

THE POLYCYSTIC KIDNEY DISEASE (PKD) CHARITY

REPORT OF THE TRUSTEES AND  
STATEMENT OF FINANCIAL ACTIVITIES

FOR THE YEAR ENDED 31 MARCH 2014

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

Ms Judith Dignum (Chair)  
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

### Management & administration

Ms Tess Harris, chief executive  
Ms Esther Wright, fundraising

### 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

### Patrons

Dr Vince Cable, MP  
Mr Laurence Isaacson, CBE  
Professor Albert Ong  
Dr Anand Saggar  
Dr Richard Sandford  
Prof Pat Wilson

### Professional advisors

**Bankers**  
CAF Bank Ltd  
25 Kings Hill Avenue  
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### Independent accounts examiner

Charles Pickin  
Fellow of Institute of Chartered Accountants in  
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Harrison Jasper Ltd  
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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 2014, 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 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). We want to give hope for the future. We want to make PKD irrelevant and ultimately curable.

### ***About PKD***

PKD is present in two forms:

**ADPKD - AUTOSOMAL DOMINANT POLYCYSTIC KIDNEY DISEASE** – is termed the **world's most common inherited life-threatening condition**. It is a progressive chronic kidney disease, typically affecting several generations of the same family. It causes kidney failure often requiring dialysis or transplantation and sometimes causing premature death. Between 1 in 800 and 1 in 1,000 people worldwide suffer from ADPKD. Over half of those affected will have kidney failure by the time they are 60 years old. If someone has ADPKD, there is a 1 in 2 likelihood that the disease will pass to each child.

We estimate at least 60-70,000 people in the UK have ADPKD. The majority of sufferers 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.

The disease is characterised by numerous fluid-filled cysts in the kidneys and often the liver and pancreas. Over time, the cysts grow and multiply, replacing normal healthy tissue and causing the kidneys to lose their function. Kidneys can enlarge to 3 to 4 times their normal size and in extreme cases weigh up to 10-12kg each.

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. Analysis from the UK Renal Registry (UKRR) shows that the

median age of starting RRT with ADPKD is 55 years and this figure has not changed in over 10 years.

Nearly 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 and 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 sometimes diagnosed late, preventing optimal treatment of complications. There is currently no approved treatment that will stop the cysts developing and growing. However, a number of drugs are currently being trialled around the world that offer hope for slowing or stopping the decline of kidney function.

**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 trustees either have PKD or a family connection. 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 2013-14, there were six ordinary trustee meetings and no special meetings. The trustees make extensive use of teleconferencing and email communications.

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

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

### ***Management and Administration***

The trustees delegate the management of charitable activities and administration to two part-time contractors: Ms Tess Harris, who provides chief executive, operational and administrative services; and Ms Esther Wright, who provides community fundraising services and event management. The trustees monitored the activities and outputs of the contractor through reports provided at trustee meetings; the chair had regular phone and face-to-face meetings with the contractors.

The trustees volunteer their time throughout the year, for example helping at information days, despatching Christmas cards and attending external events related to PKD. One trustee, Mrs Margaret Pope, handles support line calls. 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 accounting firm.

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 helped mail out leaflets and Christmas Cards; 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. This Group's aims are to advise the UKRR on the appropriate ADPKD datasets, develop clinical guidelines, develop research proposals and promote international collaboration. Ms Tess Harris is the chair of the ADPKD Study Group.

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.

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 account of. The charity regularly inputs into national consultations facilitated by these umbrella bodies.

The charity is a founder member of the **Ciliopathy Alliance**, which brings together patients, families, doctors and scientists with the aim of improving the quality of life for children and adults affected by ciliopathies – primarily genetic diseases caused by defects in the function and structure of cilia (microscopic organelles found in every human cell and vital to development). PKD is an important Ciliopathy with ADPKD having the largest patient cohort.

The charity is a 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.

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.

## CHARITABLE ACTIVITIES

We want everyone affected by PKD to have the best quality of life. Our charitable activities are categorised 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:*

- Employing outreach workers to meet with people affected by PKD to discuss their needs and concerns and signpost them to suitable support services.
- 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 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 2013-14**

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

- a. In August 2013, the charity was certified as a provider of high quality health and social care information by the Royal Society of Public Health (RSPH) and awarded **The Information Standard** quality mark. This means that we meet the Information Standard scheme criteria of producing safe and reliable health and social care information. All the content on this site within the sections 'About ADPKD' and 'About ARPKD' will be reviewed, revised and updated in accordance with the charity's accredited Information Standard process.
- b. The charity organised two **ADPKD Patient Information Days** during the year at Salford Royal Hospital and Addenbrooke's Hospital for approximately 200 patients and their families. Patient information events provide opportunities to offer advice and support to patients, their families and carers, and generate interest with local 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. In particular: Dr Grahame Wood, Mr David van Dellen, Dr Kate Hillman, Dr Hannah Stockley and Professor Pat Wilson (Salford); and Professor Fiona Karet, Dr Richard Sandford, Dr Paul Winyard, Dr Roz Simms, Mr Andrew Butler (Addenbrooke's).

Feedback was very positive. Patients and families welcomed the opportunity to talk to others with PKD and doctors.

- For example one patient at Salford said: *"Each session was informative. Talking to other people with PKD. Looking forward to the next information day so I can bring my husband and he can gain information about PKD."*
- A parent attended the PKD genetics 101 workshop at Addenbrookes' and commented: *"Very helpful. Very clear and simple to understand for people"*

*with no scientific background. Extremely helpful talking to parents and professionals about what will happen to my children. I find it really important to share my experience and story with other people.”*

- c. The charity held a second ARPKD Family Information Day at Birmingham Children’s Hospital in July 2013, with the support of Dr Larissa Kerecuk, paediatric nephrologist. Approximately 80 parents and children attended (an increase of one third over 2012-13), including a family from Norway.

The trustees thank Dr Kerecuk and the other speakers Dr Pat McKiernan, Dr Joanna Jarvis, Dr Paul Winyard, Dr Detlef Bockenhauer, Professor Carsten Bergmann, Mr Khalid Shariff and Ms Melanie Dillon. The event was supported with grants from the Arran Brown Foundation and the BCH Trust. Feedback was very enthusiastic and it was agreed to hold a similar event in 2014.

- d. The **PKD website** [www.pkdcharity.org.uk](http://www.pkdcharity.org.uk) attracted nearly 30,000 visitors, an increase of over 72% from 2012-13. Most visitors spend time on the information pages. The site contains an e-shop and online donation functionality.

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

- a. In September 2013, the charity re-formed the Research Advisory Board (RAB). Professor Pat Wilson was appointed chair, with Dr Anand Saggur as vice-chair. The intent is to direct PKD-specific research funds to fund projects that would not (yet) be eligible for support by national funding. Normally, these would be early-stage projects requiring “pump-priming” for 12-18 months to derive sufficient evidence to be competitive for longer-term, larger scale national entity funding. The RAB also supports the work of the Information Standard by providing expert opinion and content.
- b. In 2013, the trustees awarded Prof Wilson a grant of £10,000 to start a ‘biomarker’ research project. The goal of this research is to develop a simple urine test to predict when the kidneys of people with ADPKD are likely to fail. The rate at which ADPKD progresses in patients causes changes in proteins that are released into the urine. By analysing these ‘biomarker proteins’ from ADPKD patients at different stages of disease severity, characteristic patterns or “fingerprints” will be determined that represent minimal, moderate and severe disease. Urine and blood samples are collected from around 300 ADPKD patients attending the UCL/Royal Free specialist ADPKD clinic. They are processed in the laboratory, divided into multiple replicates, barcoded and stored frozen in the Bio-resource Bank and data included in the ADPKD database at the Royal Free. The combination of protein biomarker patterns identified with the clinical data will facilitate the basis and proof-of-principle for development of a new predictive test. Large-scale funding is now being sought from the NHS National Institute of Health Research (NIHR) or the Medical Research Council (MRC) to bring this biomarker test into clinical practice.
- c. In February 2014, the trustees committed to fund the PKD Bio-resource Bank at the UCL Centre for Nephrology, Royal Free Hospital in London, for a further 3 years. The Bio-resource Bank is essentially high-tech and ultra-cold freezers with more than 8,000 cell, tissue, and fluid samples of autosomal dominant polycystic kidney disease (ADPKD) and autosomal recessive polycystic kidney disease (ARPKD), plus age-matched control samples suitable for research purposes. Researchers from UCL,

King's College and Addenbrooke's have submitted successful applications for Bio-resource bank materials for PKD research projects. A number of adults and children in the UK have donated kidneys after nephrectomies.

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

- a. The charity researched opportunities for outreach and peer-to-peer support and concluded that a **telephone befriending service** was the most appropriate programme to establish as a priority – based on the experience of the phone support line and feedback from attendees at Information Days. This project is ongoing.
- 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 2,000 people registered on the PKD database, an increase of 50% over previous years. 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 over 400 calls during the year; callers' information was kept confidential and secure; referrals to medical experts were made where relevant.

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

- a. 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.
- b. The chair, various trustees and Ms Harris have attended events in 2013-14 to represent and advocate for PKD patients and families, in particular:
  - i. The Ciliopathy Alliance Family Conference in May 2013.
  - ii. The Renal Transplant Clinical Reference Group within NHS England (2 meetings in 2013).
  - iii. Co-chairing the UK Renal Registry Annual Audit Meeting in June 2013.
  - iv. The NICE scoping meeting in July 2013 on Tolvaptan, the first ever potential therapy for ADPKD which will be appraised by NICE in 2015.
  - v. The British Transplant Games in Sheffield in August 2013.
  - vi. The European ADPKD seminar in September 2013 (Ms Harris gave a personal patient experience talk).
  - vii. The NKF Annual Conference in October 2013.
  - viii. The All Party Parliamentary Kidney Group meeting at the House of Commons.
  - ix. The Rare Renal Disease Patients Council in October 2013.
  - x. Filming of patients stories for a European ADPKD awareness campaign (funded by Otsuka Pharmaceutical Europe).
  - xi. Participation in research for a UK patient support programme being developed by Otsuka Europe.
  - xii. Co-chairing an international patient group at the first-ever Controversies Conference organised by KDIGO (Kidney Disease: Improving Global Outcomes) on ADPKD in January 2014 (a report is expected Dec 2014).
  - xiii. Participation in the Crick Rare Disease Symposium in February 2014.

- xiv. World Kidney Day in March 2014 (organisation of awareness events).
- c. 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 decided to commit resources to a new database to handle the increased number of supporters and fundraisers, and the resulting communications/accounting complexities.

Following an extensive review of suitable software suppliers, the charity selected Harlequin CRM in March 2014 and began a process of migrating legacy data.

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 2013 to 31 March 2014, the charity's income was **£238,164** (2013: £111,224).

Income from **voluntary donations** increased substantially during the year to £231,912 (2013: £102,536). The charity received two substantial legacies and community fundraisers increased the number of events held. Otsuka Pharmaceutical UK gave an unrestricted donation to the charity during the year.

The charity incurred expenses of **£116,323** (2013: £95,270), resulting in a surplus of **£121,841** (2013: £15,954).

### **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.

### **Reserves**

The trustees considered that the charity had sufficient reserves at the year-end to fund its proposed activities during 2014-15.

## **FUTURE PLANS**

These include:

- Updating and creating new health information leaflets, accredited under the Information Standard.
- Distributing new information via nephrologists and genetics consultants.
- ADPKD Information Days in Edinburgh (2 events) and Dorchester.
- ARPKD Family Information Day at Great Ormond Street Hospital, London.
- Funding 'pump-priming' research projects.
- Participating in the ARPKD Study Group and chairing the ADPKD Study Group.
- Providing on-going support by phone, email, support groups and website.
- Planning the Telephone Befriending Programme, including identifying sources of funding.
- Publishing the PKD Newsletter and e-newsletters.
- Attending the Renal Association Conference in Gateshead.
- Attending and participating in conferences, workshops and events relevant to renal and genetic conditions.
- Participating in European ADPKD awareness campaigns.
- Preparing for the NICE Appraisal of Tolvaptan, including organising a patient experience survey.
- Supporting and encouraging individual and family fundraising.
- Migration of all data to the new CRM system and full deployment for fundraising, communications and support.

- Adding additional operational resources, in line with the increased charitable activities and workload of existing contractors.

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

A handwritten signature in black ink that reads "Judith Dignum". The signature is written in a cursive style with a large initial 'J'.

Judith Dignum  
Chair

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

I report on the accounts of the Trust for the year ended 31 March 2014, which are set out on pages 16 to 21.

### **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 132 of the Charities Act 2011 or under Regulation 10 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**

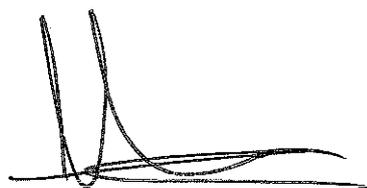
In connection with my examination, no matter has come to my attention:

(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 and Regulation 4 of the Charities Accounts (Scotland) Regulations 2006; and
- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the Charities Act 2011, Charities and Trustee Investment (Scotland) Act 2005 and Charities Accounts (Scotland) Regulations 2006;
- 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  
3 The Close, Corseley Road  
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TN3 9SE



## **STATEMENT OF FINANCIAL ACTIVITIES - 1 APR 2013 TO 31 MARCH 2014**

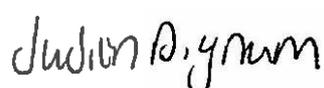
The notes on pages 18 to 21 form an integral part of these accounts.

	Note	Unrestricted funds £	Restricted funds £	2014 Total funds £	2013 Total funds £
<b>Income and expenditure</b>					
Voluntary income	2	188,363	43,549	231,912	102,536
Activities for generating funds	3	5,963	-	5,963	8,439
Investment income	4	289	-	289	249
<b>Total incoming resources</b>		<b>194,615</b>	<b>43,549</b>	<b>238,164</b>	<b>111,224</b>
<b>Resources expended</b>					
Cost of generating voluntary income	5	21,103	-	21,103	15,727
Cost of generating funds		17,775	-	17,775	12,101
Fundraising trading costs		8,259	-	8,259	1,355
		<b>47,137</b>	<b>-</b>	<b>47,137</b>	<b>29,183</b>
<b>Charitable activities</b>					
Research, grants and donations	6	-	22,526	22,526	16,769
Awareness and education		5,713	1,000	6,713	5,329
Patient support		33,624	156	33,780	35,255
		<b>39,337</b>	<b>23,682</b>	<b>63,019</b>	<b>57,353</b>
<b>Governance costs</b>	7	<b>6,167</b>	<b>-</b>	<b>6,167</b>	<b>8,734</b>
<b>Total resources expended</b>		<b>92,641</b>	<b>23,682</b>	<b>116,323</b>	<b>95,270</b>
<b>Net incoming resources for the year</b>		<b>101,974</b>	<b>19,867</b>	<b>121,841</b>	<b>15,954</b>
Fund balances brought forward at 1 April		55,432	104,360	159,792	143,838
Net incoming resources for the year		101,974	19,867	121,841	15,954
Transfers between funds		(13,507)	13,507	-	-
<b>Fund balances carried forward</b>		<b>143,899</b>	<b>137,734</b>	<b>281,633</b>	<b>159,792</b>
<b>Represented by:</b>					
Funds and reserves					
Restricted funds		-	97,734	97,734	55,440
ADPKD Bio-resource Bank Grant Fund		-	-	-	8,920
PKD Registry		-	40,000	40,000	40,000
Unrestricted funds		143,899	-	143,899	55,432
<b>Total funds</b>		<b>143,899</b>	<b>137,734</b>	<b>281,633</b>	<b>159,792</b>

**BALANCE SHEET AT 31 MARCH 2014**

	Note	Unrestricted funds £	Restricted funds £	2014 Total funds £	2013 Total funds £
<b>Fixed assets</b>					
Tangible assets	8	-	-	-	-
<b>Current assets</b>					
Stocks		-	-	-	2,672
Prepayments	9	8,384	-	8,384	12,325
Cash at bank and in hand		154,578	137,734	292,312	153,792
		<b>162,962</b>	<b>137,734</b>	<b>300,696</b>	<b>168,795</b>
<b>Total Assets</b>		<b>162,962</b>	<b>137,734</b>	<b>300,696</b>	<b>168,795</b>
<b>Current liabilities</b>					
Accruals and deferred income		19,063	-	19,063	9,004
		<b>19,063</b>	<b>-</b>	<b>19,063</b>	<b>9,004</b>
<b>Net assets</b>		<b>143,899</b>	<b>137,734</b>	<b>281,633</b>	<b>159,791</b>
<b>Represented by:</b>					
Funds and reserves					
Restricted funds	10	-	97,734	97,734	55,440
ADPKD Bio-resource Bank Grant Fund	10	-	-	-	8,920
PKD Registry	10	-	40,000	40,000	40,000
Unrestricted funds	10	143,899	-	143,899	55,432
<b>Total funds</b>	10	<b>143,899</b>	<b>137,734</b>	<b>281,633</b>	<b>159,792</b>

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



## **NOTES TO THE FINANCIAL STATEMENTS FOR YEAR ENDED 31 MARCH 2014**

### ***Accounting Policies***

#### **i) Basis of Accounting**

The financial statements have been prepared in accordance with UK Accounting Standards and the Charities Act 2011. They have been 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.

#### **v) 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 (2014)</i>	<i>Total (2013)</i>
	£	£	£	£
<b>2. Voluntary income</b>				
Donations and gifts	126,369	31,549	157,918	90,627
Trusts and foundations	-	2,000	2,000	-
Legacies	50,500	10,000	60,500	-
Gift Aid	11,494	-	11,494	11,909
<b>Total voluntary income</b>	<b>188,363</b>	<b>43,549</b>	<b>231,912</b>	<b>102,536</b>
<b>3. Activities for generating funds</b>				
Fundraising events	2,281	-	2,281	3,151
Other activities	2,207	-	2,207	4,290
Shop income	1,475	-	1,475	998
<b>Total activities for generating funds</b>	<b>5,963</b>	<b>-</b>	<b>5,963</b>	<b>8,439</b>

	<i>Unrestricted</i>	<i>Restricted</i>	<i>Total (2014)</i>	<i>Total (2013)</i>
	£	£	£	£

**4. Investment income**

Interest income	<b>289</b>	-	<b>289</b>	<b>249</b>
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**5. Cost of generating income**

Cost of voluntary income	21,103	-	21,103	15,727
Cost of fundraising	17,775	-	17,775	12,101
Goods sold	8,259	-	8,259	1,355
<b>Total cost of generating income</b>	<b>47,137</b>	-	<b>47,137</b>	<b>29,183</b>

**6. Analysis of Research and Grants:**

	<i>2014</i>	<i>2013</i>
	£	£
PKD Bio-Resources	12,528	10,580
Biomarker study	9,998	-
Other grants and donations	-	6,189
<b>Total research, grants and donations</b>	<b>22,526</b>	<b>16,769</b>

**7. Governance costs:**

	<i>2014</i>	<i>2013</i>
	£	£
Trustee meetings	2,618	4,231
Accountancy and audit	2,880	3,773
Other costs	669	730
<b>Total governance costs:</b>	<b>6,167</b>	<b>8,734</b>

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

	2014 £	2013 £
<u>Asset cost</u>		
Balance brought forward	457	457
Additions/(disposals)	-	-
Balance carried forward	457	457
<u>Accumulated depreciation</u>		
Balance brought forward	457	181
Charge for the year	-	276
Balance carried forward	457	457
<u>Net Book Value</u>		
Brought forward	-	276
Carried forward	-	-

**9. Debtors**

	2014 £	2013 £
Prepayments (membership fees)	2,500	6,500
Other debtors	5,884	5,825
<b>Total</b>	<b>8,384</b>	<b>12,235</b>

**10. Funds and reserves**

Fund	Retained surplus at 1/4/13	Income	Expenses	Transfers	Total fund at 31/3/14
	£	£	£	£	£
Activities	2,255	1,000	(1,000)	-	2,255
Harris	78	-	-	-	78
P Lockyer	1,691	-	-	-	1,691
Research	51,416	1,126	-	-	52,542
PKD Bio-resource	8,919	-	(12,528)	3,609	-
PKD Registry	40,000	-	-	-	40,000
ARPKD	-	2,228	(156)	-	2,072
ADPKD research	-	39,096	-	-	39,096
RFH Biomarker	-	100	(9,998)	9,898	-
General	55,432	194,615	(92,641)	(13,507)	143,899
<b>Total funds</b>	<b>159,791</b>	<b>238,164</b>	<b>(116,323)</b>	<b>-</b>	<b>281,632</b>

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

Trustees received no emoluments (2013: nil).

Expenses paid to trustees during the year (travel, subsistence) amounted to: £6,167 (2013: £4,231).