

Rare Community Network



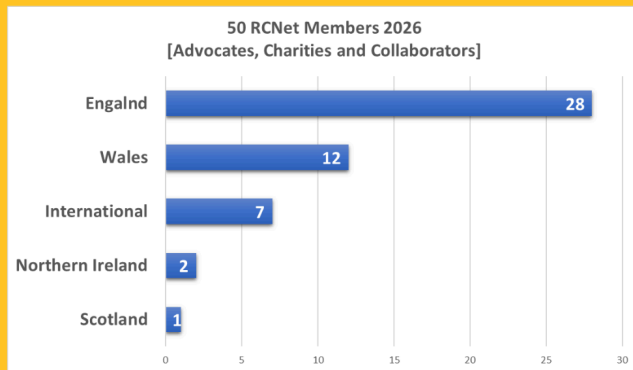
RCNet Update

May 2026

Dear RCNet Members



RCNet Members and Organisations: 50
Aiming for 100 members



Our Goal

To increase membership



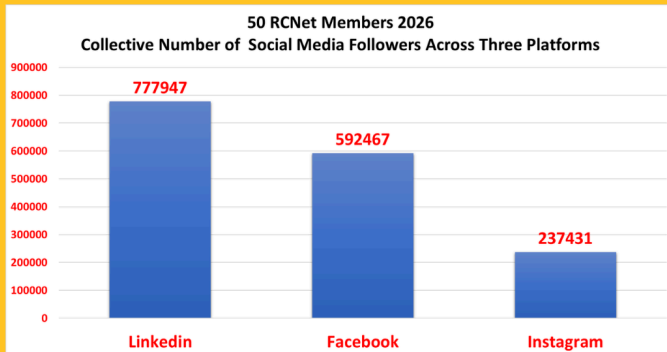
Thank you for being part of our RCNet. We are a community built on collaboration, lived experience, and practical action.

This update is here to keep us connected, celebrate what we're building together, and make it easier for members to spot opportunities to share, partner, and grow our collective impact.

We're now 50 RCNet members and organisations — and we're aiming to grow to 100 members this year.



RCNet Members and Organisations: 50
Aiming for 100 members



www.raregol.com

Share ideas and networks



As part of our membership review, we looked across members' social media profiles — and the results genuinely stopped us in our tracks.

Across LinkedIn, Facebook, and Instagram, our RCNet members have a collective reach of around:

1.6 million followers.

This is a powerful reminder that if we work together by sharing each other's work, amplify calls to action, and promote events together, we're not starting from scratch: we're building on a strong foundation of trust and community.

We will share more insights in June.



Please Welcome New Members

We are delighted to welcome four new members into RCNet. Each one brings something distinctive to our shared mission — and together, they strengthen our ability to connect lived experience, professional expertise, and practical action.



New RCNet
Member



Contributor
to EDIRA
Book of Doers

Jayne Hughes — CEO, Amy and Friends (Wales)

Jayne leads Amy and Friends, supporting families affected by Cockayne Syndrome, Trichothiodystrophy, and related disorders. We're also proud to have Jayne as a contributor to the EDIRA Book of Doers.

This is a brilliant example of how community leadership and real-world experience shape better, more inclusive practice.

Hannah Humphrey — Self Advocate & Volunteer, TANGO2UK (England)

Hannah is a self-advocate and volunteer with TANGO2UK, bringing lived experience leadership into our network. Her work reminds us that visibility, peer support, and speaking truthfully about lived experience are not “extras”. These qualities are essential to changing systems and improving quality of life.



New RCNet
Member



Rare Disease
Advocate,
Speaker & Lived
Experience
Expert
[England]

New member projects

We were delighted when some of our members from the sickle cell community came together to discuss some of the similarities and challenges of living with Sickle Cell Disease. Dr Lewis Thomas and Folusho Adeosu joined me and Rose at a meeting this month. We will be facilitating another meeting in June 2026.

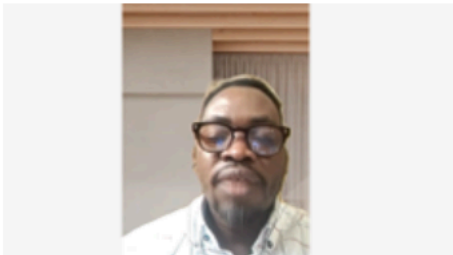
Rare Community Network



Dr Sondra Butterworth
RareQoL EDIRA



Rose Francis
RareQoL EDIRA Project Manager



Folusho Adeosu
Mo'sho Adeosun Health Initiative
Sickle Cell Warrior
[Africa]



Dr Lewis Thomas
Sickleverse
[England]

RCNet Doers Circle

One of our ambitions for our RCNet is to showcase our members and the fantastic work they are doing. On Friday 8th May 2026 we held a RCNet meeting with two of the newest members of our community: Lewis and Folusho are both from the global sickle cell community.

Both have massive followings on social media: we discussed what they have learned from their communities. Both reflected of the major challenges and similarities in accessing funding for the for sickle cell community projects. We will have another meeting next week and will invite other members of the sickle cell community who are part of our RCNET.



RCNet Doers Circle



Sickle Cell Community Group

Dr Lewis Thomas — Founder, Sickleave (England)

Dr Lewis Thomas is the founder of **Sickleave**, described as a digital universe for sickle cell education, community, and support. As a former GP building a sickle cell network, Lewis brings a powerful blend of clinical insight and community-building, this is exactly the kind of bridge RCNet exists to strengthen.

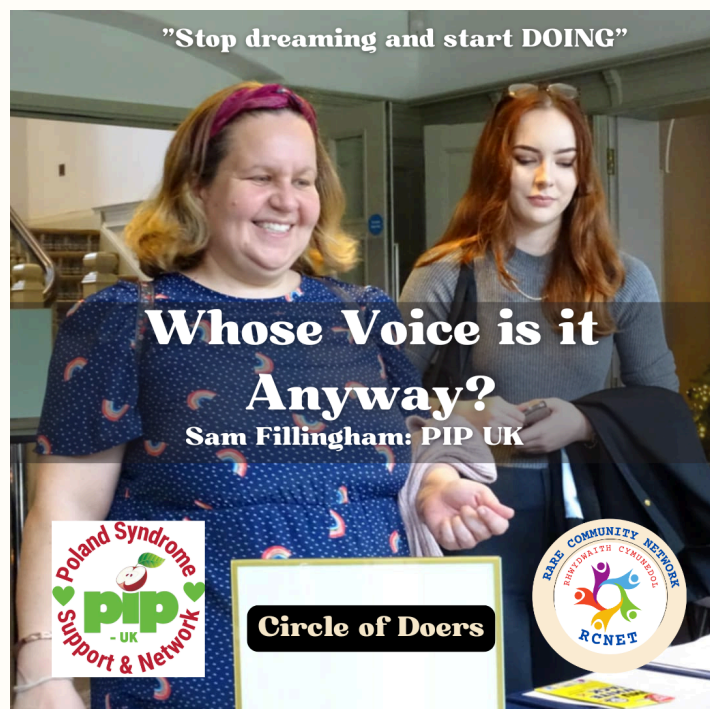
Folusho Adeosu — Mo'sho Adeosun Health Initiative (MAHI) (Africa)

Folusho joins us through MAHI and his work as a Sickle Cell Warrior. He is also a contributor to the EDIRA Book of Doers, and we're grateful to have his voice and leadership in RCNet. Folusho is helping us stay connected to global perspectives and the realities of health inequality beyond borders.

Featured Project

**Sam Fillingham CEO PIP UK
RCNet member**

Founding



We are also pleased to be able to support members who want to amplify their work. Recently, we had the pleasure of creating a promotional video for one of our founding members, Sam Fillingham (CEO, PIP UK). Sam contributed to our Book of Doer last year.

We were happy to help raise awareness about PIP UK. To watch and share the video, follow this link:

[PIP UK Awareness Video](#)



Learning and Development

Over the last 12 months, I've spoken at quite a few events, and I'd love to share some of the presentations and learning with RCNet members. Please let Rose know if you would like copies of these slides.

Topics include:

1. Inclusive research.
2. Cultural competence.
3. Community engagement.

Call To Action: Masterclass Interest

If RCNet members would be interested in a **masterclass**, we would be happy to facilitate one. If you'd like this, please reply to Rose with:

- The topic you'd most value [related to the above].
- Your preferred format (60 mins / 90 mins / half-day).
- Any specific questions or challenges you'd like covered.



Keep in touch

We'll be checking in with members individually to make sure you're still happy for us to hold your contact information, and to confirm your details are up to date.

Share your news

If you have anything you'd like to share in a future RCNet update, please let us know.

- An event
- A project
- A call for collaborators, or a resource please get in touch with our project manager **Rose**.

Rose Francis: rose.francis-admin@rareqol.co.uk.

Please share this update with your network: we are always happy to welcome new members.

"Stop dreaming and start DOING"

Whose Voice is it
Anyway?

Free membership of
our RCNet

www.rareqol.com



Key messages



Our Goal

Increase our membership



Share ideas and networks



Learning and Development

Questions?

Reach out to our Project Manager

Rose Francis: rose.francis-admin@rareqol.co.uk.

Thank you

Keep in touch!



CEO RareQoL EDIRA

COMMUNITY
Dr Sondra Butterworth
PSYCHOLOGIST

Thank you

A Rare Community Network update for our members.