

South West Wales Branch

# Newsletter

## ROUND UP

Welcome to 2021 and the Spring Edition of our Branch Newsletter.....

Having been 'locked down' for many months now, we hope you are all keeping safe and well. During these testing times the branch has been able to continue fundraising and raising awareness, albeit virtually. Our primary aim continues to provide the support and care to the people who need it, and thanks to our many volunteers, AVs and carers we have managed to persevere.



Our monthly virtual branch committee meetings continue to be fruitful with many areas being discussed and planned including Campaigning, future fundraising events, and sharing ideas with the wider Welsh and National MND community.

Whilst our annual Christmas meet was postponed, we still harbour hopes that an afternoon tea or something similar can be arranged in the near future.

Over the last few months, local fundraisers have helped raise approx. £3500 via our branch JustGiving site ([www.justgiving.com/mnda-sww](http://www.justgiving.com/mnda-sww)), news of which can be found instead this newsletter.

We also welcome our new Patron, Scarlets rugby ace Phil Price (see page 4) and confirmation that long standing Patron Madeleine Moon continues to support and represent our branch.

As always, please do get in-touch if you would like to see your news featured in the next issue.

## News

We were delighted to receive a very generous donation of **£500** from Bridgend Rotary Club.

The donation was 'virtually' presented via a conference call in November, where Branch Member Justin Hostettler-Davies was invited to give a brief talk on the SWW Branch and how we support local communities.

We would like to thank all the members of Bridgend Rotary club for their generosity and we look forward to forging further relationships and working together in the future.

For more information on the club, please visit their website by clicking [here](#)



## Act to Adapt Campaign

We are looking for people living with MND and their families who are willing to share their experiences of applying for housing adaptations in Wales.

The Motor Neurone Disease Association has recently launched a brand new campaign called Act to Adapt. The campaign aims to highlight the challenges faced by people living with MND when applying for adaptations to their homes. This is a crucial time in Welsh Government as they prepare for the election in May and a real opportunity for the charity to push for reform in this area.

The charity would be keen to hear about any challenges or barriers you may have faced, as well as examples of good practice. If you like to share your story, please get in touch with us! For more information on Act to Adapt, please visit

<https://www.mndassociation.org/get-involved/campaigning/take-action/act-to-adapt/>



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## FUNDRAISING NEWS

### Virtually Fantastic.....

Lockdown and travel restrictions have not stopped our fantastic fundraisers. A number of challenges have been completed over recent months which have, not only raised a tremendous amount of awareness, but also raised over £4500 in much needed funds for our branch and the MND.....



### **PLEDGE 4 MND**

The concept behind Pledge4MND was a simple, yet very effective one – the participant simply pledge to walk/run/cycle/row as many miles as they could throughout January, whilst helping to raise awareness and sponsorship along the way.

### **PASS THE BATON 4 MND**



### **PLEDGE - DONATE - PASS IT ON**

Pass the Baton 4 MND – was a 40-hour challenge with over 100 participants. Started at 4am Sat 28th Nov and finished at 8pm Sun 29th. Each of the challengers pledged an hour, donated an entry fee, and then choose an exercise of their choice to complete for that hour (walk / run / cycle / swim / row / anything!) – when their hour was finished – they “passed the baton” on to the next person/people – a continuous 40 hr marathon of exercising MND warriors.....



The nationwide event that aimed to cover 5000 miles, that is a mile for every person living with MND in the UK today. Throughout September, many of our supporters and committee members walked, ran & cycled to help raise over £1,010 for the SWW MND community.

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## Our New Patron – Phil Price



As a branch, we are very proud to announce that we have a new patron!

Phil Price of Scarlets Rugby has accepted our offer of becoming a patron and we are delighted to have Phil on-board. As a branch, we feel that Phil will be an excellent ambassador and we look forward to a time where we can introduce him at our events. Phil has a personal story that has motivated him towards becoming our patron as he describes in his welcoming statement below:

"At 32 years old I currently live in Bridgend with my Fiancée Sian and my 3-year-old daughter Phoebe. Having been a professional rugby player for 13 years, I spent my first 9 years at Newport Gwent Dragons until I moved west to the Scarlets in 2018 where I still play; rugby has always been my big passion.

My family and I have been heavily involved in raising much-needed awareness and funds for MNDa over the years, especially for the South West Wales Branch. Back in February 2014, we lost our mother, Janet Price, to this horrible disease. We do not know what we would have done to look after her if it was not for all the support we had from the incredible team at the branch. My mum was my biggest supporter, not only did she take me to every training session growing up; she was always at the side of the pitch, cheering me on even when she was extremely unwell. Becoming a Patron for the Motor Neurone Disease Association, who helped my mother in such a difficult time, is such an honour and a privilege. It feels like my way of giving something back. I am looking forward to working with everyone and giving as much support as possible to increase awareness of this disease.

Thank you very much for your time, and I hope you and your families all stay safe in these strange and challenging times."

We are very grateful as a branch that Phil has agreed to represent us and are very much looking forward to working with him in the future.

In the meantime, we would like to wish Phil, and all at the Scarlets, the best of luck with the rest of their season.



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## Madeleine Moon



As well as the great news on the addition of Phil, our long-standing patron Mrs Madeleine Moon (left) has also confirmed her continued patronage, for which we are very grateful.

Mrs Moon comments "I first heard of the Motor Neuron Disease in 1979 when my mother in law Phyllis was diagnosed with the condition. My husband Steve and brother in law Mike both died of MND in 2015.

*In the House of Commons, I was chair of the All Party MND group and raised the effects of the disease in numerous debates. Now that I am no longer in the Commons, I hope to be able to continue the work through the MND Association and the South West Wales branch. I look forward to continue working with everyone"*

## Branch President

We are currently looking to appoint a new Branch President and are hopeful of a positive outcome in the near future.....



## Meet our Members -Jon Price

I first heard about Motor Neurone Disease in April 2009 when my mum sat us down and told us that she had been diagnosed with MND. At the time, I had no idea what the disease was and I was completely clueless about the devastating impact the disease would have on my family.

My mum fought an extremely brave fight against MND but sadly lost her battle in February 2014. I was hugely grateful for every day that I got to spend with her during this time and the Motor Neurone Disease Association was instrumental in helping us with the care and support that my mum desperately needed. As a result of this, I decided that I would dedicate my time to raising much needed awareness and funds for the Motor Neurone Disease Association so that, in the future, it may be possible that others will not have to go through what my mum had to face.



I have completed a number of fundraising activities over the past few years including the Cardiff Half Marathon, Llanelli Half Marathon and London Marathon. I have joined Justin on the Cycle4MND, Climb4MND, Kayak4MND and Stadium2Stadium4MND challenges as well as organising a series of endurance events at my local gym, CrossFit Pen-Y-Bont.

In October 2015, after completing the Climb4MND challenge, I started looking for additional ways that I could help people living with MND. Justin introduced me to the South West Wales Branch and I became a committee member shortly after. Here, alongside my partner Kelly, I take care of the branch's social media accounts.

## MND Care Centres and Networks

Since 1990, the MND Association has developed a number of MND Care Centres and Networks across the UK including the [South Wales Care Network](#) based out of Morriston Hospital, Swansea.

They improve the support and co-ordination of services for people living with MND. They also promote effective, integrated working between health, social, research and voluntary sectors.

They do not replace an individual's existing care team, but work in partnership with them to promote and develop effective service delivery.

If you are in any doubt about where you can receive care and support, your [MND Connect](#) will be able to help you.

## Resources for Carers

There is a range of updated resources for carers on our website here:

<https://www.mndassociation.org/support-and-information/for-carers/support-for-carers/>

This includes carer **wellbeing audio and video resources** led by two experienced practitioners (scroll down towards the bottom) – please do share these resources with carers you are in touch with, as we would really value feedback on these

There is a facility to add **support groups or events for carers** here:

<https://www.mndassociation.org/support-and-information/local-support/carers-groups-and-events/>

Please can you all use this to add any event or group which can be accessed by carers in your area and encourage branches & groups to do the same

There is a section specifically for **bereaved carers** here: <https://www.mndassociation.org/support-and-information/for-carers/bereavement-support/> and a **new forum thread: living with bereavement** alongside the existing **caring for someone with MND** thread here:

<https://forum.mndassociation.org/forum>

This has all been developed by the bereavement/end of life working group – please do share these resources as required.

## AGM Virtual Meeting

You are invited to our forthcoming Annual General Meeting, on **Sunday 25<sup>th</sup> April, 2pm – 3pm.**

Unfortunately due to the current pandemic & restrictions – the meeting will be held ‘virtually’ via Microsoft Teams (details below).

We would like to extend this invitation to you as a thank you for your support of the SWW Branch of the MND Association over the past year. Your generosity and dedication is vital to us in our fight against this disease.

We do hope that you will be able to join us. We would be delighted to ‘see you, albeit virtually and can assure you of a very warm welcome.

[Click here to join the meeting](#)

**or call in** [+44 1656 508728](tel:+441656508728), [947851693#](tel:+441656508728) Phone Conference ID: 947 851 693#



### Participants wanted for research study

We are conducting a study into changes in thinking and language in Motor Neurone Disease (MND) and require **people with MND and healthy controls.**  
(LREC 18/LO/1257)



#### What does the study involve?

We will give you a series of computerised questionnaires and puzzle-like tests. The tasks will take about 2 hours in total and can be divided into shorter sessions. You will be given generous breaks between tasks.

All study participation will take place through video call apps so you can take part **from home.**

You will receive a thank you **£30** gift card for taking part

#### Who can apply as a participant with MND?

If you:

- Have Motor Neurone Disease
- Are between the ages of 18 and 75
- Have English as your native language;

Then you may be suitable for this study

#### Who can apply as a healthy control?

If you:

- Are between the ages of 18 and 75
- Have English as your native language
- Are not receiving treatment for any life-limiting illness (e.g. cancer) or neurodegenerative disease (e.g. Alzheimer's disease, Parkinson's Disease) or neurological disorder (e.g. stroke);

Then you may be suitable for this study

Please contact Lyndsay Didcote if you would like to take part or to request more information:

Email: [lyndsay.didcote@kcl.ac.uk](mailto:lyndsay.didcote@kcl.ac.uk)  
Phone: **07543 342211**

Or sign up here:

<https://forms.gle/5BmEK8eZBKnMQcmz7>



## FINANCIAL STUFF

Income and Expenditure to 31st December 2020			
Income		Expenditure	
	Year to Date		Year to Date
General Donations	2285.67	Financial Support	5303.60
In Memorium Donations	7385.00	Equipment	2741.62
Tribute Funds	1699.50	AV expenses	297.65
Corporate Donations	5.00	Carer Support	580.00
Grants	5000.00	Payments to DNH	11136.50
Other	500.00		
<b>Total Donations Received</b>	<b>16875.17</b>		
Fundraising – Branch	5031.62		
Fundraising – Others	11011.77	<b>Total Care Expenditure</b>	<b>20059.37</b>
<b>Total Fundraising Income</b>	<b>16043.39</b>	Meeting Costs	539.00
Bank Interest	73.73	Printing, Postage & Stationery	494.15
Gift Aid	325.01	IT Costs	253.59
Other	181.20	Information & Education	215.00
<b>Total Other Income</b>	<b>579.94</b>	Other	157.95
<b>Total Income</b>	<b>33498.50</b>	<b>Total Branch Admin Costs</b>	<b>1659.69</b>
<b>Net Income</b>	<b>6699.54</b>	<b>Total Expenditure</b>	<b>26798.96</b>

Allocation of funds this year have included:-

16 Heating grants - £150 each

3 support Grants – 1 ceiling track hoist -£550, 1 towards a wet-room - £1000, 1 for a riser recliner chair -£500

2 Carer's Grants – various items to support Carers

## DIARY DATES

Before lockdown, we held coffee mornings/afternoons open to anyone with MND, their families and carers. Now, we are holding these virtually and calling them **Virtual Cuppa and Chat** so we can all get together using Zoom or other remote meeting methods. As with the actual coffee mornings, these are extremely informal and will enable you to meet others in a relaxed and friendly way to chat and share experiences. Regrettably, you will have to make your own coffee or tea! It would be lovely to see you and you will be most welcome.

If you wish to speak to someone to find out more or if you have any questions, please do get in touch with either Maimie Davis, [maimiedavis@maimiedavis.plus.com](mailto:maimiedavis@maimiedavis.plus.com), Tel: 01554 777993; 07908 040413 or Carol Smith, [carol.smith@mndassociation.org](mailto:carol.smith@mndassociation.org), Tel: 01604 800615

If you would like to join us, we will need your e-mail address so that we can send you the invitation link and of course, you need to have a computer, iPad or mobile phone to access the link.

Dates for the next event: **Friday 19<sup>th</sup> Mar 11am – Midday**

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## GET IN TOUCH

As always, please do contact the committee if you have any news or events you would like to see featured in the newsletter and promoted through our social media channels.

<https://www.facebook.com/MotorNeuroneDiseaseAssociationSouthWestWales/>



Twitter: - @SWWalesMND

Do not forget, this newsletter is also available by email by contacting us or on our website at [www.mnda-southwestwales.org](http://www.mnda-southwestwales.org).

## Useful Contacts

MND Connect offers support, information and advice to people living with MND, health and social care professionals, staff and volunteers.

**mndconnect**  
0808 8026262  
[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

The South Wales MND Care Network is a network of healthcare professionals providing specialist care and support across South Wales. The South West Wales office covers our area and can be reached on: 01792 703705 or by email [abm.southwestwalesmnd@wales.nhs.uk](mailto:abm.southwestwalesmnd@wales.nhs.uk)

## Branch Contacts

Chairperson	Janet Fisher	(07484 822120)	<a href="mailto:jan@mnda-southwestwales.org.uk">jan@mnda-southwestwales.org.uk</a>
Branch Contact	Lesley Frost	(01792 865571)	<a href="mailto:lesley@mnda-southwestwales.org.uk">lesley@mnda-southwestwales.org.uk</a>
Treasurer	Maimie Davis		<a href="mailto:treasurer@mnda-southwestwales.org.uk">treasurer@mnda-southwestwales.org.uk</a>
Committee member	Mike Cottle		<a href="mailto:michaeldcottle@live.co.uk">michaeldcottle@live.co.uk</a>
Newsletter / Website	Justin H-Davies		<a href="mailto:jdnspis@hotmail.com">jdnspis@hotmail.com</a>
Social Media	Jon Price / Kelly Phipps		<a href="mailto:Jon.price86@live.com">Jon.price86@live.com</a>

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South West Wales Branch  
**Newsletter**

This newsletter was published by the South West Wales branch of the MND Association. If you no longer wish to receive information from us, please contact [jdnpis@hotmail.com](mailto:jdnpis@hotmail.com) or a member of the committee listed.

The views expressed (in this newsletter) are not necessarily those of the MND Association. The products and services mentioned or promoted should not be taken as recommendations by the Association, who cannot be held responsible should any complaint arise.

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