

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

ANNUAL REPORT AND ACCOUNTS 2020-2021

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REFERENCE AND ADMINISTRATIVE INFORMATION

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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

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*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

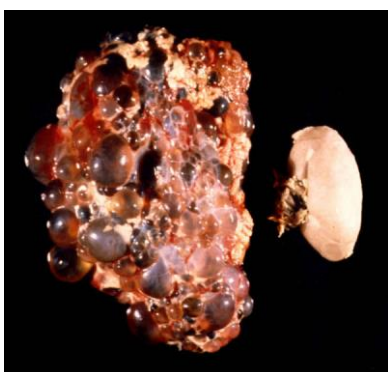
We want to improve the lives of everyone affected by PKD. We want to give hope for the future. We want to make PKD irrelevant and ultimately curable.

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.”

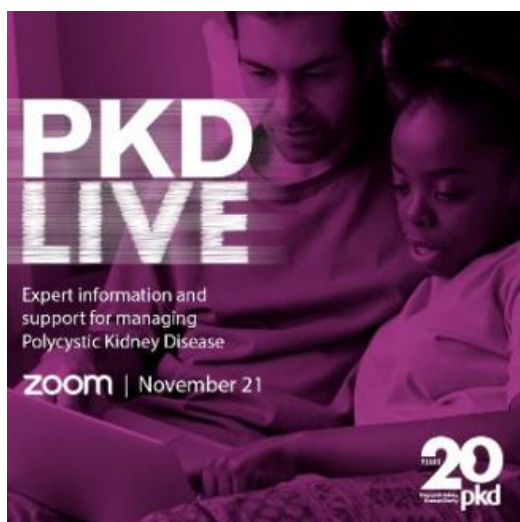
Despite the number held and interest, our meetups declined in attendance in the latter half of the year compared with previous face-to-face (possibly due to ‘Zoom-fatigue’).

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 able 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*

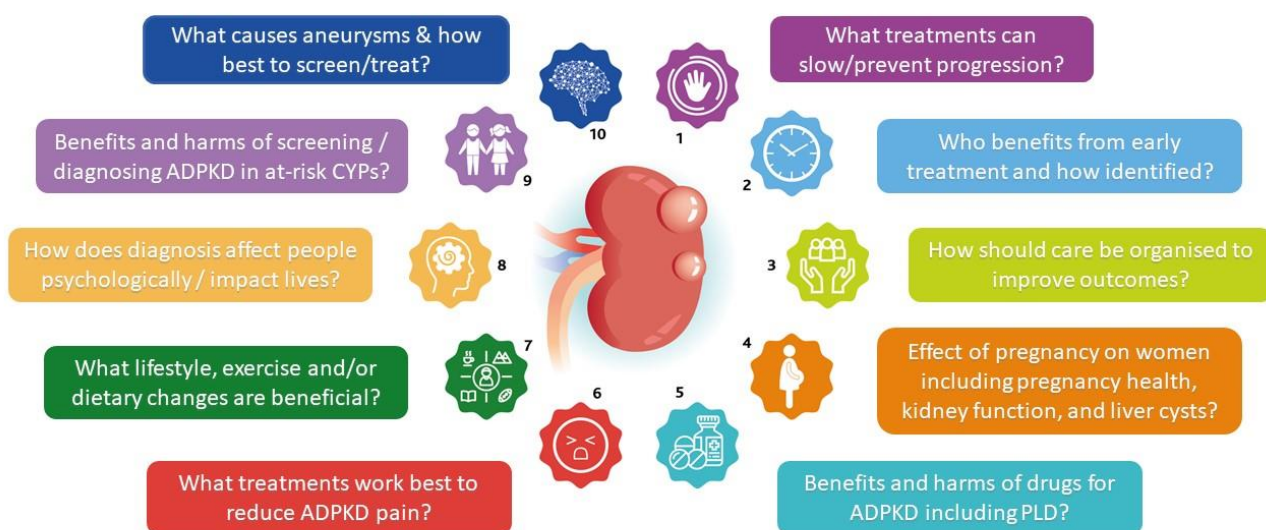
- sequencing of urine cells of autosomal dominant polycystic kidney disease patients’.*
- £8,500 to UCL Centre for Nephrology Royal Free (Professor Patricia Wilson) to fund the PKD Biobank. (Professor Wilson recused herself from the trustee decision.)
 - £15,000 to UCL Centre for Nephrology (Professor 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 & Drug 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.

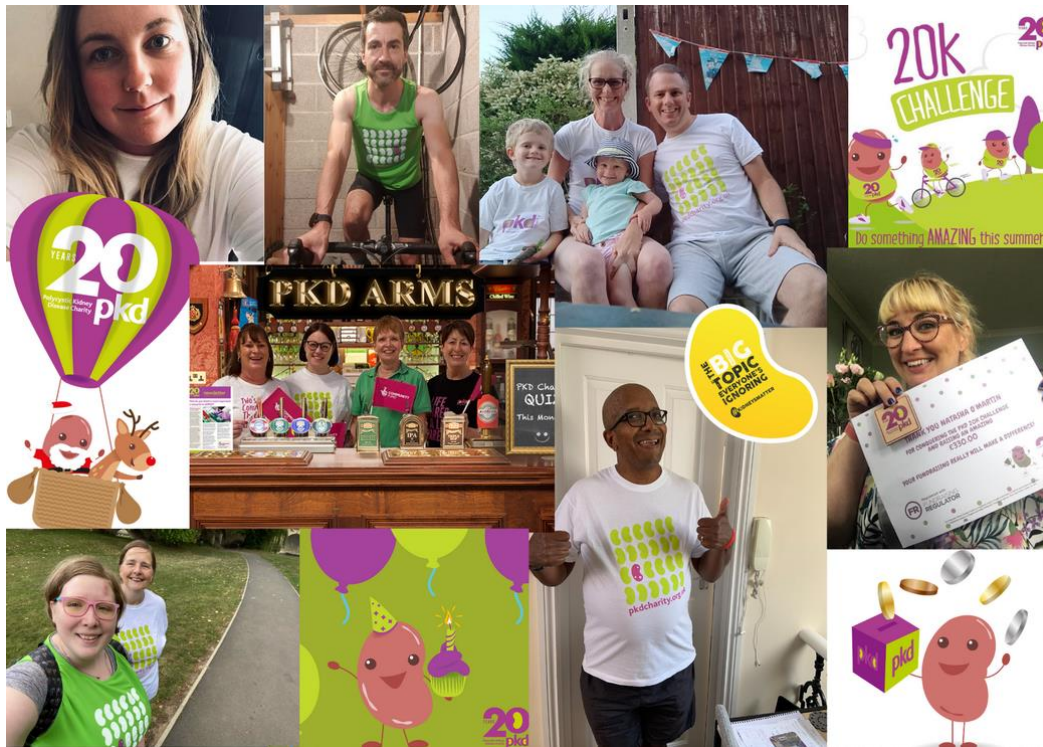
This led to the creation of a UK-only private ARPKD Facebook support group and 'Time to Chat' events, which both addressed the underlying need through new channels.

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.

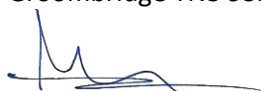
Independent examiner's statement

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

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

	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:	<u>148,127</u>	<u>113,230</u>

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

	2021	2020
This is stated after charging:	£	£
Independent Examiners Remuneration	-	-
Depreciation	3,936	-
Total:	<u>3,936</u>	<u>-</u>

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	<u>29,209</u>
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