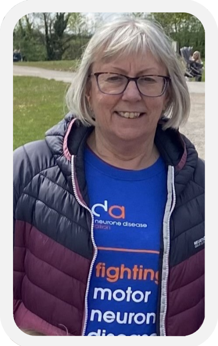
Issue 5
May 2025

South East Wales Branch Newsletter

Message from the Editor



We hope that you enjoy our newsletter. In this edition, we would like to tell you a bit about how the South East Wales Branch started, how it has grown over the last 25 years and introduce you to some of the South East Wales Branch volunteers.

If you would like to be added to our email circulation list for the newsletter, or you have any feedback or comments, please get in touch. If you have any stories, articles or fundraising activities you would like to see in a future edition, please submit them to our editor, Sharon Harford, via email: sharon.harford@mndassociation.org

www.facebook.com/SEWalesMNDA

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mnda_south_east_wales

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25 years of the South East Wales Branch

Pictured here (l-r) are members of the Gwillym family: Ellan Sims, Deborah Gwillym, Irene Gwillym and Ann Williams. Irene is holding a newspaper article on the Branch's opening.

When Branch Treasurer, Deborah Gwillym, first heard about MND in 1999, there was no Branch in South East Wales.

Deborah told us, "My uncle was diagnosed with MND and we didn't know anything about it as a family. There just was no knowledge in our area about the disease at the time."

Deborah's father and family contacted the MND Association for help and held discussions about setting up a Branch. As Deborah is an accountant, she became Treasurer of the Branch - a role she has held since its inception just over 25 years ago!

"It doesn't feel like 25 years since I started my role. Volunteering for the Association has been a real privilege and rewarding in so many ways. It's been so rewarding to be able to take part in our Branch events and raise funds."

Deborah Gwillym, Branch Treasurer

Since 1999, Deborah has seen how the Branch's place in the community has grown.

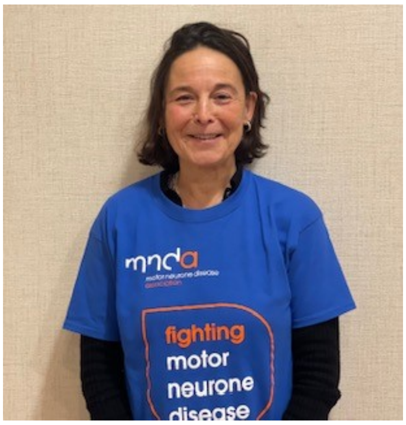
Deborah said, "We have a dedicated fundraiser now and two Association Visitors. We promote the work of the Association and share knowledge where we can. The Branch works hard to promote itself through social media and makes sure that people in the area with MND have access to assistance if they want it."

In February, our Branch organised a get together with Deborah, her mother Irene (who helped out with the Branch whenever she could!), Deborah's sister Ellan Sims, who was the Branch Secretary when it first opened, and her Aunt Ann Williams, who was an Association Visitor.

Other committee members were also present to celebrate the Branch's achievements.

Getting to know our Branch

Jennifer Burgos Watkinson, Chairperson

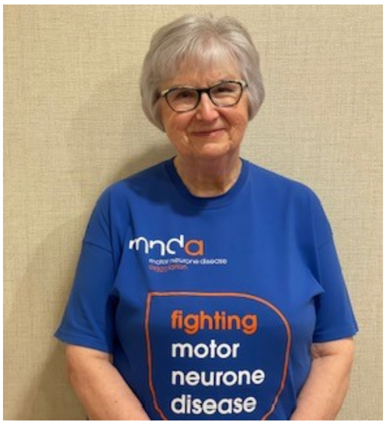


I joined the South East Wales Branch as the Chairperson in 2023. My husband had recently died of MND and I wanted to become involved with the MNDA and the South East Wales Branch.

My favourite volunteering moment was seeing how the people in the audience were moved by the music at our 'Music for MND' event that we held in Crickhowell last year. It united the audience and seemed to bring the cause to the forefront of everyone's minds.

I think that the best thing about volunteering with this Branch is feeling the energy and commitment from fellow Branch members who continue to help those affected by MND.

Judith Barbara Rice, Campaign Contact/Vice Chair

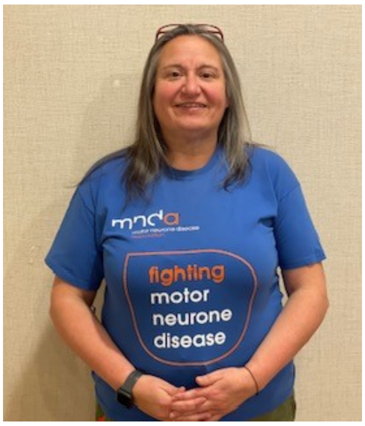


I joined the South East Wales Branch in the summer of 2017. I want to promote this illness in any way I can, for example getting MPs, Senedd Members and Leaders of the Councils involved.

My favourite volunteering moment was when I achieved my goal to get Caerphilly Borough Council on board to accept the MND Charter.

The best thing about volunteering with the Branch is that we all work as one team in achieving fundraising and promoting MND wherever we can. I am proud to be involved with this special group of people.

Tannwen Saunders, Fundraiser



I have been a volunteer with the South East Wales Branch since 2010 (with a 2 year break). I lost my Dad within eight months of diagnosis, so he is my reason for volunteering.

My favourite volunteering moments are being invited to run with Kevin Sinfield and seeing the ice bucket challenge break the 1 million pound barrier.

The best thing about volunteering for the branch is knowing that I'm making a difference to the MND community.

Getting to know our Branch

Roseanne Rothwell, Association Visitor/Branch Member

I have been a volunteer with the South East Wales Branch since 2019.

Having lost a close friend to MND, I wanted to help others who were living with MND.

My favourite volunteering moment is having the privilege of working closely with families, to signpost them to support available.

The best thing about volunteering for the Branch is being part of an amazing group of people, who all use their different talents and skills to support families living with MND.

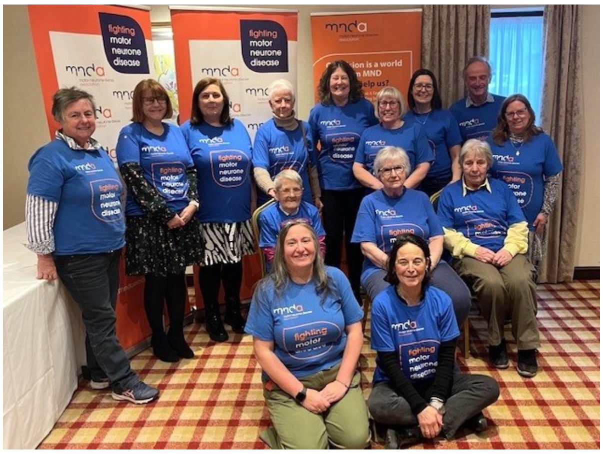
Sharon Harford, Social Media/Communications Coordinator

I have been a volunteer with the South East Wales Branch since June 2022.

My son in law has MND and seeing how it affects our family made me want to raise more awareness of MND and help people to understand it better, by using as many communication channels as possible.

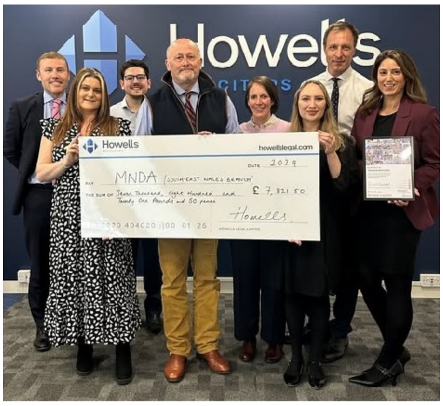
My favourite volunteering moments so far were taking part in the extra mile 'with' Kevin Sinfield, and my 'proud Mam' moments when my daughter completed the Swansea and Cardiff half marathons last year to support her husband, MND and our Branch.

The best thing about volunteering for the Branch is knowing that we all work hard together to spread awareness of MND and encourage people to engage with our cause.



Get to know more of our Branch in our next newsletter!

Thank you to our Fundraisers!



Thank you Howells Solicitors for partnering with our Branch as one of your Charities of the year for 2024/2025.

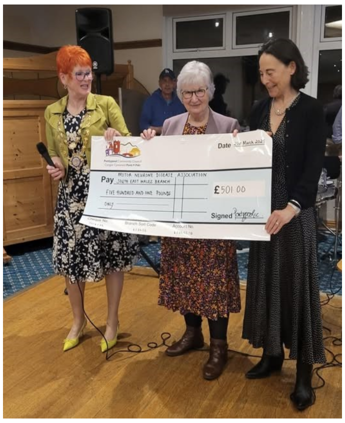
Your fundraising efforts over the past year have certainly been appreciated. Thank you so much!

Richard Shackelford (middle), Relationship Fundraiser from the MNDA national office, is pictured here receiving a cheque on our behalf from representatives of Howells.

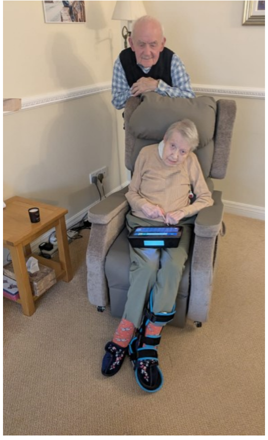
Thank you Pontypool Community Council for choosing us as one of your charities of the year.

Your support in fundraising for us is very much appreciated. Thank you!

The photograph below shows Caroline Price, Chair of the Council, awarding a cheque to Judith Rice and Jennifer Burgos, Vice Chair and Chair of our Branch.



Marilyn talks about Living with MND



Andrew, one of our Association Visitors recently visited Marilyn Hall, who told him a bit more about how MND affects her:

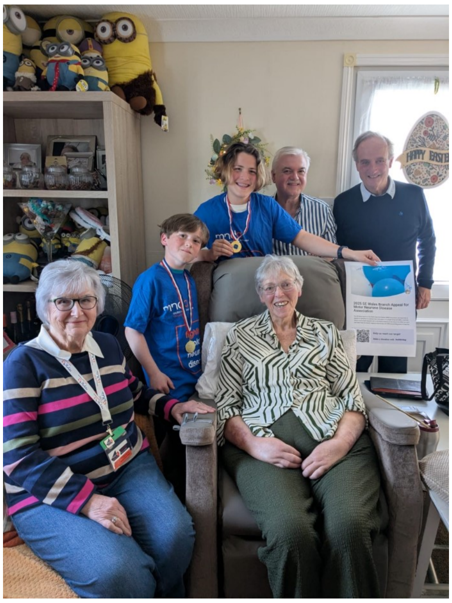
“I have a rare type of motor neurone disease, which I have had for over 11 years. I have the usual symptoms: I cannot walk or talk (I use a speaking iplayer). However, I feel well and don’t have any pain. I enjoy a normal diet. I deal with our paperwork and communicate via text and email to friends and family.

“John, my husband, has had a tough year with severe arthritis of the spine and his 2 hip replacements (20 years ago) are now wearing. He is 89 in February (I am 84) and he is managing to look after me well. We have carers on alternate days, a cleaning lady and a gardener for lawns and heavy work, but there is still a lot to do in the house and garden.

“We have 3 children who support us. We also have 4 grandchildren. We rely on our daughter, Sally, who visits every Saturday and sorts out any problems or things needing phone calls. She also drives us to appointments and accompanies us.

“John only drives to the village shop and cannot manage me in the car. Our other daughter, Lesley, does my online shopping and weekly food shopping/delivery from her home in Leicester.”

Busking for MND



Andrew and Judith, two of our volunteers recently visited Hurley and Alfie, who had been busking in December, to raise money for our Branch because their great aunt had been recently diagnosed with MND.

It was a lovely occasion for Andrew and Judith, meeting the family and hearing about Hurley and Alfie's fundraising. Here is Alfie's account of their busking experience:

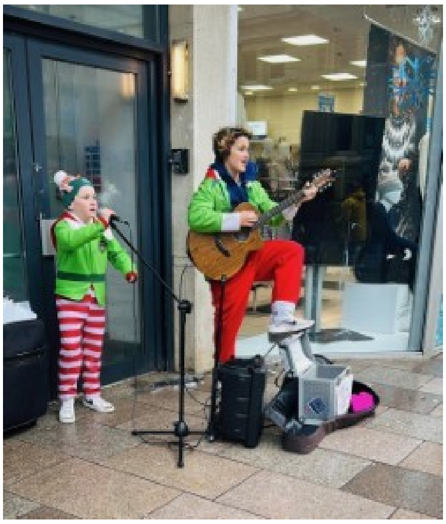
"My name is Alfie, and I'm 9 years old. I love singing and performing with my cousin Harley, who is 14. When we found out our great auntie Gaynor wasn't well, we wanted to do something to help her.

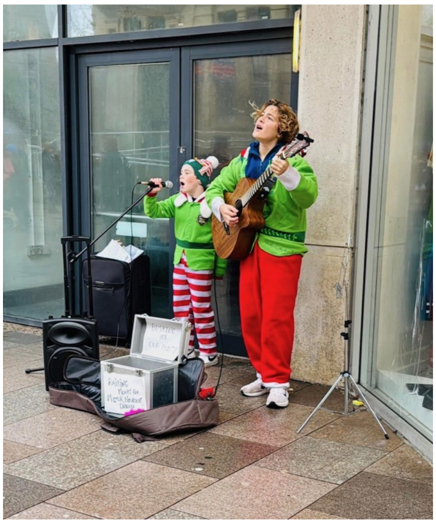
"During our school Christmas holidays, we dressed up as elves and busked in the centre of Cardiff, singing Christmas songs. People were so kind and donated money to help our auntie.

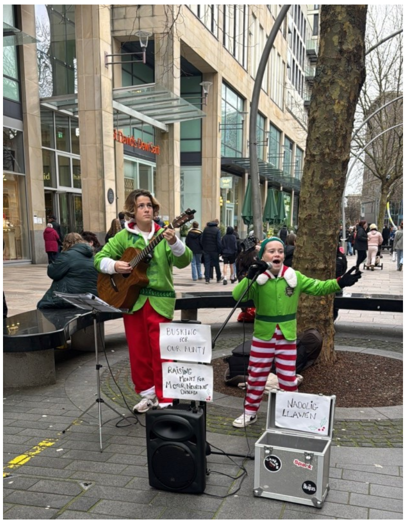
"Auntie Gaynor is really special to us - she's the fun auntie, and we love spending time with her and our Uncle Andrew. But more than that, she has always looked after everyone in our family, making sure they're okay before thinking of herself. When I was a baby and was poorly on Christmas Day, she and Uncle Andrew drove to every shop they could find just to get me Calpol to make me feel better. That's the kind of person she is - always caring for others.

"Now, we want to do something for her. We hope the money we raised can help her and others with MND. More importantly, we want to help spread awareness about MND.

"We're not stopping here! We'll keep busking and raising money, so keep an eye out for us!"







Walk to D’Feet

Join us at Cwmbran Boating Lakes on **Saturday 7th June, at 11.00 am** for a gentle stroll around the lake. Complete as many laps as you feel comfortable with. Each lap is less than 1km and is on flat, accessible paths.

The registration fee is £5 per adult and free for 14 years and under.

No minimum sponsorship target but whatever you raise will make a difference.

Please sign up via the link:

https://www.ticketsource.co.uk/sewalesmnd

Dogs on leads are welcomed, but please be aware that areas of the park are dog free. There are toilets and a cafe on site.

Walk to D'Feet South East Wales Branch

mnda motor neurone disease association

Cwmbran Boating Lake NP44 8JE
Saturday 7th June @ 11am

Join us for a gentle stroll around the lake to raise awareness and funds for the South East Wales Branch of the Motor Neurone Disease Association.
The route is wheelchair friendly with a cafe and toilets available. Dogs on leads allowed but some areas of the park have dog restrictions.

Contact Tannwen for more details - Tannwen26@gmail.com or 07547597415

Walk to d’feet MND

mndassociation @mndassoc

www.mndassociation.org
MND Association Francis Crick House, 6 Summerhouse Road, Northampton, NN3 6BJ
Registered charity no. 294354 | Created in RightMarket - 6/4/2025 - 19:14:47

Registered with FUNDRAISING REGULATOR

If you can’t make the date, we have “I can’t make it” tickets available. This will allow you to support the branch without attending the event.

Thank you for your support!

Why not volunteer with our Branch?

There are lots of ways you can get involved and support the MNDA South East Wales Branch. The Branch is run entirely by volunteers and aims to provide the best possible support to local people with MND, their families and carers. We cover the areas of Blaenau Gwent, Caerphilly, Monmouthshire, Newport, Torfaen and South Powys.

We recognise that all time is valuable, so whether you can only donate time as a one-off or become a regular volunteer, we are grateful for your support. If you would like more information, please contact Judith Rice, on 01633 894108.

Supporting our Community

We are so grateful to everyone who has donated to us during the first few months of 2025.

Your fundraising, donations and support have continued to increase, and we cannot thank you enough for your help. Over the last quarter, your donations have enabled us to support a number of grants, such as Carer’s Grants, Quality of Life Grants, Young Person’s Grant.

These grants have been used **towards** the purchase of a range of items/activities, including:

- Pilates classes
- Short break/holidays
- Profiling bed
- A scooter
- Art Therapy
- A fridge
- Taxi to a hospital appointment
- Driver’s assessment

We couldn’t do this without you. Thank you everyone. For more information about the grants we may be able to provide, please see our website: www.mndassociation.org/support-and-information/our-services/financial-support-information-for-people-with-mnd

Forthcoming Events

- Cuppa and Catch Up, Parkway Hotel, Cwmbran, 13th May
- Walk to D’Feet, Cwmbran Boating Lake, 7th June
- Cuppa and Catch Up, Tredegar House, Newport, 11th June
- Global MND Awareness Day, 21st June
- Music for MND event, 27th September (details to be confirmed)
- Cinema Event, November (details to be confirmed)

Cuppa + Catch Up

For all those affected by Motor Neurone Disease

mnda
motor neurone disease association

Please join us for casual, social time with others in your local area, who are affected by motor neurone disease.

We meet 11:00am-12:30pm with refreshments provided.

Tue 8th Apr - Chepstow Garden Centre, Pwllmeyric NP16 6LF
Tue 13th May - Parkway Hotel, Cwmbran NP44 3UW
Wed 11th Jun - Tredegar House, Newport NP10 8YW

If you would like to come along, please contact Andrew Van de Weyer

andrew.vandeweyer@mndassociation.org
07866 382 489

mndassociation @mndassoc

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