

HELPING IMPROVE THE LIVES OF EVERYONE AFFECTED BY POLYCYSTIC KIDNEY DISEASE

Our year in review

Trustees' Annual Report – 1 April 2016 to 31 March 2017



ANNUAL REPORT AND ACCOUNTS 2016-2017

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REFERENCE AND ADMINISTRATIVE INFORMATION

Principal address and registered office:

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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

Ms Judith Dignum (Chair, resigned Dec 2016)

Ms Maureen Carson (appointed Sep 2016)

Mrs Alison Carter (appointed Sep 2016)

Mrs Edwina Graham

Mr Raj Johal

Mr Sarbjit Johal

Mr Barry Harpham

Ms Rebecca Murphy-Peers

Mr Nicholas Tracey (Treasurer)

Mrs Christine Wallach

Research Advisory Board

Professor Pat Wilson (Chair)

Dr Anand Saggar (Vice-Chair)

Ms Sanela Becar (Lay Member)

Dr Jill Norman

Dr Richard Sandford

Dr John Sayer

Dr Paul Winyard

Management & administration

Ms Tess Harris, Chief Executive (contractor)

Ms Esther Wright, Fundraising (contractor)

Patrons

Rt Hon Dr Vince Cable, MP

Mr Laurence Isaacson, CBE

Professor Albert Ong

Dr Anand Saggar

Dr Richard Sandford

Prof Pat Wilson

Professional advisors

Bankers

CAF Bank Ltd

25 Kings Hill Avenue

West Malling

ME 19 4JQ

Accountant

Mrs Dalma Fulesi

Independent accounts examiner

Charles Pickin

Fellow of Institute of Chartered Accountants in
England and Wales

Harrison Jasper Ltd

Dragons Green, Florance Lane, Groombridge, TN3
9SH

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

TRUSTEES ANNUAL REPORT & DIRECTORS' REPORT

The Trustees, who are also directors of the Charity for the purpose of the Companies Act, present their annual report and financial statements of the Charity for the year ended 31 March 2017. 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.

Welcome from the Chair

The PKD Charity is the only UK charity solely dedicated to the concerns of people affected by **polycystic kidney disease** or **PKD** - a range of inherited, incurable renal conditions and a common cause of kidney failure. 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.

During 2016-17, thanks to our fundraising efforts, the generosity of our supporters and volunteers, we were able to continue our charitable work.

In particular, we progressed the pilots of the PKD Charity Telephone Befriending Service in London, the North West and Scotland. We trained volunteers and matched them to provide peer support to people affected by PKD. We awarded a second grant to Cambridge University Hospital to support the development of a research app for the DRINK pilot study into the effects on ADPKD of high water intake. We are delighted to be an active partner in this patient-led research initiative. We continued to raise awareness about PKD, the burden and impact on patients and families, through participation in relevant committees, conferences, events and consultations.

A strategic review during the year identified that the charity was performing well but there were areas for improvement. This will be a governance focus going forward.

Over the next few pages you can read more about the charity's progress during 2016-17. 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 contractors.



Alan Greenberg, Chair, Board of Trustees
(Appointed September 2017)

OUR OBJECTIVES AND AIMS

The Polycystic Kidney Disease 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.

The challenge

Up to 70,000 children and adults in the UK are thought to have polycystic kidney disease – a range of incurable, systemic genetic conditions which cause kidney failure and damage other organs. There are two forms of PKD: **autosomal dominant polycystic kidney disease (ADPKD)**, the most common inherited kidney disease and 4th 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 could have ADPKD (based on 1 in 1,000 prevalence) and 20-40 could have ARPKD (1 in 20-40,000 prevalence).

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 many 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. Many will require nephrectomies (kidney removal) due to organ size and cyst infections. A few adults 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.](#)

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 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.

The PKD Charity helps patients and families cope by providing up to date, accredited information, educational events and relevant support - personal or group, online and in person. Our aim is to improve knowledge and understanding of PKD, reduce anxiety and help everyone feel more confident about managing their or their loved ones' condition.

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; therapies to modify and slow down progression 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. Dialysis or kidney/liver transplant are at present the only life-maintaining treatment when organs fail. We aim to stimulate and fund more ADPKD and ARPKD research in the UK.

The PKD Charity provides small grants up to £10,000 to UK researchers to 'pump-prime' projects that have potential for future funding (either from the PKD Charity or other funders). Applications are peer-reviewed by the charity's Research Advisory Board. The charity also funds a bio-bank at the Royal Free Centre for Nephrology which can be accessed by researchers needing cells and tissue for their own studies. The bio-bank is curated by Prof Pat Wilson, the Research Advisory Board chair.

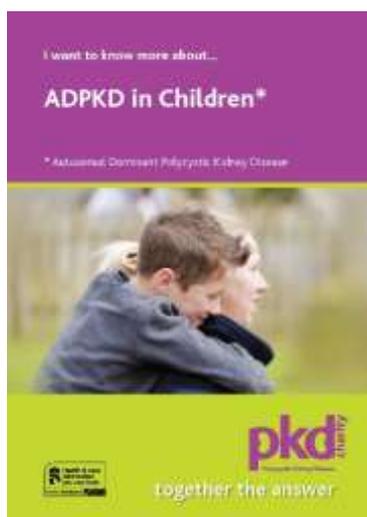
Despite being a very common kidney disease, PKD is relatively unknown. We aim to raise awareness of the impact and burden of this condition through authoritative information and targeted

communications.

The PKD Charity represents 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 patients' needs and the PKD burden are well understood. 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 2016-17

Activities in relation to information and support



During the year, we continued to update and create **health information leaflets**, following an editorial process accredited under the NHS Information Standard. We have active lay and expert readers' panels who provide constructive feedback during the process.

These leaflets were freely available online and distributed at educational and awareness events. A number of doctors and nurses gave them to their PKD patients during clinic appointments.

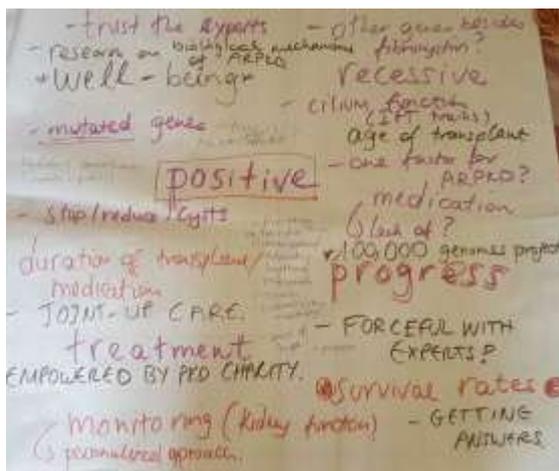
We held **ADPKD Information and Support Days** in Sheffield, Salford and Bristol, each attended by approximately 90 people. Patients and family members attend. Sessions include talks by nephrologists (kidney doctors), nurses and patients. Each event includes workshops to allow small groups to discuss 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 left the events feeling more informed, confident and positive. We used all the feedback to improve subsequent events.



We held an **ARPKD Family Day** at Kingston University for about 10 families – including parents, grandparents. Whilst the adults attended educational sessions with talks from experts and scientists, the children took part in supervised entertainment.

In the afternoon, we organised a ‘world-café’ style workshop where families and experts discussed a range of topics (see output in image). Everyone said the ARPKD Day made them feel more positive and empowered about their ARPKD experience. They stressed the need to communicate better any

information and progress on ARPKD, the need to gather resources and effort for research and raise awareness. A video was made by families and experts during the day, which is [available here](#); it was promoted on #BumpPKD Awareness weekend 2016 and Rare Disease Day 2017.

During the year, we provided personalised support by phone, email and our online support groups. ‘Support’ ranges from giving ‘factual’ information or signposting to relevant materials (on our PKD Charity site or approved 3rd party sites) to ‘listening’. On average, one person a day rings the charity helpline number - Monday is often a busy day; typically, the caller has spent the weekend searching the internet and is confused and concerned.

Our busiest support service is delivered online, via the closed Facebook groups we have set up for individuals, parents and young people. We have restricted membership to people living in the UK to avoid confusion about healthcare systems that arise in international groups. Group members generally provide mutual and sympathetic support to one another. However, we monitor and moderate all posts, correcting factual misunderstandings/errors, signposting to reliable information/resources and offering personalised help to anyone who is particularly distressed. On average, about 10 people a day posted on the Facebook group and some messages result in 20 to 30 replies, depending on the topic. The ubiquity of Facebook has resulted in a significant decrease in posts on our original forum (established more than 10 years ago.)

We also moderate HealthUnlocked ADPKD and ARPKD communities, which are hyperlinked from NHS Choices website. These are however less active than Facebook.



During the year, we developed and began to deliver the pilot of the Telephone Befriending Programme in London, the NW of England and Scotland, funded by the National Lottery Awards for All. This involves recruiting and training individuals with PKD to give personalised ‘befriending’ support to other patients or family members, who can either self-refer or be referred via hospitals. Learnings from the pilot will be used to develop the service in future years. During the year, 10

befrienders were trained; we used the Befriending Networks’ good practice guidance in the creation of our training and other resources for both befrienders and service users.

Activities in relation to research

In June 2016, the trustees agreed to award £10,000 to Cambridge University Hospital (CUH) towards the development of a smartphone app for use in a feasibility trial into water as a potential therapy for ADPKD. This trial had been stimulated by the charity proposing to the Cambridge Patient-led Research Hub that it was an important unmet need. CUH sought additional funding and the trial – called DRINK - started recruiting in 2016. Results are expected in 2018.



Prior to the DRINK trial commencing, the charity organised a survey of patients living with ADPKD to gain an understanding of current fluid intake practices, the potential acceptability of high fluid intake, and the interest in research participation. The survey was developed together with the trial's researchers. An abstract of the results was submitted to the UK Kidney Week Conference and accepted as a poster. The PKD Charity was acknowledged on the poster, highlighting the important contribution of patients to such projects.

In June 2016, the charity attended the UK Kidney Week Conference in Birmingham, organised jointly by the Renal Association and British Renal Society.

In November 2016, the trustees agreed to fund a Priority Setting Partnership (PSP) in association with the James Lind Alliance. The PSP will aim to prioritise the research topics identified at the KDIGO ADPKD Consensus Conference 2014 (published 2015) and others identified in partnership with patients, families, clinicians, nurses, allied healthcare professionals and key stakeholders. The top research priorities will be published to stimulate projects and studies that researchers can submit for funding to the charity or other funders.

In January 2017, the trustees agreed to continue funding the **bio-bank** at the Royal Free Centre for Nephrology for a further 3 years, at £10,000 per year. Professor Pat Wilson had provided a summary of the bio-bank contents, which had considerably expanded during the previous 3 years. Samples now include:

- cell pellets for tissue culture derived from PKD and age-matched normal human renal epithelial and fibroblast cells.
- frozen tissues from 72 different PKD and age-matched normal human kidneys.
- paraffin blocks of fixed tissues from PKD and age-matched normal human kidneys
- tissue sections from age-matched PKD and normal human kidneys
- cyst fluids from human ADPKD kidneys frozen in liquid nitrogen.

Overall 1337 items have been supplied for use in 49 PKD projects in the UK.

In February 2017, the Research Advisory Board reviewed the charity's research strategy, taking account of the charity's wider strategic review conducted during 2016. It was agreed that small grants were still effective along with building research capacity, eg through studentships. There are likely to be future research opportunities with the growth of the ADPKD and ARPKD patient cohorts on RaDaR.

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. Its

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members are multi-disciplinary and include patients. Its role is to stimulate ADPKD research, provide peer review to researchers and endorse worthwhile studies. Ms Harris chairs the CSG. [More information here](#). In March 2016, the CSG was aligned for governance purposes with the Rare Disease Renal Registry (RaDaR) **ADPKD Rare Disease Group** (RDG), which is chaired by Dr Richard Sandford. The two groups share common membership and goals.

- The **ARPKD Rare Disease Study Group**, which sits within the Rare Disease Renal Registry (RaDaR), chaired by Dr Larissa Kerecuk. [More information here](#)



Ms Harris, on behalf of the charity, sits on the RaDaR Operating Management Board, which reviews registry progress, ethics and other matters.

Activities in relation to awareness

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

- April 2016: ADPKD Conference organised by the Royal Society of Medicine on clinical management and new therapies. Ms Harris presented on the burden of living with ADPKD, in particular pain and the psychosocial aspects of the condition.
- May 2016: ERA-EDTA European Conference, alongside PKD International.
- June 2016: UK Kidney Week, Birmingham.
- July 2016: NHSBT Campaign Forum – to discuss involvement in donation and transplantation campaigns, in particular the #DonationConversation which would launch at UK Transplant Games.
- August 2016: Transplant Games in Liverpool.
- October 2016: NKF Annual Conference.
- November 2016: Kidney Health Partnership.
- February 2017: Transition Conference in Southampton. Ms Harris spoke on ADPKD in children and young people.
- February 2017: Rare Disease Day.
- March 2017: World Kidney Day.



On 30 September/1 October 2016, we participated in the first 'Give PKD the Bump' European Awareness Campaign, organised by PKD International. This campaign was supported by Otsuka Europe and the charity's trustees also provided funding for UK activities. The aim of the campaign is to raise general awareness of ADPKD and ARPKD, and stimulate fundraising. The trustees agreed to continue to support the campaign in future years.

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. Ms Harris co-chairs the EAF with Dr Richard Sandford.

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During the year, we published and distributed two issues of the PKD Charity newsletter to approximately 3000 households, the 80 main renal hospitals and over 200 dialysis units in the UK.

Governance activities

In April 2016, the trustees agreed to hire an independent consultant to assist with a **strategic review**.

- A questionnaire was designed and sent to approximately 3000 individuals, by post and then promoted online.
- The consultants conducted one-to-one interviews with key stakeholders (healthcare professionals, other charities, ADPKD and ARPKD patients/families), and presented a report to trustees in August 2016.
- Evidence from both the survey and the interviews suggested that the PKD Charity was undoubtedly performing well, but there was room for improvement.
- When asked what the PKD Charity is here to do, the most commonly used words matched well with the charity's main activities: "support", "information", "help", "research" and "awareness" all featured very prominently.

In September 2016, the trustees held two workshops to consider the findings and impact on the 3-year strategy agreed in 2015. It was agreed to merge 2 themes from the 2015-18 strategy ('Being the Go-to Place' and Reaching Out') as these overlapped into one and retain 'Research' and 'Awareness/Advocacy'.

In March 2016, Ms Dignum resigned as chair after 6 years of trusteeship with the charity. To increase the diversity of experience amongst the trustees and to deliver the strategy of the charity, the trustees agreed to recruit an external trustee/chair.

Fundraising activities

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.

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 befriending and peer support online mentors.

Pro bono support

We acknowledge and thank:

- Brecher & Co for legal advice regarding the DRINK app research grant.
- Microsoft, who provide software free of charge or at minimal cost.
- QuestionPro, who provide a free-of-charge survey platform.
- Vidahost, a hosting company, which gave a charity discount on the usual cost of server space

for the charity's CRM database (Harlequin).

- Google Grants.
- Virgo, a communications agency, who provided pro bono digital support.

Future plans

- We will implement the findings of the strategic review and will address fundraising effectiveness and diversification of income.
- We will continue to hold ADPKD Information and Support Days.
- We will hold an ARPKD Family Day.
- We will seek ways to measure our impact and communicate this more proactively with supporters and beneficiaries.
- We will complete the Befriending Pilot, develop and market a comprehensive range of 'Support Services'.
- We will investigate ways to fund research capacity.
- We will continue to work in partnership where possible with other kidney and genetic charities.
- We will recruit a new trustee/chair and review governance, risks and continuity.

Financial review

Performance

During the 12 months 1 April 2016 to 31 March 2017, the charity's income was **£185,604** (2016: £205,613).

Expenditure on raising funds as a percentage of total incoming resources was **30.0%** (2016: 23.4%). The trustees will address fundraising effectiveness and diversification of income, noting the challenging fundraising environment and increasing costs of fundraising.

Research expenditure **£40,516** (2016: £82,846) was focused on continuation of the charity's commitment to the Bio-bank (£30,000) and the patient-led research feasibility DRINK trial (£10,000). Research was funded out of Research-restricted reserves.

The charity increased its expenditure on charitable activities across Patient support, Awareness and Education to **£98,099** (2016: £87,222), including information days, telephone support, online/chat support and expenditure on the peer support service.

In total, the charity expended **£207,342** (2016: £227,745), resulting in a deficit for the year of **£21,738** (2016: deficit £22,132). Consistent with the prior year, this deficit arose from continued expenditure on Research, funded by drawing-down on restricted reserves. Total **fund balances carried forward at the year-end** was **£258,626** (2016: £280,364) 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 trustees require that the charity maintains sufficient reserves to maintain its activities. The trustees considered that the charity had sufficient reserves at the year-end and are of the view that the charity continues to be a going concern. As at the year end, the charity had Total Funds of £258,626 of which Unrestricted Funds were £155,767, equivalent to 9 months' total expenditure (at £207,342 for the 12 months to 31st March 2017).

Risk Management

The trustees have overall responsibility for ensuring that the PKD Charity is managing risk in a professional, responsible and constructive manner. This has involved identifying risks the charity may face, assessing potential impacts and minimising them.

Material risks for PKD Charity include: key person dependency on its Chief Executive; risk of loss of supporters; managing regulatory changes such as GDPR; and maintaining a surplus.

The trustees continue to review its 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 has established a GDPR implementation group.

The charity is exposed to financial risks, such as loss of income, which it aims to mitigate by holding sufficient reserves while continuing to diversify fundraising, for example, by increasing grant funding.

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 2016-17, there were nine ordinary trustee meetings (two face to face) and no special meetings. The trustees make extensive use of teleconferencing and email communications. In September 2016, the trustees appointed two new 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.

As at the year end March 2017, trustees were in the process of recruiting a new Chair of the charity, who was subsequently formally co-opted at the next face to face meeting of trustees, September 2017.

PKD Research Advisory Board

During 2016-17, the PKD Charity Research Advisory Board met to discuss the research strategy, provide advice on grant applications and review new or updated patient information materials (in line with our Information Standard accreditation).

Management and Administration

The Trustees delegate the management of charitable activities and administration to three part-time contractors: Ms Tess Harris, who provides chief executive, operational and administrative services; Ms Esther Wright, who provides community fundraising services and Information Day event management; and Ms Esther O'Brien, who coordinates the support services. The trustees monitor the activities and outputs of the contractors through reports provided at trustee meetings; the chair has regular phone and face-to-face meetings with Ms Harris.

The charity's bookkeeping and accounts are carried out by an external contractor.

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 certified by the **Information Standard** as a provider of 'high quality health and social care information' since 2013. More information here: <https://pkdcharity.org.uk/about-us/information-standard>

The charity is registered with the **Information Commissioner** and all supporters' and stakeholders' personal data are maintained securely according to the Principles of the Data Protection Act.

Membership of Related Organisations

The charity is a founder member of the **Kidney Charities Together** group of kidney charities, who meet quarterly to: share information; consider external matters that affect kidney patients, families and carers; and collaborate on joint advocacy campaigns and annual initiatives such as World Kidney Day.

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The charity is a member of several UK umbrella organisations representing the interests of people with long-term conditions (LTC) or genetic diseases, including **National Voices, 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 regularly 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.

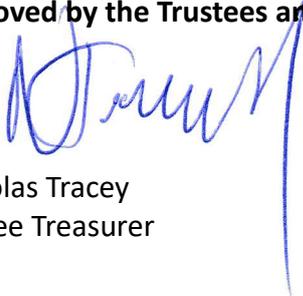
The charity is a member of the **ABPI (Association of British Pharmaceutical Industry) Patient Organisation Forum**. The forum meets regularly to discuss issues such as joint working between patient organisations and pharmaceutical companies. More information here: <http://www.abpi.org.uk/our-work/patient-organisation-forum/Pages/default.aspx>

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. Ms Tess Harris 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. ARPKD is a rare disease, having a prevalence of 1 in 20,000. 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

Approved by the Trustees and signed on their behalf by



Nicholas Tracey
Trustee Treasurer

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 2017, which are set out on pages 17 to 25.

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.

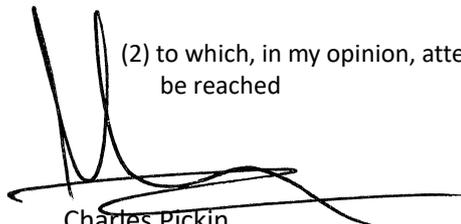
Independent examiner's statement

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 APR 2016 TO 31 MARCH 2017

The notes on pages 19 - 25 form an integral part of these accounts.

				2017	2016
	Note	Unrestricted funds	Restricted funds	Total Funds	Total Funds
		£	£	£	£
Income and expenditure					
Income from donations and legacies	2	162,006	18,443	180,449	197,869
Income from other trading activities	3	3,618	-	3,618	5,137
Investment income	4	1,537	-	1,537	2,607
Total incoming resources		167,161	18,443	185,604	205,613
Expenditure on raising funds					
Cost of fundraising	5	52,630	-	52,630	41,725
Non-charitable trading activities	5	3,130	-	3,130	6,314
		55,760	-	55,760	48,039
Expenditure on charitable activities					
Research and grants	6	516	40,000	40,516	82,846
Awareness and education		12,734	-	12,734	7,128
Patient support		79,182	6,183	85,365	80,094
		92,432	46,183	138,615	170,068
Other Expenditure					
Governance costs	7	12,967	-	12,967	9,638
Total resources expended		161,159	46,183	207,342	227,745
Net incoming / (outgoing) resources for the year		6,002	(27,740)	(21,738)	(22,132)
Fund balances brought forward at 1 April	13	139,765	140,599	280,364	302,496
Net incoming resources for the year	13	6,002	(27,740)	(21,738)	(22,132)
Fund balances carried forward	13	145,767	112,859	258,626	280,364

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

BALANCE SHEET AT 31 MARCH 2017

	Note	Unrestricted funds £	Restricted funds £	2017 Total funds £	2016 Total funds £
Fixed assets					
Tangible assets	9	4,416	-	4,416	6,624
Current assets					
Prepayments	10	15,267	-	15,267	16,077
Investments		75,000	-	75,000	75,000
Cash at bank and in hand		82,063	179,334	261,397	268,314
Total current assets		172,330	179,334	351,664	359,391
Liabilities					
Creditors: Amounts falling due within one year	11	20,979	56,475	77,454	63,982
Net current assets		151,351	82,859	274,210	295,409
Total assets less current liabilities		155,767	82,859	278,626	302,033
Creditors: Amounts falling due after more than one year	12	-	20,000	20,000	21,669
Net assets		155,767	102,859	258,626	280,364
Represented by:					
Funds and reserves					
Restricted funds	13	-	59,456	59,456	87,195
ADPKD Bio-resource Bank Grant Fund	13	-	13,403	13,403	13,403
PKD Registry	13	-	30,000	30,000	30,000
Unrestricted funds	13	155,767	-	155,767	149,766
Total funds	13	155,767	102,859	258,626	280,364

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 2017 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 19th December 2017

And signed on their behalf by

Nicholas Tracey, Trustee Treasurer



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: 91 Royal College St, London, NW1 0SE.

Notes to the Financial Statements for year ended 31 March 2017

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

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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	2017 Total Funds	2016 Total Funds
	£	£	£	£
2. Income from donations and legacies				
Donations and gifts	138,703	16,863	155,566	152,391
Trusts and foundations	-	-	-	30,235
Gift Aid	23,303	1,580	24,883	15,243
Total:	162,006	18,443	180,449	197,869
3. Income from other trading activities				
Other activities	-	-	-	1,276
Shop income	3,618	-	3,618	3,861
Total:	3,618	-	3,618	5,137
4. Investment income				
Interest income	1,537	-	1,537	2,607
5. Expenditure on raising funds				
Cost of fundraising	52,630	-	52,630	41,725
Goods sold	3,129	-	3,129	6,314
Total:	52,630	-	52,630	48,039

6. Analysis of Research and Grants:

	2017	2016
	£	£
PKD Bio-Bank	30,000	-
University of Cambridge (Smartphone app)	10,000	-
Research studentship grants	-	32,259
ADPKD Research	-	20,000
PKD Registry	-	10,000
ARPKD Research	-	15,400
Other costs	516	-
Total:	40,516	82,846

7. Governance costs:

	2017	2016
	£	£
Trustee meetings and governance	8,253	5,924
Accountancy and audit	3,000	3,016
Other professional fees	1,714	698
Total:	12,967	9,638

8. Taxation

The PKD 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

	2017
	£
	Office equipment
Cost	
At 1 April 2015	11,497
Additions / (Disposals)	-
At 31 March 2016	11,497
Accumulated depreciation	
At 1 April 2016	4,873
Charge for the year	2,208
At 31 March 2017	7,081
Net Book Value	
At 1 April 2016	6,624
At 31 March 2017	4,416

10. Debtors

	2017	2016
	£	£
Prepayments	10,709	11,455
Accrued income	4,558	4,622
Total debtors	15,267	16,077

11. Liabilities: amounts falling due within one year

	2017	2016
	£	£
Accruals and deferred income	20,979	12,224
Grant commitments	56,475	51,758
Total current liabilities	77,454	63,982

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

	2017	2016
	£	£
Grant commitments within five years	20,000	21,669

13. Funds and reserves

<i>Fund</i>	<i>Retained surplus at 1/4/16</i>	<i>Income</i>	<i>Expenditure</i>	<i>Transfer</i>	<i>Total funds at 31/3/17</i>
Activities	2,255	-	-	-	2,255
Harris	78	-	-	-	78
Research	57,679	2,667	(40,000)	-	20,346
PKD Bio-resource	13,402	-	-	-	13,402
PKD Registry	30,000	-	-	-	30,000
ARPKD	-	14,542	-	-	14,542
ADPKD	13,528	2,540	-	-	16,068
RFH Biomarker	94	-	-	-	94
A4A Lottery (England)	7,016	-	(3,339)	-	3,677
A4A Lottery (Scotland)	6,545	-	(4,150)	-	2,395
Unrestricted	149,766	167,160	(161,159)	-	155,767
Total funds	280,364	185,604	(207,342)	-	258,626

14. Related party Transactions and Trustees Remuneration

Trustees received no emoluments (2016: £nil).