

## **SOUTH HERTS BRANCH NEWSLETTER**

**MAY 2020**

### **CHAIR & VICE CHAIR MESSAGE**

Oh, my goodness – where to start! What a time we are all experiencing! For all of you with MND, not forgetting carers and families, we hope you have managed to sort your lives out to some sort of routine with deliveries of food and medicine in place.

We were asked right at the beginning of the Covid crisis, by the MNDA, to keep in touch with everyone we knew in the above criteria. We also have included those who we don't know but are known to the MNDA.

So several of us in South Herts Branch are keeping in touch regularly by phone & email with everyone who would like us to. If for some reason you read this and aren't in contact with us, please ring one of us immediately.

For ourselves, we can only say that something so negative has enabled us to get to know so many lovely people. Please know that you can phone us whenever you need or want to have a chat. We are here for you all.

I know this self isolation is torture for some of us. But we must get through it and keep strong and safe.

The best news of all is that no-one with MND in S Herts Branch area has caught Coronavirus.

Thank goodness nature decided to give us one extra special bonus after all that rain earlier. Sunshine really does lift the spirits. Even if you feel it is too hot, it's much nicer than gloomy old clouds and rain.

Looking forward to better times.

Lesley Ralston - Vice Chair & Branch Support Contact for people with MND

Hetty Smith. - Branch Chair.

Our contact details are:

Hetty Smith	Chair	0208207 5086
Lesley Ralston	Vice Chair	01923 778990

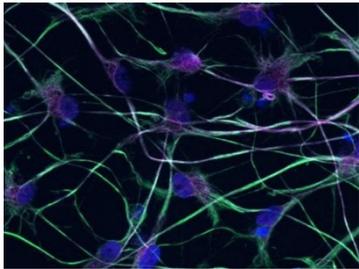


## CARERS WEEK

We also have carers week coming up on 8<sup>th</sup> to 14<sup>th</sup> June. Carers are often overlooked and can feel isolated, especially during these difficult times. Our volunteers are here to support not only PwMND but also their families and carers so if you are struggling and would like some support, please do get in touch. The MND Association are also looking into how they can support carers more, whether through accessing support, advice and information or highlighting the challenges that might make a difference to the carer experience, 'making caring visible'. If you are interested in sharing your story, giving feedback or knowing more, call Carmen Brown on 01604 800659 or email [carmen.brown@mndassociation.org.uk](mailto:carmen.brown@mndassociation.org.uk).



## RESEARCH NEWS



The MND Association supports many research projects, trying to find a cure for this terrible disease. Full details of all these are on the [MND Association Website](#). Some of the current projects being supported include:

A study being led by Role Professor Frances Platt at Oxford university which is looking into the unexplored link between MND and rare diseases called lysosomal storage diseases. Lysosomes are a part of the cell where larger molecules, no longer required, are broken down for 'recycling and disposal'. One type of molecule that the lysosomes break down are glycosphingo-lipids (GSLs). The team has recently found a link between GSLs and MND. This project will investigate the role of a specific GSL in MND, using patient blood samples, cell lines and post-

mortem tissues, as well as various samples from mouse models. The team will also test whether they can delay MND progression by targeting GSLs with therapies.

A study being led by Dr. Anny Devov at Kings College London. The aim of this study is to identify and investigate the earliest disease-specific changes that occur in MND in order to identify key cellular changes that contribute to the death of motor neurons. The project will take advantage of a new FUS mouse model of MND to investigate the interaction of mutant FUS with two important cellular structures – the endoplasmic reticulum and mitochondrion – which are essential for maintaining energy, and thus the health of cells, especially neurons.



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.

## MANAGEMENT COMMITTEE MEMBERS

NAME	ROLE	EMAIL	PHONE
Hetty Smith	Chair & Treasurer	<a href="mailto:mndassoc.southherts@gmail.com">mndassoc.southherts@gmail.com</a>	0208 207 5086
Lesley Ralston	Vice Chair – Support for PwMND	<a href="mailto:leshenhouse@gmail.com">leshenhouse@gmail.com</a>	01923 778990
Maggie Coles	Secretary	<a href="mailto:maggiecoles@talktalk.net">maggiecoles@talktalk.net</a>	01727 854583

## AREA SUPPORT COORDINATOR (ASC)

**CARMEN BROWN**

[carmen.brown@mndassociation.org](mailto:carmen.brown@mndassociation.org)

Tel: 01604 800659

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

## 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.