

100 Miles in September

Communications pack

All you need to help you share what you're doing, raise awareness of desmoid fibromatosis and amplify your fundraising.

desmoidaiduk.com

HELLO!

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Desmoid Aid UK

Information | Grants | Support

Hello,

Thank you for taking part in the Walk 100 Miles in September for Desmoid Aid UK!

This comms pack is split into three sections that will help you to share with others what you're doing and hopefully spread the word about Desmoid Aid UK and the Walk 100 Miles in September event. The first is about the charity itself, what it does and also what desmoid fibromatosis is, as well as useful things you can download, like the charity logo. The second section has helpful images/graphics and some example posts for social media and the third section is about talking to your local newspaper or radio station.

What's here are merely starting points, so feel free to get creative and make any of these things your own, and please take lots of pictures of what you're doing and tag us in when posting about Desmoid Aid UK and Walk 100 Miles in September. Our social media channels are:

- Instagram **@desmoidaiduk**
- Facebook **@Desmoid Aid UK**
- The URL to direct people to: **desmoidaiduk.com/fundraising**
- Please use the hashtag: **#Walk100forDesmoid**

Please help us amplify the event by sharing, reposting and commenting on our posts in the lead up to and during the month of September as other people are doing the Walk 100 Miles in September, it really does help! One last thing, if you haven't set up a JustGiving page, please do so now at **justgiving.com**.

Thanks all, and good luck!

Jacqui Sam Anna Julie

Jacqui, Sam, Anna, Julie
Desmoid Aid UK
desmoidaiduk.com



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About Desmoid Aid UK

Desmoid Aid UK is a UK charity providing vital information about the disease for people and their families when they have been diagnosed with Desmoid-type fibromatosis. The charity also provides small grants that help pay for unexpected costs for newly diagnosed people undergoing treatment, and signposts people to other resources and support that's available for desmoid fibromatosis.

desmoidaiduk.com

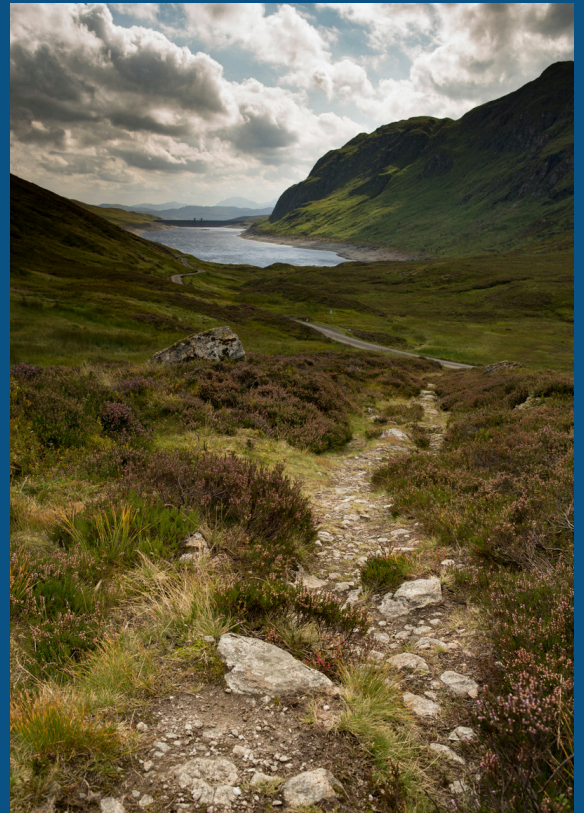
Some facts about desmoid fibromatosis

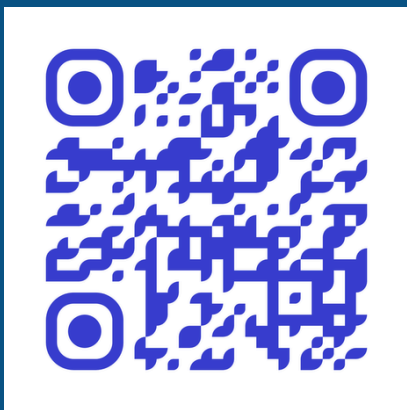
1. Every year, only about 5 to 6 people in every million are diagnosed with desmoid fibromatosis in the UK.
2. Desmoid-type fibromatosis is a soft tissue tumour formed from cells in the body known as fibroblasts which are found in the connective tissue of our body, the tissue that supports, protects and gives structure to other tissue and organs.
3. In the vast majority of cases (90%), we don't yet understand what causes desmoid fibromatosis, they occur with no history of anyone else in the family line having had desmoid fibromatosis.
4. A desmoid tumour often shows up as a firm, fixed lump and while they're usually not life-threatening, they can cause significant pain, restrict movement and reduce quality of life, becoming dangerous only when it compresses vital organs or structures.

About the Walk 100 Miles in September event

- Walk 100 Miles in September is a fundraising event supporting the charity Desmoid Aid UK.
- Desmoid Aid UK provides information about Desmoid Fibromatosis tumours and awards vital grants of £250 to people diagnosed with the disease that help with unexpected costs.
- Complete 100 miles as an individual or a team, in one go or spread over September. Dogs are most welcome to join as part of a team!
- The money raised from the event will all go to giving more grants to people across the UK affected by the disease.







If you know someone else who'd like to sign up, they can do so here throughout the month of September:

desmoidaiduk.com/fundraising

They can also scan the QR code to the right.



Can't join us for the event itself, but still want to support? Don't worry you can also simply [make a donation to Desmoid Aid UK](#) and help us support more people. Simply scan the QR code to the right.



The Desmoid Aid UK Logos

You can download the Desmoid Aid UK logo (as PNG and JPEG files) [here](#).

When you use the Desmoid Aid UK logo, try not to crowd it against too much else, give everything the space to breathe, and please don't squash or stretch the logo.

The Desmoid Aid UK colours

The colours used by the charity are (hex codes):



Dark Blue -
#095283



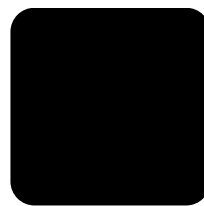
Light blue -
#00C8F0



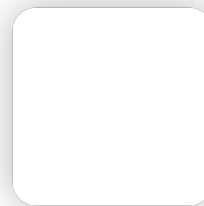
Red -
#F0513E



Yellow -
#F6CD41



Black - #000



White - #fff



Social Media

Share what you're doing and tell others. We'd love to have as many people as possible across the UK signed up and walking in aid of Desmoid Aid UK. Here's what you can do to help spread the word:

- Post on social media and tag us in so we know when you or your team are getting ready or set off
- We'll like/share your post, or comment.
- Take pictures, and use the hashtag **#Walk100forDesmoid** to make it easier to track.
- If you haven't already, do follow us on Instagram and/or Facebook.

Social media handles for Desmoid Aid UK

- Instagram [instagram.com/desmoidaiduk/](https://www.instagram.com/desmoidaiduk/) **@desmoidaiduk**
- Facebook [facebook.com/p/Desmoid-Aid-UK-61564128443648/](https://www.facebook.com/p/Desmoid-Aid-UK-61564128443648/) **@Desmoid Aid UK**

You can download the social media images (see below) to help with your social media [here](#).



What should you write?

Here's some examples of what you might write on social media, whatever platform you're on. We've used Instagram for our examples:

Before you start walking or running 100 miles:

We're really excited to be taking part in the Walk 100 Miles in September event in aid of **@desmoidaiduk**. We're signed up and just planning how we're going to cover 100 miles over the 30 days. The charity provides information about a rare non-cancerous tumour called Desmoid Fibromatosis and awards vital grants of £250 to people diagnosed with the disease that help with unexpected costs. It's not too late to sign up, and you can sponsor us using the link in my bio! Stay tuned for more updates! **#Walk100forDesmoid**

You've started doing the 100 miles:

We're off! It's day 1 of the Walk 100 Miles in September in aid of **@desmoidaiduk**, a charity that's close to our hearts because [insert reason why you're doing the challenge]. Today we're going from [start point] to [finishing point] so fingers crossed the sun stays out! Great reason to be out and about, you can sponsor us using the link in the bio!

#Walk100forDesmoid

You're coming to the end of the 100 miles:

So proud to have walked/run 100 miles over the past few days, it's been tiring, emotional and epic at points. Thank you to everyone who has sponsored us, the charity who this is for **@desmoidaiduk** means a lot to us because [insert reason why you're doing the challenge], and it means they'll be able to support more people affected by desmoid fibromatosis in the future! Well done to us and thank you!

#Walk100forDesmoid



Press, Media and Radio

Talking to your local media, which includes things like newspapers, magazines or radio stations is still an excellent and powerful way to spread the word about what you're doing and why, and it may help with your fundraising efforts. To help, we've written a template press release where you can fill in your own details, and send this to your local newspaper/radio station/news website, so they have all the information they need in one place. Don't forget to include a picture or two with your release, this can really help with getting into the paper,

To download your template press release, [click here](#).

Newsletters

Here's some copy to paste into in any newsletters, both digital and physical:

Time to get those boots on for the Walk 100 Miles in September, in aid of the charity Desmoid Aid UK. The charity is asking people across the UK to walk or run 100 miles in any way they choose over the 30 days. Desmoid Aid UK provides information about a rare non-cancerous tumour called Desmoid Fibromatosis and awards vital grants of £250 to people diagnosed with the disease that help with unexpected costs. It's not too late to sign up, register at desmoidaiduk.com/fundraising.

Need to contact us?

You can email us at Desmoid Aid UK at info@desmoidaiduk.com and we'll get back to you as soon as we can. Bear in mind we're a small team, so we'll be as fast as we can, and thank you for all of your efforts.

Most importantly of all, is thank you for supporting Desmoid Aid UK, have fun over the month, and good luck!

Good Luck!

