# THE POLYCYSTIC KIDNEY DISEASE CHARITY

Report of the Board of Trustees and Accounts – 1 April 2023 to 31 March 2024

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

# ANNUAL REPORT AND ACCOUNTS 2023-2024

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# REFERENCE AND ADMINISTRATIVE INFORMATION

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pkdcharity.org.uk

**Polycystic Kidney Disease Charity**
(Also known as the PKD Charity)
Registered charity in England and Wales
Number 1160970
Registered charity in Scotland
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A company limited by guarantee
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## Directors* and Trustees who served during the year and to the date of this report

Mr Alan Greenberg (Chair)
Mr Idriz Adedoja
Mr Raj Johal
Ms Rebecca Murphy-Peers
Mr Jon Rees
Mrs Karen Stapleton
Mr Adrian Tinsley
Mr Nicholas Tracey (retired 24th January 2024)
Professor Patricia Wilson
Mr Alexander Vickerman (appointed 10 October 2023)

## Research Advisory Board

Professor Patricia Wilson (Chair)
Ms Sanela Becar (Lay Member)
Professor Daniel Gale
Dr Richard Sandford
Professor John Sayer
Dr Manish Sinha
Professor David Wheeler

## Chief Executive

Ms Tess Harris (RIP March 2024)
Miss Alison Taylor (appointed September 2024)

## Patrons

Professor Albert Ong
Dr Anand Saggar
Dr Richard Sandford
Professor Patricia Wilson

## Professional advisors

**Bankers**
CAF Bank Ltd
25 Kings Hill Avenue
West Malling
ME 19 4JQ

**Accountants**
PEM
Salisbury House
Station Road
Cambridge, CB1 2LA

**Independent accounts examiner**
Charles Pickin
Fellow of Institute of Chartered Accountants in England and Wales
Harrison Jasper Ltd
Florance Lane, Groombridge, TN3 9SH

*The directors of the charitable company (the charity) are its trustees for the purpose of charity law.

## *TRUSTEES ANNUAL REPORT & DIRECTORS' REPORT*

The Trustees, who are also directors of the Charity for the purpose of the Companies Act, present their annual report and financial statements of the Charity for the year ended 31 March 2024. The accounts comply with the Charities Act 2011, Companies Act 2006 and the trust deed and follow the recommendations in Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

The Trustees confirm that they have complied with the duty in section 17 of the Charities Act 2011 to have due regard to the public benefit guidance published by the Charity Commission in determining the activities undertaken by the Charity.

## WELCOME FROM THE CHAIR

2023-2024 was tempered by the very sad news of the sudden loss of our CEO Tess Harris. Tess was a unique individual and she drove the PKD Charity to its current position with over 13 years of dedicated commitment as our CEO. Tess had an unwavering desire to deliver better treatment, improved patient representation, raising awareness and research in PKD in the UK and across the world and she will be sadly missed by everyone who knew her.

Tess was critical to everything the Charity did in the UK however we had taken actions to mitigate the situation and we were able to continue to deliver our core services to our community. Despite the great loss both emotionally and operationally the PKD staff did a fantastic job in providing such a high level of service.

The year was a strong one financially which enabled us to develop stronger service delivery and increase our focus on research. We have further developed the PKD Research Consortium in partnership with Kidney Research where we are striving to combine the UK's research into PKD to transform and accelerate translational PKD research in the UK with the potential to impact the lives of patients.

Over the next few pages, you can read more about the Charity's activities during 2023-24. We are unable to do our work without the generosity of those who donate money or give time: including patients and families affected by PKD, their colleagues and friends; the bereaved and those who give in memory of those who die from PKD; the healthcare professionals and researchers; our partners and foundations; our trustees and staff.

Alan Greenberg, Chair, Board of Trustees

Date: 24th December 2024

## OBJECTIVES AND AIMS

The Polycystic Kidney Disease (PKD) Charity is the only UK charity solely dedicated to improving the lives of children, adults, families, and carers affected by **polycystic kidney disease** (PKD). The Charity was formed in 2000 by a PKD patient and a genetics consultant. Throughout the past 20 years, most trustees and staff have been either PKD patients or family members.

### *About PKD*

PKD is an incurable, systemic genetic condition that causes kidney failure and damages other organs. There are two forms of PKD: **autosomal dominant polycystic kidney disease** (ADPKD), the most common inherited kidney disease and fourth cause of kidney failure worldwide; and the rare **autosomal recessive polycystic kidney disease** (ARPKD).

An estimated 70,000 people in the UK and 12 million worldwide have PKD

Be PKD Aware
PKD Awareness Week 4-10 Sept.

The prevalence of ADPKD and ARPKD is approximately 1 in 1,000 and 1 in 20-40,000 respectively. This means that each year, of the 800,000 babies born each year in the UK, 800 could have ADPKD and 20-40 could have ARPKD. As an inherited condition, PKD affects not only the individual but also their immediate family. It's a lifelong condition that can start to present even before birth.

In 2021 (latest published data), approximately 7,000 adults with PKD were receiving treatment for kidney failure – accounting for 1 in 10 of all adults in the UK on dialysis or with a kidney transplant.

**ADPKD – the more common form of PKD**

ADPKD causes multiple fluid-filled cysts to develop, grow and multiply from conception in both kidneys resulting in kidney growth and progressive kidney failure. In many patients, cysts also form in the liver, pancreas and other organs. Both kidneys can grow immensely, up to 100 times normal size - see Image 1 on left showing the impact of ADPKD kidneys on body shape. The brain and heart can also be damaged. Individuals with ADPKD will often have directly affected family members, parents and siblings, sometimes over several generations.

Most patients with ADPKD will have kidney failure by age 60 and will need kidney replacement therapy (KRT) to stay alive. KRT involves either dialysis or (if feasible) a kidney transplant. Some people will require nephrectomies (kidney removal) due to organ size and have frequent disabling, painful cyst infections that may need surgical intervention. Over 20 adults annually will also need a liver transplant owing to massively cystic livers. Some families are prone to brain aneurysms, which can fatally rupture if not discovered and treated. Acute and chronic pain is common throughout life. As ADPKD progresses, individuals experience complications such as high blood pressure, infections, bleeding, bowel and bone disorders, gout and kidney stones.

There is one disease-modifying treatment. However, this is not available to all patients, has modest efficacy and challenging side effects. Read more about ADPKD on the PKD Charity website.

*Image: 1 Hazel is affected by ARPKD (image by permission)*

**ARPKD** is rare and often diagnosed during pregnancy. Unfortunately, 1 in 3 babies will die in the first week of life owing to the rapid growth of cystic kidneys preventing lung development. The babies who survive sometimes experience early kidney and liver failure. They may need life-saving dialysis before transplant and about a third have impaired growth during childhood. Some children may need kidney or liver transplants in later life.

Despite this, many children do survive to adulthood with mild forms of ARPKD, although their kidneys and livers can be impaired. ARPKD patients frequently have very high blood pressure and are prone to liver-related problems such as bile duct infections and enlarged spleens. See Image 2 of Hazel who is frequently unwell from ARPKD symptoms, affecting her ability to enjoy a normal childhood.

There are no treatments other than symptomatic. Read more about ARPKD on the PKD Charity website.

## *Charitable objects*

To promote health and to relieve those persons suffering from or affected by PKD with a view to improving their conditions of life, in particular but not exclusively by:

- Funding research into determining the causes of PKD and into discovering treatments and a cure, with any useful results of such research being available to the public.
- Promoting awareness of PKD through the production and publication of authoritative information for the general public and health professionals about the medical, healthcare and related aspects of PKD; and
- Organising patient, family and carer information, education and support events across the UK and offering personal support to patients and their families.

## *Our objectives and activities*

### Research

Our aim is to support and fund ADPKD and ARPKD research in the UK. As a small charity, historically we have focussed on funding small research projects up to £15,000 each and contributing towards PhD studentships. To date, since 2008, we have awarded over £800,000 to research. Increasingly our research funding will be undertaken in partnership with charity partners to enable greater impact for PKD research funding in the UK.

We publish details of funded research and outcomes on the Charity website and include in our regular eNews and printed newsletter.

We participate in PKD research groups and networks in the UK and internationally.

## Information, awareness, and advocacy

ADPKD is the most common inherited kidney disease, yet few people have heard of it and awareness amongst GPs is known to be particularly low. ARPKD is rare and diagnosis/prognosis is a challenge, especially in pregnancy.

We produce and publish evidence-based information about PKD in collaboration with medical experts and patients which is available online and in print. We have PIF TICK accreditation and are designated as a ‘trusted health care information creator’ by the Patient Information Forum.

We organise frequent educational events on all aspects of PKD, with medical and health professional speakers, aimed at helping patients/carers be more knowledgeable, feel more confident and able to cope.

We represent the views and voices of patients, families and carers to UK healthcare professionals, researchers, the NHS, policy makers and the media. We educate pharmaceutical firms with an interest in PKD to ensure that they understand patients’ experiences and needs. Where appropriate, we work in partnership with other charities and umbrella groups, to raise awareness about PKD and its impact on individuals and families.

## Support

Being diagnosed with PKD is usually a shock, even if there are known family members with the condition. People report feeling isolated and overwhelmed by the health implications and have concerns for their own future, their children and family members.

We want everyone affected by PKD to have the best quality of life, despite the complications and sometimes life-threatening nature of PKD.

We support patients and carers at every stage of their life with PKD. We provide a range of community services offering practical and emotional support, information and advice including: a helpline run by people with direct experience of PKD, educational events, individual befriending, webchat/messaging, meetups, workshops, and moderated online Facebook groups.

# PERFORMANCE AND ACHIEVEMENTS DURING 2023-24

2022-23 was the second year of our 3-year strategy, approved in March 2022. Our long-term goals were:

- To promote and help deliver integrated holistic care to everyone affected by PKD
- To build an empowered, resilient, diverse PKD community
- To continue raising awareness and be the 'Voice of PKD'
- To accelerate research and development into treatments for PKD

In particular, in 2023-24, we aimed to:

1. Progress the PKD Research Consortium.
2. Recruit more volunteers to research patient groups.
3. Promote the PKD App and our Support Services directly to healthcare professionals.
4. Continue to grow and develop local PKD Groups.
5. Conduct a survey of PKD community needs.
6. Continue to focus our fundraising strategy on community fundraising.

## *Research activities during 2023-24*

### PKD Charity and Kidney Research UK partnership

During the year, discussions continued with Kidney Research UK about evolving the existing partnership between our two charities into a **PKD Research Consortium**, which will bring together clinical and scientific experts in PKD and related rare conditions, to pool resources, drive collaboration and accelerate therapeutic development.

The consortium will be a robust collaborative platform bringing together experimental models, including organoids and bio samples, and mature patient genetic and clinical data held in the UK Rare Kidney Disease Registry (RaDaR). A structured strategic approach through the consortium will generate novel disease insights and identify new targets for drug development and/or repurposing to transform patient outcomes.

We were pleased to appoint Jeremy Hughes (Professor of Experimental Nephrology at the University of Edinburgh and an Honorary Consultant Nephrologist at the Edinburgh Royal Infirmary) as our Ambassador for the programme. Jeremy will take an active role in defining, creating and supporting the Consortium.

Significant progress was achieved in defining and developing this innovative service in conjunction with scientific experts, patient representatives, PKD researchers, healthcare professionals and the pharmaceutical industry. We have developed and enhanced our vision of the Consortium and have undertaken a feasibility study with experts in Consortia to review and guide us on our work. This study successfully identified a pathway to economically drive this forward and a new phase geared to implementation and funding is currently underway.

## Research grants

The PKD Charity trustees approved:

- £10,000 continuation funding to support the PKD BioResource Bank
- £5,000 funding to support the National Registry of Rare Kidney Diseases (RaDaR)
- £37,934 of grant funding towards three research projects:
    - Professor Ian Smyth and Professor Pleasantine Mill are working to better understand the role of a specific protein which drives cyst formation in PKD with the aim of finding potential new targets for treatments.
    - Professor John Sayer from the University of Newcastle and his team are looking at specific errors caused by changes in the PKD1 gene in ADPKD. They have identified a drug which could possibly help the body 'ignore' the errors.
    - Dr Paraskevi Goggolidou from the University of Wolverhampton and her team are looking at the role of the lung in ARPKD and the potential mechanisms that may be involved in the development of the disease. Successful research outcomes could build a framework for a new approach to better diagnosis and potential treatment prospects.

## Progress report on the supply of BioResource samples for PKD research (UK)

The BioResource contains hundreds of cell tissues and fluid-based samples donated by ADPKD and ARPKD patients at various stages of kidney function decline. Samples from this unique collection have been provided to the majority of major PKD research centres in the UK. Importantly, this has also helped encourage collaborations between groups and allow investigators from other research fields to expand their studies to include PKD projects.

Professor Patricia Wilson, who curates the BioResource, reported that in a 12-month period:

- Over 800 samples were provided for use in 21 PKD-related projects
- Over 99 new donated samples were added to the BioResource Bank

## ADPKD research priorities

The research priorities were highlighted in several grant applications to external funders and have been integral in the development of the PKD consortium focus.

## Patient involvement

We were asked to support research projects and invite our community to provide feedback on a variety of grant applications. During the year we received more approaches than ever before not only to support patient involvement in research into PKD, but also to provide patients to sit on steering groups for major new projects which is hugely encouraging. Our new Patient Involvement and Engagement Officer coordinates aspects of this work, finding and supporting participants. We are indebted to the increasing numbers of patients who are volunteering to take part in these projects and over the coming year we will be investing more resources to support these initiatives.

### Other research activities

We participated in and supported UK and relevant international research activities:

- The ADPKD Clinical Study Group (CSG) - brings together doctors, nurses, surgeons and other healthcare professionals plus patient representatives to generate a portfolio of clinical studies into ADPKD. The chief executive is deputy chair and helped organise meetings.
- The ARPKD Rare Disease Study Group, established within the (National Registry of Rare Kidney Diseases (RaDaR).
- The Advanced Discovery of Visceral Analgesics via Neuroimmune Targets and the Genetics of Extreme human phenotype (ADVANTAGE) consortium funded by the Medical Research Council and partners – the aim is to improve the treatment of people with visceral diseases, such as endometriosis, colitis and polycystic kidney disease, focusing on their pain rather than just their underlying disease. The Charity is a patient partner.
- The PKD Outcomes Consortium (PKDOC) – helps establish clinical and patient reported outcomes for ADPKD research acceptable to the global regulators who authorise medicines (the US Food & Drink Administration (FDA), European Medicines Agency (EMA) and the Medicines and Healthcare products Regulatory Agency (MHRA) in the UK). The chief executive and PKD Charity Research Advisory Board (RAB) members attended monthly meetings.
- The Standardised Outcomes in Nephrology Group (SONG) - defining clinical and patient reported outcomes that can be used in PKD research and trials globally. The chief executive is an international committee member.
- The European Reference Networks for rare kidney and liver conditions (ERKNet and Rare Liver) - virtual networks involving healthcare providers and patient representatives across Europe which facilitate dissemination and exchange of knowledge and experience (e.g. clinical practice guidelines) and generate new knowledge (e.g. by conducting research studies).

## *Support services for people, carers and families affected by PKD*

During 2023-24, we continued to support our community through remote and face to face service delivery. We used our website, online channels and platforms such as Zoom, Teams, Facebook and other social media to provide support and information alongside in person meetings and events

### Phone and Facebook support

Our 0300 phone helpline was available for those feeling worried or emotional or needing information. The number of callers remained at approximately one caller per day on average. We logged the details of nearly 290 incoming calls during the year and categorise them by type: they are split equally between ‘Support’ ‘Questions’ and ‘Information’

Additionally, we respond to 1 to 2 messages a day posted on our Facebook groups or sent via direct message or text. We have help from our groups’ volunteer moderators and staff for out of hours support.

*“Thank you so much for you taking time to talk with me today. It meant a lot and reassured me to carry on living my life to the full. I relayed what you said to me about genetic testing to my children, you are greatly appreciated.”*

We manage and moderate 3 private UK-only Facebook groups with approximately 3,500 members. We are fortunate to have the support of trained volunteers who assist staff with moderation and peer support.

## Support group meetups

During the year, we were delighted to be able to return to in person support group meetings, with some groups choosing to continue with online support sessions.
We held 25 meetings during the year either in-person or via zoom. Our location-based groups are in London, Bedfordshire, Norfolk, NE England and Wales. The support groups are supplemented by online sessions on particular topics where small numbers of people can meet and talk through issues that are affecting them at specific stages in their journeys. Anyone from across the UK can join these group sessions. During the year these included group meetings on Low clearance and Tolvaptan treatment.

*"Attending the PKD Connect group was invaluable to me.  It was a chance to meet other people with PKD and, although all at different stages of the disease, interesting to hear their experiences and share my own.  Everyone was friendly and welcoming. I would recommend these groups to all who have PKD."*

*“I joined the low clearance group around a year ago. Sharing experiences about PKD-specific issues is so helpful. You are with people who truly understand our day-to-day lives. Nothing is off the table from transplant, dialysis, itching and holidays. It’s great”*

## Information & Support Days for patients and families affected by ADPKD

We held three **ADPKD Information & Support Days** during the year in London, Salford and Newcastle. The team and patients we pleased to have the first full year of in person events since pre Covid, 350 people registered for the events with 254 attending. We are indebted to the 29 medical professionals from up and down the country who prepared talks and gave up time over precious weekends to make the events possible.

The London event was held in October at St Georges, University of London. The venue had a 100-person capacity and was fully booked with a waiting list. Talks by leading experts in the field spanned PKD basics through to managing the emotional impact of PKD, along with an informal Q&A.

*“I was diagnosed in my 20’s (I’m now 47.) No doubt my fault for not seeking out further information consistently but my father died of renal and heart failure at 57, so I guess I’ve spent years simply assuming that the same thing will happen to me. It was great to meet others with the condition and hear about treatment of any kind in a supportive environment… Thank you, it was an informative, positive, and very useful day. “*

Our second event was held in Salford and had a slightly different format. We held presentations in the morning and attendees were given the opportunity to attend their choice of workshops in the afternoon. Attendees could choose from sessions on Living Donation, The dos and don’ts of Medication, Dialysis options and Diet and lifestyle. Post event surveys showed that 100% of attendees felt their knowledge of PKD had increased, with 99% reporting they felt better able to manage their ADPKD as a result of attending the event.

*“A really well organised day, superb speakers & lots of opportunity to ask questions...A lot of hard work resulted in a great day that was a credit to your Polycystic Kidney Charity. “*

We held our third ADPKD Information day of the year in March 2024 at the Freeman Hospital in Newcastle. The Newcastle team presented on a variety of topics including, surgical and transplant considerations, psychological aspects of PKD, Genetics and Research opportunities/Clinical Trials.

*“Really helpful for switching my mindset from 'this is a terrible illness that nobody understands and has had a devastating impact on my family' to 'this is, by and large, a predictable and manageable illness that doesn't prevent people from living long and full lives, with new treatments being explored”*

## Information and Support event for parents of children affected by ARPKD (autosomal recessive polycystic kidney disease)

About 1% of our community is affected by the rare form of PKD, ARPKD (autosomal recessive polycystic kidney disease), which severely affects babies and children. Our beneficiary group are predominantly parents of affected children, but we also engage with ARPKD adults.

In January 2024, we organised an in-person event for parents and children in London in collaboration with Evelina Children's Hospital. Clinical experts gave talks on a variety of topics including Nutrition in ARPKD, Liver issues, supporting young people and blood pressure management. In total 8 families were able to join us on the day, which included 9 children (aged 16 weeks to 7 years old). The children were cared for in a dedicated area by nursery nurses and DBS-checked volunteers and enjoyed various activities.

*"The children had a brilliant time and felt completely comfortable. They had lots of fun and were entertained the entire time which is usually pretty difficult!"*

*"Great to meet with other families! So thankful to have the opportunity to listen to the talks without the children in the room."*

## Online events

During the year we held 5 online events and invited medical experts to give talks on specific topics that we had identified as needed by our community. Two of the sessions were held in partnership with the National Kidney Federation. We continued with a community-friendly interactive Q & A sessions attended by 183 PKD participants.

- Skin care for Kidney Patients
- ARPKD Research Update
- Polycystic Liver Disease
- Transplant Bloods
- Polycystic Liver Disease
- ARPKD: The latest news

*"It was hugely informative. The speakers instilled calm confidence with their knowledge and expertise and so many of my questions were asked by others which reassured me that I am not alone with my thoughts or my situation."*

*"Extremely well presented, factual & gave insight into the various factors involved in the process. "*

The benefit of the talks stretches far beyond the attendees able to join the live sessions. Talks from the online information events are recorded and are available on our website and YouTube channel. During the year our YouTube channel was accessed by almost 11,000 users.

*“Thank you for steering me in the direction of the recorded talks, which are delivered by a variety of excellent kidney specialists, each person taking a slightly different angle of kidney disease, depending on their areas of expertise. “*

## Living Well with PKD Workshops

With the assistance of a Clinical Kidney Psychologist and Psychotherapist, we delivered 10 online workshops on ‘Living Well with PKD’. These explored pain, anxiety, diagnosis, relationships, grief and loss, body image and self-criticism. The workshops were held over 90 minutes via a Zoom meeting with capacity limited to 10.

The workshops were very popular with overall satisfaction rated 4.9/5. Participants were asked how likely they were to recommend this event to others in the PKD community with an average overall score of 8.6 out of 9.

*“Excellent session, presenters very compassionate and knowledgeable. It was great sharing experiences, .and nice to see that other people share the same fears, it makes it feel less lonely brilliant session “*

*“I felt very positive and uplifted by the workshop. It made me more aware of the emotions and thoughts I’ve been experiencing. The tips on how to deal with the negative thoughts and feelings have helped. Thank you.”*

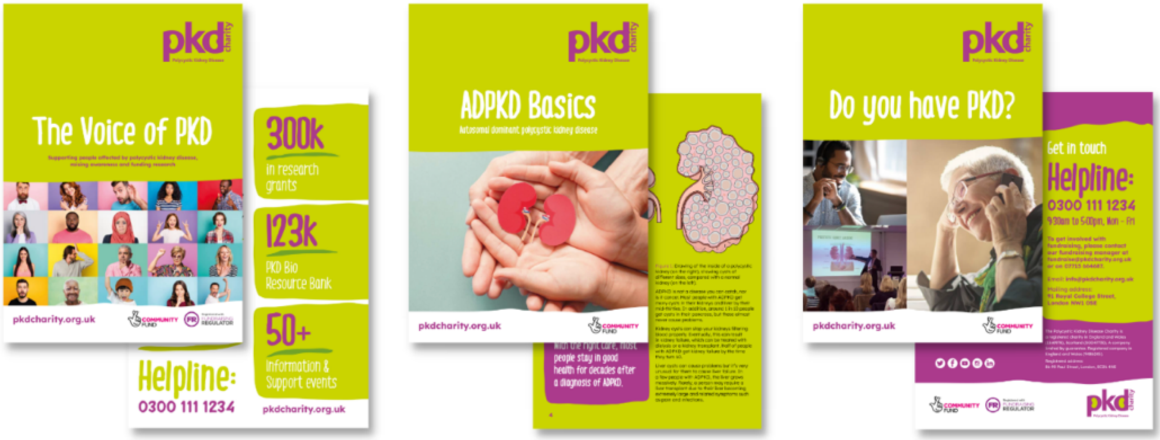
## Health information for patients and families

Providing accurate, clear and up to date information to the PKD community is a central focus of our mission. Information is key for patients and families to understand PKD, be able to support their own needs and bee truly involved in care decisions. We provide information via events, our website, printed publications and through the PKD App.

Trusted
Information
Creator
Patient Information Forum

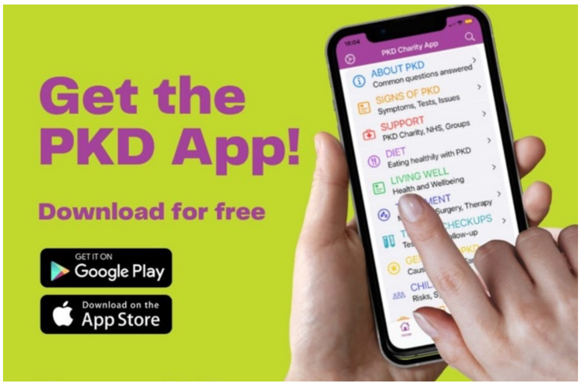
We have Patient Information Forum PIF TICK accreditation, which means that a reader can be assured that what they are reading, watching or listening to is evidence-based, understandable, jargon-free, up-to-date and produced to the best possible standard. This has enabled us to improve the distribution of our fact sheets, in particular to GPs via online directories, such as Healthinote.

All the fact sheets are available on our website, and we print booklets where required. Our website had a significant increase in users and page views over the last 12 months with 116% increase in users and 150% increase in page views.



### *PKD App*

The PKD App was launched in 2022 in partnership with patients and professionals with support from our developer Expert Self Care Ltd. The app is free to download on Apple and Google stores and requires no registration. No personal data is collected.



Android Google Play: PKD App
iPhone App Store: PKD App

We involved our PKD community through focus groups, editorial boards and rounds of content review, with every step logged for PIF TICK accreditation purposes.

The PKD App:

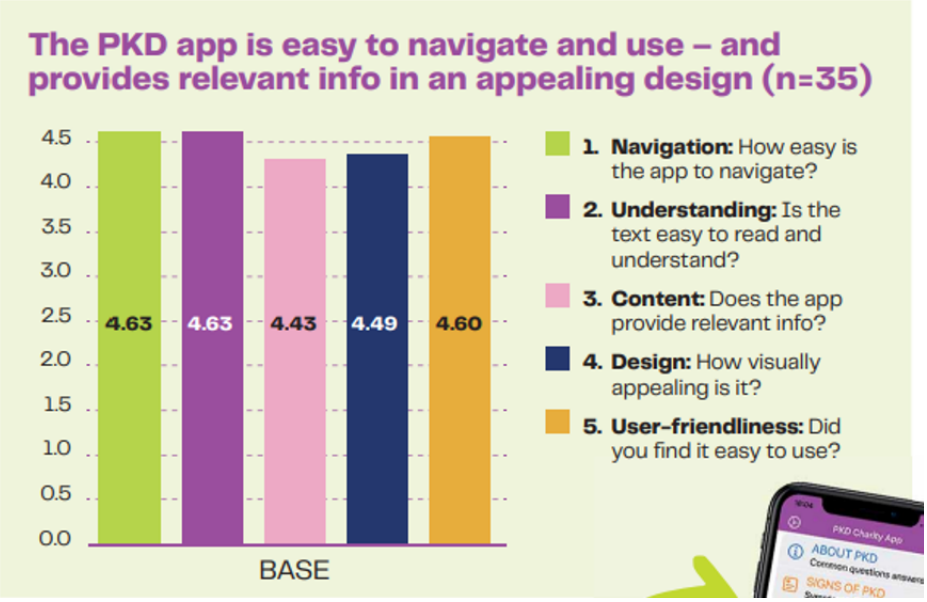
1. Provides credible information and health advice all in one place – derived from our PIFTICK accredited information.
2. Offers practical tips for everyday life.
3. Gives links to trusted further information and available support.
4. Provides reassurance

During the year the app was downloaded by 1,036 people with nearly 15,000 page views. We are pleased to see that the App store rating by users in 5/5.

**94%** said their knowledge of ADPKD has increased

**93%** felt better able to manage ADPKD

In November 2023 we conducted a survey of app users to ascertain the effectiveness and user satisfaction. We gathered insights into the app's useability, impact on self –management and overall user experience. The results were very reassuring.



The PKD app is easy to navigate and use – and provides relevant info in an appealing design (n=35)

*"I don't always have time at clinic appointments to ask everything, the app gives you answers to go back to"*

*"I' like that it is bite- sized and clear in the information it gives. All the areas receive attention and questions that I have had regarding ongoing testing and genetics have been answered in the relevant section of the app"*

*"It's so easy to navigate and includes the essential pieces of information as well as signposting to more detailed information should I want to know more. I think for those who are newly diagnosed, or have experienced disease progression or those who are struggling with their symptoms it is a very useful tool"*

## *PKD awareness/advocacy activities*

Throughout the year we shared patient stories under the banner of PKD Voices and regularly aligned our content with national campaigns run by health organisations and other charities.

Through social media posts on our Facebook page (10,000 followers), groups, Twitter/X, LinkedIn, Instagram social channels we continued to raise awareness of PKD, kidney health and our services.

We issued 2 printed full-colour newsletters to approximately 3,000 households and posted each online.

We published 30 e-newsletters in the year to over 4,500 individuals to keep the community informed. The e-news list grew by 12.5% over the previous year.

Coventry hosted the 46th British Transplant Games in July 2023. Over the two days we attended, we connected with PKD families, old and new, sharing information and cheering them on as they competed in the games.

**PKD Awareness Week** in September we shared crucial facts and statistics about PKD across various social media platforms. Additionally, we engaged existing and new audiences by inviting them to test their knowledge on PKD and kidneys through an updated version of the 'Are You PKD Aware' Quiz. We were grateful for the strong support from other kidney charities, all of whom joined in promoting PKD Awareness Week.

This year's **World Kidney Day** campaign focussed on celebrating Kidney Heroes - those friends, family members, healthcare professionals, organ donors, and even pets who support kidney patients. The campaign encouraged people to nominate their own heroes for the Kidney Charities Together (KCT) World Kidney Day award. Leading the campaign were the powerful audio stories of PKD patients: Asif, who honoured his employer for their support during his dialysis and transplant journey, and Martin, who received a life-saving kidney donation from his great-niece, Alex. By featuring these stories, the campaign amplified the voices of PKD patients.

Important facts and stats, plus ways to get support, manage kidney health, and take early action if at risk of kidney disease were also heavily featured.  helped us reach patients with little knowledge of our work.

We promoted and aligned our activity with other Awareness days/weeks, including **Rare Disease Day** in February 2023. The focus this year was on the benefits of care coordination for individuals with rare conditions, their caregivers, parents, relatives, healthcare professionals, and healthcare budgets. In a series of videos, young mum Aria candidly discussed the challenges of being mum to a child with a rare, incurable disease.

### Advocacy

Throughout the year, members of staff attended and participated in conferences, workshops and events relevant to PKD, kidney, liver, genetic and rare diseases. These included **UK Kidney Week Conference**, the **ANN UK (Association of Nephrology Nurses in the UK) Annual Conference** and the **British Association of Paediatric Nephrologists/Paediatric Nephrology Nurses Group** Conference.
The Charity continues as a member of **Kidney Charities Together** (KCT) working collaboratively to be the single powerful voice for all kidney patients in the UK. Other member charities include Kidney Care UK, Kidney Research UK, the National Kidney Federation, Kidney Wales, the UK Kidney Association.

The Charity is a member of several UK umbrella organisations representing the interests of people with long-term conditions (LTC) or genetic diseases, including **Genetic Alliance UK, the Health and Social Care Alliance Scotland, Rare Disease UK, the Kidney Health Partnership and the Specialised Healthcare Alliance**. The Charity engages with these organisations to ensure that our aims and activities are known, recognised, and considered. The Charity regularly inputs into national consultations facilitated by these umbrella bodies.

The Charity is a founder member of the **Ciliopathy Alliance**, which brings together patients, families, doctors, and scientists with the aim of improving the quality of life for children and adults affected by ciliopathies – primarily genetic diseases caused by defects in the function and structure of cilia (microscopic organelles found in every human cell and vital to development). PKD is an important ciliopathy with ADPKD having the largest patient cohort. There is a growing interest in studying a cluster of conditions called renal ciliopathies, which include ADPKD and ARPKD.

The Charity is a founding member of the **Kidney Patients Involvement Network** (KPIN), which is committed to increasing the number of patients engaged with initiatives and harness enthusiasm across a wider kidney patient and carer population, improving involvement and engagement from minority and under-served groups.

The Charity is a member of the **ABPI (Association of British Pharmaceutical Industry) Patient Organisation Forum**. The forum meets regularly to discuss issues such as joint working between patient organisations and pharmaceutical companies.

The Charity is a founder member of **PKD International** (PKDI), a global alliance of patient groups supporting people affected by all forms of PKD. These groups have similar aims to the PKD Charity. The chief executive is the current President of PKDI (a voluntary role). More information here: www.pkdinternational.org

The Charity is a member of **EURORDIS**, the European umbrella organisation of patient groups representing adults and children with rare and genetic diseases.

The Charity is a founder member of **FEDERG**, the European Federation of Patient Groups representing rare and genetic renal diseases.

## *Community involvement in the work that we do*

Our PKD community plays a vital role in the work that we do. We involve them in many aspects – directly, through volunteering, speaking about their personal experience on webinars and education events; or indirectly, by asking for their feedback, taking part in consultations and surveys.

We have approximately 91 (2023: 85) active loyal volunteers and we hugely appreciate the time and commitment they willingly give. They helped us during the year with reviewing health information, providing patient perspectives for research projects, moderating our Facebook groups, hosting support group meetings and taking part in consultations. Their sharing of personal experiences has been invaluable to others going through the PKD patient journey.

We also thank the healthcare professionals, scientists and others who gave their time to speak at the patient information events and wrote or reviewed health information materials.

## ***Community fundraising***

We thank all our wonderful fundraisers who supported the Charity’s work during 2023-24. They walked miles, ran marathons, organised garden parties, magic shows and plant sales, skydived, shaved their heads, boxed, fundraised at school, work and at home. These diverse events showcased the endless creativity and commitment of our community to raise funds to ensure that PKD Charity can continue to support people affected by PKD and fund life-changing research.

2023-2024 was a triumphant year for Team PKD, as the world embraced a return to normal with the revival of unrestricted mass-participation events. This fresh momentum was mirrored by our inspiring supporters and fundraisers who came together with renewed energy, passion, and purpose.

The year kicked off in style at the London Marathon, where Team PKD had an impressive nine runners among the 66,000 participants. This was one of our largest marathon teams to date, and each member crossed the finish line with pride and determination. Together, they raised a truly spectacular £25,000 to support PKD research and advocacy. September brought more success with the Great North Run in Newcastle, where 14 Team PKD runners took on the iconic half marathon. Their dedication and hard work were rewarded with over £12,000 raised, adding to the year’s extraordinary fundraising achievements.

In addition to these flagship events, we saw some incredible individual efforts by our supporters, far too many to mention, but each and every one made a difference. As an example in July, Chloe Smith took a leap of faith with a tandem skydive, while September’s “Walk for PKD” included Darren Creed and friends, who completed the challenging Yorkshire 3 Peaks trek.

Thanks to every participant, fundraiser, and supporter, 2023 has been a year of incredible achievements for Team PKD. Together, we are making a lasting difference and moving closer to a world without PKD. Here's to an even brighter and more impactful 2024-2025.

### *Grant fundraising*

The National Lottery Community Fund awarded year 5 of the 5-year grant for the Positive Peers Programme.
Grants from other Trusts & Foundations are shown in the Statement of Financial Activities.

### *Pro bono support*

We acknowledge and thank:

- Microsoft, who provide software free of charge or at minimal cost.
- QuestionPro, who provide a free-of-charge survey platform.
- Google (AdWords advertising grant).

## 2024-25 PLANS

Our long-term goals are:

- To promote and help deliver integrated holistic care to everyone affected by PKD
- To build an empowered, resilient, diverse PKD community
- To continue raising awareness and be the 'Voice of PKD'
- To accelerate research and development into treatments for PKD

In 2024-25, we will:

1) Provide resources to further develop the PKD Research Consortium.
2) Recruit and train more patients to provide patient perspectives on research projects.
3) Promote the PKD App and our Support Services directly to healthcare professionals.
4) Continue to grow and develop local PKD Groups.
5) Continue to focus our fundraising strategy on community fundraising.
6) Explore how we can meet the needs of young people (under 30's) who are living with PKD

# STRUCTURE, GOVERNANCE AND MANAGEMENT

## *Constitution*

The Polycystic Kidney Disease Charity is a company limited by guarantee on 12 March 2015, Company Registration No 9486245 and is registered for charitable purposes with the Charity Commission, Charity Registration No. 1160970. The Charity is governed by its Memorandum and Articles of Association. In the event of the Charitable Company being wound up, company members are each required to contribute an amount not exceeding £10.

## *Trustees*

Trustees, who are also directors of the Charitable Company, are recruited by open advertising and appointed by the other trustees. Trustee appointments are for three years, after which trustees retire but are eligible for re-appointment for a further two terms of three years.

They are unpaid volunteers and may claim reasonable out of pocket expenses. The charity's activities are planned and carried out by the trustees. All trustees are required to declare relevant interests and may be required to withdraw from trustee meetings.

All trustees are encouraged to develop their trusteeship skills and to attend external conferences and events relevant to PKD and charity governance.

## *Governance and administration*

The trustees met 5 times online during the year to review the charity's performance, determine and approve the operating plan and budget. The trustees delegate review of grant applications to the PKD Charity Research Advisory Board (RAB) who met virtually to review grant applications. The trustees delegate the management of charitable activities and administration to a small team led by the chief executive. The trustees monitored performance at trustee meetings; the chair has regular phone and face-to-face meetings with the chief executive.

## *Risk Management*

The trustees have overall responsibility for ensuring that the charity is managing risk in a professional, responsible and constructive manner. This has involved identifying risks the charity may face, assessing potential impacts and seeking to minimise them. Material risks for charity include key person dependency on its chief executive, risk of loss of supporters, managing regulatory changes, and maintaining a surplus. The trustees regularly review the charity's risk management policies, which include data protection and safeguarding – the charity is registered with the Information Commissioner and requires trustees, staff and some volunteers to undertake Adult Safeguarding Courses. The charity is exposed to financial risks, such as loss of income, which it aims to mitigate by maintaining sufficient reserves while continuing to diversify fundraising, for example, by increasing grant funding.

## *Fundraising*

The charity undertakes most of its fundraising activities in-house and used a consultant solely for the purposes of grant applications. The charity is a member of the **Fundraising Regulator**, providing reassurance to supporters, members of the public and other donors, and promoting best practice in fundraising. The charity received no complaints about its fundraising practice in this financial year.

The charity is registered with the **Information Commissioner** and all supporters' and stakeholders' personal data are maintained securely in accordance with the GDPR (2018).

## FINANCIAL REVIEW

### Performance

During the 12 months to 31 March 2024, the charity's income was **£453,815** (2023: £386,220).

Expenditure on raising funds as a percentage of total incoming resources was 17**%** (2023: 22%). Research expenditure was **£67,212** (2023: £177,340). The Charity's expenditure on charitable activities across Patient support, Awareness and Education was **£149,697** (2023: £222,839), which included information days, telephone support, online/chat support and expenditure on the peer support service.

In total, the Charity expended **£332,108** (2023: £508,629), resulting in incoming resources for the year of **£121,706** (2023: outgoing resources of £122,410). Total fund balances at the year-end were **£420,808** (2023: £299,102) and all funds maintained a surplus position at the year-end (Note 18).

### Public Benefit

All charitable activities are undertaken to further charitable purposes for public benefit. The trustees confirm they have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives and in carrying out and planning current and future activities.

### Reserves

The Charity maintains a Reserves Policy to hold reserves equivalent to between 3-6 months' ongoing expenditure, after covering current liabilities. As at the year end, the Charity had undesignated free reserves of £203,248 (2023: £126,828), equivalent to 6 months´ total expenditure (2023: 4 months). The trustees considered that the Charity has sufficient reserves at the year-end and are of the view that the Charity continues to be a going concern.

**Approved by the Trustees and signed on their behalf by**

Idriz Adedoja
Trustee-Treasurer

Date: 24th December 2024

# *Independent Examiner's Report to the Trustees of the Polycystic Kidney Disease Charity*

**Independent examiner's report to the trustees of The PKD Charity**
I report on the accounts of the company for the year ended 31 March 2024, which are set out on pages 28-43.

**Respective responsibilities of trustees and examiner**
The trustees (who are also the directors of the company for the purposes of company law) are responsible for the preparation of the accounts. The trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) or under Regulation 10 (1)(a) to (c) of The Charities Accounts (Scotland) Regulations 2006 (the 2006 Accounts Regulations) and that an independent examination is needed. The charity is required by company law to prepare accrued accounts and I am qualified to undertake the examination by being a qualified member of Institute of Chartered Accountants in England and Wales. Having satisfied myself that the charity is not subject to audit under company law and is eligible for independent examination, it is my responsibility to:

- examine the accounts under section 145 of the 2011 Act and section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 (the 2005 Act)
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act
- to state whether particular matters have come to my attention

**Basis of independent examiner's report**
My examination was carried out in accordance with the general Directions given by the Charity Commission and is in accordance with Regulation 11 of the Charities Accounts (Scotland) Regulations 2006. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the next statement.

**Independent examiner's statement**
In connection with my examination, no matter has come to my attention:

(1) which gives me reasonable cause to believe that in any material respect the requirements:

    - to keep accounting records in accordance with section 386 of the Companies Act 2006 and section 44(1)(a) of the 2005 Act and
    - to prepare accounts which accord with the accounting records, comply with the accounting requirements of the Companies Act 2006, section 44(1)(b) of the 2005 Act and Regulation 8 of the 2006 Accounts Regulations and
    - which are consistent with the methods and principles of the Statement of Recommended Practice: Accounting and Reporting by Charities
    - have not been met or

(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached

Charles Pickin
Fellow of Institute of Chartered Accountants in England and Wales
Harrison Jasper Ltd
Florance Lane
Groombridge TN3 9SH
Date: 24th December 2024

## STATEMENT OF FINANCIAL ACTIVITIES - 1 APRIL 2023 TO 31 MARCH 2024

### (INCORPORATING INCOME AND EXPENDITURE ACCOUNT)
### FOR THE YEAR ENDED 31 MARCH 2024

| | Notes | Restricted Funds 2024 £ | Unrestricted Funds 2024 £ | Total 2024 £ | Total 2023 £ |
|---|---|---|---|---|---|
| **Income from:** | | | | | |
| Donations grants and legacies | 3 | 51,935 | 394,055 | 445,990 | 367,664 |
| Charitable activities | 4 | - | - | - | 8,735 |
| Other trading activities | 5 | - | 5,559 | 5,559 | 7,361 |
| Investment income | 6 | - | 2,265 | 2,265 | 2,460 |
| **Total income** | | **51,935** | **401,879** | **453,814** | **386,220** |
| **Expenditure on:** | | | | | |
| Cost of fundraising | 7 | - | 78,446 | 78,446 | 84,320 |
| Non-charitable trading activities | 7 | - | 5,062 | 5,062 | 1,557 |
| **Total** | | - | **83,508** | **83,508** | **85,877** |
| Research and grants | 8 | 1,985 | 65,226 | 67,212 | 177,340 |
| Awareness and education | | - | 38,926 | 38,926 | 36,544 |
| Patient support | | 108,803 | - | 108,803 | 180,389 |
| Depreciation | 14 | 1,968 | - | 1,968 | 5,904 |
| **Total** | | **112,756** | **104,153** | **216,909** | **400,177** |
| **Other expenditure** | | | | | |
| Support costs | 9 | - | 31,692 | 31,692 | 22,575 |
| **Total expenditure** | | **112,756** | **219,353** | **332,109** | **508,629** |
| **Net income / (expenditure) for the year** | | (60,821) | 182,527 | 121,705 | (122,409) |
| Fund balances brought forward at 1 April | 18 | 50,275 | 248,828 | 299,103 | 421,512 |
| Net incoming resources for the year | 18 | (60,821) | 182,527 | 121,705 | (122,409) |
| Transfers between funds | 18 | 60,821 | (60,821) | - | - |
| **Fund balances carried forward** | 18 | **50,275** | **370,534** | **420,808** | **299,103** |

The Statement of Financial Activities includes all gains and losses in the year and therefore a statement of total recognised gains and losses has not been prepared.

All of the above amounts relate to continuing activities.

The notes on pages 31 - 43 form part of these financial statements.

# BALANCE SHEET AT 31 MARCH 2024

| | Notes | **2024** | 2023 |
|---|---|---|---|
| | | **£** | £ |
| **FIXED ASSETS** | | | |
| Tangible assets | 14 | **-** | **1,968** |
| **CURRENT ASSETS** | | | |
| Debtors | 15 | 22,141 | 15,705 |
| Cash at bank | | 599,339 | 519,397 |
| **Total current assets** | | **621,480** | **535,102** |
| **Liabilities** | | | |
| **Creditors: Amounts falling due within one year** | 16 | 185,988 | 107,967 |
| **NET CURRENT ASSETS** | | **435,493** | **427,135** |
| **Total assets less current liabilities** | | 435,493 | **429,103** |
| **Creditors: Amounts falling due after more than one year** | 17 | 14,684 | 130,000 |
| **NET ASSETS** | | **420,808** | **299,103** |
| **The funds of the Charity:** | | | |
| Unrestricted funds - Designated | 18 | 167,285 | 122,000 |
| Unrestricted funds - General | 18 | 203,248 | 126,828 |
| Restricted funds | 18 | 50,275 | 50,275 |
| **TOTAL FUNDS** | | **420,808** | **299,103** |

The company was entitled to exemption from audit under section 477 of the Companies Act 2006.

The members have not required the company to obtain an audit of its accounts for the year in question in accordance with section 476 of Companies Act 2006.

The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts.

The financial statements have been prepared in accordance with the provision applicable to entities subject to the small companies' regime.

The financial statements were approved by the Trustees and authorised for issue and signed on their behalf by:

Idriz Adedoja
Trustee-Treasurer

Date: 24th December 2024

The notes on pages 31 - 43 form an integral part of these accounts.

# NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2024

## 1. GENERAL INFORMATION

The Charity is a company limited by guarantee and has no share capital. In the event of the Charity being wound up, the liability in respect of the guarantee is limited to £10 per member of the Charity.
Its registered office is:

86-90 Paul Street
London
NC24 4NE

The significant accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied unless otherwise stated.

## 2. ACCOUNTING POLICIES

The principal accounting policies adopted are as follows:

### i) Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the United Kingdom and the Republic of Ireland (FRS 102) (Charities SORP FRS 102 second edition – effective January 2019) and the Charities Act 2011. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy or note.

The Polycystic Kidney Disease Charity meets the definition of a public entity under FRS102. Assets and liabilities are initially recorded at historical cost or transaction value unless otherwise stated in the relevant accounting policy.

### ii) Going Concern

The Trustees are of the view that the Charity holds sufficient funds to carry on for the next 12 to 18 months and that on this basis the assessment of the Trustees is that the Charity is a going concern.

### iii) Incoming Resources

All incoming resources are recognised once the Charity has entitlement to the resources, it is certain that the resources will be received, any performance conditions attached to the item(s) of income have been met or are fully within the control of the Charity and the monetary value of incoming resources can be measured reliably.

### iv) Investment Income

Investment income is accounted for in the period in which the Charity is entitled to receipt. Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the Charity; this is normally upon notification of the interest paid or payable by the Bank.

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2024

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### v) Resources Expended

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required, and the amount of the obligation can be measured reliably. All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category.

Governance costs principally comprise Trustees' meeting costs, accountancy costs, professional fees, and an allocation of staff time.

### vi) Grants

Provision is made for grants when the Trustees have made a binding commitment, and this has been communicated to the applicant.

### vii) Government grants

grants are accounted under the accruals model as permitted by FRS102. Grants relating to expenditure on tangible fixed assets are credited to the Statement of Financial Activities at the same rate as depreciation on the assets to which the grant relates. The deferred element of grants is included in creditors as deferred income.

### viii) Tangible fixed assets and depreciation

Depreciation is provided at rates calculated to write off the cost less the estimated residual value of each tangible fixed asset over its expected useful life.

### ix) Current asset investments

Current asset investments represent cash investments maturing within one year and are shown at carrying value.

### x) Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid after taking account of any trade discounts due.

### xi) Pensions

Employees of the Charity are entitled to join The Peoples Pension, a defined contribution pension scheme. The Charity contribution is restricted to the contributions disclosed in note 9. Pension costs are allocated to activities in proportion to the related staffing costs incurred. The defined contribution pension scheme is managed by The Peoples Pension Trustee. The Charity has no liability beyond making its contributions and paying across the deductions for the employee's contributions.

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2024

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### xii) Creditors and provisions

Creditors and provisions are recognised where the Charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

### xiii) Financial instruments

The Company only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

### xiv) Funds Structure

Funds are established to provide financial resources for aspects of the Charity's activities. Some funds were set up when the Charity received grants and donations that were made for specified purposes. Where conditions were made, the funds set up are restricted funds. The names of most of the funds convey the purposes for which they were established.

### xv) Fund Accounting

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the Charity and which have not been designated for other purposes.

Designated funds comprise unrestricted funds that have been set aside by the Trustees for particular purposes. The aim and use of each designated fund is set out in the notes to the financial statements.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the Charity for particular purposes. The costs of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements.

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2024

### 3. DONATIONS, GRANTS AND LEGACIES

| | **Restricted funds 2024 £** | **Unrestricted funds 2024 £** | **Total Funds 2024 £** | Total Funds 2023 £ |
|---|---|---|---|---|
| Donations and gifts | 949 | 367,941 | 368,890 | 270,828 |
| Trusts, foundations and grants | 50,986 | - | 50,986 | 75,995 |
| Gift Aid | - | 26,114 | 26,114 | 20,841 |
| **Total 2024** | **51,935** | **394,055** | **459,875** | **367,664** |
| **Total 2023** | **94,445** | **273,219** | **367,664** | |

### 4. INCOME FROM CHARITABLE ACTIVITIES

| | **Restricted funds 2024 £** | **Unrestricted funds 2024 £** | **Total Funds 2024 £** | Total Funds 2023 £ |
|---|---|---|---|---|
| Patient research | - | - | - | 8,735 |
| **Total 2024** | - | **-** | **-** | **8,735** |
| **Total 2023** | - | 8,735 | 8,735 | |

### 5. INCOME FROM OTHER TRADING ACTIVITIES

| | **Restricted funds 2024 £** | **Unrestricted funds 2024 £** | **Total Funds 2024 £** | Total Funds 2023 £ |
|---|---|---|---|---|
| Shop and other income | - | 5,559 | 5,559 | 7,361 |
| **Total 2024** | - | **5,559** | **5,559** | **7,361** |
| **Total 2023** | - | 7,361 | 7,361 | |

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2024

### 6. INVESTMENT INCOME

| | **Restricted funds 2024 £** | **Unrestricted funds 2024 £** | **Total Funds 2024 £** | Total Funds 2023 £ |
|---|---|---|---|---|
| Interest income | **-** | 2,265 | 2,265 | 2,460 |
| **Total 2024** | - | **2,265** | **2,265** | **2,460** |
| **Total 2023** | - | 2,460 | 2,460 | |

### 7. EXPENDITURE ON RAISING FUNDS

| | **Restricted funds 2024 £** | **Unrestricted funds 2024 £** | **Total Funds 2024 £** | Total Funds 2023 £ |
|---|---|---|---|---|
| Cost of fundraising | - | 78,446 | 78,446 | 84,320 |
| Cost of goods sold | - | 5,062 | 5,062 | 1,557 |
| **Total 2024** | **-** | **83,508** | **83,508** | **85,877** |
| **Total 2023** | - | 85,877 | 85,877 | |

# NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2024

## 8. ANALYSIS OF RESEARCH AND GRANTS

| | 2024<br>£ | 2023<br>£ |
|---|---:|---:|
| Bio Resource Bank | 10,000 | 10,000 |
| ADPKD Research | 20,000 | 3,355 |
| Kidney Research UK | - | 150,000 |
| Staff, subcontractor and other costs | 14,278 | 13,985 |
| Newcastle University | 14,684 | - |
| University of Edinburgh | 8,250 | - |
| **Total:** | **67,212** | **177,340** |

| | Grants to Institutions No. | Grants to Institutions No. |
|---|---:|---:|
| Bio Resource Bank | 1 | 1 |
| ADPKD Research | 2 | 3 |
| Kidney Research UK | - | 1 |
| Newcastle University | 1 | - |
| University of Edinburgh | 1 | |
| **Total:** | **5** | **5** |

Details of material grants are disclosed in the Trustees Report.

## 9. SUPPORT COSTS

| | 2024<br>£ | 2023<br>£ |
|---|---:|---:|
| Trustee meetings and governance | 410 | 417 |
| Accountancy and audit | 15,298 | 14,787 |
| Other professional fees | 3,362 | 2,653 |
| Staffing costs | 12,622 | 4,718 |
| **Total:** | **31,692** | **22,575** |

# NOTES TO THE FINANCIAL STATEMENTS
# FOR THE YEAR ENDED 31 MARCH 2024

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## 10. EMPLOYMENT COSTS

| | 2024<br>£ | 2023<br>£ |
|---|---|---|
| Wages and salaries | 141,612 | 135,579 |
| Social security costs | 8,859 | 8,614 |
| Defined contribution pension costs | 3,300 | 3,007 |
| **Total:** | **153,771** | **147,200** |

Employment costs are allocated to the activities to which they relate in the Statement of Financial Activities.

As at 31 March 2024 a balance of £Nil overpaid pension contributions were owed to the Charity (2023: £29).

The average number of staff employed by the Charity during the year was 6, with a full time equivalent of 4 (2023: 4).

No employee received total benefits exceeding £60,000.

Key management personnel of the Charity comprises the Trustees and the Chief Executive Officer, the Support Services Manager, the Fundraising Manager and the Community Engagement Manager. Key management personnel received total remuneration of £144,912 (2023: £136,786).

## 11. NET INCOME/(EXPENDITURE) FOR THE YEAR

| **This is stated after charging:** | 2024<br>£ | 2023<br>£ |
|---|---|---|
| Independent Examiners Remuneration | - | - |
| Depreciation | 1,968 | 5,904 |
| **Total:** | **1,968** | **5,904** |

## 12. TRUSTEE REMUNERATION & EXPENSES

The Trustees were not remunerated by the Charity for their services during the year. Total expenses reimbursed during the year totalled £89 (2023: £Nil), payable to 1 Trustee.

## NOTES TO THE FINANCIAL STATEMENTS
## FOR THE YEAR ENDED 31 MARCH 2024

### 13. TAXATION

The Charity is exempt from tax on income and gains falling within section 505 of the Taxes Act 1988 or s256 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects. No tax charges have arisen in the Charity.

### 14. ANALYSIS OF MOVEMENT OF FIXED ASSETS

| | 2024<br>£<br>Office equipment |
|---|---|
| **Cost** | |
| At 1 April 2023 | 29,209 |
| Additions | - |
| Disposals | - |
| **At 31 March 2024** | **29,209** |
| **Accumulated depreciation** | |
| At 1 April 2023 | 27,241 |
| Charge for the year | 1,968 |
| Disposals | - |
| **At 31 March 2024** | **29,209** |
| **Net Book Value** | |
| At 1 April 2023 | 1,968 |
| **At 31 March 2024** | **-** |

### 15. DEBTORS

| | 2024<br>£ | 2023<br>£ |
|---|---|---|
| Prepayments | 21,087 | 15,271 |
| Accrued income | - | - |
| Other debtors | 1,055 | 434 |
| **Total debtors** | **22,142** | **15,705** |

## NOTES TO THE FINANCIAL STATEMENTS
## FOR THE YEAR ENDED 31 MARCH 2024

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### 16. LIABILITIES: AMOUNTS FALLING DUE WITHIN ONE YEAR

| | 2024<br>£ | 2023<br>£ |
|---|---:|---:|
| Trade creditors | 14,781 | 8,354 |
| Accruals and deferred income | 18,626 | 4,325 |
| Other creditors | 555 | 20,328 |
| Grant commitments (Note 20) | 152,026 | 74,960 |
| **Total current liabilities** | **185,988** | **107,967** |

### 17. LIABILITIES: AMOUNTS FALLING DUE AFTER MORE THAN ONE YEAR

| | 2024<br>£ | 2023<br>£ |
|---|---:|---:|
| Grant commitments within five years (Note 20) | **14,684** | **130,000** |

## NOTES TO THE FINANCIAL STATEMENTS
## FOR THE YEAR ENDED 31 MARCH 2024

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### 18. FUNDS AND RESERVES – CURRENT YEAR

| **Unrestricted Funds** | **Total funds at 01/04/23** | **Income** | **Expenditure** | **Transfer** | **Total funds at 31/03/24** |
|---|---|---|---|---|---|
| Research | - | - | - | 90,000 | 90,000 |
| National Lottery – Matched Funding | 122,000 | - | - | (44,715) | 77,285 |
| General fund | 126,828 | 401,880 | (219,353) | (106,106) | 203,249 |
| **Total funds** | **248,828** | **401,880** | **(219,353)** | **(60,821)** | **370,534** |

National Lottery – Matched Funding – Designated to fund a programme of support services for people affected by polycystic kidney disease

General fund – the free reserves, after allowing all other designated funds

| **Restricted Funds** | **Total funds at 01/04/23** | **Income** | **Expenditure** | **Transfer** | **Total funds at 31/03/24** |
|---|---|---|---|---|---|
| ARPKD Research | - | - | - | - | - |
| Research | 50,275 | 300 | (300) | - | 50,275 |
| National Lottery - PPP | - | 49,986 | (110,771) | 60,785 | - |
| Trusts and Foundations | - | 1,000 | (1,000) | - | - |
| Ciliaren | - | 649 | (649) | - | - |
| PPIE | - | - | (36) | 36 | - |
| **Total funds** | **50,275** | **51,935** | **(112,756)** | **60,821** | **50,275** |

Research – Research related to PKD.

ADPKD Research – Research related solely to ADPKD.

ARPKD Research – Research related solely to ARPKD.

European PKD conference – Income received to fund the European PKD conference.

National Lottery, PPP – To fund a programme of face to face, online and telephone support for patients and families who are dealing with the traumatic and often devastating effects of PKD.

National Lottery, Nurse Co-ordinator – Income received to fund Nurse co-ordination.

PKDC/KRUK Research – to fund PKD research projects jointly with Kidney Research UK.

Transfers represent research grants that have firstly been expended against the appropriate restricted fund that is for specific types of research and once that restricted fund is fully utilised any balance is transferred to unrestricted funds.

## NOTES TO THE FINANCIAL STATEMENTS
## FOR THE YEAR ENDED 31 MARCH 2024

### 18. FUNDS AND RESERVES – PRIOR YEAR

| **Unrestricted Funds** | **Total funds at 01/04/22** | **Income** | **Expenditure** | **Transfer** | **Total funds at 31/03/23** |
|---|---|---|---|---|---|
| Research | - | - | - | - | - |
| National Lottery – Matched Funding | 76,985 | - | - | 45,015 | 122,000 |
| General fund | 148,807 | 291,775 | (168,981) | (144,773) | 126,828 |
| **Total funds** | **225,792** | **291,775** | **(168,981)** | **(99,758)** | **248,828** |

| | **Total funds at 01/04/22** | **Income** | **Expenditure** | **Transfer** | **Total funds at 31/03/23** |
|---|---|---|---|---|---|
| **Restricted Funds** | | | | | |
| ARPKD Research | 3,350 | - | (3,355) | 5 | - |
| Research | - | 10,450 | - | 39,825 | 50,275 |
| European PKD Conference | - | - | - | - | - |
| National Lottery - PPP | 14,368 | 83,995 | (186,293) | 87,930 | - |
| National Lottery – Nurse Co-ordinator | 28,002 | - | - | (28,002) | - |
| PKDC/KRUK Research | 150,000 | - | (150,000) | - | - |
| **Total funds** | **195,720** | **94,445** | **(339,648)** | **99,758** | **50,275** |

## NOTES TO THE FINANCIAL STATEMENTS
## FOR THE YEAR ENDED 31 MARCH 2024

### 19. ANALYSIS OF NET ASSETS BETWEEN FUNDS – CURRENT YEAR

| | **Unrestricted funds 2024 £** | **Restricted funds 2024 £** | **Total funds 2024** |
|---|---|---|---|
| Tangible fixed assets | - | - | - |
| Current assets | 389,159 | 232,322 | 621,481 |
| Creditors due within one year | (18,626) | (167,362) | (185,988) |
| Creditors due in more than one year | - | (14,684) | (14,684) |
| **Total:** | **370,533** | **50,275** | **420,808** |

### ANALYSIS OF NET ASSETS BETWEEN FUNDS – PRIOR YEAR

| | **Unrestricted funds 2023 £** | **Restricted funds 2023 £** | **Total funds 2023** |
|---|---|---|---|
| Tangible fixed assets | 1,968 | - | 1,968 |
| Current assets | 251,185 | 283,917 | 535,102 |
| Creditors due within one year | (4,325) | (103,642) | (107,967) |
| Creditors due in more than one year | - | (130,000) | (130,000) |
| **Total:** | **248,828** | **50,275** | **299,103** |

### 20. GRANT COMMITMENTS

| | **£** |
|---|---|
| Balance at 1 April 2023 | 204,960 |
| New commitments | 52,913 |
| Cancelled commitments | - |
| Commitments paid | (91,184) |
| Balance at 31 March 2024 | **166,710** |

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2024

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### 21. RELATED PARTY TRANSACTIONS

| | 2024 | 2023 | |
|---|---|---|---|
| Donations Received from Trustees | 624 | 1,825 | 1 Trustees (2023: 3) made donations during the year |
| Grants to related parties | - | - | |

The Charity established a casual worker contract with the daughter-in-law of a Trustee. The Trustee was not involved in the decision to appoint. The details are as follows:

**Employment Related Parties**

| Trustee | Employee | 2024 | 2023 |
|---|---|---|---|
| Alan Greenberg | Louise Greenberg | - | 1,800 |