

TRUSTEES CANDIDATE PACK



The Voice of PKD

Welcome to the PKD Charity! We are delighted that you are interested in joining our cause.

Here at the PKD Charity, our mission is to improve the lives of those affected by polycystic kidney disease (PKD) through research, education, advocacy, and support. PKD is one of the most common life-threatening genetic diseases, affecting about 70,000 adults and children in the UK. It causes kidney failure, affects other organs, reduces life expectancy, and there is currently no cure. We are dedicated to finding new treatments and helping everyone with PKD have the best life they can.

Are you living with polycystic kidney disease (PKD), or do you have close family experience of the condition? Do you want to use that experience to influence the future of the PKD Charity and help improve life for everyone affected by PKD?

The Polycystic Kidney Disease (PKD) Charity is looking for new Trustees to join our Board. For this recruitment round, we are particularly keen to hear from people with lived experience of PKD, and from family members or carers who understand first-hand the realities of living with the condition.

This is an exciting moment to join us. Over the past years, the charity has grown consistently, significantly expanded the support and information we provide to the PKD community, strengthened our voice in awareness and advocacy, and increased our impact in driving research forward. We are ambitious about what comes next, and we want people affected by PKD to help shape that future at Board level.

About the PKD Charity

Founded in 2000, we are the first and only UK charity solely dedicated to improving the lives of an estimated 70,000 people and their families affected by polycystic kidney disease (PKD) in the UK.

PKD is a group of life-threatening inherited conditions that can cause kidney failure and can affect other organs, including the liver, brain, heart, and bowels. For many people, living with PKD can mean an uncertain prognosis, intermittent pain and infections, and the possibility of dialysis and/or a kidney transplant later in life.

A rarer form of PKD can affect babies and young children. In the most severe cases, the condition can result in death during pregnancy or shortly after birth, while children who survive may require a kidney or liver transplant at a very young age.

Our purpose is simple: to ensure that no one affected by PKD feels unsupported, unheard, or alone.

What does PKD Charity do?

Our work focuses on four core areas:

- **Support and information**

We provide reliable, accessible information, a national helpline, peer support groups, online communities, and in-person and online events for people and families living with PKD, as well as the healthcare professionals who support them.

- **Awareness**

We raise public and professional awareness of PKD, helping to improve understanding of the condition and reduce the isolation experienced by those affected.

- **Research**

We support medical research to better understand PKD, develop new treatments, slow disease progression, and ultimately find a cure. We also work closely with patients, clinicians, and researchers to ensure that the experiences and priorities of people living with PKD are central to future research and healthcare decisions.

- **Campaigning and influencing**

We work to ensure that the needs and experiences of people affected by PKD are heard by decisionmakers and reflected in health policy, services, and research. We collaborate with other charities, healthcare professionals, researchers, and people affected by PKD to help bring about meaningful change.

We particularly encourage prospective trustees to read our latest Annual Report and Accounts, which provides a useful overview of the charity, our impact, and the work of our team.

[Read our latest Annual Report and Accounts](#)

About the role

Trustees are responsible for the overall governance and strategic direction of the charity. As a Trustee, you will join a committed and collaborative Board that helps ensure the charity is well run, financially sustainable, legally compliant and focused on achieving the greatest possible impact for people affected by PKD.

Trustees bring judgement, perspective and constructive challenge to Board discussions and decisions. In this recruitment round, we are especially looking for people who can bring the voice of lived experience into those conversations – helping us make better decisions, set the right priorities and stay closely connected to the needs of the PKD community.

This is a voluntary role with no salary. Reasonable expenses will be reimbursed in line with the charity's policy.

Who we are looking for

We would like to hear from people who are affected by PKD in some way, including:

- people living with PKD
- parents, partners, family members, or carers of someone with PKD
- people who understand the practical, emotional, and long-term impact of PKD on individuals and families
- people who want to use their experience to help shape support, services, awareness, and research for the PKD community

You do **not** need previous trustee experience to apply.

We are looking for people who can bring:

- lived experience and insight that can help inform the charity's strategy, priorities, and decision-making
- a strong commitment to the PKD Charity's mission and values
- good judgement, curiosity, and the confidence to contribute to Board discussions
- the ability to think about both individual experiences and the wider needs of the PKD community
- a collaborative approach and a willingness to work with fellow Trustees, staff, and volunteers
- a commitment to good governance and acting in the best interests of the charity and its beneficiaries

We also recognise that people may bring valuable professional or specialist skills alongside lived experience. While this recruitment campaign is intentionally broad, we welcome applicants whose personal connection to PKD is complemented by expertise that could strengthen the Board over time.

We are particularly interested in adding the following skillsets to our board

- Income generation / fundraising
 - GP or primary care
 - Health economics/Finance
 - Research
-

- HR and employment law, proof reading, policies, and procedures
- Comms and Marketing

What Trustees do

As part of the Board, Trustees share collective responsibility for the charity's long-term success. This includes:

- helping to shape the charity's strategy and future direction
- ensuring the charity stays focused on the needs and priorities of people affected by PKD
- overseeing performance, resources, and the effective use of funds
- supporting strong governance, financial oversight, and sound decision-making
- helping protect and strengthen the charity's reputation, sustainability, and impact
- acting as ambassadors for the charity and championing its mission
- bringing the perspective of people affected by PKD into Board conversations and decisions

More information on the role of trustees can be found from the charity commission

Charity Commission - What is a charity trustee?

[What is a charity trustee? - GOV.UK](#)

Why become a Trustee?

Trusteeship is a chance to make a meaningful contribution to a cause you care about, while also developing your own skills, confidence, and networks.

As a Trustee of the PKD Charity, you will have the opportunity to:

- play a direct role in shaping the future of the UK's only charity dedicated solely to PKD
- use your lived experience to influence strategy, services, awareness, and research
- develop leadership and strategic decision-making experience
- gain or deepen your understanding of charity governance and Board-level responsibility
- build confidence in contributing to high-level organisational decisions
- expand your network through connections with trustees, staff, clinicians, researchers, and the wider charity sector
- help ensure that the voices of people affected by PKD remain at the heart of the charity's work

We will provide induction, support and access to relevant training to help Trustees feel confident and

effective in the role.

Diversity and inclusion

The PKD Charity is proud to have a Board with a wide range of backgrounds, perspectives and experiences, and we are committed to maintaining and strengthening that diversity.

We warmly welcome applications from people from all communities affected by PKD, and particularly from those whose voices are underrepresented on charity boards. We believe that a diverse Board leads to better decisions, stronger governance, and a more effective charity.

Eligibility to be a Trustee

Becoming a trustee is an important and rewarding role, and there are a few simple eligibility requirements that we need to check before an appointment can be made.

In general, to become a trustee of PKD Charity you must be **18 or over** and legally eligible to act as a charity trustee. There are some circumstances which can prevent someone from becoming a trustee, for example certain unspent criminal convictions, bankruptcy, or insolvency, or being disqualified from acting as a company director.

Most people who are interested in becoming a trustee will have no issues with these requirements. We simply ask all prospective trustees to check their eligibility before appointment and to complete a short declaration confirming that they are able to take on the role.

You can find more information about the Charity Commission's trustee eligibility requirements here:

[Charity Commission - Automatic disqualification rules for charity trustees](#)

If you are unsure whether anything might affect your eligibility, please don't hesitate to speak to us. We are very happy to discuss this with you and, where necessary, you can seek independent advice.

As part of the appointment process, successful candidates will be asked to complete a Trustee Eligibility and Declaration Form confirming that they are eligible and understand the responsibilities that come with being a trustee. All PKD Charity Trustees are required to complete a Disclosure and Barring Service (DBS) check.

This is a standard safeguarding and governance check and applies to all trustees. The check will be arranged by the PKD Charity as part of the appointment process, and we will provide guidance on what you need to do.

A DBS check is not a test of suitability for the role, and having a previous conviction does not automatically mean that someone cannot become a trustee. If you have any questions or concerns about the process, please speak to us confidentially.

Time commitment

We aim to make trusteeship manageable alongside work, family and other commitments. The role is likely to involve:

- attendance at Board meetings during the year (remote and in person)
- reading papers and preparing for meetings in advance
- occasional involvement in committee work, events, or discussions between meetings

Terms

- This is a voluntary, unpaid Trustee role
- Reasonable expenses will be reimbursed in line with the charity's policy
- Trustees are usually appointed for a fixed term in line with the charity's governing arrangements

How to apply

If you are interested in becoming a Trustee of the PKD Charity, we would love to hear from you. To apply, please send us:

1. A short CV

This does not need to be lengthy. We are interested in understanding your experience, skills, and the perspective you could bring to the Board.

2. A short supporting statement

Please tell us:

- why you would like to become a Trustee of the PKD Charity
- what your connection to PKD is
- what you feel you could bring to the Board
- anything else you would like us to know about you.

We are particularly interested in hearing from people with lived experience of PKD, including family members and carers. You do not need previous experience of being a Trustee to apply.

Please send your application to alan.greenberg@pkdcharity.org.uk by 9am on Monday 23rd November.

What happens next?

After the closing date, we will review applications against the skills, experience, and perspectives we are looking for on our Board.

Shortlisted candidates will be invited to informal discussions with representatives of the Board. These will be opportunities for us to get to know you, hear more about your connection to PKD and what you could bring to the role, and for you to ask any questions about the charity and trusteeship.

Following the final interview, the Board will agree appointments, and we will contact all applicants to let them know the outcome.

Successful candidates will then complete the necessary eligibility and declaration checks before their appointment is confirmed.

We want the process to be a two-way conversation. We are keen for you to find out whether being a Trustee of the PKD Charity is right for you, just as we are getting to know whether you are right for the Board.

Polycystic Kidney Disease Charity

Registered charity in England and Wales 1160970

Registered charity in Scotland (SC047730) |

A company limited by guarantee - Registered company in England and Wales 9486245

Registered address: 86-90 Paul Street, London, EC2A 4NE
