THE POLYCYSTIC KIDNEY DISEASE CHARITY

England & Wales · Charity number 1160970

Details

Other names	PKD CHARITY
Status	Registered
Legal form	Charitable company
Company number	09486245
Registered	2015-03-18
Register	View on the Charity Commission register

Contact

Address	PKD Charity 86-90 Paul Street London EC2A 4NE
Phone	02073870543
Email	info@pkdcharity.org.uk
Website	www.pkdcharity.org.uk

Activities

Objects: TO PROMOTE HEALTH AND TO RELIEVE THOSE PERSONS SUFFERING FROM OR AFFECTED BY POLYCYSTIC KIDNEY DISEASE (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.•ORGANISING PATIENT, FAMILY AND CARER INFORMATION, EDUCATION AND SUPPORT EVENTS ACROSS THE UK AND OFFERING PERSONAL SUPPORT TO PATIENTS AND THEIR FAMILIES.

Activities: About 70,000 adults and children in the UK have Polycystic Kidney Disease or PKD - life-threatening inherited conditions that can cause renal (kidney) failure and affect other organs in the body.We support those affected, their families and carers.We raise awareness and fund research.

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Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, Elderly/old People, People With Disabilities

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£347,837	£377,099	-	-
2024-03-31	£453,814	£332,109	-	-
2023-03-31	£386,220	£508,629	-	-
2022-03-31	£348,243	£324,193	-	-
2021-03-31	£361,800	£267,797	-	-

Trustees

Name	Role	Appointed
ALAN GREENBERG		2017-09-22
Adrian Tinsley		2018-03-23
BULRAJ SINGH JOHAL		2015-03-12
Idriz Adedoja		2022-07-06
Jonathan David Rees		2021-03-23
Karen Sarah Mary Stapleton		2019-05-29
Professor Patricia Wilson		2018-03-23
Rebecca Murphy-Peers		2015-05-27
Victoria Lise Calais		2026-03-24
Zahra Imaan Seyyad		2026-03-24

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THE POLYCYSTIC KIDNEY DISEASE CHARITY

England & Wales - Charity number 1160970

Accounts

THE POLYCYSTIC KIDNEY DISEASE CHARITY

Report of the Board of Trustees and Accounts – 1 April 2024 to 31 March 2025

Polycystic Kidney Disease Charity |Registered charity in England and Wales (1160970) | Registered charity in Scotland (SC047730) | A company limited by guarantee
Registered company in England and Wales (9486245) |Registered address: 86-90 Paul Street, London, EC2A 4NE

ANNUAL REPORT AND ACCOUNTS 2024-2025

CONTENTS

REFERENCE AND ADMINISTRATIVE INFORMATION 3
TRUSTEES ANNUAL REPORT & DIRECTORS' REPORT 4
WELCOME FROM THE CHAIR 4
OBJECTIVES AND AIMS 5
About PKD 5
Charitable objects 6
Our objectives and activities 6
PERFORMANCE AND ACHIEVEMENTS DURING 2024-25 8
Research activities during 2024-25 8
Support services for people, carers and families affected by PKD 10
PKD App 14
PKD awareness/advocacy activities 15
Community involvement in the work that we do 18
Community fundraising 18
Pro bono support 19
2025-26 plans 20
STRUCTURE, GOVERNANCE AND MANAGEMENT 21
Constitution 21
Trustees 21
Governance and administration 21
Risk Management 21
Fundraising 21
FINANCIAL REVIEW 22
Independent Examiner's Report to the Trustees of the Polycystic Kidney Disease Charity 23
STATEMENT OF FINANCIAL ACTIVITIES - 1 April 2024 TO 31 MARCH 2025 24
BALANCE SHEET AT 31 MARCH 2025 25
NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2025 27

REFERENCE AND ADMINISTRATIVE INFORMATION

Principal address and registered office:
86-90 Paul Street
London
EC2A 4NE

Tel: 020 7387 0543
Email: info@pkdcharity.org.uk
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 Idriz Adedoja
Mr Raj Johal
Ms Rebecca Murphy-Peers
Mr Jon Rees
Mrs Karen Stapleton
Mr Adrian Tinsley
Professor Patricia Wilson
Mr Alexander Vickerman
Ms Sanela Becar (Lay Member)
Professor Daniel Gale
Dr Richard Sandford
Professor John Sayer
Dr Manish Sinha
Professor David Wheeler

Research Advisory Board

Professor Patricia Wilson (Chair)

Chief Executive

Miss Alison Taylor (appointed September 2024)

Patrons

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

Professional advisors

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

Accountants
Peters Elworthy & Moore
Salisbury House
Station Road
Cambridge, CB1 2LA

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

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

TRUSTEES ANNUAL REPORT & DIRECTORS' REPORT

The Trustees, who are also directors of the Charity for the purpose of the Companies Act, present their annual report and financial statements of the Charity for the year ended 31 March 2025. 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

This past year has been one of deep transition and reflection following the sad passing of Tess Harris shortly before the start of the reporting period. Tess was not only our CEO but the driving force behind much of what we achieved. Her loss was felt profoundly – both emotionally and operationally.

Our immediate challenge was to ensure continuity and maintain our core services for the PKD community while preparing for a future without Tess's leadership. I am proud to say that, thanks to the dedication of our staff and trustees, we continued to deliver a full range of services at a high standard. I believe Tess would have been deeply proud of what we accomplished together.

Following a rigorous recruitment process that attracted over 150 applicants, we were delighted to appoint Alison Taylor as our new Chief Executive in September. Alison stood out as an exceptional candidate, and since joining, she has brought clarity, energy, and renewed momentum to the organisation. Her leadership has already helped to stabilise operations and strengthen our strategic focus, and I am confident that she will guide us to even greater impact.

A particular highlight this year has been the progress of the **PKD Research Partnership**, our collaborative initiative with Kidney Research UK. This ambitious programme seeks to unite and accelerate PKD research efforts across the UK - with the ultimate goal of delivering innovative treatments and transforming the lives of those affected by PKD. Engagement from healthcare professionals, researchers and industry partners has been exceptional, and we are now in a strong position to fully launch and drive this initiative forward.

In the pages that follow, you will read more about the charity's work and impact during 2024–25. None of this would be possible without the generosity of our community: patients and families, friends and colleagues, those who give in memory of loved ones lost to PKD, healthcare professionals, researchers, funders, partners, volunteers, trustees, and our dedicated staff. We are deeply grateful to each and every one of you.

Alan Greenberg, Chair, Board of Trustees
Date: 17th December 2025

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 25 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.

There are 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.

- **£750 million** annually in direct NHS costs**.**
- **1 in 8** kidney transplants and dialysis cases in the UK are due to PKD**.**
- **10%** of nephrologists' time is dedicated to PKD patients.
- **4th leading cause** of kidney-related deaths in the UK

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, which can have an impact 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.

ARPKD is rare and often diagnosed during pregnancy. Unfortunately, 1 in 3 babies will die in the first week of life owing to the rapid growth of cystic kidneys preventing lung development. The babies who survive sometimes experience early kidney and liver failure. They may need life-saving dialysis before transplant and about a third have impaired growth during childhood. Some children may need kidney or liver transplants in later life. Despite this, many children do survive to adulthood with mild forms of ARPKD, although their kidneys and livers can be impaired. ARPKD patients frequently have very high blood pressure and are prone to liver-related problems such as bile duct infections and enlarged spleens. See Image 2 of Hazel who is frequently unwell from ARPKD symptoms, affecting her ability to enjoy a normal childhood. There are no treatments other than symptomatic. Read more about ARPKD on the PKD Charity website.

Charitable objects

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

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

Our objectives and activities

Research

Our aim is to support and fund ADPKD and ARPKD research in the UK. As a small charity, historically we have focussed on funding small research projects up to £15,000 each and contributing towards PhD studentships. To date, since 2008, we have awarded over £800,000 to research. During the 2024-25 year the trustees have made the decision that most research funding will now be channelled through the PKD Partnership, a joint initiative established by the charity in collaboration with Kidney Research UK when it officially launches in 2025-26.

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

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

Information, awareness, and advocacy

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

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

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

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

Support

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

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

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

PERFORMANCE AND ACHIEVEMENTS DURING 2024-25

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 2024-25, we aimed to:

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

Research activities during 2024-25

PKD Charity and Kidney Research UK partnership

This year, we are proud to continue our partnership with Kidney Research UK to drive forward research, innovation, and treatments for the PKD community. The **PKD Partnership** aims to advance scientific understanding of polycystic kidney disease and accelerate the development of innovative therapies. By combining collaborative research, cutting-edge technology, and meaningful patient engagement, we are working to transform the outlook for people living with PKD—delivering hope and practical solutions for a brighter future.

Our long-term goal is to bring forward treatments that improve quality of life, delay or prevent the need for dialysis or transplantation, and help reduce the burden on healthcare systems.

During the year, we made strong progress, with growing engagement and support from healthcare professionals, researchers, and industry partners. Important steps were also taken to strengthen fundraising, governance, legal, and operational frameworks. We were delighted to appoint **Lesley Woolnough** as the project's lead, ensuring dedicated leadership as the initiative moves into its next phase.

Looking ahead, work is progressing at pace as we prepare to formally launch the PKD Partnership to the wider community and open our first research funding round in 2025–26.

Research grants

The PKD Charity trustees approved the following research grant funding during the year:

- £10,000 continuation funding to support the PKD BioResource Bank

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 520 samples were provided for use in 19 PKD-related projects
- Over 140 new donated samples were added to the BioResource Bank

Patient involvement

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

It was also great to be able to highlight new research opportunities for our community to become involved with. We know that the patient and research community acting together will further our understanding in PKD and will help on the journey to finding new treatments.

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).
- CIILIAREN is a UK-wide initiative that aims to improve the diagnosis, management, and quality of life for patients with renal ciliopathies by challenging and transforming the clinical and

research landscape.

- The Advanced Discovery of Visceral Analgesics via Neuroimmune Targets and the Genetics of Extreme human phenotype (ADVANTAGE) consortium funded by the Medical Research Council and partners – the aim is to improve the treatment of people with visceral diseases, such as endometriosis, colitis, and polycystic kidney disease, focusing on their pain rather than just their underlying disease. The Charity is a patient partner.
- The PKD Outcomes Consortium (PKDOC) – helps establish clinical and patient reported outcomes for ADPKD research acceptable to the global regulators who authorise medicines (the US Food & Drink Administration (FDA), European Medicines Agency (EMA) and the Medicines and Healthcare products Regulatory Agency (MHRA) in the UK).
- The Standardised Outcomes in Nephrology Group (SONG) - defining clinical and patient reported outcomes that can be used in PKD research and trials globally.
- The European Reference Networks for rare kidney and liver conditions (ERKNet and Rare Liver) - virtual networks involving healthcare providers and patient representatives across Europe which facilitate dissemination and exchange of knowledge and experience (e.g. clinical practice guidelines) and generate new knowledge (e.g. by conducting research studies).

Support services for people, carers and families affected by PKD

During 2024-25, we continued to support our community through remote and face to face service delivery. We used our website, online channels and platforms such as Zoom, Teams, Facebook and other social media to provide support and information alongside in person meetings and events.

Phone and Facebook support

Our 0300-phone helpline was available for those feeling worried or emotional or needing information. The number of callers remained at approximately one caller per day on average. We logged the details of nearly 355 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 just want to say thank you too for all the charity's support. I can think of one time especially I phoned the helpline, and it made so much difference to talk to someone that understands”.

We manage and moderate 3 private UK-only Facebook groups with approximately 3,700 members. We are fortunate to have the support of trained volunteers who assist staff with moderation and peer support.

Support group meetups

We held 35 meetings during the year either in-person or via zoom. Our existing location-based groups were held in London, Bedfordshire, Norfolk, NE England and Wales. During the year we were delighted to launch new groups in Herefordshire, Manchester, Hampshire, Liverpool, Wiltshire and

online support group for young adults. We are indebted to the fabulous volunteers who lead the groups supported by our Support Servies Manager. We look forward to expanding our support groups to other areas in the country in 2025-2026

The support groups are supplemented by online sessions on particular topics where small numbers of people can meet and talk through issues that are affecting them at specific stages in their journeys. Anyone from across the UK can join these group sessions. During the year these included group meetings on Low clearance and Tolvaptan treatment.

"I didn't feel alone - it's the most amount of people in one room with PKD that I've ever met - it's the most amount of support I've ever felt".

"I don`t always want to discuss the disease with friends or other family members - it`s important to have a forum to express"

Information and Support Days for patients and families affected by ADPKD

We held two **ADPKD Information and Support Days** during the year in Swansea and Birmingham, 272 people registered for the events with 196 people attending. We are indebted to the 15 medical professionals from up and down the country who prepared talks and gave up time over precious weekends to make the events possible.

We were delighted to host our very first PKD Charity event in Wales, hosted by Consultant Nephrologist Dr. Aled Williams and Clinical Nurse Specialist Melanie Pickman, with support from a further 8 speakers. The programme covered a wide range of topics, from the basics of PKD and its genetics, through to dialysis options and the psychosocial aspects of ADPKD, including managing the emotional impact of the condition.

To strengthen community connections, we welcomed Welsh Kidney Charities, Kidney Wales, and Popham Kidney Support to exhibit at the event—helping to demonstrate unity and build support for PKD patients across the region.

"This day event was amazing and helped me realize that I am not alone and that there was lots of other people just like me in the same boat. "

Our second event was held in Birmingham, the last time we were there was in 2017, so it was good to be back. Expertly hosted by Dr Lukas Foggensteiner and Sarah Borrows, supported by the amazing Birmingham team. This was the first PKD charity event that the vast majority of attendees had taken part in and we had excellent feed-back. We held presentations in the morning on topics which included genetics, tolvaptan, and kidney transplants and attendees were given the opportunity to attend their choice of workshops in the afternoon. Attendees could choose from sessions related to staying fit and active with PKD, dialysis options, and managing pain in PKD.

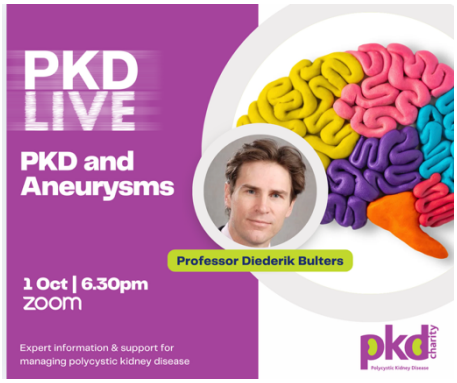
"The event was well run; knowledgeable presenters with very good information and a beautiful venue."

Online events

During the year we held 6 online events and invited medical experts to give talks on specific topics that we had identified as needed by our community. The live evening sessions were incredibly well received and attended by 474 PKD participants. We are indebted to the experts who gave of their time to inform and support the community during the year.

Topics included

- ADPKD Basics
- ADPKD Genetics and Genetic Testing
- PKD and Hypertension
- PKD and Aneurysms
- PKD and Hypertension
- Pain in PKD
- Anaemia in PKD



"Many thanks for organising the aneurysm talk tonight. It was superb. It was pitched at the just the right level and was informative, reassuring and honest."

"I have learnt so much from these sessions and the questions others have asked. Such a helpful and safe environment and very much needed"

"As someone new to the world of PKD, this has been a real eye opener, and I can't imagine not having more of this kind of support as I progress in my PKD journey. This is invaluable."

The benefit of the talks stretches far beyond the attendees able to join the live sessions. Talks from the online information events are recorded and are available on our website and YouTube channel. A further 3,842 people accessed the live sessions broadcast in the year and almost 14,000 users accessing our historic content from previous years.

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

Living Well with PKD Workshops

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

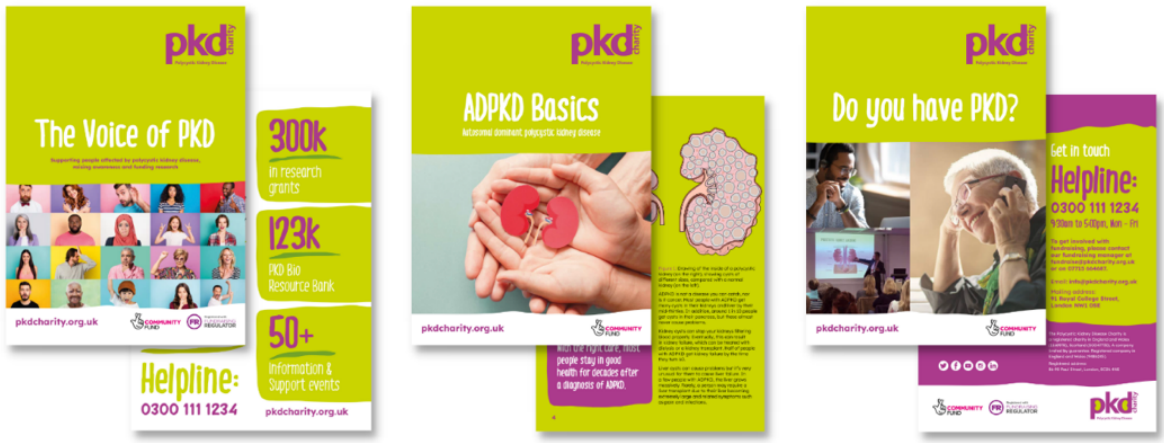
Health information for patients and families

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

Trusted Information Creator
Patient Information Forum

We have Patient Information Forum PIF TICK accreditation, which means that a reader can be assured that what they are reading, watching or listening to is evidence-based, understandable, jargon-free, up-to-date and produced to the best possible standard. During the year we began a major update cycle of our publications with the kind support of a range of medical professionals and our lay review panel.

All the fact sheets are available on our website, and we print booklets where required. Our website had an increase in users and page views over the last 12 months with 20% increase in users and 16% increase in page views.



"As someone new to the world of PKD, this has been a real eye opener and I can't imagine not having more of this kind of information and support as I progress in my PKD journey. This is invaluable."

PKD App

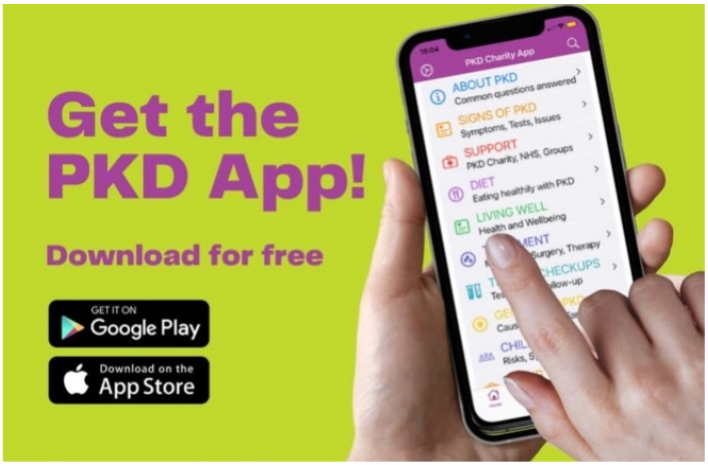
The PKD App was launched in 2022 in partnership with patients and professionals with support from our developer Expert Self Care Ltd. The app is free to download on Apple and Google stores and requires no registration. No personal data is collected.

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

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

The PKD App:

- Provides credible information and health advice all in one place – derived from our PIFTICK accredited information.
- Offers practical tips for everyday life.
- Gives links to trusted further information and available support.
- Provides reassurance to those affected by PKD



During the year the app was downloaded by 671 people with nearly 10,000 page views. We are pleased to see that the App store rating by users in 5/5.

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

PKD awareness/advocacy activities

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

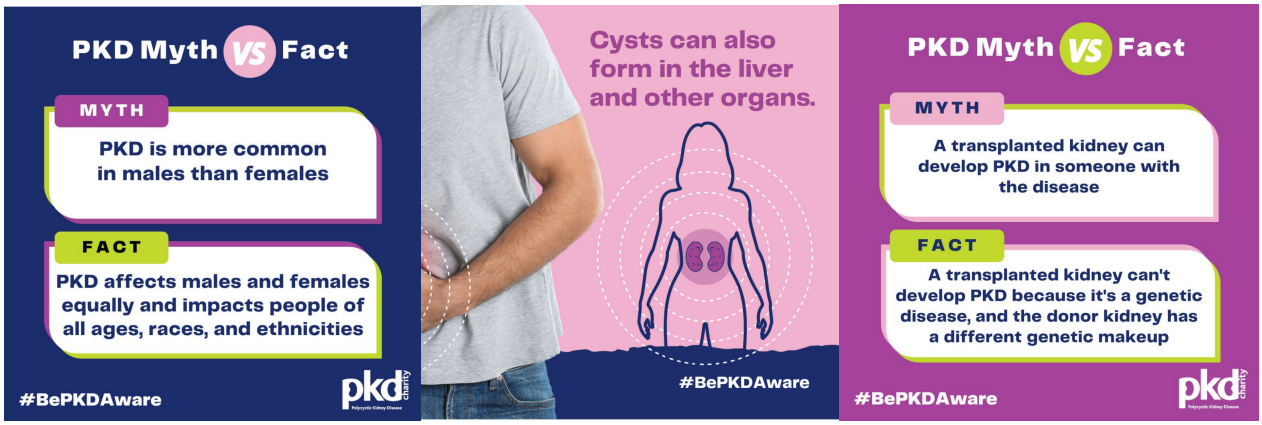
Through social media posts on our Facebook page (10,400 followers), groups, Twitter/X, LinkedIn, Instagram social channels we continued to raise awareness of PKD, kidney health and our services.

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

We published 31 e-newsletters in the year to over 5,000 individuals to keep the community informed. The e-news list grew by 16% over the previous year.

The British Transplant Games, a powerful tribute to organ donors, their families and the amazing resilience of transplant patients, was hosted by Nottingham in August 2024. Over the two days we attended, we connected with PKD families, old and new, sharing information and cheering them on as they competed in the games.

PKD Awareness Week in September. This year we focused on raising awareness of the key symptoms of PKD and debunking common myths, such as the misconception that PKD affects more women than men. The campaign was further amplified by the support of other kidney charities, who helped promote PKD awareness throughout the week. The campaign resulted in high reach and engagement.



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

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

We promoted and aligned our activity with other Awareness days/weeks, including **Rare Disease Day** in February 2025. The focus this year was on the benefits of care coordination for individuals with rare conditions, their caregivers, parents, relatives, healthcare professionals, and healthcare budgets. In a series of videos, young mum Aria candidly discussed the challenges of being mum to a child with a rare, incurable disease.

Advocacy

In June 2024, we attended UK Kidney Week, the UK Kidney Association's primary professional kidney conference. The event was a vital opportunity to connect with medical professionals and introduce our charity to new doctors and nurses.

Support Manager Susan presented an abstract on our App survey, while our Chair Alan gave a presentation honouring Tess Harris, highlighted the charity's achievements, and shared our future plans.

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

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

The Charity is a 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 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. More information here: www.pkdinternational.org

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

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

Community involvement in the work that we do

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

We have approximately 93 (2024: 91) active loyal volunteers and we hugely appreciate the time and commitment they willingly give. They helped us during the year with reviewing health information, providing patient perspectives for research projects, moderating our Facebook groups, hosting support group meetings and taking part in consultations. Their sharing of personal experiences has been invaluable to others going through the PKD patient journey.

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

Community fundraising

We thank all our wonderful fundraisers who supported the Charity's work during 2024-25. They walked miles, ran marathons, organised garden parties, magic shows and plant sales, skydived, shaved their heads, boxed, fundraised at school, work and at home. These diverse events showcased the endless creativity and commitment of our community to raise funds to ensure that PKD Charity can continue to support people affected by PKD and fund life-changing research. 2024-2025 was a fantastic year for team PKD, with a huge number of varied challenges undertaken to support the work we do. Our supporters truly are inspiring.

The year kicked off in style at the London Marathon, where Team PKD had seven runners among the 65,500 participants. Together, they raised over £15,000 to support PKD research and advocacy. September brought more success with the Great North Run in Newcastle, where 17 runners took on the iconic half marathon. Their dedication and hard work were rewarded with over £11,500 raised. Twelve participants also chose to support the charity by taking part in events in the Ultra Challenge series. With various events, from the Isle

of Wight Challenge in May to the London Winter Walk in January. This series remains popular for its flexible distances and funding options, raising a total of £6,457, adding to the year's fantastic fundraising achievements.

In addition to these flagship events, supporters have shown immense creativity and dedication in their own fundraising initiatives. Here are just some examples.

- Ben Brooks and friends completed the Welsh 3000s, raising an incredible £7,421.
- Luke and Jordan Pomeroy organized a football match in memory of their mum, raising £5,110.
- Lee Imrie ran the West Highland Way in just 24 hours, bringing in £2,700.
- In November Victoria Hyde completed a bike ride across Cambodia and raised £1,862.
- Chris Williams and his family travelled all the way to Australia in October to take part in the Melbourne Half Marathon in celebration of him receiving a kidney from his daughter. They raised £2,523.

These large contributions are complemented by many others who raised funds in their own ways and those who give direct donations whether that is through regular giving or one-off donations demonstrating the strength of PKD's supporter community.

It was also a good year for corporate support to the charity. Thrive Tribe chose PKD charity as their fundraising partner for 2024-25. During the course of the year they hosted various fundraising activities, including dress-down days and a staff away day. They also entered three runners in the Great North Run and plan to take part in the Brighton Marathon next April. Interpath was also a great supporter raising £3,234 via the Yorkshire 3 Peaks Challenge in June, followed by a corporate sports day in September, adding another £3,000.

Thanks to each and every participant, fundraiser, and supporter, 2024-25 has been a year of incredible achievements for Team PKD. Without these endeavours and funds, we would simply be unable to the work that we do.

Grant fundraising

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

Grants from other Trusts and 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).

2025-26 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 2025-26, we will:

1) Launch the PKD Research Consortium in partnership with KRUK
2) Recruit and train more patients to provide patient perspectives on research projects and clinical trials
3) Promote the PKD App and our Support Services directly to healthcare professionals
4) Continue to grow and develop local PKD Groups
5) Continue to focus our fundraising strategy on community fundraising
6) Explore how we can meet the needs of the ARPKD community

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 when required. 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 the charity include key dependency on its Chief Executive, risk of loss of supporters, managing regulatory changes, and maintaining a surplus. The trustees regularly review the charity's risk management policies, which include data protection and safeguarding – the charity is registered with the Information Commissioner and requires trustees, staff and some volunteers to undertake Adult Safeguarding Courses. The charity is exposed to financial risks, such as loss of income, which it aims to mitigate by maintaining sufficient reserves while continuing to diversify fundraising, for example, by increasing grant funding.

Fundraising

The charity undertakes most of its fundraising activities in-house and used a consultant solely for the purposes of grant applications. The charity is a member of the **Fundraising Regulator**, providing

reassurance to supporters, members of the public and other donors, and promoting best practice in fundraising. The charity received no complaints about its fundraising practice in this financial year.

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

FINANCIAL REVIEW

Performance

During the 12 months to 31 March 2025, the charity's income was **£347,837** (2024: £453,814).

Expenditure on raising funds as a percentage of total incoming resources was 29% (2024: 17%). Research expenditure was **£40,649** (2024: £67,212). The Charity's expenditure on charitable activities across patient support, awareness and education was **£182,043** (2024: £149,697), which included information days, telephone support, online/chat support and expenditure on the peer support service.

In total, the Charity expended **£377,099** (2024: £332,109), resulting in outgoing resources for the year of **£29,262** (2024: incoming resources of £121,705). Total fund balances at the year-end were **£391,546** (2024: £420,808) and all funds maintained a surplus position at the year-end (Note 18).

Public Benefit

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

Reserves

The Charity maintains a Reserves Policy to hold reserves equivalent to between 3-6 months' ongoing expenditure, after covering current liabilities. As at the year end, the Charity had undesignated free reserves of **£301,564** (2024: £203,248), equivalent to 9 months´ total expenditure (2024: 6 months). The trustees considered that the Charity has sufficient reserves at the year-end and are of the view that the Charity continues to be a going concern.

Approved by the Trustees and signed on their behalf by:

Idriz Adedoja
Trustee-Treasurer

Date: 17th December 2025

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 2025, which are set out on pages 27 - 39.

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:

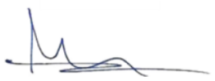
- examine the accounts under section 145 of the 2011 Act and section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 (the 2005 Act)
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act
- to state whether 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: 16th December 2025

STATEMENT OF FINANCIAL ACTIVITIES - 1 APRIL 2024 TO 31 MARCH 2025

(INCORPORATING INCOME AND EXPENDITURE ACCOUNT) FOR THE YEAR ENDED 31 MARCH 2025

	Notes	Restricted Funds 2025 £	Unrestricted Funds 2025 £	Total 2025 £	Total 2024 £
Income from:					
Donations grants and legacies	3	41,655	291,207	332,862	445,990
Charitable activities	4	-	-	-	-
Other trading activities	5	-	6,388	6,388	5,559
Investment income	6	-	8,587	8,587	2,265
Total income		**41,655**	**306,182**	**347,837**	**453,814**
Expenditure on:					
Cost of fundraising	7	-	97,996	97,996	78,446
Non-charitable trading activities	7	-	4,266	4,266	5,062
Total		-	**102,262**	**102,262**	**83,508**
Research and grants	8	40,649	-	40,649	67,212
Awareness and education		-	66,231	66,231	38,926
Patient support		41,655	73,783	115,438	108,803
Depreciation	14	374	-	374	1,968
Total		**82,677**	**140,014**	**222,692**	**216,909**
Other expenditure					
Governance costs	9	-	52,145	52,145	31,692
Total expenditure		**82,677**	**294,421**	**377,099**	**332,109**
Net income / (expenditure) for the year		(41,022)	11,761	(29,262)	121,705
Fund balances brought forward at 1 April	18	50,275	370,533	420,808	299,103
Net incoming resources for the year	18	(41,022)	11,761	(29,262)	121,705
Transfers between funds	18	80,747	(80,747)	-	-
Fund balances carried forward	18	**90,000**	**301,546**	**391,546**	**420,808**

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 27 - 39 form part of these financial statements.

BALANCE SHEET AT 31 MARCH 2025

	Notes	2025	2024
		£	£
FIXED ASSETS			
Tangible assets	14	**1,979**	**-**
CURRENT ASSETS			
Debtors	15	25,043	22,141
Cash at bank		499,336	599,339
Total current assets		**524,379**	**621,480**
Liabilities			
Creditors: Amounts falling due within one year	16	134,812	185,988
NET CURRENT ASSETS		**389,567**	**435,493**
Total assets less current liabilities		391,546	435,493
Creditors: Amounts falling due after more than one year	17	-	14,684
NET ASSETS		**391,546**	**420,808**
The funds of the Charity:			
Unrestricted funds - Designated	18	-	167,285
Unrestricted funds - General	18	301,546	203,248
Restricted funds	18	90,000	50,275
TOTAL FUNDS		**391,546**	**420,808**

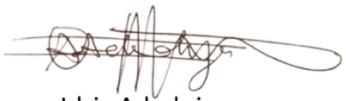
The company was entitled to exemption from audit under section 477 of the Companies Act 2006.

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

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

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

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



Idriz Adedoja
Trustee-Treasurer

Date: 17th December 2025

The notes on pages 27 - 39 form an integral part of these accounts.

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2025

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 2025

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 2025

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 2025

3. DONATIONS, GRANTS AND LEGACIES

	Restricted funds 2025 £	Unrestricted funds 2025 £	Total Funds 2025 £	Total Funds 2024 £
Donations and gifts	-	268,161	289,243	368,890
Trusts, foundations and grants	41,655	-	60,738	50,986
Gift Aid	-	23,046	23,046	26,114
Total 2025	**41,655**	**291,207**	**375,027**	**445,990**
Total 2024	**51,935**	**394,055**	**445,990**	

4. INCOME FROM CHARITABLE ACTIVITIES

	Restricted funds 2025 £	Unrestricted funds 2025 £	Total Funds 2025 £	Total Funds 2024 £
Patient research	-	-	-	
Total 2025	-	**-**	**-**	-
Total 2024	-	-	-	

5. INCOME FROM OTHER TRADING ACTIVITIES

	Restricted funds 2025 £	Unrestricted funds 2025 £	Total Funds 2025 £	Total Funds 2024 £
Shop and other income	-	6,388	6,388	5,559
Total 2025	-	**6,388**	**6,388**	**5,559**
Total 2024	-	5,559	5,559	

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2025

6. INVESTMENT INCOME

	Restricted funds 2025 £	Unrestricted funds 2025 £	Total Funds 2025 £	Total Funds 2024 £
Interest income	-	8,587	8,587	2,265
Total 2025	-	**8,587**	**8,587**	**2,265**
Total 2024	-	2,265	2,265	

7. EXPENDITURE ON RAISING FUNDS

	Restricted funds 2025 £	Unrestricted funds 2025 £	Total Funds 2025 £	Total Funds 2024 £
Cost of fundraising	-	97,996	97,996	78,446
Cost of goods sold	-	4,266	4,266	5,062
Total 2025	**-**	**102,262**	**102,262**	**83,508**
Total 2024	-	83,508	83,508	

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2025

8. ANALYSIS OF RESEARCH AND GRANTS

	2025 £	2024 £
Bio Resource Bank	10,000	10,000
ADPKD Research	-	20,000
PKD Consortium	10,174	-
Kidney Research UK	-	-
Staff, subcontractor and other costs	20,475	14,278
Newcastle University	-	14,684
University of Edinburgh	-	8,250
Total:	**40,649**	**67,212**

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

Details of material grants are disclosed in the Trustees Report.

9. GOVERNANCE COSTS

	2025 £	2024 £
Trustee meetings and governance	885	410
Accountancy and audit	13,762	15,298
Other professional fees	7,274	3,362
Staffing costs	30,223	12,622
Total:	**52,145**	**31,692**

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025

10. EMPLOYMENT COSTS

	2025 £	2024 £
Wages and salaries	191,697	141,612
Social security costs	13,578	8,859
Defined contribution pension costs	3,521	3,300
Total:	**208,796**	**153,771**

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

As at 31 March 2025, no pension contributions were owed by the Charity (2024: £Nil).

The average number of staff employed by the Charity during the year was 6 (2024: 6), with a full time equivalent of 4 (2024: 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 £195,219 (2024: £144,912).

11. NET INCOME/(EXPENDITURE) FOR THE YEAR

This is stated after charging:	2025 £	2024 £
Independent Examiners Remuneration	-	-
Depreciation	374	1,968
Total:	**374**	**1,968**

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 £167 (2024: £89), payable to 1 Trustee (2024: 1).

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025

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. TANGIBLE FIXED ASSETS

	2025 £ Office equipment
Cost	
At 1 April 2024	29,209
Additions	2,353
Disposals	-
At 31 March 2025	**31,562**
Accumulated depreciation	
At 1 April 2024	29,209
Charge for the year	374
Disposals	-
At 31 March 2025	**29,583**
Net Book Value	
At 1 April 2024	-
At 31 March 2025	**1,979**

15. DEBTORS

	2025 £	2024 £
Prepayments	21,729	21,087
Accrued income	2,268	-
Other debtors	1,046	1,055
Total debtors	**25,043**	**22,142**

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025

16. LIABILITIES: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2025	2024
	£	£
Trade creditors	5,899	14,781
Accruals and deferred income	46,512	18,626
Other creditors	1,818	555
Grant commitments (Note 20)	80,583	152,026
Total current liabilities	**134,812**	**185,988**

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

	2025	2024
	£	£
Grant commitments within five years (Note 20)	-	**14,684**

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025

18. FUNDS AND RESERVES – CURRENT YEAR

Unrestricted Funds	Total funds at 01/04/24	Income	Expenditure	Transfer	Total funds at 31/03/25
Research	90,000	275	(12,877)	(77,398)	-
National Lottery – Matched Funding	77,285	-	-	(77,285)	-
General fund	203,243	305,907	(281,545)	73,936	301,546
Total funds	**370,533**	**306,182**	**(294,422)**	**(80,747)**	**301,546**

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 01/04/24	Income	Expenditure	Transfer	Total funds at 31/03/25
ARPKD Research	-	-	(260)	260	-
Research	50,275	-	(40,649)	80,474	90,000
National Lottery - PPP	-	41,655	(41,743)	88	-
Trusts and Foundations	-	-	-	-	-
Pears Grant	-	-	(25)	25	-
Ciliaren	-	-	-	-	-
PPIE	-	-	-	-	-
Total funds	**50,275**	**41,655**	**(82,677)**	**80,747**	**90,000**

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.

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025

18. FUNDS AND RESERVES – PRIOR YEAR

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

Restricted Funds	Total funds at 01/04/23	Income	Expenditure	Transfer	Total funds at 31/03/24
ARPKD Research	-	-	-	-	-
Research	50,275	300	(300)	-	50,275
European PKD Conference	-	49,986	(110,771)	60,785	-
National Lottery - PPP	-	1,000	(1,000)	-	-
National Lottery – Nurse Co-ordinator	-	649	(649)	-	-
PKDC/KRUK Research	-	-	(36)	36	-
Total funds	**50,275**	**51,935**	**(112,756)**	**60,821**	**50,275**

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2025

19. ANALYSIS OF NET ASSETS BETWEEN FUNDS – CURRENT YEAR

	Unrestricted funds 2025 £	Restricted funds 2025 £	Total funds 2025
Tangible fixed assets	1,979	-	1,979
Current assets	353,796	170,583	524,379
Creditors due within one year	(54,229)	(80,583)	(134,812)
Creditors due in more than one year	-	-	-
Total:	**301,546**	**90,000**	**433,711**

ANALYSIS OF NET ASSETS BETWEEN FUNDS – PRIOR YEAR

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

20. GRANT COMMITMENTS

	£
Balance at 1 April 2024	166,710
New commitments	-
Cancelled commitments	-
Commitments paid	(86,127)
Balance at 31 March 2025	**80,583**

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025

21. RELATED PARTY TRANSACTIONS

	2025	2024	
Donations Received from Trustees	724	624	1 Trustees (2024: 1) made donations during the year
Grants to related parties	-	-	

THE POLYCYSTIC KIDNEY DISEASE CHARITY

England & Wales - Charity number 1160970

Accounts

THE POLYCYSTIC KIDNEY DISEASE CHARITY

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

Polycystic Kidney Disease Charity |Registered charity in England and Wales (1160970) | Registered charity in Scotland (SC047730) | A company limited by guarantee
Registered company in England and Wales (9486245) |Registered address: 86-90 Paul Street, London, EC2A 4NE

ANNUAL REPORT AND ACCOUNTS 2023-2024

CONTENTS

REFERENCE AND ADMINISTRATIVE INFORMATION 3
TRUSTEES ANNUAL REPORT & DIRECTORS' REPORT 4
WELCOME FROM THE CHAIR 4
OBJECTIVES AND AIMS 5
About PKD 5
Charitable objects 6
Our objectives and activities 6
PERFORMANCE AND ACHIEVEMENTS DURING 2023-24 8
Research activities during 2023-24 8
Support services for people, carers and families affected by PKD 10
PKD App 15
PKD awareness/advocacy activities 17
Community involvement in the work that we do 19
Community fundraising 20
Grant fundraising 21
Pro bono support 21
2024-25 plans 21
STRUCTURE, GOVERNANCE AND MANAGEMENT 22
Constitution 22
Trustees 22
Governance and administration 22
Risk Management 22
Fundraising 22
FINANCIAL REVIEW 23
Independent Examiner's Report to the Trustees of the Polycystic Kidney Disease Charity 24
STATEMENT OF FINANCIAL ACTIVITIES - 1 April 2023 TO 31 MARCH 2024 25
BALANCE SHEET AT 31 MARCH 2024 26
NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2024 28

REFERENCE AND ADMINISTRATIVE INFORMATION

Principal address and registered office:
86-90 Paul Street
London
EC2A 4NE

Tel: 020 7387 0543
Email: info@pkdcharity.org.uk
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 Idriz Adedoja
Mr Raj Johal
Ms Rebecca Murphy-Peers
Mr Jon Rees
Mrs Karen Stapleton
Mr Adrian Tinsley
Mr Nicholas Tracey (retired 24th January 2024)
Professor Patricia Wilson
Mr Alexander Vickerman (appointed 10 October 2023)

Research Advisory Board

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

Chief Executive

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

Patrons

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

Professional advisors

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

Accountants
PEM
Salisbury House
Station Road
Cambridge, CB1 2LA

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

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

TRUSTEES ANNUAL REPORT & DIRECTORS' REPORT

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

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

WELCOME FROM THE CHAIR

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

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

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

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

Alan Greenberg, Chair, Board of Trustees

Date: 24th December 2024

OBJECTIVES AND AIMS

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

About PKD

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

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

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

ADPKD – the more common form of PKD

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

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

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

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

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

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

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

Charitable objects

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

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

Our objectives and activities

Research

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

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

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

Information, awareness, and advocacy

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

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

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

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

Support

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

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

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

PERFORMANCE AND ACHIEVEMENTS DURING 2023-24

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

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

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

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

Research activities during 2023-24

PKD Charity and Kidney Research UK partnership

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

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

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

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

Research grants

The PKD Charity trustees approved:

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

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

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

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

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

ADPKD research priorities

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

Patient involvement

We were asked to support research projects and invite our community to provide feedback on a variety of grant applications. During the year we received more approaches than ever before not only to support patient involvement in research into PKD, but also to provide patients to sit on steering groups for major new projects which is hugely encouraging. Our new Patient Involvement and Engagement Officer coordinates aspects of this work, finding and supporting participants. We

are indebted to the increasing numbers of patients who are volunteering to take part in these projects and over the coming year we will be investing more resources to support these initiatives.

Other research activities

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

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

Support services for people, carers and families affected by PKD

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

Phone and Facebook support

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

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

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

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

Support group meetups

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

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

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

Information & Support Days for patients and families affected by ADPKD

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

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

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

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

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

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

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

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

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

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

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

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

Online events

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

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

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

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

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

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

Living Well with PKD Workshops

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

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

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

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

Health information for patients and families

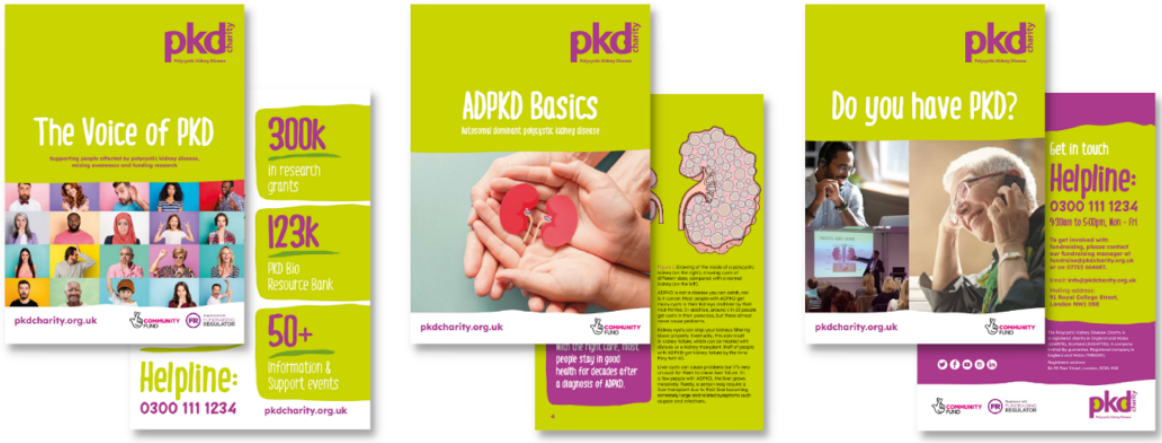
Providing accurate, clear and up to date information to the PKD community is a central focus of our mission. Information is key for patients and families to understand PKD, be able to support their own needs and bee truly involved in care decisions. We provide information via events, our website, printed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

Trusted Information Creator
Patient Information Forum

We have Patient Information Forum PIF TICK accreditation, which means that a reader can be assured that what they are reading, watching or listening to is evidence-based, understandable, jargon-free, up-to-date and produced to the best possible standard. This has

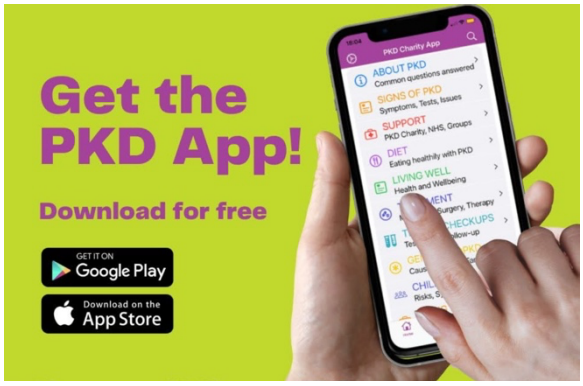
enabled us to improve the distribution of our fact sheets, in particular to GPs via online directories, such as Healthinote.

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



PKD App

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



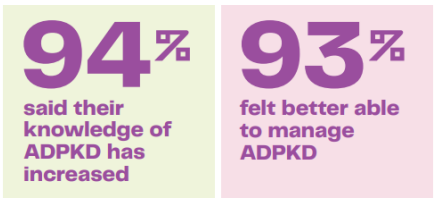
Android Google Play: PKD App
iPhone App Store: PKD App

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

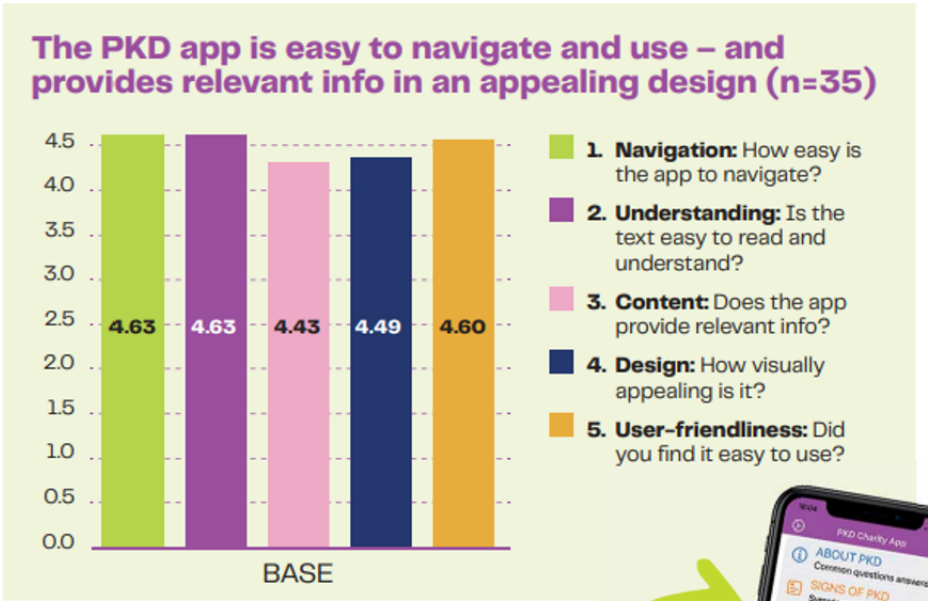
The PKD App:

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

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



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



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

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

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

PKD awareness/advocacy activities

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

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

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

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

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

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

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

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

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

Advocacy

Throughout the year, members of staff attended and participated in conferences, workshops and events relevant to PKD, kidney, liver, genetic and rare diseases. These included **UK Kidney Week Conference**, the **ANN UK (Association of Nephrology Nurses in the UK) Annual Conference** and the **British Association of Paediatric Nephrologists/Paediatric Nephrology Nurses Group** Conference.

The Charity continues as a member of **Kidney Charities Together** (KCT) working collaboratively to be the single powerful voice for all kidney patients in the UK. Other member charities include Kidney Care UK, Kidney Research UK, the National Kidney Federation, Kidney Wales, the UK Kidney Association.

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

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

cluster of conditions called renal ciliopathies, which include ADPKD and ARPKD.

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

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

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

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

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

Community involvement in the work that we do

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

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

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

Community fundraising

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

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

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

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

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

Grant fundraising

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

Pro bono support

We acknowledge and thank:

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

2024-25 PLANS

Our long-term goals are:

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

In 2024-25, we will:

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

STRUCTURE, GOVERNANCE AND MANAGEMENT

Constitution

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

Trustees

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

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

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

Governance and administration

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

Risk Management

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

Fundraising

The charity undertakes most of its fundraising activities in-house and used a consultant solely for the purposes of grant applications. The charity is a member of the **Fundraising Regulator**, providing

reassurance to supporters, members of the public and other donors, and promoting best practice in fundraising. The charity received no complaints about its fundraising practice in this financial year.

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

FINANCIAL REVIEW

Performance

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

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

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

Public Benefit

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

Reserves

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

Approved by the Trustees and signed on their behalf by

Idriz Adedoja
Trustee-Treasurer

Date: 24th December 2024

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

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

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

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

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

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

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

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

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

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

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

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

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

All of the above amounts relate to continuing activities.

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

BALANCE SHEET AT 31 MARCH 2024

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

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

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

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

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

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

Idriz Adedoja
Trustee-Treasurer

Date: 24th December 2024

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

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

1. GENERAL INFORMATION

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

86-90 Paul Street
London
NC24 4NE

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

2. ACCOUNTING POLICIES

The principal accounting policies adopted are as follows:

i) Basis of preparation

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

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

ii) Going Concern

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

iii) Incoming Resources

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

iv) Investment Income

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

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

v) Resources Expended

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

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

vi) Grants

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

vii) Government grants

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

viii) Tangible fixed assets and depreciation

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

ix) Current asset investments

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

x) Debtors

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

xi) Pensions

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

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

xii) Creditors and provisions

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

xiii) Financial instruments

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

xiv) Funds Structure

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

xv) Fund Accounting

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

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

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

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

3. DONATIONS, GRANTS AND LEGACIES

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

4. INCOME FROM CHARITABLE ACTIVITIES

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

5. INCOME FROM OTHER TRADING ACTIVITIES

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

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

6. INVESTMENT INCOME

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

7. EXPENDITURE ON RAISING FUNDS

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

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

8. ANALYSIS OF RESEARCH AND GRANTS

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

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

Details of material grants are disclosed in the Trustees Report.

9. SUPPORT COSTS

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

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

10. EMPLOYMENT COSTS

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

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

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

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

No employee received total benefits exceeding £60,000.

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

11. NET INCOME/(EXPENDITURE) FOR THE YEAR

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

12. TRUSTEE REMUNERATION & EXPENSES

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

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

13. TAXATION

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

14. ANALYSIS OF MOVEMENT OF FIXED ASSETS

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

15. DEBTORS

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

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

16. LIABILITIES: AMOUNTS FALLING DUE WITHIN ONE YEAR

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

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

	2024	2023
	£	£
Grant commitments within five years (Note 20)	**14,684**	**130,000**

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

18. FUNDS AND RESERVES – CURRENT YEAR

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

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

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

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

Research – Research related to PKD.

ADPKD Research – Research related solely to ADPKD.

ARPKD Research – Research related solely to ARPKD.

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

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

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

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

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

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

18. FUNDS AND RESERVES – PRIOR YEAR

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

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
European PKD Conference	-	-	-	-	-
National Lottery - PPP	14,368	83,995	(186,293)	87,930	-
National Lottery – Nurse Co-ordinator	28,002	-	-	(28,002)	-
PKDC/KRUK Research	150,000	-	(150,000)	-	-
Total funds	**195,720**	**94,445**	**(339,648)**	**99,758**	**50,275**

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

19. ANALYSIS OF NET ASSETS BETWEEN FUNDS – CURRENT YEAR

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

ANALYSIS OF NET ASSETS BETWEEN FUNDS – PRIOR YEAR

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

20. GRANT COMMITMENTS

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

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

21. RELATED PARTY TRANSACTIONS

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

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

Employment Related Parties

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

THE POLYCYSTIC KIDNEY DISEASE CHARITY

England & Wales - Charity number 1160970

Accounts

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THE POLYCYSTIC KIDNEY DISEASE CHARITY

Report of the Board of Trustees and Accounts – 1 April 2022 to 31 March 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: 86-90 Paul Street, London, EC2A 4NE

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ANNUAL REPORT AND ACCOUNTS 2022-2023

CONTENTS

REFERENCE AND ADMINISTRATIVE INFORMATION 3
TRUSTEES ANNUAL REPORT & DIRECTORS' REPORT 4
WELCOME FROM THE CHAIR 4
OBJECTIVES AND AIMS 5
About PKD 5
Charitable objects 6
Our objectives and activities 6
PERFORMANCE AND ACHIEVEMENTS DURING 2022-23 8
Research activities during 2022-23 8
Support services for people, carers and families affected by PKD 10
PKD Exercise App – in collaboration with 'Kidney Beam' 12
Information and Support event for parents of children affected by ARPKD 15
PKD awareness/advocacy activities 18
Community involvement in the work that we do 22
Community fundraising 22
Grant fundraising 23
Pro bono support 23
2023-24 plans 23
STRUCTURE, GOVERNANCE AND MANAGEMENT 24
Constitution 24
Trustees 24
Governance and administration 24
Risk Management 24
Fundraising 25
FINANCIAL REVIEW 25
Independent Examiner's Report to the Trustees of the Polycystic Kidney Disease Charity 27
STATEMENT OF FINANCIAL ACTIVITIES - 1 April 2021 TO 31 MARCH 2023 28
BALANCE SHEET AT 31 MARCH 2023 29
NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2023 31

DocuSign Envelope ID: F5BC5970-9DB7-42C3-B8C8-FEF3875274F6

REFERENCE AND ADMINISTRATIVE INFORMATION

Principal address and registered office:
86-90 Paul Street
London
EC2A 4NE

Tel: 020 7387 0543
Email: info@pkdcharity.org.uk
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

Professional advisors

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

Accountants
PEM
Salisbury House
Station Road
Cambridge, CB1 2LA

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

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

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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 1st 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

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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.

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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.

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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.

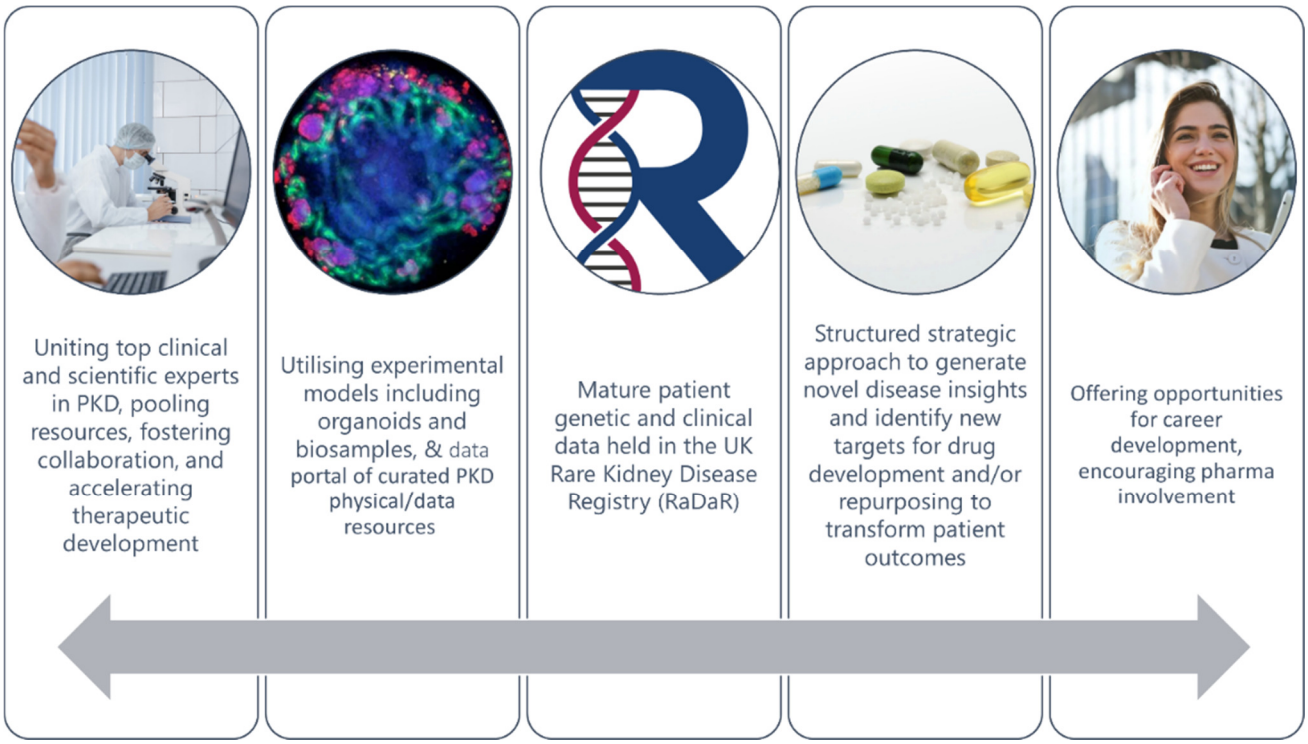

Image: 3 – Collaboration for improved patient outcomes in the PKD Research Consortium

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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.

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Other research activities

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

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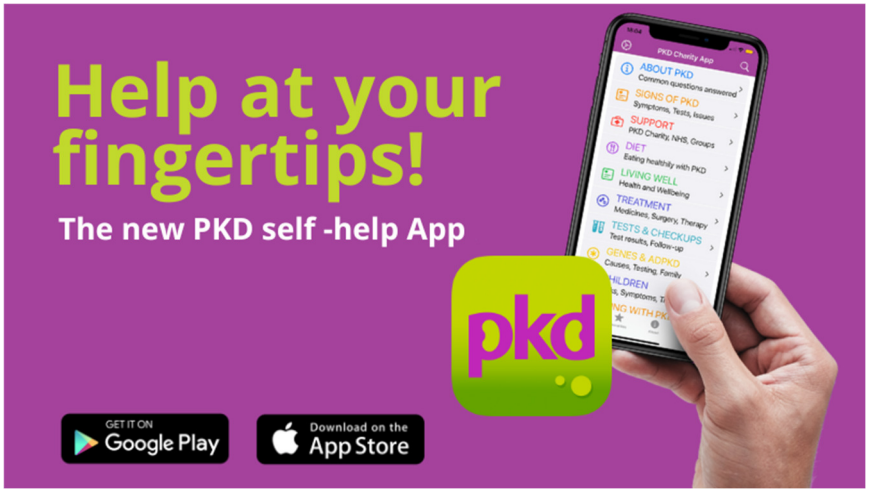
PKD App



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 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 difficulties (despite using a professional company). We decided that live streaming was not feasible and too costly for future events.

"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 10th 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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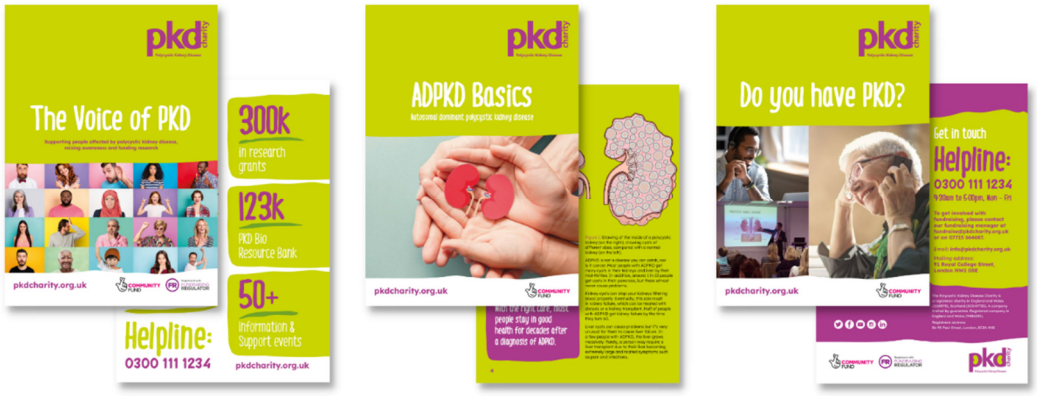
Health information for patients and families

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 'Tweetorial'

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).

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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.

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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.

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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

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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."

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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.

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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.

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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.

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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

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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

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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 £
Income from:					
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
Total income		**94,445**	**291,775**	**386,220**	**348,243**
Expenditure on:					
Cost of fundraising	7	-	84,320	84,320	67,075
Non-charitable trading activities	7	-	1,557	1,557	2,598
Total		-	**85,877**	**85,877**	**69,673**
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
Total		**339,648**	**60,529**	**400,177**	**227,519**
Other expenditure					
Support costs	9	-	22,575	22,575	27,001
Total expenditure		**339,648**	**168,981**	**508,629**	**324,193**
Net income / (expenditure) for the year		(245,203)	122,794	(122,409)	24,050
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)	-	-
Fund balances carried forward	18	**50,275**	**248,828**	**299,103**	**421,512**

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.

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BALANCE SHEET AT 31 MARCH 2023

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

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.

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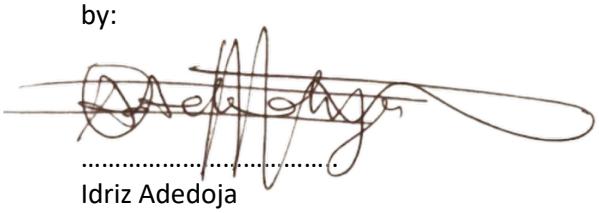
The financial statements were approved by the Trustees and authorised for issue and signed on their behalf by:



……
Idriz Adedoja
Trustee-Treasurer

Date: 22 December 2023

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

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

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.

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

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.

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

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.

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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
Total 2023	**94,445**	**273,219**	**367,664**	**339,288**
Total 2022	53,425	285,863	339,288	

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	-
Total 2023	-	**8,735**	**8,735**	**-**
Total 2022	-	-	-	

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
Total 2023	-	**7,361**	**7,361**	**7,081**
Total 2022	-	7,081	7,081	

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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
Total 2023	-	**2,460**	**2,460**	**1,874**
Total 2022	-	1,874	1,874	

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
Total 2022	**-**	**85,877**	**85,877**	**69,673**
Total 2021	-	69,673	69,673	

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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
Total:	**177,340**	**90,626**

	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
Total:	**5**	**4**

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
Total:	**22,575**	**27,001**

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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
Total:	**147,200**	**133,668**

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
This is stated after charging:	£	£
Independent Examiners Remuneration	-	-
Depreciation	5,904	5,904
Total:	**5,904**	**5,904**

12. TRUSTEE REMUNERATION & EXPENSES

The Trustees were not remunerated by the Charity for their services during the year. Total expenses reimbursed during the year totalled £Nil (2022: £Nil).

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

15. DEBTORS

	2023 £	2022 £
Prepayments	15,271	7,100
Accrued income	-	-
Other debtors	434	683
Total debtors	**15,705**	**7,783**

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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
Total current liabilities	**107,967**	**84,809**

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

	2023	2022
	£	£
Grant commitments within five years (Note 20)	**130,000**	**45,000**

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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
Total funds	**225,792**	**291,775**	**(168,981)**	**(99,758)**	**248,828**

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)	-	-
Total funds	**195,720**	**94,445**	**(339,648)**	**99,758**	**50,275**

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
Total funds	**301,671**	**294,818**	**(135,215)**	**(235,482)**	**225,792**

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
Total funds	**95,791**	**53,425**	**(188,978)**	**235,482**	**195,720**

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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)
Total:	**248,828**	**50,275**	**299,103**

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)
Total:	**195,720**	**225,792**	**421,512**

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	**204,960**

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

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:

Employment Related Parties

Trustee	Employee	2023	2022
Alan Greenberg	Louise Greenberg	1,800	5,848

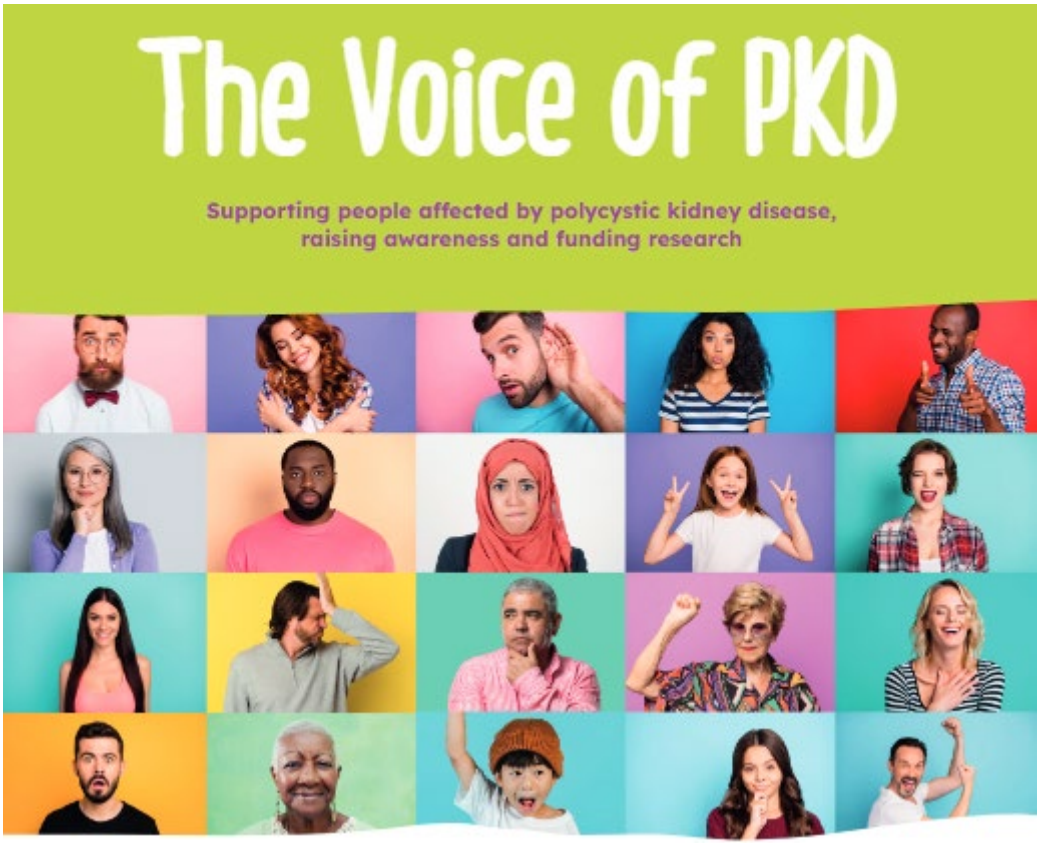
THE POLYCYSTIC KIDNEY DISEASE CHARITY

England & Wales - Charity number 1160970

Accounts

THE POLYCYSTIC KIDNEY DISEASE CHARITY

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



Polycystic Kidney Disease Charity |Registered charity in England and Wales (1160970) | Registered charity in Scotland (SC047730) | A company limited by guarantee
Registered company in England and Wales (9486245) |Registered address: 86-90 Paul Street, London, EC2A 4NE

ANNUAL REPORT AND ACCOUNTS 2021-2022

CONTENTS

REFERENCE AND ADMINISTRATIVE INFORMATION 3
TRUSTEES ANNUAL REPORT & DIRECTORS' REPORT 4
WELCOME FROM THE CHAIR 4
OBJECTIVES AND AIMS 5
About PKD 5
Charitable objects 6
Our objectives and activities 6
PERFORMANCE AND ACHIEVEMENTS DURING 2021-22 7
Ongoing impact of COVID-19 7
Research activities during 2021-22 8
Support services for people, carers and families affected by PKD 9
Survey of the PKD Community to assess performance 13
PKD awareness activities 14
Community involvement in the work that we do 17
Community fundraising 17
Grant fundraising 18
Pro bono support 18
2022-23 plans 18
STRUCTURE, GOVERNANCE AND MANAGEMENT 19
Constitution 19
Trustees 19
Governance and administration 19
Risk Management 19
Fundraising 20
FINANCIAL REVIEW 20
Independent Examiner's Report to the Trustees of the Polycystic Kidney Disease Charity 22
STATEMENT OF FINANCIAL ACTIVITIES - 1 April 2021 TO 31 MARCH 2022 23
BALANCE SHEET AT 31 MARCH 2022 24
NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022 26

REFERENCE AND ADMINISTRATIVE INFORMATION

Principal address and registered office:
86-90 Paul Street
London
EC2A 4NE

Tel: 020 7387 0543
Email: info@pkdcharity.org.uk
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

Professional advisors

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

Accountants
PEM
Salisbury House
Station Road
Cambridge, CB1 2LA

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

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

TRUSTEES ANNUAL REPORT & DIRECTORS' REPORT

The Trustees, who are also directors of the Charity for the purpose of the Companies Act, present their annual report and financial statements of the Charity for the year ended 31 March 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

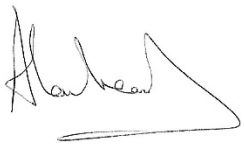
2021-2022 continued to be a challenging time for the Charity with the continued impact of COVID-19. We were still unable to deliver face-face 'in person' events and we experienced a small reduction of income compared to the previous year.

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

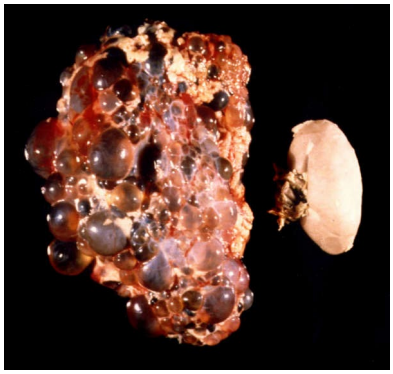
The Polycystic Kidney Disease (PKD) Charity is the only UK charity solely dedicated to improving the lives of children, adults, families, and carers affected by **polycystic kidney disease** (PKD). The Charity was formed in 2000 by a PKD patient and a genetics consultant. Throughout the past 20 years, 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 & Drink Administration (FDA), European Medicines Agency (EMA) and the Medicines and Healthcare products Regulatory Agency (MHRA) in the UK). The chief executive and PKD Charity Research Advisory Board (RAB) members attended monthly meetings.
- The Standardised Outcomes in Nephrology Group (SONG) - 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.".*

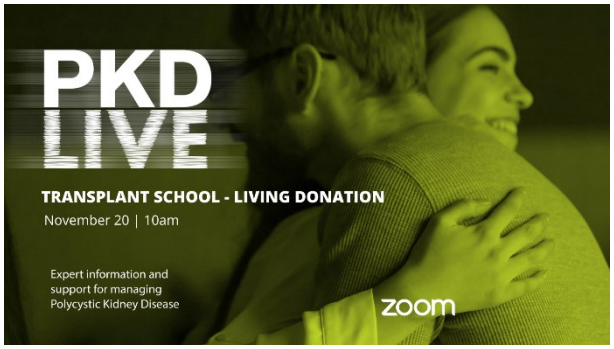
As last year, despite the interest, attendance numbers are typically about 60% of those registered, with about 7 people attending each event on average.

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.

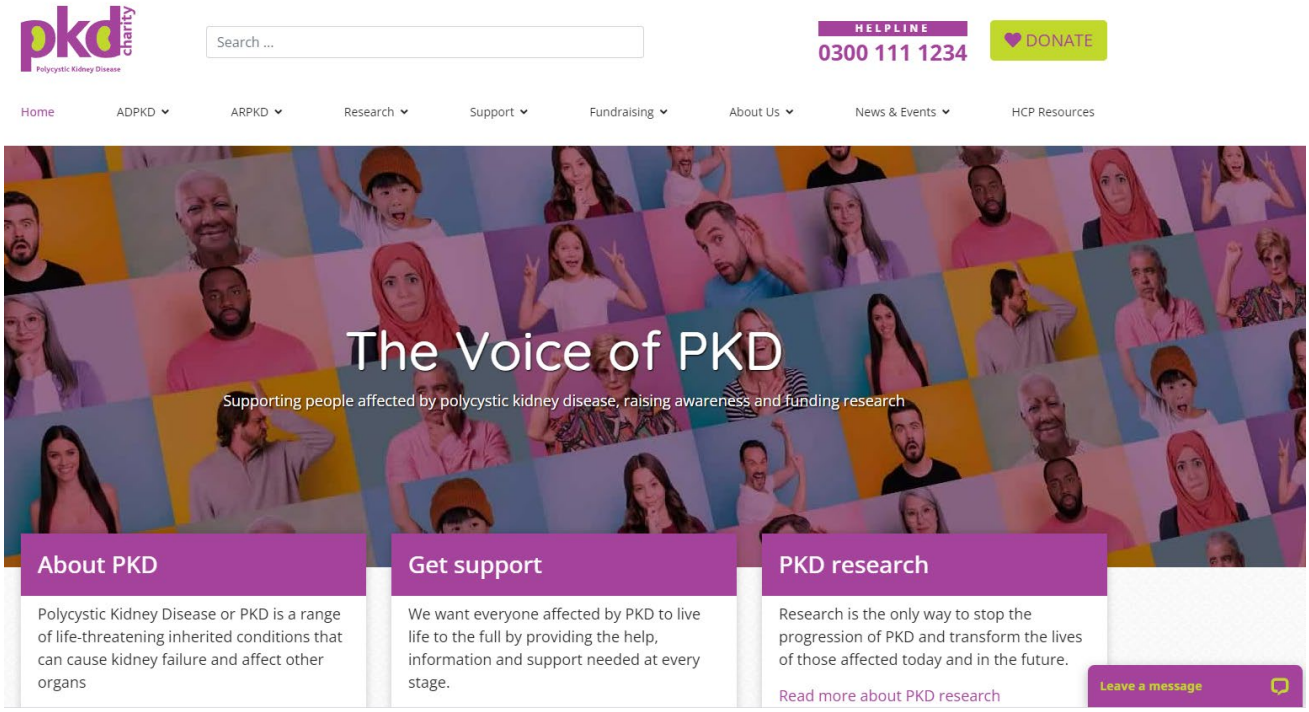
We reviewed and updated our information production processes and applied to the Patient Information for PIF TICK accreditation (achieved in May 2022).

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."

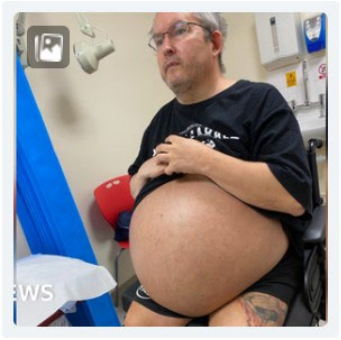
"I am extremely thankful for the charity. I have always felt supported and heard. As a mother that is young, I have often received inadequate care for my daughter and felt that I am often shrugged off. The PKD Charity has never made me feel this way, they are accepting and kind and always make you feel 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.



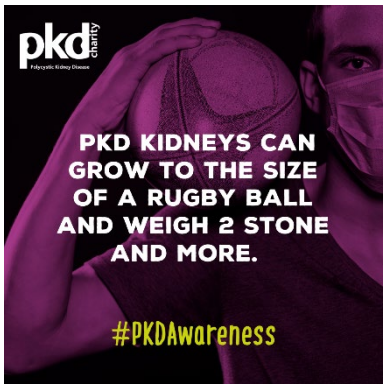
Popular posts included Warren's story of a life-or-death decision to remove both of his enormous kidneys – he shared his story with us and also via public media including the BBC. It was estimated that his kidneys weighed 35 kg after removal, the world's largest recorded.

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 was part of this campaign. Facts and statistics about PKD achieved exceptionally high organic reach and engagement on Facebook and Instagram, whist the launch of the research awards captured the media's interest on Twitter.

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.

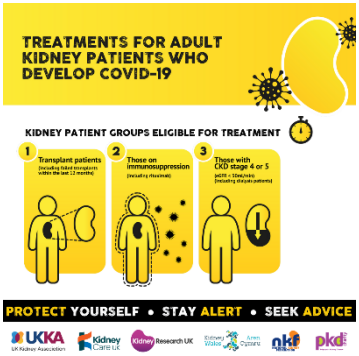
For the first time, PKD had a strong voice in the campaign by featuring the story of young mum, Lindsay, who hopes to donate a kidney to her husband, PKD patient Richard. Their story achieved the highest reach and dwell time across the whole campaign.

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

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.

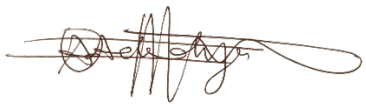
Reserves

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



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 £
Income from:					
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
Total income		**53,425**	**294,818**	**348,243**	**361,800**
Expenditure on:					
Cost of fundraising	6	-	67,075	67,075	61,792
Non-charitable trading activities	6	-	2,598	2,598	7,958
Total		-	**69,673**	**69,673**	**69,750**
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
Total		**188,978**	**38,541**	**227,519**	**176,257**
Other expenditure					
Governance costs	8	-	27,001	27,001	21,789
Total expenditure		**188,978**	**135,215**	**324,193**	**267,797**
Net income / (expenditure) for the year		(135,553)	159,603	24,050	94,004
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)	-	-
Fund balances carried forward	17	**195,720**	**225,792**	**421,512**	**397,462**

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

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

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

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

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

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

Idriz Adedoja
Trustee Treasurer
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

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

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

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
Total 2022	**53,425**	**285,863**	**339,288**	**346,325**
Total 2021	174,557	171,728	346,325	

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
Total 2022	-	**7,081**	**7,081**	**13,602**
Total 2021	-	13,602	13,602	

5. INVESTMENT INCOME

	Restricted funds 2022 £	Unrestricted funds 2022 £	Total Funds 2022 £	Total Funds 2021 £
Interest income	-	1,874	1,874	1,913
Total 2022	-	**1,874**	**1,874**	**1,913**
Total 2021	-	1,913	1,913	

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
Total 2022	**-**	**69,673**	**69,673**	**69,750**
Total 2021	-	69,750	69,750	

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
Total:	**90,626**	**70,803**

	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	-
Total:	**4**	**3**

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
Total:	**27,001**	**21,789**

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
Total:	**133,668**	**148,127**

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

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

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

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

14. DEBTORS

	2022 £	2021 £
Prepayments	7,100	9,754
Accrued income	-	-
Other debtors	683	-
Total debtors	**7,783**	**9,754**

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

15. LIABILITIES: AMOUNTS FALLING DUE WITHIN ONE YEAR

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

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

	2022	2021
	£	£
Grant commitments within five years (Note 18)	**45,000**	**10,000**

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
Total funds	**301,671**	**294,818**	**(135,215)**	**(235,482)**	**225,792**

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
Total funds	**95,791**	**53,425**	**(188,978)**	**235,482**	**195,720**

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
Total funds	**257,006**	**187,243**	**(126,650)**	**(15,928)**	**301,671**

	Total funds at 01/04/20	Income	Expenditure	Transfer	Total funds at 31/3/21
Restricted Funds					
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
Total funds	**46,452**	**174,557**	**(141,146)**	**15,928**	**95,791**

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)
Total:	**195,720**	**225,792**	**421,512**

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)
Total:	**301,671**	**95,791**	**397,462**

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	**124,113**

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 the decision to appoint. The details are as follows:

Employment Related Parties

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

THE POLYCYSTIC KIDNEY DISEASE CHARITY

England & Wales - Charity number 1160970

Accounts

IMPROVING THE LIVES OF EVERYONE AFFECTED BY POLYCYSTIC KIDNEY DISEASE

Trustees' Annual Report and Accounts – 1 April 2020 to 31 March 2021

PKD supporter raising awareness of COVID-19 vaccination in early 2021

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

ANNUAL REPORT AND ACCOUNTS 2020-2021

REFERENCE AND ADMINISTRATIVE INFORMATION 3
TRUSTEES ANNUAL REPORT & DIRECTORS' REPORT 4
Chair's report 4
ABOUT US 5
Our charitable objects 5
Our mission 5
The enduring challenge of PKD 5
Our aims 6
PERFORMANCE AND ACHIEVEMENTS DURING 2020-21 7
Support services for people and families affected by PKD during COVID-19 8
Research activities during 2020-21 11
PKD advocacy and awareness activities 13
Community involvement in the work that we do 15
Community fundraising 15
Grant fundraising 16
Governance 16
COVID-19 16
Pro bono support 16
Future plans 17
STRUCTURE, GOVERNANCE AND MANAGEMENT 17
Constitution 17
Trustees 17
PKD Research Advisory Board 17
Management and administration 17
Membership of related organisations 18
FINANCIAL REVIEW 20
Independent Examiner's Report to the Trustees of the Polycystic Kidney Disease Charity 21
STATEMENT OF FINANCIAL ACTIVITIES - 1 April 2020 TO 31 MARCH 2021 22
BALANCE SHEET AT 31 MARCH 2021 23
Notes to the Financial Statements for year ended 31 March 2021 24

REFERENCE AND ADMINISTRATIVE INFORMATION

Principal address and registered office:
49-51 East Road
London
N1 6AH

Tel: 020 7387 0543
Email: info@pkdcharity.org.uk
pkdcharity.org.uk

Polycystic Kidney Disease 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
Mrs Alison Carter (resigned Mar 2021)
Mr Raj Johal
Ms Rebecca Murphy-Peers
Ms Jade Raymond (Treasurer, appointed Mar 2021)
Mr Jon Rees (appointed Mar 2021)
Mrs Karen Stapleton
Mr Adrian Tinsley
Mr Nicholas Tracey
Mrs Elizabeth White (resigned Jul 2021)
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

Management & administration

Ms Tess Harris, Chief Executive
Mrs Madeleine Martin, Fundraising Manager
Mrs Susan Muirhead, Community Support Manager
Mrs Jane Pugh, Community Engagement Manager

Patrons

Sir Vince Cable
Professor Albert Ong
Dr Anand Saggar
Dr Richard Sandford
Professor Patricia Wilson

Professional advisors

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

Accountants
PEM
Salisbury House
Station Road
Cambridge, CB1 2LA

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

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

TRUSTEES ANNUAL REPORT & DIRECTORS' REPORT

The Trustees, who are also directors of the Charity for the purpose of the Companies Act, present their annual report and financial statements of the Charity for the year ended 31 March 2021. 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.

Chair's report

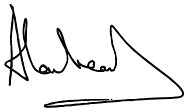
2020-2021 was a challenging year for the Charity due to the impact of COVID-19. The PKD community was disproportionately affected, our organisation was almost overwhelmed by the extra demand we had to meet. We had serious concerns about our funding/fundraising to help us meet this demand as well as the challenges of not being able to deliver face to face 'in person' services. To manage any risk to the Charity we immediately implemented an emergency budget to minimise our costs and risks.

I am pleased to say that we have managed to navigate the extreme challenges and concerns effectively. Our previous investment and skills in technology allowed us to deliver services on-line and the generosity of our supporters enabled us to continue to deliver our vital services. We were pleased that the Government/National Lottery emergency COVID-19 fund recognised our work and awarded us a grant that enabled us to continue to fully deliver our services to the community.

Despite COVID-19 we managed to maintain our focus of increasing Research in PKD. We completed the ADPKD Priority Setting Partnership (PSP) in association with the James Lind Alliance and published the Top 10 ADPKD Research priorities agreed by all stakeholders. In combination with this we agreed a partnership with Kidney Research UK to target ambitious progress identifying potential new therapies and improving outcomes within the next 10 years.

Over the next few pages, you can read more about the charity's activities during 2020-21. 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 2021

ABOUT US

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.

Our 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 mission

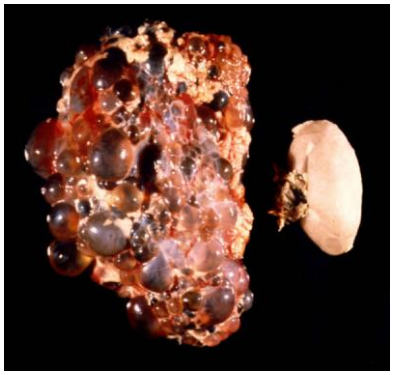
We want to improve the lives of everyone affected by PKD. We want to give hope for the future. We want to make PKD irrelevant and ultimately curable.

The enduring challenge of 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, PKD affects not only the individual but also their immediate family. It's a lifelong condition that can start to present even before birth.

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. In 2019, nearly 700 people with PKD had started dialysis or received a kidney transplant; this figure has been consistent for decades. Some people will require nephrectomies (kidney removal) due to organ size and have frequent disabling, painful cyst infections. 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 often diagnosed during pregnancy. Unfortunately, 1 in 3 babies will die before birth 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.

Our aims

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

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 psychosocial concerns for their own future, their children and family members.

Those with ADPKD often feel 'genetic guilt' because there is a 1 in 2 risk of passing on ADPKD and many have experience of family members suffering from PKD. Families affected by ARPKD must cope with often devastating consequences of the disease including possible early bereavement or the long-term implications of caring for a child with potentially life-threatening kidney and/or liver failure.

Information, education and support

People often tell us that they are not given sufficient information about PKD, especially when first diagnosed. Information that exists on the internet is often unreliable and inappropriate.

We produce evidence-based information about PKD in collaboration with medical experts, available online and in print.

We organise educational events on all aspects of PKD, with medical and health professional speakers, aimed at improving knowledge and making people feel more positive and able to cope.

We provide a range of community services offering practical and emotional support, information and advice including: a helpline, individual befriending, webchat/messaging, meetups, workshops, and moderated online Facebook groups.

Research

Our aim is to support and fund more ADPKD and ARPKD research in the UK. Since 2008, we have awarded nearly £500,000 of research grants to further understand the causes of PKD and help identify possible treatments. This is extremely important to our community; patients and families consistently encourage and support our research work, which they hope will ultimately identify a cure for PKD.

Therapies to modify and slow down progression in ADPKD are under study. However, there is only one drug (tolvaptan) which, in trials, slowed kidney cyst growth and is now licensed in the UK for a selected group of ADPKD patients. There are no disease-modifying therapies for ARPKD and very few pre-clinical studies worldwide owing to the small number of patients affected and disease variability. Dialysis or kidney/liver transplant are at present the only life-maintaining treatment when organs fail.

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 can be a challenge, especially in pregnancy.

We represent the views and voices of patients, families and carers to UK healthcare professionals, the NHS and policy makers. We seek to educate pharmaceutical firms with an interest in PKD to ensure that they understand patients' needs and the PKD burden. Where appropriate, we work in partnership with other charities and umbrella groups, to raise awareness about kidney disease and PKD.

PERFORMANCE AND ACHIEVEMENTS DURING 2020-21

Last year, we outlined our main aims for 2020-2021:

- Continue providing our blended support services by developing and scaling up our information and support services including implementing a new case management database/CRM system and processes
- Expand our community by engaging with and building partnerships with organisations and charities key to reaching people who are unaware of the charity
- Launch the research partnership with Kidney Research UK and form a joint research programme board
- Launch the results of the ADPKD research prioritisation initiative
- Implement a new CRM for more efficient recording of fundraising transactions
- Develop a new 3-year strategy

The COVID-19 pandemic caused significant changes to our plans for 2020-21. All face-to-face educational events, research and many fundraising activities were cancelled or put on hold from mid-March 2020. An emergency budget was developed for the financial year beginning 1 April, focused on maintaining our support services and fundraising whilst managing costs.

It soon became clear that kidney patients were disproportionately affected by COVID-19. People with moderate to advanced chronic kidney disease (CKD stage 3+) had increased risk of becoming very unwell or dying if infected. People receiving dialysis or with a kidney/liver transplant were at extremely high risk of illness and death. They were soon classified as 'Clinically Extremely Vulnerable' (CEV) by the Government, requiring them to shield until April 2021. Approximately 6,000 people with PKD were identified as CEV. Sadly, several PKD patients died due to COVID-19 during the year and we extend our condolences to their families.

Nearly all UK kidney and liver transplant centres closed from April to September 2020, resulting in a sharp reduction in the number of deceased and living organ donations and transplants. This was a very worrying time for those waiting for a transplant and their families. Fortunately, by May 2021, numbers had nearly returned to pre COVID-19 levels.

In general, feedback from patients and families tells us they have been left behind in 2020. Healthcare professionals have been pre-occupied with COVID-19, undiagnosed patients have not been seen, and operations and treatments have been delayed and deferred for many.

Support services for people and families affected by PKD during COVID-19

Thanks to our 5-year funding from the National Lottery Community Fund, we were able to continue supporting our community, rapidly adapting our support services and ways of working through remote delivery and frequently updated COVID-19 information.

Our staff were already working remotely and familiar with Zoom and we use Microsoft 365 throughout the charity.

Volunteer-led meetups

We worked with our existing trained regional meetup volunteers to ensure they would be willing and able to deliver equivalent virtual meetups using Zoom. Some required training, which we delivered.

We also started a 'Community Elevenses' virtual meetup, open to all regardless of where they lived.

During the year, we held 53 virtual meetups, including 4 new 'Time to Chat' virtual meetups for ARPKD parents – double the number held last year. Our community quickly became familiar with Zoom because of its general popularity enabling people to keep in touch with family and friends during COVID-19 lockdowns.

Our virtual meetups were well received:

"Thank you for setting up the meetups. Nothing is easy in these strange and stressful times".

The hints and tips often shared in these meetups can empower people. COVID-19 was not the only topic preoccupying people with PKD. For example, one person who attended a 'Community Elevenses' found it really helpful and then felt confident telephoning her GP about a troubling matter.

Another discussion regarding a toddler having tantrums at a medical appointment led to a discussion on home monitoring of BP – which the mum was able to explore with her child's healthcare team and will be starting training soon.

"It was interesting and enjoyable meeting everyone who were at different stages of coping with PKD. I got the impression that all attendees got something useful out of the occasion."

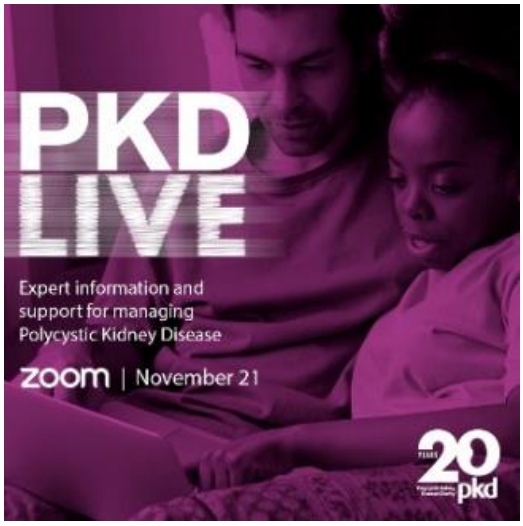
Despite the number held and interest, our meetups declined in attendance in the latter half of the year compared with previous face-to-face (possibly due to 'Zoom-fatigue').

Telephone support including helpline

Our dedicated 0300 telephone helpline was available for those feeling worried or emotional. Call volume increased by about 18% and we extended opening hours to 7 days during 2020. Out of hours calls recorded by an answer service ensuring those who left a message had their calls returned.

Information/Support Days and webinars for patients and their families

Adapting to an online and remote delivery mode meant we could achieve national reach with our educational events.



We delivered **3 live ADPKD information days** by Zoom, reaching over 450 attendees – an increase of 50% over last year.

Two events covered all aspects of ADPKD – diagnosis/genetics, diet, pain, tolvaptan. The third event focused on transplantation.

We are hugely grateful to the healthcare professionals who volunteered their time to speak at our events despite the immense NHS pressures they faced.

Post-event attendee survey results showed that on average:

- 52% described their knowledge of PKD improved greatly or a lot
- 38% said as a result of attending they are able to manage ADPKD greatly or a lot better
- 31% felt more positive about PKD

"I gained useful information from each talk and wish I had had this sort of information when I first found out I had ADPKD in 1991"

During our live Zoom online information days, a presentation of available support services was given. Overall, our online programme of information days was rated as excellent by 80%.

"To be honest, I was given more information than I have ever been by my GP or renal team; it was all really interesting"

We delivered **4 evening webinars** on specific topics suggested by people in our community. These were jointly presented by PKDC staff and a guest speaker.

Topics included: 'Emotional Wellbeing during COVID-19', ADPKD in Children, Living Donation, Polycystic Liver Disease.

Nearly 200 people attended the webinars with over 75% extremely satisfied.

These webinars were made possible by UK healthcare professionals volunteering their time.

The following comments were received by email after a webinar on the topic of donating a living kidney.

"Thank you for the excellent webinar today. The fact that one of your speakers has personal experience of the transplant process was powerful."

The talks from the information days and webinars were recorded and are available on our YouTube channel. Each topic covered is also included on an appropriate page on our website to enrich the written content.

Positives of using Zoom:
Online delivery improved our reach during the year and has other advantages for those attending:

- There are no associated travel costs.
- The event can be enjoyed from the comfort of their own home, which is important as many struggle with pain and are uncomfortable in a lecture theatre or event room seating.
- Attendees can join regardless of geographic location.

"I hope you'll continue to record and or keep online when face-to-face conferences are allowed to resume, as I probably would not be unable to attend as I live in a remote area"

Negatives of using Zoom:
Online does not have the same impact as face-to-face formats. For safeguarding reasons, we require attendees to join in 'listen-only' mode and there is none of the personal interaction that occurs at face-to-face events. When comparing our last face-to-face event with Zoom events, levels of knowledge, confidence and positivity fell by 40-50%. How much of this was due to COVID-19 is unknown however.

"I missed the buzz and the social side/human contact at live events, it takes the edge off the seriousness of living with PKD"

Facebook groups

We manage and moderate 3 private UK-only Facebook groups with nearly 3,000 members on 31 March 2021, approximately 10% growth.

With people increasingly turning to social media for support, especially when the pandemic began, these groups required careful moderation to answer questions, correct factual errors and provide

support and signposting for people who appear distressed. We are fortunate to have the support of trained volunteers who assist staff with moderation and peer support.

Telephone befriending service and volunteering

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. However, often people use the service as a 'one-off' to speak directly with someone who has been through a specific experience. Examples include removal of kidneys (known as a nephrectomy) or starting dialysis. Our volunteers helped us support those struggling during restrictions.

Health information for patients and families

Our professional medical writer continued to update and draft new information. However, we were often prevented from publishing owing to unavailability of healthcare professionals to review drafts owing to the impact of COVID-19.

From April 2020, when restrictions were imposed and many of our community had to 'shield', we realised that general COVID-19 information would not be sufficiently PKD targeted. Drawing guidance from the Renal Association, NICE and healthcare professionals, we created two COVID-19 blogs, one for those affected by ADPKD, the other for parents of children affected by ARPKD.

The blogs were updated on a regular basis (sometimes daily during if Government advice changed) and throughout the year were the second most visited pages on our website.

As in previous years, diet and lifestyle is the number one visited page on our website

The website continues to attract 100,000 visitors a year with the majority visiting the information sections.

Case management system

Thanks to the Community Fund grant, we implemented a new case management system and Customer Relationship Management (CRM) software integrated with MS 365. This has enabled us to create more rapidly, store, retrieve and analyse information about patients and family member. Our support services have greatly benefitted already being able record in real time any helpline calls and support requests, keeping a secure and confidential record.

Research activities during 2020-21

Grants awarded

The trustees suspended the research grants programme from April to September 2020. After re-opening, applications were received and the Research Advisory Board recommended three projects for funding, which were approved by the trustees.

- £14,033 to Newcastle University (Dr Elisa Molinari) for a research project: *'Single cell-RNA*

sequencing of urine cells of autosomal dominant polycystic kidney disease patients'.

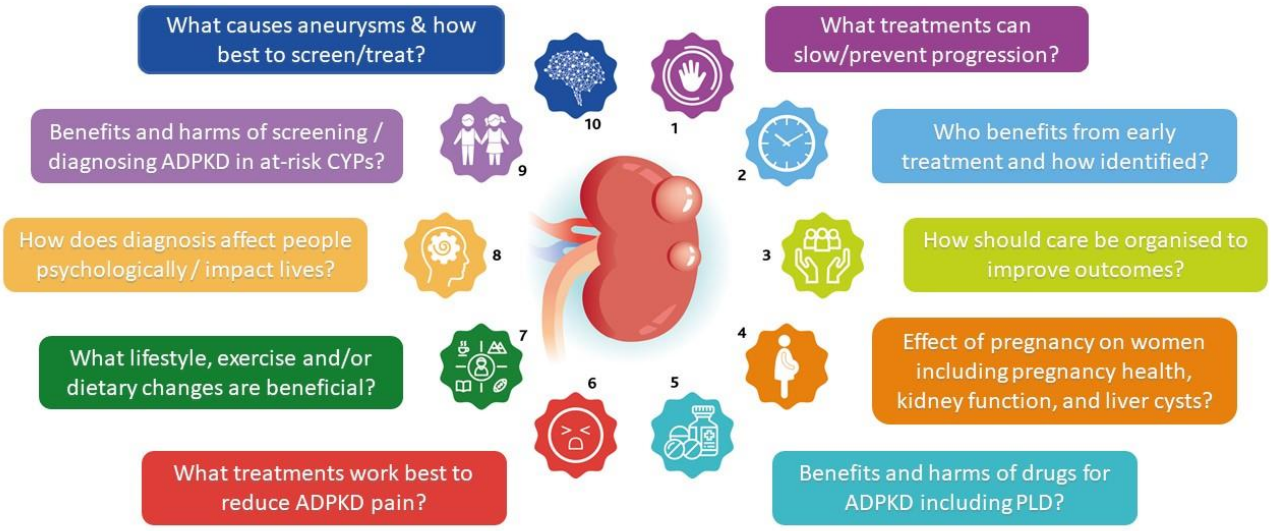
- £8,500 to UCL Centre for Nephrology Royal Free (Professor Patricia Wilson) to fund the PKD Biobank. (Professor Wilson recused herself from the trustee decision.)
- £15,000 to UCL Centre for Nephrology (Professor Jill Norman) for a research project: *'Urinary exosomal profiling to predict the efficacy of response to Tolvaptan therapy in individual paediatric ADPKD and ARPKD patients.*

ADPKD Research Prioritisation initiative

We had launched the ADPKD Priority Setting Partnership (ADPKD PSP) in 2019, in association with the James Lind Alliance (JLA).

Owing to COVID-19, we paused the initiative until September 2020 when we re-opened the prioritisation survey. Respondents were asked to rank 35 unanswered research questions (from a longer list of 117). Approximately 750 patients, family members and healthcare professionals took part. The top ranked priorities were then discussed in an online workshop in December 2020.

In January 2021, we published the Top 10 ADPKD Research priorities agreed by all stakeholders. Our goal is to encourage researchers to use the Top 10 (and the other unanswered research questions) that didn't make the top 10) to inform their research plans. See diagram below of the Top 10.



Visit our website to read the report

Collaborative research partnership programme with Kidney Research UK

In March 2021, we held the first meeting of the PKD Research Programme Board (RPB) Meeting. The

RPB was established jointly by the PKD Charity and Kidney Research UK.

On behalf of the Trustee Boards of the two charities, the PKD RPB is responsible for:

- Ensuring fulfilment of the charities' vision to 'target ambitious progress towards improvement in understanding the causes of PKD, identifying potential new therapies and improving outcomes within the next 10 years'.
- Developing the PKD Research Programme; implementing this Programme by prioritising PKD research funding; and supporting implementation of the Programme through partnering and collaboration.

The RPB discussed the structure of the proposed first-ever joint PKD research funding round.

PKD advocacy and awareness activities

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.

We supported initiatives campaigning for support for people affected by COVID-19. Regular meetings were held between the main kidney charities and the UK Kidney Association to discuss the latest data and guidance. We invited our community to participate in several consultations on a variety of issues including a national study investigating how COVID-19 was affecting people with kidney conditions and the PREM 2020 survey (The Kidney Patient Reported Experience Measure).

We continued to represent patients and families on two PKD clinical study groups:

- The **ADPKD Clinical Study Group** (CSG) sits within the UK Kidney Research Consortium (UKKRC). Its members are multi-disciplinary and include patients. Its role is to stimulate ADPKD research, provide peer review to researchers and endorse worthwhile studies. The charity's CEO is the acting chair of CSG. More information here. The CSG is also the RaDaR (National Registry of Rare Kidney Diseases) Study Group.
- The RaDaR **ARPKD Rare Disease Study Group**, chaired by Dr Larissa Kerecuk and Professor Patricia Wilson. More information here

The CEO was invited to serve as a member of the **KDIGO** (Kidney Disease: Improving Global Outcomes) ADPKD Global Guideline Working Group. It is anticipated that the Guideline will be published early 2024.

The CEO continued to attend the monthly global **PKDOC** (PKD Outcomes Consortium) conference calls. PKDOC is seeking to establish clinical and patient reported outcomes for ADPKD research, which will be acceptable to the US FDA (Food & Drink Administration) and European Medicines Agency (EMA) regulators.

During 2019-20, the CEO represented the charity at conference calls and meetings of the **Kidney and Liver European Reference Networks** (ERNs). The ERNs are virtual networks involving healthcare providers across Europe, set up to address complex or rare diseases and conditions that require highly specialised treatment and a concentration of knowledge and resources. Despite Brexit, UK patient

representatives have been invited to remain on the ERNs.

Awareness

Through social media posts on our Facebook page, groups, Twitter and LinkedIn, we raised awareness of our services and engaged with our community with a combination of Government COVID-19 guidance, signposts to our COVID-19 website blogs, success stories and ways to stay positive and active during the pandemic/lockdown.

We issued 2 printed full-colour newsletters to approximately 3,000 households and posted each online. We published a regular e-news to nearly 2,900 individuals to keep the community informed.

The PKD 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, 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.

PKD Awareness Month was held in September 2020. We ran a digital campaign to raise awareness, prompt discussion and educate new and existing patients, family members and healthcare professionals. 'PKD Voices' was part of this campaign and was in the 'top 20' most engaged social media posts during the year.

Further engagement was achieved through a 'PKD quiz', which had 741 participants. 62% opted into our database, many of whom were new to us.

At the start of the year, COVID-19 vaccinations started and our PKD CEV patients were amongst the priority groups to receive the first dose.

Many supporters shared photos of them receiving their vaccinations.

World Kidney Day (WKD) 2021 was celebrated virtually. The KCT collaborated on an awareness digital campaign with the theme: 'The BIG Topic everyone's ignoring' utilising the large yellow kidney icon developed for WKD 2020.

People affected by kidney disease were invited to submit photos and the winner was Rachel. She took this photo of her mum moments before she went to theatre to donate a kidney to a stranger as part of the UK paired donation scheme. This incredibly generous gift enabled Rachel's dad (a PKD patient) to receive a new kidney in the scheme.

Paired donation is often used when the donor and recipient are incompatible - as in this case - and are matched to another couple in a similar situation so that both people in need of a transplant receive a matched organ.

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 virtual meetups 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 2020, we acknowledged publicly the contribution made by all volunteers during Volunteer Week.

The importance of community involvement during 2020-21

Involving the community has been especially important during the last year, as we've had to adapt our services to meet changing circumstances and demand due to COVID-19.

For example, when we could not deliver our planned programme of ARPKD family days due to COVID-19 restriction, we looked for how we could still support these families. With the help of two ARPKD parent volunteers, we investigated what families needed. The biggest need was that parents wanted to be in contact with other parents as this gives them the opportunity to reflect, share and process their child's diagnosis and prognosis of ARPKD.

This led to the creation of a UK-only private ARPKD Facebook support group and 'Time to Chat' events, which both addressed the underlying need through new channels.

Community fundraising

We thank all the amazing fundraisers who continued to support the charity's work during 2021-21 despite the COVID-19 restrictions.

Community fundraising had to adapt. Many of our supporters were vulnerable or clinically extremely vulnerable. Mass participation events were cancelled, and community fundraising was only possible at a safe distance or virtually. But our supporters rose to the challenges and found new ways to fundraise: running marathons indoors; undertaking a 10,000 kettlebell swing challenge; cycling the equivalent height of Everest; taking on personal 20k challenges to mark the PKD Charity's 20th anniversary.

Our virtual balloon race proved popular allowing people to compete in an environmentally friendly balloon race from the comfort of their own homes.

Grant fundraising

The National Lottery Community Fund awarded year 2 of the 5-year grant, a further COVID-19 emergency grant and a grant to support a future PKD Nurse Care Coordinator. The trustees are grateful to the Community Fund for their understanding and support during the year.

Sanofi Pharmaceuticals UK awarded a grant to support a European educational event, organised by the PKD Charity. The event will be operated independently, and Sanofi is not involved in its content.

Governance

The charity held 6 virtual trustee meetings during the financial year. Two new trustees were appointed to the board during 2020-21. Alison Carter, Treasurer, resigned in March 2021; the trustees are extremely grateful for her financial management of the charity during the years she served as trustee.

Adult Safeguarding Courses were provided for all existing and new volunteers, including trustees.

COVID-19

The trustees monitored the risks caused by COVID-19 throughout the year. The Chair, Treasurer and CEO met weekly during the year to examine cash flow, review forecasts and control costs.

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).

Future plans

On 31 March 2021, the UK was still in the 'second wave' of COVID-19. We will continue to use virtual channels and platforms such as Zoom and Teams to maintain our support activities as much as possible and expect to rely on digital technology and communications until it's safe for people with PKD to meet each other again.

During 2021-2022, we intend to:

1. Continue providing our blended support services and introduce new services such as workshops.
2. Launch the first PKD research funding round in partnership with Kidney Research UK in September 2021.
3. Promote the ADPKD Top 10 Research priorities in the UK and internationally.
4. Develop a new 3-year strategy.
5. Launch an updated website.

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 and appointed by the other trustees. Most current trustees either have PKD or a family connection to PKD. 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.

PKD Research Advisory Board

During 2020-21, the PKD Charity Research Advisory Board (RAB) met virtually to review grant applications. Members also contributed to new or updated patient information materials.

Management and administration

The Trustees delegate the management of charitable activities and administration to a small team led by the CEO. The trustees monitored performance at trustee meetings; the chair has regular phone

and face-to-face meetings with the CEO.

Bookkeeping and accounts are carried out by PEM.

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

Membership of related organisations

The charity is a founder member of the **Kidney Charities Together** group of kidney charities, who meet to collaborate on campaigns such as World Kidney Day and consider ways to work together on initiatives to improve the lives of all kidney patients.

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 CEO is the current President of PKDI (a voluntary role). More information here: www.pkdinternational.org

The charity is a member of **EURORDIS**, the European umbrella organisation of patient groups

representing adults and children with rare diseases.

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

FINANCIAL REVIEW

Performance

During the 12 months to 31 March 2021, the charity's income was **£361,800** (2020: £284,321).

Expenditure on raising funds as a percentage of total incoming resources was 17**%** (2020: 29%). Research expenditure was **£70,803** (2020: £63,527). The Charity's expenditure on charitable activities across Patient Support, Awareness and Education was **£105,455** (2020: £114,648), which included information days, telephone support, online/chat support and expenditure on the peer support service.

In total, the Charity expended **£267,797** (2020: £286,089), resulting incoming resources for the year of **£94,004** (2020: net outgoing resources of £1,768). Total fund balances at the year-end were **£397,462** (2020: £303,458) 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 £156,353 (2020: £192,006), equivalent to 7 months´ total expenditure (2020: 8 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

Jade Raymond
Trustee Treasurer

28 December 2021

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 2021, which are set out on pages 24 to 31.

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

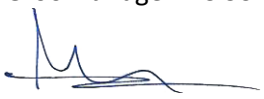
Basis of independent examiner's report
My examination was carried out in accordance with the general Directions given by the Charity Commission and is in accordance with Regulation 11 of the Charities Accounts (Scotland) Regulations 2006. An examination includes a review of the accounting records kept 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 2021

STATEMENT OF FINANCIAL ACTIVITIES - 1 APRIL 2020 TO 31 MARCH 2021

STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 MARCH 2021

	Notes	Restricted Funds 2021 £	Unrestricted Funds 2021 £	Total 2021 £	Total 2020 £
Income from:					
Donations grants and legacies	3	174,557	171,728	346,285	276,026
Other trading activities	4	-	13,602	13,602	5,450
Investment income	5	-	1,913	1,913	2,844
Total income		**174,557**	**187,243**	**361,800**	**284,321**
Expenditure on:					
Cost of fundraising	6	-	61,792	61,792	81,031
Non-charitable trading activities	6	-	7,958	7,958	3,020
Total		-	**69,750**	**69,750**	**84,051**
Research and grants	7	66,034	4,769	70,803	63,527
Awareness and education		-	30,342	30,342	34,477
Patient support		71,176	-	71,176	80,171
Support costs - depreciation	10	3,936	-	3,936	-
Total		**141,146**	**35,111**	**176,257**	**178,175**
Other expenditure					
Governance costs	8	-	21,789	21,789	23,864
Total expenditure		**141,146**	**126,650**	**267,797**	**286,089**
Net income / (expenditure) for the year		33,411	60,593	94,004	(1,768)
Fund balances brought forward at 1 April	18	46,452	257,006	303,458	305,226
Net incoming resources for the year	17	33,411	60,593	94,004	(1,768)
Transfers between funds	17	15,928	(15,928)	-	-
Fund balances carried forward	17	**95,791**	**301,671**	**397,462**	**303,458**

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 24 to 31 form part of these financial statements.

BALANCE SHEET AT 31 MARCH 2021

	Notes	2021 Total Funds £	2020 Total Funds £
FIXED ASSETS			
Tangible assets	13	**13,776**	-
CURRENT ASSETS			
Debtors	14	9,754	23,512
Cash at bank		489,650	371,792
Total current assets		**499,404**	395,303
Liabilities			
Creditors: Amounts falling due within one year	15	**105,718**	74,346
NET CURRENT ASSETS		**407,461**	320,957
Total assets less current liabilities		**407,461**	320,957
Creditors: Amounts falling due after more than one year	16	**10,000**	17,500
NET ASSETS		**397,462**	303,457
The funds of the Charity:			
Unrestricted funds - Designated	17	145,318	65,000
Unrestricted funds - General	17	156,353	192,006
Restricted funds	17	95,791	46,452
TOTAL FUNDS		**397,462**	303,458

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:
Jade Raymond

Trustee Treasurer
28 December 2021

Notes to the Financial Statements for year ended 31 March 2021

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.

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 8. 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.

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.

3. DONATIONS, GRANTS AND LEGACIES

	Restricted funds 2021 £	**Unrestricted funds 2021 £**	**Total Funds 2021 £**	Total Funds 2020 £
Donations and gifts	8,433	155,776	164,249	223,477
Trusts, foundations and grants	166,125	-	166,125	33,927
Gift Aid	-	15,952	15,952	18,622
Total 2021	**174,557**	**171,728**	**346,325**	**276,026**
Total 2020	41,548	234,478	276,026	

No government grants were received during the year (2020 £nil).

4. INCOME FROM OTHER TRADING ACTIVITIES

	Restricted funds 2021 £	**Unrestricted funds 2021 £**	**Total Funds 2021 £**	Total Funds 2020 £
Shop and other income	-	13,602	13,602	5,450
Total 2021	-	**13,602**	**13,602**	**5,450**
Total 2020	**-**	5,450	5,450	

5. INVESTMENT INCOME

	Restricted funds 2021 £	**Unrestricted funds 2021 £**	**Total Funds 2021 £**	Total Funds 2020 £
Interest income	**-**	1,913	1,913	2,844
Total 2021	-	**1,913**	**1,913**	**2,844**
Total 2020	-	2,844	2,844	

6. EXPENDITURE ON RAISING FUNDS

	Restricted funds 2021 £	Unrestricted funds 2021 £	Total Funds 2021 £	Total Funds 2020 £
Cost of fundraising	-	61,792	61,792	81,031
Cost of goods sold	-	7,958	7,958	3,020
Total 2021	**-**	**69,750**	**69,750**	**84,051**
Total 2020	**-**	84,051	84,051	

7. ANALYSIS OF RESEARCH AND GRANTS

	2021 £	2020 £
Bio Resource Bank	8,500	30,000
ADPKD Research	29,033	14,774
Staff, subcontractor and other costs	33,269	18,753
Total:	**70,803**	**63,527**

	Grants to Institutions No.	Grants to Individuals No.
Bio Resource Bank	1	-
ADPKD Research	2	-
Total:	**3**	**-**

Details of material grants are disclosed in the Trustees Report.

8. GOVERNANCE COSTS

	2021 £	2020 £
Trustee meetings and governance	131	2,998
Accountancy and audit	12,927	10,330
Other professional fees	3,866	4,056
Staffing costs	4,865	6,480
Total:	**21,789**	**23,864**

9. EMPLOYMENT COSTS

	2021 £	2020 £
Wages and salaries	136,396	105,039

Social security costs	9,351	6,685
Pension contributions	2,380	1,506
Total:	**148,127**	**113,230**

Employment costs are allocated to the activities to which they relate in the Statement of Financial Activities. As at 31 March 2021 pension contributions were overpaid by £180 and a balance was owed to the Charity (2020 £460 were payable by the Charity).

The average number of staff employed by the Charity during the year was 4 (2020 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 £132,775 (2020 £101,649).

10. NET INCOME/(EXPENDITURE) FOR THE YEAR

This is stated after charging:	**2021 £**	**2020 £**
Independent Examiners Remuneration	-	-
Depreciation	3,936	-
Total:	**3,936**	**-**

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 (2020 £735).

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

	2021 £
	Office equipment
Cost	
At 1 April 2020	11,497
Additions	17,712
Disposals	-
At 31 March 2021	**29,209**
Accumulated depreciation	
At 1 April 2020	11,497
Charge for the year	3,936

Disposals	-
At 31 March 2021	**15,433**
Net Book Value	
At 1 April 2020	-
At 31 March 2021	**13,776**

14. DEBTORS

	2021	2020
	£	£
Prepayments	9,754	14,649
Accrued income	-	8,863
Other Debtors	-	-
Total debtors	**9,754**	**23,512**

15. LIABILITIES: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2021	2020
	£	£
Trade creditors	4,280	4,818
Accruals	2,328	-
Other creditors	1,297	5,778
Grant commitments (Note 18)	97,813	63,750
Total current liabilities	**105,718**	**74,346**

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

	2021	2020
	£	£
Grant commitments within five years (Note 18)	**10,000**	**17,500**

17. FUNDS AND RESERVES – CURRENT YEAR

Unrestricted Funds	Total funds at 1/4/20	Income	Expenditure	Transfer	Total funds at 31/3/21
Research	65,000	-	-	80,318	145,318
PKD Bio-Resource	-	-	-	-	-
PKD Registry	-	-	-	-	-
General fund	192,006	187,243	(126,650)	(96,246)	156,353
Total funds	**257,006**	**187,243**	**(126,650)**	**(15,928)**	**301,671**

Research – Designated to support research for PKD
PKD Bio-Resource – Designated to fund the Bio-Resource Bank at University College London
PKD Registry – Designated to fund a project to create a PKD registry
General fund – the free reserves, after allowing all other designated funds

In July 2020 the Trustees agreed to transfer £96,246 from the General fund to Research.

Restricted Funds	Total funds at 1/4/20	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	0
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
Total funds	**46,452**	**174,557**	**(141,146)**	**15,928**	**95,791**

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, Covid-19 – To fund operating expenses during the global pandemic caused by Covid-19
National Lottery, Nurse Co-ordinator – Income received to fund Nurse co-ordination

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.

18. FUNDS AND RESERVES – PRIOR YEAR

Unrestricted Funds	Total funds at 1/4/19	Income	Expenditure	Transfer	Total funds at 31/3/20
Research	65,000	-	-	-	65,000
Bio-Resource Bank	13,402	-	(30,000)	16,598	-
PKD Registry	30,000	-	-	(30,000)	-
Undesignated general reserves	150,336	242,773	(214,818)	13,715	192,006
Total funds	**258,738**	**242,773**	**(244,818)**	**313**	**257,006**

Restricted Funds	Total funds at 1/4/19	Income	Expenditure	Transfer	Total funds at 31/3/20
Support Activities	-	2,000	-	-	2,000
ADPKD Research	13,228	3,635	(14,774)	-	2,089
ARPKD Research	24,377	1,473	-	-	25,850
Research	8,570	2,514	-	-	11,084
Royal Free Hospital Biomaker	313	-	-	(313)	-
National Lottery	-	31,927	(26,497)	-	5,430
Total funds	**46,488**	**41,548**	**(41,271)**	**(313)**	**46,452**

19. ANALYSIS OF NET ASSETS BETWEEN FUNDS – CURRENT 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)
Total:	**301,671**	**95,791**	**397,462**

20. ANALYSIS OF NET ASSETS BETWEEN FUNDS – PRIOR YEAR

	Unrestricted funds 2020 £	Restricted funds 2020 £	Total funds 2020
Tangible fixed assets	-	-	-
Current assets	267,602	127,702	395,304
Creditors due within one year	(10,596)	(63,750)	(74,346)
Creditors due in more than one year	-	(17,500)	(17,500)
Total:	**257,006**	**46,452**	**303,458**

21. GRANT COMMITMENTS

	£
Balance at 1 April 2020	81,250
New commitments	37,533
Cancelled commitments	-
Commitments paid	(10,970)
Balance at 31 March 2021	**107,813**

22. RELATED PARTY TRANSACTIONS

	2021	2020	
Donations Received from Trustees	6,120	6,341	4 Trustees (2020 6) made donations during the year
Grants to related parties	8,500	30,000	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 the decision to appoint. The details are as follows:

Employment Related Parties

Trustee	Employee	2021	2020
Alan Greenberg	**Louise Greenberg**	**6,001**	**4,896**