

South West Wales Branch

# Newsletter

Welcome to the Summer edition of our Branch Newsletter.....

This edition is slightly later than planned but full of news!! One of our busiest years to date, there have also been lots of changes, both for our branch and for the MND community.

As a branch, we were deeply saddened to learn of the death of our patron Rob Burrow CBE. Rob's fight against MND has inspired us all. We will be forever grateful to Rob for all he has done for MND and the fight against it.

Perhaps a reflection of what he inspired in others, this year we have seen a vast increase in the number of events happening all over South West Wales. With just as great a focus being on spreading awareness of MND as on fundraising.

Chair, Jan Fisher quotes *"It has been my pleasure and privilege to meet a number of people over the past couple of months, who have chosen our branch to support and donate funds to. I have used this opportunity to speak about our work and how their much-needed donations support those living with MND in South West Wales."*

*It is always a privilege to be invited to meet with the communities who raise money and awareness for our branch and MND as a whole"*

We encourage you to let us know if have an event going on, we are happy to share your endeavours with our MND community .

Our primary aim continues to be the provision of support and care to the people who need it in the South West Wales Area. We are your Branch. We are here to help you.

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## Who are we & what do we do?

We are the South West Wales Branch and cover a huge area: Bridgend, Neath Port Talbot, Swansea, Carmarthenshire, Pembrokeshire, Cardiganshire and parts of Ceredigion up to Aberystwyth.



Latest branch committee news :-

In November 2023, we officially welcomed Sian Price to our team. Sian has been a volunteer with the Branch for many years, taking photographs and video footage at lots of our events. She has taken on the role of Webmaster and will be keeping our MND information website and our new Branch website up to date.

In January 2024, our Treasurer Maimie Davis decided to step down from the role that she has held for many years. We are extremely grateful to her for keeping us on track over the years and the time and dedication she has given to this role. However, we are very happy to say that she is remaining as an integral part of our team with her vast knowledge of the Branch.

We were also very pleased to welcome Janice Hayter, Association Visitor for the Bridgend area, to our committee in January. Janice has stepped into the Treasurer role and we are delighted to have her on board. (see pg. 5)

We are also extending a very warm welcome to Paul Mason, who joined our committee in August. He is starting his training to become an Association Visitor in September. We wish him all the luck and look forward to working with him.

Finally, our partnership with our Patron Lee Trundle has ended and he is no longer affiliated with our Branch, we wish him well with his future endeavours.

Whilst our committee has grown this year, we are always looking for new members who wish to become involved with the branch in any capacity. In particular, we still have a vacancy for a branch secretary. This role involves assisting the chair with paperwork for the branch.

As a branch we typically meet virtually once a month and welcome anyone who feels they would like to join us.

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If you would like to find out more about the branch secretary role or becoming a committee member, please contact Jan Fisher (Branch Chair)  
[janet.fisher@mndassociation.org](mailto:janet.fisher@mndassociation.org) Tel 07484 822120

Or Sarah Lowther, (Area Support Coordinator) [Sarah.lowther@mndassociation.org](mailto:Sarah.lowther@mndassociation.org)  
Tel 01604 800626

Alternatively, if you would like to support your local area but cannot commit to a role in the branch, you could join our community of volunteers.

We have set up a volunteers WhatsApp group, in which we will share any upcoming events that may require additional volunteers. If this is something you might like to be a part of, please get in touch

The MND Association provides advice, support, and financial help and at a local level this is provided by our branch.

Every year across the UK around 5000 people receive a diagnosis of MND. There is no cure and life expectancy from diagnosis can be as little as 6 months. MND kills a third of people within a year and more than half within two years of diagnosis.

As motor neurones cease functioning the affected person experiences an accumulative series of symptoms that gradually wear down the body's ability to move, speak and ultimately breath

We have seen an increase in recent months in the numbers of people being diagnosed in the area which means we need funds more than ever to be able to support them.

With MND the body's deterioration can be rapid, and our financial grant scheme is vital as we are able to work quickly to issue support grants to the person concerned. Statutory grants can take weeks and even months which in the case of MND can leave the person without the equipment or modification they need.

This local support includes financial grants to help the person living with MND to live as normal a life as they can.



### Join Our Group

We have a WhatsApp group of volunteers who can volunteer at any event they choose.

Find out more today

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We provide Quality of Life Grants for funding for a wide range of needs: stairlifts, riser recliner chairs, electric wheelchairs, walk in shower conversions, bio bidets, communication aids, vehicle adaptations etc.

We also supply funding for help with Laundry, respite for MND patients and their carers. This can be nights or weekends away or just for someone to sit for an hour or two for a carer to have their hair done, a pint in the pub with friends or just to spend an hour out of the house.

Sometimes it is only £15 for a food blender but it makes all the difference, and no amount is too small.

Our volunteer Association Visitors are available to those who wish for us to contact them. They will visit and offer support and guidance; they also hold coffee mornings (see pg. 18 for info & dates) and afternoon chats.

We are grateful for any funds or donations to our local branch which allows us to allocate the monies to people in our area immediately without having to wait for Head Office approval.

You can donate direct to our Branch via our page [www.justgiving.com/mnda-sww](http://www.justgiving.com/mnda-sww)

## Getting to know our Committee.....

### Janice Hayter – AV & our new Treasurer

I first joined the MND Association and the South West Wales Branch as an Association Volunteer for the Bridgend area in February 2023 and this is a role I still carry out.

There are two reasons why I became an Association Volunteer

Firstly, I have known a few people who had been diagnosed with MND and have been very aware of the struggles they and their support network have faced.

Secondly, having logged onto the MND Association to donate on the day Doddie Weir sadly passed, there in front of me were the words "Volunteers required in Bridgend", meant to be.

I took over the role of Treasurer for the Branch when Maimie stepped down and I am enjoying being part of the team of people who keep the Branch moving forward.



### Sian Price – Our Webmaster

I joined the MND South West Wales branch committee in November, having a background in Marketing only made it fitting for me to work on the branch website.

My involvement is personal, I lost my mother-in-law to MND in 2014, which drives my commitment to support others affected by the disease.

I also enjoy getting involved in fundraising activities like the Walk to d'Feet, bucket collections, and various challenges to raise awareness and funds for research and support.

I'm excited to be part of this committee





## MND Research Symposium

Thursday 16<sup>th</sup> May marked the inaugural **MND research symposium** led by Dr Owen Peters (Cardiff University) and Caroline Bidder (South Wales MND Care & Research Network) (pictured right).

It was well attended by Researchers, Clinicians, the MND Association and the MND community.

Professor Ammar Al-Chalabi (Professor of Neurology and complex disease genetics – Kings College London) opened the afternoon and gave an insight into the world of MND Research across the UK and Jeff Hopkins, brother of the late Richard Hopkins, gave a heartfelt speech on the importance of research for the MND community.

Over the last 2 years, MND research in Wales has grown exponentially and South Wales is now one of the leading recruiters for MND SMART. The event enabled collaboration in moving forward with future research projects and there was real enthusiasm for this to become an annual event. We look forward to inviting even more of you in 2025

*"The event was informative and showed how a joined-up approach by medical professionals and stakeholders in the MND community could achieve more going forward. It demonstrated how new technologies, along with established methods in medical research might speed up progress if all partners have better communication and a central goal. Everyone involved in the event showed passion and enthusiasm to make progress, and this made me feel valued and hopeful to see significant outcomes soon" (Rob Baker – person living with MND)*



## 3in3 for MND – Chris Price

Chris's mother Janet Price was diagnosed with MND in 2008, just as Chris was starting an honours degree in Sport Development and sadly passed away in 2014 days after Chris found out he would be following in her footsteps in become a teacher by completing his PGCE in Secondary PE.

Chris began fundraising with his brothers Jonathan and Phillip for the MNDa by organising events and completing the Cardiff Half Marathon and later the London Marathon just months after his mother passed away.

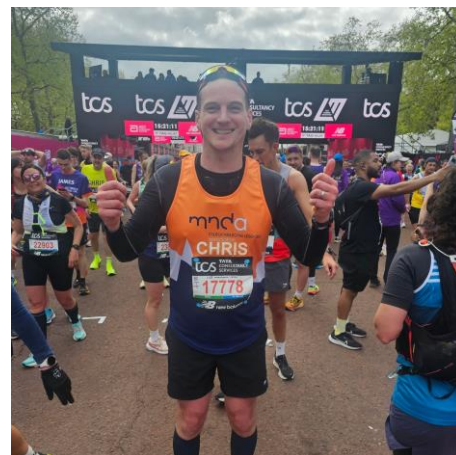
Despite having several runs planned to raise funds, Chris found it difficult to train following his mother's death, and his health and fitness suffered as a result. About a year and a half ago, Chris decided it was time to start improving his physical and mental health again. Given his connection to MNDa, running the London Marathon again seemed like a natural choice.

Unfortunately, an injury two weeks before the 2023 London Marathon forced Chris to withdraw. Undeterred, he signed up for 2024, as well as the Newport and Manchester marathons, uncertain if he would secure a spot. When he got a place in all three, he saw it as an opportunity to create a meaningful challenge in memory of his mother, marking the 10th anniversary of her passing.

Reflecting on his training, Chris shared:

"Training was fantastic, I took a leap to join a triathlon club, The Wolfpack, based in Maesteg as well as training with Yr Hen Blwyf running club. Training with fellow runners made everything ten times easier. The atmosphere in the club as well as the quality of coaching really helped to maximise the outcomes and I felt motivated throughout."

Balancing training with family life, including his wife and two young children, was challenging, particularly during longer runs. However, the support he received was incredible.



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Many people describe marathons as painful and exhausting, but Chris found the three he completed to be “amazing.”



“Manchester was a fantastic experience, I liked the course and seeing Old Trafford as a United fan was a dream come true. It was my quickest marathon of the three, and I really enjoyed it. London was just incredible; it was surreal running it again after ten years but the emotions were the same. Newport was by far the most difficult of the three. I found the route quite challenge due to the lack of support, but it was amazing to have all the family waiting for me at the end.”

Chris raised an amazing **£5414** .

He is very thankful for the support of his family, in particular his brothers and his Auntie (Jan Fisher - MND Association South West Wales Chairperson) and Uncle Mike.

Without their support this would not have been possible.

Chris is deeply grateful to his wife, Claire, and his two wonderful children, William (6) and Bronwen (2), for their unwavering support in the lead up to the challenge, when training was very long and tough, as well as the support throughout the marathons themselves. Seeing them at the end of the Newport Marathon is something that will stick with him for the rest of his life.



## Cardiff Half Marathon – Sunday 6<sup>th</sup> Oct

Any supporters attending, who wish to join the Cardiff & Vale Branch cheer points around the course can contact Kate Bryon for details. Telephone 07999 985024 or Email : [Kate.bryon@mndassociation.org](mailto:Kate.bryon@mndassociation.org)

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## Walk to D'Feet at Bridgend

This years' Annual Walk to D'Feet was held at a new venue for the first time at Newbridge Fields, Bridgend on Sunday 28th July.

And this was the most successful walk we've had for many years with a bumper turnout of over 120 walkers of all ages.

As the sun shone, walkers gathered to stroll around fields and alongside the river, spreading much needed awareness.

The walkers were addressed by Branch President Madeline Moon and the walk was officially started by Bridgend Town Mayor, Ian Williams.



Thanks to a raffle, tombola and generous donations, a brilliant **£1251.02** was raised on the day and we look forward to returning to Bridgend next year, as well as exploring new venues for additional events.

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### Bay2Bay4MND

On Friday 2<sup>nd</sup> August a team of 70 walkers and support crew set out on a mammoth 100 mile walk from Carmarthen Bay to Rest Bay in Porthcawl.

3 gruelling days on their feet, walking an average of 11 hours a day along the Welsh Coastal Path along varying terrain.

Whilst spirits remained high throughout, the toil the walk took on their feet soon became apparent. They had it all ! - Blisters, infections, tendonitis and sprained ankles! Yet this group of fundraisers never let the pain beat them.



A tremendous amount of teamwork and camaraderie saw the group complete the gruelling trek, eventually finishing at Porthcawl on Sunday afternoon with a large welcome home party to see them across the finish line.

The group raised a staggering **£21,105** for their exploits and have helped continue raising the much-needed awareness.

We hope the blisters heal soon, a massive thankyou to everyone who participated.

If anyone would still like to donate to reward the group on this challenge, please visit : <https://www.justgiving.com/page/bay2bay4mnd>

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### Pyle & Kenfig Golf Club

A huge thankyou to Pyle & Kenfig Golf Club for raising an incredible **£1386.03** to support those living with MND here in South West Wales.

"The money was raised in memory of a friend of 42 years whose life was blighted by this terrible illness for the last 3 of her life. We hope it go will a little way to easing the pressures this illness can cause for someone else"

Pictured (right) is Mary Morgan 2023 Ladies Captain presenting the donation to our Branch Chair Jan Fisher.



### Woodman Golf Society

A massive thankyou to the Woodman Golf Society for raising a fantastic **£970** back in December. The society has been raising money for various charities over the years. In 2023 the society decided to support the MNDA.

"A wife of one our players was recently diagnosed with MND, so it was a no brainer for us to raise money for this fantastic charity. After playing our Annual Golf match at Fairwood Park Golf Club, the society returned to the Woodman pub at Blackpill, Swansea for some refreshments. During the evening, a raffle and auctions took place."

Also, in June, they raised another **£410** at their Annual Society Day, where over 20 players participated in what was a very competitive & successful day.

Pictured (right) are some of the members of the Society along with Emily Parker, Manager of the Woodman Pub.



## Tractor Run

An incredible **£4,020** was raised at this year's Annual Drefach (Llanybydder) Tractor run. With a record 120 tractors taking to the roads of Ceredigion and Carmarthenshire!

This year the generous donation was shared between Club Cledlyn Club and the South West Wales MND Association! Our branch chair, Jan was delighted to receive a cheque of **£2020** to support people living with MND in South West Wales.

A huge thank you to all involved.

Pictured left to right are Jan Fisher (our branch chair) receiving a cheque from Gordon Lonsdale, Caroline Davies, Emyr Lloyd, Tomos Lewis, Leanne Thomas, Maisie Thomas and tractor owner Peter Davies who led the run on his Massey Ferguson 35!



## Sheepdog Trials

The Annual Dinner of the Llandudoch and Crosswell Sheepdog Trials, held on Sunday 12th May at the Teifi Waterside Hotel.

Llandudoch committee members presented 3 cheques to charities of their choice, with **£400** being presented to the South West Wales Committee of the MND Association.

In the picture the members of the committee are seen presenting the cheques to representatives of the three charities





## Ethan Rees Cycles 300 miles



We want to give a huge shout out to 13-year-old Ethan Rees from Lampeter, who has set himself the epic challenge of cycling 300miles in 30 days to raise money for Motor Neurone Disease, in memory of his Uncle Mathew.

Ethan clocked up the miles before and after school. Completing his challenge ahead of schedule raising **£3365**

Speaking to his local newspaper Ethan said: "I want to do what I can to raise awareness and much-needed funds for MND. The horrible disease unfortunately took the life of my Uncle Matthew, and it's so important for me that MND gets the support it so needs.

"Recently rugby player Rob Burrows died of it, and over the last few years former rugby player Kevin Sinfield has done amazing things raising money, and my uncle Barry "Finch" Davies did something great too a few years ago, cycling from Land's End to John o 'Groats, so I thought it was my turn to step up."

"I can't wait to be able to look back at how much has been raised and say to myself how proud I am that I was able to do what I could"

## Ebeneser Dyfed Chapel



Another brilliant **£500** was raised by the congregation of Ebeneser Dyfed Chapel.

The Chapel have raised funds for the branch over the last few years and we thank them for their continued support.

Pictured (left) members of the congregation presenting cheque to Branch Chair Jan Fisher on July 2<sup>nd</sup>.

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### Mumbles Tangent Club

Our branch chair, Janet Fisher, was delighted to be invited to speak at the Mumbles Tangent Club's fundraising dinner in March. The club raised an amazing **£905** for the South West Wales Branch of MND.

The same amount of money will be donated to MyName5'Doddie foundation.

The Mumbles 41 Club had also chosen to support the South West Wales Branch of MND this year too and Immediate Past Chairman Dr Attila Garai, on behalf of the Club, also presented a cheque for £250 during the dinner



### Maesteg Golf Club

We are very grateful to the continued support of Maesteg Golf Club.

Peter Williams, Carol Thomas and Neil Davies (pictured right) presented a cheque of **£660** in memory of Carol's husband Martin Thomas.



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## Ogmore Vale Skittles

A huge thank you to Ogmore Vale Skittles team for their generous donation of **£500** in memory of their member & friend Alan Butler.

## Ancient Briton

A big thankyou to Rod & Sian and their Tuesday night quiz teams at the Ancient Briton pub, Porthcawl for their kind donation of **£100**.

This was matched by Rod and also matched by an anonymous donor to donate a total of **£300**. A further £20 and a raffle prize were gratefully received.



## South Wales Care Network

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.



## Sandville

The Sandville Self Help Foundation is a charity overlooking the Porthcawl coastline where you can meet people from across Wales who are going through similar experiences.

The team at the Sandville Self Help Foundation aim to:

Provide individuals and their family members/carers with an opportunity to meet and give mutual support around life limiting and life changing diagnoses.

Share practical information and signpost to other services.

Provide access to physical, psychological, emotional and social support through accessing our services. These services include:

- Hydrotherapy Pool
- Gym/Mobility Suite where classes including Tai Chi, Physical Yoga, Relaxation, Meditation, Falls Prevention and management, Chair exercises and circuits are available.
- Complementary Therapy including: Reflexology, Reiki, Acupuncture, Hypnotherapy, Physiotherapy assessment, as well as practical help and guidance to enable you to maximise your independence
- Qualified and experienced staff and volunteers
- Plus, we have our own Café

You don't need an appointment, if you have a diagnosis of MND or a Neurological condition you would be very welcome to visit the Sandville Self Help Foundation after 10am every Thursday where we would show you the facilities and make a plan to meet your individual needs.

Please contact us on 01656 743344 or [info@sandville.org.uk](mailto:info@sandville.org.uk)

Sandville Court, Kenfig, Bridgend CF33 4PU



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# Coffee Morning.

**Swansea**

The venue is the **Sir Galahad Room, Morgan's Hotel, Somerset Place, Swansea SA1 1RR**; between 11:00 and 12.30. Parking is available opposite the hotel.

This is a drop in event but we would be grateful if you could let us know if you will be attending.

For further information, help with transport or for details of future events please phone Frances Rees Tel: 01792 203841.

We look forward to seeing you.

## Future dates:

Thursday 17 Oct 2024  
Thursday 19 Dec 2024  
Thursday 16 Jan 2025  
Thursday 20 Feb 2025  
Thursday 20 March 2025  
Thursday 15 May 2025  
Thursday 19 June 2025



# Coffee Morning.

**Pembrokeshire**

The venue is the **Hope Centre, 38 Honeyborough Road, NEYLAND, Milford Haven, Pembrokeshire, SA73 1SE**; between 11:00 and 12.00.

This is a drop in event but we would be grateful if you could let us know if you will be attending.

For further information, help with transport or for details of future events please phone Lis Cousens Tel: 07775 812987.

We look forward to seeing you.

## Future dates:

Monday 16th Sept 2024  
Monday 14th Oct 2024  
Monday 18th Nov 2024  
Monday 16th Dec 2024  
Monday 20th Jan 2025  
Monday 18th Feb 2025



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## GET IN TOUCH

If you have any financial queries around grants etc., please do not hesitate in contacting our treasurer - Email [Janice.hayter@mndassociation.org](mailto:Janice.hayter@mndassociation.org) or phone 07852929322



## Join Our Group

We have a WhatsApp group of volunteers who can volunteer at any event they choose.

Find out more today

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

Over the next couple of months, we will be constructing our new look website – which will be accessible soon via <https://www.mnda-swwales.org/>

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### 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 & Branch Contact

Janet Fisher (07484 822120)

[Janet.fisher@mndassociation.org](mailto:Janet.fisher@mndassociation.org)

#### Treasurer (& AV)

Janice Hayter

[janice.hayter@mndassociation.org](mailto:janice.hayter@mndassociation.org)

#### Committee members

Justin Hostettler-Davies  
Maimie Davis  
Jon Price (Campaigning)  
Kelly Price (Social Media)  
Sian Price (Website/Marketing)  
Paul Mason

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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 [Janet.fisher@mndassociation.org](mailto:Janet.fisher@mndassociation.org) or a member of the committee listed.

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