

THE POLYCYSTIC KIDNEY DISEASE (PKD) CHARITY

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

FOR THE YEAR ENDED 31 MARCH 2012

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

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REFERENCE AND ADMINISTRATIVE INFORMATION

Principal address:

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Tel: 0300 111 1234

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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

Mrs Edwina Graham

Ms Tess Harris (resigned June 2012)

Mr Raj Johal

Mr Sarbjit Johal

Mr Barry Harpham (appointed Chair June 2012)

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 2012, 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. During 2011-12, the trustees agreed to register the charity as a company limited by guarantee and have obtained pro bono legal support to progress this during 2012-13.

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, a part-time fundraiser (contractor) and unpaid volunteers. In 2011-12 there were six ordinary trustee meetings and no special meetings. The trustees make extensive use of teleconferencing and email communications.

During the year, Mr Raj Johal and Mr Sarbjit Johal were appointed as trustees.

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

At a trustee meeting on 10 February 2012, the trustees discussed the increasing number of activities that the chair was undertaking, whilst an unpaid volunteer for the charity. The chair, Ms Tess Harris, proposed the trustees consider hiring her as a contracted part-time manager or CEO for the charity, as the resources and time involved in an external hire would be disproportionate. The trustees, excluding Ms Harris, discussed this and approved the proposal in principle, as being in the best interests of the charity. The decision was later ratified at a trustee meeting in May 2012, Ms Harris resigned as trustee and permission was sought from the Charity Commission to make a payment to Ms Harris for administrative and executive services provided to the charity. These matters did not affect the finances or governance of the charity during the year 2011-2012.

Mr Barry J Harpham was subsequently appointed chair of the charity in May 2012.

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 or who have participated in an external fundraising event (eg the London Marathon) where the charity has paid for the entry fee. 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 contractor.

During the year, the charity paid an honorarium to the sister of one trustee for administration. The Charity Commission had 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. However, in December 2011, the volunteer was unable to continue the book-keeping and in February 2012, the trustees agreed to contract out the accounts administration to an external 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 Complaints Return to the FRSB. No fundraising complaints were submitted to the charity during the 2011-12 year and a nil Return was made 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. The charity also manages a Twitter account.

Membership of Related Organisations

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, and Rare Disease UK**. 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 2011-12, the new NHS Health and Social Care Bill and the UK Rare Disease Strategy.

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. (Others are very rare conditions). The study of ciliopathies is now an international endeavour and attracting significant interest and potential research funding. The chair (now CEO) of the PKD Charity was hired (in a personal capacity) by a member charity of the Ciliopathy Alliance to establish the organisation and organise an international conference held in May 2012. The chair (now CEO) 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. The chair (now CEO) was appointed President of PKDI in April 2011 for a 3-year term. This is 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. (ADPKD is 'technically' not 'rare' in Europe, having a prevalence of 1 in 800-1000).

In January 2012, the charity became 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. The chair of the Group is Dr Larissa Kerecuk, consultant nephrologist at Birmingham Children's Hospital. 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. Families are typically isolated (as is the case with many rare conditions) and the PKD Charity will play a vital role in achieving this goal. The Group will also develop an ARPKD dataset for the shared Rare Disease Renal Registry being developed to capture and analyse patient data across the UK.

In February 2012, the charity became a founder member of the **ADPKD Study Group** (hosted by 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. The PKD Charity chair (now CEO) was asked to chair this Study Group for 2 years from April 2012.

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 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. Analyses 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 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 2011-12

Patient support

1. The charity organised two **ADPKD Patient Information Days** during the year: in July 2011 at the Royal Free Hospital, London; in January 2012 at Leicester General Hospital. Over 200 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 Professor Pat Wilson, Dr Jill Norman and colleagues at the Royal Free and Dr Graham Warwick, Professors Albert Ong and John Feehally plus other colleagues at Leicester for arranging the venues and speaking.

Trustees attended and assisted at both Information Days.

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. Below is a sample of the feedback:

- *"I am reassured that I am well informed and able to assess and plan and control my life and help my family".*
 - *"Has given me loads of confidence for the future. Thank you."*
 - *"Everything was of interest and helpful."*
 - *"Superb informative day...will help me in the future."*
 - *"Very grateful to the PKD Charity for putting on this event. Thank you."*
2. The PKD Newsletter was published and mailed to over 1000 people registered on the PKD database, in addition 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.
 3. The **PKD website** www.pkdcharity.org.uk attracted nearly over 12,000 visitors during the year, an increase in one third. Over 9,000 were 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 and Twitter account www.twitter.com/PKDCharity continued to attract more followers, providing a low-cost communication and fundraising channel for the charity's activities.

PKD Charity Survey 2011

In March 2011, the charity issued a survey in printed and e-format in the newsletter and promoted extensively via the forum, Facebook, Twitter and email. The aims were to better understand the latest needs of people with ADPKD specifically and their families/ carers. In particular, unmet needs with regard to information provision and other support services were probed, at a time when the charity was 10 years old and reviewing current and future service provisions.

In July 2011, the results were collated and analysed by an independent consultant. Over 350 completed responses were received – 315 from people with PKD and an additional 51 by carers/ relatives.

The key findings and recommendations were:

- Given that ADPKD is the most common life-threatening genetic disease, the most common inherited renal disease, general awareness of the condition, and latest knowledge about optimum management, appeared to be generally quite low.
- Vastly differing approaches to the management of the person with ADPKD and their families were apparent around the country. Some undoubted centres of excellence and examples of best practice were revealed, but these were in stark contrast to experiences reported by others.
- There was a continuing need to raise further awareness of the condition, its presentation and on-going implications – and to facilitate the sharing of best practice in management amongst all relevant stakeholders. This can only help provide appropriate information and support and ensure that people with ADPKD around the country are given optimum treatment based on latest evidence.
- It can only be hoped that on-going and future research will provide significant treatment advances – if not necessarily the holy grail of a ‘cure’. Meanwhile, however, more consistent and informed management could play a pivotal role in minimising the negative impact of the condition for all involved.

The trustees agreed as a priority to commit resources to updating existing patient information leaflets (web and print) and to producing new ones to reflect the information needs identified by the respondents. Accreditation of all patient information would be sought 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.

The survey results were published in the Autumn 2011 newsletter and made widely available. As a result, Dr Donal O’Donoghue, the UK Clinical Director Renal Services, recommended that an abstract of the results be submitted to the Renal Association Conference in June 2012. The abstract was accepted and a poster produced and presented by Ms Harris at the RA Conference.

ARPKD Rare Disease Study Group

The group held its first meeting in January 2012 and there was agreement to hold a Family Conference in June 2012 at Birmingham Children’s Hospital. The charity took on the promotion and management of the registration, in addition to agreeing to commit funds to support the event.

Medical Research

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

At the date of this report, eight requests had been made to Prof Wilson from a PKD researcher at King's in London for tissue sample; and some human tissue samples from nephrectomies had been donated by UK patients with both ADPKD and ARPKD.

ADPKD UK-wide Registry

The trustees were concerned that there was little likelihood of an ADPKD patient registry being developed for many years, owing to NHS funding cuts and lack of external funding. The charity didn't have sufficient funds to develop its own and were uncertain about next steps.

Professor Pat Wilson submitted a proposal to review the situation regarding ADPKD registries and databases in the UK and develop a technical requirement with appropriate datasets, which could then form the foundation of a PKD Charity Registry. The proposal would also propose some methods of funding. The trustees agreed a 6-month contract with Prof Wilson through her consultancy company, Analogica, from January 2012.

Awareness

(NB: The chair referred to below is the chair during the financial year 2011-12, Ms Tess Harris).

1. The chair and a trustee attended the formal launch of the PKD International Alliance in Geneva in April 2011.
2. The chair attended the combined Renal Association/British Renal Society Conference in June 2011 and participated in a meeting to discuss the formation of ARPKD Study Group. Newsletters were distributed.
3. The chair attended the Rare Disease UK AGM in September 2011.
4. The chair and a trustee attended the annual conference of the National Kidney Federation in October 2011.
5. The chair presented on PKD to over 200 biology undergraduates at Kingston University in October 2011.
6. The chair attended the Genetic Alliance AGM in November 2011.
7. A trustee attended the National Voices conference in November 2011.
8. The chair attended a summit at the House of Commons on 'Kidney Disease and Transplantation in Culturally Diverse Groups, including Black and Minority Ethnic groups' in November 2011.
9. The chair attended the launch of the NHS Kidney Care 'Shared Decision Making' change programme in December 2011.
10. The chair presented on PKD to the annual meeting of the Association of Renal Social Workers in February 2012.
11. The chair and a trustee attended the Rare Disease Day event in February 2012 at the University of Holloway.
12. Charity volunteers participated in fundraising and awareness activities around World Kidney Day in March 2012.
13. The chair was invited to be one of two patient representative members of the Clinical Reference Group drafting the new Service Specifications for the national Commissioning of Renal Transplants in England for implementation in April 2013.

14. The chair participated in meetings of the Ciliopathy Alliance and PKD International during 2011-12.

Fundraising Strategy

The trustees reviewed fundraising at each trustee meeting and given the increasing numbers of supporters engaged in events around the UK, the trustees agreed to hold a Fundraising Strategy Workshop in January 2012 in Leicester.

Around 10 enthusiastic supporters met with trustees, facilitated the charity's contracted fundraiser. After a constructive and lively debate, the trustees agreed to commit resources to a Family Fun Day in September 2012 and also to consider ways to better support local fundraisers.

A major review of all fundraising will take place at the charity's strategy meeting in January 2013.

FINANCIAL REVIEW

Performance

During the 12 months 1 April 2011 to 31 March 2012, the charity's income was **£90,124** (2011: £101,573).

The charity incurred expenses of **£67,781** (2011: £83,571), resulting in a surplus of **£22,343** (2011: £18,002).

Income overall fell in the year because the previous year's income had included the September 2010 Conference fees. Income from **voluntary donations** increased substantially however during the year to £79,939 (2011: £51,952).

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 2012-13.

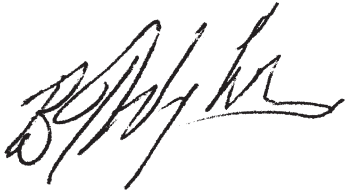
The trustees agreed to designate £40,000 to fund a potential future project regarding the ADPKD Registry.

FUTURE PLANS

These include:

- ADPKD Patient Information events at Manchester and Birmingham.
- ARPKD Family Information Day at the Birmingham Children's Hospital.
- 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, and accrediting the information under the Information Standard.
- Developing and supporting local/family groups in their fundraising and organising more 'planned' runs and activities
- Planning the first PKD Charity Family Fun Day.
- Continuing to fund the PKD Charity Bio-Resource Grant.
- Participating in CILIA2012- the first International Conference on Ciliopathies, organised by the Ciliopathy Alliance.
- Participating in the ARPKD and ADPKD Study Groups.
- Presenting at the Renal Association Conference in June 2012.
- Attending and participating in conferences, workshops and events relevant to renal and genetic conditions.
- Holding a strategic review in January 2013 and developing a new 3 to 5 year strategy.

Approved by the Trustees and signed on their behalf by

A handwritten signature in black ink, appearing to read 'Barry J Harpham', written in a cursive style.

Barry J Harpham
Chair

29 January 2013

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 2012, which are set out on pages 17 to 20.

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:

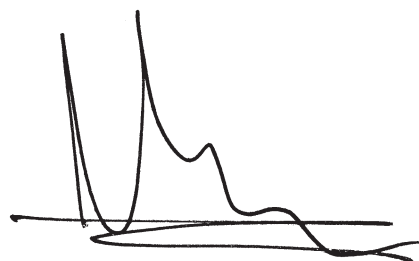
(1) which gives me reasonable cause to believe that in any material respect the requirements:

- 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



STATEMENT OF FINANCIAL ACTIVITIES - 1 APR 2011 TO 31 MAR 2012

The notes on pages 18 to 20 form an integral part of these accounts.

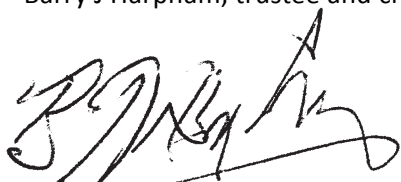
	Not e	Unrestricted funds £	Restricted funds £	2012 Total funds £	2011 Total funds £
Income and expenditure					
Voluntary income	2	79,939		79,939	51,952
Activities for generating funds	3	9,810		9,810	21,781
Investment income	4	245		245	195
Incoming resources from charitable activities		130		130	27,645
Total incoming resources		90,124		90,124	101,573
Resources expended					
Cost of generating voluntary income	5	17,448		17,448	2,667
Cost of generating funds		14,349		14,349	16,661
Fundraising trading costs		265		265	1,423
		32,062	0	32,062	20,751
Charitable activities					
Grants and donations	6	500	10,000	10,500	2,500
Registry & consultancy		3,703		3,703	
Conference		-			45,873
Patient support		19,242		19,242	13,036
		23,445	10,000	33,445	61,409
Governance costs					
	7	2,274		2,274	1,411
Total resources expended		57,781	10,000	67,781	83,571
Net incoming resources for the year		32,343	-10,000	22,343	18,002
Statement of total recognised gains and losses					
Net movement in funds		32,343	-10,000	22,343	18,002
Fund balances brought forward at 1 April		42,649	78,846	121,495	103,493
Fund balances at		74,992	68,846	143,838	121,495
Fund transfer		-30,000	30,000	0	0
Fund balances carried forward		44,992	98,846	143,838	121,495
Represented by:					
Funds and reserves					
Restricted funds		0	49,346	49,346	49,346
ADPKD Bio-resource Bank Grant Fund		0	19,500	19,500	29,500
PKD Registry		0	40,000	40,000	0
Unrestricted funds		34,992	0	34,992	42,649
Total funds		34,992	108,846	143,838	121,495

BALANCE SHEET AT 31 MAR 2012

	Note	Unrestricted £	Restricted £	2012 Total £	2011 Total £
Income and expenditure					
Tangible assets	8	276	-	276	276
		276	-	276	276
Current assets					
Stocks		1,866		1,866	2,487
Prepayments	9	6,536		6,536	3,769
Cash at bank and in hand		142,334		142,334	118,335
		150,736	-	150,736	124,591
Total assets		151,012	-	151,012	124,867
Current liabilities					
Accruals		600		600	-
Deferred income		6,574		6,574	3,372
		7,174	-	7,174	3,372
Net assets		143,838	-	143,838	121,495
Represented by:					
Funds and reserves	10				
Restricted funds		-	49,346	49,346	49,346
ADPKD Bio-resource Grant Fund		-	19,500	19,500	29,500
PKD Registry		-	40,000	40,000	-
Unrestricted funds		34,992	-	34,992	42,649
Total funds		34,992	108,846	143,838	121,495
FUND BALANCES:					
		Retained surplus	Surplus / deficit	Total fund	
			year to date	at 31/3/2012	
		£	£	£	
Activities		2,255	-	2,255	
Harris		78	-	78	
Plockyer		1,691	-	1,691	
Research		45,322	-	45,322	
Designated		29,500	30,000	59,500	
General		42,650	-7,658	34,992	
Funds total		121,496	22,342	143,838	

Approved by the trustees on *29 January 2013*
and signed on their behalf by

Barry J Harpham, trustee and chairman



NOTES TO THE FINANCIAL STATEMENTS FOR YEAR ENDED 31 MARCH 2012

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 (2012)</i>	<i>Total (2011)</i>
	£	£	£	£

2. Voluntary income

Donations and gifts	-	64,716	64,716	30,378
Trusts and Foundations	-	8,480	8,480	11,500
Gift Aid	-	6,743	6,743	10,074
Total	-	79,939	79,939	51,952

3. Activities for generating funds

Fundraising events	-	1,648	1,648	18,301
JustGiving Activities	-	6,870	6,870	-

Card Aid and shop income	-	1,292	1,292	1,798
New Year's raffle	-	-	-	1,682
Total	0	9,810	9,810	21,781

4. Investment income

Interest income	-	245	245	195
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5. Cost of generating income

Cost of voluntary income	-	17,448	17,448	2,667
Cost of fundraising	-	14,349	14,349	16,661
Card Aid and goods sold	-	265	265	453
Raffle cost	-	-	-	988
Total	-	32,062	32,062	20,751

6. Analysis of Research and Grants:

	2012	2011
Grant made to PKD Bio-Resources	£10,000	£2,500
Grant made to Ciliopathy Alliance	£ 500	£ 0

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.

The grant to the Ciliopathy Alliance was in furtherance of that charity's aims. The PKD Charity is a member of the Ciliopathy Alliance.

7. Governance costs:

	2012	2011
Trustee meetings	1,031	756
Professional fees	1,243	-

8. Analysis of Movement of Fixed Assets

	2012	2011
<u>Asset cost</u>		
Balance brought forward	457	457
Additions/(disposals)	0	0
Balance carried forward	457	457
<u>Accumulated depreciation</u>		
Balance brought forward	181	67
Charge for the year	-	114
Balance carried forward	181	181
<u>Net Book Value</u>		
Brought forward	276	390
Carried forward	276	276

9. Debtors

Prepayments (membership fees)	4,000	3,769
Other debtors	2,536	-
Total	6,536	3,768

10. Transfer between funds:

£10,000 was transferred from the Designated fund into the ADPKD Bio-Resource Fund. £40,000 was transferred from the General fund into a new designated fund for the PKD Registry.

Related party Transactions and Trustees Remuneration

Trustees received no emoluments (2011: nil)

Expenses during the year (travel, subsistence, conference fees): £1,031 (2011: £756)

During the year the Charity paid an honorarium of £3,000 (2011: £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.