
MYELOPATHY.ORG

TRUSTEES' REPORT AND FINANCIAL STATEMENTS

FOR THE PERIOD ENDED 30 JUNE 2019

MYELOPATHY.ORG

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**REFERENCE AND ADMINISTRATIVE DETAILS OF THE CHARITY, ITS TRUSTEES AND ADVISERS
FOR THE PERIOD ENDED 30 JUNE 2019**

Trustees

Dr Mark Kotter
Lady Julia K H Carter of Coles
Mrs Weslie R Janeway
Dr Johann Graggaber
Ms Helen J Wood

Charity registered number

1178673

Principal office

Lakin Rose
Pioneer House
Vision Park
Histon
Cambridge
CB24 9NL

Accountants

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

TRUSTEES' REPORT
FOR THE PERIOD ENDED 30 JUNE 2019

The Trustees present their annual report together with the financial statements of the charity for the period 6 June 2018 to 30 June 2019.

Objectives and Activities

Policies and objectives

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 support for patients, carers and health professionals.

(1) Research

The following section summarises the projects that Myelopathy.org has been involved in which further our first charitable aim, namely 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. Therefore, we believe that this is fully for future public benefit and hence fulfilling our obligations as trustees.

Myelopathy.org is committed to pioneering and pursuing **patient directed research** for public benefit and has founded '**SMART-Research**' (**S**uffers with **M**yelopathy **A**sks / **A**pproved **R**esearchers **T**o **R**esearch). This is a focus group of Degenerative Cervical Myelopathy (DCM) sufferers and their supporters, who provide peer-review for external proposals, or develop research questions of their own. The ambition is the group, together with Myelopathy.org, will provide the raw ingredients (ideas, evidence synthesis, assessment of public interest) to inform or support healthcare funding calls.

Myelopathy.org is also a partner in www.recode-dcm.com an international consensus initiative to involve sufferers, alongside healthcare professionals, in the design and direction of DCM research. It includes a James Lind Alliance Priority Setting Scheme, which is currently underway. This process will shortlist 10 research questions which are a priority for the field. This will direct future Myelopathy.org funding and strategies.

Current Research Themes and Projects

Myelopathy.org is currently focused on two themes, identified as priorities by its community.

- 1) Improving timely diagnosis: Sufferers wait on average 2-5 years for diagnosis. However, treatment within 4 months is associated with the best chance of a full recovery. Hence, delays lead to greater dependence and disability, with over half of sufferers unable to return to work. For this reason, as well as others, DCM sufferers have amongst the worst quality of life scores of all chronic diseases.
- 2) Strategies to improve recovery after surgery: Currently surgery is the only evidence-based treatment for DCM. It is able to stop further damage to the spinal cord, but recovery is dependent on the amount of spinal cord damage that has already occurred at the time of surgery. Strategies such as rehabilitation, or novel medicines that support neural plasticity are needed to allow more considerable recovery.

**TRUSTEES' REPORT (continued)
FOR THE PERIOD ENDED 30 JUNE 2019**

Therefore, Myeloapthy.org is currently supporting three research studies:

- 1) **Health Systems Visualisation (Hamilton)** (University of Cambridge) – A collaboration with the THIS Institute (The Healthcare Improvement Studies <https://www.thisinstitute.cam.ac.uk/>). The project is looking to develop new methods for modelling diagnostic pathways and will be using DCM as a case study. The investigators interview focus groups, of sufferers and professionals, to understand and model current experience. By identifying the key drivers and barriers to diagnostic flow, the researchers will be able to identify an optimum pathway.
- 2) **How does DCM surgery affect your ability to exercise?** (University of Nottingham) – A qualitative study on the impact of surgery on exercise. This was a project initiated by the wife of a DCM sufferer, previously working as a GP. She was frustrated by her husband's transition from active sportsman and father of two small children, to inactivity. She felt there was a lack of information and advice for sufferers on how to rehabilitate. As an initial step she has been conducting qualitative interviews to understand the experience of others. The aspiration is this project supports a consensus initiative to produce some recommendations on surgical aftercare.
- 3) **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.

UK Academic Spine Symposium

Myelopathy.org also held the first UK Academic Spine Symposium at the Royal Society of Medicine this year. This meeting brought together the leaders in the field of academic spine surgery to talk about the clinical research studies they are involved in, for example the [FORVAD trial](#), the [NERVES trial](#) and the [GIRFT National Report](#).

(2) Awareness

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

Charity Launch

On 7th May Myelopathy.org held the official charity launch to the public and professional worlds hosted by the Lord and Lady Carter of Coles at the House of Lords. In attendance were clinicians, journalists, politicians, patients, and representatives of the NHS, including CEO Simon Stevens, and NICE as well as several related charities along with our colleagues and collaborators. We had several talks, both from clinicians treating the condition and people suffering with it, which effectively illustrated the issues surrounding DCM. We had a great response from the guests with offers of help and support from many. We are currently working through all of these kind offers with everyone involved to make sure that we make the most of this significant event for Myelopathy.org and hope to inform on some of these in future reports. We feel that due to the wide-spread exposure that this event gave the charity to important opinion-formers in the field of healthcare that it has been the one of the most important activities we have carried out this year in terms of raising awareness of the condition with the people that can really make a difference and this was done to help those already suffering and those that have not yet been diagnosed and hence is clearly for public benefit.

**TRUSTEES' REPORT (continued)
FOR THE PERIOD ENDED 30 JUNE 2019**

Professional Education

In September 2018 Myelopathy.org had an exhibitor stand at the Society of British Neurological Surgeons (SBNS) meeting in London. This meeting gave us exposure to health care professionals (HCPs) in the field as well as other similar charities. We learnt a huge amount from the experience about what we should be focussing on as a charity, how to engage people in our cause and ideas for how to communicate information to our followers and people newly diagnosed.

Then in April 2019 we attended the British Association of Spine Surgeons (BASS) meeting in Brighton with an exhibitor stand. We improved several things about the stand based on our experience at the SBNS meeting so that we were better able to engage HCP and bring them to our stand as well as getting their views and input on a questionnaire we produced.

Patient Education

In May 2019 we unveiled our new and updated website. The primary aim of redoing the website was to improve our search engine optimisation (SEO) in order to help our website, reach more people that may be affected by the condition. However, we also re-did the homepage so that it better reflected our charitable aims with a section for information directed at patients and HCPs, a section with patient stories and a section directing people to different routes to support. In addition to this we added some new content including a promo video welcoming people to the organisation and explaining how we started up and what our aims are. This was done to better direct people to information about the condition and where they can find support and has been done for public benefit.

(3) Support

Our Myelopathy Support page on Facebook continues to grow.

Achievements and performance

Review of activities

Below is a brief summary of the charities main achievements this year

- We have launched a new website which is GDPR Compliant – www.myelopathy.org (details above).
- We have registration with the Fundraising Regulator to abide by their rules on fundraising and we display their logo on our new website and all literature.
- We have registered with the Neurological Alliance which is a coalition of more than 80 organisations that have the aim of transforming outcomes for people with neurological conditions.
- We held the first UK Academic Spine Symposium (details above).
- We held the official launch event for Myelopathy.org (details above).
- We run RECODE-DCM.com a consensus project being run to define the key research topics for DCM (details above).
- We had a Lancet Neurology Editorial written about the launch of the charity (details can be found on our website).
- We ran an exhibitor stand at the SBNS Conference 2018 (details above).
- We ran an exhibitor stand at the BASS Conference 2019
- The Myelopathy Support Facebook page which we run now has >2500 Users.
- We received our first Donations, as described and filed in the accompanying accounts
- Our BMJ Article on Degenerative Cervical Myelopathy now appears as the first hit for anyone searching for DCM on Google.

**TRUSTEES' REPORT (continued)
FOR THE PERIOD ENDED 30 JUNE 2019**

Financial review

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.

Reserves policy

At present Myelopathy.org is minimal (<£500) annual liabilities. Consequently, and based on the limited annual turnover, 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

Constitution

The charity was incorporated on 6 June 2018.

Trustees' responsibilities statement

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 the incoming resources and application of resources of the charity 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 in the Charities SORP;
- make judgments and accounting estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards 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 operation.

**TRUSTEES' REPORT (continued)
FOR THE PERIOD ENDED 30 JUNE 2019**

The Trustees are responsible for keeping proper 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.

This report was approved by the Trustees, on

and signed on their behalf by:

Dr Mark Kotter
Trustee

MYELOPATHY.ORG

**CHARTERED ACCOUNTANTS' REPORT TO THE TRUSTEES ON THE PREPARATION OF THE
UNAUDITED FINANCIAL STATEMENTS OF MYELOPATHY.ORG
FOR THE PERIOD ENDED 30 JUNE 2019**

We have prepared for your approval the financial statements of Myelopathy.org for the period ended 30 June 2019 which comprise the statement of financial activities, the balance sheet and the related notes from the charity's accounting records and from information and explanations you have given to us.

As a member firm of the Institute of Chartered Accountants in England and Wales (ICAEW), we are subject to its ethical and other professional requirements which are detailed at <http://www.icaew.com/en/membership/regulations-standards-and-guidance>.

This report is made solely to the Trustees in accordance with the terms of our engagement letter dated 20 November 2019. Our work has been undertaken solely to prepare for your approval the financial statements of Myelopathy.org and state those matters that we have agreed to state to the Trustees in this report in accordance with ICAEW Technical release TECH07/16AAF. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than Myelopathy.org and its Trustees for our work or for this report.

It is your duty to ensure that Myelopathy.org has kept adequate accounting records and to prepare statutory financial statements that give a true and fair view of the assets, liabilities, financial position and net incoming resources of Myelopathy.org. You consider that Myelopathy.org is exempt from the statutory audit requirement for the period.

We have not been instructed to carry out an audit or review of the financial statements of Myelopathy.org. For this reason, we have not verified the accuracy or completeness of the accounting records or information and explanations you have given to us and we do not, therefore, express any opinion on the statutory financial statements.

Lakin Rose Limited

Chartered Accountants

Pioneer House
Vision Park
Histon
Cambridge
CB24 9NL

Date:

STATEMENT OF FINANCIAL ACTIVITIES
FOR THE PERIOD ENDED 30 JUNE 2019

	Note	Unrestricted funds 2019 £	Total funds 2019 £
INCOME FROM:			
Donations	2	16,812	16,812
TOTAL INCOME		<u>16,812</u>	<u>16,812</u>
EXPENDITURE ON:			
Charitable activities	5	12,177	12,177
TOTAL EXPENDITURE		<u>12,177</u>	<u>12,177</u>
NET INCOME BEFORE OTHER RECOGNISED GAINS AND LOSSES		4,635	4,635
NET MOVEMENT IN FUNDS		4,635	4,635
RECONCILIATION OF FUNDS:			
Total funds brought forward		-	-
TOTAL FUNDS CARRIED FORWARD		<u>4,635</u>	<u>4,635</u>

The notes on pages 10 to 13 form part of these financial statements.

MYELOPATHY.ORG

BALANCE SHEET
AS AT 30 JUNE 2019

	Note	£	2019 £
CURRENT ASSETS			
Debtors	7	1,563	
Cash at bank and in hand		4,146	
		<u>5,709</u>	
CREDITORS: amounts falling due within one year	8	<u>(1,074)</u>	
NET CURRENT ASSETS			<u>4,635</u>
NET ASSETS			<u>4,635</u>
CHARITY FUNDS			
Unrestricted funds	9		<u>4,635</u>
TOTAL FUNDS			<u>4,635</u>

The financial statements were approved by the Trustees on

and signed on their behalf, by:

Dr Mark Kotter

The notes on pages 10 to 13 form part of these financial statements.

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE PERIOD ENDED 30 JUNE 2019**

1. ACCOUNTING POLICIES

1.1 Basis of preparation of financial statements

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 on 16 July 2014 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

The financial statements have been prepared under the historical cost convention with items recognised at cost or transaction value unless otherwise stated in the relevant notes to these accounts. The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014 and Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and Charities Act 2011.

Myelopathy.org constitutes a public benefit entity as defined by FRS 102.

1.2 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.

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

1.3 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.

Support costs are those costs incurred directly in support of expenditure on the objects of the charity. Governance costs are those incurred in connection with administration of the charity and compliance with constitutional and statutory requirements.

Charitable activities and Governance costs are costs incurred on the charity's operations, including support costs and costs relating to the governance of the charity apportioned to charitable activities.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE PERIOD ENDED 30 JUNE 2019

1. ACCOUNTING POLICIES (continued)

1.4 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 within interest payable and similar charges.

1.5 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.

2. INCOME FROM DONATIONS

	Unrestricted funds 2019 £	Total funds 2019 £
Donations	16,812	16,812

3. DIRECT COSTS

	Charitable activities	Total 2019
Conference expenses (BASS)	927	927
Conference expenses (SBNS)	235	235
Conference expenses (HoL)	5,197	5,197
Conferences expenses (S Forum)	4,327	4,327
	<u>10,686</u>	<u>10,686</u>

4. SUPPORT COSTS

	Charitable activities £	Total 2019 £
General office expenses	371	371
Computer expenses	10	10
	<u>381</u>	<u>381</u>

NOTES TO THE FINANCIAL STATEMENTS
FOR THE PERIOD ENDED 30 JUNE 2019

5. GOVERNANCE COSTS

	Unrestricted funds 2019 £	Total funds 2019 £
Accountancy	1,060	1,060
Legal and professional	50	50
	<u>1,110</u>	<u>1,110</u>

6. NET INCOME/(EXPENDITURE)

During the period, no Trustees received any remuneration, benefits in kind or reimbursement of expenses.

7. DEBTORS

	2019 £
Tax recoverable	<u>1,563</u>

8. CREDITORS: Amounts falling due within one year

	2019 £
Accruals and deferred income	<u>1,074</u>

9. STATEMENT OF FUNDS

STATEMENT OF FUNDS - CURRENT YEAR

	Balance at 6 June 2018 £	Income £	Expenditure £	Balance at 30 June 2019 £
Unrestricted funds				
General Funds	<u>-</u>	<u>16,812</u>	<u>(12,177)</u>	<u>4,635</u>

NOTES TO THE FINANCIAL STATEMENTS
FOR THE PERIOD ENDED 30 JUNE 2019

SUMMARY OF FUNDS - CURRENT YEAR

	Balance at 6 June 2018 £	Income £	Expenditure £	Balance at 30 June 2019 £
General funds	-	16,812	(12,177)	4,635