

**THE POLYCYSTIC KIDNEY DISEASE (PKD) CHARITY**

**REPORT OF THE TRUSTEES AND  
STATEMENT OF FINANCIAL ACTIVITIES**

**FOR THE YEAR ENDED 31 MARCH 2015**

**Registered Charity in England and Wales Number 1085662  
Registered Charity in Scotland Number SC038279**

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## REFERENCE AND ADMINISTRATIVE INFORMATION

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### Registered Charity in England and Wales

Number 1085662 | 20 March 2001

### Registered Charity in Scotland

Number SC038279 | 25 May 2007

### Trustees who served during the year

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Mrs Edwina Graham

Mr Raj Johal

Mr Sarbjit Johal

Mr Barry Harpham

Ms Rebecca Murphy

Mrs Margaret Pope

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

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Ms Esther Wright, Fundraising

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Dr Richard Sandford, Senior Fellow in Clinical  
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Dr Paul Winyard, Institute of Child Health, London

### Patrons

Dr Vince Cable

Mr Laurence Isaacson, CBE

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Dr Richard Sandford

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## TRUSTEES ANNUAL 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 2015, and confirm they comply with Part 8 of the Charities Act 2011, the Charities Accounts (Scotland) Regulations 2006, the trust deed and applicable law.

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

### ***The PKD Charity's objects:***

1. To relieve people affected by all forms of PKD, in particular by providing information, advice and support to affected patients and families.
2. To fund research into determining the causes of PKD and into discovering treatments and a cure for PKD. Research results are made available to the medical community and the public, reported on the website and in newsletters.
3. To raise awareness of PKD, providing information to the public, the medical community and the media.

### ***Our mission***

We want to improve the lives of everyone affected by all forms of Polycystic Kidney Disease (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 kidney disease, typically affecting several generations of the same family. 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.

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

ADPKD causes kidney failure often requiring 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.

The disease is characterised by numerous 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 150 g; an ADPKD kidney can grow over 50 times as big. In one extreme case, two ADPKD kidneys together weighed 22 kg 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.

Symptoms include pain, bleeding from burst cysts, urinary and kidney infections, kidney stones and kidney failure. If the kidneys fail - often in early middle age – RRT (renal replacement therapy of dialysis or transplantation) is required. 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.

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.

Most ADPKD patients experience symptoms in adulthood but around 1 in 12 of patients is a child. Despite its commonness, ADPKD remains unknown to the public and many health professionals are unfamiliar with its effects.

ADPKD is sometimes diagnosed late, preventing optimal treatment of complications. At the time of this report, there was no approved treatment for ADPKD. However, a number of drugs are being trialled around the world that offer hope for slowing or stopping the decline of kidney function. One drug, Tolvaptan, is undergoing a NICE 'technology appraisal' process.

**ARPKD - AUTOSOMAL RECESSIVE POLYCYSTIC KIDNEY DISEASE** occurs in children and results in enlarged kidneys with or without cysts, liver enlargement and often high blood pressure. In ARPKD, 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. A number of adults with ARPKD are known to the charity.

ARPKD is designated a 'rare' disease affecting approximately 1 in 20-40,000 people. It 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 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.

High blood pressure is a very common complication in 80% of the children. They also have enlarged kidneys with or without cysts and liver enlargement. Kidney transplantation is common amongst these child patients, and sometimes liver transplantation is necessary.

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.

## GOVERNANCE AND MANAGEMENT

### ***Governance***

The PKD Charity was established in 2000. Its governing document is a Declaration of Trust (dated 10 December 2000). The trustees are responsible for the governance of the charity.

Trustees are recruited and appointed by the trustees. All 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 2014-15, there were six ordinary trustee meetings (2 face to face) and no special meetings. The trustees make extensive use of teleconferencing and email communications. During 2014-15, the trustees resolved to appoint an Honorary Treasurer and began advertising the role late in 2014.

All trustees are required to declare relevant interests and may be required to withdraw from Board meetings.

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

During 2014-15, 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).

During 2014-15, the incorporation of the charity was progressed and in June 2014, the trustees formally agreed the incorporation of a new charitable company and subsequent re-registration with the Charity Commission. The trustees delegated the incorporation work to Ms Tess Harris. Pro bono help with the process was provided by Brecher & Co solicitors. During the incorporation process, it was resolved to change the name of the charity from 'The Polycystic Kidney Disease Charity' to 'Polycystic Kidney Disease Charity'. Approval was given by the Charity Commission to use the word 'charity' in the new charitable company's name, which was registered at Companies House on 12 March 2015.

The Charity Commission required the new charitable company to register and following discussion, updated charitable objects were agreed as follows:

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

- *Funding research into determining the causes of PKD and into discovering treatments and a cure, with any useful results of such research being available to the public.*

- *Promoting awareness of PKD through the production and publication of authoritative information for the general public and health professionals about the medical, healthcare and related aspects of PKD.*
- *Organising patient, family and carer information, education and support events across the UK and offering personal support to patients and their families.*

### ***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 joined in February 2015 and provides operational assistance with patient information and 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 trustees volunteer their time throughout the year, for example helping at information days and attending external events related to PKD. One trustee, Mrs Margaret Pope, handles support line calls and posts Christmas Cards. Additional help is provided by unpaid volunteers, for example proof-reading information and assisting with monitoring online forums.

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

The charity 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 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 charity would not be able to function without voluntary help. 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 a founder member of the **ADPKD Study Group**, within the UK Renal Registry. During 2014-15, this group was merged with the **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 defining several projects for future research. Ms Tess Harris is the chair of the CDSCG. 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 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, Transplant 2013, 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](http://www.ciliopathyalliance.org)

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](http://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](http://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](http://www.federg.org)



## 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 ARPDK 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 ARPDK 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 inequality in the services and treatments that PKD patients receive.
- We will create a single voice for people living with ADPKD and ARPDK 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 2014-15**

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

- a. During 2014-15, the charity 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. The charity organised three **ADPKD Information & Support Days** during the year at Dorchester Hospital, Edinburgh University and Newcastle Freeman Hospital. A further 'ADPKD Conference' was held in Edinburgh, jointly organised with an enthusiastic local supporters' group. Over 400 people attended all four events – patients, relatives and professionals. These events provide 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
- Potential treatments and drug development
- Coping with PKD

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

Feedback was very positive. 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 Dorchester said: *"It was helpful to have*

*explanations and to 'normalise' issues for people whilst still having opportunity to have concerns alleviated."*

- A parent at Edinburgh commented: *"As someone in the very early stages of PKD I didn't have a lot of information because I didn't feel the need to know but coming to this conference and think about things slightly more long term."*

Those attending are now asked 'outcome' oriented questions in feedback surveys. After the Newcastle event:

- 43% said their knowledge of ADPKD had increased a 'great deal'
  - 28% felt better able to manage their ADPKD
  - 32% felt more positive
- c. The charity held its third **ARPKD Family Information & Support Day** at Great Ormond Street Hospital in June 2014, with the support of Dr Paul Winyard. Approximately 20 families attended. Of particular interest were the workshops on coping and benefits, reflecting concerns expressed by similar rare disease patients and families. The event was supported with a grant from the Arran Brown Foundation.
- d. The **PKD website** [www.pkdcharity.org.uk](http://www.pkdcharity.org.uk) attracted nearly 42,000 visitors, an increase of 54% from 2013-14. Visitors spend most time on the information pages. The site contains an e-shop and online fundraising functionality.
- e. The charity established several closed Facebook groups to enable online interaction between patients and carers, plus parents. These are administered and closely monitored by Ms Harris and trusted volunteers. When necessary, group members are referred to reliable information sources, such as those provided by the charity.

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

- a. In October 2014, the charity awarded £10,000 to UCL Institute of Child Health/Great Ormond St Hospital for a study investigating the optimal blood pressure level in children and young people with ADPKD (Autosomal Dominant Polycystic Kidney Disease).
- i. High blood pressure (BP) or hypertension is a common problem in adults with ADPKD. Some patients develop major complications of hypertension in the vessels, resulting in a heart attack and stroke, before they have significant kidney issues.
  - ii. There is increasing evidence that hypertension may start in childhood but there is very little research on BP in children and young people with ADPKD. This is a pilot study to investigate the optimal BP level in children with ADPKD at two major UK children's hospitals: Great Ormond Street and the Evelina London Children's Hospital.
  - iii. The researchers will measure BP in 3 ways (i) in the normal way using a standard arm cuff in clinic, but also (ii) check it repeatedly over 24 hours at home using a portable device around the size of a smartphone and (iii) using a home BP monitor measured by parent/ young person. They will also assess the health of the heart and blood vessels using a new device similar to a small, unobtrusive ultrasound machine. Urine and blood samples will be collected at the same time as normal clinic tests, and stored as a children's ADPKD biobank for later investigation.

- iv. The project will comprehensively document BP and its effects in children and young people with ADPKD. They are aiming for 50 patients which will already be the largest study in such detail, but hope to roll this out across the country in future studies if, as expected, they find evidence of early hypertension that needs treatment. Diagnosing BP problems early in the disease may be the key to long term health benefits.
  - v. PRINCIPAL INVESTIGATOR: Dr Matko Marlais (Academic Clinical Fellow in Paediatrics)
  - vi. CO-INVESTIGATOR: Dr Paul Winyard (Reader in Paediatric Nephrology), Dr Manish Sinha (Consultant Paediatric Nephrologist).
- b. An additional grant of £2,000 was awarded to Dr Evi Goggolidou to further the ARPKD grant previously awarded to study a potential modifying gene.

### **3. Reaching out so people don't feel alone**

- a. The charity progressed the preliminary work on the **telephone befriending service** and the trustees agreed to submit an application to Awards 4 All to fund the pilot scheme.
- b. The charity manages a number of **online Support Groups** which provide peer support and advice throughout the year. The charity moderator ensures that no erroneous information is circulated and that anyone in distress is contacted and supported.
- c. The PKD Newsletter was published and mailed to nearly 3,000 people registered on the PKD database. It was also sent to over 80 UK Renal Units (approximately 10 in Scotland), over 300 dialysis satellite units, the 60+ UK Kidney Patients' Associations including the Scottish KPA, the UK Genetics Centres, plus other interested persons.
- d. The **telephone support helpline** (managed by a trustee) 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.
- e. Two 'face-to-face' support groups have been established: the London Friendship Group (meets bi-monthly); and the NW Group, which is centred upon the NW of England.

### **4. By being the voice of PKD patients and families**

- a. During 2014-15, the charity was invited to make a submission to NICE for the future appraisal by NICE (in 2015) of the drug Tolvaptan, the first-ever therapy shown to slow the progression of ADPKD. This entailed:
  - i. Organising a survey of ADPKD patients and carers to gather the experiences of living with ADPKD, ranging from medical to psychosocial
  - ii. Identifying and nominating patient experts who had taken part in the clinical trials of Tolvaptan and could speak about their experiences
  - iii. Identifying and nominating clinical experts
  - iv. Writing a submission based on the survey and other knowledge of ADPKD and its effects on those affected (patients, carers, families).
- 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.
- c. The charity produced a flyer which was sent to 10,000 GP practices in the UK, as part of a joint promotion. The flyer has been used subsequently at awareness and fundraising events.
- d. The Chair, various trustees and Ms Harris have attended events in 2014-15 to represent

and advocate for PKD patients and families, in particular:

- i. The Renal Transplant Clinical Reference Group within NHS England (2 meetings in 2014-15).
  - ii. The joint Renal Association & British Renal Society Conference in April 2014.
  - iii. The UK Renal Registry Annual Audit Meeting in May 2014.
  - iv. The ERA-EDTA Congress in May/June 2014.
  - v. The British Transplant Games in Bolton in August 2014.
  - vi. The NKF Annual Conference in October 2014.
  - vii. Cilia 2014, the bi-annual international ciliopathies conference in Paris, November 2014.
  - viii. The All Party Parliamentary Kidney Group meeting at the House of Commons in January 2015, where threatened 'tariff' cuts to dialysis commissioning services in England were discussed with Earl Howe.
  - ix. The European ADPKD Forum (EAF) - which met several times during 2014-15 - culminating in the launch of the EAF Policy Report: 'Translating science into Policy to improve ADPKD care in Europe' in January 2015. More information here:  
[http://www.pkdinternational.org/eaf\\_adpkd\\_forum\\_policy\\_report\\_2015/](http://www.pkdinternational.org/eaf_adpkd_forum_policy_report_2015/)
  - x. The new Renal GeCIP within the 100,000 Genomes England project. (PPI role)
  - xi. World Kidney Day events during March 2015.
- e. The charity uses a Facebook page [www.facebook.com/pkdcharity](http://www.facebook.com/pkdcharity) and Twitter account [www.twitter.com/PKDCharity](http://www.twitter.com/PKDCharity) to engage with supporters and external stakeholders, where relevant.

### ***Fundraising Activities***

The trustees 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***

During the year, the charity made use of its new database (Harlequin CRM) to handle the increased number of supporters and fundraisers, and streamline communications/accounting procedures.

The trustees thank Vidahost, the CRM software hosting company, which gave a charity discount on the usual cost of server space.

## **FINANCIAL REVIEW**

### **Performance**

During the 12 months 1 April 2014 to 31 March 2015, the charity's income was **£168,431** (2014: **£238,164**).

The charity incurred expenses of **£147,568** (2014: **£116,323**), resulting in a surplus of **£20,863** (2013: **£121,841**).

Income from **voluntary donations** declined during the year to **£164,349** (2013: **£223,439**). The previous year, the charity had received two legacies. However, underlying income, primarily from supporters' fundraising, remained buoyant. Otsuka Pharmaceutical UK gave an unrestricted donation to the charity during the year.

### **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.

During 2014-15, the charity opened two 1 year term accounts with Cater Allen and United Trust Bank, and deposited **£85,000** in each. The sum is the maximum guaranteed by the UK government and these accounts generate more interest than CAF Bank.

### **Reserves**

The trustees considered that the charity had sufficient reserves at the year-end to fund its proposed activities during 2015-16.

## **FUTURE PLANS**

These include:

- Continuing to update and create health information leaflets, accredited under the Information Standard.
- ADPKD Information Days in London, Birmingham, Belfast and one other venue.
- ARPKD Family Information Day at Leeds General Infirmary.
- Funding research projects.
- Participating in the Cystic Diseases and ARPKD Clinical Study Groups.
- Providing on-going support by phone, email, support groups and website.
- Piloting the Telephone Befriending Programme in London, the NW of England and Scotland.
- Publishing the PKD Newsletter and e-newsletters.
- Attending the Renal Association held jointly with the ERA-EDTA Congress in London.
- Attending and participating in conferences, workshops and events relevant to renal and genetic conditions.
- Participating in the European ADPKD Forum policy activities and planning a European awareness campaign in collaboration with European PKD and kidney patient groups.
- Preparing for the NICE Appraisal of Tolvaptan and the subsequent decision to prescribe or not.
- Supporting and encouraging individual and family fundraising.

**Approved by the Trustees and signed on their behalf by**

*Judith Dignum*

Judith Dignum  
Chair

*21 December 2015*

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

Report to the trustees of The Polycystic Kidney Disease Charity on the accounts for the year ended 31 March 2015, which are set out on pages 17 to 23.

### **Respective responsibilities of trustees and examiner**

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144 of the Charities Act 2011 (the Charities Act) or under Regulation 10(1) (d) of the Charities Accounts (Scotland) Regulations 2006 and that an independent examination is needed. The charity is preparing accrued accounts and I am qualified to undertake the examination by being a qualified member of the Institute of Chartered Accountants in England and Wales.

It is my responsibility to:

- examine the accounts under section 145 of the Charities 2011 Act and under section 44(1) (c) of the Charities and Trustee Investment (Scotland) Act 2005;
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act; and
- 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 statement below.

### **Independent examiner's statement**

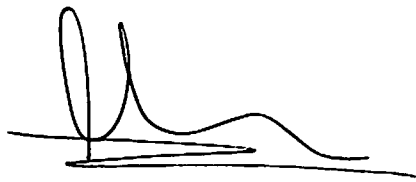
In connection with my examination, no matter has come to my attention:

(1) which gives me reasonable cause to believe that in any material respect the requirements:

- to keep accounting records in accordance with section 130 of the Charities Act 2011, with section 44(1) (a) of the 2005 Act and Regulation 4 of the 2006 Accounts Regulations; and
- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the Charities Act 2011 and Regulation 9 of the 2006 Accounts Regulations;
- 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  
Dragons Green  
Florance Lane  
Groombridge  
TN3 9SH



21 December 2015



STATEMENT OF FINANCIAL ACTIVITIES - 1 APR 2014 TO 31 MARCH 2015

The notes on pages 19 to 23 form an integral part of these accounts.

	Note	Unrestricted funds £	Restricted funds £	2015 Total funds £	2014 Total funds £
<b>Income and expenditure</b>					
Voluntary income	2	157,052	7,297	164,349	231,912
Activities for generating funds	3	3,802	-	3,802	5,963
Investment income	4	280	-	280	289
<b>Total incoming resources</b>		<b>161,134</b>	<b>7,297</b>	<b>168,431</b>	<b>238,164</b>
<b>Resources expended</b>					
Cost of generating voluntary income	5	3,077	-	3,077	21,103
Cost of generating funds		26,115	-	26,115	17,775
Fundraising trading costs		3,789	-	3,789	8,259
		<b>32,981</b>	<b>-</b>	<b>32,981</b>	<b>47,137</b>
<b>Charitable activities</b>					
Research, grants and donations	6	-	40,667	40,667	22,526
Awareness and education		15,087	-	15,087	6,713
Patient support		48,205	1,000	49,205	33,780
		<b>63,292</b>	<b>41,667</b>	<b>104,959</b>	<b>63,019</b>
<b>Governance costs</b>	7	<b>9,628</b>	<b>-</b>	<b>9,628</b>	<b>6,167</b>
<b>Total resources expended</b>		<b>105,901</b>	<b>41,667</b>	<b>147,568</b>	<b>116,323</b>
<b>Net incoming resources for the year</b>		<b>55,233</b>	<b>(34,370)</b>	<b>20,863</b>	<b>121,841</b>
Fund balances brought forward at 1 April		143,899	137,734	281,633	159,792
Net incoming / (outgoing) resources for the year		55,233	(34,370)	20,863	121,841
Transfers between funds		(50,927)	50,927	-	-
<b>Fund balances carried forward</b>		<b>148,205</b>	<b>154,291</b>	<b>302,496</b>	<b>281,633</b>
<b>Represented by:</b>					
<b>Funds and reserves</b>					
Restricted funds		-	100,888	100,888	97,734
ADPKD Bio-resource Bank Grant Fund		-	13,403	13,403	-
PKD Registry		-	40,000	40,000	40,000
Unrestricted funds		148,205	-	148,205	143,899
<b>Total funds</b>		<b>148,205</b>	<b>154,291</b>	<b>302,496</b>	<b>281,633</b>

**BALANCE SHEET AT 31 MARCH 2015**

	Note	Unrestricted funds £	Restricted funds £	2015 Total funds £	2014 Total funds £
<b>Fixed assets</b>					
Tangible assets	8	8,832	-	8,832	-
<b>Current assets</b>					
Prepayments	9	13,578	-	13,578	8,384
Investments	10	-	170,000	170,000	-
Cash at bank and in hand		140,909	17,458	158,367	292,312
<b>Total current assets</b>		<b>154,487</b>	<b>187,458</b>	<b>341,945</b>	<b>300,696</b>
<b>Liabilities</b>					
Creditors: Amounts falling due within one year	11	15,114	26,500	41,614	19,063
<b>Net current assets</b>		<b>139,373</b>	<b>160,958</b>	<b>300,331</b>	<b>281,633</b>
<b>Total assets less current liabilities</b>		<b>148,205</b>	<b>160,958</b>	<b>309,163</b>	<b>281,633</b>
Creditors: Amounts falling due after more than one year	12	-	6,667	6,667	-
<b>Net assets</b>		<b>148,205</b>	<b>154,291</b>	<b>302,496</b>	<b>281,633</b>
<b>Represented by:</b>					
<b>Funds and reserves</b>					
Restricted funds	13	-	100,888	100,888	97,734
ADPKD Bio-resource Bank Grant Fund	13	-	13,403	13,403	-
PKD Registry	13	-	40,000	40,000	40,000
Unrestricted funds	13	148,205	-	148,1205	143,899
<b>Total funds</b>	13	<b>148,205</b>	<b>154,291</b>	<b>302,496</b>	<b>281,633</b>

*Judith Dignum*

Approved by the trustees on  
And signed on their behalf by  
Judith Dignum, Trustee

21 December 2015

## **NOTES TO THE FINANCIAL STATEMENTS FOR YEAR ENDED 31 MARCH 2015**

### ***Accounting Policies***

The financial statements have been prepared in accordance with the Statement of Recommended Practice, 'Accounting for Charities' (revised 2005), applicable accounting standards, the Charities Act 2011 and the Financial Reporting Standard for Smaller Entities (effective April 2008). 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. Accounting policies applied are consistent with those for the prior year.

#### **ii) Investment Income**

Investment income is accounted for in the period in which the charity is entitled to receipt.

#### **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 and the monetary value of incoming resources can be measured with sufficient reliability.

#### **iv) Resources Expended**

Liabilities are recognised as resources expended as soon as there is legal or constructive obligation committing the charity to the expenditure. 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.

#### **v) Grants**

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

#### **vi) 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 and software – 20% straight line

#### **vii) 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.

	<i>Unrestricted</i>	<i>Restricted</i>	<i>Total (2015)</i>	<i>Total (2014)</i>
	£	£	£	£
<b>2. Voluntary income</b>				
Donations and gifts	131,685	6,297	137,982	157,918
Trusts and foundations	10,001	1,000	11,001	2,000
Legacies	-	-	-	60,500
Gift Aid	15,366	-	15,366	11,494
<b>Total voluntary income</b>	<b>157,052</b>	<b>7,297</b>	<b>164,349</b>	<b>231,912</b>
<b>3. Activities for generating funds</b>				
Fundraising events	-	-	-	2,281
Other activities	1,355	-	1,355	2,207
Shop income	2,447	-	2,447	1,475
<b>Total activities for generating funds</b>	<b>3,802</b>	<b>-</b>	<b>3,802</b>	<b>5,963</b>
<b>4. Investment income</b>				
Interest income	280	-	280	289
<b>5. Cost of generating income</b>				
Cost of voluntary income	3,077	-	3,077	21,103
Cost of fundraising	26,115	-	26,115	17,775
Goods sold	3,789	-	3,789	8,259
<b>Total cost of generating income</b>	<b>32,981</b>	<b>-</b>	<b>32,981</b>	<b>47,137</b>
<b>6. Analysis of Research and Grants:</b>				
	<b>2015</b>	<b>2014</b>		
	£	£		
PKD Bio-Resources	26,667	12,528		
Biomarker study	-	9,998		
ARPKD Research	14,000	-		
<b>Total research, grants and donations</b>	<b>40,667</b>	<b>22,526</b>		

**7. Governance costs:**

	<b>2015</b>	<b>2014</b>
	<b>£</b>	<b>£</b>
Trustee meetings and governance	4,012	2,618
Accountancy and audit	2,910	2,880
Other professional fees	2,706	669
<b>Total governance costs:</b>	<b>9,628</b>	<b>6,167</b>

**8. Analysis of Movement of Fixed Assets**

	<b>2015</b>	<b>2014</b>
	<b>£</b>	<b>£</b>
	<b>Office equipment</b>	<b>Office equipment</b>
<b>Cost</b>		
At 1 April 2014	457	457
Additions/(disposals)	11,040	-
<b>At 31 March 2015</b>	<b>11,497</b>	<b>457</b>
<b>Accumulated depreciation</b>		
At 1 April 2014	457	457
Charge for the year	2,208	-
<b>At 31 March 2015</b>	<b>2,665</b>	<b>457</b>
<b>Net Book Value</b>		
At 1 April 2014	-	-
<b>At 31 March 2015</b>	<b>8,832</b>	<b>-</b>

**9. Debtors**

	<b>2015</b>	<b>2014</b>
	<b>£</b>	<b>£</b>
Prepayments	7,911	2,500
Accrued income	4,780	5,884
Other debtors	887	-
<b>Total debtors</b>	<b>13,578</b>	<b>8,384</b>

**10. Analysis of movement of current asset investments**

	<b>2015</b>
	<b>£</b>
Carrying value at beginning of year	-
Additions	170,000
<b>Carrying value at end of year</b>	<b>170,000</b>

**11. Liabilities: amounts falling due within one year**

	<b>2015</b>	<b>2014</b>
	<b>£</b>	<b>£</b>
Accruals and deferred income	17,614	19,063
Grant commitments	24,000	-
<b>Total current liabilities</b>	<b>41,614</b>	<b>19,063</b>

**11. Liabilities: amounts falling due after more than one year**

	<b>2015</b>	<b>2014</b>
	<b>£</b>	<b>£</b>
Grant commitments within five years	6,667	-

**12. Funds and reserves**

<i>Fund</i>	<i>Retained surplus at 1/4/14</i>	<i>Income</i>	<i>Expenses</i>	<i>Transfers</i>	<i>Total fund at 31/3/15</i>
Activities	2,255	-	-	-	2,255
Harris	78	-	-	-	78
P Lockyer	1,691	-	-	-	1,691
Research	52,542	950	-	-	53,492
PKD Bio-resource	-	70	(26,667)	39,999	13,402
PKD Registry	40,000	-	-	-	40,000
ARPKD	2,072	1,000	(14,000)	10,928	-
ADPKD	39,096	5,277	(1,000)	-	43,373
RFH Biomarker	-	-	-	-	-
General	143,899	161,134	(105,901)	(50,927)	148,205
<b>Total funds</b>	<b>281,633</b>	<b>168,431</b>	<b>(147,568)</b>	<b>-</b>	<b>302,496</b>

**11. Related party Transactions and Trustees Remuneration**

Trustees received no emoluments (2014: £nil).