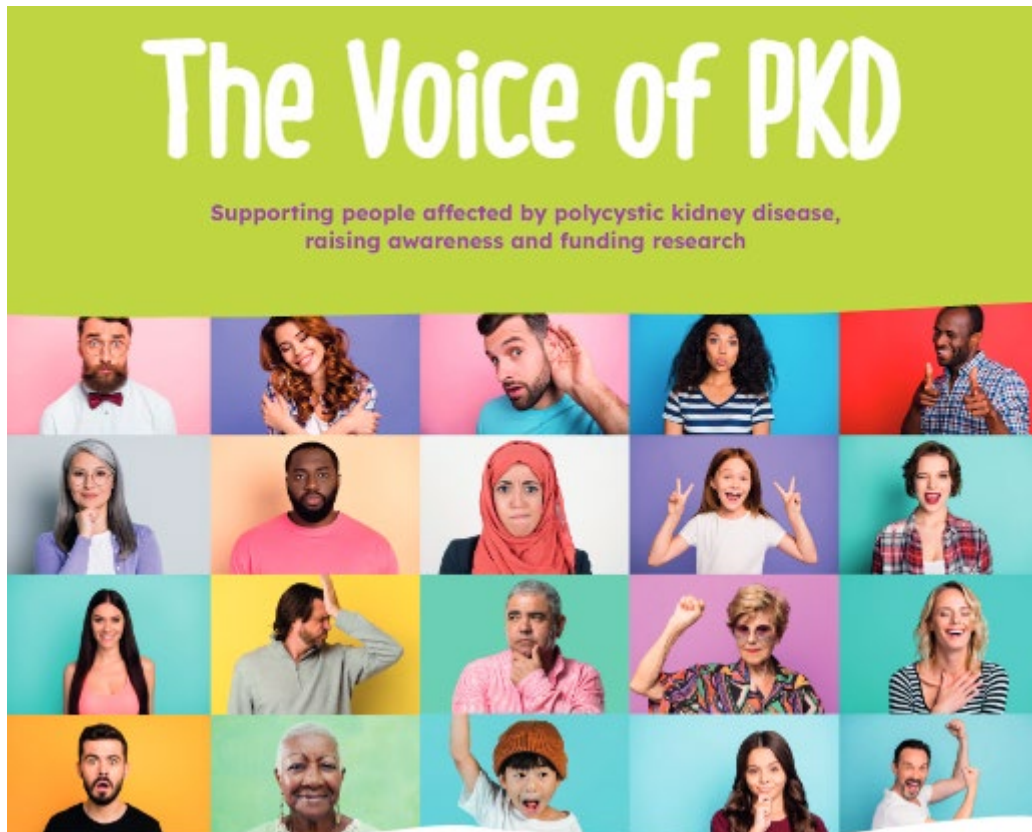


# THE POLYCYSTIC KIDNEY DISEASE CHARITY

Report of the Board of Trustees and Accounts – 1 April 2021 to 31 March 2022



## ANNUAL REPORT AND ACCOUNTS 2021-2022

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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

Mr Idriz Adedoja (Treasurer, appointed Jul 2022)

Mr Raj Johal

Ms Rebecca Murphy-Peers

Ms Jade Raymond (resigned Mar 2022)

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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ME 19 4JQ

#### Accountants

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#### 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.

## **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 2022. 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**

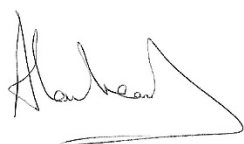
2021-2022 continued to be a challenging time for the Charity with the continued impact of COVID-19. We were still unable to deliver face-face 'in person' events and we experienced a small reduction of income compared to the previous year.

I am pleased to say we were able to navigate the continuation of the pandemic effectively and we delivered a full set of services to our community online, and our income was not impacted as much as the general Charity sector.

During the year we developed a new ambitious 3-year strategic plan to deliver significant benefits for our community. A major focus is to increase research and this year we began promotion of the top 10 Research Priorities from the ADPKD Priority Partnership that were determined last year.

I am also really excited by the launch of the first ever PKD/KRUK jointly funded PKD research awards round. We believe our collaboration with KRUK will accelerate PKD research and an initial £537k worth of research awards for 3 programmes were made under this partnership.

Over the next few pages, you can read more about the Charity's activities during 2021-22. 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  
28 December 2022

## OBJECTIVES AND AIMS

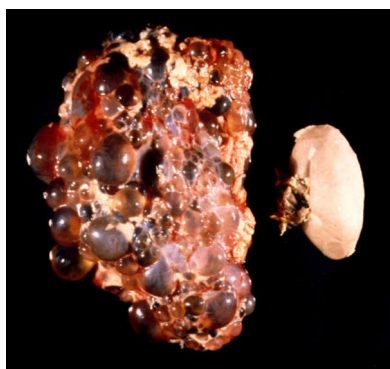
The Polycystic Kidney Disease (PKD) Charity is the only UK charity solely dedicated to improving the lives of children, adults, families, and carers affected by **polycystic kidney disease** (PKD). The Charity was formed in 2000 by a PKD patient and a genetics consultant. Throughout the past 20 years,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

Of the 800,000 babies born a year in the UK, we estimate that 800 – over 2 a day - could have ADPKD (based on 1 in 1,000 prevalence) and 20-40 could have ARPKD (based on 1 in 20-40,000 prevalence). As an inherited condition, ADPKD affects not only the individual but also their immediate family. It's a lifelong condition that can start to present even before birth.

In 2020, approximately 7,000 adults with PKD were receiving treatment for kidney failure -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 on left of ADPKD kidney compared with normal kidney). 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 complete kidney failure by age 60 and will need kidney replacement therapy (KRT) to stay alive – this 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. [Read more about ADPKD on the PKD Charity website.](#)



**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. [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). However, in 2021, the trustees agreed to contribute £151,000 of restricted and unrestricted reserves towards a joint research programme in partnership with Kidney Research UK. 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.

#### **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 2021-22**

We achieved the main aims we set for 2021-2022:

- Launched the first PKD research funding round in partnership with Kidney Research UK.
- Continued providing our blended support services and introduced new services such as workshops – held online whilst COVID-19 persisted, and our community were 'shielding'.
- Promoted the ADPKD Top 10 Research priorities in the UK and internationally.
- Developed a new 3-year strategy.
- Launched an updated website.

### ***Ongoing impact of COVID-19***

In April 2021, the UK was in the 'second wave' of COVID-19. A third wave of the new Delta variant began in July 2021 during which deaths and hospitalisations was lower than with the first two waves, attributed to the vaccination programme. Public health restrictions were gradually lifted and ended by August 2021. However, in early December 2021, the Omicron variant arrived causing record infection levels, and new restrictions were put in place by the UK government. These restrictions were all removed by March 2022.

Many in our PKD community remained classified as 'Clinically Extremely Vulnerable' (CEV) with some being offered additional vaccination doses, up to five in total. All face-to-face educational events and many fundraising activities were on hold again. However, we were able to continue working remotely and delivering our services using online technology such as Teams and Zoom.

## **Research activities during 2021-22**

### **Joint research funding round in partnership with Kidney Research UK**

In September 2021, the first-ever jointly funded PKD research awards round was launched. By collaborating with Kidney Research UK, we aimed to accelerate PKD research. The awards round invited researchers to apply for grants. For ADPKD research, we asked them to focus on the top research priorities for ADPKD. Applications for ARPKD were also welcomed.

Kidney Research UK managed the 2-stage grant application process which concluded in March 2022. 14 applications were received and reviewed by a panel of experts and patients. Three research projects were funded with grants worth a total of £537,000, with the PKD Charity contributing £150,000:

- The first project is led by Professor Albert Ong from The University of Sheffield. Building on some of their existing work in PKD, Professor Ong and his team are on a mission to better understand PKD cysts, with the aim of developing ways to stop them forming - potentially a major step towards finding a cure for ADPKD. [Click to read more.](#)
- The second research project will see Professor Colin A Johnson at the University of Leeds look for novel treatments for ADPKD. Professor Johnson and his team have identified two existing drugs that could be repurposed to treat ADPKD, by conducting tests on kidney organoids. [Click to read more.](#)
- The third project is led by Dr Joe Cockburn of Leeds University, who will study 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.](#)

### **Other grants awarded**

The PKD Research Advisory Board recommended three projects for funding, which were approved by the trustees.

- £45,000 grant to the UCL Division of Medicine at the Royal Free Hospital London to part-fund a 3-year PhD Studentship. The PhD student will undertake a research project on '*Drug Therapy in 3-dimensional Human Polycystic Kidney Disease (PKD) Organoids*'. These PKD organoids are made from human stem cells in a lab dish and have the same genetic faults that cause PKD in people. They can be used to test potential therapeutic drugs. The aim of the research is to inform future clinical trial developments in paediatric and adult ADPKD and ARPKD patients.
- £5,000 to Kidney Research UK towards a UK-wide COVID-19 project to recruit 1200 patients to study the efficacy of Covid-19 vaccinations in in-centre haemodialysis patients. Outcomes to include: efficacy across cohort by type of vaccine, & by sub-groups, e.g ethnicity, ADPKD; duration of immunity; timing of booster.
- £10,000 to Mr Diederik Bulters, the Wessex Neurological Centre, to study '*The influence of*



*autosomal dominant polycystic kidney disease on risk of rupture of intracranial aneurysms'.*

## **Promotion of the top ADPKD research priorities**

The chief executive presented the results of the ADPKD Priority Setting Partnership (PSP) at these virtual meetings:

- June 2021 – PKD Foundation US Conference
- June 2021 – Australia/New Zealand Meeting
- July 2021 – UK Kidney Association ADPKD Seminar
- October 2021 - UK Kidney Week
- October 2021 – UK Cilia Network Meeting
- November 2021 – US American Society of Nephrology Congress

In September 2021, the PSP manuscript was submitted to the BMJ Open. (It was published in May 2022. [Link here.](#))

## **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) - is 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 2021-22, we continued to support our community through remote service delivery and frequently updated health and COVID-19 information, using online channels and platforms such as

Zoom, Teams and Facebook.

### Online support group meetups

During the year, we held 28 online support group calls via Zoom to either chat and share experiences, or to discuss popular topics such as tolvaptan (a disease-modifying drug), polycystic liver disease and nephrectomy (kidney removal) at which a volunteer spoke about their own personal experience.

*“Thanks for organising the chat on nephrectomy. Have been at many patient group meetings over the years but usually only a small number of us have PKD & we never get around to talking about nephrectomy. It was great to meet other PKD patients all focused on the same topic. Specially interesting to hear from people about their personal experiences.”*

As last year, despite the interest, attendance numbers are typically about 60% of those registered, with about 7 people attending each event on average.

### Telephone support including helpline

Our dedicated 0300 telephone helpline was available for those feeling worried or emotional or needing information. The number of callers reverted to previous years with one caller per day on average. Monday is usually the busiest day. Out of hours calls are recorded by an answer service ensuring those who left a message had their calls returned.

### Information/Support events and webinars for patients and their families

We delivered **3 ADPKD information days** by Zoom on:



- **Living Donation** (72 attendees) – which included personal stories from a donor and transplant recipient.
- **ADPKD in Children and Young People** (58 attendees).
- **The Latest on ADPKD** – involving leading European speakers and simultaneous translation into 6 languages, supported by an unrestricted educational grant from Sanofi Pharmaceutical Ltd;

the event was organised by PKD Charity and attracted 500 attendees from 70 countries (100 from UK).

We experimented switching from a webinar, ‘listen-only’ mode to interactive meeting mode. With careful moderation of those attending and gathering questions in advance, we were able to record the presenters and manage the live Q&A without issues.

Feedback was positive:

*“Thank you for the excellent event today. The fact that one of your speakers has personal experience of the living donation and transplant process was powerful.”*

*“All was extremely helpful. I thought the range and flow of speakers worked well and I enjoyed*

*hearing the lived experience at the end.”*

*“I learnt something from every speaker. I was particularly interested in PKD and Covid and found the findings of diets and PKD very interesting. The psychological pressure session was very good too.”*

Many commented on the benefits of being able to attend without travelling. However, many also told us that 6 hours online was too long, and they would prefer shorter information days in future. We took this into account when planning future events.



We organised an online event for **ARPKD parents and families**. Six guest speakers gave an overview of ARPKD, including liver complications, dialysis, and transplantation.

Despite 43 registering, the attendance was just 14. However, our ARPKD community is very small, and most are young working parents juggling caring for very sick children and possibly other siblings.

50% of attendees said it was their first ARPKD event and most felt more able to manage ARPKD, were more positive about it and their knowledge of ARPKD increased.

*“Overall, the event was great and although I would love it to be in person it was a nice introduction as my first event as I didn't know what to expect. Thanks so much for organising, it really was invaluable.”*

We held **4 evening webinars/live Q&A meetings**. These were jointly presented by PKDC staff and guest speakers:



- The Role of the Alkaline Diet on Kidney Health
- Introduction to the PLADO Diet
- Visceral Pain Research
- Shake Your Salt Habit

Nearly 319 (60% increase over last year) attended the webinars and between 65-80% were very satisfied.

The talks from the information events and webinars were recorded and are available on our website and [YouTube](#) channel. Each topic recorded 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 Workshop**

We commissioned a Clinical Kidney Psychologist and Psychotherapist to create and deliver a unique series of online workshops for the PKD Charity on 'Living Well with PKD'. These explored pain, anxiety, diagnosis and relationships. The workshops were held over 90 minutes via a Zoom meeting with capacity limited to 10.

One ADPKD workshop was held in December 2021 (the start of the series) and 6 attended. Two smaller workshops were held for ARPKD families with 8 attending. Overall, feedback was very positive.

### **Facebook groups**

We manage and moderate 3 private UK-only Facebook groups with approximately 3,000 members. We are fortunate to have the support of trained volunteers who assist staff with moderation and peer support. COVID-19 related posts declined during the year compared with the previous year as people reverted to their daily issues of managing PKD. We have noticed that many people are experiencing delays in seeing specialists or are rarely seeing them in-person, which is concerning.

### **Telephone befriending service**

We continued to offer a personalised telephone befriending service, with trained volunteers with lived experience of PKD. This is a service for patient and family members, enabling them to develop an ongoing relationship with a volunteer befriender.

### **Health information for patients and families**

During the year we continued to update and draft new information. However, as in previous years, we struggled with the availability of healthcare professionals to review drafts owing to the impact of COVID-19.

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



We reviewed and updated our information production processes and applied to the Patient Information for PIF TICK accreditation (achieved in May 2022).

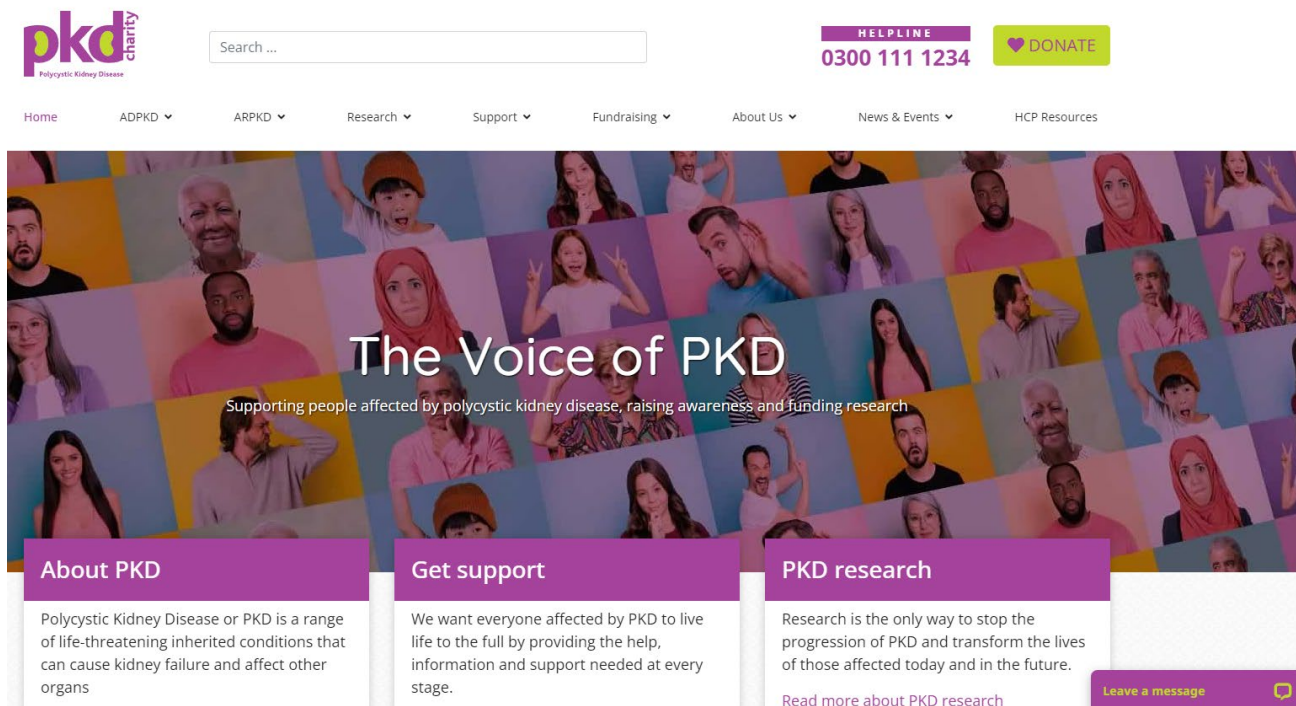
This information quality mark will enable us to improve the distribution of our fact sheets, in particular to GPs via online directories.

### **PKD website**

The website underwent a major technical and content update and went live in September 2021. Visitor numbers increased 19% in the period from 1/10/2021 to 31/3/2022, compared with the same



period the previous year.



### ***Survey of the PKD Community to assess performance***

We published a survey in Autumn 2021 to assess the charity’s performance in meeting beneficiaries’ needs, the community’s wellbeing, and identify unmet needs. It was published online and posted to 3000 households in our Autumn Newsletter.

The survey was based on previous surveys, the last being in 2017. We consulted on the draft with colleagues at Genetic Alliance UK and piloted it with members of our community.

305 responded from all regions of the UK and with ages ranging from 1 to over 80, with the majority between 50-59.

Overall, we were satisfied that our services were valued and beneficial:

- Nearly 90% agreed that the charity made them better informed about PKD
- 60% agreed that the charity made them feel more confident about managing my own health or the health of people I care for
- 54% said that the charity always had someone to talk to
- 70% said the charity made them feel less alone

The free text comments reflected high levels of community satisfaction:

*“Whenever I have reached out and asked questions, I have always been pointed in the right direction for the advice I need whether it be via the PKD website or being pointed to my consultant to ask questions etc. I feel very fortunate to have come across this charity as before*

*I found it, I did feel very alone and very worried about the disease, but now I know there are other people I can connect with who understand it makes it a little easier to comprehend.”*

*“I know it's been a long time since I was diagnosed with PKD but when I attended the information day everyone made me feel so welcome and I gained so much from that day and felt less scared about my outcome especially meeting and hearing from other PKD patients. To this day the team keep everyone updated on everything we need to know and being part of the FB group and the Group chat page has been even more helpful.”*

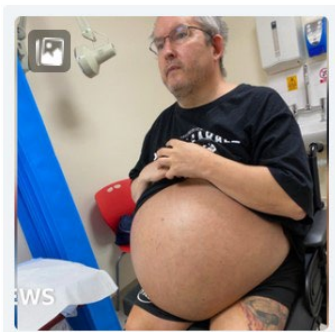
*“I am extremely thankful for the charity. I have always felt supported and heard. As a mother that is young, I have often received inadequate care for my daughter and felt that I am often shrugged off. The PKD Charity has never made me feel this way, they are accepting and kind and always make you feel at ease. When I have a question, they are quick to respond and either help me themselves or point me in the right direction of someone else if needed.”*

## **PKD awareness activities**

### **Awareness**

Through social media posts on our Facebook page, groups, Twitter, LinkedIn, Instagram and affiliate social channels, we continued to raise awareness of PKD, kidney health and our services. Facebook and Twitter reach increased significantly to over 275,000 and 13,900 respectively.

Facebook was the dominant social media channel. Our community always enjoys stories of transplant/organ donation and PKD patient stories.



Popular posts included Warren’s story of a life-or-death decision to remove both of his enormous kidneys – he shared his story with us and also via public media including the BBC. It was estimated that his kidneys weighed 35 kg after removal, the world’s largest recorded.

Warren is now on dialysis and hoping to receive a transplant.

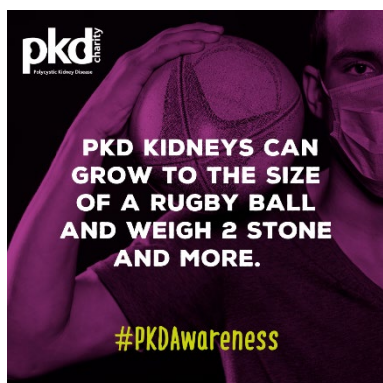
We issued 2 printed full-colour newsletters to approximately 3,000 households and posted each online.





We published a regular e-news to over 3,000 individuals to keep the community informed. These achieved good engagement:

- Average unique opens: 41% (nearly double non-profit average)
- Average click-to-open rate: 14% (over 6 times higher than non-profit average)



PKD Awareness Week Month was held in September 2021. We ran a digital campaign to raise awareness, prompt discussion and educate new and existing patients, family members and healthcare professionals. We posted 'PKD Voices' stories as part of this campaign. Facts and statistics about PKD achieved exceptionally high organic reach and engagement on Facebook and Instagram, whilst the launch of the research awards captured the media's interest on Twitter.

**Top media Tweet** earned 2,878 impressions

Brand-new PKD Research Awards round launched this week!  
Make sure to get your application in by 5pm on Monday 4 October [bit.ly/3t6XniY](https://bit.ly/3t6XniY)

@Kidney\_Research  
@LindAlliance  
#PKDAwareness  
[pic.twitter.com/NcTkVFDGqJ](https://pic.twitter.com/NcTkVFDGqJ)

A post featuring 3 brothers who had each received kidney transplants was very popular.

World Kidney Day (WKD) 2022 was celebrated digitally again in March 2022. The KCT collaborated on an awareness digital campaign. This year the focus was on the experiences of real kidney patients and family members.





For the first time, PKD had a strong voice in the campaign by featuring the story of young mum, Lindsay, who hopes to donate a kidney to her husband, PKD patient Richard. Their story achieved the highest reach and dwell time across the whole campaign.

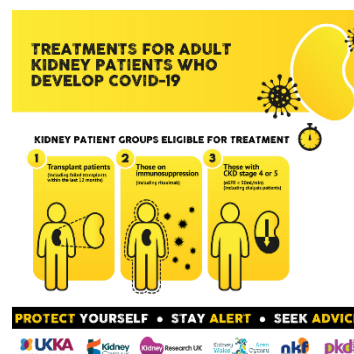
We promoted and aligned our activity with other Awareness days/weeks, including Rare Disease Day in February 2022 (by sharing the story of ARPKD patient Luke, and PKD facts and stats), Salt Awareness Week (holding Shake Your Salt Habit webinar that week) and Organ Donation Week (by sharing PKD transplant stories, and posts that encourage families to share organ donation wishes).

### Advocacy

Throughout the year, members of staff attended and participated in conferences, workshops and events relevant to COVID-19, kidney, liver, genetic and rare diseases.

90% of the respondents to the Autumn 2021 agreed that the charity was an effective voice for PKD patients and families in the UK.

The charity is 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 (formerly the UK Renal Association and British Renal Society). 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 the charity’s aims and activities are known, recognised, and taken into account. 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.

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)

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

In June 2021, we acknowledged publicly the contribution made by all volunteers during Volunteer Week.

### ***Community fundraising***

We thank all the amazing fundraisers who continued to support the charity's work during 2021-22 despite the COVID-19 restrictions.

Mass participation, in person fundraising events gradually returned after the summer.





Sisters Lynette and Nicky took part in the London Landmarks Half Marathon in August and the London Marathon in October wearing handmade tutus bearing the names of PKD patients past and present. Four generations of their family have been diagnosed with PKD.

Many of our supporters organised their own community fundraising events such as garden parties or taking on walking, hiking, running and swimming challenges.

Jenny, a longstanding supporter, published her autobiography and donated all profits to the charity.



### **Grant fundraising**

The National Lottery Community Fund awarded year 3 of the 5-year grant for the Positive Peers Programme.



The trustees are grateful to the Community Fund for their understanding and support during the year.

### **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).

### **2022-23 PLANS**

2022-23 will be the first year of our 3-year strategy, approved in March 2022. 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 particular, in 2022-23, we will:

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

## 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.

## **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 2022, the charity's income was **£348,243** (2021: £361,800).

Expenditure on raising funds as a percentage of total incoming resources was 19% (2021: 17%). Research expenditure was **£90,626** (2021: £70,803). The Charity's expenditure on charitable activities across Patient support, Awareness and Education was **£136,839** (2021: £105,455), which included information days, telephone support, online/chat support and expenditure on the peer support service.

In total, the Charity expended **£324,193** (2021: £267,797), resulting incoming resources for the year of **£24,050** (2021: £94,003). Total fund balances at the year-end were **£421,512** (2021: £397,462) and all funds maintained a surplus position at the year-end (Note 17).

### **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 Unrestricted Funds of £111,857 (2021: £156,353), equivalent to 4 months' total expenditure (2021: 7 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.



## **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**

A handwritten signature in black ink, appearing to read 'Idriz Adedoja', with a long horizontal flourish extending to the right.

Idriz Adedoja  
Trustee Treasurer  
28 December 2022

## ***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 2022, which are set out on pages 23-36.

#### **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**

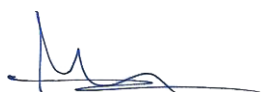
In connection with my examination, no matter has come to my attention:

(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



28 December 2022

**STATEMENT OF FINANCIAL ACTIVITIES - 1 APRIL 2021 TO 31 MARCH 2022**  
**(INCORPORATING INCOME AND EXPENDITURE ACCOUNT)**  
**FOR THE YEAR ENDED 31 MARCH 2022**

	Notes	Restricted Funds 2022 £	Unrestricted Funds 2022 £	Total 2022 £	Total 2021 £
<b>Income from:</b>					
Donations grants and legacies	3	53,425	285,863	339,288	346,285
Other trading activities	4	-	7,081	7,081	13,602
Investment income	5	-	1,874	1,874	1,913
<b>Total income</b>		<b>53,425</b>	<b>294,818</b>	<b>348,243</b>	<b>361,800</b>
<b>Expenditure on:</b>					
Cost of fundraising	6	-	67,075	67,075	61,792
Non-charitable trading activities	6	-	2,598	2,598	7,958
<b>Total</b>		<b>-</b>	<b>69,673</b>	<b>69,673</b>	<b>69,750</b>
Research and grants	7	88,595	2,031	90,626	70,803
Awareness and education		15,454	36,510	51,964	30,342
Patient support		79,025	-	79,025	71,176
Depreciation	10	5,904	-	5,904	3,936
<b>Total</b>		<b>188,978</b>	<b>38,541</b>	<b>227,519</b>	<b>176,257</b>
<b>Other expenditure</b>					
Governance costs	8	-	27,001	27,001	21,789
<b>Total expenditure</b>		<b>188,978</b>	<b>135,215</b>	<b>324,193</b>	<b>267,797</b>
<b>Net income / (expenditure) for the year</b>		<b>(135,553)</b>	<b>159,603</b>	<b>24,050</b>	<b>94,004</b>
Fund balances brought forward at 1 April	18	95,791	301,671	397,462	303,458
Net incoming resources for the year	17	(135,553)	159,603	24,050	94,004
Transfers between funds	17	235,482	(235,482)	-	-
<b>Fund balances carried forward</b>	<b>17</b>	<b>195,720</b>	<b>225,792</b>	<b>421,512</b>	<b>397,462</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 26 - 36 form part of these financial statements.

## BALANCE SHEET AT 31 MARCH 2022

	Notes	2022 Total Funds £	2021 Total Funds £
<b>FIXED ASSETS</b>			
Tangible assets	13	<b>7,872</b>	13,776
<b>CURRENT ASSETS</b>			
Debtors	14	7,783	9,754
Cash at bank		535,666	489,650
<b>Total current assets</b>		<b>543,449</b>	499,404
<b>Liabilities</b>			
<b>Creditors: Amounts falling due within one year</b>	15	84,809	105,718
<b>NET CURRENT ASSETS</b>		<b>458,640</b>	393,685
<b>Total assets less current liabilities</b>		<b>466,512</b>	407,461
<b>Creditors: Amounts falling due after more than one year</b>	16	45,000	10,000
<b>NET ASSETS</b>		<b>421,512</b>	<b>397,462</b>
<b>The funds of the Charity:</b>			
Unrestricted funds - Designated	17	76,985	145,318
Unrestricted funds - General	17	148,807	156,353
Restricted funds	17	195,720	95,791
<b>TOTAL FUNDS</b>		<b>421,512</b>	<b>397,462</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.

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

A handwritten signature in black ink, appearing to read 'Idriz Adedoja', written over a horizontal line.

Idriz Adedoja  
Trustee Treasurer  
28 December 2022

The notes on pages 26-36 form an integral part of these accounts.

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

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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:

86-90 Paul Street  
London  
EC2A 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 2022

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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 2022

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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 2022

#### 3. DONATIONS, GRANTS AND LEGACIES

	Restricted funds 2022 £	Unrestricted funds 2022 £	Total Funds 2022 £	Total Funds 2021 £
Donations and gifts	300	261,785	262,085	164,249
Trusts, foundations and grants	53,125	-	53,125	166,125
Gift Aid	-	24,078	24,078	15,952
<b>Total 2022</b>	<b>53,425</b>	<b>285,863</b>	<b>339,288</b>	<b>346,325</b>
<b>Total 2021</b>	<b>174,557</b>	<b>171,728</b>	<b>346,325</b>	

No government grants were received during the year (2021: £Nil).

#### 4. INCOME FROM OTHER TRADING ACTIVITIES

	Restricted funds 2022 £	Unrestricted funds 2022 £	Total Funds 2022 £	Total Funds 2021 £
Shop and other income	-	7,081	7,081	13,602
<b>Total 2022</b>	<b>-</b>	<b>7,081</b>	<b>7,081</b>	<b>13,602</b>
<b>Total 2021</b>	<b>-</b>	<b>13,602</b>	<b>13,602</b>	

#### 5. INVESTMENT INCOME

	Restricted funds 2022 £	Unrestricted funds 2022 £	Total Funds 2022 £	Total Funds 2021 £
Interest income	-	1,874	1,874	1,913
<b>Total 2022</b>	<b>-</b>	<b>1,874</b>	<b>1,874</b>	<b>1,913</b>
<b>Total 2021</b>	<b>-</b>	<b>1,913</b>	<b>1,913</b>	

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

### 6. EXPENDITURE ON RAISING FUNDS

	Restricted funds 2022 £	Unrestricted funds 2022 £	Total Funds 2022 £	Total Funds 2021 £
Cost of fundraising	-	67,075	67,075	61,792
Cost of goods sold	-	2,598	2,598	7,958
<b>Total 2022</b>	<b>-</b>	<b>69,673</b>	<b>69,673</b>	<b>69,750</b>
<b>Total 2021</b>	<b>-</b>	<b>69,750</b>	<b>69,750</b>	

### 7. ANALYSIS OF RESEARCH AND GRANTS

	2022 £	2021 £
Bio Resource Bank	-	8,500
ADPKD Research	54,750	29,033
Kidney Research UK	5,000	-
UCL Great Ormond Street Institute of Child Health	14,960	-
Staff, subcontractor and other costs	15,916	33,269
<b>Total:</b>	<b>90,626</b>	<b>70,803</b>

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

Details of material grants are disclosed in the Trustees Report.

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

### 8. SUPPORT COSTS

	2022 £	2021 £
Trustee meetings and governance	1,008	131
Accountancy and audit	13,917	12,927
Other professional fees	5,497	3,866
Staffing costs	6,579	4,865
<b>Total:</b>	<b>27,001</b>	<b>21,789</b>

### 9. EMPLOYMENT COSTS

	2022 £	2021 £
Wages and salaries	119,739	136,396
Social security costs	10,943	9,351
Defined contribution pension costs	2,986	2,380
<b>Total:</b>	<b>133,668</b>	<b>148,127</b>

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

As at 31 March 2022 a balance of £29 overpaid pension contributions was owed to the Charity (2021: £180).

The average number of staff employed by the Charity during the year was 6, with a full time equivalent of 4 (2021: 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 £116,877 (2021: £132,775).

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

<b>This is stated after charging:</b>	2022 £	2021 £
Independent Examiners Remuneration	-	-
Depreciation	5,904	3,936
<b>Total:</b>	<b>5,904</b>	<b>6,186</b>

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

### 11. 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 (2021: £Nil).

### 12. 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.

### 13. ANALYSIS OF MOVEMENT OF FIXED ASSETS

	<b>2022</b>	<b>£</b>
		<b>Office equipment</b>
<b>Cost</b>		
At 1 April 2021	29,209	
Additions	-	
Disposals	-	
<b>At 31 March 2022</b>	<b>29,209</b>	
<b>Accumulated depreciation</b>		
At 1 April 2021	15,433	
Charge for the year	5,904	
Disposals	-	
<b>At 31 March 2022</b>	<b>21,337</b>	
<b>Net Book Value</b>		
At 1 April 2021	13,776	
<b>At 31 March 2022</b>	<b>7,872</b>	

### 14. DEBTORS

	<b>2022</b>	<b>2021</b>	
	<b>£</b>	<b>£</b>	
Prepayments	7,100	9,754	
Accrued income	-	-	
Other debtors	683	-	
<b>Total debtors</b>	<b>7,783</b>	<b>9,754</b>	

**NOTES TO THE FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 31 MARCH 2022**

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**15. LIABILITIES: AMOUNTS FALLING DUE WITHIN ONE YEAR**

	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>
Trade creditors	2,480	4,280
Accruals	3,245	2,328
Other creditors	(29)	1,297
Grant commitments (Note 18)	79,113	97,813
<b>Total current liabilities</b>	<b>84,809</b>	<b>105,718</b>

**16. LIABILITIES: AMOUNTS FALLING DUE AFTER MORE THAN ONE YEAR**

	<b>2022</b>	<b>2021</b>
	<b>£</b>	<b>£</b>
Grant commitments within five years (Note 18)	<b>45,000</b>	<b>10,000</b>

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

### 17. FUNDS AND RESERVES – CURRENT 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>

Research – Designated to support research for PKD

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 01/04/21	Income	Expenditure	Transfer	Total funds at 31/03/22
Support Activities	2,000	-	-	(2,000)	-
ARPKD Research	25,850	-	(22,500)	-	3,350
Research	-	300	(66,095)	66,095	-
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>

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.

In March 2022, the Trustees agreed to transfer £150,000 from the general fund to PKDC Research.



## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

### 18. FUNDS AND RESERVES – PRIOR YEAR

Unrestricted Funds	Total funds at 01/04/20	Income	Expenditure	Transfer	Total funds at 31/03/21
Research	65,000	-	-	80,318	145,318
PKD Bio-Resource	-	-	-	-	-
PKD Registry	-	-	-	-	-
General fund	192,006	187,243	(126,650)	(96,246)	156,353
<b>Total funds</b>	<b>257,006</b>	<b>187,243</b>	<b>(126,650)</b>	<b>(15,928)</b>	<b>301,671</b>

Restricted Funds	Total funds at 01/04/20	Income	Expenditure	Transfer	Total funds at 31/3/21
Support Activities	2,000	-	-	-	2,000
ADPKD Research	2,089	2,150	(14,033)	9,794	-
ARPKD Research	25,850	-	-	-	25,850
Research	11,084	6,283	(23,500)	6,134	-
European PKD Conference	-	31,500	-	-	31,500
National Lottery - PPP	5,430	78,122	(75,112)	-	8,439
National Lottery – Covid-19	-	28,501	(28,501)	-	-
National Lottery – Nurse Co-ordinator	-	28,002	-	-	28,002
<b>Total funds</b>	<b>46,452</b>	<b>174,557</b>	<b>(141,146)</b>	<b>15,928</b>	<b>95,791</b>

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

## NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

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

	Unrestricted funds 2021 £	Restricted funds 2021 £	Total funds 2021
Tangible fixed assets	13,776	-	13,776
Current assets	290,222	209,182	499,404
Creditors due within one year	(2,328)	(103,390)	(105,718)
Creditors due in more than one year	-	(10,000)	(10,000)
<b>Total:</b>	<b>301,671</b>	<b>95,791</b>	<b>397,462</b>

### 21. GRANT COMMITMENTS

	£
Balance at 1 April 2021	107,813
New commitments	74,710
Cancelled commitments	-
Commitments paid	(58,410)
Balance at 31 March 2022	<b>124,113</b>

### 22. RELATED PARTY TRANSACTIONS

	2022	2021	
Donations Received from Trustees	2,381	6,120	4 Trustees (2021: 4) made donations during the year
Grants to related parties	-	8,500	Professor P Wilson – UCL, is a Trustee of the Charity

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

	Employee	2022	2021
Alan Greenberg	Louise Greenberg	5,848	6,001