

South Wales Motor Neurone
Disease Care & Research Network

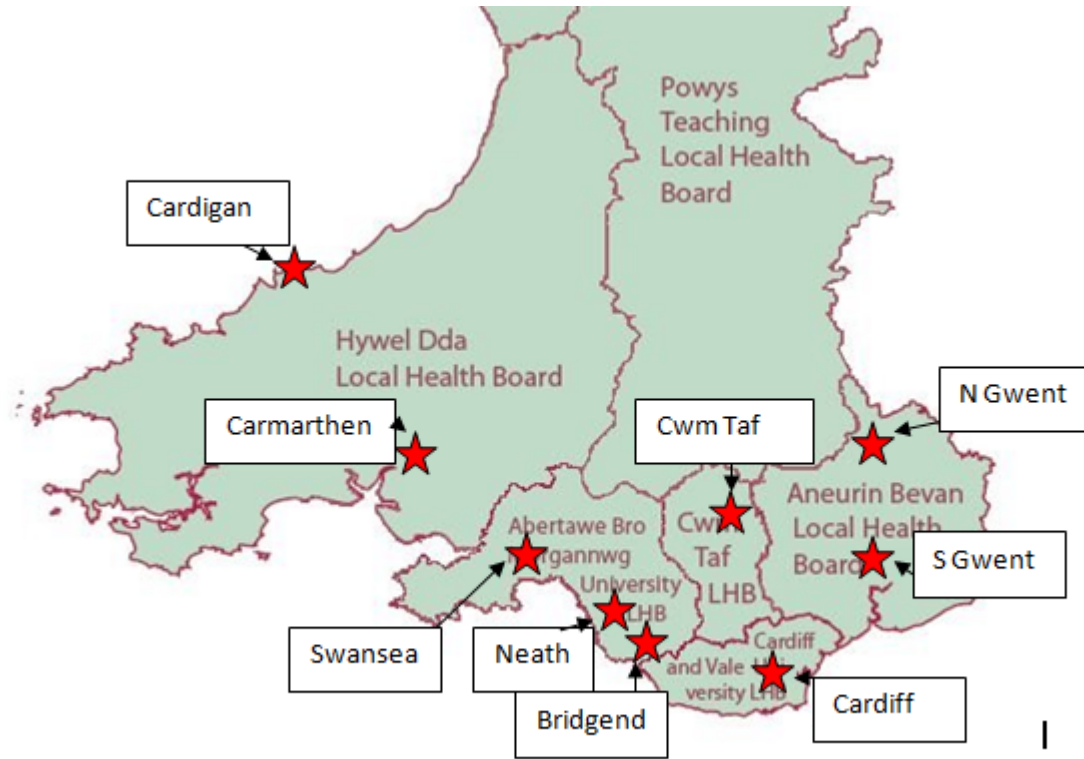
MND

Rhydwaith Gofal Clefyd
Niwronau Motor De Cymru

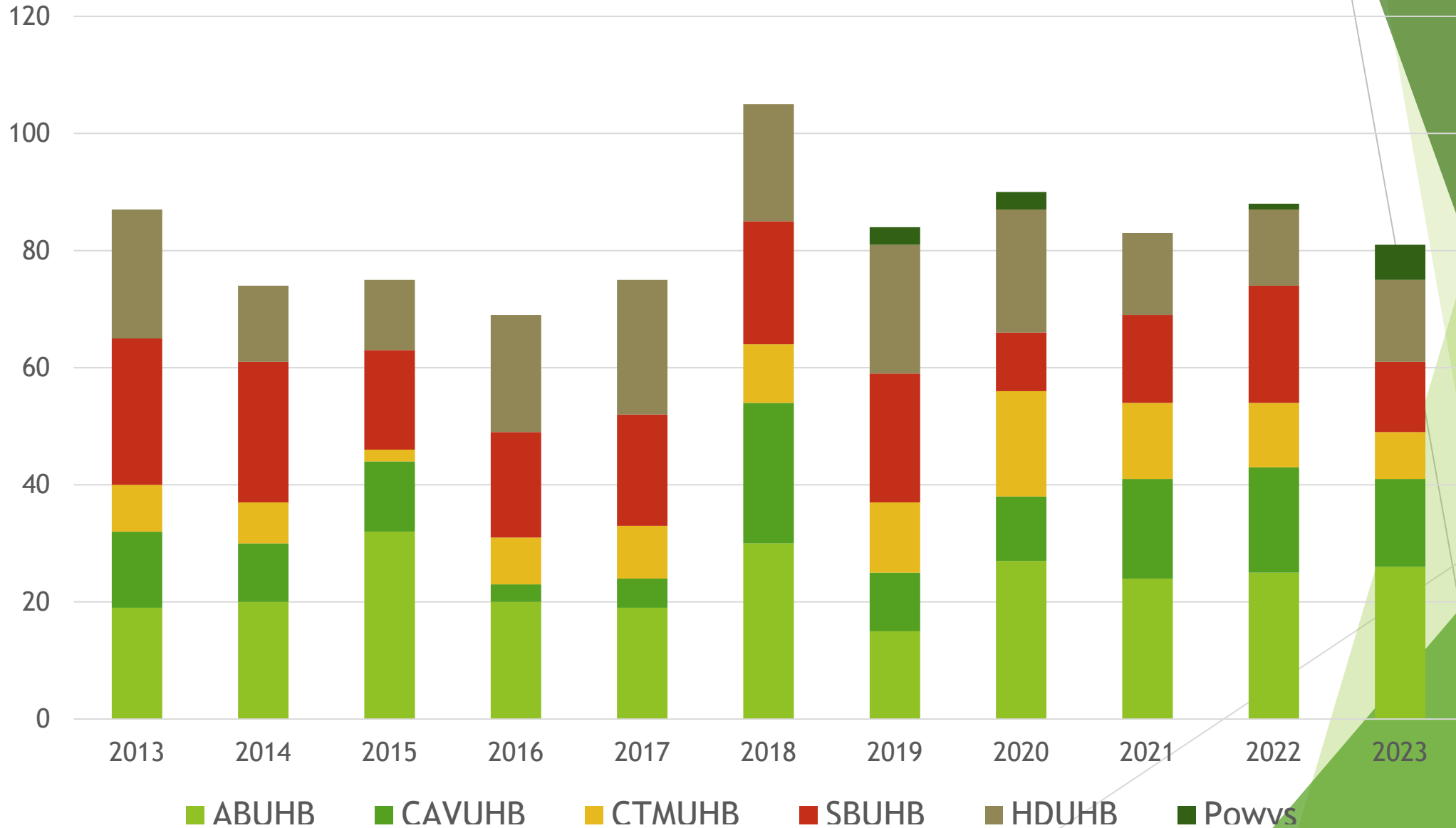
Research and Network Update

Caroline Bidder - Network Lead

12 MDT Clinics



Referrals to SWMNDCRN



MND Information & Support Day

- ▶ For people newly diagnosed with MND (plus family and friends)
 - ▶ Nutrition
 - ▶ Communication
 - ▶ Planning for the future
 - ▶ Breathing
 - ▶ Exercise
 - ▶ Wellbeing
- ▶ Last ran this course: May 2023
- ▶ Feedback: *“very informative, amazing team” “Positivity, the future can still be something to wish for” “ Gained knowledge from the experience of others”*

Introduction to MND Staff Education day

- ▶ Designed for staff fairly new to MND
- ▶ 35 attendees (range of health and social care professionals
- ▶ 100% of attendees said they would recommend the event to a colleague.

“Very good overview of MND - really enjoyed listening to the different specialities come together to paint a complete picture of the experiences a person with MND may face”

“Very useful in gaining knowledge of MND and how it links with our role in management”.

Community of practice

- ▶ Expert core
- ▶ To support best care for people living with MND
- ▶ Professional development
- ▶ Service development
- ▶ Cross disciplinary awareness
- ▶ Cross disciplinary engagement
- ▶ Share resources, knowledge and good practice
- ▶ A way to speak directly with the workforce

Activities

- ▶ Information and Knowledge Exchanges
- ▶ Webinars
- ▶ Annual networking event
- ▶ Online professionals' forum
- ▶ CPD fund
- ▶ Infographics

Information and Knowledge Exchange

2024 Dates

- | | |
|----------|--|
| 26 March | Through thick and thin - Managing saliva |
| 25 June | Managing High Tone |
| 24 Sept | Coping with complexity |
| 9 Oct | Annual Networking Event |

Webinars Dates 2024

- ▶ **30 January** - Identifying and managing behavioural change in MND: from the MiND-B to the MiND Toolkit
- ▶ **27 February**- Anticipatory Grief - the challenges presented by a progressive condition for people living with and affected by MND
- ▶ **30 April** -“If it affects one of us, it affects us all.” The whole family approach, effective support for household living with a diagnosis of MND
- ▶ **16 July** -“You matter because you are you, and you matter to the end of your life.” - dispelling the myths of hospice care
- ▶ **26 November** -A focus on tube feeding in MND: current evidence, managing risks and exploring good practice

Future Plans 2024 and beyond

- ▶ More Information and support days
- ▶ Expert Patient Programme
- ▶ More study days - Cognitive changes in MND study day, Introduction to MND
- ▶ Continue to support Community of Practice
- ▶ Annual MDT day
- ▶ Pilot wellbeing programmes

Genetics

- ▶ Links with Cardiff University - Dr Owen Peters
- ▶ Genetic testing closer to home?
- ▶ Genetic counselling
- ▶ Genetics on patient care
- ▶ Genetic management Pathway- standardisation



NHS
CYMRU
WALES

MND Research

Caroline Bidder

Network Lead Care Coordinator

South Wales MND Care and Research Network

Health and Care Research Wales support

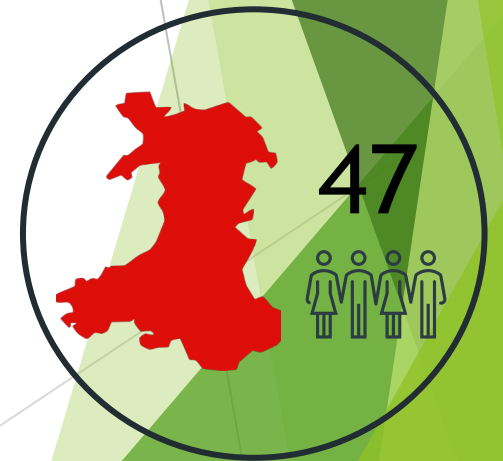


- ▶ Identification of all new MND projects added to any National UK Research Portfolio, providing a pipeline for future research opportunities.
- ▶ Approach each new trial team to establish whether Welsh patients and locations can participate.
- ▶ Coordination of study setup and approvals at Health Boards across the South Wales MND Network
- ▶ Research nurse and practitioner support required for study delivery and follow-up.



MND Smart

- ▶ Designed to speed up the time it takes to find medicines that slow, stop, or reverse the progression of, MND.
- ▶ Based in the Heath, Cardiff.
- 2 arms - Memantine and Trazadone have been dropped leaving only Amantadine (2 of our patients)
- Currently in the process of taking everyone off and re entering them on the trial. All want to re-join.
- 47 patients at present
- End of November will start rescreens after washout period
- ▶ <https://www.mnd-smart.org> -Self refer.

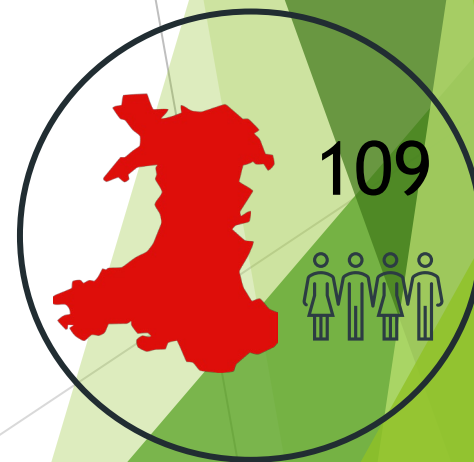


KCL Register

The MND Register for England, Wales and Northern Ireland is the first comprehensive source of information collected by healthcare professionals about people with MND

Register aims:

- To count how many people currently have MND in the UK
- Establish where people live, to help improve care in those areas
- Collect detailed information to detect changes in rates of MND over time
- Identify best practice and improve patient care and outcomes



Mind Toolkit



Online platform for management of behavioural changes in Motor Neurone Disease

The Network is one of only 8 participating pilot sites

Developed to support carers in the management of behavioural changes in MND- behavioural changes are associated with greater burden in carers.

Provides on line education, tools and techniques for healthcare professionals and carers.

Now closed to evaluate. Feedback from London conference was positive.



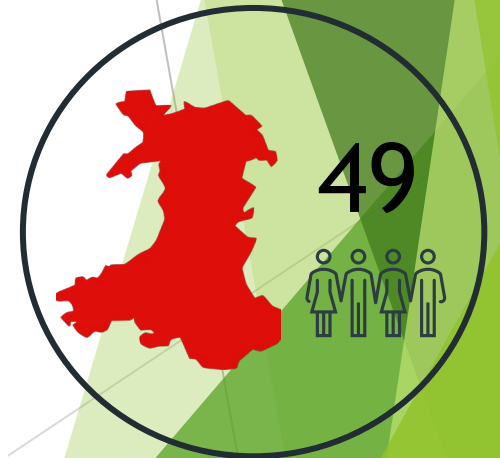
Trajectories of Outcome in Neurological Conditions

TONiC is a national study examining the factors that influence quality of life in patients with neurological conditions. Historically recruited to phase 2,3,4 - any new patients will be invited

Phase 5+6 is currently going through setting up process and assessing capacity at each site

It will include:

1. Questionnaire on diet/environment/occupation
2. Blood or saliva sample for genetics
3. Stool/urine sample



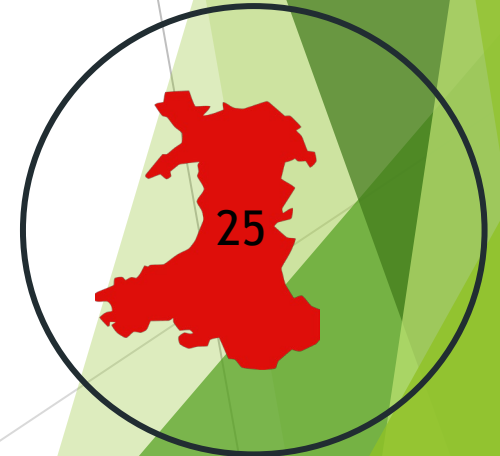
Peer to peer support

Virtual Peer-to-Peer Support for Informal Caregivers of Individuals with Motor Neurone Disease

Aims to determine the efficacy of a 12-week virtual peer-to-peer support programme on caregiver psychological health and caregiver burden.

Participants randomised to the intervention arm will have access to a 12-week online programme including:

1. Weekly, carer led, Zoom discussion forums
2. Minimum of a weekly text msg/check in and chat with a peer supporter
3. Two “Ask the expert” sessions
4. Discussion forums in which participants can post questions
5. Access to informational resources



OptiCALS

A Randomised Controlled Trial investigating if getting nutrition right for people living with MND can improve quality of life and survival.

The group allocated to receive the OptiCALS intervention will have a daily calorie target set that is informed by an ALS specific total daily energy expenditure (TDEE) predictive equation, their current calorie intake and the direction in which their weight is moving.

Participants will record their dietary intake using the myfood24 dietary assessment tool embedded within the OptiCALS online portal.

Participants will be encouraged to use the OptiCALS website which provides advice on how to meet their individual calorie goal and manage common barriers to eating and drinking faced by people living with MND.

The logo for OptiCALS, featuring the word 'OptiCALS' in a bold, sans-serif font. The 'O' is a black circle with a white dot in the center. The 'i' is black, and 'CAL' is black, while 'S' is orange. The entire text is enclosed in a black and orange rounded rectangular border.

MND-SMART
participants cannot co-
enroll

Gastrostomy decision making in MND



Research project aiming to understand how healthcare professionals, as individuals and part of multidisciplinary teams, support people with MND to make decisions about gastrostomy feeding tube placement.

Three MND clinics will be recruited as case study 'sites' - One of which is Swansea Bay UHB

A range of different data collection methods will be used including interviews of people with MND, caregivers and HCPs, a review of medical notes, focus groups with the MND MDT, documentation review and observation of practice.

In collaboration with the study participants, the findings will be used to develop professional guidance and recommendations for practice. The research and guidance will better inform MND MDTs how to organise the decision support they deliver to people with MND.



Recruited



University of
Sheffield

NIHR | National Institute
for Health Research

Microbiome

The aim of this study is to determine whether gut bacteria influence the development and severity of MND by comparing gut bacteria in MND patients and controls who have a matched diet, BMI and environment.

- ▶ This project will be the largest study to date to look at the gut microbiome as a factor in MND development, disease progression and severity.
- ▶ The results of this study may **help to guide clinical care in ALS**. The research could reveal the **gut microbiome as a new potential therapeutic target**.



Due to start
recruitment soon

TiM - Telehealth in Motor Neuron Disease



Online platform through which people living with MND, and their carers, can enter information about their condition on a weekly basis.

Their answers are then available to their MND care team, who can make plans to support the person living with MND. The platform allows patients/ caregivers to report progress and symptoms from their homes using a remote digital application.

Clinicians can remotely monitor patients and are alerted to concerns/ changes in their condition. Information leaflets and resources are linked to the TiM system ensuring patient's access to reliable and useful information.

Network lead has been invited by the research team to be a co-applicant in a TiM-add on which will aim to look at how specialist MND MDTs coordinate and communicate with non-specialist community teams.



6 participants
in SBUHB



University of
Sheffield

Research recently completed



▶ MND Diary Project

The MND diary project aims to improve healthcare for people living with MND, their families and carers by listening to people's stories about how they cope with MND in their lives and their experiences with healthcare.

▶ COMMEND

A feasibility study and randomised controlled trial of Acceptance and Commitment therapy for people with Motor Neurone Disease

▶ VentMND

Exploring end of life decision making with patients with Motor Neurone Disease (MND) using home mechanical ventilation: The perspectives of people with MND and families