



north wiltshire group

newsletter



The Queen's Award
for Voluntary Service

Welcome to the April issue of our Newsletter

All the hard work of isolating, lock downs and taking care are now paying dividends and we seem to be winning the Covid battle!

Most of us have had at least one vaccination and can now look forward to some brighter times ahead but we know that care will still be needed. So for the time being we are still doing most of our work remotely by Zoom and telephone. Support meetings, Carer Support Meetings and our Committee meetings remain safely on line. Working to strict safety guidelines, our Association Visitors (AVs) will shortly be able to recommence home visits so we hope for warm and sunny weather in order to meet in gardens!

We are delighted to now formally welcome Helen Box as an AV and having recently completed her training, introducing her to our local families.

This year our Group is 33 years old and to mark this we have introduced the **North Wiltshire 3 '4' 33 Challenge**. Three of us are walking 3 miles a day for 33 days from 29th April to 31st May. You can read more about this inside, and we would love it if you would share our *Just Giving* page link with family and friends and give us a wave if you see us walking!

Best wishes to you all and keep safe ,

Alison Ariss

Group Chair

Local support for local people

Fundraising & Awareness



mnda
motor neurone disease
association

3 '4' 33 Challenge

3 miles a day for 33 days raising money for
North Wiltshire MND Group's 33rd anniversary

Happy Birthday! The North Wiltshire Group is 33 years old this year! Alison, Heather and Natasha are marking this by completing a challenge, **walking 3 miles a day for 33 days** during May (we're guessing they will smash the 99 mile target!). Please join in wishing them every success and thanking them for their amazing support to the Group. If you would like to donate, a *Just Giving* page has been set up at <https://www.justgiving.com/fundraising/northwiltshiregroup3433challenge>

Len Johnrose's #IceFoot92 Challenge

Former professional footballer Len Johnrose was diagnosed with MND in 2017. Len played for Burnley, Swansea City, Blackburn Rovers, Bury, Preston North End and Hartlepool United, and is challenging his football family – all 92 clubs across the top four divisions in England and Wales as well as their fans – and also anyone else who's cool enough to take his **#IceFoot92 challenge**. Len hopes to raise £92,000 towards the MND Association's care and research work. A number of high profile players and celebrity supporters of the Association have pledged to be among the first to take the Challenge.

The Challenge is to put your feet in a bucket of ice water for 92 seconds – one second for each league club. **You** can take the Challenge. Just:

- ♦ **Film** yourself standing in a bucket of ice water for all or some of the 92 seconds
- ♦ **Donate** £10 during filming by texting MNDLEN to 70085 (NB texts cost £10 plus one standard message rate)
- ♦ **Nominate** some of your mates in your film to pass on the Challenge to them
- ♦ **Share** your film on your digital channels using **#IceFoot92** and tagging your nominees in too

Swindon Community Lottery

Don't forget, the **Swindon Community Lottery** is an easy way to raise regular funds for the North Wiltshire Group.

Players are able to choose which good cause they wish to support. So please do nominate the **Motor Neurone Disease Association North Wiltshire Group** as your designated good cause. It's simple to join; go to:

<https://www.swindonlottery.co.uk/support/motor-neurone-disease-association>



Update on AmazonSmile

In October 2020 we reported on Amazon's initiative which allows you to donate to the charity of your choice while shopping on line with them. In February AmazonSmile reported that over £15,900 has now been raised for the MND Association since the scheme began (and approaching £7.5 million for charities nationally).

AmazonSmile donates 0.5% of the net purchase price of your eligible AmazonSmile purchases at no cost to you. All you have to do is visit smile.amazon.co.uk and select the MND Association (the national Association not the North Wiltshire Group) as your preferred charity before you begin shopping. There is also a phone App. After that, every eligible purchase you make through AmazonSmile will result in a donation to the MND Association. Fab!

Petition: Increase Funding for Urgent Research into Devastating MND

Making a difference! Over 100,000 people have signed this important online petition. That is the magic number which means the Government must consider holding a debate in Parliament, which in turn will open up the public debate on this vital subject.

'We ask Government to significantly increase targeted research funding for motor neurone disease (MND). A new investment of £50m over 5 years could kickstart a pioneering MND Research Institute. This would lead to better, faster and more definitive research outcomes, and hope for those with MND.'

A lot of people subsequently emailed their MP and ask them to support the campaign. As a result the MND Association has now set up a meeting with the Minister. To follow progress go to the following page on the MND Association website:

<https://www.mndassociation.org/get-involved/campaigning/take-action/united-to-end-mnd/>

For Carers

We had a very interesting and informative Carer Support Zoom session in February, with Matthew Hollis from the MND Association giving an overview of **Communication Aids and Voice Banking**, and Richard Cave giving an update on the exciting **Euphonia Project**. Richard also demonstrated the use of a free app, **'Look to Speech'**, which uses the head and eyes to select phrases and letters for speech. We introduced **'Cuppa and Chat'** sessions in March, where we have no scheduled speaker, to allow carers to speak about any topic that they wish, and are now holding these bi-monthly, with a speaker at the Zoom session on the alternating months. The **Respiratory Support** session on 17th March proved very popular, with 15 carers attending to hear an excellent and detailed presentation from the wonderful Anita Sinclair, Neurology Respiratory Specialist in Wiltshire. The recording (speaker section only) was sent out for those unable to attend, and we will aim to do this for future presentations .

Upcoming sessions:

- 'Talking about End of Life' with Dr Emma Husbands – Weds 12th May, 7pm
- National Carers Week 'Coffee and Chat' – Weds 9th June, 7pm
- Speaker TBC – Weds 21st July, 7pm
- 'Cuppa and Chat' session – Weds 18th Aug, 7pm
- PEG feeding with Alice Williams and Ella Warsop – Weds 15th Sept, 7pm

For further information, or for 1:1 support, please **contact** our Carers' Champion, Tash Flintoft on carersupport@mndnorthwiltshire.org.uk or 07961 821097, who runs the sessions jointly with Liz Attwood from the MND Association Gloucs Branch, with support from Alex Millard, Bath & Bristol Group.

New Podcast — MND Matters

A new Podcast called **MND Matters** has been launched by the MND Association. It is designed to offer people living with and affected by MND access to information, informal advice and expertise.

This Podcast will continue to explore a wide range of subjects alongside people affected by MND. As well as being an extra information source for the MND community, **MND Matters** is also a new tool for raising awareness among the wider community.

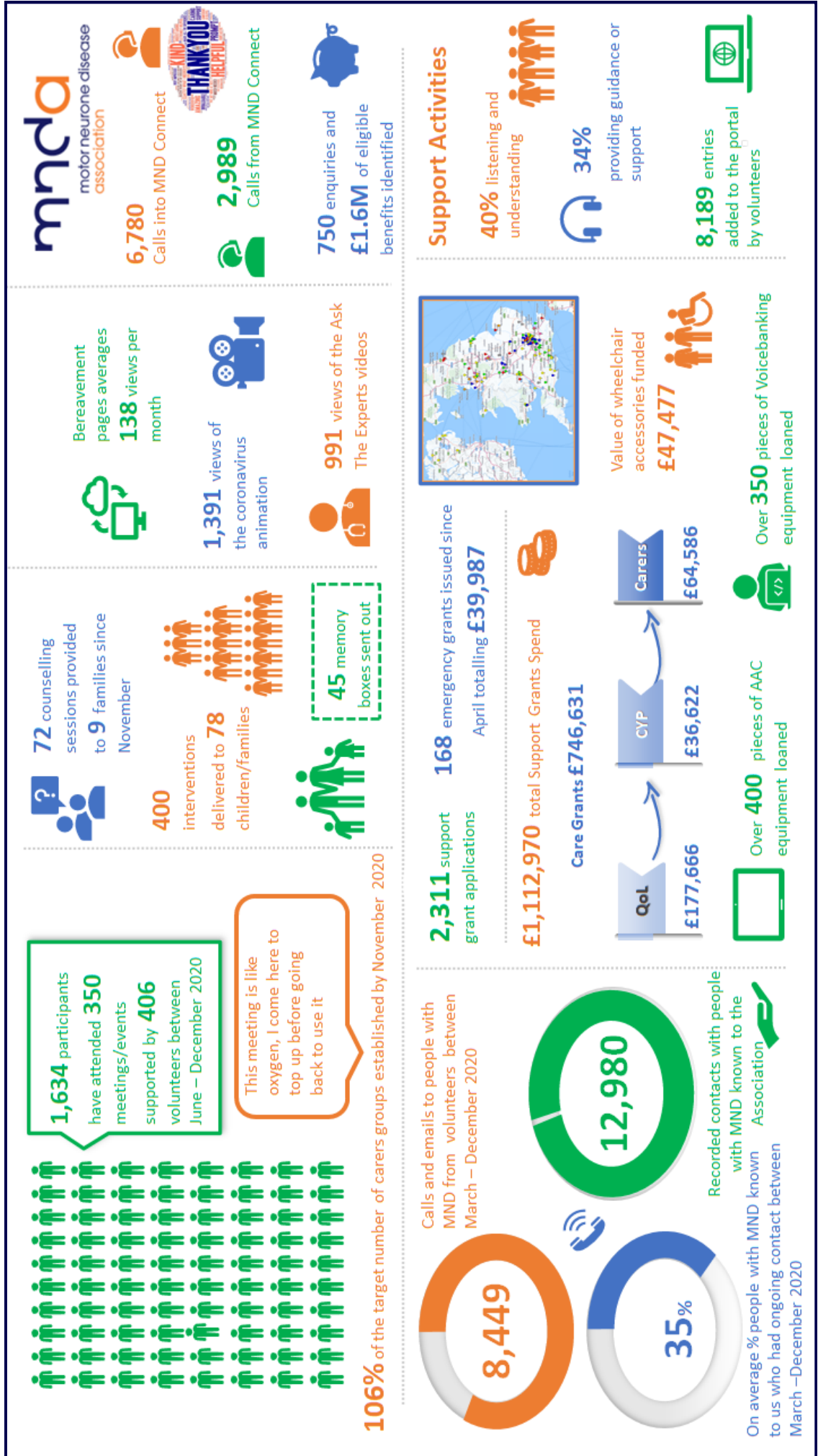
Listen to episodes of **MND Matters** using the link below. **MND Matters** is also available on Spotify, Apple Podcasts and other podcast providers.

https://www.mndassociation.org/media/mnd-matters/?dm_i=40VS,1A0YA,2S9FAE,4M2N8,1



The pandemic: how we helped

This graphic highlights some of the ways in which the **MND Association and its volunteer Branches and Groups** have responded to the pandemic to support plwMND. It has inspired imaginative ideas as well as time



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 article 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 **19th June 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