

IMPROVING THE LIVES OF EVERYONE AFFECTED BY POLYCYSTIC KIDNEY DISEASE

Our year in review

Trustees' Annual Report – 1 April 2018 to 31 March 2019



ANNUAL REPORT AND ACCOUNTS 2018-2019

CONTENTS

REFERENCE AND ADMINISTRATIVE INFORMATION	3
TRUSTEES ANNUAL REPORT & DIRECTORS' REPORT	4
Chair's Report.....	4
OUR OBJECTIVES AND AIMS	5
Our charitable objects.....	5
Our mission	5
The challenge of PKD	5
What we aim to do.....	6
PERFORMANCE AND ACHIEVEMENTS DURING 2018-19.....	7
Servicing our beneficiaries	7
Funding and supporting PKD research.....	9
Activities in relation to awareness	10
Governance	11
Fundraising.....	12
Contribution made by volunteers	12
Pro bono support	12
Future plans	13
STRUCTURE, GOVERNANCE AND MANAGEMENT	13
Constitution.....	13
Trustees	13
PKD Research Advisory Board	14
Management and Administration	14
Membership of Related Organisations	14
FINANCIAL REVIEW	16
Independent Examiner's Report to the Trustees of the Polycystic Kidney Disease Charity	17
STATEMENT OF FINANCIAL ACTIVITIES - 1 April 2018 TO 31 MARCH 2019	18
Notes to the Financial Statements for year ended 31 March 2019.....	20

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 (appointed Jul 2019)

Ms Maureen Carson (resigned Jan 2019)

Mrs Alison Carter (Treasurer)

Mr Raj Johal

Mr Sarbjit Johal

Ms Rebecca Murphy-Peers

Mrs Karen Patterson (appointed May 2019)

Ms Harriet Rimbault (resigned Mar 2019)

Mr Adrian Tinsley

Mr Nicholas Tracey (Treasurer)

Mrs Elizabeth White (appointed May 2019)

Professor Patricia Wilson

Research Advisory Board

Professor Patricia Wilson (Chair)

Dr Anand Saggar (Vice-Chair)

Ms Sanela Becar (Lay Member)

Professor Jill Norman

Dr Richard Sandford

Professor John Sayer

Professor Paul Winyard

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

Rt Hon Sir Vince Cable, MP

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

Florence Lane, Groombridge, TN3 9SH

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

TRUSTEES ANNUAL REPORT & DIRECTORS' REPORT

The Trustees, who are also directors of the Charity for the purpose of the Companies Act, present their annual report and financial statements of the Charity for the year ended 31 March 2019. 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 2015).

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

The PKD Charity is the only UK charity solely dedicated to the concerns of people affected by **polycystic kidney disease** or **PKD** – incurable, genetic long-term conditions which are a common cause of kidney failure and affect other organs in the body. There are two main forms of PKD: Autosomal Dominant PKD (ADPKD) and Autosomal Recessive PKD (ARPKD). You can read more about ADPKD and ARPKD below.

I am pleased to report that during the year, thanks to the generosity of our supporters and volunteers, we were able to continue our charitable work which makes a difference to patients and their families. In the past year we have made some significant progress and our reach and influence continues to exceed our size.

Key highlights included a significant increase in the number of people who have used our services and our revenues growing for the first time in 3 years which has enabled us to deliver major improvements to our support services. The Information and Support days remain very popular and we have experienced a large increase in activity on our social media platforms. We have delivered a substantial advancement in our sustainability and governance which places the charity on a much stronger footing to continue to deliver major benefits to our beneficiaries.

Our work in funding and influencing research continues as we are entering an exciting time with advancements in technology and medicines. We are endeavouring to create a framework for research where we can be at the forefront of focussing world-wide research for the benefit of PKD patients and our work with establishing the ADPKD Priority Setting Partnership (PSP) described in this document is a significant step in making this happen.

Over the next few pages you can read more about the charity's progress during 2018-19. 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
13 December, 2019



OUR 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).

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 PKD Charity was formed in 2000 by a PKD patient and a genetics consultant. Since then, PKD patients, parents and family members have governed and run the charity. The majority of trustees and staff are directly affected by PKD. We understand the experiences and challenges of the estimated 70,000 people – children and adults – and their families in the UK coping with PKD on a daily basis.

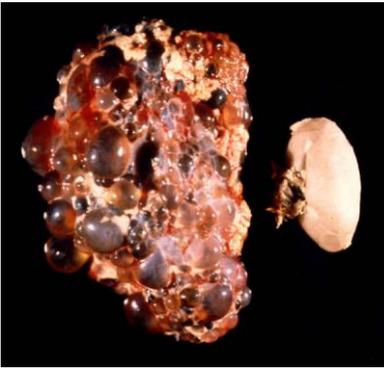
Our focus for the 2018-19 year was transformation. We wanted to enable the charity to continue servicing our beneficiaries whilst coping with increased demand, growing our supporter base, identifying new funding sources and embedding sustainability.

The 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 (1 in 20-40,000 prevalence). Being 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 birth in both kidneys resulting in kidney growth and progressive renal 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 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.



The majority of patients with ADPKD will have complete kidney failure by age 60, necessitating renal replacement therapy (RRT) to stay alive – either dialysis or (if feasible) a kidney transplant. Nearly 300 kidney transplants are performed annually. Some will require nephrectomies (kidney removal) due to organ size and frequent, disabling cyst infections. Over twenty 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, anaemia, bone disorders, gout and kidney stones. [Read more about ADPKD on the PKD Charity website.](#)



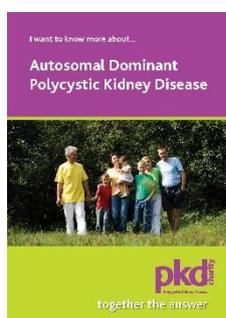
ARPKD is often diagnosed during pregnancy. Unfortunately, 1 in 3 babies will die before birth owing to the rapid growth of cystic kidneys preventing lung development. The babies who survive sometimes experience early kidney and liver failure. They may need life-saving dialysis before transplant and about 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.](#)

What we aim to do

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 often 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. ADPKD patients often feel ‘genetic guilt’ because there is a 1 in 2 risk of passing on ADPKD. Families affected by ARPKD have to 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.

We produce extensive website content, leaflets and publications about PKD, reviewed by medical experts, to NHS Information Standard principles. These provide information and reassurance for patients and help educate medical professionals, leading to better healthcare and earlier diagnosis.



"You were the only place I found that could help me. When first told that I had PKD, I felt very alone because the hospital, GP etc. did not seem to be able to answer my questions.

*You made me understand that I had not been given a death sentence."
(Feedback from a PKD patient.)*

There have been major advances in understanding the genetic and biological nature of PKD in the past 40 years. The clinical characteristics are well known, but there is a wide variability of disease expression owing to genetic heterogeneity. For example, it is not unusual to see a significant difference between ages of kidney failure in ADPKD family members with the same PKD mutation. 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 studies worldwide owing to the small number of patients affected and the genetic variability. Dialysis or kidney/liver transplant are at present the only life-maintaining treatment when organs fail. Our aim to stimulate and fund more ADPKD and ARPKD research in the UK.

We fund medical research – over £330,000 since 2008 - that increases understanding of the causes of PKD, identifies possible treatments and makes patients' lives easier and more comfortable. 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.

Despite being a common kidney disease, few people seem to have heard of ADPKD and awareness amongst GPs is known to be low. ARPKD is rarely seen and diagnosis can be a challenge, especially in pregnancy. We aim to raise awareness of the impact and burden of both conditions through authoritative information and targeted communications.

We represent the views and voices of patients, families and carers to UK healthcare professionals, NHS England 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. We also endeavour where possible to inform the general public about PKD.

PERFORMANCE AND ACHIEVEMENTS DURING 2018-19

Servicing our beneficiaries

During the year, demand for support continued to grow, in particular from ADPKD patients. 'PKD clinics' have formed in many hospitals to manage the screening and prescribing of tolvaptan.

Previously, most patients were seen in general nephrology outpatients or by GPs. More patients are discovering the charity by internet or Facebook search, or are given PKD Charity leaflets/newsletters by doctors.

Visitors to the PKD Charity website rose by 30% compared with the previous year. The charity’s Facebook page grew by 10% and the closed UK support group grew by 33%.

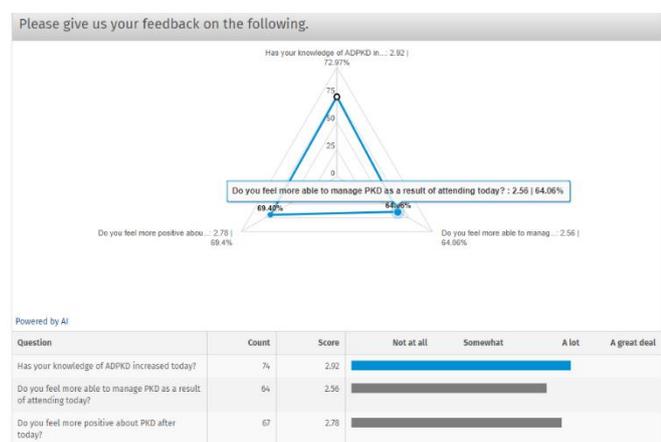
We continued to update and create **health information factsheets**, following our established editorial process (NHS Information Standard principles), involving lay and expert readers’ panels who provide constructive feedback during the process.

These factsheets are freely available directly from the website or from links in online support groups, and distributed at educational and awareness events. Healthcare professionals download and can order printed booklets to give to their PKD patients during clinic appointments.

As in previous years, the most popular factsheets are ‘Diet and Lifestyle’, ‘Managing Pain’ and ‘Polycystic Liver Disease’. During the year, the Diet and Lifestyle factsheet was Highly Commended for the 2018 BMA Patient Information Awards.

We held **ADPKD Information and Support Days** in Cambridge and Newcastle, attended by nearly 200 patients and family members. Sessions include talks by kidney doctors, nurses and patients. Each event includes workshops to allow small groups to discuss in detail matters such as coping with ADPKD, pain, diet and lifestyle.

We ask attendees 3 questions in our feedback forms to assess the impact of these events:



- Has your knowledge of ADPKD increased today?
- Do you feel more able to manage PKD as a result of attending today?
- Do you feel more positive about PKD after today?

The majority felt more informed, confident and positive. We learn from every event and use the feedback to improve subsequent events.

“Excellent day, inspired by patients’ stories.”

“Extremely useful day, meeting other people with experiences offering recently diagnosed hope.”

We continued to provide personalised support by phone, email and our online support groups. ‘Support’ ranges from giving non-medical information or signposting to relevant materials (on our PKD Charity site or approved 3rd party sites) to ‘listening’.

“I was dealing with cyst bursts that were more painful and more frequent than previous years, and it was suggested I use the peer support phone service so I had someone that I could talk to who understood, as I am the only one in the family who has it. The service has been amazing.”

On average, one person a day rings the charity helpline number. The webchat on our website responds to a visitor a day, acting as a ‘triage’ service, handling simple requests – such as providing information about fundraising or signposting to information pages – and forwarding the more complicated or sensitive questions to our CEO. Our closed Facebook groups are very active with an increase in 45% of message posts in last 12 months. We monitor and moderate all posts, with support from trained volunteers.

During the year, a number of local ‘Meetups’ took place several times a year in Aberdeen, Bristol, Falkirk, London and Southend, with 12 to 15 people at each. Trained volunteers host the meetups. Post-meetup evaluation shows that people feel better informed and ‘listened to’.



We started a free monthly support conference call service on specific topics such as ‘Newly Diagnosed’, ‘Transplants’, ‘Dialysis’. The calls are held in the evening for up to 8 people, facilitated by trained volunteer peer supporters.

Our trained peer supporters continue to support about 10 patients one-to-one by phone throughout the year.

We launched a webinar series and held three during the year: ‘ADPKD in Children’, ‘Tolvaptan’ and ‘Genetics of PKD’.

A medical expert presented each webinar live and the recordings can be viewed for free on the PKD Charity website or [YouTube channel](#).



Because of the increased demand and range of services to beneficiaries, we reviewed and restructured the support services. Two new roles were created to replace the Support Services Coordinator: Community Support Manager (part-time) and Community Engagement Manager (full-time). Following advertisement, a candidate for the first role was hired in March 2019 and a candidate for the second role was hired in June 2019.

Funding and supporting PKD research

Grants awarded

During the year, the Research Advisory Board recommended four projects for funding.

- £10,000 to fund a research nurse to help with the enrichment of the ADPKD paediatric cohort

within RaDaR (National Registry of Rare Kidney Diseases). The nurse undertaking this activity was already working on the ARPKD paediatric cohort data enrichment, using funds provided last year by the charity.

- £10,000 to Dr Qihe Xu of King's College London for '*Is normalising renal retinoic acid signalling a viable ARPKD therapeutic strategy?*'
- £10,000 to Dr Evi Goggolidou of the University of Wolverhampton for '*Characterisation of the genetic and protein profiles of ARPKD kidneys*'.
- £250 to support the Birmingham Children's Hospital Stars Together Rare Disease Registry.

PKD and related research initiatives

We began planning the ADPKD Priority Setting Partnership (PSP), run in association with the James Lind Alliance. This project will continue until Spring 2020.

We supported a research application to Kidney Research UK by Professor Paul Winyard (Institute of Child Health), relating to the management of children and young people with ADPKD.

The charity-funded PKD Biobank, curated by Professor Patricia Wilson at UCL Centre for Nephrology Royal Free Hospital continues to provide samples for use in PKD-related research. Since 2010, the Biobank has provided 2,500 samples and methods for over 90 projects in the UK.

During the year, the charity represented patients and families on two 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 CEO chairs the CSG. [More information here](#). The UKKRC met in June and December 2018. The CSG met several times during the year, mostly by phone. The CSG is also the RaDaR Study Group.
- The RaDaR **ARPKD Rare Disease Study Group**, chaired by Dr Larissa Kerecuk. [More information here](#)

The CEO is a member of the RaDaR Management Board.



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.

The CEO represented the charity as a member of the SIMPLIFIED (Vitamin D) clinical trial Steering Group and the ORCHARD (kidney disease and pregnancy) study Steering Group.

Activities in relation to awareness

Throughout the year, we attended and participated in conferences, workshops and events relevant to renal and genetic conditions:

- May 2018: SHAREHD Advisory & Dissemination Board

- June 2018: UK Kidney Week, Harrogate. (CEO gave two talks on clinical trials and PKD outcomes)
- July 2018: NHSBT Kidney and Liver Patient Support Groups meetings
- July 2018: British Transplant Games in Birmingham
- September 2018: Organ Donation Week UK
- September 2018: Genetic Alliance UK AGM
- October 2018: NKF Annual Conference.
- October 2018: ADPKD Multi-disciplinary Workshop (organised by Otsuka Pharmaceuticals UK)
- October 2018: Kidney Patient Involvement Network
- November 2018: NICE Scoping Meeting for new CKD Guidelines
- November 2018: Kidney Health Partnership meeting
- December 2018: Kidney Charities Together
- January 2019: Renal Transplant Services Meeting
- February 2019: Rare Disease Day
- March 2019: World Kidney Day

During the year, we published and distributed two issues of the PKD Charity newsletter to approximately 3000 households, the main renal hospitals and dialysis units in the UK.

The charity participates in the **European ADPKD Forum (EAF)**, a collaborative initiative launched in 2014, to raise awareness of ADPKD and its implications for patients, health services and economies in Europe — issues that are often under-recognised by many health stakeholders and policymakers. The CEO co-chairs the EAF with Dr Richard Sandford. In March 2019, the EAF held the first European ADPKD Summit in Brussels, attended by the charity's CEO and Chair.

During 2018-19, 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. The impact of Brexit on continuing involvement is unknown.

The CEO continued to represent the charity on the international SONG-PKD Steering Group. SONG-PKD will publish a core outcome set for ADPKD for use in all research and trials in late 2019.

Governance

Sustainability

During the year, we focused extensively on the charity's sustainability:

- Appointed external accountants, replacing former volunteer accountancy support.
- Introduced new and updated financial controls.
- Consolidated technology with the implementation of Office 365.
- Maintained strict risk registers.
- Documented business processes.
- Agreed new HR processes.

Trustees

- Held 8 trustee meetings during the FY.
- Appointed two new trustees following resignation of two trustees during the year.
- Held new trustee induction sessions.
- Updated trustee declarations in line with new requirements.

GDPR

- In May 2018, we published GDPR Data Protection policies.
- GDPR re consenting resulted in reduction by ~40% of email database but the list 'quality' has improved significantly as a consequence.

Safeguarding

- Updated Safeguarding Policies were developed and implemented.
- All trustees, volunteers and staff were required to take online safeguarding training.

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 respectively.

Fundraising

We thank all the amazing fundraisers who support the charity's work through a wide range of community activities and events: marathons, triathlons, runs, skydives, baking, school collections, etc. All fundraisers receive a pack with t-shirts and other items, plus sponsorship forms. Everyone is encouraged to sign Gift Aid declarations, an important income stream.

During the year, we hired a new full-time Fundraising Manager and began to expand our activities. The majority of the charity's income is from individual donations from supporters and beneficiaries. As our PKD community grows, we need to have the capacity to service our fundraisers.

Contribution made by volunteers

We acknowledge and thank all our volunteers for their commitment and enthusiasm in supporting the charity's activities. In particular, the trustees 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; supporters who proofread communication materials; and especially the phone and online peer supporters.

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.
- Michael Langdon, an IT consultant, who provides support for the charity's CRM database (Harlequin).

- Google (AdWords advertising grant).
- SR Group and Huron Consulting (room hire)

Future plans

We are ambitious to accelerate our impact during 2019-20, leverage our influence and bring our community together.

- We will publish the Top Ten research priorities in early 2020 – enabling us to set a robust patient-led long-term research agenda for ADPKD.
- We will develop a collaborative research programme with Kidney Research UK to accelerate research into new treatments for both types of PKD.
- We will work on developing partnerships with other organisations (UK and international) to improve patient care and health outcomes.

Additionally:

- We will continue to hold Information and Support Days – in particular increasing the number of events for ARPKD families.
- We will continue to provide our blended range of Support Services – offering practical, emotional and social support wherever people need it, online, by phone, webinars, meet-ups.
- We will update our website and refresh the content based on input from our community.
- We will grow our engagement with hospitals with the long-term aim that all PKD patients will be aware of the charity and the support we offer.
- We will develop and expand our fundraising activities outside our community – in particular by applying to trusts and foundations for our support services.

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.

In 2018-19, there were 11 ordinary trustee meetings (two face to face) and no special meetings. The trustees make extensive use of teleconferencing and email communications.

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 2018-19, the PKD Charity Research Advisory Board met 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 Ms Tess Harris (CEO). The trustees monitored performance at trustee meetings; the chair has regular phone and face-to-face meetings with Ms Harris.

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 according with the new 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, the Health and Social Care Alliance Scotland, Rare Disease UK, the Kidney Health Partnership, the Specialised Healthcare Alliance and the James Lind Partnership**. 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. More information here: www.ciliopathyalliance.org

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 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. More information here: <http://www.abpi.org.uk/our-work/patient-organisation-forum/Pages/default.aspx>

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. More information here: www.eurordis.org

The charity is a founder member of **FEDERG**, the European Federation of Patient Groups representing rare and genetic renal diseases. More information here: www.federg.org

FINANCIAL REVIEW

Performance

During the 12 months to 31 March 2019, the charity's income was **£237,460** (2018: £181,592).

Expenditure on raising funds as a percentage of total incoming resources was 24% (2018: 20%), in line with the Trustees' commitment to fundraising effectiveness. Research expenditure was **£20,250** (2018: £36,166). Research was funded out of restricted reserve funds. The charity's expenditure on charitable activities across Patient support, Awareness and Education was **£89,070** (2018: £104,769), which included information days, telephone support, online/chat support and expenditure on the peer support service.

In total, the charity expended **£185,574** (2018: £186,875), resulting in net income for the year of **£51,884** (2018: deficit £5,283). Total **fund balances carried forward at the year-end** was **£305,225** (2018: £253,341) and all funds maintained a surplus position at the year-end (Note 13).

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 respectively.

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 £150,336 (2018: £95,658), equivalent to 9 months' total expenditure net of current liabilities (2018: 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.

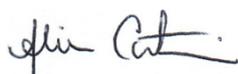
Risk Management

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



Alison Carter, CA, CPA, CFA
Trustee Treasurer
13 December, 2019

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 2019, which are set out on pages 18-26.

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



STATEMENT OF FINANCIAL ACTIVITIES - 1 APRIL 2018 TO 31 MARCH 2019

The notes on pages 20 - 26 form an integral part of these accounts.

	Note	Unrestricted funds £	Restricted funds £	2019 Total funds £	2018 Total funds £
Income and expenditure					
Income from donations and legacies	2	209,678	23,973	233,651	176,384
Income from other trading activities	3	2,295	-	2,295	3,551
Investment income	4	1,514	-	1,514	1,657
Total incoming resources		213,487	23,973	237,460	181,592
Expenditure on raising funds					
Cost of fundraising	5	60,111	-	60,111	36,145
Non-charitable trading activities	5	1,625	-	1,625	1,892
		61,736	-	61,737	38,037
Expenditure on charitable activities					
Research and grants	6	-	20,250	20,250	36,166
Awareness and education		8,853	-	8,853	5,026
Patient support		73,755	6,516	80,271	99,743
		82,608	26,766	109,374	140,935
Other expenditure					
Governance costs	7	14,464	-	14,464	7,903
Total resources expended		158,908	26,766	185,574	186,875
Net incoming / (outgoing) resources for the year		54,678	(2,793)	51,884	(5,283)
Fund balances brought forward at 1 April	13	95,658	157,685	253,341	258,626
Net incoming / (outgoing) resources for the year	13	54,678	(2,793)	51,884	(5,283)
Transfers between funds	13	-	-	-	-
Fund balances carried forward	13	150,336	154,892	305,225	253,341

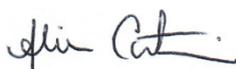
The statement of financial activities includes all gains and losses recognised in the year.
All income and expenditure is derived from continuing activities.

BALANCE SHEET AT 31 MARCH 2019

	Note	Unrestricted funds	Restricted funds	2019 Total funds £	2018 Total funds £
Assets					
Fixed assets					
Tangible assets	9	-	-	-	2,116
Current assets					
Debtors	10	19,832	8,000	27,832	35,163
Cash at bank and in hand		249,912	146,964	396,875	325,063
Total current assets		269,744	154,964	424,707	360,226
Liabilities					
Creditors falling due within one year	11	11,005	76,476	87,482	57,001
Net current assets		258,738	78,488	337,225	303,225
Total assets less current liabilities		258,738	78,488	337,225	305,341
Creditors falling due after more than one year	12	-	32,000	32,000	52,000
Net assets		258,738	46,488	305,225	253,341
The funds of the charity:					
Restricted funds	13	-	46,488	46,488	49,281
Unrestricted funds					
Designated	13	108,402	-	108,402	108,402
General	13	150,336	-	150,336	95,658
Total funds		258,738	46,488	305,225	253,341

These accounts are prepared in accordance with the special provisions of Part 15 of the Companies Act relating to small companies. For the year ending 31 March 2019 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies. The members have not required the company to obtain an audit of its accounts for the year in question in accordance with section 476. The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts.

Approved by the trustees on
And signed on their behalf by
Alison Carter, CA, CPA, CFA, Trustee Treasurer



Notes to the Financial Statements for year ended 31 March 2019

1a Accounting Policies

The principal accounting policies adopted are as follows:

i) Basis of preparation

The financial statements have been prepared in accordance with the Statement of Recommended Practice, 'Accounting and reporting by Charities' (Charities SORP - FRS102), applicable accounting standards, the Charities Act 2011, Companies Act 2006 and the Financial Reporting Standards applicable in the UK (FRS 102). Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy or note.

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 and professional fees.

vi) Grants

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

vii) 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 as follows:

Computer equipment – 20% straight line

viii) Current asset investments

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

ix) 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.

x) 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.

xi) Funds Structure

Funds are established to provide financial resources for aspects of the Charity's activities. Many 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.

1b. Legal status of the Charity

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.

	Unrestricted funds	Restricted funds	2019 Total funds	2018 Total funds
	£	£	£	£
2. Income from donations and legacies				
Donations and gifts	200,162	22,473	222,634	143,806
Trusts and Foundations	-	1,500	1,500	24,000
Gift Aid	9,516	-	9,516	8,577
Total:	209,678	23,973	233,650	176,383
3. Income from other trading activities				
Shop income	2,295	-	2,295	3,551
Total:	2,295	-	2,295	3,551
4. Investment income				
Interest income	1,514	-	1,514	1,657
5. Expenditure on raising funds				
Cost of fundraising	60,111	-	60,111	36,145
Cost of goods sold	1,625	-	1,625	1,892
Total:	61,736	-	61,736	38,037
6. Analysis of research and grants:				
	2019		2018	
	£		£	
Research studentship grants	-		48,000	
ADPKD Research	10,000		(22,000)	
ARPKD Research	10,000		10,000	
Stars Together Birmingham Childrens Hospital Registry	250		-	
Other costs	-		166	
Total:	20,250		36,166	

7. Governance costs:

	2019	2018
	£	£
Trustee meetings and governance	2,785	2,256
Accountancy and audit	9,625	4,760
Other professional fees	2,054	886
Total:	14,464	7,902

8. 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.

9. Analysis of Movement of Fixed Assets

	2019
	£
	Office equipment
Cost	
At 1 April 2018	11,497
Additions / (Disposals)	-
At 31 March 2019	11,497
Accumulated depreciation	
At 1 April 2018	9,381
Charge for the year	2,116
At 31 March 2019	11,497
Net Book Value	
At 1 April 2018	2,116
At 31 March 2019	-

10. Debtors

	2019	2018
	£	£
Prepayments	18,197	11,163
Accrued income	8,000	24,000
Other debtors	1,635	-
Total debtors	27,832	35,163

11. Liabilities: amounts falling due within one year

	2019	2018
	£	£
Accruals and deferred income	11,005	12,832
Grant commitments	76,476	44,169
Total current liabilities	87,481	57,001

12. Liabilities: amounts falling due after more than one year

	2019	2018
	£	£
Grant commitments due after more than one year	32,000	52,000

13. Funds and reserves

Analysis of movements in restricted funds

<i>Restricted fund</i>	<i>Retained surplus at 1 April 2018</i>	<i>Income</i>	<i>Expenditure</i>	<i>Transfer</i>	<i>Total funds at 31 March 2019</i>
	£	£	£	£	£
Support activities	5,016	1,500	(6,516)	-	-
Research	8,346	474	(250)	-	8,570
ARPKD research	16,257	18,120	(10,000)	-	24,377
ADPKD research	19,568	3,660	(10,000)	-	13,228
Royal Free Hospital biomarker	94	219	-	-	313
Total restricted funds	49,281	23,973	(26,766)	-	46,488

<i>Name of Restricted Fund</i>	<i>Description, nature and purposes of the fund</i>
Support activities	To fund support related activities, such as information days
Research	To fund research related to PKD
ARPKD research	To fund research related solely to ARPKD
ADPKD research	To fund research related solely to ADPKD
Royal Free Hospital biomarker	Created to fund a project at the Royal Free Hospital for the identification of PKD related biomarkers

Analysis of Movements in Unrestricted Funds

<i>Unrestricted fund</i>	<i>Retained surplus at 1 April 2018</i>	<i>Income</i>	<i>Expenditure</i>	<i>Transfer</i>	<i>Total funds at 31 March 2019</i>
	£	£	£	£	£
Designated research	65,000	-	-	-	65,000
Designated PKD bio-resource	13,402	-	-	-	13,402
Designated PKD registry	30,000	-	-	-	30,000
General fund	95,658	213,487	(158,809)	-	150,336
Total unrestricted funds	204,060	213,487	(158,908)	-	258,738

Name of Unrestricted Fund	Description, nature and purposes of the fund
Designated research	Designated to support research for PKD
Designated PKD Bio-resource	Designated to fund the Bio-Resource Bank at UCL
Designated PKD Registry	Designated to fund a project to create a PKD registry
General fund	The free reserves, after allowing for all other designated funds

14. Related Party Transactions and Trustees Remuneration

Trustees received no emoluments (2018: £nil).