



Listening • Learning • Supporting

Do you have PKU?

If yes, then join us as a trustee – Make a Difference with NSPKU!

At the **National Society for Phenylketonuria (NSPKU)**, we are a small but mighty community – bound together by care, determination, and a shared purpose: to support, empower and champion people living with **Phenylketonuria (PKU)**.

Since 1973, we've been a trusted voice for those affected by PKU, working alongside families, clinicians, researchers, food producers and policy-makers. Together, we're helping people with PKU lead full, healthy and active lives.

Now, we're growing – and we'd love you to grow with us.

Why Join Us as a Trustee?

Our work is rooted in compassion, and every member of our team – including our Trustees – brings lived experience, passion or specialist knowledge to help us serve our community better.

As a Trustee, you'll help shape the future of a charity that:

- **Supports families** with advice, helplines, and community connections.
- **Advocates for change**, championing better treatment and care across the UK.
- **Collaborates with clinicians** and researchers to promote understanding and improve lives.
- **Builds community** through events, conferences, youth engagement, and digital spaces.

We know we can do more. And that's why we're reaching out to people like you – people who care, who want to help, and who are ready to bring their voice and ideas to the table.

What we're Looking For

We're particularly keen to hear from individuals who:

- Have PKU.
- Are passionate about creating a more inclusive and diverse charity.
- Want to help us grow our reach across **England, Scotland, Wales, Northern Ireland and beyond**.
- Are open to learning, collaborating and making a real, lasting impact.
- Can bring professional skills (e.g. digital, finance, governance, health, communications, networking).

Whether you're experienced in governance or new to the idea of charity boards, **you'll be welcomed, supported and valued.**

The Commitment

Being a Trustee with NSPKU is a meaningful voluntary role. You'll join a dedicated group that meets regularly (virtually and occasionally in person), where everyone has an equal voice in:

- Shaping our strategic direction.
- Supporting vital decisions on funding, campaigns and community support.
- Advocating for people with PKU in the places that matter most.

We'll provide you with training and ongoing support. You don't need to be an expert – just bring your enthusiasm, perspective and willingness to contribute.

Why Now?

We're at a turning point – and there's so much positive momentum:

- We have healthy finances and ambitious plans for outreach, events, and research.
- We're embracing new technology to reach more people without barriers.
- We want to hear more voices, reflect more experiences, and unlock new ideas.

Your involvement could help take us further than ever before.

How to Apply

If you're interested in becoming a Trustee – we'd love to hear from you.

Please write a short statement outlining why you would like to join us as a Trustee, and how you hope to make a difference to:

Alison Green, Charity Coordinator - info@nspku.org

Deadline: 5pm, Friday 11th July.

Shortlisted candidates will be invited for a friendly virtual chat with our Council of Management.

If you have any access needs or concerns about the format, please let us know – we want to make this as easy and welcoming as possible.

Let's Work Together

Whether you're stepping up for the first time or bringing seasoned experience, this is your chance to be part of something special – a community that cares deeply, acts boldly, and never stops working for a brighter future for people with PKU.

We hope you'll consider joining us.

Together, we can do more.