Myelopathy.org

# Summer Fundraiser 2023

## Guide for Participants

## Shining a Light on DCM

**It's time for the Myelopathy.org Summer Fundraiser.**

Working with our community, friends & families, and researchers, we aim to raise over £30,000 throughout the summer to continue to fund our crucial work for those living with DCM.

This is the first time we are fundraising directly with our community, and we can't wait to see the creativity and passion a project like this could unleash!

Read below to find out more.

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**"Remember, every donation, no matter the size, can make a difference!**

**By fundraising for Myelopathy.org, you become a catalyst for positive change, helping to improve the lives of individuals living with myelopathy and working towards a future where this condition is better understood and effectively managed.**

**Together, we can make a lasting impact and bring hope to those in need."**

**- Iwan Sadler, Mark Kotter, and Benjamin Davies, Founders**



# Executive Summary

We need your help!

At Myelopathy.org, we need to fundraise so we can continue the crucial work we complete in the DCM community.. Our aim for the 2023 Summer Fundraiser: Shining a Light on DCM is to raise £30,000 through a series of activities within our community – people with DCM, their friends and families, and our research partners.

In order to get involved, each participant needs to set up a fundraising page, plan an activity or two that they are comfortable enough completing, and start raising money! Remember, these activities should only be what you can manage!

If you don't feel up to a fundraising activity, please find out how you can get involved – just having you along for the ride is enough to get momentum going on this campaign!



Step 1: Plan what kind of fundraising activity you would like to complete – this could be through social media posts, a sponsored run, or a charity bake sale!



Step 2: Set up your fundraising page – this could be through GoFundMe, JustGiving, or Facebook Fundraiser. Include a description of your fundraiser!



Step 3: Launch your fundraising page and start raising money! Remember to post your progress frequently on social media, getting friends and family involved!

Please read the rest of the document to get a more in-depth understanding of what your participation will involve, more detailed guidance on how to do so, and why your fundraising activities are essential to our work.

Should you have any questions or want to find out how you can be more involved, please contact us by email at **fundraising@myelopathy.org** and we will get back to you.

Only together can we build a future free of pain through community, support, and research.

## Introduction

Thank you for being a valued member of the Myelopathy.org family. We greatly appreciate your support!

Today, we're contacting you to ask for your help in raising funds for Myelopathy.org, which will enable us to continue our vital support for individuals just like you. Here at Myelopathy.org, we pride ourselves in our spirit as a small but mighty charity. Our team's unwavering commitment to community- and outcome-focused work ensures that we consistently deliver the support you deserve.

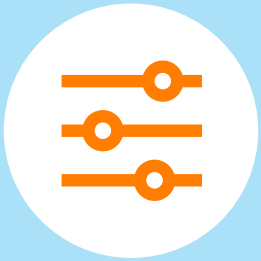
However, to keep our crucial work going, we find ourselves in urgent need of funding. In order to continue supporting people with DCM, we are aksing you for help.

Starting this July, we are running an online summer fundraiser, one which puts our community at the heart of our activities, whether that is people with DCM, their carers, friends and family, or our amazing research community!

Our work would greatly benefit from your participation. We ask each of you to join us, raising both funds and awareness of this disease as we strive to reach the goal of £30,000 raised by the end of August.



To maintain our operations, we have an annual running cost of £60,000 – we hope to raise this over the next year



For our Summer Fundraiser 2023, we aim to raise £30,000, supporting the crucial work we do



Our Fundraiser will work directly with the DCM community, the first of its kind for Myelopathy.org

## Our Summer Event

# TAKING PART

Taking part is easy: set up your own online fundraiser through platforms like JustGiving, GoFundMe, or Facebook Fundraising, and rally your friends and family to contribute.

Rest assured, we will provide you with all the guidance, support, and anything else you require to establish and maintain a successful fundraiser. Together, we can make Myelopathy Matter, and we look forward to what we can achieve!

This document will outline how to participate in our Summer Fundraiser and provide further guidance on how to do so, as we need your help to keep our charity going! If you have any questions or concerns, feel free to contact us at **fundraising@myelopathy.org.**

# Suggested Fundraising Activities

To raise the money needed, there are plenty of things you can do to get involved. Please see below for suggestions.

Whether you have DCM, are a friend or family member, or are part of our amazing research community, there are so many activities that you get stuck into! But remember, if you are currently living with DCM, only participate in the ways that you are able, and we will make it as easy as possible for you to help fundraise.



**Working directly with our amazing DCM community is the focus of this fundraiser. We aim to hear the stories of those with DCM to boost awareness and raise money.**

- Share your story via social media, posting about how DCM impacts your life.
- We'd love to hear stories of hope and how you are able to manage your condition.
- If you feel up to it, post a video online about your experiences – we're more than happy to help with this.



**For those who feel able, we encourage you to explore your creativity and see what activities you can do to raise money!**

- Consider hosting a charity bake sale – just prepare or buy your favourite cakes and sweet treats and sell them to friends and family!
- If it is your birthday soon, ask friends to donate to Myelopathy.org instead of buying a present.
- A charity BBQ – fire up the grill, bring round your loved ones, and enjoy the summer sun in style!




**Particularly for friends & family, and the wider DCM community, we'd be thrilled to see what else you can do!**

- Complete a sponsored run – 5K, 10K, half marathon, whatever your legs allow!
- Find hiking trails nearby and see how many miles you can walk over summer. Remember to ask those around you for sponsorship!
- Stair climbing competition – can you scale Mount Everest in a month?

# Why Your Fundraising Matters

Here at Myelopathy.org, we strive to improve the lives of our fantastic DCM community through a combination of our online support group, raising awareness of this disease amongst physicians and the general public, and supporting international research into DCM.

It is only with your help that we can continue to provide these support services to our community. We encourage you to read below to find out how your participation in our fundraiser is essential to our work!



## Our Community Support Group

Founded in 2015, we have built up a huge community of people with DCM. Hosted on Facebook, this is a great place where members can share their experiences with DCM, tell stories of hope, and share advice on how to cope with their condition.

Your donations will allow us to continue running this essential source of support for our members!



## Awareness & Education

DCM is a very poorly understood condition, even amongst healthcare professionals, meaning that its signs are often missed, and it goes undiagnosed.

Through providing disease-specific information to physicians and supporting academic institutions in educating their students about DCM, we are helping to produce a generation of doctors who will recognise this condition.



**Supporting**

**Cutting-Edge Research Globally**



### Supporting 2 Clinical Trials

1. RECEDE Trial: Trialling a novel drug to determine its impact on pain and patient recovery.
2. POLYFIX-DCM: Head-to-head study com paring the effectiveness of 2 different kinds of surgery for DCM patients, revolutionising care pathways!

### Research Priorities

Our RECODE-DCM platform brings hundreds of researchers together with people with DCM.

Here, we work to define what people with DCM want out of research.

We strive to put the individual at the heart of all DCM research, having developed 10 priority areas to focus research efforts!

# Getting Donations for your Fundraiser

Below is an example of the sort of story you could write to encourage your supporters to donate to your fundraiser. You can write it completely differently, or follow the same sort of outline – this is completely up to you. We have put this here as a guide.

## Title: "Shining a Light on DCM: Myelopathy.org's Summer Fundraiser/ Myelopathy.org: Our Fundraising Drive"



[Image: Optional - if you would like to share photos, you can add a picture of yourself, of a pet, or anything you can think of! Including these pictures really boosts engagement.]

Dear friends & family,

As many of you will know, I was diagnosed with Degenerative Cervical Myelopathy (DCM) [however long ago]. Even before my diagnosis, I had been dealing with back pain, mobility issues, and a number of other symptoms that have made these past few years a real challenge. And, for a long time, I was in need of help and support.

Myelopathy.org, the first global charity dedicated to individuals with DCM, has been with me throughout my journey with this disease and provided me with the support I need. They have been a great source of information about my disease and how to manage it, providing a pioneering online support group where I am free to talk about my condition amongst those who understand and go through the same challenges. The charity also supports and funds essential research to help beat this disease.

To ensure they can continue their important work for years to come, I need your help. Over the next month, I have set myself the goal of raising £500 for Myelopathy.org. Instead of physical challenges, I will be sharing my experiences and challenges of living with DCM through social media posts over the months of July and August.

I am writing to ask you to support me and Myelopathy.org. Every donation will take me closer to my goal and allow Myelopathy.org to continue to support individuals like me.

Donate here [put link to JustGiving/GoFundMe here], if you would like to support us. Thank you in advance for your kindness and generosity. It means a lot to have you with us. Together, we can build a life free of pain and fear through research, awareness, and support!

Yours,

[Name, Signature]

#DCMFundraiser #MakingADifference #SupportMyelopathyResearch #MyelopathyMatters

## Setting Up Your Fundraiser

These sites allow individuals to log in and make donations to your cause, whilst also giving you a space to explain your campaign and why you are participating.

Please find detailed instructions for how to set up your fundraiser here. If you have any questions regarding this document, please contact us at fundraising@myelopathy.org and we will help.

**To manage your fundraising, we encourage you to set up a campaign via one of the following portals:**

- GoFundMe: https://www.gofundme.com/en-gb
- JustGiving: https://www.justgiving.com/
- Facebook Fundraisers: https://www.facebook.com/fundraisers/explore

To see our how-to guide for setting up your fundraiser, please click here.

## Your Fundraising Target

Depending on where you are based, we are providing you with a rough estimate for the fundraising total you should be aiming for.

**£500**

**$1,000**

Of course, these are just estimates for you to put down as your fundraising target – but the sky's the limit!

"In as little as 10 minutes, you can have your fundraising pages set up and start bringing in donations.

To make all of this simpler, we are providing a short how-to guide, which walks you through the process with a series of links and guiding images."

**- Oliver Longstaff, Campaign Manager**



## Updating Your Progress

This event will see all participants fundraising through July and August and, if they wish, sharing their stories throughout the fundraiser. To keep everyone up to date on developments, we are providing some guidance below on how to do this.

Only share as much or as little as you wish!



Share a written post or video on social media, explaining a challenge you faced that week or something to make you feel positive!



Post regular updates on major fundraising milestones, such as reaching your target's half-way point! Reasons to congratulate yourselves!



Share information on any large donations that you receive, such as who donated and how much!

Remember, this is just guidance and we encourage you to tailor your posts however you see fit. If you need any help editing these, let us know – our team at Myelopathy.org is happy to help!

As we strive to increase awareness of the disease online, we encourage you to contribute as frequently as possible!

Our suggested goal is to aim for one post per a week. But remember that any contribution at all is truly appreciated and will contribute to our collective mission of raising awareness.

# Introduction on DCM

We are providing some general information about DCM below, just in case you want to include any information about the condition in your posts.

You can of course get all this and more from our website. Visit: https://myelopathy.org/key-facts/



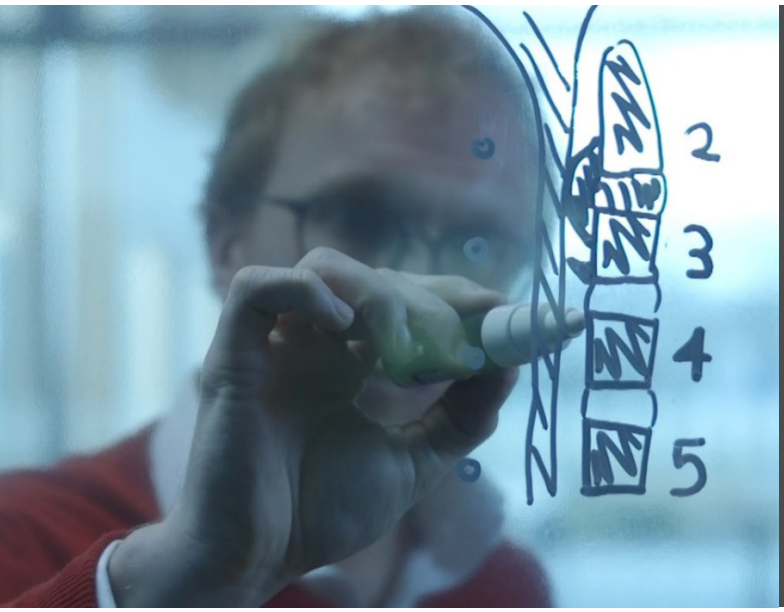
Degenerative Cervical Myelopathy (DCM) is a type of myelopathy that affects the spinal cord. It is the most common cause of spinal cord disease worldwide, estimated to affect 1 in 50 adults. It is a frequently overlooked and underdiagnosed condition, and can lead to life-changing disability.



DCM is caused when arthritic changes in the neck compress and injure the spinal cord, causing a slowly progressive spinal cord injury. This can result in symptoms that affect the whole body, including pain, lack of hand-eye coordination, and difficulty walking.



The only effective treatment is an operation to decompress the spinal cord. Owing to the risks of surgery, this is reserved for patients with moderate to severe disease. Each year 5,000 adults in the UK undergo surgery for DCM. However, this is the tip of the iceberg, estimated to be fewer than 20% of actual cases. This could mean that over 1 million people in the UK are living with DCM, yet without an explanation for their symptoms.




"I could see there was great unmet need, vastly limited resources, and research was predominantly focused on surgery, which is only a small aspect of a lifelong condition.

My intention in developing AO Spine RECODE-DCM was to target all of these in one hit."

**- Benjamin Davies, Founder**

## A note from our Director, Zahabiya Karimi:



"This campaign is the first of its kind – working directly with our community is always exciting and I know this will be no different!

Your strength and passion for this cause inspires us every day, and with this campaign we will show that to more people. Your participation helps us tremendously – every donation and every fundraiser takes us closer towards our goal!

We want to keep supporting and working with you, and together we can make Myelopathy Matter!"

**Thank you again for your dedication and support.**

# Let's make this summer a season of positive change for Myelopathy.org and those affected by DCM.