

POLYCYSTIC KIDNEY DISEASE (PKD) CHARITY

REPORT OF THE TRUSTEES AND STATEMENT OF FINANCIAL ACTIVITIES

FOR THE YEAR ENDED 31 MARCH 2016

FOR THE COMBINED CHARITIES

The Polycystic Kidney Disease Charity
Registered Charity in England and Wales Number 1085662

Polycystic Kidney Disease Charity
Registered charity in England and Wales (1160970) | A company limited by guarantee
Registered company in England and Wales (9486245)
Registered address: 91 Royal College St, London, NW1 0SE.

Registered Charity in Scotland Number SC038279

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REFERENCE AND ADMINISTRATIVE INFORMATION

Principal address and registered office:

91 Royal College St
London
NW1 0SE

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Email: info@pkdcharity.org.uk

www.pkdcharity.org.uk

The Polycystic Kidney Disease Charity

Registered Charity in England and Wales
Number 1085662 | 20 March 2001

Polycystic Kidney Disease Charity

Registered charity in England and Wales
Number 1160970 | 18 March 2015
A company limited by guarantee
Registered company in England and Wales
Number 9486245 | 12 March 2015

Registered Charity in Scotland

Number SC038279 | 25 May 2007

Directors* and Trustees who served during the year

Ms Judith Dignum (Chair)
Mrs Edwina Graham
Mr Raj Johal
Mr Sarbjit Johal
Mr Barry Harpham
Ms Rebecca Murphy-Peers
Mr Nicholas Tracey (appointed 2016)
Mrs Margaret Pope (resigned 2016)
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)
Ms Julie Adams, Operations (contractor)

Medical advisors

Dr Anand Saggar, Consultant in Clinical Genetics,
St George's Hospital Medical School, London
Dr Richard Sandford, Senior Fellow in Clinical
Research & Genetics Consultant, Addenbrooke's
Hospital, Cambridge
Prof Paul Winyard, Institute of Child Health,
London

Patrons

Dr Vince Cable
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
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ME 19 4JQ

Independent accounts examiner

Charles Pickin
Fellow of Institute of Chartered Accountants in
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Harrison Jasper Ltd
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9SH

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

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TRUSTEES ANNUAL REPORT & DIRECTORS' REPORT

The trustees of the Polycystic Kidney Disease (PKD) Charity present their annual report and statement of financial activities for the year ended 31 March 2016. The accounts comply with the Charities Act 2011, the Charities Accounts (Scotland) Regulations 2006, 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).

Message from the Chair of the PKD Charity

The PKD Charity is the only UK charity solely dedicated to the concerns of people affected by 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 2015-16, thanks to fundraising efforts and generosity of our supporters, we have been able to continue our charitable work and in some areas to increase our activity. We launched the PKD Charity Telephone Befriending Service with pilots in London, the North West and Scotland, using charitable reserves and additional funding from Big Lottery Awards for All.

We awarded three 'pump-priming' research grants. The first grant will support continuing research into biomarkers of ADPKD progression, building on grants given by the charity to earlier stages of this work. The second grant has enabled the researchers to collect essential data and develop a protocol for a pilot study into the effects on ADPKD of high water intake (the DRINK trial). The third grant will fund critical data programming to support the expansion of the two UK-wide, all stages and ages, registries of ADPKD and ARPKD patients. We were particularly delighted that the first-ever ADPKD registry was launched in early 2016: this has the potential to transform future research in the UK as well as providing a better understanding of the natural history of ADPKD.

In May 2015, we heard the momentous news that the European Medicines Agency (EMA) had approved the first-ever disease-modifying drug therapy - JINARC® (tolvaptan) - for adults in Europe with ADPKD. The EMA granted the marketing authorisation to Otsuka Pharmaceutical Co Ltd (Otsuka), based on the findings of the pivotal Phase III randomised, double-blind and placebo-controlled TEMPO 3:4 trial – the largest clinical study conducted in ADPKD to date. ([Link to trial document](#))

In September 2015, we were delighted that the National Institute for Health and Care Excellence (NICE) had approved tolvaptan for the treatment of adults in England and Wales. In January 2016, the Scottish Medicines Consortium (SMC) Committee approved tolvaptan for adults in Scotland. Both NICE and the SMC agreed that tolvaptan was an effective, innovative therapy and addressed an unmet need. We are deeply grateful to the many patients in the UK who took part in the TEMPO clinical trial and to everyone who contributed their views to NICE and the SMC during the appraisal process. We also thank the researchers and Otsuka who studied and tested tolvaptan for over 10 years to bring hope to patients and families that there is drug at last that targets the underlying disease and not just the management of symptoms and complications of ADPKD.

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There is now a sense that PKD research is gaining momentum internationally. Data from PUB-MED shows continuing growth of PKD scientific publications and other pharmaceutical firms are showing interest following the TEMPO trial. There has been rapid progress from gene discovery ('80s and '90s) and understanding of the pathophysiology to the first effective treatment (tolvaptan). Nonetheless, ADPKD remains incurable. Only a few adults will benefit from tolvaptan (owing to restricted licensing criteria). Individuals will continue to experience the medical burden of the disease and its psycho-social impact on them and their families. For those affected by ARPKD, owing to disease rarity, there is even less hope of any therapies (other than symptomatic) at present.

During 2015-16, we concluded the incorporation of the PKD Charity.

Over the next few pages you can read more about PKD and the charity's progress during 2015-16. As a small charity, we would be 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.

Judith Dignum, Chair

The PKD Charity's charitable objects are:

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 all forms of PKD.

About PKD

PKD is present in two forms:

ADPKD - AUTOSOMAL DOMINANT POLYCYSTIC KIDNEY DISEASE – is the world's most common inherited kidney disease and the fourth cause of kidney failure. It is a progressive chronic systemic disease, typically affecting several generations of the same family.

True prevalence is unknown and global rates range from 1 in 500 to 1 in 4,000, with a large number of individuals being undiagnosed during life. ADPKD can be diagnosed at any time, in adulthood or in

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children (sometimes in utero). We estimate that 60-70,000 people in the UK could have ADPKD.

The disease is characterised by the relentless formation, growth and proliferation of innumerable fluid-filled cysts in the kidneys and often the liver and pancreas. Over time, the cysts profoundly enlarge the size, weight and volume of the kidneys, and replace healthy tissue. A normal kidney weighs approximately 150g; an ADPKD kidney can grow over 50 times as big. In one extreme case, two ADPKD kidneys together weighed 22kg or approximately one fifth of the patient's body weight. Individual cysts themselves can expand to 9 or 10 cm in length – which is the size of an average, normal human kidney.

ADPKD causes kidney failure often requiring RRT (renal replacement therapy) of dialysis or transplantation and sometimes causing premature death. Over half of those affected will have kidney failure by the time they are 60 years old. Data from the UK Renal Registry in England and Wales, for the period 1 January 2000 and 31 December 2011, showed that the median age of those with ADPKD starting renal replacement therapy (RRT) for dialysis or transplantation was 55 years. This compared with 62 and 66 years in those with diabetes or other kidney disease. This young age of starting RRT had not changed within the ADPKD group over the 10-year period. In a recent survey conducted by the charity, this early onset of kidney failure and RRT can cause substantial loss of personal and family earnings.

Symptoms include chronic (long-term) and acute pain, bleeding from burst cysts, urinary and kidney infections, kidney stones and kidney failure. Cystic livers are common and can enlarge massively, particularly in women. In rare cases, liver transplantation may be necessary owing to the effects of life-threatening bulk accompanied by pain and infections. Periods of illness or hospitalisation from these other complications are debilitating and impact negatively on quality of life.

Over two thirds of people with ADPKD will develop high blood pressure. Treating blood pressure with drugs can slow the rate at which the kidneys deteriorate. Without treatment for high blood pressure the risk of a stroke or heart attack increases.

However, not everyone with ADPKD will develop kidney failure. Some people may never have any problems and some may be unaware they have the condition throughout their lives. Understanding why some people never have 'end stage renal failure' is a goal of many PKD researchers.

ADPKD is caused by mutations in 2 genes: PKD1 and PKD2. One in 10 cases, however, is due to new or spontaneous genetic mutations. PKD1 mutations are associated with a faster progression but there is wide variability between individuals and families with the same mutation. If someone has ADPKD, there is a 1 in 2 likelihood that the disease will pass to each child. 'Genetic guilt' (of passing on ADPKD) is commonly felt and expressed.

ADPKD is sometimes diagnosed late, preventing optimal treatment of complications. Most ADPKD patients experience symptoms in adulthood but around 1 in 12 of diagnosed patients is a child. Children and young people with ADPKD are at risk of early hypertension which can often be overlooked or undiagnosed.

At the time of this report, there is one licensed disease-modifying treatment for ADPKD – Tolvaptan
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(JINARC®) which was approved during 2015 for some adult patients in the UK. A number of other drugs are being trialled around the world that offer hope for slowing or stopping the decline of kidney function.

ARPKD - AUTOSOMAL RECESSIVE POLYCYSTIC KIDNEY DISEASE – is a rare form of PKD which is typically diagnosed during pregnancy or soon after birth. True prevalence is unknown but it is believed to affect 1 in 20-40,000 live births.

ARPKD results in enlarged kidneys with or without cysts, liver enlargement and often high blood pressure. Sadly, around a third of ARPKD infants die at birth or shortly thereafter, primarily as the result of underdeveloped lungs. However, 8 to 9 in 10 babies that survive the first year of life are alive at 5 years.

High blood pressure is a very common complication in nearly all ARPKD children. They also have enlarged kidneys and often liver (due to fibrosis). Kidney transplantation is common during childhood and sometimes liver transplantation is necessary. These children usually have impaired growth and suffer over their lifetimes from the effects of chronic kidney disease, such as mineral and bone disorders, anaemia and cardiovascular complications.

Improvements in the treatment of newborn babies, control of blood pressure and liver complications, and management of renal failure are resulting in children with ARPKD living longer with a much better quality of life into adulthood.

ARPKD is caused by a mutation in a gene called PKHD1. Everyone has two copies of the PKHD1 gene, one from each of our parents. ARPKD only occurs when a child is conceived from parents who each pass on a copy of the PKHD1 gene with a mutation.

Parents of children with ARPKD do not have the disease themselves because they each have one normal copy of the gene in addition to the mutated copy. They are often called 'carriers'. The number of ARPKD carriers in the general public is 1 in 70.

If both parents are carriers, the chance of a child inheriting the faulty gene from both parents is one in four (25 per cent). If the child receives only one copy of the mutated gene, they will not have ARPKD but will be a carrier of the disease.

Families affected by ARPKD have to cope with often devastating consequences of the disease including early bereavement or the long-term implications of caring for a child with potentially life-threatening kidney and/or liver failure.

GOVERNANCE AND MANAGEMENT

Governance

The Polycystic Kidney Disease Charity (Old Charity) was first established in December 2000 by patients, professionals and members of families affected by PKD. The governing document is a

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Declaration of Trust (dated 10 December 2000) and it was registered with the Charity Commission in 2001 (No 1085562).

In 2015, the Trustees agreed to establish a charitable incorporated organisation to take forward the Old Charity's work. Wishing to retain the same name and following approval by the Charity Commission, the Polycystic Kidney Disease Charity (Charitable Company) was constituted as a company limited by guarantee on 12 March 2015, Company Registration No 9486245. The Charitable Company 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.

Subsequently, the new Charitable Company was registered with the Charity Commission on 18 March 2015, No 1160970. The assets and income of the Old Charity were transferred to the new Charitable Company on 27 May 2015.

This report is a combined report of the combined charities.

The Trustees would like to thank Brecher & Co for pro bono assistance with the incorporation.

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 Charitable Company's activities are planned and carried out by the Trustees.

In 2015-16, there were seven ordinary Trustee meetings (two face to face) and no special meetings. The Trustees make extensive use of teleconferencing and email communications. During 2015-16, the Trustees appointed one new Trustee as Honorary Treasurer and one Trustee resigned.

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.

During 2015-16, the PKD Charity Research Advisory Board met, via email, to provide advice on grant applications and review new or updated patient information materials (Information Standard accredited).

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 Julie Adams, who provides operational assistance with patient information and support services. The Trustees monitor the activities and outputs of the contractors through reports

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provided at Trustee meetings; the chair has regular phone and face-to-face meetings with Ms Harris.

The Trustees volunteer their time throughout the year, for example helping at information days and attending external events related to PKD, handling support calls, and posting Christmas Cards. Additional help is provided by unpaid volunteers, for example proof-reading information and assisting with monitoring online forums.

The Charitable Company's book-keeping is carried out by an external book-keeper.

The Charitable Company is a member of the **Fundraising Standards Board (FRSB)**, providing reassurance to supporters, members of the public and other donors, and promoting best practice in fundraising. Each year, the charity submits an Annual Return to the FRSB.

The Charitable Company is certified by the **Information Standard** as a provider of 'high quality health and social care information' since 2013. More information here: <http://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.

The Trustees acknowledge and thank all the charity's 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 all the friends and families who have raised funds for the charity throughout the years.

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.

The charity is represented on the UK **Cystic Diseases Clinical Study Group (CDCSG)**. This group is a multidisciplinary group dedicated to stimulating and nurturing clinical research into all forms of renal cystic diseases which include a wide range of paediatric and adult inherited and non-hereditary diseases. ADPKD is the primary cystic disease and the group's members are working on several research projects. Ms Tess Harris is the chair of the CDCSG. More information here: <https://www.kidneyresearchuk.org/research/cystic-diseases>

The charity is a founder member of the **ARPKD Rare Disease Study Group** in the UK, whose goal is to facilitate an improved and widely comprehensive healthcare service for both adults and children with ARPKD, including contributing to the development of the Rare Disease Renal Registry. One of the group's objectives is to bring families together to learn more about ARPKD from experts and share

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their personal experiences of coping with this condition. In conjunction with the Study Group, the charity organises annual ARPKD Family Information Days. More information here: <http://rarerenal.org/rare-disease-groups/arpkd-rdg/>

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. Ms Tess Harris is a board member. More information here: www.federg.org

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CHARITABLE ACTIVITIES

We want everyone affected by PKD to have the best quality of life. Our charitable activities are grouped under four strategic themes:

1 Being the 'Go To' place for PKD in the UK

The Challenge:

- People with PKD and their families find it difficult to access reliable, consistent information, which inhibits their ability to make suitable decisions about their condition.
- The PKD Charity will be the 'Go To' place for information about ADPKD and ARPKD for patients, families, medical professionals and other stakeholders.

We aim to address this challenge by:

- Providing information that is always evidence-based, Information Standard accredited and accessible for stakeholders, press, other charities, DH/NHS, patients, families, carers, other healthcare professionals (HCPs).
- Holding regular Information Days around the UK on ARPKD and ADPKD.

2 Funding research into improved quality of life

The Challenge:

- The quality of life of people living with PKD varies considerably from patient to patient and at varying stages of the condition.
- This means that people have little information about what to expect from the condition and often receive conflicting advice from the medical profession.
- The PKD Charity will fund research that will identify how to improve the quality of life of people living with PKD.

We aim to address this challenge by:

- Commissioning research into early intervention with a focus on nutrition.
- Supporting relevant studies either solely or jointly with other charities.

3 Reaching out so people don't feel alone

The challenge:

- PKD patients and their families feel isolated by the condition and often do not know anyone else with PKD.
- The PKD Charity will reach out to people affected by PKD, both patients and their families to provide advice, support and an opportunity to talk

We aim to address this challenge by:

- Providing Peer-to-Peer support through a network of PKD volunteers.
- Developing and engaging with a passionate 'tribe' of PKD champions who provide friendly advice and support to people in their local area affected by PKD.

4 By being the voice of PKD patients and families

The challenge:

- Access to PKD information and services within the UK is patchy and inconsistent resulting in
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inequality in the services and treatments that PKD patients receive.

- We will create a single voice for people living with ADPKD and ARPKD that is heard by the medical profession, NHS and government.

We aim to address this challenge by:

- Advocating with and through other groups on issues relevant to PKD patients.
- Representing the concerns of patients, families and carers in government (in partnership with other charities where appropriate) on 4 key issues: transplantation, free prescriptions, inequality to access in benefits and access to unlicensed trial drugs.
- Campaigning to implement nationally commissioned specialised services for ARPKD and ADPKD.
- Developing and maintaining appropriate relationships with drug companies that are researching treatments for PKD.

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.

ACTIVITIES AND ACHIEVEMENTS DURING 2015-16

1. Being the 'Go To' place for PKD in the UK

- a. During 2015-16, we progressed with the production of new and updated health and social care information, in accordance with the requirements of **The Information Standard** accredited process.
- b. We held two **ADPKD Information & Support Days** at the Royal Free Hospital London and the Queen Elizabeth Hospital Birmingham. These events provided opportunities to offer advice and support to patients, their families and carers; update on the latest research; and generate interest with local patients, nephrologists, renal nurses and geneticists.

Topics covered included:

- Genetics and pathology of PKD
- Progression of the disease and preventive measures
- Brain aneurysms
- Diet and lifestyle
- Transplantation and other surgical procedures
- Research
- Treatments and drug development
- Coping with PKD

We thank the doctors, surgeons and other professionals who give their time voluntarily to these events.

Those attending the events are asked to complete feedback surveys, which include specific questions intended to assess the outcome of these events. After the Royal Free

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event, which attracted over 120 people:

- 23% and 34% said their knowledge of ADPKD had increased a 'great deal' and 'a lot' respectively
- 11% and 31% % felt better able to manage their ADPKD a 'great deal' and 'a lot' respectively
- 17% and 38% felt more positive a 'great deal' and 'a lot' respectively

After the Birmingham event, which attracted more than 100 patients and families:

- 44% and 23% said their knowledge of ADPKD had increased a 'great deal' and 'a lot' respectively
- 16% and 26% % felt better able to manage their ADPKD a 'great deal' and 'a lot' respectively
- 16% and 32% felt more positive a 'great deal' and 'a lot' respectively

Patients and families welcomed the opportunity to talk to others with PKD and raise issues with doctors they don't have time to cover in clinic appointments.

- For example, one patient at the Royal Free felt: *"Very comforted by being invited, to be with other PKD sufferers, always felt alone and isolated, was great to share experiences and get a boost!"*
- A parent at Birmingham commented: *"A really wonderful opportunity to meet fellow PKD patients and carers. Interesting sessions and lots of information gathered."*

We review all feedback – positive and negative - and use for planning of future events.

- c. We held our fourth **ARPKD Family Information & Support Day** at the Royal Infirmary Leeds. Approximately 20 families attended. Feedback showed that families felt better able to manage ARPKD in their children. Of particular interest was the talk on liver aspects of ARPKD by Dr Suzanne Davison, who agreed to help with an information leaflet.
- d. The **PKD website** www.pkdcharity.org.uk attracted nearly 72,000 users, an increase of 70% from 2014-15. 78% were new visits and many of these subscribed to the charity's e-newsletter. Visitors spend most time on the information pages with the diet and pain pages receiving most visits as in previous years. There were peaks during the year which coincided with the announcements about the approval of Tolvaptan - the first-ever drug to treat ADPKD. The site contains an e-shop and online fundraising functionality.

2. **Funding research into improved quality of life**

- a. During 2015-16, we awarded the following grants:
 - i. £32,259 to the UCL Royal Free Centre for Nephrology to support the funding of 3 year Royal Free Joint PhD Studentship. The award is payable in 3 instalments over 3 years. Ms Katie Rabey was awarded the studentship and is under the supervision of Dr Jill Norman and Prof Patricia Wilson. **Katie commented: "I am thrilled to have received a PhD studentship that is co-funded by the PKD charity and I am very excited to start my project entitled 'The composition**

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and functional roles of exosomes in Autosomal Dominant Polycystic Kidney Disease (ADPKD)'. The opportunity to work on the identification of biomarkers in the progression of ADPKD is very exciting. To try and understand the progression pathway of ADPKD by identifying specific molecules in exosomes, which then have the potential to be clinically relevant is of great interest to me."

- ii. £10,000 to Addenbrooke's Charitable Trust to support a 1 year Cambridge Clinical Research Fellowship. The selected Fellow, Dr Ragada El-Damanawi, will work specifically on the data collection and protocol development for the feasibility phase of a UK water trial called DRINK. Dr Ragada attended the Birmingham Information and Support Day, with her supervisor, Dr Thomas Hiemstra. She has submitted the results of a survey into water drinking habits - co-designed and distributed by the charity – for publication. The DRINK feasibility study has now received ethics approval and with additional funding from other funders will start late 2016.
 - iii. £10,000 to the UK Renal Registry Request to part-fund a programmer to accelerate the coding and validation of programming work to add condition-specific data fields for the new ADPKD Registry & the existing ARPKD Registry. The Cystic Diseases and ARPKD Study Groups will collaborate with the programmer to ensure that the data collected was internationally interoperable and the most valuable for future research and a better understanding of both ADPKD and ARPKD natural history.
- b. Thanks to a generous donation from Arran Brown Foundation, we awarded £15,000 to UCL Centre for Nephrology Royal Free for the purchase of an additional freezer to house the expanding PKD bio-resource.

3. Reaching out so people don't feel alone

- a. During 2015-16, Ms Adams and Mrs Pope underwent training with the Befriending Networks and achieved accreditation whilst developing the documentation (policies, training etc) for the pilot **telephone befriending service**. We made successful applications to the Big Lottery Awards 4 All in England/Wales and Scotland to fund the pilot scheme in London/NW England and Scotland. We launched the pilot in Salford and London around World Kidney Day, March 2016. The aim of the service is to reduce isolation and provide support for people who are unable to attend information events or join online groups, help build confidence and make people feel more positive.
 - b. We manage **online Support Groups** such as closed Facebook and Health Unlocked communities, to enable online interaction between patients and carers, plus parents. These are administered and closely monitored by Ms Harris and trusted volunteers to ensure that no erroneous information is circulated and that anyone in distress is contacted and supported. Anecdotal feedback highlights the benefits to members of the groups: ***"I really value this group as a source of information and support"; "I have been a member for months and read with great interest all your comments, certainly finding out more from this than anywhere else!"***
 - c. The PKD Newsletter was published and mailed in Spring and Autumn to nearly 3,000 people registered on the PKD database. It was also sent to over 80 UK Renal Units (approximately 10 in Scotland) and over 300 dialysis satellite units. We issue regular e-
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- Newsletters to over 3,000 individuals with topical updates and new fundraising ideas.
- d. Our **telephone support helpline** (managed during 2015-16 by Mrs Pope and Ms Harris) received between 1 and 2 calls a day during the year; callers' information was kept confidential and secure; referrals to medical experts were made where relevant. Callers ranged from the newly diagnosed (including parents of ARPKD babies) to patients experiencing change in their condition. Callers enquiring about employment and benefits issues were referred to the Advocacy Service provided by the National Kidney Federation and the British Kidney Patient Association.
 - e. The **London Friendship Group** set up by Mrs Pope meets bi-monthly and has an expanding membership. An informal group was established in Glasgow by a PKD patient with the endorsement of the charity.

4. By being the voice of PKD patients and families

- a. During 2015-16, we represented patients and families at the appraisal meetings into tolvaptan held by NICE and SMC. We supported our nominated patient experts who had taken part in the clinical trials of Tolvaptan and spoke about their experiences at the appraisal meetings. NICE initially rejected Tolvaptan; we subsequently asked all our supporters to join us and request that the drug be approved. We believe that the huge number of moving responses to NICE, made by people affected by PKD, helped in the later decision to approve Tolvaptan.
- b. The Chair and Ms Harris attended meetings of the Kidney Charities Together group, which also includes Kidney Research UK, the National Kidney Federation, the British Kidney Patient Association and Kids Kidney Research. We believe that by working together, we can raise more awareness and campaign more efficiently on matters that affect kidney patients than on our own.
- c. The Chair, various trustees and Ms Harris have attended events in 2015-16 to represent and advocate for PKD patients and families, and raise awareness of PKD, in particular:
 - i. The Renal Transplant Clinical Reference Group within NHS England (2 meetings in 2015-16).
 - ii. The joint Renal Association/ERA-EDTA Congress in May/June 2015.
 - iii. The British Renal Society Conference in June 2015.
 - iv. The NHSBT (NHS Blood & Transplant) annual stakeholder event in July 2015.
 - v. The British Transplant Games in Gateshead in August 2015.
 - vi. The NHS and Monitor Renal Tariff meeting in August 2015.
 - vii. The 'Knitted Genetic Landscape' event held at Kings College in October 2015.
 - viii. The NKF Annual Conference in October 2015.
 - ix. The Cystic Diseases Clinical Study Group in November 2015 (continuing)
 - x. The UK Renal Registry Renal Data Collaboration Programme Board in January 2016 (continuing).
 - xi. The Steering Committee developing Guidelines for Children and Young People with ADPKD in January 2016 (continuing). The charity recruited two parents of children already diagnosed with ADPKD to join the committee and bring their family experiences to this important work.
 - xii. The Renal GeCIP within the 100,000 Genomes England project. (PPI role continuing)
 - xiii. Rare Disease Day in February 2016.

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- xiv. Salt Awareness Day in February 2016.
 - xv. World Kidney Day events during March 2016.
 - xvi. During 2015-16, Ms Harris continued to co-chair the European ADPKD Forum (EAF), which held a multi-disciplinary event in January 2016 and is now progressing a 'Joint Position Statement' (to be published late 2016) on Principles of Care for ADPKD patients.
- d. During 2015-16, we participated in the development of a European PKD Campaign, in collaboration with the patient groups from France, Germany, Italy, Spain and Switzerland (to be launched late September 2016). The campaign aims to generate and promote awareness of both ADPKD and ARPKD, and raise funds for each participating European patient organisation.
- e. The charity has a public Facebook page www.facebook.com/pkdcharity and Twitter account www.twitter.com/PKDCharity to engage with supporters and external stakeholders.

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.

PKD Charity Database

We thank Vidahost, a hosting company, which gave a charity discount on the usual cost of server space for the charity's CRM database (Harlequin). The database enables donations to be processed more efficiently and provides a secure place for storing personal information about supporters and donors.

FINANCIAL REVIEW

Performance

During the 12 months 1 April 2015 to 31 March 2016, the charity's income was **£203,946** (2015: £168,431). Income from **voluntary donations** increased by 19% to **£196,203** (2015: £164,349).

Expenditure on raising funds increased as a percentage of Total incoming resources to **22.7%** (2015: 19.6%), explained largely by increased cost of fundraising activities and events **£40,059** (2015: £26,115), such as purchasing places in charity fun-runs and marathons.

The charity increased its charitable research grant funding activity, including the award of 3 new research grants. Research grants increased to **£82,846** (2015: £40,667). This increased charitable activity was funded out of current and prior year restricted donations, whose purpose was to fund research (ADPKD, ARPKD, PKD Registry and Research funds). The trustees plan to review the research strategy, consulting the Research Advisory Board, and will ensure reserves continue to be applied to fund the charitable activities for which they were intended.

The charity also increased its charitable activities across Patient support, Awareness and Education to **£87,222** (2015: £64,292), including information days, telephone support and expenditure on the pilot befriending service.

In total, the charity expended **£226,078** (2015: £147,567) a 53% increase in expenditure on charitable activities and fundraising, resulting in a deficit for the year of **£22,132** (2015: surplus £20,863). Total **fund balances carried forward at the year end** was **£280,364** (2015: £302,496) all funds maintained a surplus position at the year end (Note 13).

Reserves

The trustees require that the charity maintains sufficient reserves to maintain its charitable 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 £280,364 of which Unrestricted Funds were £148,204, equivalent to 10 months' expenditure on charitable activities at £170,068 for the 12 months to 31st March 2016.

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 impact and minimising them.

Material risks for PKD Charity include: key person dependency on its Chief Executive; any risk of loss of supporters. 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.

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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.

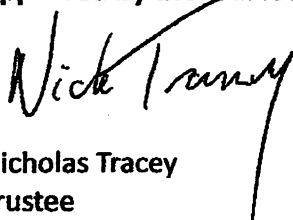
During 2014-15, the charity opened two 1 year term accounts with Cater Allen and United Trust Bank in order to maximise interest income. It deposited £85,000 in each, the sum was the maximum guaranteed by the UK government, minimising investment risk.

FUTURE PLANS

These include:

- Carrying out a strategic review.
- Continuing to update and create health information leaflets, accredited under the Information Standard.
- ADPKD Information Days in Sheffield, Salford, Bristol and Belfast.
- ARPKD Family Information Day at Kingston University.
- Providing on-going support by phone, email, support groups and website.
- Completing the pilot of the Telephone Befriending Programme in London, the NW of England and Scotland.
- Publishing the PKD Newsletter and e-newsletters.
- Reviewing the research strategy with the Research Advisory Board.
- Participating in the Cystic Diseases and ARPKD Clinical Study Groups.
- Attending the joint Renal Association and British Renal Society conference in Birmingham.
- Attending and participating in conferences, workshops and events relevant to renal and genetic conditions.
- Participating in the European ADPKD Forum policy activities and implementing the European awareness and fundraising campaign in collaboration with European PKD and kidney patient groups.
- Supporting and encouraging individual and family fundraising.

Approved by the Trustees and signed on their behalf by



Nicholas Tracey
Trustee

12 Dec 2016

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INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF THE POLYCYSTIC KIDNEY DISEASE CHARITY

Independent examiner's report to the trustees of The PKD Charity

I report on the accounts of the company for the year ended 31 March 2016, which are set out on pages 20 to 31.

Respective responsibilities of trustees and examiner

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

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

Basis of independent examiner's report

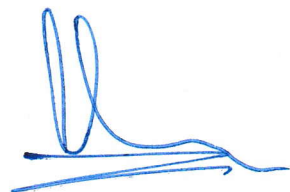
My examination was carried out in accordance with the general Directions given by the Charity Commission and is in accordance with Regulation 11 of the Charities Accounts (Scotland) Regulations 2006. An examination includes a review of the accounting records kept by the charity and a comparison of the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

Independent examiner's statement

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

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

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



12/12/16

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COMBINED STATEMENT OF FINANCIAL ACTIVITIES - 1 APR 2015 TO 31 MARCH 2016
(including consolidated Income and Expenditure account)

The notes on pages 23 - 31 form an integral part of these accounts.

				2016	2015
	Note	Unrestricted funds	Restricted funds	Total Funds	Total Funds
		£	£	£	£
Income and expenditure					
Income from donations and legacies	2	137,230	60,639	197,869	164,349
Income from other trading activities	3	5,137	-	5,137	3,802
Investment income	4	2,607	-	2,607	280
Total incoming resources		144,974	60,639	205,613	168,431
Expenditure on raising funds					
Cost of fundraising	5	41,725	-	41,725	29,192
Non-charitable trading activities	5	6,314	-	6,314	3,789
		48,039	-	48,039	32,981
Expenditure on charitable activities					
Research and grants	6	187	82,659	82,846	40,667
Awareness and education		7,128	-	7,128	15,087
Patient support		78,420	1,674	80,094	49,205
		85,735	84,333	170,068	104,959
Other Expenditure					
Governance costs	7	9,638	-	9,638	9,627
Total resources expended		143,412	84,333	227,745	147,567
Net incoming / (outgoing) resources for the year		1,562	(23,694)	(22,132)	20,863
Fund balances brought forward at 1 April	14	148,204	154,292	302,496	281,633
Net incoming resources for the year	14	1,562	(23,694)	(22,132)	20,863
Fund balances carried forward	14	149,766	130,598	280,364	302,496

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

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ANALYSIS OF PRINCIPAL SOFA COMPONENTS BETWEEN COMBINED CHARITIES

		PKD Charity 1/3/15 – 27/5/15		PKD Charitable Company 28/5/15 – 31/3/16		2016	2015
	Note	Un-re- stricted funds	Restricted funds	Un-re- stricted funds	Restricted funds	Total Funds	Total Funds
		£	£	£	£	£	£
Income and expenditure							
Income from donations and legacies	2	23,573	50	113,657	60,589	197,869	164,349
Income from other trading activities	3	97	-	5,040	-	5,137	3,802
Investment income	4	-	-	2,607	-	2,607	280
Total incoming resources		23,670	50	121,304	60,589	205,613	168,431
Expenditure on raising funds							
Cost of fundraising	5	10,014	-	31,711	-	41,725	29,192
Non-charitable trading activities	5	308	-	6,006	-	6,314	3,789
		10,322	-	37,717	-	48,039	32,981
Expenditure on charitable activities							
Research and grants	6	55	-	132	82,659	82,846	40,667
Awareness and education		1,076	-	6,052	-	7,128	15,087
Patient support		8,088	-	70,332	1,674	80,094	49,205
		9,219	-	76,516	84,333	170,068	104,959
Other Expenditure							
Governance costs	7	1,889	-	7,749	-	9,638	9,627
Total resources expended		21,430	-	121,982	84,333	227,745	147,567
Net incoming / (outgoing) re- sources for the year		2,240	50	(678)	(23,744)	(22,132)	20,863
Fund balances brought forward at 1 April	14	148,204	154,292	-	-	302,496	281,633
Net incoming resources for the year	14	2,240	50	(678)	(23,744)	(22,132)	20,863
Transfer of assets to PKD Charitable company		(150,444)	(154,342)	150,444	154,342	-	
Fund balances carried forward	14	-	-	149,766	130,598	280,364	302,496

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BALANCE SHEET AT 31 MARCH 2016

	Note	Unrestricted funds £	Restricted funds £	2016 Total funds £	2015 Total funds £
Fixed assets					
Tangible assets	9	6,624	-	6,624	8,832
Current assets					
Prepayments	10	16,077	-	16,077	13,578
Investments	11	75,000	-	75,000	170,000
Cash at bank and in hand		64,290	204,024	268,314	158,367
Total current assets		155,367	204,024	359,391	341,945
Liabilities					
Creditors: Amounts falling due within one year	12	12,225	51,757	63,982	41,614
Net current assets		143,142	152,267	295,409	300,331
Total assets less current liabilities		149,766	152,267	302,033	309,163
Creditors: Amounts falling due after more than one year	13	-	21,669	21,669	6,667
Net assets		149,766	130,598	280,364	302,496
Represented by:					
Funds and reserves					
Restricted funds	14		87,195	87,195	100,888
ADPKD Bio-resource Bank Grant Fund	14		13,403	13,403	13,403
PKD Registry	14		30,000	30,000	40,000
Unrestricted funds	14	149,766		149,766	148,205
Total funds	14	149,766	130,598	280,364	302,496

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 2016 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.

The trustees have prepared combined (merger) accounts in accordance with section 904 of the Companies Act 2006, section 310 of the Charities Act 2011 and section 27.12 of the Charities SORP (accounting for charity reconstructions).

Approved by the trustees on
And signed on their behalf by

Nicholas Tracey, Trustee



12 DEC 2012

The Polycystic Kidney Disease Charity | Registered Charity in England and Wales Number 1085662

NOTES TO THE FINANCIAL STATEMENTS FOR YEAR ENDED 31 MARCH 2016

1a Accounting Policies

The financial statements have been prepared in accordance with the Statement of Recommended Practice, 'Accounting for Charities' (Charities SORP (FRSSE)), applicable accounting standards, the Charities Act 2011, Companies Act 2006 and the Financial Reporting Standard for Smaller Entities (effective January 2015).

The principal accounting policies adopted are as follows:

i) Basis of preparation

The financial statements are prepared under the historical cost convention, as modified by the inclusion of investments at market value, and under accruals accounting principles. This is the first year in which the financial statements have been prepared under Charities SORP (FRSSE). The trustees have considered whether a restatement of comparative items was required in applying the accounting policies applicable. All accounting policies are in accordance with the requirements of FRSSE 2015 and are consistent with those for the prior year.

The charity's legal form changed with the transfer of the PKD Charity's assets to the PKD Charitable Company on 27 May 2015, nevertheless the board of trustees, purpose and beneficiary class remained unchanged, therefore following the guidance of the Charities SORP (FRSSE) section 27.12 this was treated as charity reconstruction and accounted for as a merger and not as an acquisition.

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.

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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.

xii) Merger accounting on incorporation of charity

The assets and income of the original charitable trust (No 1085662) were transferred to the new charitable company on 27 May 2015 (see Note 16). The charity has changed its legal form, nevertheless its purpose and beneficiary class remained unchanged. Under the Charities SORP (FRSSE) paragraph 27.12 this reconstruction was treated as merger as:

- the use of the merger accounting method is not prohibited by company law or other relevant legislation;
- the beneficiary class has not changed;
- the purposes for which funds are held have not changed;
- the persons who constitute the trustee body have not changed; and
- no non-controlling interest in the net assets of the charity is altered by the transfer.

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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.

	PKD Charity 1/3/15 – 27/5/15		PKD Charitable Company 28/5/15 – 31/3/16		2016	2015
	Unrestricted Funds	Restricted Funds	Unrestricted Funds	Restricted Funds	Total Funds	Total Funds
	£	£	£	£	£	£
2. Income from donations and legacies						
Donations and gifts	23,470	50	98,517	30,354	152,391	137,982
Trusts and foundations	-	-		30,235	30,235	11,001
Gift Aid	103	-	15,140	-	15,243	15,366
Total:	23,573	50	113,657	60,589	197,869	164,349
3. Income from other trading activities						
Other activities	-	-	1,276	-	1,276	1,355
Shop income	97	-	3,764	-	3,861	2,447
Total:	97	-	5,040	-	5,137	3,802
4. Investment income						
Interest income	-	-	2,607	-	2,607	280
5. Expenditure on raising funds						
Cost of fundraising	10,014	-	31,711	-	41,725	29,192
Goods sold	308	-	6,006	-	6,314	3,789
Total:	10,322	-	37,717	-	48,039	32,981

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6. Analysis of Research and Grants:

	2016	2015
	£	£
PKD Bio-Resources	-	26,667
Research studentship grants	32,259	-
ADPKD Research	20,000	-
PKD Registry	10,000	-
ARPKD Research	15,400	14,000
Total:	82,846	40,667

7. Governance costs:

	Charity	Company	2016	2015
	£	£	£	£
Trustee meetings and governance	763	5,161	5,924	4,012
Accountancy and audit	500	2,516	3,016	2,910
Other professional fees	626	72	698	2,706
Total:	1,889	7,749	9,638	9,628

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.

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Polycystic Kidney Disease Charity | Registered charity in England and Wales (1160970) | A company limited by guarantee
Registered company in England and Wales (9486245) | Registered address: 91 Royal College St, London, NW1 0SE.

Registered Charity in Scotland Number SC038279

9. Analysis of Movement of Fixed Assets

	2016
	£
	Office equipment
Cost	
At 1 April 2015	11,497
Additions / (Disposals)	-
At 31 March 2016	11,497
Accumulated depreciation	
At 1 April 2015	2,665
Charge for the year	368
At 31 March 2016	3,033
Net Book Value	
At 1 April 2015	8,832
At 31 March 2016	6,624

10. Debtors

	2016	2015
	£	£
Prepayments	11,455	7,911
Accrued income	4,622	4,780
Other debtors	-	887
Total debtors	16,077	13,578

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11. Analysis of movement of current asset investments

	2016
	£
Carrying value at beginning of year	170,000
Disposals	(95,000)
Carrying value at end of year	75,000

12. Liabilities: amounts falling due within one year

	2016	2015
	£	£
Accruals and deferred income	12,224	17,614
Grant commitments	51,757	24,000
Total current liabilities	63,981	41,614

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

	2016	2015
	£	£
Grant commitments within five years	21,669	6,667

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14. Funds and reserves

<i>Fund</i>	<i>Retained surplus at 1/4/15</i>	<i>Income</i>	<i>Expenses</i>	<i>Transfers</i>	<i>Total fund at 31/3/16</i>
Activities	2,255	-	-	-	2,255
Harris	78	-	-	-	78
P Lockyer	1,691	-	-	(1,691)	-
Research	53,492	2,896	400	1,691	57,679
PKD Bio-resource	13,402	-	-	-	13,402
PKD Registry	40,000	-	10,000	-	30,000
ARPKD	-	15,000	15,000	-	-
ADPKD	43,373	27,415	57,259	-	13,528
RFH Biomarker	-	94	-	-	94
A4A Lottery (England)	-	8,690	1,674	-	7,016
A4A Lottery (Scotland)	-	6,545	-	-	6,545
Unrestricted	148,205	143,307	141,746	-	149,766
Total funds	302,496	203,946	226,078	-	280,364

15. Related party Transactions and Trustees Remuneration

Trustees received no emoluments (2015: £nil).

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16. Assets and funds transferred to charitable company

The assets and income of the PKD Charity (No 1085662) were transferred to the new charitable company on 27 May 2015. The charity has changed its legal form, nevertheless its purpose and beneficiary class remained unchanged. Under the Charities SORP (FRSSE) 27.12 this reconstruction was treated as merger as

- the use of the merger accounting method is not prohibited by company law or other relevant legislation;
- the beneficiary class is not significantly changed;
- the purposes for which funds are held are not significantly changed;
- the persons who constitute the trustee body are not significantly changed; and
- no non-controlling interest in the net assets of the charity is altered by the transfer

Names and descriptions of the charities:

The Polycystic Kidney Disease Charity (Registered Charity in England and Wales Number 1085662) 'old Charity' ceased trading on 27 May 2015.

The Polycystic Kidney Disease Charity (Registered Charity in England and Wales (1160970) and registered company (9486245) 'Charitable Company' commenced trading on 28 May 2015.

Date of merger and transfer of assets: 27 May 2015

- The PKD Charity did not trade after the transfer of assets, therefore the results reported by the PKD Charity from 1/3/15 – 27/5/15 represent all trading up to the date of the transfer. The PKD Charitable Company did not trade before the date of the transfer, therefore the results reported by the PKD Charitable company represent all trading after the date of the transfer.
- No significant adjustment was considered necessary in order to align accounting policies, as these did not change on transfer of assets.
- The principal components of the previous period's SoFA accounts (comparative amounts) represent the results of the PKD Charity as the PKD Charitable Company did not trade before 27 May 2015.
- the carrying amount of the net assets of the PKD Charitable Company was £nil at the date of transfer of assets
- the carrying amount of the net assets of the PKD Charity transferred to the PKD Charitable Company as at 27 May 2015 were as follows:

	Unrestricted Funds	Restricted Funds	Total Funds
Fixed assets (NBV)	8,464		8,464
Debtors and prepayments	8,212		8,212
Cash and short term investments	145,332	187,509	332,841
Creditors	(11,564)	(33,167)	(44,731)
Total funds transferred	150,444	154,342	304,786
Unrestricted Funds	150,444		
PKD Registry		40,000	
Research		53,542	
ADPKD Research		43,373	
Bio-Resource		13,403	
Other restricted		4,024	
Total funds transferred	150,444	154,342	

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