



## **Introduction**

The PKD Charity is a dedicated organisation delivering world-class support to our community through diverse mediums, including online platforms, social media, and in-person services. Our support and research involvement is exemplary and highly regarded within the health care and research community.

We are ambitious, and this role is designed to lead our charity to new heights in support, advocacy, and research. Polycystic Kidney Disease (PKD) is a complex medical condition, and the successful candidate must have a deep understanding of PKD and the ability to engage effectively with our stakeholders. We expect our CEO to take a high-profile role and establish themselves as a key figure within our community and among our partners.

## **Team and Management**

Currently, our team consists of five staff members and a few external key service providers. The CEO will oversee and guide this team, which includes:

- Operations Manager
- Support Manager
- Communications & Events Manager
- Fundraising Manager
- Patient Involvement Officer

All staff work remotely, with occasional requirements to attend face-to-face events.

## **Network and Collaboration**

We are at the heart of an extensive network both in the UK and internationally, collaborating with partner patient organizations. This role will involve active participation and occasional leadership within this ecosystem.

## **Strategic Leadership**

The CEO will work closely with the Chair and the Trustees to deliver our strategy and ensure effective operational management.

## **ROLE**

Chief Executive Officer [CEO]

Location: Remote with occasional travel

Responsible to: Board of Trustees

Working time: 3-5 days a week (to be agreed)

Salary: Circa £60-70,000 per annum (pro rata), depending on experience

Contract Type: Permanent

Holiday: 25 days per annum plus public holidays

## **DUTIES AND RESPONSIBILITIES**

### **Strategy and Leadership:**

- Provide leadership to the charity for developing our strategic plan as well as implement and oversee delivery of the Charity's strategic plan.
- Act as an ambassador and positive role model for the organisation both internally and externally.
- Maintain and develop external partnerships with key stakeholders and International partners.
- Keep up to date with new developments in the field of PKD and ensure that the Charity can respond rapidly to them.

### **Organisational Management and Compliance**

- Provide accurate, clear and concise information to the Board and Committee.
- Work with the Operations Manager to:
  - Ensure compliance with contractual requirements and standards, ensure the charity complies with all relevant legislation.
  - Ensure that all legal reporting requirements are adhered to including reporting to the Charity Commission as well as ongoing responsibilities to the Association of Medical Research Charities and the Fundraising Regulator.
  - Ensure that operational risks are effectively assessed and managed.
- Manage, Inspire and motivate staff and volunteers.
- Manage all consultants used by the Charity in its activities.
- Ensure effective communication and information exchange between all staff and volunteers and to the Board.
- Have ultimate responsibility for ensuring that the organisation is appropriately staffed and run and follows best practice employment policy.

## **Finance:**

- Work with the Operations Manager to:
  - Oversee the production of an annual budget and monthly management accounts.
  - Ensure that adequate financial controls are in place, and that regular financial and fundraising reports are accurate and appropriate and presented to the Board.

## **Fundraising, Communications and PR:**

- Working with the Fundraising Manager and Communications Manager to:
  - Agree fundraising objectives and oversee activities and their effectiveness.
  - Build and maintain relationships with existing and new donors.
  - Explore and develop new funding opportunities.
  - Proactively seek to raise the profile of the Charity amongst target audiences and stakeholders, acting as the official spokesperson for the organisation as required.
  - Oversee the communications and marketing strategy: annual review, newsletters, booklets etc. Ensure the Charity communicates effectively and regularly with its stakeholders.

## **Community Support:**

- Working with the Support Manager to:
  - Agree Support objectives and activities.
  - Proactive involvement in Support activities including attendance at Information days and on-line Webinars.
  - Actively interact with the PKD community and be available to offer support.
  - Work with our 3<sup>rd</sup> party suppliers to ensure that our Information is up to date reliable and accredited.

## **Research:**

- Drive our Research agenda.
- Proactive networking to facilitate Research that delivers significant benefits to the PKD community.
- Active involvement in all aspects of the PKD/KRUK Research Consortium.
- Lead and encourage Patient Involvement in PKD and associated conditions.
- Work with our Patient Involvement Officer in resourcing and delivering 1<sup>st</sup> class support for Research programmes.

## **Person Specification / Key Qualifications**

### **Essential:**

- Previous senior leadership either as a CEO or as part of a wider senior team.
- Charity experience or a close relationship with the PKD community.
- Ability to understand complex medical topics.
- Creating or contributing to annual business plans and strategies.
- Excellent verbal and written communication skills.
- Exceptional management skills.
- Overseeing budgets.
- Experience in strategic planning and development.
- Strong leadership and ambassadorial skills, with the ability to advocate for an organisation and build effective strategic partnerships externally.
- Understanding of (but not necessarily an expert in) business functions such as finance, HR, operations, research and communications.

### **Desirable:**

- Experience in bringing together stakeholders with diverse backgrounds to achieve a common goal, including academics and funding organisation.
- Experience working with a medical or health-related organisation, niche charity or non-profit organisation.