

MYELOPATHY.ORG

England & Wales - Charity number 1178673

Details

Status Registered

Legal form CIO

Registered 2018-06-06

Register [View on the Charity Commission register](#)

Contact

Address Lakin Rose Ltd
Oakington Road
Girton
Cambridge
CB3 0QH

Phone 01223748405

Email info@myelopathy.org

Website www.myelopathy.org

Activities

Objects: TO ADVANCE HEALTH AND EDUCATION IN ALL ASPECTS OF MYELOPATHY IN PARTICULAR BUT NOT EXCLUSIVELY BY:1. SUPPORTING AND FUNDING SCIENTIFIC RESEARCH INTO ALL ASPECTS OF MYELOPATHY 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 SUPPORTING FOR PATIENTS, CARERS AND HEALTH PROFESSIONALS

Activities: Supporting and funding scientific research into all aspects of myelopathy and ensuring the useful results are publicly disseminated.Raising awareness and understanding of myelopathy.Supporting and promoting improved physical and mental outcomes for patients and supporting patients, carers and healthcare professionals.

Classification

- **How:** Provides Advocacy/advice/information
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives
- **Who:** People With Disabilities

Geography

- United States
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-06-30	£93,075	£91,962	-	-
2024-06-30	£74,925	£75,118	-	-
2023-06-30	£79,215	£97,406	-	-
2022-06-30	£81,608	£82,342	-	-
2021-06-30	£123,284	£75,354	-	-

Trustees

Name	Role	Appointed
Helen Wood	Chair	2019-11-07
Carol Sun-Schuster		2020-02-27
Dr Aditya Vedantam		2024-11-13
Dr Benjamin Davies		2024-11-13
Dr MARK KOTTER		2018-06-06
Dr Rory Murphy		2024-11-25
Esther Martin-Moore		2026-01-08
Iwan Lloyd Sadler		2021-03-15
Mary Sheila Dugan		2026-01-08
Steven Czick		2024-06-27

MYELOPATHY.ORG

England & Wales - Charity number 1178673

Accounts

MYELOPATHY.ORG

TRUSTEES' REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 30 JUNE 2025

MYELOPATHY.ORG

CONTENTS

	Page
Reference and administrative details of the charity, its Trustees and advisers	1
Trustees' report	2 - 9
Independent examiner's report	10
Statement of financial activities	11
Balance sheet	12
Notes to the financial statements	13 - 20

**REFERENCE AND ADMINISTRATIVE DETAILS OF THE CHARITY, ITS TRUSTEES AND ADVISERS
FOR THE YEAR ENDED 30 JUNE 2025**

Trustees

Mr Steven Czick
Dr Benjamin Davies (appointed 13 November 2024)
Mrs Mary Sheila Dugan (appointed 8 January 2026)
Dr Eldrid Herrington (resigned 5 January 2026)
Dr Mark Kotter
Mrs Esther Martin-Moore (appointed 8 January 2026)
Dr Rory Murphy (appointed 25 November 2025)
Mr Iwan Lloyd Sadler
Mr Roy Smith
Ms Carol Sun-Schuster
Dr Aditya Vedantam (appointed 13 November 2024)
Ms Helen J Wood, Chair

Charity registered number

1178673

Principal office

Lakin Rose Limited
Cambridge House
Camboro Business Park
Girton
Cambridge
CB3 0QH

Independent examiner

C P J Dougherty, FCA
Lakin Rose Limited
Cambridge House
Camboro Business Park
Girton
Cambridge
CB3 0QH

TRUSTEES' REPORT
FOR THE YEAR ENDED 30 JUNE 2025

The Trustees present their annual report together with the financial statements of Myelopathy.org for the year 1 July 2024 to 30 June 2025.

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

Myelopathy.org's partnership 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 was wound down during 2024-2025. AOSpine has taken over the management of RECODE DCM although [Myelopathy.org](https://www.myelopathy.org) remains associated with the project.

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.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2025**

Objectives and activities (continued)

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. It is hoped these will be published by the end of 2026.

The incubator has also created a triage algorithm for urgent investigation for MRI scan called CHANGE.

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 incubator has reviewed the terminology used for pre-symptomatic DCM and will be conducting a DELPHI consensus process to select a single unifying term.

The **Peri-Operative Incubator** is examining non-operative aspects of DCM management and developing an enhanced recovery pathway for patients prior to, during, and after surgery. The team is working with the Enhanced Recovery After Surgery (ERAS) Society, who seek to improve care pathways so as to help patients achieve better and earlier recovery following major surgery, to develop DCM specific peri-operative guidelines.

Myelopathy.org Research Prize

Each year Myelopathy.org picks the most significant and original research contribution that aligns with the [RECODE-DCM Research Priorities](#). We had submissions from all over the world, but our independent experts were in agreement that the 2024 winner was "Antibiotic administration decreases microglial and macrophage activation in a sex-dependent manner following Degenerative Cervical Myelopathy" by Pia M Vidal from the Universidad Católica de la Santísima Concepción (UCSC) in Chile.

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, Motor Neuron 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 and Helen Wood, Chair of the Board of Trustees of Myelopathy.org sits on the trial Steering Committee

The first patient was recruited to the trial at Addenbrooke's Hospital in Cambridge on 7 July 2023 and by the end of June 2025 the trial had recruited a further 236 participants. 26 sites have now opened and are recruiting with a further 6 sites being set up (4 outside the UK).

(2) Awareness

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

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2025**

Objectives and activities (continued)

Myelopathy.org website

Following the launch of our enhanced website in April 2023 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.

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.

Google Ads and Digital Marketing

Myelopathy.org has continued to benefit from the Google Ad Grant awarded during 2024-25. 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.

We partner with Studio East, a specialist digital marketing agency, to strengthen our online reach and ensure that people searching for information about myelopathy can find reliable support quickly. Studio East manages our Google Ads programme, continuously optimising campaigns, keywords, and landing pages to increase visibility, drive traffic to key information pages, and encourage meaningful actions such as seeking diagnosis information or making donations. Their work includes performance monitoring, testing new strategies, analysing user behaviour, and refining targeting to maximise impact within our budget. Monthly reports show sustained growth in website visits and engagement, helping us reach patients, families, and clinicians worldwide who might otherwise remain unaware of the condition and the support available.

(3) Support

Support Group

Our Myelopathy Support page on Facebook continues to grow and now has over 4,400 followers. Myelopathy.org also runs an on-line private support group on Facebook which has approximately 4,500 members. This group is growing and we typically see 200 posts, 3,000 comments and 5,000 reactions each month.

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

The [Myelopathy.org Caregivers Support Group](#) has continued to operate. 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.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2025**

Objectives and activities (continued)

Coffee with Esther

Esther Martin-Moore has continued to run her hugely popular virtual Coffee Break meetings for people with DCM. The coffee breaks have become an increasingly popular feature of the Support Group and are much appreciated by the members. Topics discussed are varied and have included topics such as diet and management of DCM, emotional intimacy, music and mobility.

DCM Helpline

In April 2024 we received notification that we had been successful in securing £49,990 of funding from The National Lottery (TNL) under its Reaching Communities programme to run a pilot helpline project for those affected by DCM.

Recruitment and preparation for the project started in October 2024 and the helpline was officially launched on 24 February 2025. This has been one of the biggest projects we have worked on at Myelopathy.org and is an opportunity to better serve our community by providing clear, compassionate and expert guidance and most importantly a friendly voice at the end of the telephone.

The team behind the project have included Zahabiya Karimi, Esther Cole, Casey Scarlett, Jay Wardropper, Georgios Toumbas and Prabav Santhosh Kumar. In addition we have recruited a number of volunteers for the all important task of manning the telephones and this has included people with DCM who bring their unique insight into the difficulties of living with the condition.

From the very first call, it was clear how much this service mattered. Over the course of the pilot, our dedicated volunteer call-handlers offered direct support and guidance to more than 100 individuals seeking help with DCM. Every single caller told us that they felt more informed or reassured after speaking with us, and more than three-quarters had their concerns resolved. Almost 95% rated the service four out of five or higher, with many describing it as an essential service that must continue. For some, the helpline was a lifeline – simply having a place to talk openly and receive compassionate guidance was transformative.

Here are just a few of the voices that remind us why this service is so important:

- “Please keep your funding and service for people like us as we have no support and doctors don’t understand. Struggling to get neurosurgeons involved at the minute. So little info on this condition. I’m so happy to find Myelopathy.org and this helpline.”
- “To receive a welcome at the beginning of the call and to know I was speaking to a person with my condition who not only cared but understood my fear and isolation was a light at the end of a tunnel.”
- “I contacted the helpline today and I spoke to one of the volunteer call handlers. The information he gave me confirmed that I’m going down the correct pathway to get a proper diagnosis. It was really helpful.”

Beyond the numbers and testimonials, the helpline played a wider role too. It created a safe space where people could share their struggles, ask questions, and connect with others who understood. It encouraged closer collaboration with medical professionals, helping ensure up-to-date and reliable information reached those who needed it. And it contributed to our wider mission of raising awareness about the importance of early diagnosis and appropriate management of DCM.

Although this pilot ended on 24 August 2025, we are already working on the next phase. Our experience over the past six months has shown how vital this service is, and we are determined to build on its success. This pilot has shown what we already knew to be true: that people affected by DCM need, value, and deserve this kind of dedicated support.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2025**

Objectives and activities (continued)

We have submitted a reapplication to TNL for 3 years of continued funding.

Achievements and performance

a. Review of activities

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

Fundraising

Miles for Myelopathy 2025

In May 2025 we invited our beneficiaries to join us for Miles for Myelopathy 2025, our first annual fundraising initiative encouraging individuals to take part in activities of their choice to raise donations for [Myelopathy.org](https://myelopathy.org). We set an ambitious target of raising £2,000 and amazingly we more than doubled this figure, raising an astonishing **£4,300**.

The idea for Miles for Myelopathy was created by our inspiring community member Lorraine Gilliver, and invited our beneficiaries to move in any way that suited them—walking, running, rolling, swimming, or cycling—and tracking miles throughout May.

People also supported the effort by buying the Miles for Myelopathy merchandise which included t-shirts and hoodies in bold orange, classic black, and crisp white.

Thank you to everyone who was involved for what we hope will be an annual event.

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 2024-25 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 the DCM Helpline.

Operations, outreach, and communication

Programmes

We have continued to be a partner in RECODE-DCM and continue to work with AO Spine on this project. We have continued to partner NIHR funded clinical trials to bring the voice of people with DCM to these trials. During 2024-5 we received £49,990 of funding from The National Lottery (TNL) under its [Reaching Communities](#) programme to run a pilot helpline project for those affected by DCM. The helpline was launched for a 6 month pilot period at the end of February 2025.

We have continued to develop weekly blogs to better inform our community about the work of Myelopathy.org.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2025**

Achievements and performance (continued)

Conferences

The Society of British Neurological Surgeons Annual Conference, Birmingham, UK September 2024.

Our Chair of Trustees, Helen Wood and Director, Zahabiya Karimi attended this conference to raise awareness of [Myelopathy.org](https://myelopathy.org).

AIMS Summit: Innovating Healthcare Through Collaboration, Chicago, USA, March 2025.

Trustee Dr Rory Murphy spoke at this conference of the urgent need to raise awareness of DCM, emphasising early diagnosis, patient-centred care and cross-speciality collaboration.

Royal College of Nursing London Spinal Nursing Conference, May 2025, London UK.

Our Chair of Trustees, Helen Wood, Director, Zahabiya Karimi and patient Michelle Caton Richard attended this conference to raise awareness of Myelopathy.org amongst spinal nurses.

Helen and Michelle both made speeches about the need for awareness raising and early diagnosis. Michelle, a nurse with over 25 years experience shared her story of struggling to receive a diagnosis of DCM and the disability she has subsequently suffered.

Global Spine Conference, May 2025, Rio de Janeiro, Brazil.

Our co-founder Dr Ben Davies and fellow trustee Dr Aditya Vedantam spoke at this conference of over 2,200 spine professionals from over 80 countries about personalised medicine in DCM treatment.

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.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2025**

Structure, governance and management (continued)

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.

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 judgements 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.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2025**

Approved by order of the members of the board of Trustees on 10 Apr 2026 and signed on their behalf
by:



Helen Wood (Apr 10, 2026, 1:36pm)

Ms Helen J Wood
Trustee

**INDEPENDENT EXAMINER'S REPORT
FOR THE YEAR ENDED 30 JUNE 2025**

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 2025.

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: 10 Apr 2026

C P J Dougherty FCA
Christopher Dougherty (Apr 10,

Lakin Rose Limited

Cambridge House
Camboro Business Park
Girton
Cambridge
CB3 0QH

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 30 JUNE 2025

	Note	Unrestricted funds 2025 £	Restricted funds 2025 £	Total funds 2025 £	Total funds 2024 £
Income from:					
Donations	3	57,567	35,442	93,009	69,773
Charitable activities	4	-	-	-	5,152
Investments	5	66	-	66	-
Total income		57,633	35,442	93,075	74,925
Expenditure on:					
Raising funds	6	5,280	1,920	7,200	1,800
Charitable activities		51,240	33,522	84,762	73,318
Total expenditure		56,520	35,442	91,962	75,118
Net movement in funds		1,113	-	1,113	(193)
Reconciliation of funds:					
Total funds brought forward		37,305	-	37,305	37,498
Net movement in funds		1,113	-	1,113	(193)
Total funds carried forward		38,418	-	38,418	37,305

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

The notes on pages 13 to 20 form part of these financial statements.

MYELOPATHY.ORG

BALANCE SHEET
AS AT 30 JUNE 2025

	Note	2025 £	2024 £
Current assets			
Debtors	11	1,059	6,276
Cash at bank and in hand		60,561	36,303
		<u>61,620</u>	<u>42,579</u>
Current liabilities			
Creditors: amounts falling due within one year	12	(23,202)	(5,274)
		<u>38,418</u>	<u>37,305</u>
Net current assets		<u>38,418</u>	<u>37,305</u>
Total net assets		<u><u>38,418</u></u>	<u><u>37,305</u></u>
Charity funds			
Restricted funds	13	-	-
Unrestricted funds	13	38,418	37,305
		<u>38,418</u>	<u>37,305</u>
Total funds		<u><u>38,418</u></u>	<u><u>37,305</u></u>

The financial statements were approved and authorised for issue by the Trustees on
10 Apr 2026 and signed on their behalf by:



Helen Wood (Apr 10, 2026, 1:36pm)

Ms Helen J Wood
Trustee

The notes on pages 13 to 20 form part of these financial statements.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2025

1. General information

The charity is a charitable incorporated organisation (CIO). The charity's address is Lakin Rose Limited, Cambridge House, Camboro Business Park, Girton, Cambridge, CB3 0QH.

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 2025

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 Interest receivable

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the institution with whom the funds are deposited.

2.5 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.

2.6 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.

2.7 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 2025

3. Income from donations

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total funds 2025 £	Total funds 2024 £
Donations	57,567	-	57,567	56,490
Grants	-	35,442	35,442	13,283
	<u>57,567</u>	<u>35,442</u>	<u>93,009</u>	<u>69,773</u>
<i>Total 2024</i>	<u>56,490</u>	<u>13,283</u>	<u>69,773</u>	

4. Income from charitable activities

	Unrestricted funds 2025 £	Total funds 2025 £	Total funds 2024 £
Research services	-	-	5,152
	<u>-</u>	<u>-</u>	<u>5,152</u>

5. Investment income

	Unrestricted funds 2025 £	Total funds 2025 £	Total funds 2024 £
Interest receivable	66	66	-
	<u>66</u>	<u>66</u>	<u>-</u>

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2025

6. Expenditure on raising funds

Costs of raising voluntary income

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total funds 2025 £	Total funds 2024 £
Costs of raising voluntary income	5,280	1,920	7,200	1,800
<i>Total 2024</i>	<u>1,800</u>	<u>-</u>	<u>1,800</u>	

7. Analysis of expenditure by activities

	Activities undertaken directly 2025 £	Support costs 2025 £	Total funds 2025 £	Total funds 2024 £
Charitable activities	3,740	81,022	84,762	73,318
<i>Total 2024</i>	<u>2,057</u>	<u>71,261</u>	<u>73,318</u>	

Analysis of direct costs

	Charitable activities 2025 £	Total funds 2025 £	Total funds 2024 £
Education	90	90	2,057
Research	3,650	3,650	-
	<u>3,740</u>	<u>3,740</u>	<u>2,057</u>

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2025

7. Analysis of expenditure by activities (continued)

Analysis of support costs

	Charitable activities 2025 £	Total funds 2025 £	<i>Total funds 2024 £</i>
Staff costs	36,153	36,153	29,066
General office expenses	5,066	5,066	3,426
Computer expenses	390	390	613
Insurance	491	491	495
Subscriptions	519	519	267
Travel and subsistence	547	547	-
Google/Meta advertisements	17,621	17,621	24,524
Bank charges	53	53	-
Training / supervision	1,254	1,254	-
Grants payable	2,705	2,705	-
Consultancy	11,213	11,213	11,100
Governance costs	5,010	5,010	1,770
	<u>81,022</u>	<u>81,022</u>	<u>71,261</u>

8. Independent examiner's remuneration

The independent examiner's remuneration amounts to an independent examiner fee of £5,010 (2024 - £1,770).

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2025**

9. Staff costs

	2025	<i>2024</i>
	£	£
Wages and salaries	35,314	<i>28,401</i>
Contribution to defined contribution pension schemes	839	<i>665</i>
	36,153	<i>29,066</i>
	36,153	<i>29,066</i>

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

	2025	<i>2024</i>
	No.	No.
Management	1	<i>1</i>
	1	<i>1</i>
	1	<i>1</i>

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

10. Trustees' remuneration and expenses

During the year ended 30 June 2025, no Trustees received any remuneration or other benefits (*2024 - £NIL*).

During the year ended 30 June 2025, no Trustee expenses have been incurred (*2024 - £NIL*).

11. Debtors

	2025	<i>2024</i>
	£	£
Prepayments and accrued income	1,059	<i>2,276</i>
Tax recoverable	-	<i>4,000</i>
	1,059	<i>6,276</i>
	1,059	<i>6,276</i>

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2025

12. Creditors: Amounts falling due within one year

	2025 £	2024 £
Other taxation and social security	5,224	1,756
Other creditors	174	2,078
Accruals and deferred income	17,804	1,440
	<u>23,202</u>	<u>5,274</u>

13. Statement of funds

Statement of funds - current year

	Balance at 1 July 2024 £	Income £	Expenditure £	Balance at 30 June 2025 £
Unrestricted funds				
General Funds	37,305	57,633	(56,520)	38,418
Restricted funds				
DCM Helpline	-	35,442	(35,442)	-
Total of funds	<u>37,305</u>	<u>93,075</u>	<u>(91,962)</u>	<u>38,418</u>

DCM Helpline Fund

The National Lottery Community Fund provided grants through the Reaching Communities/Partnerships programme over one year to enable Myelopathy.org to pilot a dedicated, accessible and compassionate helpline service for individuals affected by DCM as well as their families and carers.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2025

13. Statement of funds (continued)

Statement of funds - prior year

	<i>Balance at 1 July 2023</i>	<i>Income</i>	<i>Expenditure</i>	<i>Balance at 30 June 2024</i>
	£	£	£	£
Unrestricted funds				
General Funds	37,498	61,642	(61,835)	37,305
Restricted funds				
Decision Making in DCM (previously DCM COINS) Project	-	7,910	(7,910)	-
POLYFIX-DCM Trial fund	-	5,373	(5,373)	-
	-	13,283	(13,283)	-
Total of funds	37,498	74,925	(75,118)	37,305

Decision Making in DCM Project

This fund relates to grants 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 (**PO**sterior **L**aminectomy and **FIX**ation for **D**egenerative Cervical **M**yelopathy) trial.

Income and expenses relating to the PPI element of the Distressed Study (a sub study which is part of POLYFIX) and to set up a mechanism to administer any patient travel expenses related to the trial and for a Podcast about the trial.



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Parties involved with this document

Document processed	Party + Fingerprint
Fri, 10th Apr 2026 13:36:56 BST	Helen Wood - Signer (4bb6b36df1a144aa7c86d457b3f0e7af)
Fri, 10th Apr 2026 13:48:29 BST	Christopher Dougherty - Signer (10cf3c0d616ecbd140e154597061a93a)

Audit history log

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Fri, 10th Apr 2026 10:54:31 BST	Envelope generated by Andrew Robinson (185.145.90.242)
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Fri, 10th Apr 2026 11:09:15 BST	Sent the envelope to Helen Wood (helen@myelopathy.org) for signing (185.145.90.242)
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Fri, 10th Apr 2026 13:36:56 BST	Helen Wood signed the envelope (92.239.90.118)
Fri, 10th Apr 2026 13:36:56 BST	Sent the envelope to Christopher Dougherty (chris.dougherty@lakinrose.co.uk) for signing (92.239.90.118)
Fri, 10th Apr 2026 13:36:56 BST	Document emailed to chris.dougherty@lakinrose.co.uk
Fri, 10th Apr 2026 13:46:58 BST	Christopher Dougherty viewed the envelope (185.145.90.242)
Fri, 10th Apr 2026 13:47:15 BST	Christopher Dougherty viewed the envelope (72.145.144.237)
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Fri, 10th Apr 2026 13:48:29 BST	This envelope has been signed by all parties (185.145.90.242)
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Fri, 10th Apr 2026 13:48:29 BST	Signed document confirmation emailed to chris.dougherty@lakinrose.co.uk (185.145.90.242)

Fri, 10th Apr 2026 13:48:29 BST

Signed document confirmation emails have been sent to all parties.

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<https://api.signable.app/shareable/envelope?t=c161915e-5ff1-438e-b2f5-d54bb2a9356c> (185.145.90.242)

MYELOPATHY.ORG

England & Wales - Charity number 1178673

Accounts

MYELOPATHY.ORG

TRUSTEES' REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 30 JUNE 2024

MYELOPATHY.ORG

CONTENTS

	Page
Reference and administrative details of the charity, its Trustees and advisers	1
Trustees' report	2 - 9
Independent examiner's report	10
Statement of financial activities	11
Balance sheet	12
Notes to the financial statements	13 - 21

**REFERENCE AND ADMINISTRATIVE DETAILS OF THE CHARITY, ITS TRUSTEES AND ADVISERS
FOR THE YEAR ENDED 30 JUNE 2024**

Trustees

Mr Steven Czick (appointed 27 June 2024)
Dr Benjamin Davies (appointed 13 November 2024)
Dr Johann Graggaber (resigned 12 December 2023)
Dr Eldrid Herrington
Mrs Weslie R Janeway (resigned 25 May 2024)
Dr Mark Kotter
Dr Rory Murphy (appointed 25 November 2024)
Mr Iwan Lloyd Sadler
Mr Roy Smith
Ms Carol Sun-Schuster
Mr David Townshend (resigned 1 May 2024)
Dr Aditya Vedantam (appointed 13 November 2024)
Ms Helen J Wood, Chair

Charity registered number

1178673

Principal office

Lakin Rose Limited
Cambridge House
Camboro Business Park
Girton
Cambridge
CB3 0QH

Independent examiner

C P J Dougherty, FCA
Lakin Rose Limited
Cambridge House
Camboro Business Park
Girton
Cambridge
CB3 0QH

**TRUSTEES' REPORT
FOR THE YEAR ENDED 30 JUNE 2024**

The Trustees present their annual report together with the financial statements of the Myelopathy.org for the year 1 July 2023 to 30 June 2024.

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.

The Steering Committee, established in October 2022 has continued to work 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 2024**

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.

A series of formative papers have now been submitted for review to the Global Spine Journal. These include systematic reviews of the diagnostic value of clinical symptoms, and clinically important signs and attributes in distinguishing DCM from other conditions (Dr. L. Tetreault, New York University). We are also submitting an analysis of inclusion and exclusion criteria to be utilised within DCM trials (Prof. K. Margitis, Mount Sinai).

The incubator has just received ethical approval from The University of Cambridge for a Delphi consensus process that would allow us to define diagnostic criteria to help diagnose and manage patients in clinical practice. Our team has also developed a survey for healthcare professionals to rate the signs and symptoms of DCM, in order to inform our diagnostic criteria. We are currently trialling this survey with members of our incubator around the world.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2024**

Objectives and activities (continued)

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 incubator has just published a research paper on the results of an international survey to determine how both mild DCM and asymptomatic spinal cord compression (ASCC) are managed in clinical practice across the world. This research demonstrated that health professionals typically offer regular outpatient follow-up visits with patients, but what investigations take place during these visits varies widely. Further research is needed to define best practice and support patient care.

The **Peri-Operative Incubator** is examining non-operative aspects of DCM management and developing an enhanced recovery pathway for patients prior to, during, and after surgery. **The incubator** is currently being led by Caroline Treanor, who is overseeing a workstream to develop guidelines for the peri-operative management of DCM. Here, our team is working with the Enhanced Recovery After Surgery (ERAS) Society, who seek to improve care pathways so as to help patients achieve better and earlier recovery following major surgery.

Myelopathy.org Research Prize

Each year Myelopathy.org picks the most significant and original research contribution that aligns with the RECODE-DCM Research Priorities. We had submissions from all over the world, but our independent experts were in unanimous agreement that the 2023 winner was Dr Satkunendrarajah and Dr Aditya from Wisconsin, USA who submitted an innovative research paper on breathing difficulties in people with DCM.

You can listen to Dr. Satkunendrarajah and her co-investigator Dr. Aditya Vedantam on our [Myelopathy Matters podcast](#) discuss the research.

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, Motor Neuron 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 and Helen Wood, Chair of the Board of Trustees of Myelopathy.org sits on the trial Steering Committee

The first patient was recruited to the trial at Addenbrooke's Hospital in Cambridge on 7 July 2023 and by the end of June 2024 the trial had recruited a further 138 participants. 25 sites have now opened and are recruiting with a further 10 sites being set up.

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:

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2024**

Objectives and activities (continued)

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.

We have now completed this project and have:

- provided a comprehensive review of DCM educational resources and an article capturing patient perspectives on available information, establishing a clear rationale for the project and the development of the CIS and process map.
- successfully developed the first educational tool for DCM, the DCM Diagnosis CIS, with input from an international panel of clinicians and patients.
- developed the first DCM process map, detailing key decision points in clinical care, in collaboration with an international panel of clinicians and patients.
- piloted the CIS at Addenbrooke's Hospital, gathering initial feedback from patients and clinicians using both in-house measures and pre-validated tools.

The work completed establishes a solid rationale and launchpad for future research focused on enhancing knowledge and awareness of DCM among patients and clinicians. Notably, this work has laid the groundwork for developing patient decision-making tools. The preliminary assessment of the CIS at Addenbrooke's Hospital provides an essential foundation for evaluating its feasibility for adoption in NHS clinical practice.

(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

Following the launch of our enhanced website in April 2023 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.

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 5 was launched in January 2025. 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.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2024**

Objectives and activities (continued)

Google Ads

Myelopathy.org has continued to benefit from the Google Ad Grant awarded during 2023-24. 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.

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

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

(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 3500 members. This group is growing and we typically see 200 posts, 3,000 comments and 5,000 reactions each month.

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. 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.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2024**

Objectives and activities (continued)

Yoga

Helen McBain, a yoga teacher, launched a series of on-line yoga sessions for members of our support group in 2023. The sessions were devised specifically for people with DCM and the emphasis was about listening to your body. Helen tailored the sessions to individual needs to ensure everyone was able to get the most out of the session.

Achievements and performance

a. Review of activities

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

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.

In July 2023 we launched our first Summer Fundraiser when we invited our community to raise much needed funds by getting involved in challenges. Our Festive Fundraiser invited our community to become regular donors. Regular donations (whatever the size) are incredibly important to us and help us to plan for the future.

2024 saw the launch of the Myelopathy.org stationery collection. The products are designed by people living with DCM and this initiative raises much needed awareness and funds.

In May 2024 Dr Rory Murphy from the Barrow Neurological Institute in the USA and now a trustee Myelopathy.org ran across the Grand Canyon to raise awareness and funds. Rory smashed his fundraising target of US\$1,500 by raising over US\$2,200.

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 2023-24 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

Programmes

We have continued to be a partner in RECODE-DCM and continue to work with AO Spine on this project.

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.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2024**

Achievements and performance (continued)

During 2023-24 Myelopathy.org applied for funding to The National Lottery (TNL) under its Reaching Communities programme to run a pilot helpline project for those affected by DCM. We received notification that we had been successful in securing £49,990 of funding from TNL in April 2024 and we are absolutely delighted to be able to run this exciting new pilot project for our beneficiaries during 2024-25.

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.

Conferences

Ben Davies (co-founder and trustee of Myelopathy.org) was invited by Manabu Ito, a leading spine surgeon from Japan, to deliver a keynote speech at the Japanese Spine Society (JSS) on Degenerative Cervical Myelopathy (DCM). The JSS is Japan's foremost professional society for spine surgery, dedicated to advancing research, education and clinical excellence in spinal disorders. During the speech, Ben emphasised the critical need for international collaboration to accelerate discoveries in DCM, highlighting that innovation anywhere should be able to help patients everywhere.

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.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2024**

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.

Statement of Trustees' responsibilities

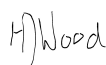
The Trustees are responsible for preparing the Trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

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 judgements 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 07 Apr 2025 and signed on their behalf by:



Helen Wood (Apr 7, 2025, 4:43pm)

Ms Helen J Wood
Trustee

**INDEPENDENT EXAMINER'S REPORT
FOR THE YEAR ENDED 30 JUNE 2024**

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 2024.

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:

C P J Dougherty FCA

Lakin Rose Limited
Cambridge House
Camboro Business Park
Girton
Cambridge
CB3 0QH

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 30 JUNE 2024

	Note	Restricted funds 2024 £	Unrestricted funds 2024 £	Total funds 2024 £	Total funds 2023 £
Income from:					
Donations	3	13,283	56,490	69,773	72,863
Charitable activities	4	-	5,152	5,152	6,351
Investments	5	-	-	-	1
Total income		13,283	61,642	74,925	79,215
Expenditure on:					
Raising funds	6	-	1,800	1,800	-
Charitable activities		13,283	60,035	73,318	97,406
Total expenditure		13,283	61,835	75,118	97,406
Net movement in funds		-	(193)	(193)	(18,191)
Reconciliation of funds:					
Total funds brought forward		-	37,498	37,498	55,689
Net movement in funds		-	(193)	(193)	(18,191)
Total funds carried forward		-	37,305	37,305	37,498

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

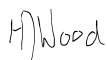
The notes on pages 13 to 21 form part of these financial statements.

MYELOPATHY.ORG

BALANCE SHEET
AS AT 30 JUNE 2024

	Note	2024 £	2023 £
Current assets			
Debtors	11	6,276	4,363
Cash at bank and in hand		36,303	38,188
		<u>42,579</u>	<u>42,551</u>
Creditors: amounts falling due within one year	12	(5,274)	(5,053)
Net current assets		<u>37,305</u>	<u>37,498</u>
Total net assets		<u><u>37,305</u></u>	<u><u>37,498</u></u>
Charity funds			
Restricted funds	13	-	-
Unrestricted funds	13	37,305	37,498
Total funds		<u><u>37,305</u></u>	<u><u>37,498</u></u>

The financial statements were approved and authorised for issue by the Trustees on 07 Apr 2025 and signed on their behalf by:



Helen Wood (Apr 7, 2025, 4:43pm)

Ms Helen J Wood
Trustee

The notes on pages 13 to 21 form part of these financial statements.

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2024**

1. General information

The charity is a charitable incorporated organisation (CIO). The charity's address is Lakin Rose Limited, Cambridge House, Camboro Business Park, Girton, Cambridge, CB3 0QH.

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 2024

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 2024

3. Income from donations

	Restricted funds 2024 £	Unrestricted funds 2024 £	Total funds 2024 £	Total funds 2023 £
Donations	-	56,490	56,490	45,036
Grants	13,283	-	13,283	27,827
	<u>13,283</u>	<u>56,490</u>	<u>69,773</u>	<u>72,863</u>
<i>Total 2023</i>	<u>27,827</u>	<u>45,036</u>	<u>72,863</u>	

4. Income from charitable activities

	Unrestricted funds 2024 £	Total funds 2024 £	Total funds 2023 £
Research services	5,152	5,152	6,351
	<u>5,152</u>	<u>5,152</u>	<u>6,351</u>

5. Investment income

	Unrestricted funds 2024 £	Total funds 2024 £	Total funds 2023 £
Interest receivable	-	-	1
	<u>-</u>	<u>-</u>	<u>1</u>

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2024

6. Expenditure on raising funds

Costs of raising voluntary income

	Unrestricted funds 2024 £	Total funds 2024 £	<i>Total funds 2023 £</i>
Costs of raising voluntary income	1,800	1,800	-

7. Analysis of expenditure by activities

	Activities undertaken directly 2024 £	Support costs 2024 £	Total funds 2024 £	<i>Total funds 2023 £</i>
Charitable activities	2,057	71,261	73,318	97,406
<i>Total 2023</i>	2,460	94,946	97,406	

Analysis of direct costs

	Charitable activities 2024 £	Total funds 2024 £	<i>Total funds 2023 £</i>
Education	2,057	2,057	2,460

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2024

7. Analysis of expenditure by activities (continued)

Analysis of support costs

	Charitable activities 2024 £	Total funds 2024 £	<i>Total funds 2023 £</i>
Staff costs	29,066	29,066	23,469
General office expenses	3,426	3,426	2,754
Computer expenses	613	613	485
Insurance	495	495	474
Subscriptions	267	267	410
Travel and subsistence	-	-	1,747
Grant funded Google advertisements	24,524	24,524	31,200
Consultancy	11,100	11,100	33,147
Governance costs	1,770	1,770	1,260
	<u>71,261</u>	<u>71,261</u>	<u>94,946</u>

8. Independent examiner's remuneration

The independent examiner's remuneration amounts to an independent examiner fee of £1,770 (2023 - £1,260).

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2024

9. Staff costs

	2024 £	2023 £
Wages and salaries	28,401	22,953
Contribution to defined contribution pension schemes	665	516
	<u>29,066</u>	<u>23,469</u>

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

	2024 No.	2023 No.
Management	<u>1</u>	<u>1</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 2024, no Trustees received any remuneration or other benefits (2023 - £NIL).

During the year ended 30 June 2024, no Trustee expenses have been incurred (2023 - £NIL).

11. Debtors

	2024 £	2023 £
Prepayments and accrued income	2,276	3,496
Tax recoverable	4,000	867
	<u>6,276</u>	<u>4,363</u>

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2024

12. Creditors: Amounts falling due within one year

	2024	2023
	£	£
Trade creditors	-	1,040
Other taxation and social security	1,756	727
Other creditors	2,078	1,886
Accruals and deferred income	1,440	1,400
	<u>5,274</u>	<u>5,053</u>

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2024

13. Statement of funds

Statement of funds - current year

	Balance at 1 July 2023 £	Income £	Expenditure £	Balance at 30 June 2024 £
Unrestricted funds				
General Funds	37,498	61,642	(61,835)	37,305
Restricted funds				
Decision Making in DCM (previously DCM COINS) Project	-	7,910	(7,910)	-
POLYFIX-DCM Trial fund	-	5,373	(5,373)	-
	-	13,283	(13,283)	-
Total of funds	37,498	74,925	(75,118)	37,305

Decision Making in DCM Project

This fund relates to grants 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 (**PO**sterior Laminectomy and **FIX**ation for **D**egenerative **C**ervical **M**yelopathy) trial.

Income and expenses relating to the PPI element of the Distressed Study (a sub study which is part of POLYFIX) and to set up a mechanism to administer any patient travel expenses related to the trial and for a Podcast about the trial.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2024

13. Statement of funds (continued)

Statement of funds - prior year

	<i>Balance at 1 July 2022</i>	<i>Income</i>	<i>Expenditure</i>	<i>Balance at 30 June 2023</i>
	£	£	£	£
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 (**PO**sterior **L**aminectomy and **FIX**ation 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.



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Parties involved with this document

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Mon, 7th Apr 2025 16:43:55 BST	Helen Wood - Signer (155bfe1dea6acbef393ea63b999f48e7)

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Date	Action
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Mon, 7th Apr 2025 13:55:36 BST	Document generated with fingerprint 591edbe97cb6a8cff1d29eb2cabb023c (62.31.185.2)
Mon, 7th Apr 2025 14:00:46 BST	Sent the envelope to Helen Wood (helen@myelopathy.org) for signing (62.31.185.2)
Mon, 7th Apr 2025 14:00:46 BST	Document emailed to helen@myelopathy.org (35.178.171.104)
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Mon, 7th Apr 2025 16:43:55 BST	This envelope has been signed by all parties (82.44.241.98)

MYELOPATHY.ORG

England & Wales - Charity number 1178673

Accounts

MYELOPATHY.ORG

TRUSTEES' REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 30 JUNE 2023

MYELOPATHY.ORG

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).

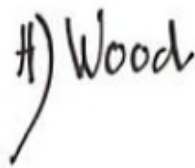
The law applicable to charities in England & Wales requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of its incoming resources and application of resources, including its income and expenditure, for 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 19.3.24 and signed on their behalf by:

Ms Helen J Wood
Trustee



**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 £	Total funds 2022 £
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.

MYELOPATHY.ORG

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 19 March 2024 and signed on their behalf by:

Ms Helen J Wood
Trustee

19 March 2024
H) Wood

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 £	Total funds 2022 £
Costs of raising voluntary income	-	-	3,785

7. Analysis of expenditure by activities

	Activities undertaken directly 2023 £	Support costs 2023 £	Total funds 2023 £	Total funds 2022 £
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 £	Total funds 2022 £
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
	<u>94,946</u>	<u>94,946</u>	<u>75,862</u>

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

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

	2023 No.	2022 No.
Management	<u>1</u>	<u>1</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 £	2022 £
Trade debtors	-	2,252
Prepayments and accrued income	3,496	167
Tax recoverable	867	625
	<u>4,363</u>	<u>3,044</u>

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

12. Creditors: Amounts falling due within one year

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

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 (**PO**sterior **L**aminectomy and **FIX**ation 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
Restricted funds				
Facing Myelopathy Together	4,094	-	(4,094)	-
Decision Making in DCM (previously DCM COINS) Project	-	4,524	(4,524)	-
	<u>4,094</u>	<u>4,524</u>	<u>(8,618)</u>	<u>-</u>
Total of funds	<u><u>56,423</u></u>	<u><u>81,608</u></u>	<u><u>(82,342)</u></u>	<u><u>55,689</u></u>

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.

MYELOPATHY.ORG

England & Wales - Charity number 1178673

Accounts

MYELOPATHY.ORG

TRUSTEES' REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 30 JUNE 2022

MYELOPATHY.ORG

CONTENTS

	Page
Reference and administrative details of the charity, its Trustees and advisers	1
Trustees' report	2 - 9
Independent examiner's report	10
Statement of financial activities	11
Balance sheet	12
Notes to the financial statements	13 - 20

**REFERENCE AND ADMINISTRATIVE DETAILS OF THE CHARITY, ITS TRUSTEES AND ADVISERS
FOR THE YEAR ENDED 30 JUNE 2022**

Trustees

Dr Mark Kotter
Lady Julia K H Carter of Coles
Mrs Weslie R Janeway
Ms Helen J Wood
Dr Johann Graggaber
Ms Carol Sun
Mr David Townshend
Mr Iwan Lloyd Sadler
Mr Roy Smith (appointed 6 January 2023)

Charity registered number

1178673

Principal office

Lakin Rose
Pioneer House
Vision Park
Histon
Cambridge
CB24 9NL

Independent examiners

Lakin Rose Limited
Pioneer House
Vision Park
Histon
Cambridge
CB24 9NL

TRUSTEES' REPORT
FOR THE YEAR ENDED 30 JUNE 2022

The Trustees present their annual report together with the financial statements of the Myelopathy.org for the year 1 July 2021 to 30 June 2022.

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. The top 10 research priorities were identified in November 2019 (see table below) followed by a Core Outcome Set and Core Data Elements in October 2020. These outcomes are those that matter most to people living with DCM as well as those who treat them. They include life impact, economic impact, and pain and neuromuscular function. The data elements include demographics, co-morbidities, imaging and surgical details. Taken together this constitutes what to measure in all future DCM studies.

The third and final consensus meeting took place on 1 June 2022 at the Global Spine Congress in Las Vegas, Nevada, USA. The healthcare professionals of RECODE-DCM came together, with much-valued representation from people living with DCM, to decide which measurement tools to use in all DCM research going forward. Factors which were considered were the tools' quality, popularity, feasibility to use (i.e. not too onerous on the patient) and how relevant they were to the core outcomes.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2022**

Objectives and activities (continued)

The following measurement tools were selected by consensus:

- The modified Japanese Orthopaedic Association Score (mJOA)
- The SF-36 Life Impact Scale
- The Neck Disability Index
- The Spinal Adverse Events Severity System

These tools were felt to be the best options at present for a Core Measurement Set. All investigators should find opportunities to extend these assessments in their trials, depending on their research question. In addition during 2021 and 2022 the first three special interest groups were formed to drive advances in 3 of the top 10 research priorities.

The Diagnostic Criteria incubator members are working on a signs and symptoms review, to generate a solid framework for ruling DCM in and ruling it out.

The Natural History incubator members are undertaking a survey to establish current practice for asymptomatic cervical cord compression, and mild myelopathy. The survey so far has almost 600 responses.

The Peri-Operative Rehabilitation incubator members are designing the world's first and largest scoping survey to establish what rehabilitation there is at present, what the evidence is, and how we can do better.

In May 2022 Myelopathy.org entered into a 3-year transition agreement with AO Spine to ensure the efficient handover of the RECODE DCM project to Myelopathy.org.

Myelopathy.org is establishing a strategy to both fund and manage the RECODE DCM network and we are excited to work on this initiative during the next year.

TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2022

Objectives and activities (continued)

The Top Ten Research Priorities

	Short Title	Full Priority Wording
1	Raising Awareness	What strategies can increase awareness and understanding of DCM amongst healthcare professionals and the public? Can these strategies help improve timely diagnosis and management of DCM?
2	Natural History	What is the natural history of DCM? What is the relationship between DCM and asymptomatic spinal cord compression or canal stenosis? What factors influence the natural history of the disease?
3	Diagnostic Criteria	What are the diagnostic criteria of DCM? What is the role of imaging and when should imaging be used in the assessment of DCM?
4	Assessment and Monitoring	What assessment tools can be used to evaluate functional impairment, disability and quality of life in people with DCM? What instruments, tools or methods can be used or developed to monitor people with DCM for disease progression or improvement either before or after surgical treatment?
5	Pathophysiology	What is the pathophysiology of DCM? What are the mechanisms of neurological injury and the molecular and anatomical consequences?
6	Rehabilitation	What is the role of rehabilitation following surgery for DCM? Can structured postoperative rehabilitation improve outcome following surgery for DCM? What are the most effective strategies?
7	Novel Therapies	Can novel therapies, including stem-cell, gene, pharmacological and neuroprotective therapies, improve the health and wellbeing of people living with DCM and slow down disease progression?
8	Socio-economic Impact	What is the socio-economic impact of DCM? (<i>The financial impact of living with DCM to the individual, their supporters and society as a whole</i>)
9	Imaging Techniques	What is the role of dynamic or novel imaging techniques and neurophysiology in the assessment of DCM?
10	Individualising Surgery	Are there clinical and imaging factors that can help a surgeon select who should undergo surgical decompression in the setting of DCM? At what stage of the disease is surgery the preferred management strategy?

These research priorities will direct future Myelopathy.org funding and strategies.

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. After pandemic related delays the trial recruited it's first patients in Cambridge during 2021-22.

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. Recruitment to the trial commenced during 2022.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2022**

Objectives and activities (continued)

DCM Core Information Set (COINS)

Myelopathy.org has continued to receive support by way of a grant from the Evelyn Trust to create the first comprehensive education framework for people with DCM. The aim of the project is to define key points at which people with DCM require information and the content of this. We will develop a series of Core Information Sets, 'checklists,' to help ensure professionals and people with DCM cover critical concepts at key points in their journey. This is hugely important for people with DCM and will better support shared decision making in DCM, a National Institute for Health and Care (NICE) recommendation and help to bring evidence-based care into every clinic. This will empower people with DCM to ensure their care is in-line with the latest evidence.

(2) Awareness

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

Myelopathy.org website and branding

In April 2022, we launched our new website and rebrand of Myelopathy.org. This fresh look and improved content has had such a positive impact on all our community – making it easier to access much needed information about DCM.

In particular we would like to thank our amazing volunteers from Mu Digital who assisted with web design and development and Andrea Malaskova for her amazing illustrations.

Our website is our hub of information about the charity and also a vital resource for people with DCM and healthcare professionals.

Weekly Blog

In April 2022 in conjunction with the launch of our new website we have also introduced 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 2022. 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 2021-22. 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.

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

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

TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2022

Objectives and activities (continued)

(3) Support

Support Group

Our Myelopathy Support page on Facebook continues to grow and now has over 3,000 followers. Myelopathy.org also runs an on-line private support group on Facebook which has approximately 2100 members. There has been an increase in the number of requests to join the support group since the re-launch of the website and introduction of the weekly blogs.

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.

Coffee with Esther

In January 2022 a member of our support group, Esther Martin-Moore established a virtual Coffee Break meeting for people with DCM. Esther describes below why she came up with the idea.

"The coffee breaks idea was from a conversation I had with my husband. Throughout the pandemic, we would do video calls with family and friends as a group, had quizzes and caught up. But as restrictions were lifted, everyone slowly went back to their normal lives. I was once again home alone and trying to live day-by-day. I realised others must live like this. Surely they would like to chat to someone, make new friends face-to-face. So I messaged Iwan and asked if we could hold a virtual coffee break. Each coffee break gives me a boost for that day, knowing I have spoken to people that understand. We talk about all sorts of topics and offer advice, not medical advice, but on things that can help. We also talk about how we are feeling, how everyone's week has been. It's just like talking to a friend you know."

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.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2022**

Achievements and performance

a. Review of activities

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

2021-22 has been a year of organisational growth for Myelopathy.org. Following the success of the appointment of Zahabiya Karimi as a consultant during 2020-21 to assist the board to produce a strategic plan for developing the charity and subsequent fundraising, Myelopathy.org appointed our first member of staff. Zahabiya was appointed as Director of Myelopathy.org and took up the role on a part-time basis on 1 July 2021.

- **Fundraising**

Myelopathy.org held its first fundraising challenge event in 2021. 30 supporters took part in the Cambridge Half Marathon in November 2021 and raised an incredible £15,000.

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

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 2021-22 we continued to build up a professional volunteer programme to expand our capacity. Volunteers have continued to work on the following projects; website design and re-development, charity rebranding, content for all areas of our work, general charity administration, grant writing and research, Human Resources and DCM COINS.

- **Operations, outreach, and communication**

During 2021-22 we have continued working on Myelopathy.org's compliance which has included putting additional policies in place to cover Equalities and Diversity, Safeguarding, On-line safety, Maternity and Parental Leave and Complaints.

In April 2022 we completed and launched our new website (both design and content) and charity re-brand and introduced a weekly blog post.

- **Programmes**

We have continued to be a partner in RECODE-DCM and in May 2022 Myelopathy.org entered into a 3-year transition agreement with AO Spine to ensure the efficient handover of the RECODE DCM project to Myelopathy.org.

Myelopathy.org is establishing a strategy to both fund and manage the RECODE DCM network and we are excited to work on this initiative during the next year.

We have continued work on the DCM COINS 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.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2022**

Achievements and performance (continued)

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

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. Further details regarding the adoption of the going concern basis can be found in the accounting policies.

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 2022**

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 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 *22 April 2023* and signed on their behalf by:

Ms Helen J Wood
Trustee

HJ Wood

**INDEPENDENT EXAMINER'S REPORT
FOR THE YEAR ENDED 30 JUNE 2022**

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

We report to the charity Trustees on our examination of the accounts of the charity for the year ended 30 June 2022.

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').

We report in respect of our examination of the charity's accounts carried out under section 145 of the 2011 Act and in carrying out our examination we 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.

We 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.

We have completed our examination. We confirm that no matters have come to our attention in connection with the examination giving us 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.

We 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. Our work has been undertaken so that we might state to the charity's Trustees those matters we are required to state to them in an independent examiner's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's Trustees as a body, for our work or for this report.

Signed:



Dated: 24 April 2023

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 2022**

	Note	Restricted funds 2022 £	Unrestricted funds 2022 £	Total funds 2022 £	Total funds 2021 £
Income from:					
Donations	3	4,524	74,829	79,353	118,317
Charitable activities	4	-	2,252	2,252	4,946
Investments	5	-	3	3	21
Total income		4,524	77,084	81,608	123,284
Expenditure on:					
Raising funds	6	-	3,785	3,785	1,842
Charitable activities		8,618	69,939	78,557	73,512
Total expenditure		8,618	73,724	82,342	75,354
Net movement in funds		(4,094)	3,360	(734)	47,930
Reconciliation of funds:					
Total funds brought forward		4,094	52,329	56,423	8,493
Net movement in funds		(4,094)	3,360	(734)	47,930
Total funds carried forward		-	55,689	55,689	56,423

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

The notes on pages 13 to 20 form part of these financial statements.

MYELOPATHY.ORG

BALANCE SHEET
AS AT 30 JUNE 2022

	Note	2022 £	2021 £
Current assets			
Debtors	11	3,044	7,237
Cash at bank and in hand		54,885	54,261
		<u>57,929</u>	<u>61,498</u>
Creditors: amounts falling due within one year	12	(2,240)	(5,075)
Net current assets		55,689	56,423
Total net assets		55,689	56,423
		<u><u>55,689</u></u>	<u><u>56,423</u></u>
Charity funds			
Restricted funds	13	-	4,094
Unrestricted funds	13	55,689	52,329
Total funds		55,689	56,423
		<u><u>55,689</u></u>	<u><u>56,423</u></u>

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

22 April 2023

Ms Helen J Wood
Trustee

HJ Wood

The notes on pages 13 to 20 form part of these financial statements.

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022**

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 2022

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 2022

3. Income from donations

	Restricted funds 2022 £	Unrestricted funds 2022 £	Total funds 2022 £	Total funds 2021 £
Donations	-	73,829	73,829	106,229
Grants	4,524	1,000	5,524	12,088
	<u>4,524</u>	<u>74,829</u>	<u>79,353</u>	<u>118,317</u>
<i>Total 2021</i>	<u>12,088</u>	<u>106,229</u>	<u>118,317</u>	

4. Income from charitable activities

	Unrestricted funds 2022 £	Total funds 2022 £	Total funds 2021 £
Research services	2,252	2,252	4,946
	<u>2,252</u>	<u>2,252</u>	<u>4,946</u>

5. Investment income

	Unrestricted funds 2022 £	Total funds 2022 £	Total funds 2021 £
Interest receivable	3	3	21
	<u>3</u>	<u>3</u>	<u>21</u>

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

6. Expenditure on raising funds

Costs of raising voluntary income

	Unrestricted funds 2022 £	Total funds 2022 £	Total funds 2021 £
Costs of raising voluntary income	3,785	3,785	1,842

7. Analysis of expenditure by activities

	Activities undertaken directly 2022 £	Support costs 2022 £	Total funds 2022 £	Total funds 2021 £
Charitable activities	2,695	75,862	78,557	73,512
<i>Total 2021</i>	5,964	67,548	73,512	

Analysis of direct costs

	Charitable activities 2022 £	Total funds 2022 £	Total funds 2021 £
Education	2,538	2,538	3,095
Research	157	157	2,869
	2,695	2,695	5,964

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

7. Analysis of expenditure by activities (continued)

Analysis of support costs

	Charitable activities 2022 £	Total funds 2022 £	Total funds 2021 £
Staff costs	14,291	14,291	-
General office expenses	584	584	71
Computer expenses	1,000	1,000	768
Insurance	426	426	398
Subscriptions	194	194	157
Travel and subsistence	72	72	-
Grant funded Google advertisements	49,920	49,920	50,519
Consultancy	8,115	8,115	14,375
Governance costs	1,260	1,260	1,260
	<u>75,862</u>	<u>75,862</u>	<u>67,548</u>

8. Independent examiner's remuneration

The independent examiner's remuneration amounts to an independent examiner fee of £1,260 (2021 - £1,200).

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

9. Staff costs

	2022 £	2021 £
Wages and salaries	13,581	-
Contribution to defined contribution pension schemes	710	-
	<u>14,291</u>	<u>-</u>

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

	2022 No.	2021 No.
Management	<u>1</u>	<u>-</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 (2021 - £NIL).

During the year ended 30 June 2022, no Trustee expenses have been incurred (2021 - £NIL).

11. Debtors

	2022 £	2021 £
Trade debtors	2,252	-
Prepayments and accrued income	167	149
Tax recoverable	625	5,000
Grants receivable	-	2,088
	<u>3,044</u>	<u>7,237</u>

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

12. Creditors: Amounts falling due within one year

	2022 £	2021 £
Trade creditors	1,040	1,875
Accruals and deferred income	1,200	3,200
	<u>2,240</u>	<u>5,075</u>

13. Statement of funds

Statement of funds - current year

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

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.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2022

13. Statement of funds (continued)

Statement of funds - prior year

	<i>Balance at 1 July 2020</i> £	<i>Income</i> £	<i>Expenditure</i> £	<i>Balance at 30 June 2021</i> £
Unrestricted funds				
General Funds	8,493	111,196	(67,360)	52,329
Restricted funds				
Facing Myelopathy Together	-	10,000	(5,906)	4,094
DCM COINS Project	-	2,088	(2,088)	-
	-	12,088	(7,994)	4,094
Total of funds	8,493	123,284	(75,354)	56,423

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.

MYELOPATHY.ORG

England & Wales - Charity number 1178673

Accounts

MYELOPATHY.ORG

TRUSTEES' REPORT AND FINANCIAL STATEMENTS

FOR THE YEAR ENDED 30 JUNE 2021

MYELOPATHY.ORG

CONTENTS

	Page
Reference and administrative details of the charity, its Trustees and advisers	1
Trustees' report	2 - 7
Independent examiner's report	8
Statement of financial activities	9
Balance sheet	10
Notes to the financial statements	11 - 16

REFERENCE AND ADMINISTRATIVE DETAILS OF THE CHARITY, ITS TRUSTEES AND ADVISERS
FOR THE YEAR ENDED 30 JUNE 2021

Trustees

Dr Mark Kotter
Lady Julia K H Carter of Coles
Mrs Weslie R Janeway
Ms Helen J Wood
Dr Johann Graggaber
Ms Carol Sun
Mr David Townshend
Mr Iwan Lloyd Sadler (appointed 15 March 2021)

Charity registered number

1178673

Principal office

Lakin Rose
Pioneer House
Vision Park
Histon
Cambridge
CB24 9NL

Independent examiners

Lakin Rose Limited
Pioneer House
Vision Park
Histon
Cambridge
CB24 9NL

**TRUSTEES' REPORT
FOR THE YEAR ENDED 30 JUNE 2021**

The Trustees present their annual report together with the financial statements of the Myelopathy.org for the year 1 July 2020 to 30 June 2021.

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

Myelopathy.org continues to be a partner in AO Spine RECODE DCM, an international consensus initiative to involve people with DCM alongside healthcare professionals, in the design and direction of DCM research. The top 10 research priorities have been identified and we are now involved in forming task forces to develop diagnostic criteria, understand the natural history of DCM and develop an integrated pathway for those undergoing surgery (all top 10 research priorities).

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2021**

Objectives and activities (continued)

The Top Ten Research Priorities

	Short Title	Full Priority Wording
1	Raising Awareness	What strategies can increase awareness and understanding of DCM amongst healthcare professionals and the public? Can these strategies help improve timely diagnosis and management of DCM?
2	Natural History	What is the natural history of DCM? What is the relationship between DCM and asymptomatic spinal cord compression or canal stenosis? What factors influence the natural history of the disease?
3	Diagnostic Criteria	What are the diagnostic criteria of DCM? What is the role of imaging and when should imaging be used in the assessment of DCM?
4	Assessment and Monitoring	What assessment tools can be used to evaluate functional impairment, disability and quality of life in people with DCM? What instruments, tools or methods can be used or developed to monitor people with DCM for disease progression or improvement either before or after surgical treatment?
5	Pathophysiology	What is the pathophysiology of DCM? What are the mechanisms of neurological injury and the molecular and anatomical consequences?
6	Rehabilitation	What is the role of rehabilitation following surgery for DCM? Can structured postoperative rehabilitation improve outcome following surgery for DCM? What are the most effective strategies?
7	Novel Therapies	Can novel therapies, including stem-cell, gene, pharmacological and neuroprotective therapies, improve the health and wellbeing of people living with DCM and slow down disease progression?
8	Socio-economic Impact	What is the socio-economic impact of DCM? (<i>The financial impact of living with DCM to the individual, their supporters and society as a whole</i>)
9	Imaging Techniques	What is the role of dynamic or novel imaging techniques and neurophysiology in the assessment of DCM?
10	Individualising Surgery	Are there clinical and imaging factors that can help a surgeon select who should undergo surgical decompression in the setting of DCM? At what stage of the disease is surgery the preferred management strategy?

These research priorities will direct future Myelopathy.org funding and strategies.

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. Ethical approval of the trial was obtained in early 2020 but the ongoing COVID 19 pandemic has resulted in a further delay to its implementation

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. Recruitment to the trial is expected to commence during 2022.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2021**

Objectives and activities (continued)

DCM Core Information Set (COINS)

Myelopathy.org has received a grant from the Evelyn Trust to create the first comprehensive education framework for people with DCM. The aim of the project is to define key points at which people with DCM require information and the content of this. We will develop a series of Core Information Sets, 'checklists,' to help ensure professionals and people with DCM cover critical concepts at key points in their journey. This is hugely important for people with DCM and will better support shared decision making in DCM, a National Institute for Health and Care (NICE) recommendation and help to bring evidence-based care into every clinic. This will empower people with DCM to ensure their care is in-line with the latest evidence.

(2) Awareness

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

Myelopathy.org website

Our website is our hub of information about the charity and also a vital resource for people with DCM and healthcare professionals.

Myelopathy Matters PodCasts

Myelopathy Matters is a PodCast series produced by Myelopathy.org. 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. For example, our special series covering the top 10 research priorities with AO Spine was listened to over 10,000 times.

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 2019-20. 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.

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

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

We are working on further developing our website and marketing efforts to help implement their recommendations to help us raise awareness and target the people we want to reach.

(3) Support

Our Myelopathy Support page on Facebook continues to grow and now has over 3,000 followers. Myelopathy.org also runs an on-line private support group on Facebook which has approximately 1750 members. 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.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2021**

Objectives and activities (continued)

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.

Achievements and performance

a. Review of activities

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

2020-21 has been a year of consolidation for Myelopathy.org where we have focussed on developing a strategy to allow the charity to grow in a sustainable manner and move forward to continue to fulfil our charitable aims, namely, to advance health and education in all aspects of degenerative cervical myelopathy.

The Trustees provided the funding to engage an experienced charity professional in November 2020 to assist the board to produce a strategic plan for developing the charity. In particular, the strategic plan addressed fundraising, programme management, website content and design, compliance and volunteer management.

This appointment was on a consultancy basis and its success and subsequent fundraising has enabled Myelopathy.org to appoint our first member of staff. Zahabiya Karimi has been appointed as Director of Myelopathy.org and took up the role on a part-time basis on 1 July 2021.

We have appointed three new trustees to the Board of Myelopathy.org. Carol Sun is a marketing executive and David Townshend is a former investment banker who is also a qualified accountant. Our co-founder Iwan Sadler was also appointed a trustee in June 2021. Helen Wood took over the role of Chair of the Board of Trustees in November 2020.

• **Fundraising**

We successfully applied for 2 grants during 2020-21. Awards for All (part of the National Lottery) awarded us a grant and The Evelyn Trust awarded us a Health & Wellbeing grant to fund the DCM COINS project. 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.

Myelopathy.org's income has increased by approximately 265% in 2020-21, from £33,728 to £123,284.

As part of our strategic plan the board commissioned a Case for Support which is being used on an on-going basis to help us with our grant applications. We also started work on our first challenge event – entering a team in the Cambridge half marathon in October 2021 – to raise funds and awareness of Myelopathy.org.

• **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 2020-21 we have started to build up a professional volunteer programme to expand our capacity. This has involved creating structured processes to closely manage and maintain volunteer development. Additional volunteers have been recruited to work on the following projects; website design and re-development, charity rebranding, support group analysis, content for all areas of our work, general charity administration, grant writing and research, Human Resources and DCM COINS.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2021**

Achievements and performance (continued)

- **Operations, outreach, and communication**

During 2020-21 we have been working on Myelopathy.org's compliance which has included putting policies in place and ensuring our compliance with GDPR. In addition, we have started the process of updating our website (both design and content) and are working on a charity re-brand. The new website and re-brand will be launched in 2022. As part of this process, we have been examining how we communicate with all our stakeholders both by traditional means and via social media.

- **Programmes**

We have continued to be a partner in RECODE-DCM which has now identified the Top 10 research priorities for DCM and we are now involved in forming task forces to develop the research priorities further.

We have started work on the DCM COINS 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.

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

2020-21 saw the continuation of the COVID-19 global pandemic and this highlighted the need for Myelopathy.org to continue its work to inform and support our community. Our digital platform has enabled us to continue this work seamlessly but has highlighted the need to improve how we do this to best support our community who has been hard hit by the restrictions to much of normal life.

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. Further details regarding the adoption of the going concern basis can be found in the accounting policies.

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.

**TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 30 JUNE 2021**

Structure, governance and management (continued)

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.

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 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 **26 April 2022** and signed on their behalf by:

Ms Helen J Wood
Trustee

Helen J Wood

**INDEPENDENT EXAMINER'S REPORT
FOR THE YEAR ENDED 30 JUNE 2021**

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

We report to the charity Trustees on our examination of the accounts of the charity for the year ended 30 June 2021.

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').

We report in respect of our examination of the charity's accounts carried out under section 145 of the 2011 Act and in carrying out our examination we 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.

We 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.

We have completed our examination. We confirm that no matters have come to our attention in connection with the examination giving us 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.

We 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. Our work has been undertaken so that we might state to the charity's Trustees those matters we are required to state to them in an independent examiner's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's Trustees as a body, for our work or for this report.

Signed:

Carla Barnes

Dated: 27 April 2022

Carla Barnes FCCA

Lakin Rose Limited

Pioneer House, Vision Park, Histon, CB24 9NL

**STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 30 JUNE 2021**

	Note	Restricted funds 2021 £	Unrestricted funds 2021 £	Total funds 2021 £	Total funds 2020 £
Income from:					
Donations	3	12,088	106,229	118,317	26,001
Charitable activities	4	-	4,946	4,946	7,727
Investments	5	-	21	21	-
Total income		12,088	111,196	123,284	33,728
Expenditure on:					
Raising funds	6	-	1,842	1,842	-
Charitable activities		7,994	65,518	73,512	29,870
Total expenditure		7,994	67,360	75,354	29,870
Net movement in funds		4,094	43,836	47,930	3,858
Reconciliation of funds:					
Total funds brought forward		-	8,493	8,493	4,635
Net movement in funds		4,094	43,836	47,930	3,858
Total funds carried forward		4,094	52,329	56,423	8,493

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

The notes on pages 11 to 16 form part of these financial statements.

MYELOPATHY.ORG

BALANCE SHEET
AS AT 30 JUNE 2021

	Note	2021 £	2020 £
Current assets			
Debtors	10	7,237	2,587
Cash at bank and in hand		54,261	6,656
		<u>61,498</u>	<u>9,243</u>
Creditors: amounts falling due within one year	11	(5,075)	(750)
Net current assets		<u>56,423</u>	<u>8,493</u>
Total net assets		<u><u>56,423</u></u>	<u><u>8,493</u></u>
Charity funds			
Restricted funds	12	4,094	-
Unrestricted funds	12	52,329	8,493
Total funds		<u><u>56,423</u></u>	<u><u>8,493</u></u>

The financial statements were approved and authorised for issue by the Trustees on
26 April 2022 and signed on their behalf by:

Ms Helen J Wood
Trustee

Helen Wood

The notes on pages 11 to 16 form part of these financial statements.

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2021**

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 2021

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 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.

3. Income from donations

	Restricted funds 2021 £	Unrestricted funds 2021 £	Total funds 2021 £	Total funds 2020 £
Donations	-	106,229	106,229	26,001
Grants	12,088	-	12,088	-
	<u>12,088</u>	<u>106,229</u>	<u>118,317</u>	<u>26,001</u>
<i>Total 2020</i>	<u>-</u>	<u>26,001</u>	<u>26,001</u>	

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2021

4. Income from charitable activities

	Unrestricted funds 2021 £	Total funds 2021 £	<i>Total funds 2020 £</i>
Research services	4,946	4,946	7,727

5. Investment income

	Unrestricted funds 2021 £	Total funds 2021 £	<i>Total funds 2020 £</i>
Interest receivable	21	21	-

6. Expenditure on raising funds

Costs of raising voluntary income

	Unrestricted funds 2021 £	Total funds 2021 £	<i>Total funds 2020 £</i>
Costs of raising voluntary income	1,842	1,842	-

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2021

7. Analysis of expenditure by activities

	Activities undertaken directly 2021 £	Support costs 2021 £	Total funds 2021 £	Total funds 2020 £
Charitable activities	5,964	67,548	73,512	29,870
<i>Total 2020</i>	8,424	21,446	29,870	

Analysis of direct costs

	Charitable activities 2021 £	Total funds 2021 £	Total funds 2020 £
Education	3,095	3,095	3,559
Research	2,869	2,869	4,865
	5,964	5,964	8,424

Analysis of support costs

	Charitable activities 2021 £	Total funds 2021 £	Total funds 2020 £
General office expenses	71	71	1,020
Computer expenses	768	768	647
Insurance	398	398	248
Subscriptions	157	157	157
Travel and subsistence	-	-	182
Grant funded Google advertisements	50,519	50,519	18,632
Consultancy	14,375	14,375	-
Governance costs	1,260	1,260	560
	67,548	67,548	21,446

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2021

8. Independent examiner's remuneration

The independent examiner's remuneration amounts to an independent examiner fee of £1,200 (2020 - £750).

9. Trustees' remuneration and expenses

During the year ended 30 June 2021, no Trustees received any remuneration or other benefits (2020 - £NIL).

During the year ended 30 June 2021, no Trustee expenses have been incurred (2020 - £NIL).

10. Debtors

	2021	<i>2020</i>
	£	£
Prepayments and accrued income	149	<i>149</i>
Tax recoverable	5,000	<i>2,438</i>
Grants receivable	2,088	<i>-</i>
	7,237	<i>2,587</i>

11. Creditors: Amounts falling due within one year

	2021	<i>2020</i>
	£	£
Trade creditors	1,875	<i>-</i>
Accruals and deferred income	3,200	<i>750</i>
	5,075	<i>750</i>

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2021

12. Statement of funds

Statement of funds - current year

	Balance at 1 July 2020 £	Income £	Expenditure £	Balance at 30 June 2021 £
Unrestricted funds				
General Funds	8,493	111,196	(67,360)	52,329
Restricted funds				
Facing Myelopathy Together	-	10,000	(5,906)	4,094
DCM COINS Project	-	2,088	(2,088)	-
	-	12,088	(7,994)	4,094
Total of funds	8,493	123,284	(75,354)	56,423

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.

Statement of funds - prior year

	Balance at 1 July 2019 £	Income £	Expenditure £	Balance at 30 June 2020 £
Unrestricted funds				
General Funds	4,635	15,096	(11,238)	8,493