

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

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

**FOR THE YEAR ENDED 31 MARCH 2011**

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

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## **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 Tess Harris, Chairman

Ms Judith Dignum

Mrs Edwina Graham

Mr Barry Harpham

Ms Rebecca Murphy

Mrs Margaret Pope

Mrs Christine Wallach

### **Scientific and Research Advisory Board (SCARAB)**

Chairman: Dr Anand Saggar, Consultant in Clinical Genetics, St George's Hospital Medical School

### **Medical advisors**

Dr Anand Saggar, Consultant in Clinical Genetics, St George's Hospital Medical School, London

Dr Richard Sandford, Senior Fellow in Clinical Research & Genetics Consultant, Addenbrooke's Hospital, Cambridge

Prof Pat Wilson, UCL Centre for Nephrology Royal Free, London

### **Patrons**

Dr Vince Cable, MP

Mr Laurence Isaacson, CBE

### **Professional advisors**

#### **Bankers**

CAF Bank Ltd

25 Kings Hill Avenue

West Maling

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 2011, and confirm they comply with the requirements of the Charities Act 1993, as amended by the Charities Act 2006, the Charities Accounts (Scotland) Regulations 2006, the trust deed and applicable law.

### **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 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, with the help of a part-time administrator, part-time fundraisers (contractors) and unpaid volunteers. In 2010-11 there were five ordinary trustee meetings and no special meetings. The trustees make extensive use of teleconferencing and email communications.

During the year, Ms Judith Dignum and Mrs Edwina Graham were appointed as trustees.

The trustees review the charity's finances at each meeting. A strategy 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 community fundraising to an experienced contractor who responds to enquiries from volunteers and provides support to individuals and families undertaking fundraising around the UK. During the year, the charity contracted with a second fundraiser who supported the charity's fundraising activities with targeted grant applications to trusts and foundations. The trustees monitored the activities and outputs of both fundraisers through reports provided at trustee meetings; the chair has regular phone meetings with both individuals.

During the year, the charity paid an honorarium to the sister of one trustee for administration. The Charity Commission has no objection to this arrangement.

The charity's book-keeping and accounts were maintained by a volunteer who reported to the trustees throughout the year and prepared the final accounts for independent examination.

The charity is a member of the Fundraising Standards Board, providing reassurance to supporters, members of the public and other donors, and promoting best practice in fundraising.

The charity would be unable 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 is a member of several umbrella organisations, including National Voices, Genetic Alliance, Rare Disease UK and Eurordis. The charity's chair engages regularly with these organisations to ensure that the charity's aims and activities are known, recognised and taken account of.

The charity is a member of the newly-formed Ciliopathy Alliance and PKD International.

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.

## **OBJECTIVES AND ACTIVITIES**

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.

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 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, PKD remains unknown to the public and many health professionals.

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.

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 and the charity has a strategic goal to gather and analyse data from a significant number of ADPKD patients to further such investigative research.

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 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, 30% to 50% of ARPKD infants die at birth or shortly thereafter, primarily as the result of underdeveloped lungs.

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.

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.

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.

**The charity's objects are:**

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.

**To achieve these 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 2010-11**

### **Patient support**

1. The charity organised two **ADPKD Patient Information Days** during the year: in April 2010 at the Freeman Hospital, Newcastle; in September 2010 at St George's Hospital, Tooting. Approximately 180 people attended in total. Patient Information Days are highly appreciated 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 John Sayer and colleagues at the Freeman and Dr Anand Saggarr and colleagues at St George's for arranging the venues and speaking.

#### Topics covered included:

- Genetics and pathology of PKD
- Progression of the disease and preventive measures
- Brain aneurysms
- Diet and lifestyle
- Research
- Potential treatments and drug development
- Coping with PKD

Feedback was very positive. Patients and families welcomed the opportunity to talk to other sufferers and doctors. One person said: *"I feel better informed and able to assess and plan and control my life and help my family"*.

2. Two issues of the PKD Newsletter were published and mailed to nearly 1000 people registered on the PKD database, in addition to over 80 UK Renal Units (approximately 10 in Scotland), over 200 dialysis centres, the 70+ UK Kidney Patients' Associations including the Scottish KPA, the UK Genetics Centres, plus other interested persons.
3. The **PKD website** [www.pkdcharity.org.uk](http://www.pkdcharity.org.uk) attracted nearly 9,000 visitors during the year, 68% being new to the site. Visitors searched for information, registered for the newsletter and other information, and purchased PKD merchandise. Information leaflets were sent to people who register on the website.
4. The **Online Support Group** (moderated by a trustee) provided peer support and advice throughout the year. All posts were read and the trustee-moderator ensured that no erroneous information was circulated.
5. The **telephone Helpline** (managed by a trustee) received on average one call a day; callers' information was kept confidential and secure; referrals to medical experts were made where relevant.
6. 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.

### **Research**

During the year, the charity undertook two research activities.

#### **Scientific and Medical ADPKD Conference**

In the previous year, the trustees had agreed to organise a conference on ADPKD in September 2010 and invite the world's leading clinicians and researchers to present the latest known science and genetics, updates on worldwide research and clinical trials, current and future treatments and therapies, and debate the top issues in clinical management of adults and children.

The Conference was held on 23 and 24 September 2010 and attracted over 100 delegates from 14 countries. All the presentations were filmed and later uploaded to the charity website, for visitors to view at no charge.



Delegates reported that the conference programme was excellent and the content would be useful in their scientific and clinical work. A selection of comments is provided below:

***Good mixture of clinical and research***  
***So many world class PKD researchers together!***  
***Well thought out useful topics***  
***I will modify my clinical practice***  
***As someone new to the therapeutic area, it was a great introduction***  
***You need to repeat this meeting in a few years' time!***

The trustees would like to thank the **Steering Group** members for their help in planning this conference:

Dr Kate Hillman, Consultant Nephrologist, Manchester Royal Infirmary  
Dr Iain MacPhee, Consultant Nephrologist, St George's Hospital  
Dr Donal O'Donoghue, Consultant Renal Physician and National Clinical Director for Renal Services  
Dr Peter Harris, Professor of Biochemistry/Molecular Biology and Medicine in the Division of Nephrology and Hypertension, Mayo Clinic, Rochester, USA  
Professor Albert Ong, DM, FRCP, Head, Academic Unit of Nephrology, University of Sheffield  
Dr Imran Rafi, MRCP, Medical Director, RCGP Clinical and Innovation Research Centre  
Dr Anand Sagar, FRCP, St George's Hospital  
Dr Richard Sandford, PhD, FRCP, Addenbrooke's Hospital  
Dr Charlie Tomson, FRCP, Consultant Nephrologist, past President Renal Association  
Dr David Wheeler, MD, FRCP, Reader in Nephrology, Royal Free Campus London  
Professor Pat Wilson, Professor of Medicine, UCL Medical School Centre for Nephrology, Royal Free Hospital

The trustees would also like to thank the team of volunteers who worked for 12 months organising the conference, preparing materials, finding sponsors and helping at the venue.

### **Grant Funding for a PKD Bio-Resource**

In September 2010, following extensive discussion, the trustees agreed to award a 3-year grant to Professor Pat Wilson of the UCL Centre for Nephrology, Royal Free to support a dedicated **PKD Bio-resource** for future research.

Professor Wilson, a long-time advisor to the PKD Charity and world-renowned PKD researcher, recently returned to the UK from the US. The grant funded the transportation back to the UK of Prof Wilson's large 20-year collection of kidney tissue and its establishment at the Royal Free in London. The grant will fund the maintenance of the resource and enable the establishment of a database compatible with those of other UK collections, such as St George's, the Renal Registry and Addenbrooke's. It is hoped that this will be the foundation for a PKD national registry that in turn will accelerate laboratory studies and clinical trials by quickly identifying sufficiently large cohorts of PKD patient data to produce definitive results.

Prof Wilson said: ***"This award should greatly help speed-up PKD research in the UK and is the start of very exciting collaboration. The long-term success and acceleration of PKD research depends on well-characterized human PKD and age-matched normal control tissues, cell lines and animal models that faithfully recapitulate the genotypic and phenotypic characteristics of the disease, together with well-annotated PKD patient cohorts. This award will facilitate high quality, translational PKD research projects in the UK by enabling us to provide project-ready, controlled sample sets."***

At the date of this report, one request had been made to Prof Wilson from a PKD researcher at King's in London for tissue samples.

## **Awareness**

1. The chair and a trustee exhibited at the Association of Genetics Counsellors and Nurses conference in April 2010.
2. The chair and a trustee presented on PKD to genetics students at Manchester Infirmary in June 2010.
3. A trustee attended the Genetic Alliance Conference and AGM in June 2010.
4. Letters of support for the Scientific and Medical Conference in September 2010 were received from All Party Parliamentary Kidney Group and the local London MP. Professor Pat Wilson submitted a conference report to the Renal Association.
5. The charity exhibited at the launch of the Ciliopathy Alliance at the Cilia Awareness Day in November 2010; the chair presented on PKD to over 100 delegates.
6. The chair attended a Rare Disease Workshop organised by the Association of Medical Research Charities in December 2010.
7. The chair attended the Rare Disease Day event in February 2011 at the House of Commons.
8. The chair attended the NHSBT Kidney Patient Support Group Meeting in March 2011.
9. The chair participated in meetings of the Ciliopathy Alliance.
10. The charity joined EURORDIS, the European umbrella organisation for rare diseases.
11. The charity joined PKD International, a newly formed global alliance of PKD support groups.

## **FINANCIAL REVIEW**

### **Performance**

During the 12 months 1 April 2010 to 31 March 2011, the charity's income increased to **£101,573** (2010: £63,938).

The charity incurred **expenses of £83,571** (2010: £48,847), resulting in a surplus of **£18,002** (2010: £15,091).

The main source of income growth is from voluntary donations which increased significantly during the year to **£51,952** (2010: £26,057) as a result of growth in the number of individuals undertaking fundraising activities.

Income of **£26,785** (2010: Nil) was received from delegate fees and sponsor donations from the September PKD Conference. However, the Conference generated a loss after deduction of expenses.

### **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**

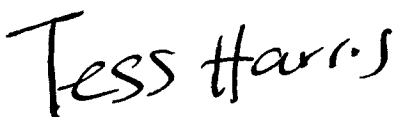
The trustees considered that the charity had sufficient reserves at the year end to fund its proposed activities during 2011-12.

## **FUTURE PLANS**

These include:

- PKD Patient Information event at the Royal Free Hospital in July 2011
- PKD Patient Information Day at Leicester Hospital in January 2012
- Publishing two issues of the PKD Newsletter
- Providing on-going support by phone, email, support groups and website
- Updating all the patient information leaflets on the website and in print
- Developing and supporting local/family groups in their fundraising and organising more 'planned' runs and activities
- Planning the first ARPKD Family Conference
- Participating in conferences, workshops and events relevant to renal and genetic conditions

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



Tess Harris  
Chair

*24 January 2012*

## **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 2011, which are set out on pages 13 to 18.

### **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 43(2) of the Charities Act 1993 (the 1993 Act) or under Regulation 10(1)(a) to (c) of the Charities Accounts (Scotland) Regulations 2006 (the 2006 Regulations) 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 43 of the Charities 1993 Act and under section 44(1) (c) of the Charities and Trustee Investment (Scotland) Act 2005 (the 2005 Act);
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 43(7)(b) of the 1993 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:

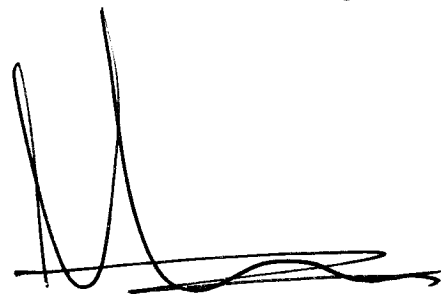
(1) which gives me reasonable cause to believe that in any material respect the requirements:

- to keep accounting records in accordance with section 41 of the 1993 Act and 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 1993 Act and section 44(1) (b) of the 2005 Act and Regulation 8 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  
3 The Close, Corseley Road  
Groombridge  
TN3 9SE  
24 January 2012



## STATEMENT OF FINANCIAL ACTIVITIES - 1 APR 2010 TO 31 MAR 2011

The notes on pages 15 to 18 form an integral part of these accounts.

### Statement of financial activities

To 31 March 2011

	Notes	Unrestricted funds £	Restricted funds £	2011 Total funds £	2010 Total funds £
<b>Income and expenditure</b>					
Voluntary income	2	47,758	4,194	51,952	26,058
Activities for generating funds	3	21,781	-	21,781	37,429
Investment income	6	195	-	195	186
Incoming resources from charitable activities	4,5	<u>27,645</u>	<u>-</u>	<u>27,645</u>	<u>265</u>
<b>Total incoming resources</b>		<b>97,379</b>	<b>4,194</b>	<b>101,573</b>	<b>63,938</b>
<b>Resources expended</b>					
Cost of generating voluntary income	7	2,667		2,667	
Cost of generating funds	8	16,661		16,661	22,525
Fundraising trading costs		1,423		1,423	6,921
Investment management costs		-		-	-
		<u>20,751</u>	<u>-</u>	<u>20,751</u>	<u>29,446</u>
<b>Charitable activities</b>					
Research	9	22,937	2,500	25,437	-
Awareness and education		22,937	-	22,937	4,121
Patient support		13,036	-	13,036	14,238
		<u>58,909</u>	<u>2,500</u>	<u>61,409</u>	<u>18,359</u>
<b>Governance costs</b>	10	<b>1,411</b>	<b>-</b>	<b>1,411</b>	<b>1,042</b>
<b>Total resources expended</b>		<b>81,071</b>	<b>2,500</b>	<b>83,571</b>	<b>48,847</b>
<b>Net incoming resources for the year</b>		<b>16,308</b>	<b>1,694</b>	<b>18,002</b>	<b>15,091</b>
<b>Statement of total recognised gains and losses</b>					
Net movement in funds		16,308	1,694	18,002	15,091
Fund balances brought forward at 1 April 2010		26,341	77,152	103,493	
Fund balances as at		42,649	78,846	121,495	
Fund transfer		-	-	-	
<b>Fund balances carried forward</b>		<b>42,649</b>	<b>78,846</b>	<b>121,495</b>	
<b>Represented by:</b>					
<b>Funds and reserves</b>					
Restricted funds		-	49,346	49,346	45,152
ADPKD Bio-resource Bank Grant Fund		-	29,500	29,500	32,000
Unrestricted funds		42,650	-	42,650	26,341
<b>Total funds</b>		<b>42,650</b>	<b>78,846</b>	<b>121,496</b>	<b>103,493</b>

## BALANCE SHEET AT 31 MAR 2011

Balance sheet  
as at 31 March 2011

	Notes	Unrestricted	Restricted	Total this year	Total last year
<b>Fixed assets</b>					
Tangible assets	11	£ 276	£ -	£ 276	£ 390
		£ 276	£ -	£ 276	£ 390
<b>Current assets</b>					
Stocks		£ 2,488	£ -	£ 2,488	£ 209
Pre-payments	12	£ 3,769	£ -	£ 3,769	£ 10,757
Cash at bank and in hand		£ 118,335	£ -	£ 118,335	£ 92,137
		£ 124,592	£ -	£ 124,592	£ 103,103
<b>Total assets</b>		£ 124,868	£ -	£ 124,868	£ 103,493
<b>Current liabilities</b>					
Creditors		£ -	£ -	£ -	£ -
Deferred income		£ 3,372	£ -	£ 3,372	£ -
		£ 3,372	£ -	£ 3,372	£ -
				£ -	
<b>Net assets</b>		£ 121,496	£ -	£ 121,496	£ 103,493
<b>Represented by:</b>					
<b>Funds and reserves</b>	13				
Restricted funds			£ 49,346	£ 49,346	£ 45,152
ADPKD Bio-resource Bank Grant Fund		£ -	£ 29,500	£ 29,500	£ 32,000
Unrestricted funds		£ 42,650	£ -	£ 42,650	£ 26,341
<b>Total funds</b>		£ 42,650	£ 78,846	£ 121,496	£ 103,493

### FUND BALANCES:

	Retained surplus	Surplus/deficit year to date	Total fund as at 31/3/2011
Activities	£ 2,255	£ -	£ 2,255
Harris	£ 48	£ 30	£ 78
Plockyer	£ 1,594	£ 97	£ 1,691
Research	£ 41,255	£ 4,067	£ 45,322
Designated	£ 32,000	-£ 2,500	£ 29,500
General	£ 26,341	£ 16,309	£ 42,650
<b>Funds total</b>	£ 103,493	£ 18,003	£ 121,496

Approved by the trustees on 24 January 2012 and signed on their behalf by

*Tess Harris*

Tess Harris, trustee and chairman

## **NOTES TO THE FINANCIAL STATEMENTS FOR YEAR ENDED 31 MARCH 2011**

### **1. Accounting Policies**

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

The financial statements have been prepared in accordance with the Statement for Recommended Practice: Accounting and Reporting by Charities (SORP 2005) issued in March 2005 and applicable UK Accounting Standards and the Charities Act 1993. 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>Restricted</i>	<i>Unrestricted</i>	<i>Total</i>	<i>Total</i>
	<i>£</i>	<i>£</i>	<i>£</i>	<i>£</i>
<b>2. Voluntary income</b>				
Donations and gifts	3,099	27,279	30,378	19,890
Trusts and Foundations	0	11,500	11,500	1,950
Gift Aid	0	10,074	10,074	4,217
<b>Total</b>	<b>3,099</b>	<b>48,853</b>	<b>51,952</b>	<b>26,057</b>

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

Fundraising events	0	18,301	18,301	31,047
Card Aid and shop income	0	1,798	1,798	4,594
New Year's raffle	0	1,682	1,682	1,787
<b>Total</b>	<b>0</b>	<b>21,781</b>	<b>21,781</b>	<b>37,428</b>

**4. Patient support**

Info Day fees	0	860	860	265
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**5. PKD Conference**

Delegates	0	12,085	12,085	n/a
Sponsors	0	14,700	14,700	n/a
<b>Total</b>	<b>0</b>	<b>26,785</b>	<b>26,785</b>	<b>n/a</b>

**6. Investment income**

Interest income	0	195	195	186
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**7. Cost of generating income**

Cost of voluntary income	0	2,667	2,667	2,993
Fundraising	0	16,661	16,661	19,532
Card Aid and goods sold	0	435	435	6,019
Raffle cost	0	988	988	900
<b>Total</b>	<b>0</b>	<b>20,751</b>	<b>20,751</b>	<b>29,444</b>

**8. Cost of charitable activities**

PKD Bio-research grant	2,500	0	2,500	n/a
PKD Conference	0	45,873	45,873	107
Patient support	0	13,036	13,036	16,492
<b>Total</b>	<b>2,500</b>	<b>58,909</b>	<b>61,409</b>	<b>16,599</b>

**9. Analysis of Grants:**

	2011	2010
Grant made to PKD Bio-Resources	£2,500	£-

The grant will fund the maintenance of the PKD Bio-Resources and enable the establishment of a database compatible with those of other UK collections, such as St George's, the Renal Registry and Addenbrooke's. It is hoped that this will be the foundation for a PKD national registry that in turn will accelerate laboratory studies and clinical trials by quickly identifying sufficiently large cohorts of PKD patient data to produce definitive results.



**10. Governance costs:**

	2011	2010
Trustee meetings (travel expenses)	£756	£808

**11. Analysis of Movement of Fixed Assets**

	2011	2010
<u>Asset cost</u>		
Balance brought forward	457	0
Additions/(disposals)	0	457
Balance carried forward	457	457

Accumulated depreciation

Balance brought forward	67	0
Charge for the year	114	67
Balance carried forward	181	67

Net Book Value

Brought forward	390	0
Carried forward	276	390

**12. Debtors**

Prepayments (membership fees)	3,769	£0
Prepayments (PKD Conference venue)	0	£10,757
<b>Total</b>	<b>3,769</b>	<b>10,757</b>

**13. Transfer between funds:**

	2011	2010
Transfer to PKD Bio-Resources fund	£0	£32,000

The grant will fund the maintenance of the PKD Bio-Resources and enable the establishment of a database compatible with those of other UK collections, such as St George's, the Renal Registry and Addenbrooke's. It is hoped that this will be the foundation for a PKD national registry that in turn will accelerate laboratory studies and clinical trials by quickly identifying sufficiently large cohorts of PKD patient data to produce definitive results.

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

Trustees received no emoluments (2010: nil)

Expenses during the year (travel, subsistence, conference fees) £1,411 (2010: £1,042)

During the year the Charity paid an honorarium of £3,000 (2010: £3,000) to Justina Wilkinson, the sister of one trustee for administration (database maintenance, Information Day management and financial control). The Charity Commission has no objection to this arrangement.