

SOUTH HERTS BRANCH NEWSLETTER

JULY 2020

CHAIR'S MESSAGE

Despite the new way of life we are all having to lead, we at South Herts have been very busy. We continue to call those living with MND on a regular basis to find out how you are doing or if you need any help from us. Some of the ways we have been able to help are arranging supermarket delivery slots, arranging grants for equipment and just being there to listen to any concerns you have. If you have not had a call from us and would like contact, please do not hesitate to let me know and I will arrange this for you.

Thanks to the efforts of Carmen Brown, our Area Support Coordinator, we have a new committee member. I am delighted to welcome Alice Eveleigh to our committee. Alice is a newly qualified secondary school teacher – it is great to have ‘young blood’ on our committee. Alice is very keen to help us with our fundraising efforts and as well as this, her strength is social media.

She will, therefore, be updating our website and raising awareness through Facebook, Twitter and Instagram. This has been a long held wish for the branch but we never had anyone onboard who was able to help us with this.

She has definitely moved quickly – within a few weeks of joining us she has set us up on Twitter.

Our Twitter log in is:

Username: @shertsmnda



We are very excited to have Alice with us and look forward to a long and great relationship with her.



Some weeks ago, during Volunteer Week in June, I was asked to submit a profile about myself which I was told may be used on social media, etc. As a result, a quote from my profile and photo was posted on Twitter

CARERS, COFFEE AND CHAT DROP-IN – via Zoom – 11th August from 2-3.00pm.

Are you currently looking after a loved one with MND? Support is especially important during these challenging times and we understand how important it is to also to care for you, the carer.

We are therefore piloting a '**Carers, Coffee and Chat 'virtual' drop in**, specifically for carers of people with MND across all of Hertfordshire. It would be great to welcome you for the full hour, but if you can just drop in for a small time, you're more than welcome. This will provide you the opportunity to come together with other carers, share useful tips or information, make friends and provide peer support to one another.

Please note this is a 'carers only' group. If you are a person with MND or a carer who would like to attend a virtual group together, please see the other virtual groups our South Herts Branch have on offer.

To join the carers group, please forward your name and email address to your local Branch or Area Support Coordinator. Alternatively, if are in contact with an Association Visitor, you can let them know and they will pass the information on to us. You will then be sent joining instructions for the Zoom meeting.

Carmen Brown, Area Support Coordinator
carmen.brown@mndassociation.org

Hetty Smith, Chair
mndassoc.southherts@gmail.com

FUNDRAISING

As I mentioned in my last newsletter, all events have had to be cancelled which has greatly reduced our income. However, our Covid 19 appeal was a great success raising just under £1000 for the branch. I am attending various funding surgeries on line to find out what funding streams we meet the criteria for and submitting online applications. Any ideas you may have for virtual events that you may be interested in to raise funds, would be very welcome – please let me know – perhaps we could hold a virtual quiz evening if enough people would be interested in joining.

One of our new PwMND is holding an event soon by way of shaving her own head. All the proceeds will go to National Office to fund research. Please visit her page on Just Giving to read her inspiring story on this link

<https://www.justgiving.com/fundraising/Diana-Colville>

RESEARCH NEWS

As you may have heard, due to the uncertainty and risk associated with the coronavirus pandemic, the Association made the difficult decision to cancel this year's international MND research conference in Montreal, Canada. However, the research development team at the Association have been busy putting together plans for a fantastic virtual symposium, to take place this December. Further details will be available soon via the research team's Twitter @mndresearch and website: <https://symposium.mndassociation.org/>.

Meanwhile labs are gradually opening again and whilst some researchers were furloughed in the UK, many others have been analysing data, writing up research papers, building up collaborations and planning new research. Research slowed but didn't stop, see the research team's blog for the latest research releases, including the first results from a SOD-1 gene therapy phase 1 trial published earlier this month: <https://mndresearch.blog/2020/07/13/emerging-gene-targeting-therapies-for-sod1-als/>.



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 and I will provide you with the branch account details.

BRANCH CONTACT DETAILS

NAME	ROLE	EMAIL	PHONE
Hetty Smith	Chair & Treasurer	mndassoc.southherts@gmail.com	0208 207 5086
Lesley Ralston	Vice Chair – Support for PwMND & Acting AV	leshenhouse@gmail.com	01923 778990
Carmen Brown	Area Support Coordinator	carmen.brown@mndassociation.org	01604 800659

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

TWITTER ACCOUNT Username: @shertsmnda

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

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