motor neurone disease association

West Sussex North

December 2022

Swim for MNDA, and for Adrian

On the morning of Sunday 18th September, a group of friends gathered on a chilly Brighton beach with smiles on their faces and an air of expectancy. Something wonderful was going to happen. Sue Sheppard (from our Branch) and her friend Tessa Walder went along to help shake some buckets (along with other volunteers) on what was, in fact, a beautiful sunny morning if you weren't swimming!!

Supported by friends and family, 20 of them took to the water. They swam with determination and purpose, to show their support and love for their friend Adrian and his family who are going through the most difficult of times living with MND. They actually swam between the two piers in Brighton (a return trip of a mile)!

An hour or so later, it was done. Weeks of fundraising, planning, training and preparation in their wake, their efforts were not in vain. Together they raised more than their target of £12,500 (£13,601 and counting), which was sent to MNDA Head Office. An amazing amount of money to benefit others in the future.

The organiser of the event, Rick Fieldwick, said afterwards:

"The biggest most heartfelt thank you to all of the swimmers, the supporters, the donors, to Mat & Jo and the lifeguards from Brighton Seafront Office for keeping us safe and to the MNDA volunteers who came along to lend their support. Most of all, thank you to Adrian Henry for allowing us to complete this event in his name. We all send our love to you brother."

N.B. Adrian sadly passed away peacefully on 10 October, at home with his family beside him.

In this issue:

Interview with Dr Brian Dickie

Director of Research Development, MND Association

How did you get into the field of MND research and working for the Association?

I have a neuroscience research background - though I'd be dangerous if they let me loose in the lab these days! I was working on nerve cell death in Parkinson's Disease at Oxford University when the opportunity arose to join the MND Association, with the task of building up our research programme. When I joined, we were funding three studies. Now we fund well over 80 projects, from laboratory 'discovery' science, through to healthcare research and clinical drug trials.

How much research is being conducted into MND diagnosis and treatment right now?

The past two decades have seen an incredible increase in research activity around the world, with MND moving from a relative 'scientific backwater' to the forefront of research into neurodegenerative disease. Whilst the vast amount of new knowledge has not yet led to effective treatments, it has helped attract an unprecedented number of drug companies to turn their attention - and their investment - to developing new and effective drugs for MND.

How big a difference did the funds from the ice bucket challenge make to the research programme of the Association?

Our members wanted the majority of the funds raised through the Ice Bucket Challenge to be used to support research, so we used the money to support three large-scale research programmes. The first was to accelerate research into the role of genetics in MND, though a collaboration with the international Project MinE gene-hunting consortium (https://www.projectmine.com/) . This research has identified many new genes involved in MND, catalysed scientific research around the world and also uncovered new potential treatment targets.

The second was to create a Biobank, where people with MND would donate skin, blood, cerebrospinal fluid and other samples throughout the course of their disease. The AMBRoSIA Project (https://mndresearch.blog/2016/09/12/ambrosia-our-biggest-ever-research-project/), run through MND Care Centres in Oxford, London and Sheffield, has created a world-class resource for biomarker research, looking to develop tests that can be used to speed up diagnosis, predict disease progression and tell us more rapidly whether experimental drugs in trials are working.

The third was to provide additional support for a drug trial that was being planned. The MIROCALS trial of the drug Interleukin-2 received €6 million from the European Union, but it needed additional funding to build in more clinical research and sample analysis, making it the most comprehensive MND drug trial in the world (https://www.mndassociation.org/research/clinical-trials/mirocals/). It has been one of the most challenging and complex trials ever run in MND, exacerbated by both Brexit and COVID-19, but is nearing completion, with the headline results to be presented at our International Symposium in December 2022.

By what area of research, which is happening at the moment, are you personally most excited?

The results of the trial of the drug Tofersen are looking very encouraging. Although this treatment only targets a rare inherited form of the disease caused by the SOD1 gene, which accounts for 2%-3% of all cases, it does appear to be having a significant impact in slowing progression. If this drug is genuinely effective, it provides 'proof of principle' that motor neurons can be protected, which will be relevant for all forms of MND. Indeed, we are seeing several similar approaches now being taken for other rare inherited forms of MND, as well as the more common 'sporadic' MND.

What do you hope diagnosis and treatment for MND might look like in 10 years' time?

I believe early diagnosis is vital. As with cancer, treatments for MND will have the most impact if they can hit the disease early. I would hope that neurologists would have a diagnostic test for MND, but this needs to be accompanied by early and rapid GP referral, so we need to also raise awareness about MND with GPs.

Whilst I would definitely hope that there will be effective treatments for at least some forms of the disease, at the very least I would want to see everyone diagnosed with MND not only having the opportunity to take part in clinical trials, but also that potential therapies would be targeted to their specific form of MND. Once again, we can learn from cancer and their philosophy of *"A trial for every patient and a patient for every trial"*

During our wide-ranging interview with Dr Dickie, we raised two subjects - the potential link between rugby and MND, and the Biogen phase 3 clinical trial of Tofersen - that have recently featured on the MND Research Blog.

If you would like to dig a little deeper into either topic, check out the following blog posts - each is just a 6-minute read!

***Link between rugby and MND*:**

New research: Is there a link between rugby and MND? - MND Research Blog

***Tofersen trial*:**

https://mndresearch.blog/2022/06/10/valor-biogens-tofersen-trial-a-look-at-the-open-label-extension-data/

Going the extra mile(s) to raise funds for MNDA

On 23 April 2023, Kevin Comper will run the London Marathon, to raise funds for the MND Association. This will not be Kevin's first London Marathon, but it will be a special one; he has been inspired to run by his brother Martin, who was diagnosed with Motor Neurone Disease in June 2020, at the age of 39.

Martin was himself a keen runner, who ran the 2018 and 2019 London Marathons, which motivated Kevin to start running again. After Martin's diagnosis, he made it his mission to raise funds for the MNDA, to support those suffering from MND today, and those who will be diagnosed with the illness in the future.

Over to Kevin, to explain his motivation for running the marathon, in his own words:

"After Martin's diagnosis,we decided to run the virtual London marathon in October 2020 and Martin completed the last 7 miles with me. We received unbelievable support- it was both the most emotional but also the best marathon I have completed.

Martin remains an inspiration to me. Despite his diagnosis and the fact he can no longer walk, he still retains his brilliant personality.

I have decided to run the London marathon one last time, to support MNDA. It seems appropriate, as it was watching Martin complete the same marathon that inspired me to take up running. I know it will be a hugely emotional day, but I also know that Martin will be with me the whole way round."

To support Kevin, go to his JustGiving page: https://www.justgiving.com/fundraising/kevin-comper5

Donate via PayPal!

Raise funds for us, by simply using this link to donate via PayPal.

Branch Socials

We look forward to seeing you at our 2023 in-person Branch socials, at The Ark Community Centre, Turners Hill!

Next year's socials are scheduled to take place in April, July, October, December. We will let you know exact dates and times, once we have confirmed details with the Ark.

First carers' online meeting, 17 January 2023

Are you supporting someone with MND and would you welcome the opportunity to talk to others in a similar situation? If so, you may be interested in joining our first online carers' meeting, which we hope will become a regular event.

Groups will be small and the conversation informal. Support will come from talking to others who understand your situation.

Meetings will be run by our very own Beck Cedar, who many of you may know from her previous role within the MND Association.

See below for details of how to join:

Would you like to host a paint club night?

In September, we reported on a fundraiser hosted by Committee Member Sue Sheppard; a paint club night, held in her back garden.

On a beautiful July evening, 12 friends gathered to have a go at painting a canvas. Local Paint Club artist, John, gave step-by-step instructions, from the first brush stroke to the last, to help everyone create their own mini masterpiece.

Although most of the group last painted when they were still at school, it was a lovely relaxing and fun evening. They not only raised funds for MNDA, but also ended up with a beautiful pride of lions!

If anyone would like help to host a similar event, please contact Sue, at sue@mndwestsussexnorth.com.

Digging deep for our branch

Long-standing supporter Marilyn Emmett hosted the East Grinstead ploughing match, at Imberhorne Farm, on 3 September.

The match included horse-drawn ploughs, GPS-navigated tractors and every era in between!

Families donated £245 for tractor and trailer rides, and children's activities, whilst a dog show proved hugely popular.

Thank you, Marilyn, for flying the flag for MNDA.

Double the opportunity: seeking Branch Treasurer and Secretary!

In September, we announced that Treasurer Mike Abbott is stepping down, after many years as a dedicated volunteer to the Branch.

We are still seeking a new Treasurer, who would be responsible for Branch finances, by maintaining proper records and following the MNDA's accounting procedures. Total time commitment would be roughly 2 hours per week, plus attendance of Branch Committee meetings, via Zoom.

Full training and induction will be provided.

We announced at our December social that after 17 years of outstanding support, longstanding Branch Secretary Liz Carter will step down from her role, in April. This provides a second opportunity to volunteer with the West Sussex North Branch, to support local people with MND, or who are affected by MND.

If you know anyone who could take on either role, please share details with them, or ask them to contact Julie at julie@mndwestsussexnorth.com

Fundraising update

With all of the different fundraising platforms and options to now be able to donate to the Branch - whether that be through your usual online shopping, recycling or straight forward donations - we wanted to keep you updated and say thank you!

Easyfundraising: £273.14

Recycle for Good Causes: £40

Giving Lottery: £471.60

Just Giving: £380

Text2Donate: £25

Tri-Branch Brighton Walk, Sunday 28 May, 2023

A reminder that the Brighton walk has been rescheduled for Sunday 28 May, 2023. The seafront walk is a 4-mile trip from the Big Beach Café, Hove Lagoon, to Brighton's West Pier, and back again.

To sign up and to get your MNDA T-shirt, please contact Julie at julie@mndwestsussexnorth.com, or call her on 07709 425957.

National News

Greetings to our new CEO - and farewell to our outgoing CEO!

In November, it was announced that Tanya Curry will join the MND Association on 9 January 2023, as our new CEO, replacing Sally Light, who is stepping down after more than 10 years in the role.

Tanya has worked in the charity sector for more than 20 years and we wish her all the best in her new role. For more details of Tanya's appointment, see the following link: https://www.mndassociation.org/introducing-our-new-ceo/

We would also like to bid a fond farewell to Sally. If you would like to hear Sally reflecting on 10 years as CEO, that is the subject of the latest MND Matters Podcast:

https://anchor.fm/mndassociation/episodes/MND-Matters-Episode-22-Sally-Light---Reflecting-on-10-years-as-CEO.

Treasurer's list of monies received and spent

Thank you to everyone for their contributions. The below are the cleared funds received for the third quarter 2022.
(All information was the best available at time of going to press).

Money received

Money from activities

Fundraising - Giving Lottery	£26
Haywards Heath Swimming Club - Swimarathon	£337
Horsham Street Collection	£1,259
Ian Walder - Golf Challenge	£9,794
The Coot, Horsham - Live Music Showcase	£653
Pat Bendall - Sale of Cards	£35
Rick Fieldwick - Swim a Mile for MND	£30
Horsham Bowls Club - President's Day 2022	£312
Sale of Donated Items	£50
Sale of Goods - The Ark	£15
Easyfundraising	£42

Donations and gifts

Fred King	£264
Paul Meehan	£3,750

Donations and gifts in memoriam

In memoriam - Derek Dente	£209

Notes

The grand total for the Ian Walder Golf Challenge was £10,386. A small amount of this came to us in June and was reported last quarter.

Money spent

Financial support for members and carers

Wetroom Adaptation	£568
iPad	£500
Washer/Drier	£1,500

Other

South East Network Study Day	£60

Your West Sussex North Branch Committee

Chair: Julie Taghan

Vice Chair: Chris Sheridan

Secretary: Liz Carter

Treasurer: Mike Abbott

Newsletter Editor: Christian Goldsmith

Committee Members: Joan Moon & Sue Sheppard

Association Visitors:
Chris Sheridan
Mike Agius

Keep in touch...

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If you do not wish to receive further information please contact a member of the Committee.

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