

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

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

**FOR THE YEAR ENDED 31 MARCH 2013**

Registered Charity in England and Wales Number 1085662

Registered Charity in Scotland Number SC038279

## CONTENTS

### Contents

REFERENCE AND ADMINISTRATIVE INFORMATION .....	3
TRUSTEES ANNUAL REPORT.....	4
The PKD Charity's objects: .....	4
Our mission .....	4
About PKD .....	4
GOVERNANCE, STRUCTURE AND MANAGEMENT .....	5
Governance .....	5
Management and Administration .....	6
Communication with Supporters and Stakeholders .....	7
Membership of Related Organisations .....	7
CHARITABLE ACTIVITIES .....	8
ACTIVITIES AND ACHIEVEMENTS DURING 2011-12 .....	8
FINANCIAL REVIEW .....	13
FUTURE PLANS .....	13
INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF THE POLYCYSTIC KIDNEY DISEASE CHARITY.....	14
STATEMENT OF FINANCIAL ACTIVITIES - 1 APR 2012 TO 31 MAR 2013.....	15
BALANCE SHEET AT 31 MAR 2013.....	16
NOTES TO THE FINANCIAL STATEMENTS FOR YEAR ENDED 31 MARCH 2013 .....	17

## REFERENCE AND ADMINISTRATIVE INFORMATION

### Principal address:

The PKD Charity  
91 Royal College St  
London, NW1 0SE

Tel: 0300 111 1234  
Email: [info@pkdcharity.org.uk](mailto:info@pkdcharity.org.uk)  
[www.pkdcharity.org.uk](http://www.pkdcharity.org.uk)

### 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 (Hon Treasurer)  
Mrs Edwina Graham  
Mr Raj Johal  
Mr Sarbjit Johal  
Mr Barry Harpham (Chair)  
Ms Rebecca Murphy  
Mrs Margaret Pope  
Mrs Christine Wallach

### Research Advisory Board

Chair: Prof Pat Wilson, UCL Centre for Nephrology  
Royal Free, London  
Vice-chair: Dr Anand Saggar, Consultant in Clinical  
Genetics, St George's Hospital Medical School

### Administration Services

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  
Prof Albert Ong  
Dr Anand Saggar  
Dr Richard Sandford  
Prof Pat Wilson

### Professional advisors

#### Bankers

CAF Bank Ltd  
25 Kings Hill Avenue  
West Malling  
ME 19 4JQ

### Independent accounts examiner

Charles Pickin  
Fellow of Institute of Chartered Accountants in  
England and Wales  
Harrison Jasper Ltd  
3 The Close, Corseley Road  
Groombridge  
TN3 9SE

## 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 2013, 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 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.

In November 2012, Otsuka Pharmaceutical Ltd reported on a global trial of Tolvaptan, the first ever drug to demonstrate a decrease in the rate of kidney function decline in ADPKD patients. Patients in the UK were enrolled in the trial. The drug is currently undergoing the approval process for a product licence; if this is approved by the European Medicines Agency, it will be appraised in the UK for potential prescribing.

**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 genetic disease**' affecting approximately 1 in 20-40,000 people. ARPKD is usually a prenatal and infantile disease; the baby inherits two copies of the defective gene, one from each parent. There is a 1 in 4 chance of inheriting 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, STRUCTURE 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 2012-13, there were six ordinary trustee meetings and no special meetings. The trustees make extensive use of teleconferencing and email communications.

The trustees review the charity's finances at each meeting. A financial review is held annually.

All trustees are required to complete a declaration of interests and may be required to withdraw from relevant proceedings during a Board meeting.

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

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

The trustees delegate some of the operations and administration to two part-time contractors: Ms Tess Harris, who provides chief executive and administrative services; and Ms Esther Wright, who provides community fundraising services. 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 also 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 Maggie Pope, handles support line calls. Additional help is provided by unpaid volunteers, for example proof-reading information and assisting with monitoring online forums.

During the year, the death of Justina Wilkinson occurred, from ADPKD complications. Justina had provided administrative support, in particular dealing with voluntary donations and helping project manage the information days. The trustees extended their condolences, on behalf of the charity, to Justina's family.

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

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; supporters who proofread communication materials and helped mail out leaflets and Christmas Cards; a dedicated team who ensured the PKD International Conference took place successfully; and especially all the friends and families who have raised funds for the charity throughout the years.

### ***Communication with Supporters and Stakeholders***

The charity communicates with supporters, stakeholders and interested parties through opt-in email newsletters, twice yearly printed newsletters, and attendance at relevant Department of Health and NHS events, and participation in related renal and genetics events/meetings.

The charity manages an active Facebook page and participates in several PKD Facebook groups, which provide a communication channel for news and information, and a means of supporting individuals who use those types of social networks and cannot attend information days. The charity also manages a Twitter account.

During the year, the charity was a co-founder of a new informal group of kidney charities in the UK. These charities' chairs and executives now meet quarterly to share, discuss and agree collaborative activities (such as for the annual World Kidney Day) and promote kidney patients' needs.

### ***Membership of Related Organisations***

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 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 organised the first ARPKD Family Information Day at Birmingham Children's Hospital in July 2012.

The charity is a member of several 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** and **Transplant 2013**. 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, in particular during 2012-13, the new Clinical Reference Groups established in NHS England for Renal Transplants and Dialysis.

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 participated in CILIA 2012, the first international conference on the research and clinical development of ciliopathies, held in May 2012 at the Institute of Child Health in London. Ms Tess Harris represents the PKD Charity at regular meetings of the Ciliopathy Alliance.

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. In February 2013, the PKDI held a meeting of European patient groups and formed a Steering Committee to consider and coordinate European awareness activities.

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

### To achieve the charity's objects, we aim to:

1. Ensure that anyone who contacts the charity receives the support they need - in person, by phone, on the website, by email or in writing
2. Build up a research fund through fundraising to enable us to support top-quality PKD research
3. Find ways to bring PKD to the attention of the media, healthcare professionals, policy makers and the government
4. Develop and maintain beneficial relationships with the medical profession, other kidney and related genetic charities, scientists and industry to better inform patients and interested others about current research, existing and potential treatments

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 2011-12**

### **Patient Support**

1. The charity organised an **ADPKD Patient Information Day** during the year at the Birmingham City Hospital. Patient information events provide opportunities to provide advice and support to patients, their families and carers, and generate interest with local nephrologists, renal nurses and geneticists. The trustees thank Dr Lukas Foggensteiner, transplant surgeons Mr Nick Inston and Mr David van Dellen, the Leicester Renal Exercise Team, Nurse Gabby Hadley for speaking; and Nurse Sarah Borrows for organising the venue.

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

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



with PKD and doctors.

2. The charity organised the first ARPKD Family Information Day at Birmingham Children's Hospital in July 2012, with the help of Dr Larissa Kerecuk, paediatric nephrologist. Around 60 parents and children attended. The trustees thank Dr Kerecuk and the other speakers Dr Pat McKiernan, Dr Joanna Jarvis, Prof Pat Wilson, Mr Khalid Shariff, Dr Lisa Guay-Woodford and Prof Max Liebau. The event was supported with grants from the Arran Brown Foundation and the BCH Trust. Feedback was very positive and it was agreed to hold a similar event in 2013.
3. The PKD Newsletter was published and mailed to nearly 1,500 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 200 dialysis centres, the 60+ UK Kidney Patients' Associations including the Scottish KPA, the UK Genetics Centres, plus other interested persons.
4. The **PKD website** [www.pkdcharity.org.uk](http://www.pkdcharity.org.uk) was completely renewed in October 2012; since then visitor traffic has quadrupled over preceding years and continues to grow. Primarily, visitors searched for information but also the numbers of people interested in fundraising increased. The site contains an e-shop which sells Christmas cards and other merchandise. Newsletter registrations also increased.
5. The **Online Support Group** provided peer support and advice throughout the year. All posts were read and the charity moderator ensured that no erroneous information was circulated.
6. 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.
7. The Facebook page [www.facebook.com/pkdcharity](http://www.facebook.com/pkdcharity) and Twitter account [www.twitter.com/PKDCharity](http://www.twitter.com/PKDCharity) continued to attract more followers, providing a low-cost communication and fundraising channel for the charity's activities.

### **PKD Health and Social Care Information for Patients, Families and Carers**

Work started on the updating and creating of information, based on the findings from the 2011 Patient and Carer Information Survey.

During the year, the charity obtained a bursary to support accreditation of scripted information through the Information Standard (IS), a certification scheme for all organisations producing evidence-based health and social care information for the public. The IS helps the public and patients quickly identify reliable sources of quality, evidence-based information through the use of an easily recognised quality mark.

### **Medical Research**

During the year, the charity continued to support the PKD Bio-Resource Bank grant held by Professor Pat Wilson of the UCL Centre for Nephrology, Royal Free in London.

During the year, human tissue samples from nephrectomies were donated by UK patients with both ADPKD and ARPKD. Researchers from University and Kings' Colleges London, the Institute of Child Health/Great Ormond Street Hospital, the Royal Free London and Addenbrooke's Cambridge, have submitted successful applications for Bio-resource Bank materials in frozen, live cell and/or fixed sectioned states to use for PKD research projects.

In January, 2013, the trustees agreed to award a grant of £10,000 to Dr Jill Norman, for a future biomarker study at the Royal Free. The results would deliver 'proof of principle' support for an application from the Royal Free for substantial NIHR funding.

### **ADPKD Registry**

In 2012, the trustees had commissioned an external consultancy, Analogica, to review the status of ADPKD registries and databases in the UK and develop a technical requirement with appropriate datasets and indicative costing for an ADPKD Charity Registry.

At the conclusion of the study, it was decided not to proceed with a registry funded and developed by the charity. The datasets delivered by Analogica were circulated to the members of ADPKD Study Group for comment; they were then submitted to the UK Renal Registry to contribute to an updated IT initiative which will recruit all patients with chronic kidney disease from CKD stage 2 to 5. This expanded registry will contain most of the ADPKD patients in the UK.

Analogica provided a database of images and scientific references for use in publicity.

### **All Party Parliamentary Kidney Group (APPKG)**

In July 2012, the charity presented on PKD at the AGM of the APPKG, chaired by Madeleine Moon MP. Immediately after, Ms Moon asked a number of questions in the House of Commons, focusing on lack of research and the experiences of patients.

On November 6, 2012, Ms Moon obtained an Adjournment Debate in the House of Commons on 'Polycystic Kidney Disease', the first time that PKD has been debated in parliament.

### **PKD Awareness**

The chair, various trustees and Ms Harris have attended events in 2012-13 to raise awareness of PKD and the charity, notably:

1. The Renal Association Conference in Gateshead in June 2012, where a poster was presented of the 2011 Patient and Carer Survey.
2. The NKF Annual Conference in October 2012.
3. The European Steering Committee of the PKD International Alliance in Geneva in February 2013. (Expenses were funded directly by Otsuka Pharmaceutical Europe Ltd.)
4. The AGMs of Rare Disease UK, Genetic Alliance and National Voices.
5. CILIA 2012 International Conference.

In addition, charity volunteers participated in fundraising and awareness activities around World Kidney Day in March 2013.

### **Fundraising Activities**

The charity organised a Family Fun Day and Run/Walk in September 2012 in Milton Keynes. The trustees thank the enthusiastic local supporters, in particular Dave Loveridge, for helping make the event both a fundraising and awareness success. Although the charity had anticipated organising more similar events, the trustees decided that such events were not cost-effective and would not be considered as part of the fundraising strategy.

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, even a sponsored silence. 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.

## **Governance**

In January 2013, the trustees held a strategy review and developed four strategic goals to guide its work from 2013-17:

We want everyone affected by PKD to have the best quality of life by:

### **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 will do this 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 for 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 will do this 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 will do this 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 based at renal units around the UK.
- 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 will do this by:*

- Advocating with and through other groups on issues relevant to PKD patients.
- Lobbying government (in partnership with other charities where appropriate) on 4 key issues affecting PKD patients; 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.

The trustees will report on the strategy in the next Annual Report.

#### **Incorporation Update**

The trustees had intended to register the charity as a company limited by guarantee during 2012-13. This was delayed for operational reasons to later in 2013 and is anticipated to take effect by 31 March 2014. Pro bono legal support has been obtained to achieve this.

## **FINANCIAL REVIEW**

### **Performance**

During the 12 months 1 April 2012 to 31 March 2013, the charity's income was **£111,225** (2012: £90,124).

The charity incurred expenses of **£95,270** (2012: £67,781), resulting in a surplus of **£15,952** (2012: £22,343).

Income from **voluntary donations** increased substantially however during the year to £102,536 (2012: £79,939). Costs increased owing to payments to the additional contractor and Analogica.

### **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 2013-14.

## **FUTURE PLANS**

These include:

- ADPKD Patient Information events in Salford and Cambridge.
- ARPKD Family Information Day at the Birmingham Children's Hospital.
- Publishing the PKD Newsletter and e-newsletters.
- Providing on-going support by phone, email, support groups and website.
- Updating and creating new health information leaflets, accredited under the Information Standard.
- Planning and raising funds for a Befriending pilot in London.
- Continuing to fund the PKD Charity Bio-Resource Grant.
- Participating in the ARPKD and ADPKD Study Groups.
- Attending and participating in conferences, workshops and events relevant to renal and genetic conditions.
- Supporting and encouraging individual and family fundraising.
- Developing a Legacy Campaign.

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



Judith Dignum  
Trustee

## **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 2013, which are set out on pages 15 to 19.

### **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  
Groombridge  
TN3 9SE



## **STATEMENT OF FINANCIAL ACTIVITIES - 1 APR 2012 TO 31 MAR 2013**

The notes on pages 17 to 19 form an integral part of these accounts.

	Note	Unrestricted funds £	Restricted funds £	2013 Total funds £	2012 Total funds £
<b>Income and expenditure</b>					
Voluntary income	2	96,442	6,094	102,536	79,939
Activities for generating funds	3	8,439	0	8,439	9,810
Investment income	4	249	0	249	245
<b>Total incoming resources</b>		<b>105,131</b>	<b>6,094</b>	<b>111,225</b>	<b>90,124</b>
<b>Resources expended</b>					
Cost of generating voluntary income	5	15,727	0	15,727	17,448
Cost of generating funds		12,101	0	12,101	14,349
Fundraising trading costs		1,355	0	1,355	265
		<b>29,183</b>	<b>0</b>	<b>29,183</b>	<b>32,062</b>
<b>Charitable activities</b>					
Grants and donations	6	10,580	0	10,580	10,500
Research		6,189	0	6,189	3,703
Awareness and education		5,329	0	5,329	-
Patient support		35,255	0	35,255	19,242
		<b>57,353</b>	<b>0</b>	<b>57,353</b>	<b>33,445</b>
<b>Governance costs</b>	7	<b>8,734</b>	<b>0</b>	<b>8,734</b>	<b>2,274</b>
<b>Total resources expended</b>		<b>95,270</b>	<b>0</b>	<b>95,270</b>	<b>67,781</b>
<b>Net incoming resources for the year</b>		<b>9,861</b>	<b>6,094</b>	<b>15,955</b>	<b>22,343</b>
<b>Statement of total recognised gains and losses</b>					
Net movement in funds		9,861	6,094	15,955	18,002
Fund balances brought forward at 1 April		45,571	98,266	143,838	121,495
Fund transfer		0	0	0	0
<b>Fund balances carried forward</b>		<b>55,432</b>	<b>104,360</b>	<b>159,792</b>	<b>143,838</b>
<b>Represented by:</b>					
Funds and reserves					
Restricted funds		0	55,440	55,440	49,346
ADPKD Bio-resource Bank Grant Fund		0	8,920	8,920	19,500
PKD Registry		0	40,000	40,000	40,000
Unrestricted funds		55,432	0	55,432	34,992
<b>Total funds</b>		<b>55,432</b>	<b>104,360</b>	<b>159,792</b>	<b>143,838</b>

**BALANCE SHEET AT 31 MAR 2013**

	Note	Unrestricted	Restricted	2013 Total	2012 Total
		£	£	£	£
<b>Fixed assets</b>					
Tangible assets	8	-		-	276
		-	-	-	<b>276</b>
<b>Current assets</b>					
Stocks		2,672		2,672	1,866
Prepayments	9	12,325		12,325	6,536
Cash at bank and in hand		153,798		153,798	142,334
		<b>168,795</b>	-	<b>168,795</b>	<b>150,736</b>
<b>Total assets</b>		<b>168,795</b>	-	<b>168,795</b>	<b>151,012</b>
<b>Current liabilities</b>					
Accruals		-		-	600
Deferred income		-		-	6,574
		<b>9,004</b>	-	<b>9,004</b>	<b>7,174</b>
<b>Net assets</b>		<b>159,791</b>	-	<b>159,791</b>	<b>143,838</b>
<b>Represented by:</b>					
Funds and reserves					
Restricted funds		-	55,440	55,440	49,346
ADPKD Bio-resource Bank Grant Fund		-	8,920	8,920	19,500
PKD Registry		-	40,000	40,000	40,000
Unrestricted funds		55,432	-	55,432	34,992
<b>Total funds</b>		<b>55,432</b>	<b>104,360</b>	<b>159,792</b>	<b>143,838</b>
<b>FUND BALANCES:</b>					
		Retained surplus	Surplus / deficit	Total fund	
		at 31/3/2012	year to date	at 31/3/2013	
		£	£	£	
Activities		2,255	-	2,255	
Harris		78	-	78	
Plockyer		1,691	-	1,691	
Research		45,322	6,094	51,416	
Designated		59,500	10,580	48,920	
General		34,992	20,440	55,432	
<b>Funds total</b>		<b>143,838</b>	<b>15,954</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 2013**

### **1. 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.

#### *Restricted Unrestricted Total (2013) Total (2012)*

*£ £ £ £*

### **2. Voluntary income**

Donations and gifts	6,094	84,533	90,627	64,716
Trusts and foundations	0	0	0	8,470
Gift Aid	0	11,909	11,909	6,743
	<b>6,094</b>	<b>96,442</b>	<b>102,536</b>	<b>79,939</b>

### **3. Activities for generating funds**

Fundraising events	0	3,151	3,151	1,648
JustGiving activities	0	4,290	4,290	6,870
Shop income	0	998	998	1,292
<b>Total</b>	<b>0</b>	<b>8,439</b>	<b>8,439</b>	<b>9,810</b>

*Restricted Unrestricted Total (2013) Total (2012)*

£ £ £ £

**4. Investment income**

Interest income	<b>0</b>	<b>249</b>	<b>249</b>	<b>245</b>
-----------------	----------	------------	------------	------------

**5. Cost of generating income**

Cost of voluntary income	0	15,727	15,727	17,448
--------------------------	---	--------	--------	--------

Cost of fundraising	0	12,101	12,101	14,349
---------------------	---	--------	--------	--------

Goods sold	0	1,355	1,355	265
------------	---	-------	-------	-----

<b>Total</b>	<b>0</b>	<b>28,183</b>	<b>29,183</b>	<b>32,062</b>
--------------	----------	---------------	---------------	---------------

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

	2013	2012
--	------	------

Grant made to PKD Bio-Resources	£10,580	£10,000
---------------------------------	---------	---------

The PKD Bio-Resources grant funds the maintenance of the PKD Bio-Resources. It is hoped that this will accelerate laboratory studies and clinical trials.

**7. Governance costs:**

	2013	2012
--	------	------

Trustee meetings	4,231	1,031
------------------	-------	-------

Professional fees	3,773	1,243
-------------------	-------	-------

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

	2013	2012
--	------	------

Asset cost

Balance brought forward	457	457
-------------------------	-----	-----

Additions/(disposals)	0	0
-----------------------	---	---

Balance carried forward	457	457
-------------------------	-----	-----

Accumulated depreciation

Balance brought forward	181	181
-------------------------	-----	-----

Charge for the year	276	-
---------------------	-----	---

Balance carried forward	457	181
<u>Net Book Value</u>		
Brought forward	276	276
Carried forward	0	276

#### **9. Debtors**

Prepayments (membership fees)	6,500	4,000
Other debtors	5,825	2,536
<b>Total</b>	<b>12,325</b>	<b>6,536</b>

#### ***Related party Transactions and Trustees Remuneration***

Trustees received no emoluments (2012: nil).

Expenses during the year (travel, subsistence, conference fees): £4,231 (2012: 1,031).

The Chief Executive was contracted to provide patient support, fundraising, website development and administrative services during the year and for this work received fees of £25,960. The Chief Executive had formerly served as a trustee and the trustees contacted the Charity Commission in regard to this payment. The trustees were satisfied that these fees were reasonable and in the interests of the charity, and that they had followed the duty of care set out in the Trustee Act 2000. The Charity Commission confirmed that no authority was needed for this payment.