



## Trustee Annual Report 2022 – 2023

Thanks to our dedication of our volunteers and supporters, the charity has been able to continued to offer extensive services and support throughout the difficulties and restrictions caused by the pandemic. The majority of our services have remained online with monthly meetings, craft classes and coffee afternoons, delivered by Zoom. This has the added advantage of our bed and house-bound members, all over N.I. and Ireland, being able to join in or watch back when health allows.

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

We are associate members of World M.E. Alliance, unique alliance of 21 ME organisations from around the world. Our membership is made up of senior leads/representatives from national ME organisations, working together to achieve change for people with ME at a national and international level.

Our campaign for specialist NHS services for M.E. continues, through lobbying politicians and liaising with HSC officials, and academics in N.I.'s two universities to provide specific training on M.E. to be included in the medical curriculum.



The charity a member of the CPD Certification Service, in preparation for our 2023 in-person conference for healthcare providers, to be held in May and future, planned events. CPD stands for Continuing Professional Development and is the term used to describe the learning activities professionals engage in to develop and enhance their abilities. CPD is a holistic approach towards the enhancement of personal skills and proficiency throughout a professional's career.

### Charity Trustee and Committee Members

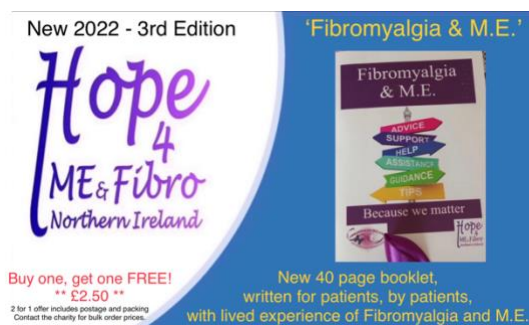
- **Chairperson & Healthcare Professional Education Officer:** Mrs. Linda Campbell (2022)
- **Treasurer & Coordinator:** Mrs. Joan McParland (2011)
- **Vice-treasurer:** Mr. Hugh Boyle (2011)
- **Membership Secretary:** Mrs. Catherine Lynch (2017)
- **Parent Rep:** Mrs. Eilidh Gilmore (2014)
- **Admin Support & Zoom Meetings Coordinator:** Ms. Rachel Carlisle ( 2022)

### Sub-committee Members ( Volunteers, formally elected to sub-committee January 2022 AGM)

- **Volunteer Adviser.** Mrs. Anne Norrie
- **Press Officer / Fundraiser** Gary Campion
- **Coin collection boxes/fundraiser (Bessbrook & Newry).** Jill Freeburn
- **North Coast Hub and Fundraiser** Heather Ward
- **Lurgan Hub** Rosalind McKinley
- **Craft Group Coordinator** Claire Kennedy
- **Joint Craft Group Coordinator/Severe M.E. Liaison** Aileen McCullough.

A key activity of the Charity is supporting members with monthly meetings where we invite keynote speakers to provide members with information to help manage their illness

We produced a third edition of our joint booklet with Gemma Flood, Coordinator of 'Fibromyalgia Ireland.' The booklet is a collection of self-help tips, compiled by M.E., Fibromyalgia and Long Covid patients, for patients!



**The HOPE online Craft Group** is also helping address isolation and inspire a growing number of members to share and learn new creative talents.

\*\*\*\*\*

**The HOPE Coffee & Chat Zoom** meetings continue to be popular for peer support and online socialising.



A number of Zoom meeting were held with representatives from **CAPITA** to discuss the difficulties faced by M.E., Fibromyalgia and Long Covid patients when applying for health related benefits.



We were delighted that various N.I. health departments agreed to share the first ever designated World M.E. Day 2022 by sharing link to our partner organisation World M.E. Alliance website!

**Detailed below is a list of the monthly meetings held from April 2022 to March 2023.**

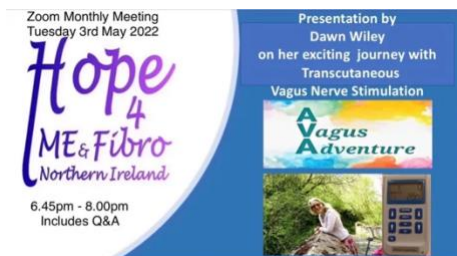


**5<sup>th</sup> April 2022**

Speaker – Joan Crawford Chartered Counselling Psychologist

– Practitioner Psychologist HCPC Registration

Topic – A reflective space to share feelings, garner hope and collectively come together to share hopes and fears.



**3<sup>rd</sup> May 2022**

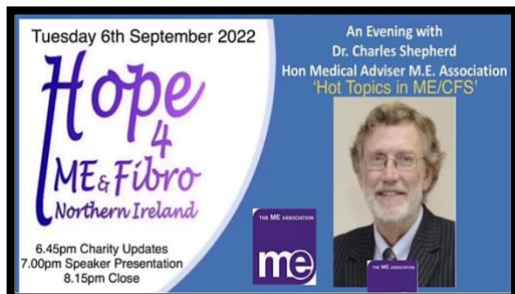
Speaker – Dawn Wiley

Topic – A presentation by Dawn Wiley on her exciting journey with Transcutaneous Vagus Nerve stimulation.

**7<sup>th</sup> June 2022**

Speaker – Ashley Montgomery Advanced Practitioner Physiotherapist  
Pain Management Pain Clinic Ulster Hospital

Topic – Me and What Matters



**6<sup>th</sup> September 2022**

Speaker – Dr Charles Shepherd Hon Medical Adviser M.E. Association

Topic – 'An evening with Dr Charles Shepherd

**22<sup>nd</sup> September 2022**

Volunteer Rosalind McKinley launched and hosted a new Lurgan Hub Topic – Tea & Chat Self Help Group. Thanks to volunteer Rosalind McKinley New Lurgan Branch Leader for facilitating this monthly event.



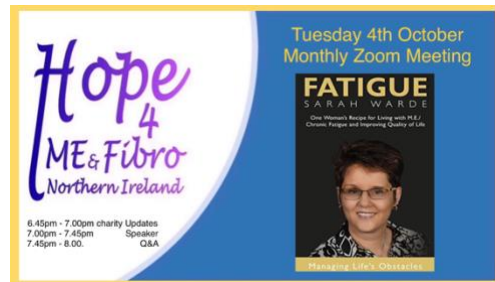
**August - September 2022 (online)**

Speaker – Sinead McParland Promoting Wellbeing Division Southern Health and Social Care Trust  
Topic – Chi ME



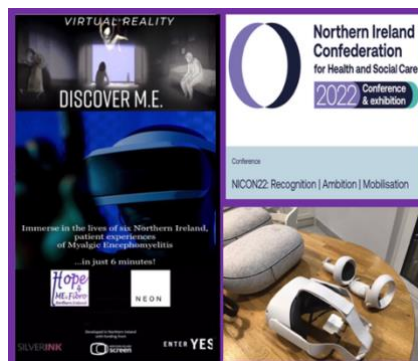
**4<sup>th</sup> October 2022**

Speaker – Sarah Warde  
Author of new book on managing fatigue



**20<sup>th</sup> October 2022 NICON (Northern Ireland Confederation for Health and Social Care) Annual Conference**

We launched 'Discover M.E. Experience' at NICON 22 first in-person conference for healthcare providers since the pandemic. Delegates watched 'Discover ME' film via virtual reality headsets, on average rated the film 9/10 for raising awareness of the lived experience of ME/CFS. (Max score was 10 being excellent)



**1st November 2022**

Innovation Recovery facilitator provided an informative session focused on ‘Getting a Good Night’s Sleep’



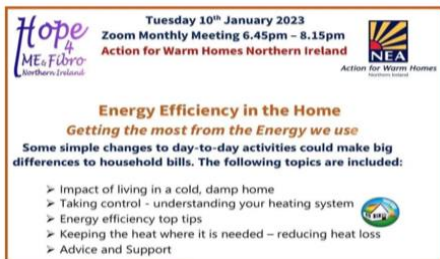
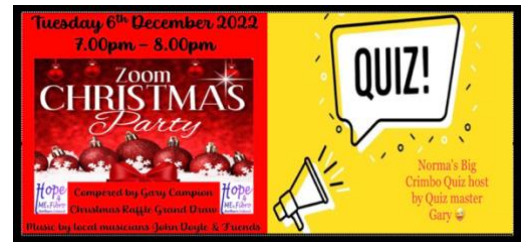
**November 2023 Newry Mourne and Down District Council kindly** hosted an official celebration event to mark the charity being awarded the Queen’s Award for Voluntary Services.

**December 2022 Annual Christmas Party**

Volunteer Gary Campion compared our annual Online Christmas party and quiz. Christmas dinners were provided for house/bed bound members.

**PHA Warm Packs** we’re provided to members in the NMDD Council areas.

1 year FREE subscriptions were provided to members wishing to use **CALM App for improving self-management.**



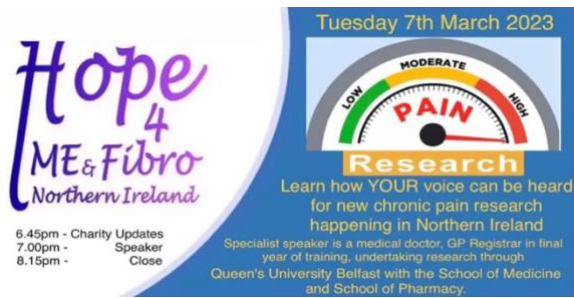
**10th January 2023**

Topic- Action for Warm Homes facilitated a session on energy efficiency in the home.

**Tuesday 7th February 2023**

An introduction to PATTERNS App, a self-help, management tool for pain.



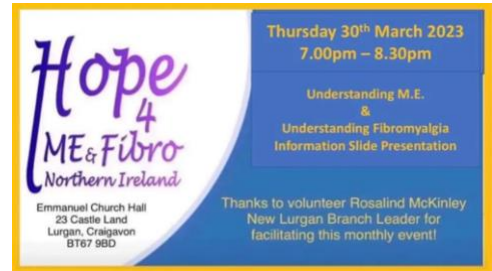


**Tuesday 7<sup>th</sup> March 2023**

Queens University Belfast, School of Medicine and School of Pharmacy research information and recruitment session.

**30<sup>th</sup> March 2023**

Lurgan Hub meeting topic, Understanding M.E. and Fibromyalgia slide presentation.



I wish to offer my sincere thanks as Founder of the Charity in 2011, to the Trustees, Committee and Sub-committee, who all work tirelessly, on a voluntary basis, to raise awareness and provide educational events for healthcare providers on behalf of the patients we represent. Our governance committee is made up of patients and our family members, without whom, none of what we do would be possible.

Keep up to date with the charity work and services here: <https://hope4mefibro.org/>

*This report has been compiled by Mrs. Joan McParland MBE and content agreed by all Trustees. 31/07/2023*