

SOUTH HERTS BRANCH NEWSLETTER

OCTOBER 2020

CHAIR'S MESSAGE

First and foremost, a huge 'Well Done' to our former Chair – Lesley Ralston, who has completed the Association Visitor training and is now a fully-fledged A.V. The training was quite long and intensive and we are all, at the Branch, very proud of your achievement, Lesley. We know it was not easy! Lesley already supports many PwMND in our area who I am sure will continue to be very grateful for all her efforts on their behalf.



I was honoured to be asked by National Office if I would be part of a virtual meeting alongside the Chair of the North Herts branch, Kent Allen, with a local MP to discuss the Scrap 6 months campaign. *Scrap 6 Months* was launched in June 2018 and calls on the Government to change the law so that people with MND and other terminal illnesses can access benefits quickly and with dignity. In July 2019, in response to the National Office campaign, the Department for Work and Pensions (DWP) announced a review of the welfare system to “make life easier for people with a terminal illness. One year

has passed and we are still waiting for the outcome of the review. Bin Afolami is MP for Hitchin and Harpenden and Parliamentary Private Secretary to the MP for Works and Pension who has responsibility for this campaign. We had a very good meeting with him, explaining in detail why this is so important and Bin assured us he would report back to the relevant department and come back to us. So far, we are very disappointed that no progress has been made. However, Kent & I will continue to pursue this with Bin Afolami. We would urge you to contact your local MP to highlight this campaign. If required, I can send you detailed information of what the Association is trying to achieve so you can pass this on to local MPs.

Even though fundraising has virtually had to stop completely, the requests for support do not stop coming in and we are able, with the help of National Office and the My Name's Doddie Foundation, to be able to meet these requests which is hugely important, especially during these difficult times. Jennifer Hay, one of our wonderful and long-serving committee members, has been researching eligibility for applications to various Trusts and I have been writing applications to them and other organisations which means we have the funds to continue to be able to meet these requests.

Carmen Brown, our Area Support Coordinator, has done it again. For the third newsletter in a row I am delighted to report that we have another new committee member. This time, I am thrilled to welcome Alisha Shah to our committee. Alisha has joined us as yet another Association Visitor (we now have three) supporting people living with MND in the South Herts area. She will also be helping Alice Eveleigh raise awareness on social media. Welcome on board, Sam.

'Checking In' calls to all PwMND living in our area to offer help and assistance continue on a regular basis and some wonderful connections have been made.

Please don't hesitate to contact us if you are a PwMND or carer/family member who would like our support.

Next week I am moving to Letchworth Garden City. Please note my new contact details at the end of this newsletter. Although South Herts branch does not cover this area, I will be continuing as Chair of our branch – I hope you think this is good news!

FUNDRAISING



TRIATHLON - On 4th October one of our newer members and his wife, David & Kim Davies had, in conjunction with a local gym, JJK Fitness in Kings Langley planned to hold a Triathlon which the branch was supporting. Unfortunately, as a result of the Rule of 6 brought in by the Government, this has had to be postponed and Joe, the gym owner, has set a new date for June 2021. Fingers crossed this can go ahead. Fundraising events have been an integral part of the JJK calendar for the last few years. Despite lockdown and a huge gym refurbishment, JJK have managed to run 3 big events generating over £14k for charity this year alone. We thank Joe for planning this event (under his Giving Back banner) and hope it can go ahead next year. This event has been arranged in support of David, who is living with Motor Neurone Disease. David has been a member of the gym for many years and they are supporting and working hard with David, ensuring he maintains his physical fitness.

SKY DIVE – Another consequence of the current situation is a Sky Dive that one of our new committee members, Alice Eveleigh, was going to undertake this month. She was doing this to raise funds in memory of her father who she lost to MND last year very soon after diagnosis. This was to be for both the South Herts branch and the South and West Somerset branches (her family live in Somerset.). As she is currently only allowed two people to come and support her, she now hopes to do this next year. Brave woman!

VIRTUAL QUIZ – On 6th December we are planning a Christmas Quiz on Zoom. This is being held in conjunction with the Mid Kent Branch. Elaine & Steve from that branch are very experienced and will be our quiz masters on the night. So, please join us and don your Christmas sweaters to make it a festive, fun event. We are asking for a minimum donation of £5 to take part. Please see the enclosed (attached) flyer.

WINTER APPEAL – Our annual Christmas Appeal has been renamed due to the current pandemic. We will be running it for longer than our usual Christmas Appeal to try and raise more funds than ever before to help us carry out our work for PwMND, their carers and families in our area. Look out for the appeal letter which will be sent out early December.

FUNDING REQUEST TO ST. ALBANS COMMUNITY GRANT FUND - As mentioned in our newsletter, we were waiting to hear the outcome of our application to this fund. Having met the criteria which included providing support for people to recover from impact of coronavirus measures, re-establish social networks, provide support to vulnerable communities and enabling local people to become involved in community life, we have been awarded £1577.00. This money has to be used to support PwMND in the St. Albans area, of which there are about 25 on our member's list. This allows us to use other monies raised to be awarded to PwMND in other areas covered by our branch, Thank you most sincerely to this fund for making this donation to us – we are extremely grateful.

MEETINGS

GET TOGETHERS FOR PEOPLE LIVING WITH MND – These continue to be held on Zoom on the first Wednesday of each month. They are hugely successful with more and more people joining us each time.

Future Get Together dates are: Nov 4th, Dec 2nd.



CARER'S MEETING – Carmen Brown, our Area Support Coordinator, initiated these meetings two months ago, specifically for carers and families of PwMND. They are held in conjunction with the North Herts branch and, again, are proving to be very popular with more and more people joining us each time they are held. Please see the flyer attached for details about how to join these meetings.

Item for Sale

As you know, the branch always supports any requests received for Riser/Recliner chairs. We have been informed of a chair for sale. If you know anyone who would like to buy this in return for a donation to the branch, please let me know. It is in excellent condition. Please note that neither the Association or Branch will take any responsibility for any defects/damage found.

Covid Advice and Help

Don't forget, as previously mentioned, the Association constantly updates it's website with the latest advice. Please see links below.

If you cannot find information you are looking for, please let me know and I will make enquiries for you.



<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 – Latest news from National Office:

Neuroprotective M102 progresses into clinical trials: M102, a potential new treatment for MND, is advancing to its first clinical study in people with MND through a partnership between researchers at the University of Sheffield Institute for Translational Neuroscience (SITraN) and Aclipse Therapeutics.

Phase 2 clinical trial planned for new gene therapy Engensis: A Phase 2 trial of Engensis, a potential gene therapy for treating MND, is planned in the USA. Engensis is a circular piece of DNA called a plasmid that carries instructions for hepatocyte growth factor (HGF) protein. HGF promotes the formation of new blood vessels, prevents muscle atrophy and participates in the growth and survival of nerve cells, potentially promoting nerve regeneration. Boosting HGF production might slow or stop disease progression. Phase 1 results showed a trend towards improvement in disease progression for 2-3 months after

treatment with Engensis, and it is hoped that these results will be replicated in the upcoming Phase 2 trial.



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 nearly £10,000 to the MND Association which is £4000 more than stated in my last newsletter in September which is fantastic Every penny counts towards Research projects run by National Office, especially during these difficult financial times.

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, 7 Farthing Drive, Letchworth Garden City, Herts., SG6 2TR

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	07930 462870
Lesley Ralston	AV and branch contact for PwMND	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>

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

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