnd/mnd-and-coronavirus/>

<https://www.mndassociation.org/app/uploads/2020/07/MND-face-mask-exempt-2020.pdf>

## **RESEARCH NEWS**

An exciting milestone in the search for effective therapies for MND was reached this month as early phase results of [tofersen for SOD1-ALS](#) were published, marking the beginning of genomic therapies for MND.

Although MND is a neurodegenerative disease, researchers are increasingly also interested in events happening outside the brain and spinal cord. We report on results from a pilot study of a therapy ([low dose IL-2](#)) that may slow disease progression by boosting a certain type of immune cells in MND.

### **Emerging gene-targeting therapies for SOD1-ALS**

Mutations in the SOD1 gene accounts for the second most common inherited form of MND and approximately 2% of all MND cases. Results published from the Phase 1/2 trial of Biogen's antisense oligonucleotide therapy for SOD1-ALS, **tofersen**, showed it was safe and generally well-tolerated over three months, and appeared to lower SOD1 protein levels in the central nervous system. Overall, the results support the continued investigation of tofersen to confirm safety and effectiveness in the ongoing Phase 3 trial [VALOR](#), currently recruiting SOD1 patients.

### **New insights on Riluzole's impact on survival**

Riluzole is the only drug to be licensed for the treatment of MND in the UK and approved for use by the NHS. It is not a cure for MND, but it is shown to have a modest impact on survival for people with MND. A recently published review based on 15 real-world evidence studies indicates that riluzole extends survival in MND patients more than what was previously shown in the drug's clinical trials (6 to 19 month increase in median survival).



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If you are a regular Amazon shopper, we would encourage you to convert to **Amazon smile** where a small amount of all purchases is made to a nominated charity. Please select Motor Neurone Disease as your nominated charity. To date Amazon Smile has donated over £6000 to the MND Association which is £2000 more than stated in my last newsletter in January which is fantastic Every penny counts!

## **IF YOU WOULD LIKE TO DONATE TO THE BRANCH –**

Please do so in one of the following ways:

Send **cheques** payable to MNDA South Herts Branch, to:

Ms Hetty Smith, 16 Percheron Road, Borehamwood, Herts. WD6 2SR

Donate online via our website at: <http://www.mndasouthherts.org>

Or email me at: [mndassoc.southherts@gmail.com](mailto:mndassoc.southherts@gmail.com) and I will provide you with the branch account details.

## **BRANCH CONTACT DETAILS**

| <b>NAME</b>    | <b>ROLE</b>                     | <b>EMAIL</b>   | <b>PHONE</b>  |
|----------------|---------------------------------|--|---------------|
| Hetty Smith    | Chair & Treasurer               | <a href="mailto:mndassoc.southherts@gmail.com">mndassoc.southherts@gmail.com</a>     | 0208 207 5086 |
| Lesley Ralston | AV and branch contact for PwMND | <a href="mailto:leshenhouse@gmail.com">leshenhouse@gmail.com</a>                     | 01923 778990  |
| Carmen Brown   | Area Support Coordinator        | <a href="mailto:carmen.brown@mndassociation.org">carmen.brown@mndassociation.org</a> | 01604 800659  |

**THE MND SOUTH HERTS WEBSITE** <http://www.mndasouthherts.org>

**SOUTH HERTS TWITTER ACCOUN** Username: @SouthHertsMNDA

## **THE MND CONNECT HELPLINE**

MND Connect Helpline offers advice, practical and emotional support and is able to direct people living with MND and their families/carers to many other services and agencies.

Tel. No: 0808 8026262

Email Address: [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

Office hours are: Monday - Friday 9.00 a.m. to 5.00pm. and 7.00 p.m. - 10.30 p.m.