



Trustee Annual Report April 2023 – March 2024

Thanks to our dedication of our volunteers and supporters, the charity has been able to continue to offer extensive services and support to our members as restrictions are eased from the worst of the pandemic. To accommodate our members who are unable to travel we have continued the majority of our services online with monthly meetings, craft classes and coffee afternoons, delivered by Zoom. This year our volunteers in Belfast, Lurgan and Portstewart organised in person meet-ups, giving a welcome opportunity for old and new friends to catch up! The online monthly meetings have the added advantage that our bed and house-bound members, all over N.I. and Ireland, are able to join in or watch back when health allows.

We are very grateful to the growing number of fundraisers and supporters who make it possible for the charity to continue offering support to patients who suffer from M.E., Fibromyalgia and Long Covid and to enable the charity to continue providing free educational programs and information packs to healthcare providers.

World M.E. Alliance

We were honoured to be accepted as associate members of World M.E. Alliance, a unique alliance of 21 M.E. organisations from around the world. Membership is made up of senior leads/representatives from National M.E. organisations, working together to achieve change for people with M.E. at a national and international level.

Hope 4 M.E. & Fibro Northern Ireland Charity Trustee and Committee Members

- Coordinator & Treasurer Mrs. Joan McParland (2011)
- Chairperson: Mrs. Linda Campbell (2022)
- Vice-treasurer: Mr. Hugh Boyle (2011)
- Member Secretary: Mrs. Catherine Lynch (2015)
- Parent Rep: Mrs. Eilidh Gilmore (2013)
- Admin Support &
Zoom Meetings Coordinator: Ms. Rachel Carlisle (2022)

Sub-committee Members
(Previously volunteers)
(Formally elected to sub-committee 2022 AGM)

Volunteer Advisor
 Annual Fundraiser
 Coin Collection Boxes Fundraiser (Bessbrook)
 Coin Collection Boxes Fundraiser (Portstewart).
 Craft Group Coordinator
 Craft Group Support/severe M.E. Liaison
 Craft Group/Admin support.

Mrs. Anne Norrie
 Gary Campion
 Jill Freeburn
 Heather Ward
 Claire Kennedy
 Aileen McCullough
 Kathryn McGowan

April Monthly Meeting

Queens University Belfast, research opportunity for our members on Fibromyalgia

12th May 2023 Annual Conference for Healthcare Providers (in-person)



Videos of speaker's sessions are available on our Website under 'Conferences' section. The highlight of the evening was that the two universities in Northern will be including M.E. education into the curriculum by using our 'Discover ME Experience' including information packs. CPD certificates were issued to all attendees. The closing slides from the universities below!

Plans for new content



- Year 5 Primary care rotation
- Case-based discussion based on 'Discover ME', and experience of real patients seen by students in practice
- Focus on attitudes, and management as per NG206.



Thank you for your partnership with us in training

"tomorrow's doctors"



Craft Group members provided a very moving display of their work, focused on visually depicting PEM (Post-Exertional Malaise)



To mark International ME and Fibromyalgia Awareness Day, various Council buildings were lit up blue!

In May 2023, Mrs. Joan McParland, our charity Founder, was awarded an MBE in the King's first Birthday Awards.

“For services to people with Myalgic Encephomyelitis and to their families and carers in Northern Ireland”

We are delighted with this recognition from the Government Cabinet Office in what we believe to be a first for Myalgic Encephomyelitis advocacy in the U.K.



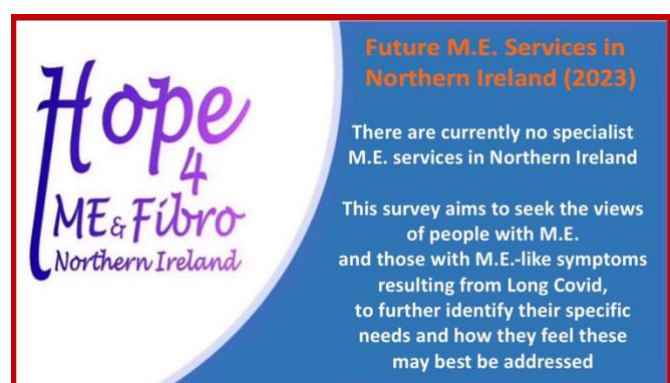
Tuesday 6th June Monthly Meeting

New in-person Coffee & Chat Meetings hosted in Belfast, Lurgan and Portstewart!



July 2023

In 2020, the Charity carried out a survey to assess patients needs and preferences, if an ME Support Clinic were to be established within Primary Care with a supportive Multi Disciplinary Team. There were many interesting results from this survey, which have been relayed in many circles since. It was always the intention to repeat and update this survey.



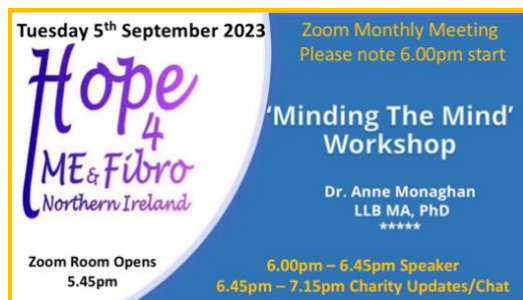
We are pleased to announce and share the link below with you, for the 2023 ME Survey: 'Future ME Services in Northern Ireland'. This has been developed in light of our very recent successful ME Conference, the new NICE Guideline for ME/CFS, our aim to meet with PHA Commissioners, and our endless push to establish Specialist ME services in NI.

We hope to use the results to positively influence the PHA and Commissioners of Healthcare Services in Northern Ireland. Please help us to progress such discussions, by giving us your views and experiences, as to how you would like to shape ME Services in Northern Ireland!

Read 'Future M.E. Services in Northern Ireland' (2023) full document here-
<https://1drv.ms/w/s!AjEToPrFeTbvpgGFYNheo0bz7cj6>

No online Monthly Meetings in July or August to accommodate charity event planning

September Monthly Meeting



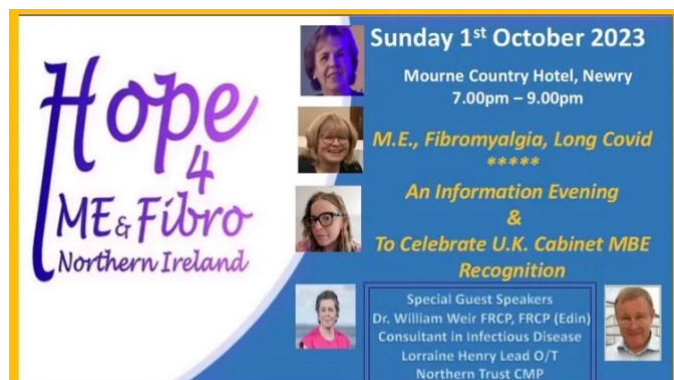
Dr. Anne Monaghan Workshop 'Minding the Mind' Focusing on supporting mental health whilst living with chronic illness.

26th September - Teams meeting Hope and Dominica Gilroy from the Public Health Agency N.O., re Opioid Improvement Collaborative - seeking our views and input.

October Newry Conference

We were delighted to bring Dr. Weir to Newry, to join us in celebrating Joan's MBE award and to catch up with new research developments!

Lorraine Henry Lead O.T. in the only M.E. Condition Management Programme in the Northern Trust, also provided patient management advice along with Linda and Joan giving an overview of M.E., Fibromyalgia and Long Covid, and what the charity is doing to address the lack of specialist services and the issues faced by patients.



November Monthly Meeting



Dr. Pamela Bell provided an update on services and issues specific to Fibromyalgia management.

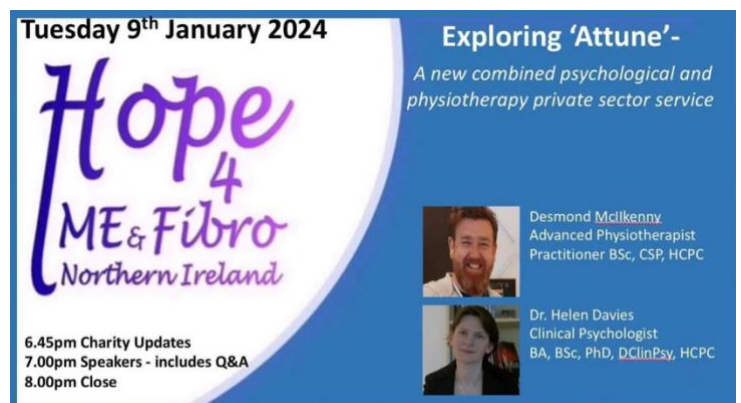
December Celebrations

The charity hosted two Christmas celebration events, in-person in Newry and online! Members were treated to festive music by the Ceili Chairde Music Group, we are grateful to our member Bernadette Smyth who is a member of and secured the group this year again!



February Monthly Meeting

Dr. Helen Davies and Desmond McKenny have an overview of their new combined 'Attune' clinic based in Moira.



Zoom Monthly Meeting

Hope
4
ME & Fibro
Northern Ireland

6.45pm Charity Updates
7.00pm Speaker
Includes Q & A
8.15pm Close

Tuesday 6th February 2024

Disability Action Facilitator
Norma Kelly



Disability Advice Service
&
Employment Advocacy programme

February Monthly Meeting

Disability Action Facilitator and member, Norma Kelly explained the help and support offered by the organisation.

March Monthly Meeting

Members requested guided breathing and meditation guidance provided by facilitator Becca from 'Rise Wellness' N.I. Centre.

Zoom Monthly Meeting

Hope
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ME & Fibro
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6.45pm Charity Updates
7.00pm Speaker
Includes Q & A
8.15pm Close

Wednesday 6th March 2024

Guided Breathing &
Meditation Session



Delivered by Becca
Specialist Facilitator
Rise Wellness N.I.