

WORLD SICKLE CELL DAY

2024



We Are
Stronger Together
Building a Future for Sickle Cell Care

"We are stronger together" is this year's theme for World Sickle Cell Day because it highlights the importance of community and joint working to tackle the challenges faced by people living with the condition.

Here's 3 reasons why we chose this theme :

- 1 The challenges of accessing care, expanding treatment options, and advancing research cannot be tackled by any one person alone.
- 2 Many individuals with sickle cell disorder lead fulfilling lives with the support of family, friends, and healthcare providers, relying on this community for their mental and physical well-being.
- 3 We see firsthand how powerful it is when we unite to influence those who have the power to make the changes needed for people living with the condition.



Support networks

People living with sickle cell need support and understanding from their family, friends, doctors, nurses, and patient groups. We enhance this support with our children and young people's peer mentoring scheme and our helpline service. Additionally, many people download and share materials from our website to educate teachers and HR departments about the condition, aiming to broaden their network of support and acceptance.

Teamwork

As a charity, part of our mission is to campaign for essential changes to improve the lives of people living with sickle cell disorder. In the past, we successfully advocated for newborn testing for sickle cell. More recently, we achieved success in our campaign to get the drug Voxelotor approved for use in the NHS in England and Scotland. We accomplished this with the support of the sickle cell community, who shared their personal stories about the impact of the condition and the urgent need for new treatment options.

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We work with the NHS, researchers, members of Parliament, and many other organisations and groups to push for better medical research, improved treatment options, and fair access to healthcare for everyone. We have worked hard to earn a place at the tables where decisions are made and to gain access to key influencers who can create change. We achieve all of this in partnership with the sickle cell community.

Future proofing

Historically, research in sickle cell has not been prioritised. Because of this, there are few treatment options available for people who are living with the condition. There is also limited understanding of how and why sickle cell affects people so differently, making complications difficult to predict and treatments hard to develop.

We are working with the Diverse Data initiative, which looks at how to improve research opportunities for sickle cell to create better options and outcomes for patients. We are doing this in partnership with Genomics England (part of the Department for Health and Social Care) and the James Lind Alliance. In the future, this work will enable researchers to be guided to focus on areas that will bring maximum benefit to patients.

Raising awareness

World Sickle Cell Day is a chance to amplify the voices of those affected by sickle cell, and to educate the public about the condition.

By working together, and creating a strong community of support, we can tackle misinformation, reduce stigma, raise understanding and push for important policy changes that make a real difference to the lives of people living with the condition.

"**We are stronger together**" is a reminder that community, support and collaboration are essential. By working together, we can make big strides in improving the lives of those affected by sickle cell disorder, for generations to come, enabling them to live the full life they deserve.



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www.sicklecellsociety.org



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