# BETTER together

## NEWSLETTER
**Summer 2023**

community@super-rare.org

Our six small but mighty charities are working together as part of a National Lottery Community Fund grant funded project:
**Better Together for Healthy Bone Marrow.**

Because of this project, our collective communities will be "better informed, less isolated, more connected, and more resilient"

## The Better Together Emotional Wellbeing Team

We are incredibly lucky to have an Emotional Wellbeing Team as part of the Better Together Project. The Psychology Team sits within this wider team, and is responsible for overseeing the emotional wellbeing support we are providing our communities.

**Lesley**

**Naomi**

Our Emotional Wellbeing Framework has been designed by our Lead Clinical Psychologist, Lesley Howells. Lesley is seconded to the Better Together project from Maggie's (cancer care charity). Lesley is supported by Naomi White (also a clinical psychologist), our Emotional Wellbeing Practitioner.

If you sign up for any of our courses and webinars, you will no doubt get to meet these amazing members of the team!

## Super Rare 2023

Our first collaborative fundraising campaign raised over £32,000 across all the charity partners during February and March 2023!

**A HUGE thank you** to everyone who donated, took on a challenge, walked, ran, baked, climbed, crafted, danced, performed, bunjeed and more! **You are truly amazing and you made this campaign a massive success!**

Please start thinking about what you might like to do for Super Rare 2024! We are beyond excited about what the campaign will achieve next year!

For more information regarding the Better Together for Healthy Bone Marrow project, please email community@super-rare.org

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## Emotional Wellbeing Support from the Better Together Project

We are currently running two online courses that some of you are participating in:

- **Managing Stress & Uncertainty**
- **Mindfulness**

These courses will be repeated throughout the next two years, so keep an eye out for your charity sharing details of how to register for the next one. We hope to see you there!

On the horizon we also have a '**Where Now?**' course, which is a course specific to those who are post bone marrow transplant.

In addition to these courses, we will also be setting up / delivering:

- Support groups
- Webinars
- Information Resources

If you have any ideas about types of emotional wellbeing support that you would like to see offered, please email **community@super-rare.org**

## Meet the Project Delivery Team

As the Better Together project progresses, you may well cross paths with one of the project delivery team by email, attending one of our online courses/webinars, or at an in-person event! Claire Baggott is our Project Manager for Better Together, and she is supported by Hannah Mitchell (Project Officer) and Vicky Burford (Community Support Lead). As a team we are really loving our roles, it very exciting & rewarding to be supporting our six communities!

Claire, Vicky & Hannah in their Super Rare tees!

## How Can You Help?

If you would like to find out more about the Better Together project, or would like to **register your interest in finding out about volunteering opportunities**, please email **community@super-rare.org**

If you attend any events, courses or webinars - you may be sent an evaluation survey to complete. We would be incredibly grateful if you could spare the time to share your feedback. **Not only will your feedback help shape how our charities support you, but it will help them secure future funding to keep providing this support.**

We would love to include some community/patient stories in our next newsletter, if you are interested in sharing your story please email community@super-rare.org

# OUR CHARITIES

**The Aplastic Anaemia Trust** provides information, advice, and support to help people affected by aplastic anaemia to lead healthy and fulfilling lives. The charity also enables research into the causes of aplastic anaemia.

**Congenital Anaemia Network** (CAN) is a charity that connects people with rare inherited anaemias, so they can build support networks and access high quality information.

**DC Action** works to improve the diagnosis and treatment of Dyskeratosis Congenita (DC) and Telomere Biology Disorders in the UK. DC Action raises awareness with medical professionals and people affected.

**Fanconi Hope** works to improve the lives of people affected by Fanconi Anaemia. Fanconi Hope connects families, provides information and signposting, sponsors research, and raises awareness both amongst families and the wider public.

**PNH Support** is a charity that supports people affected by Paroxysmal Nocturnal Haemoglobinuria (PNH). The charity provides information and peer support, brings people together and holds a biennial family conference.

**SDS UK** supports people affected by Shwachman-Diamond Syndrome (SDS). The charity connects and supports families, patients, and medical professionals. It promotes access to health and educational services and resources.

***A little bit of a change....*** when the Better Together project was launched, our alliance included seven charities, but DBA UK has withdrawn from the project since our last newsletter. DBA UK are passionately dedicated to serving their community and have taken the decision to focus on other priorities. The remaining alliance partners wish DBA UK all the very best for the future.

This project is supported by The National Lottery Community Fund – thanks to players of The National Lottery.