



## **SOUTH HERTS BRANCH NEWSLETTER**

**JANUARY 2019**

### **CHAIR'S REPORT**

Since our last newsletter I have met some great people in my efforts to raise awareness and seek support for our branch. These include two local Rotary Clubs at which Lesley Ralston, Vice Chair, and I gave presentations about the work we do. One of these has raised £400 on our behalf from their Christmas event - please see below.

With Roger Widdecombe, Regional Fundraiser from National Office for our area, I have also met with local non profit making organisations, Jaspal's Voice and Emery Little - please see below for events being held by them in support of our branch (as well as other charities.)

Again I have been writing many letters and sending numerous emails to try and raise funds for our branch. Amongst these requests were letters sent to the six Deputy Mayors in our area in the hope that one may select us as their Charity of the Year for 2020 when they are elevated to the Mayoral office - as yet no news!

As mentioned in my last newsletter, Alison Murdoch has stepped down as Treasurer. On behalf of the committee I thank her for all her hard work in keeping us financially 'in order' over the last 10 years. Sian Goodwin has also resigned from the committee and we also thank her for all her support - she was our personal Quiz Supper organiser and we look forward to seeing her at this year's event.

We have a new member on our committee - Vivien Frey. Unfortunately she was unable to attend our committee meeting this month but will be joining us at our next one in March. Vivien is a very active fundraiser in her own right and we are looking forward to gaining from her experience on behalf of our branch.

I am planning to include an article each month about the extensive research that is taking place. You may have heard in the press of the different trials taking place and I feel it is important to make all our members aware of these developments which hopefully will lead to positive treatments for this terrible disease - although this will take some time yet.

If you would like to get in touch with me, my contact details are:

E-Mail: [mndassoc.southherts@gmail.com](mailto:mndassoc.southherts@gmail.com)  
Home Phone: 0208 207 5086  
Mobile: 07930 462870

## PAST EVENTS

### NORTH HERTS GALA - 3RD NOVEMBER 2019

Jenny Fellas, Association Visitor, and I - with 6 of her friends went along to this wonderful event organised by the North & East Herts branch when over £9000 was raised, split between the North Herts branch and National Office.

### ABBEY THEATRE EVENT

We were very sorry to have to cancel this event in October as we were, for the first time, unable to sell sufficient tickets. I would appreciate feedback from you as to why this event was not as popular as it has been in previous years. Was it the location or the production we chose? Please send me your feedback to [mndassoc.southherts@gmail.com](mailto:mndassoc.southherts@gmail.com) which will help us ensure we book an event in future that will suit more people.

### THE ANNEX - BERKHAMSTED

Daisy Hawkins, manager of the salon, held another fundraising event on our behalf in October which raised £202.00 for the branch. We are very grateful for all the support of Daisy and members of her team in supporting us. Without people like Daisy we would not be able to support PwMND in our area.

### CHRISTMAS APPEAL

Our Christmas Appeal raised the magnificent sum of £905.00 - we are very grateful to all those who supported the appeal, which in turn helps us to support people living with MND in our area.

## FUTURE EVENTS

### JASPAL'S VOICE



As mentioned, I visited this non profit making organisation whose mission is to supply communication tools to people living with MND and give them a 'voice' to communicate with their family and friends via a new app being developed initially for iPhone users in collaboration with National Office. Please see their website at [jaspalsvoice.co.uk](http://jaspalsvoice.co.uk) for information about the great work they are doing on behalf of the MND Association.

## **EMERY LITTLE - GOLF DAY AND TOUGH MUDDER**

Emery Little is a wealth management company based in Berkhamsted that I visited with Roger Widdecombe. The second generation of this company are celebrating their 21st anniversary. To mark this milestone they have created a project named 21 PROJECT. 21 Project is 21 months to celebrate their 21st anniversary. During this time all fundraising is targeted to support three major charities, one of which is the MND Association. Last summer a group of people took part in an expedition to Mount Kilimanjaro. We plan to support two future events - a Golf Day on 15th July in Berkhamsted (details to follow) and a Warrior Adrenaline Race being held on 25th April in Hertford. Full details are available on the WAR website at [warrioradrenalinerace.co.uk](http://warrioradrenalinerace.co.uk). This is a great family day out watching loved ones/friends/colleagues tackle an obstacle race. For anyone who signs up to take part and is associated directly with our branch, all proceeds would come to the branch. My son-in-law is entering a team of ten friends/family to tackle the 10 km course - we would love to see other families/groups there. For all those participating for our branch we will supply merchandise, e.g, t-shirts etc. Please pass this information to sons, daughters and friends - it would be great to have more teams competing for our branch.

## **QUIZ EVENING 2020**

We have booked the date for our annual Quiz Evening for 2020. This very well supported and highly enjoyable event will be held on 27th March 2020 so put the date in your diary. More information will be sent out nearer the time.

## **ROTARY CLUB ST. ALBANS CYCLE RIDE**

Each year the St. Albans Rotary Club support the St. Albans Charity Cycle Ride being held this year on 13th May. If you have family members who are keen cyclists, we would be delighted to see them there. Please visit the SACCR website at [sacccr.co.uk](http://sacccr.co.uk) for full details.

## **GET TOGETHERS FOR PEOPLE LIVING WITH MND**

Our monthly get togethers are usually held on the first Wednesday of each month, from 2.00 - 4.00pm and continue to be extremely well supported.

Jenny Fellas and Lesley Ralston, Vice Chair usually run these together and I know all the attendees are very happy to have somewhere to come where they feel safe and relaxed. They are held at The Box Moor Trust Centre, London Road, Hemel Hempstead, HP1 2RE. London Road, Hemel Hempstead, HP1 2RE.

Future Get Together dates are: Feb 2nd, Mar 4th, Apr 1st, May 6th, Jun 3rd, Jul 1st, Aug 5th, Sep 2nd, Oct 7th, Nov 4th, Dec 2nd.

If you require help with transport please arrange a taxi for both journeys. Make sure you get a receipt with the date, your name and the cost.

For further help with transport or any more information, please contact Jenny Fellas on 01582 621387 or [chris\\_jennyfellas@hotmail.com](mailto:chris_jennyfellas@hotmail.com)

## **NEW MND GENE IDENTIFIED**

Professor Ammar Al-Chalabi, Professor of Neurology and Complex Disease Genetics at King's College London tweeted about the discovery of a new MND gene – DNAJC7. The DNAJC7 protein helps other proteins to fold into the correct shape and helps to clear proteins that have been damaged. When this process goes wrong, proteins build up in nerve cells and they die. This discovery means we now understand a little bit more about what causes MND, and this gives us new ways to think about developing an effective treatment. It also opens up the possibility of a specific future therapy for people with this genetic change.

## **INTERNATIONALSYMPOSIUM**

Another International Symposium has drawn to a close  
It's all over! Another successful International Symposium on ALS/MND has now reached an end and what a fantastic 3-days it was! Bringing together the brightest minds in MND research and healthcare, nearly 1,000 delegates enjoyed 110 talks over 24 sessions, 22 plenary speakers, more than 420 posters and five fantastic awards.

At the end of the first day, everyone was encouraged to take part in a Global Walk to D'feet MND, wearing a t-shirt representing their countries ALS/MND association or institution, along Perth's picturesque Swan River to raise awareness of the disease. Following this, Cytokinetics invited participants to join them for an Australian BBQ to honour and recognise the contribution of advocacy groups worldwide. All Symposium news will be reported on our [Periodic Table of MND Research](#) so keep checking these via the MND Association website as they will continue to update them over the coming weeks.

## **2019 UK BIOBANK OF THE YEAR**

The MND Association has been awarded the prestigious accolade of 2019 UK Biobank of the Year. The award recognises their work to create and use the UK MND Collections, a bank of biological samples from people living with MND and controls, used by researchers to study MND. Kirsten Kelly, Research Projects and Partnerships Manager and Sarah Thompson, Research Co-Ordinator (~~Abstracts and Collections~~), from the Research Development Team at the Association, attended the event to receive the award. Heartfelt thanks go to all who provided samples without whom this resource would not exist.

## **FDA APPROVES DISSOLVABLE FORM RILUZOLE**

A dissolving film form of riluzole, called Exservan, has been approved by the US Food and Drug Administration (FDA). The film is placed onto the tongue where it dissolves and is absorbed into the body. Exservan is formulated to be taken without the need for water, making it particularly useful for people who are experiencing difficulties with swallowing. Aquestive Therapeutics, who developed Exservan, has granted a license to Zambon Pharma for the drug as a treatment for MND in the EU. Zambon will still need to obtain regulatory approval from the European Medicines Agency (EMA) before the Exservan can be prescribed in the EU. Hopefully this will then be picked up by the Medicines and Healthcare Products Regulatory Agency (MHRA) for approval in the UK.

## **MND REGISTER HITS THE 2,000 MARK!**

Over 2,000 people have now joined the MND Register of England, Wales and Northern Ireland. The MND Register is funded by the MND Association and is led by Prof Ammar Al-Chalabi at King's College London and Prof Kevin Talbot at University of Oxford. It aims to collect information about every person living with MND. This will help plan the care for people living with MND and tell researchers more about what might be causing the disease.

For more information, and to register, see the website at [www.mndregister.ac.uk](http://www.mndregister.ac.uk)

## **MY NAME'5 DODDIE FOUNDATION**

Did you see the inspiring documentary about Doddie Weir (the former Scottish rugby player suffering from MND) broadcast in December. His foundation raises a huge amount of money for the MND Association and has supported us locally in South Herts, providing funds for equipment for people living with MND. Please take a look at the charity website for information about the great work he and his team do on behalf of MND Association at: <https://www.myname5doddie.co.uk>

## **MND CONNECT**

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. Their contact details are:

Tel.No: 0808 8026262  
EMail Address: [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)  
Their office hours are: Monday - Friday 9.00 a.m. to 5.00pm. and 7.00 p.m. - 10.30 p.m.

## **AMAZON SMILE**



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 £4000 to the MND Association.  
Every penny counts!

## **THANKS TO THE NOKE**

We would like to thank the Mercure St Albans Noke Hotel who allow us to use their hotel for our meetings and provide very welcome refreshments.

**IF YOU WOULD LIKE TO DONATE TO THE BRANCH -**

Please do so in one of the following ways:

Send **cheques** payable to the MNDA South Herts Branch to:  
Ms Hetty Smith, 16 Percheron Road, Borehamwood, Herts., WD6 2SR

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

If you would like to pay by **bank transfer**, please contact me by email

Or donate **online** at: [mndasouthherts.org](http://mndasouthherts.org)  
and click on the Donate to the Branch link in the left hand menu

The National Office Helpline is 0808 8026262  
Motor Neurone Disease Association – Registered Charity No. 294354