
MYELOPATHY.ORG

TRUSTEES' REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 30 JUNE 2023

CONTENTS

	Page
Reference and administrative details of the charity, its Trustees and advisers	1
Trustees' report	2 - 12
Independent examiner's report	13
Statement of financial activities	14
Balance sheet	15
Notes to the financial statements	16 - 24

**REFERENCE AND ADMINISTRATIVE DETAILS OF THE CHARITY, ITS TRUSTEES AND ADVISERS
FOR THE YEAR ENDED 30 JUNE 2023**

Trustees

Dr Mark Kotter
Mrs Weslie R Janeway
Ms Helen J Wood
Dr Johann Graggaber (resigned 12 December 2023)
Ms Carol Sun
Mr David Townshend
Mr Iwan Lloyd Sadler
Mr Roy Smith (appointed 6 January 2023)
Dr Eldrid Herrington (appointed 22 May 2023)

Charity registered number

1178673

Principal office

Lakin Rose
Pioneer House
Vision Park
Histon
Cambridge
CB24 9NL

Independent examiner

C P J Dougherty, FCA
Lakin Rose Limited
Pioneer House
Vision Park
Histon
Cambridge
CB24 9NL

**TRUSTEES' REPORT
FOR THE YEAR ENDED 30 JUNE 2023**

The Trustees present their annual report together with the financial statements of the Myelopathy.org for the year 1 July 2022 to 30 June 2023.

Objectives and activities

a. Policies and objectives

To advance health and education in all aspects of Degenerative Cervical Myelopathy (DCM) in particular but not exclusively by:

1. Supporting and funding scientific research into all aspects of DCM and ensuring the useful results of such research are publicly disseminated.
2. Raising awareness and understanding of the condition in all its forms including sharing current research and healthcare information.
3. Supporting and promoting improved physical and mental outcomes for patients including establishing support for patients, carers and health professionals.

In setting objectives and planning for activities, the Trustees have given due consideration to general guidance published by the Charity Commission relating to public benefit, including the guidance 'Public benefit: running a charity (PB2)'.

b. Main activities undertaken to further the charity's purposes for the public benefit

(1) Research

The following section summarises the projects that Myelopathy.org has been involved in which further our first charitable aim, to support research in the field of DCM. Below we have included further explanations of each of the projects which in each case are being done to better understand the condition and the best ways to treat it, in order to improve the lives of the people affected by it. We believe that this is for the future public benefit and fulfils our obligations as trustees.

AO Spine RECODE DCM - transition to Myelopathy.org

Myelopathy.org has continued to partner with AO Spine RECODE DCM, an international consensus initiative to involve people with DCM alongside healthcare professionals, in the design and direction of DCM research. Myelopathy.org has taken the lead in managing this collaboration during the year after entering into a 3-year transition agreement with AO Spine In May 2022 to ensure the efficient handover of the RECODE DCM project to Myelopathy.org.

During 2022-2023 Myelopathy.org has worked with a project manager to develop a strategy to both fund and manage the RECODE DCM network.

In October 2022 we established a Steering Committee to strategise and guide this scientific expansion. We are very grateful to this team of experts, with both lived experience and professional experience of Degenerative Cervical Myelopathy (DCM), who have risen to the challenge of resolving key scientific and clinical problems.

TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2023

Objectives and activities (continued)

RECODE-DCM Steering Committee

David Anderson, physiotherapist, Australia
Tammy Blizzard, person with DCM, USA
Tim Boerger, person with DCM, USA
Chad Cook, physiotherapist, USA
Sheila Dugan, person with DCM, USA
Michael Fehlings, neurosurgeon, Canada
Julio Furlan, neurologist, Canada
James Guest, neurosurgeon, USA
Manabu Ito, orthopaedic surgeon, Japan
Sukhvinder Kalsi-Ryan, physiotherapist, Canada
Mark Kotter, neurosurgeon and co-founder of Myelopathy.org, UK
Abdul Lalkhen, pain specialist, UK
Anna MacDowall, orthopaedic surgeon, Sweden
Allan Martin, neurosurgeon, USA
Esther Martin-Moore, person with DCM, UK
James Milligan, family doctor, USA
Aria Nouri, neurosurgeon, Switzerland
Iwan Sadler, person with DCM and co-founder of Myelopathy.org, UK
Lindsay Tetreault, neurologist, USA
Caroline Treanor, physiotherapist, UK
Luiz Vialle, orthopaedic surgeon, Brazil
Lianne Wood, physiotherapist, UK
Carl Zipser, neurologist, Switzerland

The RECODE-DCM research network now has over 1000 professional members from over 15 different healthcare disciplines.

RECODE-DCM Incubators

The goal of our incubators is to resolve the Top 10 Research Priorities that were identified through the AO Spine RECODE-DCM study, in which AO Spine and Myelopathy.org brought together all key stakeholder groups to pinpoint the most crucial questions in DCM. Our international, multidisciplinary incubator teams meet regularly via Zoom to conduct research and share expertise. We sincerely thank all of our incubator members for sparing their time and energy to propel the incubators forward.

The Diagnostic Criteria Incubator is working on the world's first set of reliable diagnostic criteria for DCM. Early diagnosis is the key to optimal outcomes. At present, people with DCM wait an average of 2 to 5 years for a diagnosis; however, treatment within 4 months is associated with the best chance of a full recovery. Our incubator's mission is the publication and widespread uptake of robust diagnostic criteria. Papers have been submitted for publication and are now under review.

The **Natural History Incubator** is working to understand how DCM begins and develops. The group is looking at management of asymptomatic spinal cord compression, and identifying the factors associated with progression into symptomatic DCM. Comprehensive knowledge of the disease course will open avenues for effective intervention.

The **Perioperative Rehabilitation Incubator** is examining non-operative aspects of DCM management and developing an enhanced recovery pathway for patients prior to, during, and after surgery. The growing team is bringing in fresh perspectives from diverse disciplines, to identify the required domains of care and create best-practice frameworks.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2023**

Objectives and activities (continued)

Myelopathy.org Research Prize

During 2022 Myelopathy.org launched its inaugural research award for best piece of research aligned with a RECODE-DCM Top 10 Research Priority:

- 1 Raising Awareness of DCM
- 2 Natural History
- 3 Diagnostic Criteria
- 4 Assessment and Monitoring
- 5 Biological Basis
- 6 Peri-Operative Rehabilitation
- 7 Novel Therapies
- 8 Socio-Economic Impact
- 9 Imaging and Electrophysiology
- 10 Individualising Surgery

The RECODE-DCM Management Committee conceived this new award in order to stimulate high-quality research focussing on the questions that matter most to people with DCM. In its first year, our contest attracted high-quality competitors from as far afield as India, China, Canada and Portugal. Submissions were received in all categories except 2, Natural History and 9, Imaging and Electrophysiology. The most popular categories were 1, Raising Awareness and 7, Novel Therapies.

The 2022 winner was Dr Michael G Fehlings from Toronto, Canada for his paper, The influence of ApoE4 on the clinical outcomes and pathophysiology of degenerative cervical myelopathy by Alexa Desimone, James Hong, Sydney T Brockie, Wenru Yu, Alex M Laliberte and Michael G Fehlings.

RECEDE Myelopathy [Regeneration in Cervical Degenerative Myelopathy] (University of Cambridge and National Institute for Health Research)

Phase III, double blind, placebo randomised controlled efficacy study of Ibudilast (a medicine) as an additional therapy to decompressive surgery (the gold standard treatment) for DCM. Ibudilast is a medicine currently under investigation for treatment of Multiple Sclerosis, Motoneuron Disease (ALS) and Brain Tumours. Myelopathy.org continues to support this clinical research trial.

POLYFIX-DCM

(University of Cambridge and National Institute for Health Research).

Myelopathy.org is a partner and supports this clinical trial to compare two types of surgery for DCM. We have brought the voice of people with DCM to the design of this clinical trial.

The first patient was recruited to the trial at Addenbrooke's Hospital in Cambridge on 7 July 2023 and a further 13 sites have opened and started recruiting patients during the year.

Decision Making in DCM (SHARED-DCM) (Formerly DCM COINS)

In May 2021, Myelopathy.org was awarded an Evelyn Trust Health and Wellbeing Grant to help lay the foundations for quality shared decision making (SDM) in Degenerative Cervical Myelopathy (DCM) in two ways: First, developing a Core Information Set (CIS) for DCM to support the "Preparation Phase". A CIS represents a baseline information "checklist" intended to facilitate a dialogue between patients and professionals in order for patients to make better value-based decisions about their healthcare when multiple options are available. A DCM CIS was proposed, recognising that patients currently struggle to find information about DCM and have no general knowledge, making it difficult for them to enter into a SDM process.

Second, process mapping the care pathway in DCM, to establish the key points at which decisions are made, and if/how a SDM process can be supported. We anticipate that a detailed map of the DCM care pathway could also support other areas of DCM research.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2023**

Objectives and activities (continued)

Core Information Set

During the first step of this work, we conducted a review of the existing educational content sources. Scientific publications, videos, health websites and patient leaflets were included. Our analysis showed that an overwhelming majority (80%) of resources are geared towards professionals, leaving patients with limited resources to improve their knowledge.

Next, we wanted to understand the perspectives and information needs of people with DCM. We conducted and analysed qualitative, semi-structured interviews from twenty people with DCM recruited from the Myelopathy.org Support Group on Facebook. Preliminary results indicated critical, wide-ranging knowledge deficiencies on the topics of the condition and its trajectory, pre- and post-operative guidance, finances, employment, and mental health management.

We then entered the CIS development phase. Using robust methodology (the Delphi consensus procedure) and the input of key stakeholders we refined and agreed on a final DCM Diagnosis CIS. This was completed during 2023 and this tool is now being validated at Addenbrooke's Hospital in Cambridge to demonstrate its effectiveness in clinical practice.

Process Map

The process mapping exercise also commenced during 2023 and people with DCM, their supporters and clinicians were invited to participate in a comprehensive semi-structured interview conducted online, via Zoom. Interviews focussed on understanding a number of aspects related to the clinical care pathways associated with DCM, including:

- The timepoints at which decisions need to be made
- The nature of decisions under consideration
- The magnitude (level of risk / importance) of decisions under consideration
- The information required to support each decision under consideration.

The process map(s) will be developed iteratively and validated by all key stakeholders who contribute to the study. We are taking an international approach, inviting the participation of stakeholders from all over the world, to ensure a globally shared understanding of DCM care. This is key as, ultimately, the process map will inform the design and implementation of SDM tools.

Patient Decision Aid

One of the common tools used to help patients participate in decision making is called a patient decision aid. This can take a variety of different formats but aims to help the patient understand the context of the decision, and help them define and articulate their priorities, whilst presenting the pros and cons of different options. Myelopathy.org and RECODE-DCM are working with a team from the University of Melbourne, Australia, to produce a "Should I Have Surgery?" patient decision aid. Why Is This Considered Part of the RECODE-DCM Toolkit?

Whilst SHARED-DCM and its resources may appear more applicable to clinical practice than research, we have included these resources within the toolkit for a number of reasons:

1. Ensuring that research participants are well informed is a critical part of consent into research. The CIS may have a role here.
2. Understanding the DCM care pathway can help investigators refine their recruitment strategies (e.g. where, how, and by whom should participants be recruited?). The process map may have a role here.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2023**

Objectives and activities (continued)

3. It can also help understand how their evidence will contribute to practice; perhaps to refine the research question or design, but also to inform their planned implementation strategy (e.g. who are the key stakeholders?). The process map may have a role here.

(2) Awareness

This section describes the activities of Myelopathy.org has been involved in furthering our second charitable aim, to raise awareness of DCM.

Myelopathy.org website and branding

Following the launch of our new website and rebrand of Myelopathy.org in April 2022 our website has continued to be the 'shop front' of all that we do at Myelopathy.org. This fresh look and improved content has continued to have a positive impact on all our community making it easier to access much needed information about DCM.

In April 2023 we launched the second version of our new website following feedback received after the April 2022 launch. This second version is a more visually appealing and user-friendly experience. We especially want to thank our trustee Carol Sun-Schuster for leading this project and working together with our volunteers Heather Bidwell and Josef Hejzman in making this happen.

Most importantly, we've added a new and improved Research section. This contains detailed information on the RECODE-DCM initiative and Myelopathy.org's spin-out research program in Degenerative Cervical Myelopathy (DCM).

Myelopathy.org Signposting Leaflet

Following feedback gained during our conversations with the RECODE -DCM steering committee we have produced a signposting leaflet which can be given to people with DCM at appointments with healthcare professionals. This simple leaflet is something which a person with DCM can take away from an appointment and signposts them to our website and support group.

We distributed this to delegates at BRITSPINE and have continued to circulate it to healthcare professionals throughout the year. The leaflet is available to download from our website.

Weekly Blog

Following its launch in April 2022 we have continued to publish a weekly blog post which includes interviews with volunteers, updates from our support group and articles about DCM research. All our blogs are available to listen to as well as read as people with DCM sometimes find it more comfortable to listen to content rather than read it.

Myelopathy Matters PodCasts

Myelopathy Matters is a PodCast series produced by Myelopathy.org and series 4 was launched in February 2023. The aim of the PodCast is to bring the latest information on living with, managing and understanding DCM, through expert guests from around the world.

PodCasts are a popular medium, and well suited for listeners with DCM, who may become uncomfortable sitting watching a screen for example.

Google Ads

Myelopathy.org has continued to benefit from the Google Ad Grant awarded during 2022-23. This has enabled Myelopathy.org to take advantage of the \$10,000 USD monthly budget of in-kind Google Ads advertising credit through the Google Ad Grants program.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2023**

Objectives and activities (continued)

Our Google Ads campaigns has focused on two key objectives in different geographical locations:

1. targeting aware groups
2. targeting non-aware groups

BRITSPINE 2023

Myelopathy.org was chosen as the nominated charity for The UK Spine Societies Board (UKSSB) 2023 conference which was held at the Scottish Event Campus from April 18-20 2023.

Trustees Helen Wood and Roy Smith, together with our co-founders Mark Kotter and Benjamin Davies and Liz Roberts our RECODE-DCM project manager attended as representatives of the charity. The conference attracted over 600 delegates across the spine care profession and we were allocated a Myelopathy.org booth in the exhibition hall, which attracted a busy stream of visitors. Delegates signed up to our RECODE-DCM research network and took away information about our support groups and research program to share with patients and colleagues. We showed our new signposting leaflet to hundreds of delegates, asking them to print it to hand out to their patients.

The program had a strong focus on Degenerative Cervical Myelopathy (DCM), with enlightening talks from orthopaedic surgeon and RECODE-DCM collaborator Dr Brian Kwon (Vancouver, Canada), Myelopathy.org Co-Founders Dr Benjamin Davies and Dr Mark Kotter, and Scientific Adviser Dr Michael Fehlings, alongside many of our RECODE-DCM Steering Committee and Incubator members. Co-Founder Iwan Sadler, although unable to attend in person, linked in virtually with a highly engaging video describing his struggle for a diagnosis and stressing the importance of early recognition of DCM to all those who treat spine patients. The Glasgow meeting was a long-awaited opportunity for the community to come together, after the previous BritSpine was cancelled due to COVID-19.

At the conference dinner, the charity was the beneficiary of a fundraising raffle. Helen Wood gave a rousing speech in support of Myelopathy.org and managed to raise £4500. In conclusion, Myelopathy.org's success in raising awareness of DCM at BritSpine proves the importance of spreading the word and making connections at scientific conferences. Relevant Content Shared at BritSpine to Help Raise Awareness of DCM

Keynote Speeches

Dr Mark Kotter: An Update on Degenerative Cervical Myelopathy

Dr Brian Kwon: Novel Approaches to Cervical Spinal Cord Injury

Dr Benjamin Davies: Degenerative Cervical Myelopathy – Beyond the Operating Theatre

Debate

Dr Mark Kotter and Dr Brian Kwon: The Asymptomatic Patient with Spinal Cord Compression – What Should I Do? Arguments for Early Surgery or Observation

Oral Presentations

Dr Benjamin Davies, Dr Michael Fehlings (virtual), Dr Lindsay Tetreault (virtual), Dr Chad Cook (virtual; RECODE-DCM Steering Committee): Myelopathy Research Priorities

Dr Matthew Dixon (Natural History Incubator): Now or Later? Emergency vs Elective Surgery for DCM – A Service Evaluation from Practice

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2023**

Objectives and activities (continued)

Dr Julia Tabrah (Diagnostic Criteria Incubator): Can a Training Workshop on DCM be Used to Increase Awareness and Triage Confidence among General Practitioners? A Pilot Study: Can an Informal Consensus Process be used to Identify the Early, Middle and Late Stage Symptoms of DCM?

Dr Christine Fraser (Perioperative Rehabilitation Incubator) and Karen Outram: Exploring the Nuances of Managing a Patient with DCM from Primary to Secondary Care

Dr Lianne Wood (Perioperative Rehabilitation Incubator): The Evolution of a Secondary Care Advanced Practitioner Myelopathy Pathway

Brett Seagrave (Support Group Member; virtual): Personal Experience and Challenge in Accessing Services and Getting a Diagnosis

Student Society

In recent years, the Myelopathy.org Student Society conducted a national education survey to assess Degenerative Cervical Myelopathy (DCM) education received by our future doctors in medical school. This was inspired by the top research priority identified by RECODE-DCM: raising awareness. There was an outstanding response from the community, with 751 students taking the time to respond to the survey.

Findings from the survey were recently published in the British Journal of Neurosurgery: "Degenerative cervical myelopathy education in UK medical schools: a national cross-sectional survey of medical".

As expected, we identified deficiencies in DCM medical education, namely an absence of teaching in many medical schools and low student confidence in their knowledge of DCM.

In order to address this educational deficit The Myelopathy.org Student Society has been making strides in promoting education and awareness about spinal cord disorders among medical students across the UK.

Thanks to changes in the delivery of medical school teaching, the society successfully organised two events via Zoom that attracted a diverse audience and received positive feedback from participants.

The first event featured Dr Sybil Stacpoole, a consultant neurologist and neurosciences teaching lead at Cambridge University Medical School. Sybil presented an interesting collection of teaching cases, including a presentation of Degenerative Cervical Myelopathy (DCM). She provided a brief overview of the pathophysiology, clinical manifestations, and referral pathway for DCM. Medical students attended from different universities across the UK, who appreciated the opportunity to learn from an expert in the field. The interactive format of the session allowed for lively discussions and a question-and-answer session, enabling participants to deepen their understanding of DCM and related conditions.

The second event was delivered by our co-founder Dr Benjamin Davies. Ben gave a lecture on academic clinical careers in the UK, using his journey in the world of DCM research as a case study. He shared his experiences as a clinician-scientist, discussing the challenges and rewards of conducting research while working as a neurosurgeon. Ben also provided practical advice on how to pursue an academic clinical career, including tips on finding a PhD, building collaborations, and balancing clinical and research responsibilities.

(3) Support

Support Group

Our Myelopathy Support page on Facebook continues to grow and now has over 4,000 followers. Myelopathy.org also runs an on-line private support group on Facebook which has approximately 3000 members. This group is growing by approximately 230 members a month and we typically see 200 posts, 3,000 comments and 5,000 reactions each month.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2023**

Objectives and activities (continued)

This group helps to reduce isolation for our community and increases their knowledge of DCM. The group is run by volunteers, all of whom have DCM, and provides a unique space for our community to interact and engage on a one-to-one basis with people in similar circumstances. The group provides emotional support, social networks and educational resources. Members of the DCM community also run a peer mentoring programme where people with significant lived experience of DCM provide information and support to others during different stages of their DCM journey.

Both groups are led by Iwan Sadler, co-founder of Myelopathy.org and a person with DCM.

Caregivers Support Group

In February 2023 the Myelopathy Support Group launched a Myelopathy.org Caregivers Support Group. This separate group provides a safe and supportive space for caregivers

to openly talk to each other and also give them the help and support they also need. We would like to thank Kevin Martin-Moore for leading this initiative.

Coffee with Esther

Esther Martin-Moore has continued to run her hugely popular virtual Coffee Break meetings for people with DCM. 400 people have attended these sessions during the year. The coffee breaks have become an increasingly popular feature of the Support Group and are much appreciated by the members.

Podcasts

The Myelopathy Matters PodCast series offers the DCM community an additional platform to learn about what is happening at Myelopathy.org. The series includes information on research projects, interviews with leading healthcare professionals in the field of DCM and information from people with DCM. This helps to fulfil our objective of supporting and improving the physical and mental outcomes for people with DCM by providing a supportive and informative information source.

Benefits Advice Workshops

Myelopathy.org organised and executed a Benefits Advice Workshop in May and June 2023 for those affected by DCM. People with DCM very often find themselves requiring benefits, and being unable to be in work due the disabling effects of DCM, such as being unable to properly use their hands and being unable to walk properly. In addition, the process of applying for benefits can be extremely stressful, difficult to navigate, and requires a huge amount of effort and energy. Thus, working with an expert that would advise them on the process was identified by the beneficiaries as a high priority.

We received funding for this project from a National Lottery Awards for All grant, and we partnered with Hastings Advice and Representation Centre (HARC) who provided professional confidential Welfare Benefits advice and information, through a series of online workshops. HARC's Benefits Advice expert Teresa Andrews worked with a total of 11 participants over a series of three sessions, advising them in detail on the benefits system, its challenges and how to address them. Feedback from the sessions showed that the majority (95%) of participants found the session incredibly helpful, with all of them feeling much more confident in applying for benefits after the session, "It was interactive, with specific information that was tailored to our needs, rather than just a bullet point description of benefits available".

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2023**

Achievements and performance

a. Review of activities

Below is a brief summary of the main achievements of Myelopathy.org this year.

2022-23 has been another exciting year for Myelopathy.org with a particular focus on developing the AO Spine RECODE-DCM research network .

Fundraising

We continue to receive support from the Evelyn Trust for our Shared DCM project and now also receive support from AO Spine for the RECODE -DCM project.

We have also been the recipient of a £10,000 grant from the National Lottery Reaching Communities fund to run our series of Benefits Advice Workshops.

We raised £4,500 from our involvement as the nominated charity for the 2023 BritSpine Conference.

In addition to these we have continued to receive much needed donations from our beneficiaries and their supporters together with donations (both large and small) from other donors.

Volunteers

Volunteers are key to everything we do at Myelopathy.org and we could not continue to operate without their incredible support, in particular our fantastic group of volunteers (all people with DCM) who run our support group. During 2022-23 we continued to build up a professional volunteer programme to expand our capacity. Volunteers have continued to work on the following projects; website maintenance, content for all areas of our work, general charity administration, grant writing and research, Human Resources and Shared DCM.

Operations, outreach, and communication

In April 2023 we completed and launched the second version of our new website which included a whole new section aimed at our professional followers.

Programmes

We have continued to be a partner in RECODE-DCM and continue to work with AO Spine on this project. During the year we have hired a project manager to lead this project and have established an international steering committee to oversee all aspects of the associated research.

We have continued work on the Shared DCM project to create the first comprehensive education framework for people with DCM.

We have continued to partner NIHR funded clinical trials to bring the voice of people with DCM to these trials. In addition we have held a series of workshops for the UK based members of our support group to help them navigate the benefits system.

We have continued to develop and broadcast our Myelopathy Matters PodCast series and weekly blogs to better inform our community about the work of Myelopathy.org.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2023**

Achievements and performance (continued)

Financial review

a. Going concern

After making appropriate enquiries, the Trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. For this reason, they continue to adopt the going concern basis in preparing the financial statements.

b. Reserves policy

At present Myelopathy.org has minimal annual liabilities. Consequently, and based on the limited annual income, it is felt that a reserve fund is not required nor possible at this time.

This position will be reviewed annually by the Trustees.

Structure, governance and management

a. Constitution

Myelopathy.org is a registered charity, number 1178673, and was incorporated on 6 June 2018.

b. Methods of appointment or election of Trustees

The management of the charity is the responsibility of the Trustees who are elected and co-opted under the terms of the Constitution.

c. Financial risk management

The Trustees have assessed the major risks to which the charity is exposed, in particular those related to the operations and finances of the charity, and are satisfied that systems and procedures are in place to mitigate exposure to the major risks.

Members' liability

The Members of the charity guarantee to contribute an amount not exceeding £1 to the assets of the charity in the event of winding up.

TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2023

Statement of Trustees' responsibilities

The Trustees are responsible for preparing the Trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England & Wales requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of its incoming resources and application of resources, including its income and expenditure, for that period. In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles of the Charities SORP (FRS 102);
- make judgments and accounting estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards (FRS 102) have been followed, subject to any material departures disclosed and explained in the financial statements;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charity's transactions and disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the Trust deed. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by order of the members of the board of Trustees on
by:

19.3.24

and signed on their behalf

Ms Helen J Wood
Trustee

HJ Wood

**INDEPENDENT EXAMINER'S REPORT
FOR THE YEAR ENDED 30 JUNE 2023**

Independent Examiner's Report to the Trustees of Myelopathy.org ('the charity')

I report to the charity Trustees on my examination of the accounts of the charity for the year ended 30 June 2023.

Responsibilities and Basis of Report

As the Trustees of the charity you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the 2011 Act').

I report in respect of my examination of the charity's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent Examiner's Statement

Your attention is drawn to the fact that the charity has prepared the accounts in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) in preference to the Accounting and Reporting by Charities: Statement of Recommended Practice issued on 1 April 2005 which is referred to in the extant regulations but has been withdrawn.

I understand that this has been done in order for the accounts to provide a true and fair view in accordance with the Generally Accepted Accounting Practice effective for reporting periods beginning on or after 1 January 2015.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the charity as required by section 130 of the 2011 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

This report is made solely to the charity's Trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. My work has been undertaken so that I might state to the charity's Trustees those matters I am required to state to them in an independent examiner's report and for no other purpose. To the fullest extent permitted by law, I do not accept or assume responsibility to anyone other than the charity and the charity's Trustees as a body, for my work or for this report.

Signed:

Dated: 20 March 2024

C P J Dougherty FCA

Lakin Rose Limited

Pioneer House

Vision Park

Histon

Cambridge

CB24 9NL

**STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 30 JUNE 2023**

	Note	Restricted funds 2023 £	Unrestricted funds 2023 £	Total funds 2023 £	<i>Total funds 2022 £</i>
Income from:					
Donations	3	27,827	45,036	72,863	79,353
Charitable activities	4	-	6,351	6,351	2,252
Investments	5	-	1	1	3
Total income		27,827	51,388	79,215	81,608
Expenditure on:					
Raising funds	6	-	-	-	3,785
Charitable activities		27,827	69,579	97,406	78,557
Total expenditure		27,827	69,579	97,406	82,342
Net movement in funds		-	(18,191)	(18,191)	(734)
Reconciliation of funds:					
Total funds brought forward		-	55,689	55,689	56,423
Net movement in funds		-	(18,191)	(18,191)	(734)
Total funds carried forward		-	37,498	37,498	55,689

The Statement of Financial Activities includes all gains and losses recognised in the year.

The notes on pages 16 to 24 form part of these financial statements.

**BALANCE SHEET
AS AT 30 JUNE 2023**

	Note	2023 £	2022 £
Current assets			
Debtors	11	4,363	3,044
Cash at bank and in hand		38,188	54,885
		<u>42,551</u>	<u>57,929</u>
Creditors: amounts falling due within one year	12	(5,053)	(2,240)
Net current assets		<u>37,498</u>	<u>55,689</u>
Total net assets		<u><u>37,498</u></u>	<u><u>55,689</u></u>
Charity funds			
Restricted funds	13	-	-
Unrestricted funds	13	37,498	55,689
Total funds		<u><u>37,498</u></u>	<u><u>55,689</u></u>

The financial statements were approved and authorised for issue by the Trustees on and signed on their behalf by:

19 March 2024
HJ Wood

Ms Helen J Wood
Trustee

The notes on pages 16 to 24 form part of these financial statements.

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2023**

1. General information

The charity is a charitable incorporated organisation (CIO). The charity's address is c/o Lakin Rose, Pioneer House, Vision Park, Histon, Cambridge, CB24 9NL.

2. Accounting policies

2.1 Basis of preparation of financial statements

The financial statements have been prepared in accordance with the Charities SORP (FRS 102) - Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Charities Act 2011.

The financial statements have been prepared to give a 'true and fair' view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a 'true and fair' view. This departure has involved following the Charities SORP (FRS 102) published in October 2019 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

Myelopathy.org meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy.

2.2 Income

All income is recognised once the charity has entitlement to the income, it is probable that the income will be received and the amount of income receivable can be measured reliably.

Grants are included in the statement of financial activities on a receivable basis. The balance of income received for specific purposes but not expended during the period is shown in the relevant funds on the balance sheet. Where income is received in advance of entitlement of receipt, its recognition is deferred and included in creditors as deferred income. Where entitlement occurs before income is received, the income is accrued.

Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

2.3 Expenditure

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is classified by activity. The costs of each activity are made up of the total of direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources. Central staff costs are allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use.

Expenditure on raising funds includes all expenditure incurred by the charity to raise funds for its charitable purposes and includes costs of all fundraising activities events and non-charitable trading.

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2023**

2. Accounting policies (continued)

2.3 Expenditure (continued)

Expenditure on charitable activities is incurred on directly undertaking the activities which further the charity's objectives, as well as any associated support costs.

All expenditure is inclusive of irrecoverable VAT.

2.4 Liabilities and provisions

Liabilities are recognised when there is an obligation at the balance sheet date as a result of a past event, it is probable that a transfer of economic benefit will be required in settlement, and the amount of the settlement can be estimated reliably.

Liabilities are recognised at the amount that the charity anticipates it will pay to settle the debt or the amount it has received as advanced payments for the goods or services it must provide.

Provisions are measured at the best estimate of the amounts required to settle the obligation. Where the effect of the time value of money is material, the provision is based on the present value of those amounts, discounted at the pre-tax discount rate that reflects the risks specific to the liability. The unwinding of the discount is recognised in the statement of financial activities as a finance cost.

2.5 Pensions

The charity operates a defined contribution pension scheme and the pension charge represents the amounts payable by the charity to the fund in respect of the year.

2.6 Fund accounting

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the charity and which have not been designated for other purposes.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the charity for particular purposes. The costs of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements.

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2023**

3. Income from donations

	Restricted funds 2023 £	Unrestricted funds 2023 £	Total funds 2023 £	<i>Total funds 2022 £</i>
Donations	-	45,036	45,036	73,829
Grants	27,827	-	27,827	5,524
	<u>27,827</u>	<u>45,036</u>	<u>72,863</u>	<u>79,353</u>
<i>Total 2022</i>	<u>4,524</u>	<u>74,829</u>	<u>79,353</u>	

4. Income from charitable activities

	Unrestricted funds 2023 £	Total funds 2023 £	<i>Total funds 2022 £</i>
Research services	6,351	6,351	2,252
	<u>6,351</u>	<u>6,351</u>	<u>2,252</u>

5. Investment income

	Unrestricted funds 2023 £	Total funds 2023 £	<i>Total funds 2022 £</i>
Interest receivable	1	1	3
	<u>1</u>	<u>1</u>	<u>3</u>

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2023**

6. Expenditure on raising funds

Costs of raising voluntary income

	Unrestricted funds 2023 £	Total funds 2023 £	<i>Total funds 2022 £</i>
Costs of raising voluntary income	-	-	3,785

7. Analysis of expenditure by activities

	Activities undertaken directly 2023 £	Support costs 2023 £	Total funds 2023 £	<i>Total funds 2022 £</i>
Charitable activities	2,460	94,946	97,406	78,557
<i>Total 2022</i>	2,695	75,862	78,557	

Analysis of direct costs

	Charitable activities 2023 £	Total funds 2023 £	<i>Total funds 2022 £</i>
Education	2,460	2,460	2,538
Research	-	-	157
	2,460	2,460	2,695

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2023**

7. Analysis of expenditure by activities (continued)

Analysis of support costs

	Charitable activities 2023 £	Total funds 2023 £	<i>Total funds 2022 £</i>
Staff costs	23,469	23,469	14,291
General office expenses	2,754	2,754	584
Computer expenses	485	485	1,000
Insurance	474	474	426
Subscriptions	410	410	194
Travel and subsistence	1,747	1,747	72
Grant funded Google advertisements	31,200	31,200	49,920
Consultancy	33,147	33,147	8,115
Governance costs	1,260	1,260	1,260
	<hr/> 94,946 <hr/>	<hr/> 94,946 <hr/>	<hr/> 75,862 <hr/>

8. Independent examiner's remuneration

The independent examiner's remuneration amounts to an independent examiner fee of £1,260 (2022 - £1,200).

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2023**

9. Staff costs

	2023	<i>2022</i>
	£	£
Wages and salaries	22,953	<i>13,581</i>
Contribution to defined contribution pension schemes	516	<i>710</i>
	<u>23,469</u>	<u><i>14,291</i></u>

The average number of persons employed by the charity during the year was as follows:

	2023	<i>2022</i>
	No.	No.
Management	<u>1</u>	<u><i>1</i></u>

No employee received remuneration amounting to more than £60,000 in either year.

10. Trustees' remuneration and expenses

During the year ended 30 June 2022, no Trustees received any remuneration or other benefits (*2022 - £NIL*).

During the year ended 30 June 2023, no Trustee expenses have been incurred (*2022 - £NIL*).

11. Debtors

	2023	<i>2022</i>
	£	£
Trade debtors	-	<i>2,252</i>
Prepayments and accrued income	3,496	<i>167</i>
Tax recoverable	867	<i>625</i>
	<u>4,363</u>	<u><i>3,044</i></u>

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2023

12. Creditors: Amounts falling due within one year

	2023 £	2022 £
Trade creditors	1,040	1,040
Other taxation and social security	727	-
Other creditors	1,886	-
Accruals and deferred income	1,400	1,200
	<u>5,053</u>	<u>2,240</u>

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2023**

13. Statement of funds

Statement of funds - current year

	Balance at 1 July 2022 £	Income £	Expenditure £	Balance at 30 June 2023 £
Unrestricted funds				
General Funds	55,689	51,388	(69,579)	37,498
Restricted funds				
Decision Making in DCM (previously DCM COINS) Project	-	8,009	(8,009)	-
POLYFIX-DCM Trial fund	-	9,867	(9,867)	-
Benefits workshops	-	9,951	(9,951)	-
	-	27,827	(27,827)	-
Total of funds	55,689	79,215	(97,406)	37,498

Decision Making in DCM (previously DCM COINS) Project

This fund relates to a grant receivable from Evelyn Trust to support this project. A detailed description of this project can be found in the trustees' report.

POLYFIX-DCM Trial Fund

Grant funding towards patient and public engagement with the POLYFIX-DCM (**P**Osterior **L**aminectomy and **F**IXation for **D**egenerative **C**ervical **M**yelopathy) trial.

Benefits workshop fund

Grant funding from National Lottery Communities Fund towards running workshops to help beneficiaries navigate the benefits system.

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2023**

13. Statement of funds (continued)
Statement of funds - prior year

	<i>Balance at 1 July 2021 £</i>	<i>Income £</i>	<i>Expenditure £</i>	<i>Balance at 30 June 2022 £</i>
Unrestricted funds				
General Funds	52,329	77,084	(73,724)	55,689
	<hr/>	<hr/>	<hr/>	<hr/>
Restricted funds				
Facing Myelopathy Together	4,094	-	(4,094)	-
Decision Making in DCM (previously DCM COINS) Project	-	4,524	(4,524)	-
	<hr/>	<hr/>	<hr/>	<hr/>
	4,094	4,524	(8,618)	-
	<hr/>	<hr/>	<hr/>	<hr/>
Total of funds	56,423	81,608	(82,342)	55,689
	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>	<hr/> <hr/>

Facing Myelopathy Together Fund

This fund relates to a grant from Awards for All (part of National Lottery) which is towards staff costs and website costs.

DCM COINS Project

This fund relates to a grant receivable from Evelyn Trust to support this project. A detailed description of this project can be found in the trustees' report.