motor neurone disease association
cymdeithas clefyd motor niwron

Autumn 2023
ISSUE No. 6
Registered Charity No 294354

South West Wales Branch Newsletter

ROUND UP

Welcome to the Autumn Edition of our Branch Newsletter…………

A year has gone by since we last published a newsletter and a busy year it has been.

We welcomed a new Area Support Coordinator Sarah Lowther to our Area earlier in the year (read more about Sarah on pg. 11)

And Seren Jones and Janice Hayter also joined the area as Association Visitors.

We proudly announce ex Swansea City legend Lee Trundle as one of our new Patrons. We're very excited to be working with Lee in the upcoming months to help raise the profile of the branch and more awareness of MND across our area.

We held our first Branch Open Day in July supported by MND Association speakers and it was a great success and hopefully the first in what we hope will be a yearly event.

As you will see in the newsletter lots of fundraising has been going on this year throughout our area . We have seen an increase in people becoming involved and wanting to take part.

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 and also Aberystwyth, Builth Wells and Llangammach Wells.

Former patron Mrs Madeleine Moon, retired MP is now our new branch President, with our 2 patrons Phil Price, ex Scarlets & Dragons rugby player now with Bridgend RFC and Swansea footballing legend Lee Trundle.

Three committee members have stepped down in recent months. Lesley Frost, one of the founders of the branch due to ill health and Cathryn Williams & Kelly Lewis due to work and family commitments .

Our Branch committee is made up of a small dedicated team who work together to raise funds and awareness to improve the lives of people living with MND in this area and their families and carers.

We usually meet once a month in the evening for an hour to discuss what is happening in our branch area, plan what events are happening, requests for us to attend presentations and how to spend our funds etc.

These meetings are more often than not held over teams , especially in the winter months as our team is spread over a wide branch area.

We are currently recruiting for a new secretary and a new Treasurer as Maimie is wishing to step back from the Treasurer's role after serving for many years.

However, being part of the committee does not necessarily require a lot of your time. Sharing ideas, and the willingness to work together to achieve our goals is what makes us a happy, successful team.

If you are interested in joining us please contact either Jan Fisher or Sarah Lowther

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 breathe.

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.

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. 13 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 JustGiving page
www.justgiving.com/mnda-sww
Or contact our treasurer Maimie on 01554 777993

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Branch Open Day

We had noticed our members and supporters were showing an interest in knowing where their donations were being used and what was happening in the world of research. So, our committee decided to hold an event that would showcase how supporter's donations are used in the area, provide updates on care and campaigning, and give an update on research and development.

So on Saturday 19th July 2023 at Morgans hotel in Swansea, we held our first South West Wales Branch Open Day.

Clare-Ann Magee Head of Regional Care Partnerships gave update on what is happening in the Care sector, especially in Wales with Sarah Lowther, Area Support Coordinator for South West Wales updating further on what is happening in our branch area.

Millie Jenkins Senior Policy and Public Affairs Adviser - Wales gave updates on ongoing and upcoming campaigns and spoke about events & support in the Senedd.

Richard Shackelford MNDA Regional Fundraiser spoke about charity & fundraising.

Sian Guest Public Affairs Manager – Westminster and Devolved Nations (*pictured right*) gave an update on Research & Development.

(Continued overleaf)

We never lose hope. We strive to find a cure for MND and to support everyone affected by this devastating disease.

And Dr Owen Peters UK Dementia Research Institute, Cardiff (*pictured right*), gave a talk on what DNA can tell us about MND. Using genetics to understand the causes of neurodegenerative disease and can genetics help us develop MND therapies.

Also, our committee member and branch fundraiser Justin Hostettler-Davies was presented with a Certificate of Recognition for the organisation of his crazy challenges over the last 10 years.

More photos of the event can be found at

https://www.owenmathiasclients.com/Clients/2023/Commercial/MNDA/South-West-Wales/Swansea-Event-29-July-2023/n-ssLGqK/

Also, videos are now available on the Association's YouTube channel for those who would be interested in viewing the various speeches.

Millie: https://youtu.be/HwjjvpvV8qo
Richard: https://youtu.be/h-C44X7IiJU
Sarah and Clare-Anne: https://youtu.be/7jLtUh2w7Q4
Sian Guest and Dr Owen Peters: https://youtu.be/-kvz65WxGxU

This was an informal event that made for an enjoyable and informative afternoon and our thanks go to the speakers who attended to help make the day a success.

We would also be interested to hear any feedback from the event and/or videos, especially if you are interested in attending if we were to hold another one.

Also, whether you would be interested if we held something on a smaller scale in your area.

Pictured right: our South West Wales Branch Committee members.

(Phil Price, Justin Hostettler-Davies, Jan Fisher, Maimie Davis, Kelly Price, Jon Price)

We're urging the government to stop energy bills going 'through the roof'

This Autumn the Association has published Through The Roof, a report on the experiences of people with MND and their families during the current cost of living crisis. This was based on a survey of people with MND and their families earlier in the year.

The report found people affected by MND had been disproportionately affected by the crisis. In many cases, this was forcing people to make difficult, and sometimes impossible, choices between spending money on essential living expenses or on maintaining their own health and wellbeing. The report and a summary can be found on the campaign homepage. The report makes a range of proposals to address this but for campaigning purposes we are focussing on the issue of energy costs.

While there have been significant rises in bills for all households over the past two years, again people with MND have been disproportionately affected.
Given this problem, the aim of the Through The Roof campaign is to secure targeted support on energy bills from the UK Government for people affected by MND. We are keeping an open mind on exactly what this targeted support looks like. There is a wider political debate with different ideas for who should be covered by such a scheme and how it should work.

One way of doing this would be an Energy Social Tariff (a discount on energy prices for specific groups), which is a method we favour, but it's certainly not the only way. The important thing for us is there is a system in place which ensures that people with MND get help, year on year.

More information can be found at *https://www.mndassociation.org/get-involved/campaigning/take-action/through-the-roof*

If you'd like any help with taking action or if you have any questions, get in touch with us on campaigns@mndassociation.org

Walk to D'Feet – Gnoll Park

This summer we organised our Annual Walk to D'Feet. Held in Gnoll Park, Neath on Sunday 11th June.

Walkers gathered to stroll around the beautiful lake and surroundings. Luckily the weather was kind too !

A brilliant £**451.79** was raised in sponsorship and it is now hoped for more regular similar walks can be organised across the South West Wales region.

10 Peaks 4 MND Challenge

Over 50 intrepid trekkers took on a mammoth 10 Peaks Challenge to raise much needed funds and awareness of Motor Neurone Disease.

With the majority of participants coming from the S-Wales area.

They drove up to Scotland and climbed the following 10 peaks - Ben Nevis, Ben Macdui, Braeriach, Cairn Toul, Carn na Criche, Sgor An Lochain Uaine, Scafell Pike, Snowdon, Garnedd Ugain & Penyfan.

This was all carried out in just 3 days with no rest in between - the only sleep they had was that on the minibuses travelling between the peaks. In doing so they raised a staggering **£28,700** and loads of much needed awareness !

Over the last 10 years this group of crazy individuals have managed to raise circa £200,000 for Motor Neurone Disease.

In Memory of Rev Cen Llwyd

On 16th July 2023 a special service was held at Ciliau Aeron Unitarian Chapel, near Aberaeron in memory of the Rev Cen Llwyd, who sadly died from MND last year.

The Unitarian community in Ceredigion had raised £3,000 for Motor Neurone Disease and our Branch Chairman Jan Fisher attended the event and was presented with a cheque, and said a few words about the Branch work and MND research.

The small chapel, with its peaceful atmosphere, was filled with caring members of the community, and a special contribution was made by Bois y Gilfach choir, who had been part of the fundraising efforts.
It was a pleasure to attend and meet family and friends involved in the fundraising.
The family requested that the money raised be donated to the Research Department at Cardiff University and we were happy to pass on the money raised to Dr Owen Peters, Research Institute Cardiff University. Dr Peters will update us as to how the money is used.
We are also very grateful to receive a further £350 donation from a collection that was made at a special service in a nearby Chapel that is celebrating 250 years in existence, who chose to donate to MNDA also in memory of Cen Llwyd

Ar y 16eg o Orffennaf 2023 cynhaliwyd gwasanaeth arbennig yng nghapel Undodaidd Ciliau Aeron, ger Aberaeron er cof am y Parch Cen Llwyd, bu farw o ganlyniad i glefyd Motor Niwron y llynedd. Cododd Undodiaid Ceredigion £3,000 i elusen Motor Niwron a gwnaeth Cadeirydd ein cangen, Jan Fisher, fynychu'r digwyddiad. Cyflwynwyd siec iddi ac yna dwedodd ambell air am waith y gangen a gwaith ymchwil i glefyd Motor Niwron.

Roedd y capel â'i awyrgylch heddychlon yn llawn aelodau gofalgar o'r gymuned, a gwnaed cyfraniad arbennig gan gôr Bois y Gilfach, oedd yn rhan o'r ymdrechion codi arian. Roedd yn bleser i gwrdd â theulu a ffrindiau oedd ynghlwm â'r codi arian.

Dyhead y teulu yw i'r arian a godwyd ei gyfrannu i Adran Ymchwil Prifysgol Caerdydd ac roedd yn bleser gennym i drosglwyddo'r arian i Dr Owen Peters, Sefydliad Ymchwil Prifysgol Caerdydd. Bydd Dr Peters yn ein diweddaru sut y bydd yr arian yn cael ei ddefnyddio.
Roeddem hefyd yn ddiolchgar o dderbyn £350 ychwanegol o gasgliad gan gapel cyfagos, eto er cof am Cen Llwyd. Penderfynodd y gynulleidfa gyfrannu i elusen Motor Niwron mewn gwasanaeth arbennig a gynhaliwyd ganddynt i ddathlu 250 mlynedd o fodolaeth y capel

Sarn Helen Running and Orienteering Club

On Sun 8th April – the Hag Harris Memorial Race was run in memory of a great and dearly missed Mr Harris, who sadly passed away last year. His wife Jan had passed away the year before after suffering from MND for over 20 years

Pictured right is Wish Gdula who was a close friend of Hag Harris and they were both part of the founding group of Sarn Helen Running and Orienteering Club. Together with Dee Jolly and Eleri Rivers who were race directors and organisers of the Hag Harris Memorial Race and our Branch Chair Jan Fisher. The race raised a fantastic ***£1437****.*

In Memory of Tony Wintle

On Sunday August 27th family & friends of Tony held their annual bank holiday event in the Trefelin BGC Club , Ynys Park , Port Talbot in memory of the late Tony Wintle, who they sadly lost due to motor neurone disease.

It was a huge success once again. They raised a fantastic total of £1635.00 by selling raffle tickets and entry fee.

Friends and family were so generous and kind donating prizes and spending the day with us to raise awareness of this dreadful disease.

Robin & Mikes Drive to Cure MND

On September 23rd & 24th Robin and Mike drove from the most easterly point in the UK, Ness Point, Lowestoft, to the most westerly, St David's Head in Wales, and back again.

They have managed to raise over £6300 (thus far) for the Norfolk, Norwich and Waveney Branch of the Motor Neurone Disease Association.

They journeyed on quieter roads in Robin's 1936, Austin Opal 7, with a travelling time of 12 hours each way, over two days.

Robin and Mike, both members of the Wroxham and Bure Valley Rotary Club were supported by fellow members and friends. Robin's brother, Matthew, and friend, Andrew, also joined them on the western leg of the trip in another Austin 7 and a Morris Minor!

Robin's father, David, passed away in 2016, aged 82, having been diagnosed with MND only a few months earlier. Mike's son, Justin, battled MND for 2 years after diagnosis, and died in January 2023 aged 50.

David had completed restoration of the Austin Opal 7 in 1998 and drove it north to south from John O'Groats to Land's End for charity. David was a Rotarian and spent much of his time raising funds for local and international causes. Now his son, Robin, took the same little car on the East West East Endurance Drive, raising funds for MND, in what was a fitting tribute to his father.

His co-driver, Mike, helped care for his son during his MND journey at Justin's home in Sale, Manchester, along with other family members.

Meet our Member – Sarah Lowther

As an Area Support Coordinator within the MND Association I ensure People with MND can access support and all Associations services which is delivered primarily through a team of amazing volunteers. I also work closely with a range of Health Care Professionals and the South Wales MND Care Network ensuring all aspects of care and support are in place. And where gaps may appear, to work with the person with MND and appropriate other contacts to resolve those issues

I joined the MND Association on the 10th January. I have worked for several charities, most latterly the British Liver Trust.

Experience includes patient support and inclusion, awareness raising, working with Health care Professionals, advocacy and staff and volunteer management.

I am really keen to work closely with the South West Wales branch and continue developing an already brilliant branch. And further improve the support available for people with MND across South West Wales.

In my spare time I have a number of hobbies such as cross stitch, reading and walking. I am single mum to two teenagers who keep me on my toes, Most recently I have started Zumba to try and regain fitness lost through lockdown.

Sarah can be contacted on 01604 800626 or via email at sarah.lowther@mndassociation.org

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.

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/carer 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

Sandville Court, Kenfig, Bridgend CF33 4PU

Coffee Mornings

You are invited to our forthcoming coffee mornings. These events are an opportunity for people living with MND and their carers to drop in, meet others and have a relaxing cup of coffee/tea in a comfortable setting.

We hope to provide a comfortable informal occasion where ideas can be exchanged, new friendships forged, or old acquaintances renewed.

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)

Upcoming dates:

Thursday 23rd November 2023 & Thursday 21st December 2023

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 Maimie Davis Tel: 01554 777993; maimiedavis@maimiedavis.plus.com or Frances Rees Tel: 01792 203841

Past Carers Group

Also, Sarah Lowther, our Area Support Coordinator has started running a Virtual Past Carers group. With the last one being run on 27th September.

These are currently still being trialled but if you are interested in joining future sessions, please contact Sarah on 01604 800626

Christmas Cards

Christmas Cards, wrapping paper, 2024 diaries are all available to order at www.mndassociation.org or using the order/enquiry line 01604 611777.

We are also aware that last year, some people had an issue with not receiving raffle tickets from MND Head Office. Should anyone have any issues this year please let Jan know.

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: - *@SWWalesMNDA*

Do not forget, this newsletter is also available by email by contacting us or on our website at 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

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

Branch Contacts

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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 jdnspis@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.

We never lose hope. We strive to find a cure for MND and to support everyone affected by this devastating disease.