

Welcome

In this edition we remind readers of the invaluable work of members of the Motor Neurone Disease Association (MND). As well as familiar faces from the previous editions - the association visitors, the care coordinators and staff members over the last year we also introduce Ian Chandler who is the new Campaigns Manager for our area.

Our main fundraising event for the year takes place on Saturday June 16th when those living with MND, their carers, volunteers and supporters will once again **walk to d'feet MND** taking place along Llandudno Promenade. The walk starts at 11am and we would be very pleased if you can come along and support the event. Please see page 7 for further details. Last year we covered the promenade with a blue wave and more importantly raised the profile and understanding of motor neurone disease.



Best wishes

North Wales Forum

Useful Contacts

North West Wales Group Contact

Roger Sowersby
Tel: 01248 681 238
Email:
rogersowersby@gmail.com

Volunteer Team

Sioned Roberts Jones
Georgina Llewellyn
Howard Mence
Jen Roberts
June Watkins

Clwyd

Branch Contact

Chris Allen
Tel: 07908292621
Email:
eslessred@yahoo.co.uk

Volunteer Team

Helen Carey
Elin Roberts
Rachel Ritchie

Out of Hours GP

Tel: 0300 123 55 66

Out of Hours

Social Services

Angelsey & Gwynedd
Tel: 01248 353551
Conwy Tel: 01492515777
Wrexham County
Tel: 0345 0533116
Flintshire County
Tel: 01352 803444

Details of the MND Association staff can be found at the end of this newsletter.

Help at Hand

We invite you to come to any or all of our support meetings.

Our Support Meetings

Our Support Meetings offer an opportunity for you to come along and meet others living with MND and their carers in a relaxed and friendly setting to share experiences over a cup of tea or coffee.

We would love you to come and join us. Refreshments are provided free of charge for people living with MND and a family member or carer. Whether you are able to pop along for 10 minutes or stay for 2 hours it would be great to see you.

You are welcome to attend any meeting whichever ones are the most convenient for you.

North West Wales Group Support Meetings Contact Roger rogersowersby@gmail.com

These are held at Ty Golchi, Ffirdd Caernarfon, Bangor LL57 4BT in the afternoons from 2:30pm.

Dates for the next few meetings are:

18 April
9 May
16 June
18 July
12 September

Clwyd Branch Support Meetings Contact Chris eslessred@yahoo.co.uk

Clwyd branch support meetings take place at
Cunliffe Arms Jeffreys Rd, Wrexham LL12 7PD .

Dates for next meeting :

16 May

Usually they are the third Wednesday of every month 7pm-9pm

Additional Support Meetings Contact Judith judith@northop567.plus.com

These are held at Tweedmill Shopping Outlet, Llannerch Park, St Asaph Road, St. Asaph LL17 0UY in the daytime from 10:45AM – 1PM.

Dates for the next few meetings are:

April 23rd
May 21st
June 25th
July 16th
August 20th

Support

We point you in the direction of support which is available locally.
This newsletter we remind you of some of the team helping you to find local support.

Staff Team



Kevin



Jo



Richard

Kevin Thomas
Regional Care Development Adviser (RCDA), North Wales, Mid Powys & Isle of Man

Jo Cunnah
Volunteer Development Coordinator Wales, Northern Ireland and Isle of Man

Richard Shackelford
Regional Fundraiser for Wales & Northern Ireland

Local Campaigns Manager (please read the article on page 4)

Care Coordinators



Angela



Kathryn

Angela Mitchell
MND Care coordinator North East Wales

Kathryn Lancelote
MND Care Coordinator North West Wales

Association Visitors



Judith

Judith Harper
Association Visitor Coordinator



Chris

Chris Allen
Association Visitor



Joanne

Joanne Mills
Association Visitor

Introducing Ian Chandler



Hello everyone. I am Ian Chandler and have just joined the MND Association in February, as the Local Campaigns Coordinator for the West Region (ie. Tim's replacement). I live in South East Wales with my wife and three children. For 30 years I have been working in the charity sector specialising in campaigning, influencing and communications.

I am looking forward to meeting you all and working with you to campaign for improved care and services for all those affected by MND in North Wales.

If you want to get in touch you can reach me on 07702 336552 or at ian.chandler@mndassociation.org

North Wales MND Care Coordination Service – One year on.

The North Wales MND Care Coordination Service was launched in February 2017 when Kathryn Lancelotte and Angela Mitchell began working as MND Care Coordinators. Their profiles were introduced in our Summer 2017 Newsletter. They are employed by Betsi Cadwaladr University Health Board (BCUHB), funded by a MND Association Ice Bucket Challenge innovation grant. The funding runs until October 2018 with a commitment from the Health Board to take up the funding if the service meets agreed objectives.



The agreed objectives included:

- providing all people living with MND and their carers in North Wales with a key worker
- providing a single point of contact to MND services in North Wales for people affected by MND and health professionals
- Supporting people living with MND during periods of hospital admission and reducing length of inpatient stays.

A steering Group involving Kevin Thomas, RCDA, oversees and monitors progress of the service. All of the agreed objectives have been met several months ahead of schedule. Additionally, MND services in North Wales have been audited against the MND Guidelines issued by the National Institute for Clinical Excellence (NICE) using the 'Transforming MND Care' Audit tool developed by the MND Association, and included a survey of people living with MND. The audit showed that MND Services in North Wales achieved a compliance with the NICE Guidelines of 86%.

The MND Care Coordinator Steering Group met with key representatives of the Health Board on 13th March to report on progress in its first 12 months of service. The Health Board was represented by Dr Peter Higson, Chair, BCUHB and Dr Evan Moore, Medical Director, BCUHB. Also in attendance was Sally Light, Chief Executive of the MND Association and Chris Bennett, Regional Delivery Manager. As well as reporting on progress the Steering Group were able to present its proposals for further service developments with ongoing funding including a partnership between the MND Association, BCUHB, and Bangor University to carry out research into Care Coordination services. This was a very positive and constructive meeting from which we are confident that ongoing funding of the MND Care Coordinator roles will be secured. We will keep you informed of progress.

Carer's Corner



Nightingale House Hospice
Hospis Tŷr Eos



Carers Information and Support Sessions

The MND Association have partnered with Nightingale House Hospice, Wrexham, and St David's Hospice, Llandudno, to run Information and Support Sessions for Carers of people living with MND. The sessions are for all of those who care for people living with MND whether they are husband, wife, partner friend or other close family relative.

Kevin Thomas, RCDA, and colleagues at Nightingale House Hospice piloted the sessions in October with 9 Carers attending. A second session was held with colleagues from St David's Hospice in February with another 8 Carers in attendance.

The programme is very flexible and informal allowing plenty of time for questions and answers. Refreshments and a light lunch is provided and kindly funded by the MND Association's Clwyd Branch and North West Wales Group. Feedback has been very positive and valued, not only for the information about services provided by the Hospices and MND Association, but equally for the opportunity to meet with other Carers, sharing and learning from each other's experiences

As a result both Nightingale House Hospice and St David's Hospice have agreed to facilitate 2 Carer Information and Support sessions each per year in partnership with the MND Association. The next session will be held in Nightingale House Hospice, Wrexham, on 27th April. Invites have been sent out to all of those in the catchment area and further invites will be sent out for the next session in the St David's catchment area in due course. However, attendance isn't restricted to catchment areas and Carers are welcome to attend any session. If you require further information, please contact Kevin Thomas, RCDA.

The MND Association also have a Carers Hub on the website

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

Here you will find a range of resources to help you think about how to look after yourself as a Carer and how to plan ahead if you were unable to care. For example, the *Motor Neurone Disease checklist* and the *Understanding My Needs* booklet are helpful tools to think about what others would need to know about the person living with MND if you as the Carer could not. If you do not have access to the Carers Hub on the internet you can request a copy of 'Caring and MND' by phoning MND Connect on 0808 8026262. If you have an Association Visitor, ask him or her if they can help you use these tools to think about planning ahead.

Raising Funds

We raise money locally that goes to support our efforts in helping people living with MND and their carers.



Clwyd Branch website : <http://mndclwyd.org> Website : mndassociation.org
Facebook : <http://www.facebook.com/clwydmnda> Facebook : North West Wales MND Support Group
Twitter : @clwydmnda Twitter : mndnorthwa

16.6.18 **WALK TO D-FEET MND** **Llandudno**
LL30 2LP

Mae pob cam yn gwneud gwahaniaeth. Cerddwn mewn gobaith, cerddwn er cof am rywun arbennig ac i roi cefnogaeth. Cerddwn gyda'r gobaith o weld y byd yn rhydd o Glefyd Motor Niwron.
GAD I NI GAMU 'MLAEN GYDA'N GILYDD!

Every step makes a difference. We walk for hope, we walk in support, we walk in memory and we walk so that one day we will see a world free of Motor Neuron Disease.

TOGETHER, LET'S TAKE STEPS TO D-FEET MND!

Dewch at eich gilydd efo teuluoedd a ffrindiau (croeso i blant ac anifeiliaid) i gerdded 3.5 milltir i helpu codi arian tuag at Glefyd Motor Niwron.
Come together with friends and family (kids and pets welcome!) for a 3.5 mile walk in aid of Motor Neuron Disease.

Cofrestru o 10:30yb, Cerdded am 11:00yb (mynedfa i bier Llandudno)
Registration from 10:30am, Walk begins 11:00am (entrance to Llandudno Pier)

Those of you who participated in last years "Walk to D'Feet MND" event on Llandudno promenade will be pleased to know that the event is being repeated this year on Saturday June 16th. Registration will be from 10.30am with the walk starting at 11.00am.

The walk last year was a tremendous success with 200 hundred MND tshirt wearing walkers raising awareness along the promenade. Nearly £7,000 was raised in sponsorship and donations which was split equally between the Clwyd Branch and the North West Wales Support Group. An added bonus was that everyone enjoyed the event and the camaradie that ensued. New friendships were made and old ones renewed.

This year we hope to improve on the attendance level and thus raise even more awareness and even more funds to enable us to assist those living with MND, and their families across North.

Therefore we ask that as many of you as possible find the time to attend the event. Please also ask family, friends, workmates etc if they would like to attend.

In the first instance please contact Roger Sowersby ,rogersowersby@gmail.com, 01248 681238, for further information, registration forms and sponsorship forms.

North West Wales Group



At the monthly Support Group meeting in February we were pleased to be able to launch our new bilingual website for those living with MND in the area, their carers, their family and their friends.

Kevin Thomas, Regional Care Development Adviser, said "It looks fantastic. Well done and thank you so much to the team at Delwedd. The site looks very friendly and welcoming to users". A huge thanks to [Delwedd](#) for sponsoring our website.

Please take a look at <http://www.mndnorthwestwales.org>

We have collections at the Tesco in Llandudno Junction on Friday 4th May and Saturday 5th May, We need volunteers who should contact Georgina at gmllewellyn@gmail.com.

Clwyd Branch

The Clwyd branch now have a just giving page:

https://www.justgiving.com/fundraising/Clwyd_MND_Branch

Donations can be also made by text: Send message "CMND70 £5" to 70070.

We've had a few fundraising events lately.

February

A bucket collection at Tesco Broughton raised £227.

A charity night at Brymbo Sports and Social Club raised £1227.

March

A bucket collection at Bangor on Dee races.

Awareness Raising

We try hard to raise public awareness of MND and celebrate the success and support given by individuals and organisations.

Patron celebrates MNDA support in Wales



Princess Anne, who is Royal Patron of the association, attended a reception at Aberystwyth Arts Centre on Tuesday 16th January to celebrate the work done in Wales by volunteers for the Motor Neurone Disease Association. She met people living with MND, their families and carers and gave a speech.

Five members of the North West Wales Support Group were invited to attend the event. Princess Anne met a number of staff and volunteers from North Wales that included Kevin Thomas, Jo Cunnah, Roger Sowersby, Jennifer Roberts and Ceri Roberts. After lunch Jennifer Roberts gave a talk about her experience of MND and how she became involved in volunteering.

Annual Conference

This year's annual conference and AGM takes place on Saturday 14 July 2018. The event will be held as in previous years at the Raddison Blu Hotel, East Midlands airport. It is a one day event although some members chose to stay overnight. The full programme will be available later in April. For more information please contact the conference team on 01604 611822 or at conference@mndassociation.org.

MND Connect

The MND Connect team offers information and support on all aspects of **motor neurone disease** (MND), including symptom control, practical management, improving quality of life, clinical research and signposting to other organisations. **MND Connect is available Monday to Friday between 9am to 5pm and 7pm to 10:30pm.** You can call direct on **0808 802 6262** or e-mail at: mndconnect@mndassociation.org.

Would you like to share your story?

We are looking for Welsh and non Welsh speakers living with MND or caring for someone with MND to come forward and support us with our media work. This could involve sharing your story on local radio or TV, being featured in press articles or on social media. Your support will help us to ensure that people with MND in Wales have a voice and enable us to raise the profile of all aspects of our work within the Welsh media. If you, or someone you know, would like to find out more, please contact **Jo Cunnah**, Volunteering Development Co-ordinator, 03453 751856 .

Future Editions of our Newsletter

We hope that you have enjoyed reading this edition of our newsletter which is available by post and by email. Below are a list of staff members and details of how to contact them directly should you have any questions for them.

We would be pleased to receive feedback and any contributions to the newsletter. (See below)

NAME	PHONE	EMAIL
Regional Care and Development Advisor Kevin Thomas	012488 53428	kevin.thomas@mndassociation.org
Care Coordinator Kathryn Lancelotte Angela Mitchell	01745 448720 extension 2772.	BCU.MNDCoordinators@wales.nhs.uk
Volunteering Development Coordinator Jo Cunnah	03453 751856	jo.cunnah@mndassociation.org
Regional Fundraiser Richard Shackelford	01497821247	richard.shackelford@mndassociation.org
Local Campaigns Manger Ian Chandler	07702 336552	ian.chandler@mndassociation .org
Newsletter Editor Howard Mence	01492548649	mence1@hotmail.co.uk

Social Media

In the North West of Wales

Why not follow us on Twitter @northwestwales or join us on Facebook

<https://m.facebook.com/North-West-Wales-MND-Support-Group-Grwp-MND-Gogledd-Orllewin-Cymru-174854996057613/>

or visit the new website <http://www.mndnorthwestwales.org>

In the Clwyd area

Why not follow us on Twitter @ clwydmnda, or join us on Facebook

www.facebook.com/clwydmnda or visit our website www.mndclwyd.org.

FINALLY

Watch out for details of the **Sirenian Singers** concert in June on the websites.