motor neurone disease association

West Sussex North

December 2023

Going the Extra Mile

Sussex branches join Kevin Sinfield's fundraising marathon in Brighton

On Wednesday 6th December, rugby player Kevin Sinfield arrived in Brighton as part of his most recent fundraising challenge, a series of ultramarathons. The West Sussex North team were out in force along with the other Sussex Branches and many supporters of the MND Association. Kevin Sinfield arrived and greeted all of the people living with MND with their carers. The 100 invited people ran, wheeled or walked the "extra mile" along Hove Seafront to the i360.

The sun shone brightly on a great event. Our branch is so grateful to everyone who has supported us with their generous donations. At the time of going to print the Just Giving page total is at £2,625 plus Gift Aid. Our page is still open:

https://www.mndwestsussexnorth.com/fundraising-news/going-the-extra-mile-with-kevin-sinfield

In this issue:

Impressions from The Extra Mile, Brighton

Members of West Sussex North and other Sussex branches join Kevin Sinfield

Neil Billing (back), Dave Setters, Helen Setters, Sue Sheppard, Julie Taghan

Sue Sheppard, Julie Taghan, Ian Walder, Keith Walder

Julie Taghan, Liz Carter, Joan Moon, Christian Goldsmith

Fundraising success

Amateur photographer Sandra Blaskett raised £250 for the branch with the sale of her calendar of wildlife images. See more of her work on Instagram @sandy_bphotos

Save the Date: "A Fete Worse Than Death"

Murder Mystery Evening with The Goring Regional Occasional Players

"As the St. Cleve annual summer fete is in full swing, allegations of blackmail, embezzlement, cheating, amorous attentions and a multitude of other secrets emerge, culminating in the discovery of a body floating in a water feature in the walled garden in the grounds of the manor. Is this simply a swimming attempt gone horribly wrong or a sinister case of … murder! Come along and help us find out".

The date is 27 April 2024 at The Greenway Academy, Greenway, Horsham, RH12 2JS.

We will have more details on ticket prices nearer the time. Please contact Sue Sheppard via email: sue.sheppard@mndassociation.org

UK MND Research Institute launched!

A direct result of the successful *United to End MND* campaign, which attracted an additional £50m of Government funding over 5 years

Leading scientists, charities, health professionals, funding agencies, government officials and, of course, patients gathered at King's College, London, on November 3 to formally launch this virtual Institute, dedicated to targeted translational research to accelerate the arrival of new therapies to, first, slow the progression of MND and ultimately find a cure. See also https://www.mndassociation.org/media/latest-news/launch-uk-mnd-research-institute-accelerate-search-cure-mnd

The media was also present, as were well-known ambassadors for the MND Association and Doddie Foundation, Charlotte Hawkins, Kenny Logan and Phil Vickery.

The key thinking behind it is to bring the leading MND research brains in the country together to work on a collaborative plan, using the specialist expertise at the leading research centres at Universities in London, Oxford, Liverpool, Sheffield and Edinburgh. In turn, they are reaching out to other centres across the UK, meaning that over 20+ research teams are now involved. Please see video here: https://ukmndri.org/about-us/

The initial work started a year ago and is focused on developing the building blocks of the plan. This includes bringing together the gathering of bio samples from patients, improving the usability of the enormous amount of data on patients which is currently not available in one place and improving how the progression of MND can be measured.

All of this work will enable future trials to be more efficient as well as available to a greater number of patients. The most exciting development will be next year's launch of a programme called EXPERTS. This aims to screen drugs, new or already existing for other conditions, so that the most promising compounds can go to full trial on platforms such as MND Smart or TRICALS much more quickly. More information at: https://mndresearch.blog/2023/06/21/experts-als-a-new-drug-testing-platform-from-the-uk-mnd-research-institute/

The Institute is funded by the MND Association, MND Scotland, My Name5 Doddie Foundation, Lifearc and government agencies, the National Institute for Health Research (NIHR) and the Medical Research Council (MRC). The ambition of the charities is to match the Government funding over the next five years and the Institute also aims to attract international investment from the pharmaceutical and life sciences industries.

Professors Ammar Al Chalabi (King's College London) and Chris McDermott (University of Sheffield) are the joint heads of the Institute with all the other leading MND neuroscientists also deeply involved. There are also three patient representatives on the board, including David Setters and Lee Millard from the south-east. These two people living with MND initiated the original campaign. See https://academic.oup.com/brain/article/146/8/3103/7175272

You can find out more about the Institute and its work here: https://ukmndri.org/

If you can't find the answers you're looking for David is happy to receive any questions on the Institute via email at davidsetters@Hotmail.com

Professor Ammar Al Chalabi

Helen and Dave Setters with MNDA patron Charlotte Hawkins

Interview with Sophie Graham-Hyde

Complementary Therapy Co-ordinator / Therapist,

St Peter & St James Hospice

Can you tell us about your role at St Peter & St James Hospice?

My role at the hospice is to co-ordinate the Complementary Therapies Service, and to deliver treatments to both patients and carers. During Covid, the service shut down completely, so it has been a busy time building a new service that is available to people out in the community, in the Living Well Centre and at the Inpatient Unit. Since 2019, the hospice and the MNDA have been working together to facilitate the MNDA Complementary Therapy Service for people living with MND, and for their Carers. I have been delivering this service and continue to do so as part of my role at St Peter & St James.

Can you tell us a little more about what complementary therapy is, how it works and its benefits specifically to those with MND?

Complementary therapies can be beneficial and supportive, helping to manage symptoms, reduce stress and promote relaxation. The service offers massage, aromatherapy and reflexology sessions -all of which can be received alongside medical treatment. Massage offers a gentle rhythmic touch that can help to relieve tension and muscle stiffness. Reflexology is based on the principle that there are points on the feet and hands that correspond to areas on the body. Gentle massage and pressure techniques are used to help restore balance. Aromatherapy uses essential oils extracted from plants that can be combined with massage, reflexology or inhaled using an aroma stick.

All treatments can help to relax both mind and body. Complementary therapies may particularly benefit people living with MND, helping to ease muscular cramps, pain and tension, improving poor circulation and sleep as well as helping with stress and anxiety.

What do you enjoy most about your role?

It is all about the people for me! I enjoy meeting people and their families. Everyone has a story to tell! When people are living with life-limiting conditions, they deal with medical and care interventions daily. Complementary therapy offers them a different type of touch that they can enjoy, look forward to and be in control of. It is rewarding to see people relaxing and benefiting from treatments.

How did you get into working in complementary therapy?

I have always had an interest in Wellbeing. After enjoying an Indian head massage evening class, I decided to do my professional training to become a Complementary Therapist. Once I had completed my training, personal experience led me to volunteer at the hospice. I quickly came to realise how beneficial treatments are within palliative care and that this was the area that I would like to work in.

How can patients access your services?

People living with MND and their carers can access the service if they live within the hospice catchment area (there is a map and a list of catchment area postcodes on the hospice website: https://stpjhospice.org/our-care/refer-to-us/) Referral to the service can be made by an MND Specialist Nurse Practitioner, a hospice CNS, a physiotherapist or an Association Volunteer.

Can you tell us one thing about yourself which people may find surprising?

I'm not sure if this counts as surprising or just a bit more about me! Food is a passion of mine. In partnership with my mum, I spent 25 years running a vegetarian café in Lewes. It was a real family business, with all generations involved!

Final Branch Social of 2023

Sunday 3 December was our last branch social at The Ark in Turners Hill. We were entertained by the Bells of Hammerwood, who belong to East Grinstead u3a. The Bells are in a trust left for them by Mrs Mary Brown who wanted ringers to enjoy her bells and raise funds for charity. The group take no costs themselves.

£39.80 was raised for our branch on the day. Everyone had a great afternoon and enjoyed singing along to the carols.

Fundraising update

Easyfundraising: £347.48

Recycle for good causes: £40

Giving Lottery: £586.40

Just Giving: £680.00

Text2Donate: £25

As at 18 December 2023

New recent diagnosis online group

NEW

If you, or a loved one, have been recently diagnosed with MND, you are welcome to join our friendly online group. It is an opportunity to meet others in the same position, ask questions and find out about available support. These meetings are held monthly via Zoom on the 3rd Friday of the month at 2pm. For more information and joining details, please contact Lisa Burnard:

lisa.burnard@mndassociation.org

Join our next carers' support group online meeting

Hosted by Beck Cedar, Thursday 18 January, 7.30pm

Zoom Link

Meeting ID: 853 1333 6255

Passcode: 694816

Latest MND Matters Podcast

Don't forget to tune in to the podcast. The latest episode discusses Cultural challenges with MND. Click on the link to listen now!

THROUGH THE ROOF

People affected by MND have been disproportionately affected by the cost of living crisis. The MNDA's Through The Roof campaign is calling on the Government to urgently implement more targeted energy support, to protect people's energy bills from going through the roof.

To learn more about the campaign, including the MNDA's report on the experience of households affected by MND during the cost of living crisis, click on the following link: **Through the Roof**

Peer Support CHC Group

Anyone living with MND, who needs help navigating the process of obtaining Continuing Health Care (CHC) funding, or who is facing problems with an existing care package, is invited to join meetings of the MNDA's peer support group.

The group meets every six weeks, by Zoom. Upcoming dates are 8 January, 19 February and 1 April. For more information and joining details, please contact Anne Anderson:

anne.anderson@mndassociation.org

Tel: 01604 611893

Treasurer's list of monies received and spent

Thank you to everyone for their contributions. The below are the cleared funds received for the period October-November 2023.
(All information was the best available at time of going to press).

Money received

Money from activities

Fundraising - Giving Lottery	£18
Haywards Heath Arts Festival	£1,500
A. Fry - FBC Run 60 miles	£55
Nick Butcher - Great South Run	£809
Gift Aid	£97
Easy Fundraising	£34

Donations and gifts in memoriam

Donations - Cleethorpes & Grimsby	£847
Bequest in memoriam Kelvin Knowles	£33,933
Lottery prize donation—S. Spriggs	£25

Miscellaneous

Reimbursed grant	£430

Money spent

Financial support for members and carers

Adaptation Grant	£1,500
2 x Quality of Life Grant	£589
2 x Riser/Recliner Chair Grant	£1,260

Miscellaneous

CEO Appeal	£6,000

Expenses

Area Co-ordinator	£89

Your West Sussex North Branch Committee

Chair: Julie Taghan
Vice Chair: Chris Sheridan
Secretary: Christian Goldsmith

Treasurer: Keith Walder
Committee Members:
Joan Moon & Sue Sheppard

Association Visitors:
Chris Sheridan
Mike Agius

Keep in touch...

www.mndwestsussexnorth.com
westsussexnorth@mndassociation.org
@mndwestsussexnorth
@mndwestsussex

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

PUBLISHED BY: West Sussex North Branch of the MND Association. The views expressed in this newsletter are not necessarily those of the MND Association. If products and services are mentioned, these should not be taken as recommendations by the Association, who cannot be held responsible should any complaint arise. We would like to keep in contact with you about the important work we do.