

MINUTES OF MND SCOTLAND 40th AGM

HELD ON WEDNESDAY 15th MARCH 2023

ONLINE VIA ZOOM 6:30pm

PRESENT & APOLOGIES	
See Appendix 1	

GOVERNANCE	
1.0	Chairman' s Welcome
	<p>At 6.30 pm and the meeting being quorate¹, Adrian Murphy, Chairperson, welcomed Members, Staff, Trustees and the Auditor to the AGM. He reflected on:</p> <ol style="list-style-type: none"> 1. The last 18 months have been a period of transformational change for the charity following the appointment of Rachel Maitland as CEO in July 2021. 2. There have been significant changes across both the Board of Trustees and the Employee team. During the year we seen the departure of the Head of Direct Services (Rosalyn Scholaris), the Head of Finance (Andrew Luke) and the Head of Fundraising (Iain McWhirter) and the recruitment of a new Executive Leadership Team. 3. The launch of the new 3-year strategy and new branding. <p>The Chair confirmed that the changes alongside the impact of covid resulted in a delay in holding AGM with an extension granted by HMRC for submission of accounts for financial year 21/22.</p> <p>The Chair confirmed the format of the meeting and proceeded to Agenda Item 2.0</p>
2.0	Apologies for Absence
	The Chair confirmed that several apologies had been received and these would be recorded in the Minutes Appendix.
2.0	Minutes of the 2021 40th AGM
	The Chair confirmed that the Minutes of the 2021 40 th AGM were made accessible via the website. The CEO made apologies and highlighted due to a technical problem with the website on the 15/3/23 the link to the minutes was unavailable. The Chair proposed the minutes and this was seconded by Linda Reid. The Minute was unanimously adopted as a true and accurate record.
3.0	Annual Review
	<p>The Chairperson introduced the CEO, Rachel Maitland, who reflected on the 2021/2022 challenges and achievements, highlighting:</p> <p>The financial year 21/22 continued to be marked by the impact of the coronavirus pandemic across all of the charity's activities with face-to-face fundraising and services on hold. However,</p>

¹ Quorum = 20

we remained focused on our vision of a world without MND and mission to find a cure and deliver and transform care.

Key achievements

Transformational Care

- For the people with MND time is precious. MND Scotland strives to help when time matters most providing a helping hand of support, so the people living with MND can make time count with the ones they love. In 2021/2022:
- 107 people with MND were supported to:
 - Move into homes that met their needs.
 - Access adaptations to stay where they were already living.
 - Access care packages that meant they could live longer in their homes with comfort and dignity
- 346 people with MND gained £814k of income, accessed by our Welfare & Benefits Team. This allowed them to feel less anxious and stressed about their finances meaning they and their families could get on with having fun, building precious memories and making time count.
- 556 hours of counselling were provided to people with MND, their carers and family members and bereaved carers and family members, helping them to work through their feelings.
- 222 people with MND and their carers accessed the newly introduced Wellbeing grant to pay for Complimentary Therapies such as relaxing massages and reflexology, manicures, pedicures, hair styling and beard trimming.

Innovative Research

The financial year 21/22 seen transformational change in the MND Research Programme, with several new appointments including the Chair of the Research Committee, Chair of the Scientific Advisory Panel and the addition of a new post (Head of Research). This has facilitated a range of improvements in the structure and governance of our activities.

MND Scotland continue to support five separate research award schemes to a total funding commitment per annum close to £750,000 including PhD Studentship; Academic research; Clinical Research Fellowship and Gordon Aikman Scholarships.

3. Clinical trials, specifically MND-SMART funded over 5 years (2018-23, £300,000 pa)
4. Awareness of MND research has been enhanced as a result of the high profile 'United 2 End MND' campaign, of which MND Scotland is a key partner alongside the MND Association and My Name's Daddie Foundation. Initiated and led by patient campaigners, in November 2021 this secured a pledge of £50million from the UK Government for research into MND.
5. In March 2022, MND Scotland committed £250,000 to a LifeArc-led Consortium to establish a UK wide MND Translational Research Institute. This £4.25 million initiative is a true partnership of the three leading MND charities in the UK, the Medical Research Council and National Institute for Health Research, and leading MND researchers in the UK.

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	<p>Fundraising</p> <p>The Director of Fundraising, Chris O’Sullivan shared a PowerPoint presentation highlighting various fundraising activities undertaken by MND Scotland supporters throughout the period. This covered detail on a range of different fundraising streams, which included Community & Events fundraising, Corporate Partnerships (including, Chivas, Scotrail, Heart of Midlothian FC) and Individual Giving & Legacies.</p> <p>COS acknowledged the enormous generosity which the charity relies on and makes MND possible. He recognised the strength of feeling and support for MND Scotland and provided thanks for every donation.</p> <p>The CEO gave thanks to MND Clinical Nurses and Consultants, fundraisers, staff and board of trustees for their ongoing support and contribution over the past year. She extended thanks to all attendees at the AGM, for taking time to attend.</p> <p>The CEO again provided many thanks for support shown and confirmed it was a privilege to be the CEO of MND Scotland.</p>
4.0	<p>Treasurer’s Report</p>
	<p>The Vice Chair, Liz McRobb was introduced to speak on the Treasurer’s Report. The Chair confirmed that David McGraw, Treasurer had recently stepped down from his position of Treasurer for personal reasons. The Vice Chair expressed gratitude to David for his long standing contribution as Treasurer/Trustee. She advised that having been a member of the Finance, Risk & Audit Committee for the last year she was delighted to step in and present the Treasurer’s report for the Financial Year Ended 31 March 2022.</p> <p>The Vice Chair confirmed that in accordance with the rules, the Annual Accounts had been approved at the Board of Trustees Meeting 09/02/23 and were now presented to the AGM. Directing Members to their copies of the accounts available on the website, she highlighted key points, including:</p> <ol style="list-style-type: none"> 1. The Statement of Financial Activities shows net expenditure for the year of £723,603 for the year ended 31 March 2022, compared to £51,559 in the prior year. As a result, the charities reserves fell from £4,873,596 to £4,149,993. 2. The Charity’s income increased by 4% from £2,154,708 to £2,231,361. Whilst this is a small increase in income, we are encouraged we can grow on this in the year ahead as we start to reintroduce fact to face fundraising events and strength our fundraising team post pandemic. 3. The Charities Expenditure increased by 29% from £2,342,852 to £3,012,763, the cost of raising funds increased from £360,536 to £453,536 and cost of Charitable activities increased from £1,982,316 to £2,559,227. Aside from increased staffing costs some of the key increases were grants made to people with MND increased from £213,249 in 20/21 to £479,470 (paid to 313 individuals) in 21/22 (primary driver was the introduction of the Wellbeing Grant as face-to-face activities were not possible during the pandemic); We also increased provision of equipment to people with MND with spend increasing from £99,925 to £216,369. 4. Unrestricted General Fund reserves fell from £3,902,143 to £3,483,376. The charity’s outstanding research commitments as of 31 March 2022 were £1,580,560. This includes

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	<p>£519K in relation to MND Smart Clinical Trials (of which £372K is held in designated funds); £250k in relation to Life Arc led consortium to establish a UK wide MND Translational Research Institute; and in January 2023 we secured a further £227k in funding from the UK Government Covid Medical Research Charity Support Fund in relation to committed research projects for the financial year 22/23.</p> <p>Completing the Treasurer's update the Vice Chair introduced Allison Devine, senior statutory auditor for Alexander Sloan Accountants and Business Advisers to provide the Auditor's Statement.</p>
5.0	Auditors 22/23
	<p>Allison Devine of Alexander Sloan, Auditors confirmed the financial statements reported on the period to 31st March 2022.</p> <p>Independent of MND Scotland, Board of Trustees and Executive Leadership Teams the auditor confirmed it was their responsibility to provide an independent view of MND Scotland to its members as to whether the financial statement prepared provided a true and fair view of the financial position of the charity.</p> <p>She advised that the Treasurer had given an excellent overview of the accounts and then referred to the principal Auditors report, confirming the auditors are satisfied that:</p> <ol style="list-style-type: none"> 1. the accounts give a true and fair view 2. the accounts are prepared in accordance with relevant legislation and regulations that are required for a Scottish charity 3. For comfort of the members, a few inclusions within the auditors report were highlighted as follows: <ol style="list-style-type: none"> 3.1 Viability of the Charity – The charity is a going concern for the period of 12 months ahead – with no concerns. Taking into account the extensive obligations and commitments under Research projects, the charity has good reserves and the accounts continue to show that MNDS is in a strong financial position. 3.2 Exception Report – The auditor confirmed that appropriate and accurate records are being maintained by MND Scotland. Financial statements are presented in accordance with underlying records and there is a satisfactory system of controls and procedures. Good information and explanation necessary has been provided to enable the auditors opinion. There were no deviations or adverse matters to report. 4. In summary, the auditor's statement contained within the financial statements is referred to as a clean, unqualified, unmodified audit report, providing a high level of assurance for the Board of Trustees and members. <p>The Auditor thanked the CEO, Board and Finance staff for allowing Alexander Sloan to complete the audit. The Auditor invited questions. No questions were raised.</p>
6.0	Auditors 2022/23
	<p>The Chair informed the AGM attendees that after many years audit service from Alexander Sloan, the Board are currently seeking tenders for the audit of financial year 2022/23, with the successful firm to be appointed in due course.</p> <p>The Chair thanked Alexander Sloan for the long and good relationship.</p>

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7.0	Board appointments
	<p>Following a period of Trustee recruitment in November 2021. The Chair acknowledged the following Board of Trustee Appointments</p> <ul style="list-style-type: none"> ▪ Liz McRobb (Vice Chair) 26/11/21 ▪ Graham Binnie 25/11/21 ▪ David Buglass 25/11/21 ▪ Myles Fitt 25/11/21 ▪ Deborah Atkins 25/11/21 ▪ Donald McLeod (<i>son of charity founder who was recently appointed in December 2022</i>) <p>The Chair also acknowledged the following Trustees who have stepped down during the year and thank them for their contribution.</p> <ul style="list-style-type: none"> • Carrie-Anne Carson 28/2/22 • Carole Ferguson 10/8/22 • Fiona King 28/2/22 • Graeme Hardie 12/10/22 • David McGraw (<i>not detailed in accounts – resignation Feb 2023</i>) <p>Concluding the AGM procedures, the Chair opened up the AGM for any member questions. A lengthy discussion was held on many sensitive and heartfelt areas, namely – the progress towards a cure and the challenge of moving through the necessary steps to deliver good science against the time pressure people face living with MND – and the structural challenges with social care provision in particular.</p> <p>Following discussion on the MND Smart Trial, a proposal to provide a focus presentation on the MND Smart Trial was put forward as an agenda item for the next AGM .It was agreed it would be beneficial to arrange given some of the member concerns raised and desire for an update,. The Board Secretary noted this as an Action for the next AGM.</p> <p>Scott Bryson, Co Chair of the Scientific Advisory Panel contributed to the research discussion by recognising the difficult balance the charity faces funding the MND Smart Trial. He stressed, that in terms on clinical trials, the MND Smart Trial has gained excellent international respect and reputation. He provided further assurance that evaluations undertaken indicate enough promise and early progress to continue with the long term research strategy and investment.</p> <p>SB confirmed he would be happy to address any member concerns offline.</p> <p>The current grants offerings was also raised, with the current high cost of living, a few members expressed their view that the grants were financially inadequate, dated and in need of an urgent review. A number of member recommendations for approval were put forward.</p> <p>The CEO agreed that the grants system has been long overdue by confirming this has been recognised and that the charity is currently reviewing the grants systems in addition to growing the support services by investing in advocacy services and the welfare & benefits team in order to best support people with income maximisation. Sharon Gillies, Director of Operations confirmed that member points raised would be taken into account whilst the review in being undertaken and that the new grants offerings would be launched in April 2023.</p> <p>Bringing the AGM to a close, the CEO confirmed that the Charity are highly alert to members concerns and experiences as they are key to helping the charity make progress, champion hope and lead the fight against MND.</p>

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The Chair recognised it had been an emotional and intense meeting and a much need reminder of the cause. The Chair thanked everyone who contributed to the discussion, for expressing and sharing their very touching and personal experiences.

The Chair brought the meeting to a close at 8:00pm

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Appendix 1

In attendance		
1	Adrian Murphy	Chair MND Scotland
2	Alastair Semple	MND Staff (temp)
3	Alison Devine	Alexander Sloans
4	Angela Kubski	MND Staff
5	Bill Bonar	member
6	Brian Murphy	member
7	Carole Ferguson	member
8	Chris O'Sullivan, Director of Stakeholder, Engagement & Fundraising	MND Staff
9	David Arthur	member
10	Deborah Atkins	Trustee
11	Donald MacLeod	Trustee
12	Dougal Campbell	member
13	Fiona M McOwan	member
14	Gemma Catton	member
15	Graham Binnie	Trustee
16	Graeme Hardie	Member (former Trustee)
17	Greta Auld	member
18	Jenny Leitch	member
19	Jim Maxwell	member
20	John Gilbertson	member
21	Kenneth Page	member
22	Lesley Campbell	member
23	Linda Reid	Trustee
24	Liz McRobb	Vice Chair MND Scotland, Trustee
25	Margaret Kennedy	Trustee
26	Myles Fitt	Trustee
27	Rachel Maitland, CEO	MND Staff
28	Scott Bryson	Trustee
29	Sharon Gillies, Director of Operation	MND Staff
30	Sheila James	member
31	Shuna Colville	member
32	Steven Pert	member
33	William Hendry	member
Apologies		
1	John Glendinning	
2	Sonya Davidson	
	Rena Moore	
4	Robert Elliot	
	Owen McGhee	
6	Alan Barr	
7	Colin Hunter	

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