



# THE POLYCYSTIC KIDNEY DISEASE CHARITY

Report of the Board of Trustees and Accounts – 1 April 2022 to 31 March 2023



## ANNUAL REPORT AND ACCOUNTS 2022-2023

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## REFERENCE AND ADMINISTRATIVE INFORMATION

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[pkdcharity.org.uk](http://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

Number SC047730

A company limited by guarantee

Registered company in England and Wales

Number 9486245

### Directors\* and Trustees who served during the year and to the date of this report

Mr Alan Greenberg (Chair)

Mr Jordan Adams (resigned Apr 2023)

Mr Idriz Adedoja (Treasurer, appointed Jul 2022)

Mr Raj Johal

Ms Rebecca Murphy-Peers

Mr Jon Rees

Mrs Karen Stapleton

Mr Adrian Tinsley

Mr Nicholas Tracey

Professor Patricia Wilson

### 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

### Patrons

Professor Albert Ong

Dr Anand Saggar

Dr Richard Sandford

Professor Patricia Wilson

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West Malling

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#### Accountants

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Station Road

Cambridge, CB1 2LA

#### Independent accounts examiner

Charles Pickin

Fellow of Institute of Chartered Accountants in  
England and Wales

Harrison Jasper Ltd

Florence Lane, Groombridge, TN3 9SH

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

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## **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 2023. 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**

2022-2023 saw an initial return to normal working following COVID with the reintroduction of face-to-face events and we were pleased to experience an increase in our income to help us deliver our ambitious programmes to help benefit those suffering from PKD.

The year was heavily shaped by our drive to deliver the 1<sup>st</sup> year of our new 3-year strategic plan and I am really pleased to say that we delivered significant parts of this well ahead of schedule including the launch of the PKD App, significant advancement of our drive to increase research and the development of exercises for PKD integrated into the Kidney Beam app.

Following our successful partnership with Kidney Research UK we have built on this further with an exciting development of a PKD Research Consortium where we are striving to combine the UK's research into PKD to help accelerate translational PKD research in the UK with therapeutic potential to impact the lives of patients.

Over the next few pages, you can read more about the Charity's activities during 2022-23. 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: 22 December 2023

## 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).

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.



*Image: 1 – Katie wanted the public to see how big polycystic kidneys can grow*

#### 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: 2 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, we focus on funding small research projects up to £15,000 each and contributing towards PhD studentships (future capacity building). To date, since 2008, we have awarded over £650,000 to research.

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.

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## **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, 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 2022-23

2022-23 was the first 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 2022-23, we aimed to:

1. Evolve our research partnership with Kidney Research UK.
2. Develop and launch a PKD information app, co-produced with our community.
3. Participate in the development of PKD-specific exercise modules within the Kidney Beam app.
4. Grow and develop local PKD Groups and recruit more volunteers to help organise their activities.
5. Focus our fundraising strategy on community fundraising in conjunction with our Groups.

### Research activities during 2022-23

#### 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.

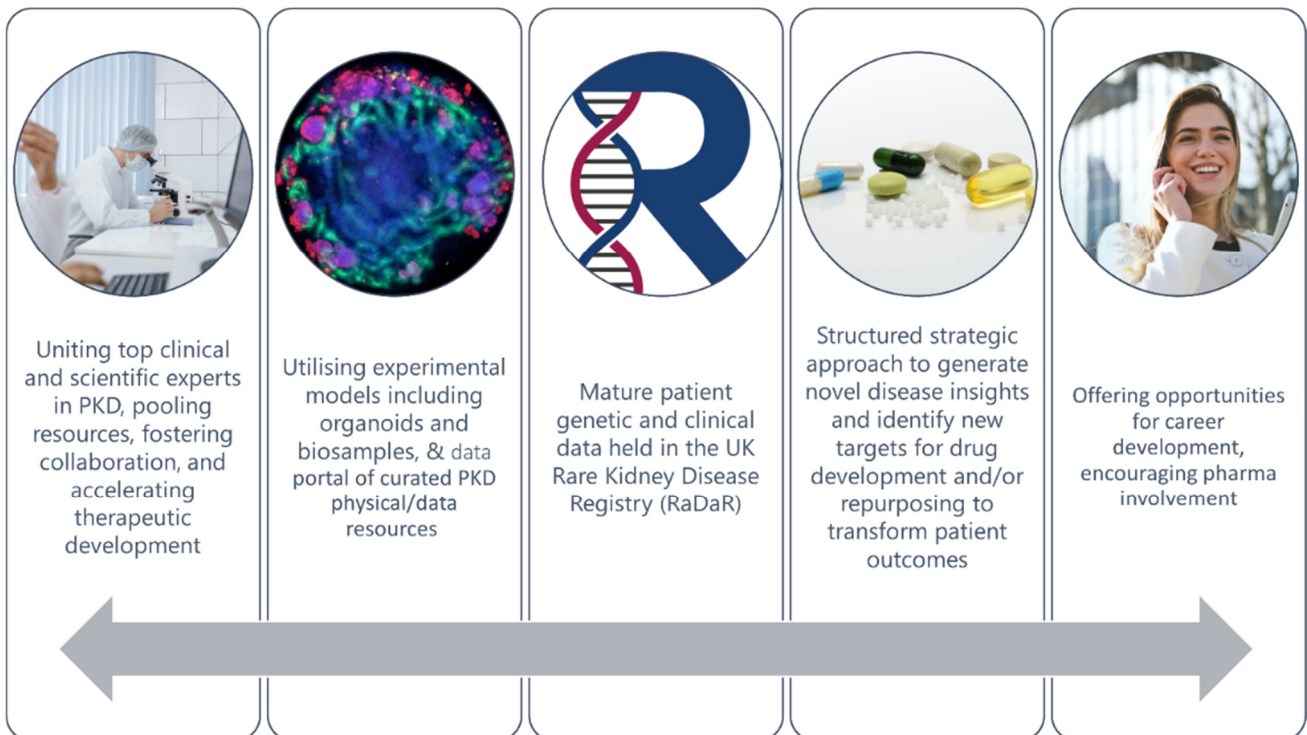


Image: 3 – Collaboration for improved patient outcomes in the PKD Research Consortium



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The consortium will be a robust collaborative platform bringing together experimental models, including organoids and biosamples, 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. See Image 3.

## Research grants

The PKD Charity trustees approved:

- £10,000 continuation funding to support the PKD BioResource Bank
- £150,000 of grant funding towards three research projects:
  - Professor Albert Ong from The University of Sheffield and his team are working to better understand PKD cysts, with the aim of developing ways to stop them forming. [Click to read more.](#)
  - Professor Colin A Johnson at the University of Leeds and his team are looking for novel treatments for ADPKD. They have identified two existing drugs that could be repurposed to treat ADPKD. [Click to read more.](#)
  - Dr Joe Cockburn of Leeds University is undertaking a PhD into the genetics of ARPKD - the rare form of PKD - which could lead to the development of new treatments for ARPKD and inform parents and would-be parents about the clinical course of the disease. [Click to read more.](#)

## 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 430 samples were provided for use in 19 PKD-related projects
- Over 520 new donated samples were added to the BioResource Bank

## Failure of two major ADPKD clinical trials

During the year, we were disappointed to learn that two pharmaceutical-sponsored clinical trials of drugs for ADPKD were stopped.

## ADPKD research priorities

The research priorities were highlighted in several grant applications to external funders, including the National Institute for Health and Care Research (NIHR).

## Patient involvement

We were asked to support research projects and invite our community to provide feedback on grant applications.

## Other research activities

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

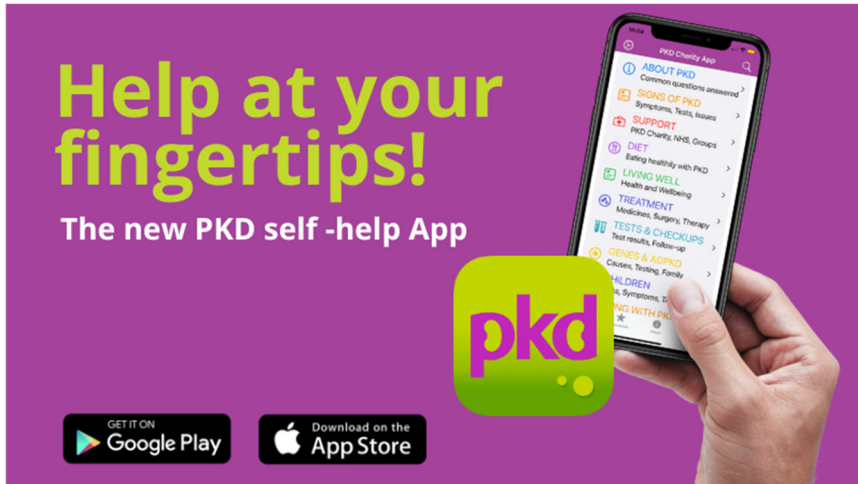
- The ADPKD Clinical Study Group (CSG) - brings together doctors, nurses, surgeons and other healthcare professionals plus patient representatives to generate a portfolio of clinical studies into ADPKD. The chief executive is deputy chair and helped organise meetings.
- The ARPKD Rare Disease Study Group, 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 & Drug 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 (eg clinical practice guidelines) and generate new knowledge (eg by conducting research studies).

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

During 2022-23, we continued to support our community through remote service delivery and publishing frequently updated health and COVID-19 information. We used our online channels and platforms such as Zoom, Teams, Facebook and other social media, and were also able to return to in-person events. We also launched the first-ever PKD App.

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## PKD App



In November 2022, we launched the PKD App, after a tender process. The developer, Expert Self Care Ltd, was established by a GP with extensive experience of developing similar healthcare apps with charities and the NHS. In addition to the technical development, they provided editorial assistance and will assist with promotion to their NHS contacts.

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 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](#)

The app will help us deliver our information to an under-represented group in our community – the newly diagnosed and those at early stages of PKD. Historically we have had challenges reaching and supporting these patients due to:

1. Lack of awareness of PKD and the PKD Charity in GP surgeries – these patients tend to be seen by a GP first and a surgery may only have 1 or 2 PKD patients.
2. General lack of awareness about PKD and the PKD Charity in hospitals – these patients often get diagnosed incidentally (eg during an ultrasound for another issue) and then referred to their GP for follow-up.
3. Hospital doctors/nurses don't refer patients to the PKD Charity. Hospital leaflets/posters are inefficient – high cost of production/distribution to 300 hospitals with renal units, they are often not visible or displayed in out-patient clinics, not at hand when needed and many clinics have removed non-NHS Trust information).

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In our app focus groups, patients and carers commented:

- People looking for information at diagnosis ‘go down rabbit holes’ and find it hard to answer their questions when looking for credible information on PKD.
- People often get confused by conflicting information online and ‘scary images’.
- People are exposed to other people’s comments on PKD or have seen the impact on older family members which can cause anxiety.
- Reading others experiences online can be frightening, as you may not be at that stage in the PKD journey.

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

At 31 March 2023:

- ✓ More than 500 downloads
- ✓ Total page views of more than 10,000

*“I have had a look at the app & it looks great!! I love the way it's easily accessible & can allow the user to use delve into the sections that they want to further.”*

*“I'm sure this will be a great success & look forward to be able tell others I know about this app as PKD is one disease that many people do not know much about at all (even those who have family members/friends that have it!)”*

*“We found the App easy to navigate and up to date with all the information on PKD. The key advantage I found was it accessible on my phone and helpful to explain to my family, as it also allowed them to read it for themselves.”*

### **PKD Exercise App – in collaboration with ‘Kidney Beam’**

A collaborative opportunity arose to work with an established webservice called ‘Kidney Beam’ to develop a set of exercise classes for PKD patients. Kidney Beam is a web app (accessed via a portal), set up by UK kidney doctors and physiotherapists who developed and published a range of exercises specifically for people with kidney disease. PKD patients have special needs owing to extended abdomens and pain, plus they need to be careful about not causing a kidney cyst to rupture during exercise but there were no modules designed for their needs.

Exercise routines for PKD were created with patient involvement and modules were filmed for final testing in December 2022. The classes were launched Spring 2023. We expect to receive a report from Kidney Beam end 2023 with the outcomes of the exercises on PKD patients (as part of a research project).

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## Online support group meetups

During the year, we held 31 online support group calls either via Zoom or in-person. Our location-based groups are in London, Bedfordshire, Norfolk, NE England and Wales. The online groups are open to anyone in the UK and either focus on a health topic or just bring people together to chat and share experiences.

*“It was so valuable to hear other people's experiences and meet other fellow PKD/PLD sufferers. The group were so amazingly strong, open and honest and the hosts were amazing at holding the space and full of compassion. It almost felt like a relief to share my experience with people who totally understood and appreciated your anxieties and concerns.”*

*“As a PKD patient now on the national transplant list, it's so important having access to these services and support groups, particularly as this disease doesn't show externally, so people think there is nothing wrong with you. The Low Clearance support group allows me to listen to other people who are in the same position as me; making me feel like I'm not alone. This then goes towards helping me manage my mental health, self-esteem and confidence.”*

Attendance varies from about 20 for the London group to 7-8 for the other groups.



Image: 4 - Some of the London regulars arriving for the support group

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## 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 180 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.

*"I'm glad I reached out for support as it's definitely helping me. It makes all the difference being able to speak with someone who understand PKD."*

We use our CRM case management module to record all phone/online support requests. This enabled us to follow up on cases that needed extra support after the initial outreach.

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

We held an **ADPKD Information & Support Day** in Sheffield, the **first time in-person** since February 2020, pre-COVID. We offered masks and had sanitisers available, and informed everyone that they came at their own risk.



Image: 5 – Speakers at Sheffield Info & Support Day

The venue had a 100-person capacity and was fully booked. We added live streaming for an online audience as a trial. Along with presentations by leading experts in ADPKD, the event included an informal Q&A, giving the in-house and online audiences the opportunity to fully interact with the panel.

Despite extensive promotion, the online audience was smaller than hoped (33) and there were some technical

not feasible and too costly for future events.

difficulties (despite using a professional company). We decided that live streaming was

*"Just wanted to say a huge thank you to you and your team for today. You are such warm friendly people and fellow PKD patients which I honestly did not realise. I will access your website much more now as a result of today."*

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*“The most helpful was learning about blood pressure, but I found the whole event informative, and professionally done, even down to the disabled parking you arranged for me.”*

## **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 November 2022, we organised an in-person event for parents and children in collaboration with Birmingham Children’s Hospital (BCH) who kindly allowed us to use their new Rare Disease Centre exclusively on a Saturday. It was also the 10<sup>th</sup> anniversary of our first ARPKD event at BCH.



In the morning, four doctors gave talks to the parents, and in the afternoon a clinical psychologist ran a workshop. We also invited an ARPKD scientist to talk about current research.



The children were cared for in a dedicated area by nursery nurses and DBS-checked volunteers and entertained by a magician and a petting zoo. A psychotherapist ran a workshop for the children showing them techniques to help with their anxiety.  
(Permission given by all parents to use photos)

### **Online events**

During the year, we held 6 online topic-focused events with Q&A, attended by 300 in total:

- Living Well – how to care for our emotional wellbeing
- Tolvaptan
- Exercise – staying fit and healthy
- Pregnancy and Family Planning
- Polycystic Liver Disease
- Nephrectomy (removal of one or more PKD kidneys)

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*"I submitted 2 questions. The doctor's sensible approach and knowledge made this a very informative session."*

*"I am constantly asked by friends and relatives why they don't take the PKD kidneys out when I am suffering in some way from them and I haven't really had the answer just assumed it too expensive or risky to do, so it's good to have some facts from the experts."*

We also held 3 events jointly with the National Kidney Federation. We alternated the hosting which enabled us to reach more people and optimise our limited personnel resources.

- Benefits for kidney patients
- Cost of Living
- Renal Pharmacy

Talks from the online information events were recorded and are available on our website and [YouTube](#) channel. Each topic video is also included on an appropriate page on our website to enrich written content.

During the year, we also shared information about events organised by other charities on topics such as COVID-19 and benefits.

**We are very grateful to the UK healthcare professionals for volunteering their time on weekend evenings and Saturdays to present to and answer questions from our community.**

### **Living Well with PKD Workshops**

With the assistance of a Clinical Kidney Psychologist and Psychotherapist, we delivered 13 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 4.8/5.

*"These workshops are so useful, I'd never considered joining one until recently but so glad I did and hope to attend more in the future, really helps to improve my own mindset around having PKD."*

### **Facebook groups**

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. As in the previous FY, we noticed that many people were experiencing delays in seeing specialists. However, we also noticed a growth in posts on PKD genetics, reflecting the increasing number of patients are now getting genomic testing.



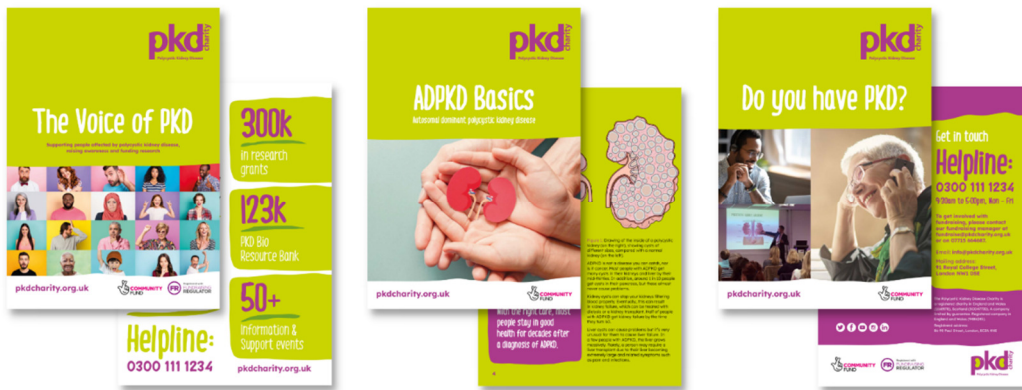
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## Health information for patients and families



During the year we continued to update and draft new information. 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, eg 'ADPKD Basics'.



Feedback on 'ADPKD Basics' factsheet: *"I thought it was a clear, brilliantly worded piece. It was really easy to understand without being patronising. I wish we had been given this when my husband was first diagnosed rather than the hospital leaflet!"*

However, as in previous years, we struggled with the availability of healthcare professionals to review drafts owing to the pressures on NHS staff.

We regularly updated the COVID-19 information in line with Government and other health guidance.

### ADPKD 'Tweeterial'

The chief executive was invited by an international academic group to write a series of posts about ADPKD from the patients' perspective. [Link to the tweetorial on X \(formerly Twitter\).](#)

## PKD awareness/advocacy activities

### Support Services campaign

We designed and implemented a digital campaign to promote Support Services which centred around the thoughts, fears, and feelings of isolation typically experienced by many affected by PKD. The campaign strapline aimed to remind the community that whether they required information, practical advice or just someone to talk to, we're here to help:

**'YOU'RE NOT ALONE  
YOU'VE GOT US'**

A suite of graphics was created which linked to the Support section of our website. Links were measured to assess performance. The post with the highest reach and engagement was 'No one understands'.



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## Awareness

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 a regular e-news to over 4,000 individuals to keep the community informed. The e-news list grew by 25% over the previous year. Emails achieved high unique opens, with several over 50%, demonstrating good engagement.



After a 2-year pause due to COVID-19, the **British Transplant Games** made a welcome return in July 2022 in Leeds. The eagerly anticipated event saw hundreds of people competing in a variety of sports at venues across the city over 4 excitement-filled days.

This was a welcome opportunity for the team to meet members of the PKD community in person, and to cheer them on as they competed in the Games.



PKD Awareness Week Month was held in September 2022 and attracted wide interest online. We led with the story of Katie Banks (left), mum of two children, who bravely shared her experience of living with one of the more distressing symptoms of the disease, the 'PKD Belly'.

One Facebook post featuring her photo and story achieved a record-breaking organic reach of 89,520, 16% engagement and 600+ comments, not only the highest for the year but all time. It resonated with the PKD community UK-wide and internationally, with hundreds thanking Katie and the Charity for addressing the widespread emotional anguish caused by living with grossly enlarged cystic kidneys.

World Kidney Day (WKD) 2023 was celebrated digitally and at an in-person event in March, in collaboration with the Kidney Charities Together group.



We promoted and aligned our activity with other Awareness days/weeks, including Rare Disease Day in February 2023.

### 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** held in-person in June 2022 for the first time since 2019, the **European Renal Association** congress and the **British Association of Paediatric Nephrologists/Paediatric Nephrology Nurses Group** Conference.

During the year, the leads of three renal genomics projects invited the Charity to participate in their work to embed genomics and genetic testing into the kidney care pathway. The work was ongoing at 31 March 2023.

Additionally, the Charity participated in a UK-wide review of renal services during COVID-19 and joined a new Kidney Policy Forum, convened by Kidney Research UK.

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 KCT met regularly to agree unified communications around COVID-19 and plan World Kidney Day activities.

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 member of **Befriending Networks**, the UK's leading resource on befriending whose accreditation was obtained during 2015.

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](http://www.pkdinternational.org)

Polycystic Kidney Disease Charity  
Annual Report and Financial Statement for the year ended 31 March 2023

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 85 (2022: 60) active loyal volunteers and we hugely appreciate the time and commitment they willingly give. They helped us during the year with reviewing health information, moderating our Facebook groups, hosting online 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 2022-23. They walked miles, ran marathons, organised garden parties and plant sales, skydived, hula hooped, shaved their heads, fundraised at school, work and at home to raise funds to ensure that PKD Charity can continue to support people affected by PKD and fund life-changing research. Below are a few stories.

Ed set himself the challenge to complete 500,000 steps in the month of September as part of Walk for PKD. He did it!

*"I was 50 earlier this year & so 500,000 steps seemed an apt challenge, it equates to around 8 miles a day of walking. I hope this charity event & others throughout the year taken on by hundreds of sufferers, donors & supporters helps to raise both awareness & funds to combat PKD."*

Morgan and her friends took part in Walk for PKD in 2022.

*"The PKD Charity is very close to myself and my family's hearts. My Mum has PKD and has suffered many years with the different side effects. Many people don't know about PKD and the seriousness that it has on the effected people's lives."*





Sam and her friends, Sujata and Tony shaved their heads.

*"I have suffered from Polycystic Kidney Disease for most of my life. When my father succumbed to this awful illness, there were no chances of a transplant, dialysis, and certainly no medicinal treatments. The wonderful PKD Charity is trying to change this situation, funding research and providing support networks and initiatives so that sufferers can hope for a better future. To raise funds for this wonderful charity, two close friends, Sujata and Tony, and I shaved our heads (and beard in Tony's case!)."*

### **Grant fundraising**



The National Lottery Community Fund awarded year 4 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).

### **2023-24 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 2023-24, we will:

- 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.

## 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 continue to review the risks caused by COVID-19, with a view to mitigating these risks. 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.



Polycystic Kidney Disease Charity  
Annual Report and Financial Statement for the year ended 31 March 2023

## **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 2023, the charity's income was **£386,220** (2022: £348,243).

Expenditure on raising funds as a percentage of total incoming resources was 22% (2022: 19%). Research expenditure was **£177,340** (2022: £90,626). The Charity's expenditure on charitable activities across Patient support, Awareness and Education was **£222,839** (2022: £136,893), which included information days, telephone support, online/chat support and expenditure on the peer support service.

In total, the Charity expended **£508,629** (2022: £324,193), resulting outgoing resources for the year of **£122,410** (2022: incoming resources of £24,050). Total fund balances at the year-end were **£299,102** (2022: £421,512) 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**

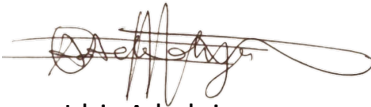
The Charity maintains a Reserves Policy to hold reserves equivalent to a minimum 3 months' ongoing expenditure, after covering current liabilities. As at the year end, the Charity had undesignated free reserves of £124,860 (2022: £140,935), equivalent to 3 months' total expenditure (2022: 5 months). 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.

Polycystic Kidney Disease Charity  
Annual Report and Financial Statement for the year ended 31 March 2023

### **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 continue to review succession plans and to survey the satisfaction of its beneficiaries and supporters, with a view to mitigating these risks. The trustees regularly review the Charity's risk management policies, which include data protection and safeguarding. 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.

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



Idriz Adedoja  
Trustee-Treasurer

Date: 22 December 2023

Polycystic Kidney Disease Charity  
Annual Report and Financial Statement for the year ended 31 March 2023

## ***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 2023, which are set out on pages 23-38.

#### **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: 22 December 2023

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: 49-51 East Road, London, N1 6AH

Polycystic Kidney Disease Charity  
Annual Report and Financial Statement for the year ended 31 March 2023

## STATEMENT OF FINANCIAL ACTIVITIES - 1 APRIL 2021 TO 31 MARCH 2023

### (INCORPORATING INCOME AND EXPENDITURE ACCOUNT)

### FOR THE YEAR ENDED 31 MARCH 2023

	Notes	Restricted Funds 2023 £	Unrestricted Funds 2023 £	Total 2023 £	Total 2022 £
<b>Income from:</b>					
Donations grants and legacies	3	94,445	273,219	367,664	339,288
Charitable activities	4	-	8,735	8,735	-
Other trading activities	5	-	7,361	7,361	7,081
Investment income	6	-	2,460	2,460	1,874
<b>Total income</b>		<b>94,445</b>	<b>291,775</b>	<b>386,220</b>	<b>348,243</b>
<b>Expenditure on:</b>					
Cost of fundraising	7	-	84,320	84,320	67,075
Non-charitable trading activities	7	-	1,557	1,557	2,598
<b>Total</b>		<b>-</b>	<b>85,877</b>	<b>85,877</b>	<b>69,673</b>
Research and grants	8	153,355	23,985	177,340	90,626
Awareness and education		-	36,544	36,544	51,964
Patient support		180,389	-	180,389	79,025
Depreciation	14	5,904	-	5,904	5,904
<b>Total</b>		<b>339,648</b>	<b>60,529</b>	<b>400,177</b>	<b>227,519</b>
<b>Other expenditure</b>					
Support costs	9	-	22,575	22,575	27,001
<b>Total expenditure</b>		<b>339,648</b>	<b>168,981</b>	<b>508,629</b>	<b>324,193</b>
<b>Net income / (expenditure) for the year</b>		<b>(245,203)</b>	<b>122,794</b>	<b>(122,409)</b>	<b>24,050</b>
Fund balances brought forward at 1 April	18	195,720	225,792	421,512	397,462
Net incoming resources for the year	18	(245,203)	122,794	(122,409)	24,050
Transfers between funds	18	99,758	(99,758)	-	-
<b>Fund balances carried forward</b>	18	<b>50,275</b>	<b>248,828</b>	<b>299,103</b>	<b>421,512</b>

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.

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: 49-51 East Road, London, N1 6AH

## BALANCE SHEET AT 31 MARCH 2023

		<b>2023</b>	2022
	<b>Notes</b>	<b>£</b>	<b>£</b>
<b>FIXED ASSETS</b>			
Tangible assets	14	<b>1,968</b>	<b>7,872</b>
<b>CURRENT ASSETS</b>			
Debtors	15	15,705	7,783
Cash at bank		519,397	535,666
<b>Total current assets</b>		<b>535,102</b>	<b>543,449</b>
<b>Liabilities</b>			
<b>Creditors: Amounts falling due within one year</b>	16	107,967	84,809
<b>NET CURRENT ASSETS</b>		<b>427,135</b>	<b>458,640</b>
<b>Total assets less current liabilities</b>		<b>429,103</b>	<b>466,512</b>
<b>Creditors: Amounts falling due after more than one year</b>	17	130,000	45,000
<b>NET ASSETS</b>		<b>299,103</b>	<b>421,512</b>
<b>The funds of the Charity:</b>			
Unrestricted funds - Designated	18	122,000	76,985
Unrestricted funds - General	18	126,828	148,807
Restricted funds	18	50,275	195,720
<b>TOTAL FUNDS</b>		<b>299,103</b>	<b>421,512</b>

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

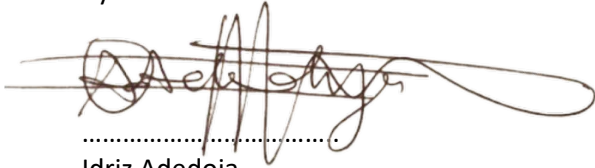
The members have not required the company to obtain an audit of its accounts for the year in question in accordance with section 476 of Companies Act 2006.

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.

Polycystic Kidney Disease Charity  
Annual Report and Financial Statement for the year ended 31 March 2023

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

A handwritten signature in brown ink, appearing to read 'Idriz Adedoja', is written over a horizontal dotted line. The signature is stylized and extends to the right.

Idriz Adedoja  
Trustee-Treasurer

Date: 22 December 2023

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

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2023

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### 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:

49-51 East Road  
London  
N1 6AH

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 2023

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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 2023

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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 2023

#### 3. DONATIONS, GRANTS AND LEGACIES

	Restricted funds 2023 £	Unrestricted funds 2023 £	Total Funds 2023 £	Total Funds 2022 £
Donations and gifts	18,450	252,378	270,828	262,085
Trusts, foundations and grants	75,995	-	75,995	53,125
Gift Aid	-	20,841	20,841	24,078
<b>Total 2023</b>	<b>94,445</b>	<b>273,219</b>	<b>367,664</b>	<b>339,288</b>
<b>Total 2022</b>	<b>53,425</b>	<b>285,863</b>	<b>339,288</b>	

No government grants were received during the year (2022: £Nil).

#### 4. INCOME FROM CHARITABLE ACTIVITIES

	Restricted funds 2023 £	Unrestricted funds 2023 £	Total Funds 2023 £	Total Funds 2022 £
Patient research	-	8,735	8,735	-
<b>Total 2023</b>	<b>-</b>	<b>8,735</b>	<b>8,735</b>	<b>-</b>
<b>Total 2022</b>	<b>-</b>	<b>-</b>	<b>-</b>	

#### 5. INCOME FROM OTHER TRADING ACTIVITIES

	Restricted funds 2023 £	Unrestricted funds 2023 £	Total Funds 2023 £	Total Funds 2022 £
Shop and other income	-	7,361	7,361	7,081
<b>Total 2023</b>	<b>-</b>	<b>7,361</b>	<b>7,361</b>	<b>7,081</b>
<b>Total 2022</b>	<b>-</b>	<b>7,081</b>	<b>7,081</b>	

Polycystic Kidney Disease Charity  
Annual Report and Financial Statement for the year ended 31 March 2023

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2023

### 6. INVESTMENT INCOME

	Restricted funds 2023 £	Unrestricted funds 2023 £	Total Funds 2023 £	Total Funds 2022 £
Interest income	-	2,460	2,460	1,874
<b>Total 2023</b>	<b>-</b>	<b>2,460</b>	<b>2,460</b>	<b>1,874</b>
<b>Total 2022</b>	<b>-</b>	<b>1,874</b>	<b>1,874</b>	

### 7. EXPENDITURE ON RAISING FUNDS

	Restricted funds 2023 £	Unrestricted funds 2023 £	Total Funds 2023 £	Total Funds 2022 £
Cost of fundraising	-	84,320	84,320	67,075
Cost of goods sold	-	1,557	1,557	2,598
<b>Total 2022</b>	<b>-</b>	<b>85,877</b>	<b>85,877</b>	<b>69,673</b>
<b>Total 2021</b>	<b>-</b>	<b>69,673</b>	<b>69,673</b>	

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## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2023

### 8. ANALYSIS OF RESEARCH AND GRANTS

	2023 £	2022 £
Bio Resource Bank	10,000	-
ADPKD Research	3,355	54,750
Kidney Research UK	150,000	5,000
UCL Great Ormond Street Institute of Child Health	-	14,960
Staff, subcontractor and other costs	13,985	15,916
<b>Total:</b>	<b>177,340</b>	<b>90,626</b>

	Grants to Institutions No.	Grants to Individuals No.
Bio Resource Bank	1	-
ADPKD Research	3	2
Kidney Research UK	1	1
UCL Great Ormond Street Institute of Child Health	-	1
<b>Total:</b>	<b>5</b>	<b>4</b>

Details of material grants are disclosed in the Trustees Report.

### 9. SUPPORT COSTS

	2023 £	2022 £
Trustee meetings and governance	417	1,008
Accountancy and audit	14,787	13,917
Other professional fees	2,653	5,497
Staffing costs	4,718	6,579
<b>Total:</b>	<b>22,575</b>	<b>27,001</b>

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## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2023

### 10. EMPLOYMENT COSTS

	2023	2022
	£	£
Wages and salaries	135,579	119,739
Social security costs	8,614	10,943
Defined contribution pension costs	3,007	2,986
<b>Total:</b>	<b>147,200</b>	<b>133,668</b>

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

As at 31 March 2023 a balance of £29 overpaid pension contributions was owed to the Charity (2022: £29).

The average number of staff employed by the Charity during the year was 5, with a full time equivalent of 4 (2022: 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 £136,786 (2022: £116,877).

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

	2023	2022
<b>This is stated after charging:</b>	£	£
Independent Examiners Remuneration	-	-
Depreciation	5,904	5,904
<b>Total:</b>	<b>5,904</b>	<b>5,904</b>

### 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 £Nil (2022: £Nil).

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2023

### 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

	2023 £
<b>Office equipment</b>	
<b>Cost</b>	
At 1 April 2022	29,209
Additions	-
Disposals	-
<b>At 31 March 2023</b>	<b>29,209</b>
<b>Accumulated depreciation</b>	
At 1 April 2022	21,337
Charge for the year	5,904
Disposals	-
<b>At 31 March 2023</b>	<b>27,241</b>
<b>Net Book Value</b>	
At 1 April 2022	7,872
<b>At 31 March 2023</b>	<b>1,968</b>

### 15. DEBTORS

	2023 £	2022 £
Prepayments	15,271	7,100
Accrued income	-	-
Other debtors	434	683
<b>Total debtors</b>	<b>15,705</b>	<b>7,783</b>

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## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2023

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

	2023	2022
	£	£
Trade creditors	8,354	2,480
Accruals	4,325	3,245
Other creditors	20,328	(29)
Grant commitments (Note 20)	74,960	79,113
<b>Total current liabilities</b>	<b>107,967</b>	<b>84,809</b>

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

	2023	2022
	£	£
Grant commitments within five years (Note 20)	<b>130,000</b>	<b>45,000</b>

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2023

### 18. FUNDS AND RESERVES – CURRENT YEAR

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

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 01/04/22	Income	Expenditure	Transfer	Total funds at 31/03/23
ARPKD Research	3,350	-	(3,355)	5	-
Research	-	10,450	-	39,825	50,275
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)	-	-
<b>Total funds</b>	<b>195,720</b>	<b>94,445</b>	<b>(339,648)</b>	<b>99,758</b>	<b>50,275</b>

Support Activities – Support related activities, such as information days

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.



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## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2023

### 18. FUNDS AND RESERVES – PRIOR YEAR

Unrestricted Funds	Total funds at 01/04/21	Income	Expenditure	Transfer	Total funds at 31/03/22
Research	145,318	-	(2,031)	(143,287)	-
National Lottery – Matched Funding	-	-	-	76,985	76,985
General fund	156,353	294,818	(133,184)	(169,180)	148,807
<b>Total funds</b>	<b>301,671</b>	<b>294,818</b>	<b>(135,215)</b>	<b>(235,482)</b>	<b>225,792</b>

Restricted Funds	Total funds at 01/04/21	Income	Expenditure	Transfer	Total funds at 31/3/22
Support Activities	2,000	-	-	(2,000)	-
ARPKD Research	25,850	-	(22,500)	-	3,350
Research	-	300	(66,095)	65,795	-
European PKD Conference	31,500	-	(15,454)	(16,046)	-
National Lottery - PPP	8,439	53,125	(84,929)	37,733	14,368
National Lottery – Nurse Co-ordinator	28,002	-	-	-	28,002
PKDC/KRUK Research	-	-	-	150,000	150,000
<b>Total funds</b>	<b>95,791</b>	<b>53,425</b>	<b>(188,978)</b>	<b>235,482</b>	<b>195,720</b>

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## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2023

### 19. ANALYSIS OF NET ASSETS BETWEEN FUNDS – CURRENT 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)
<b>Total:</b>	<b>248,828</b>	<b>50,275</b>	<b>299,103</b>

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

	Unrestricted funds 2022 £	Restricted funds 2022 £	Total funds 2022
Tangible fixed assets	7,872	-	7,872
Current assets	191,093	352,356	543,449
Creditors due within one year	(3,245)	(81,564)	(84,809)
Creditors due in more than one year	-	(45,000)	(45,000)
<b>Total:</b>	<b>195,720</b>	<b>225,792</b>	<b>421,512</b>

### 20. GRANT COMMITMENTS

	£
Balance at 1 April 2022	124,113
New commitments	165,306
Cancelled commitments	(1,951)
Commitments paid	(82,508)
Balance at 31 March 2023	<b>204,960</b>

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## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2023

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### 21. RELATED PARTY TRANSACTIONS

	2023	2022	
Donations Received from Trustees	1,825	2,381	3 Trustees (2022: 4) 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:

<b>Employment Related Parties</b>			
		2023	2022
Trustee	Employee		
Alan Greenberg	Louise Greenberg	1,800	5,848