

BETTER *together*

NEWSLETTER
Spring 2023

community@super-rare.org

Our seven 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"



What is Better Together?

Welcome to our first Better Together Newsletter.

Better Together for Health Bone Marrow is a **National Lottery Community Fund** Grant funded project. It is a three year project, bringing together our seven small and micro charities.

The aim of this project is to help both the partner charities and the communities they support:

Because of *Better Together for Healthy Bone Marrow*, people affected by these rare bone marrow failures will be **better informed, less isolated and more connected, and more resilient**. Through the project, the partners will become stronger and more resilient organisations, better placed to work with and for their communities into the future.

Over the three years of this project, you will see more opportunities to connect with others within your community, and those from the other charities as well.



Super Rare 2023

Raise £200 throughout February and March, earn your t-shirt and be there for anyone diagnosed with a super rare bone marrow condition



Super Rare 2023 is our first collaborative fundraising campaign and we have seen some fantastic events and activities.

A huge thank you to everyone who has taken part in fundraising events for Super Rare 2023 already. Collectively **we have raised over £20,000 so far**, which is absolutely amazing.



If you'd like to participate or donate, there is still time, please go to super-rare.org for more information.



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



What to Expect...



One of the most exciting things about the Better Together project, is the creation of an Emotional Wellbeing Framework that all seven charities will benefit from.

What does this mean for you personally? Our charities will have access to professional emotional wellbeing services such as **support groups, courses, events, webinars and counselling services**. These are being developed so that they are tailored to our communities and what they need. Look out for notifications from your charity, regarding when these offerings become available. Or, email community@super-rare.org

There will also be new information resources being produced, printed and digital, that all our communities can access and benefit from.

If you have any ideas or requests you'd like to share, please do get in touch,



Our Seven Communities are Represented

As part of this project we have set up a Community Reference Group. This is an amazing group of volunteers, one from each of the seven charities' communities - each a patient or a parent of a patient. **Special thanks goes to each of the volunteers** in this group, their time and contribution is so valuable in shaping the project and helping to ensure that what the Better Together project is delivering - is in line with what our communities' need.



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 Vicky (our wonderful Better Together Community Support Lead) 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.



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.



DBA UK delivers support, research, and hope to the Diamond Blackfan Anaemia (DBA) community. DBA UK funds research projects and has been instrumental in changing, improving, and advancing medical care for its community.



DC Action works to improve the understanding and treatment of Dyskeratosis Congenita (DC) 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.