July 2021 registered charity no. 294354 issue 54

fighting mnd together
mnda
motor neurone disease association

north wiltshire group newsletter

The Queen's Award for Voluntary Service

Welcome to the July issue of our Newsletter

As we carefully emerge from lockdown, this issue features some of the fundraising and awareness raising events, taking place in support of our work.

We thank the organisers of Tadpole Garden Allotments Open Day for inviting us to take part in this event and others later in the year.

You may have seen the TV coverage about the 'Spennylympics'. This is an Olympic themed opportunity that everyone can join to raise funds and awareness for MNDA and the work of the North Wiltshire Group in particular. Perhaps it will catch your imagination!

We can now accept donations by text:

We hope you enjoy reading our news, and however you are spending the summer, keep safe.

With very best wishes,

Alison Aviss
Group Chair

Fundraising & Awareness

Three cheers to Alison, Heather and Tash who completed the **3 ‘4’ 33 Challenge** to walk **3 miles a day for 33 days in May**, marking the North Wiltshire Group’s 33rd anniversary this year — despite the wet weather!

A *Just Giving* page was set up at https://www.justgiving.com/fundraising/northwiltshiregroup3433challenge and the fundraising target was smashed. The Challenge raised a fabulous **£2118.50**. Tremendous effort!

Alison: ‘When we planned the challenge, we imagined walking in warm, sunny days like last May. How wrong we were! It was a struggle to go out on the cold, wet and windy days but I knew we were all determined to do it. I’ve really enjoyed my time walking in the country lanes, seeing the crops and animals develop, and have definitely caught the walking bug! The morning walk sets me up for the day so I will definitely be continuing, but probably not so much on rainy days!’

Tash: ‘The challenge turned out to be quite a bit harder than I anticipated, especially with trying to fit it in around moving house (a self-move I might add!), decorating and all that comes with it, whilst still working most days. But it was still enjoyable, being able to really appreciate nature and our surroundings, and I spent the time thinking about what the cause is all about. We are totally humbled by the level of support that we have received both in generous donations and morale-boosting comments, so thank you all.’

Alison, Heather and Tash would like to thank everyone for the massive support and very generous donations they received. All of the money raised will be used to provide support grants to local families affected by MND.

Local support for local people

Raising awareness at Tadpole Garden Village

The North Wiltshire Group were privileged to be invited to attend the recent Tadpole Garden Allotments Open Day. Alison, Paul and Barbara were made very welcome by the team and given a prime spot at the entrance gates to set up our gazebo. Despite damp weather, there was a good turnout and many donations were dropped into our collection bucket.

The event was well organized, not only showing the benefits of having an allotment, but also offering an interesting range of produce for sale including plenty of rhubarb and some delicious cakes!

We are very grateful to the TGV team for supporting us and recognising the work that we do to support local people affected by MND. The next open day is on Sunday 8th August from 10am to 1pm at De Morgan Crescent, Tadpole Garden Village SN25 2PZ.

Bake It!

Sharon, Tom and Barbara held a very successful **Bake It!** for MND on 26th June.

Thanks to many generous donations of cakes, cookies and cash, an amazing £600.32 was raised to support local people affected by MND. Grateful thanks to all who supported the event.

Justin Tomlinson MP was unable join us on the day; however, Councillor Roger Smith represented him (pictured with Sharon and Barbara).

Ashley & Sean's 100 miles for MND

When their father was diagnosed with MND earlier this year, Ashley and Sean decided to act. Ashely said, "Our Dad has been amazing since his diagnosis, but the fact that there is no cure has left us feeling pretty helpless, so we wanted to try to do something positive. We have decided to raise money for the (National) MND Association, in the hope that with research a breakthrough could be made in the treatment of this terrible disease".

They decided to walk from the West Bromwich head office of Ashley's employer, GreenSquareAccord, to their home in Chippenham. Sean added, "We're excited to be taking on the huge personal challenge of more than 100 miles over the course of just 4 days! We are so grateful for any support, no matter how small".

The brothers smashed their fundraising target, with well over £3,000 at time of writing. "So we did it! 100 miles in 4 days (NEVER again!) and even home in plenty of time to watch the footy later! We knew it would be a challenge, but had no idea just how tough it would be. Our feet are covered in blisters and now we've sat down, I'm not sure we'll be able to get up again anytime soon! But so pleased to have raised so much money for the MNDA. Thank you all so much for your donations and support, we couldn't have finished without it!"

Denise Davies, Head of Community Fundraising at the MND Association, said: "Without the amazing support of people like Ashley and Sean, the MND Association simply would not be able to provide its vital support services, fund research to find a cure and campaign and raise awareness of MND. Together we are making a real difference for people affected by this devastating disease".

Its not too late to support Ashely and Sean on their walk. Visit their JustGiving page *https://www.justgiving.com/fundraising/ashley-quantick*

Spennylympics – your Olympic dream!

Charlotte and Stuart will be completing **every single Olympic event** during the 17 days of the Tokyo Olympics (23rd July-8th August) – that's **95 events** in total – raising awareness and funds for the MND Association. They have managed to recruit over 60 Olympians as ambassadors, including Tessa Sanderson CBE, Sally Gunnell OBE and Holly Bradshaw, who are helping raise awareness of their incredible challenge.

Spennylympics is named after Stuart's much-loved brother Spencer, known to all as Spenny, who sadly passed away in August 2011. Charlotte and Stuart have generously handed the Spennylympic torch to all Groups to fundraise through their own Olympic-themed events and raise money for their own funds.

You don't have to be an athlete to join in! For example, if you can knit perhaps you could make a 'long jumper' or if you are a quick knitter try 'triple jumpers' during the Olympics? See the ideas below or use your imagination to come up with your own (tenuously) Olympic-themed ideas. So why not get into the Olympic spirit this summer!

Please follow Charlotte and Stuart on their remarkable challenge too – they will need all the support we can give them to complete this momentous challenge!

Charlotte & Stuart talk about their challenge:
https://www.spennylympics.com/

Give to the North Wilts Group on our *JustGiving* page (see web site), or here is Charlotte & Stuart's fundraising page:
https://www.justgiving.com/fundraising/spennylympics

Try-athlon

Join Spennylympics and get sponsored for your own Try-athlon. Try anything new this summer. You don't have to take on any or all Olympic sports to make a difference

Long Jumper

Get your knitting needles out and knit a long jumper throughout the 17 days of the Olympics. sign up to the Triple Jump Challenge and knit three jumpers!!

Poll Voting

Sign up to be a campaigns volunteer this Olympic season and help us contact MP's to help improve the lives of people living with MND

BMX

"Baking to the MAX"

Be an athlete in the kitchen!! Bake cakes and sell them to raise money for local people facing MND

Surfing

Raise money while surfing the internet! Sign up to easy fundraising and Amazon Smile to become a gold medal surfer

Support

Helen's story

Helen has recently completed her training as an Association Visitor. She explains why she chose to volunteer.

Helen has a passion for helping people, and for some time has volunteered at Prospect Hospice where she still works as patient support at the In Patient Unit. But she wanted to do more!

As a Rugby League fan, she had often watched Rob Burrows when Leeds Rhinos played Bradford Bulls, so she was aware of his diagnosis and high profile campaigning. That was the trigger for her interest in MND – and proof of the importance of awareness raising.

The next step was to speak to Claire (MNDA Area Support Co-ordinator) and Alison (our Chair) about the AV role, and she found herself on the next 'virtual online' training course with about 20 new volunteers. They were a real mix of people – some in full time employment, others retired, whilst some were still at Uni – who all shared the same goal, to help others. The sessions were very good though quite intensive – every evening for 2½ hours – and covering lots of topics. Now Helen is just waiting to be paired with someone lwmnd.

She has found the MND North Wiltshire Group very welcoming and full of passion and support for all those with MND and for their families too. It is comforting for her to know that she will be supported whilst she finds her feet in her new and rather scary role, and that she can ask our two wonderful and experienced AVs (Alison and Anita) for support and advice. Helen is excited: 'I'm really looking forward to getting started on my journey as an AV'.

Carer Support Zoom sessions

The next Carer Support session will be on Wednesday 18th August at 7pm. Contact carersupport@mndnorthwiltshire.org.uk for more information.

Local support for local people

6 Months scrapped!

SCRAP6MONTHS

Earlier this month the Government finally pledged to make it easier for people with a terminal illness, including MND, to claim benefits using the Special Rules for Terminal Illness.

Sally Light (CEO of the MND Association) welcomed the announcement: "This is a victory for the hundreds of campaigners across the country who have worked tirelessly alongside the MND Association for three years, raising awareness of the flaws in the current system and urging the Government to change the rules."

"The six month rule has always been a barrier for people living with complex and unpredictable terminal illnesses such as MND. It remains the case that providing an accurate prognosis for someone living with MND is near impossible. On balance we believe that if the rules change as proposed the vast majority of people with MND should be able to access the Special Rules."

She also challenged the Government: "**Now the recommendations must be implemented quickly** to ensure no more people, already facing the most difficult time of their life, have to suffer the indignity of a long drawn out process to claim the support they not only desperately need but are entitled to."

MND Global Awareness Day, 21st June

Each year, MND Associations across the globe mark 21st June as a special day of recognition, acknowledging the impact that MND has on people around the world.

This date is selected for the special reason that it marks a solstice, seen by many as a turning point in the year the start of a new season of hope. MND Associations around the world undertake a range of activities to express their hope that this day will be another turning point in the search for the cause, treatment and cure of MND.

Did you notice that the Greenbridge Roundabout lights in Swindon were in the familiar colours of blue and orange this June? This was just one of many iconic structures around the country at were lit in the Association's colours to mark the day.

To get in touch call MND Connect:
0808 802 6262
or email the North Wiltshire Group:
info@mndnorthwiltshire.org.uk

Things to Know

Useful Contacts

N Wilts Group website
www.mndnorthwiltshire.org.uk

N Wilts Group contact
info@mndnorthwiltshire.org.uk
or phone MND Connect

Facebook http://www.facebook.com/MNDNorthWiltshire

Twitter @MNDNorthWilts

Letters will be forwarded from:
North Wiltshire Group, c/o MNDA,
PO Box 246, Northampton NN1 2PR

MND Connect 0808 802 6262

MNDA national website
www.mndassociation.org

MNDA Volunteering Team
01604 611681

MND Benefits Advice Service
0808 8010620

Prospect Hospice 01793 813355

Dorothy House 01225 722988

Support Meetings

In place of our regular Support Meetings at The Lawns Community Centre, Swindon, and at Seend Community Centre, which have had to be suspended until the present health crisis is over, we are hosting a 'virtual' Support Meeting on Zoom. Watch your emails for dates and passwords.

Meanwhile, you can still **contact your AVs at** *alisonaviss@mndnorthwiltshire.org.uk* and *anitacreamer@mndnorthwiltshire.org.uk*

Don't forget that you can still find information and advice at the numbers and addresses on the left.

For Carer Support meetings see the note in this issue.

We are thinking about you all and are here to support you.

Vacancies

The North Wiltshire Group has vacancies for volunteers, including:

- **Social Media Officer** to take responsibility for our Twitter and Facebook presence
- **Fundraiser** to encourage local organisations to raise funds in aid of the Group

If either of these might be you, email Alison for a chat at *alisonaviss@mndnorthwiltshire.org.uk*

MND Corona Virus Hub

For advice, FAQs and links to organisations providing up-to-date information visit
https://www.mndassociation.org/about-mnd/coronavirus-and-mnd

Contact the editor
The deadline for submission for the next issue of the newsletter will be **18th September 2021**. The editor would love to receive your news, comment and photos for inclusion: please email him on *info@mndnorthwiltshire.org.uk*
To **unsubscribe** from this newsletter email your name and 'unsubscribe' to *secretary@mndnorthwiltshire.org.uk*