

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

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

**FOR THE YEAR ENDED 31 MARCH 2009**

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

## 1. LEGAL 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

### Registered Charity in Scotland

Number SC038279

### Board of Trustees

Ms Tess Harris, Chairman  
Mr Chris Butler-Donnelly (resigned 1 September 2009)  
Mr Barry Harpham (joined 1 November 2009)  
Mrs Pam Hooley (resigned 1 November 2009)  
Ms Emma Kennedy (resigned 1 September 2009)  
Ms Rebecca Murphy  
Mrs Margaret Pope  
Mrs Alison Sanderson  
Mrs Christine Wallach

### Scientific and Research Advisory Board (SCARAB)

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

### Patron

Dr Vince Cable, MP

### Professional advisors

#### Bankers

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

#### Independent accounts examiner

Ms Sarah Hutchison, FCCA  
36 Epple Rd  
London SW6 4DH

## 2. GOVERNANCE, STRUCTURE AND MANAGEMENT

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

### Trustees

Trustees are appointed by the Board. All the trustees have PKD or a family connection. They are all unpaid volunteers and may claim reasonable out of pocket expenses. The charity's activities are planned and carried out by the trustees, a project manager, a part-time fundraising manager and unpaid volunteers. In 2008-9 there were six ordinary meetings of the Board (one a teleconference) and no special meetings. The trustees make extensive use of email communications between meetings.

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.

### Governance

During the year, an account with CAF (Charities Aid Foundation) Bank Ltd was opened and the Lloyds Bank account was closed.

The charity announced its first patron, Dr Vince Cable, MP, during the year.

### **Management and Administration**

During the year, the charity hired a part-timer fundraiser, Esther Wright, to support the charity's fundraising activities and begin work on a future fundraising strategy.

During the year the charity paid an honorarium to the sister of one trustee for project management and help with book-keeping. The Charity Commission has no objection to this arrangement.

We would be unable to function without voluntary help. We would, therefore, like to recognise and thank all our **volunteers** for their commitment and enthusiasm in supporting our activities. In particular, we thank those who gave their time to speak and help at the Patient Information events, those who proofread our written materials and helped mail out leaflets and Christmas Cards, and all the friends and families who have raised funds for the charity throughout the years.

### **3. WHO WE ARE**

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 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 50% 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 8% of patients are children. Despite its commonness, PKD remains unknown by 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.

ADPKD is often 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.

Symptoms vary from minimal to a variety of problems including pain, bleeding, 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 or be unaware they have the condition.

**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 a **rare genetic disease** affecting approximately 1 in 6,000 to 1 in 40,000 people. ARPKD is usually an 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.

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. .

#### **4. WHAT WE DO**

##### **Our objects are:**

1. To relieve people affected by Polycystic Kidney Disease, in particular by providing information, advice and support to patients and families affected by Polycystic Kidney Disorder.
2. To fund research into determining the causes of Polycystic Kidney Disease 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, email or in writing
2. Build up a research fund through fundraising and by setting aside a percentage of all incoming unrestricted resources in order to fund
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

We believe that by focusing our efforts towards common goals we can all help to make a difference: together we can help to both improve the current situation and to provide more hope for the future for those whose lives are affected by PKD.

#### **5. OUR ACTIVITIES AND ACHIEVEMENTS DURING 2008-9**

##### **Patient support**

- 1 We hold regular **ADPKD Patient Information Days** around the UK and these remain important ways to provide advice and support to patients, their families and carers, and generate interest with local nephrologists, renal nurses and geneticists. Two Information Days were held during the year: at the Edinburgh Royal Infirmary in April 2008 and the Royal Devon & Exeter Hospital in October 2008. We would like to thank Professor Neil Turner (Edinburgh) and Dr Coralie Bingham (Exeter) for arranging the venues and speaking on the day.
  - a. Topics covered included:
  - b. Genetics and pathology of PKD
  - c. Brain aneurysms
  - d. Diet
  - e. Potential treatments and drug development
  - f. Coping with PKD

Around 100 people attended both events. As in previous years, feedback was very positive. In particular, everyone appreciated the opportunity to talk to other people with PKD and to the renal specialists. **One patient commented: "I now feel more positive and hopeful about the future."**

- 2 We produced two more **information leaflets** during the year on genes and genetic testing, and coping with PKD. These are available on our website or can be mailed to individuals not on the internet. We get regular requests for all our leaflets and are aware that some are downloaded by renal nurses.

- 3 Two issues of the **PKD Newsletter** were published and mailed to nearly 1000 people registered on the PKD database, in addition to all 80 UK Renal Units and the 70+ UK Kidney Patients' Associations, plus other interested persons.
- 4 The **PKD website** [www.pkdcharity.org.uk](http://www.pkdcharity.org.uk) was updated and more content added. The site attracted over 11,000 unique visitors during the year, nearly 50% more than last year. Visitors can find out information, register for the newsletter and other information, and buy PKD merchandise direct from our e-shop.
- 5 The **Online Support Group** membership increased to nearly 450, a 50% increase over last year; content is reviewed for topics of interest; personalised advice is provided where necessary or requested. Nearly 10,000 messages have been posted in the past 3 years.
- 6 The two local **PKD Support Groups**, managed by Margaret Pope, trustee, continued in Chester and Richmond.
- 7 The **telephone helpline** was operated by Pam Hooley and Tess Harris, trustees; around 5-8 calls a week are received at present. Tess Harris also deals with **emails** received via the website; approximately 6 per month are received. The charity would like to thank its **medical advisors** for their fast and considerate responses to questions raised that cannot be answered by general advice.

## Research

There is no government-funded research into either ADPKD or ARPKD, and we are unable to fund significant research in the UK owing to insufficient resources. We do have some restricted research funds from donations and the trustees have designated a percentage of incoming donations for future research purposes.

One research priority is the development of a **UK-wide ADPKD Registry** – a Clinical Database and Repository of ADPKD patients with clinical data and DNA across all disease stages, sufficient to:

- 1 Provide greater understanding of presentation, progression and treatment
- 2 Establish large patient cohorts, promote a new research agenda, create opportunities for social, medical and scientific research and permit new research partnerships
- 3 Generate scientifically robust data to support best practice guidelines' development and identify longer-term research priorities.

During the year, we prepared a submission to the **Big Lottery Research Programme** to fund a Registry at a projected cost of £500,000 over 3 years.

We would like to record our thanks to the members of the Big Lottery Steering Group for their help with Research Programme grant application:

Mr Martin Beresford

Dr Kate Hillman, Consultant Nephrologist (Royal Free Hospital)

Dr Iain MacPhee, Consultant Nephrologist (St George's Hospital)

Dr Donal O'Donoghue, Consultant Renal Physician (National Clinical Director for Renal Services)

Dr Jon Machtynger, IBM

Ms Jo Moore

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 Saggat, FRCP (St George's Hospital)

Dr Richard Sandford, PhD, FRCP (Addenbrookes Hospital)

Dr Charlie Tomson, FRCP, Consultant Nephrologist, President Renal Association

Dr David Wheeler, MD, FRCP, Reader in Nephrology (Royal Free Campus)

Professor Pat Wilson, Director Kidney Disease Research (Medical College of Wisconsin)

We would also like to thank the charity Action Duchenne who freely provided documents prepared for their own patient registry.

## Awareness

- 1 In **October 2008**, the charity exhibited at the annual **NKF Conference** in Warwick. The charity would like to thank the NKF for providing the space free of charge.
- 2 In February 2009, trustees attended a **Rare Disease Awareness Event** at the House of Commons.

- 3 In March 2009, to coincide with **World Kidney Day**, the charity organised a 'Collecting Tin Day' and several volunteers raised funds in public places.
- 4 The charity continues to strengthen its relationships with other organisations providing services to renal patients, namely the Department of Health/NHS, the National Kidney Federation, Kidney Research UK and the Blood Pressure Association. This aim is to avoid duplication of services to kidney patients, share information and gain a stronger voice for the charity and PKD in the renal community.
- 5 The charity is a member of the National Voices umbrella organisation (formerly LTCA) and the Genetic Interest Group.

### **Fundraising manager**

We recognise that the majority of our future funds will come from voluntary income, from donations, in memoriam legacies and local fundraising (either organised by the charity or by individuals).

We hired Esther Wright, as part-time fundraising manager, halfway through the last year to develop and build our fundraising capability, identify and build relationships with local fundraisers, and plan charity events. She concentrated initially on establishing fundraising materials, systems and events that can be developed in future years.

Additionally, she undertook a number of other activities that had a beneficial effect on fundraising income, whilst not directly raising any income, including updates for the PKD website and the newsletter on fundraising initiatives and success stories to inspire others, talking at Information Days and preparing a generic application for approaching trusts and grant-making foundations for specific projects.

Finally, she has contributed towards the development of a 3 year 'growth' strategy which will be adopted in November 2009.

## **6. OUR FUTURE PLANS**

We will continue with our established activities for 2009-10:

- 1 Hold one PKD Patient Information event at the Sheffield Northern General Hospital in April 2009
- 2 Organise the 1<sup>st</sup> Charity Abseil Fundraiser in Sheffield April 2009
- 3 Purchase place for our 1<sup>st</sup> charity runners in the Manchester 10k in May 2009
- 4 Exhibit at the NKF Conference in October 2009
- 5 Publish two issues of the PKD Newsletter
- 6 Provide ongoing support by phone, email, support groups and website

In addition, we will:

- 7 Upgrade and redesign the website to provide enhanced accessibility and permit content to be updated more easily
- 8 Plan the charity's 10<sup>th</sup> Anniversary Scientific and Clinical Conference to be held on 23-24 September 2010
- 9 Develop and agree a 3 year 'growth' strategy with the aim of raising significant funds for research
- 10 Recruit additional trustees

## **7. FINANCIAL REVIEW & NOTES TO ACCOUNTS**

During the 12 months 1 April 2008 to 31 March 2009, total **income was £37,231** (£46,671 for the 15 months ended 31 March 2008).

The principal source of income is voluntary donations and similar.

In particular:

- Fundraising events (managed by JustGiving.com) generated nearly £12,000

- The Murphy family raised nearly £3,000
- The family of Dr Peter Lockyer raised £1,639 towards research
- Jina Davis raised over £1,000
- Sales of Christmas Cards generated over £,000
- Sales of merchandise (wristbands, t-shirts, stress kidneys) generated £260

As in previous years, the trustees voted to designate 20% of incoming unrestricted income to research.

The charity incurred **expenditure of £31,303** (£34,448 for the 15 months ended 31 March 2008).

In particular:

- Nearly £10,000 was spent on recruiting and paying for the part-time fundraiser
- The two Patient Information Days cost nearly £6,000, but some of the costs were covered by registration fees and merchandise sales on the day (approximately £1,200)
- The two newsletters cost around £6,500 to produce, print and mail
- Approximately £1,300 was spent on the April Abseil and May Run – income from these events will show in the 2009-10 accounts

In last year's accounts, it was reported that a sum of **£40,000** had been designated towards a Clinical Research Nurse at St George's Hospital, Tooting. This is no longer required, owing to a cancellation of the anticipated project.

The charity had cash of **£88,403** (£82,474 in 2008-7) at the year end with sufficient resources to fund its proposed activities during 2009-10. This sum includes £47,881 which is restricted either for research (donations from the public) or designated by the trustees.

#### 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.

Approved and signed on behalf of the Board of Trustees

*Tess Harris*

Tess Harris  
Chairman

Date: *20 November 2009*

*Sarah Hutchison*

Sarah Hutchison, FCCA  
Independent Examiner  
20 Sandringham Rd  
London NW11 9DP

**THE POLYCYSTIC KIDNEY DISEASE CHARITY  
STATEMENT OF FINANCIAL ACTIVITY 1 APR 2008 TO 31 MAR 2009**

Registered Charity in England and Wales Number 1085662

Registered Charity in Scotland Number SC038279

**Trustees:**

Ms Tess Harris, Chairman

Mr Chris Butler-Donnelly (resigned 1 September 2009)

Mr Barry Harpham (joined 1 November 2009)

Mrs Pam Hooley (resigned 1 November 2009)

Ms Emma Kennedy (resigned 1 September 2009)

Ms Rebecca Murphy

Mrs Margaret Pope

Mrs Alison Sanderson

Mrs Christine Wallach

**Independent Examiner:**

Ms Sarah Hutchison, FCCA

36 Epple Road

London

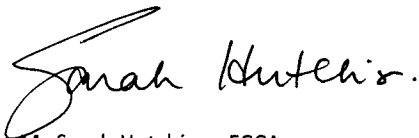
SW6 4DH



**THE POLYCYSTIC KIDNEY DISEASE CHARITY  
ACCOUNTS FOR THE YEAR ENDED 31 MARCH 2009**

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

<b>Respective responsibilities of trustees and examiner</b>	<p>The charity's trustees consider that an audit is not required for this year (under section 43(2) of the Charities Act 1993 (the Act), as amended by s.28 of the Charities Act 2006) and that an independent examination is needed.</p> <p>It is my responsibility to:</p> <ul style="list-style-type: none"><li>• examine the accounts (under section 43 of the Act, as amended),</li><li>• to follow the procedures laid down in the General Directions given by the Charity Commission (under section 43(7)(b) of the Act, as amended), and</li><li>• to state whether particular matters have come to my attention.</li></ul>
<b>Basis of independent examiner's statement</b>	<p>My examination was carried out in accordance with General Directions given by the Charity Commission. 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 the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently I do not express an audit opinion on the accounts.</p>
<b>Independent examiner's statement</b>	<p>In the course of my examination, no matter has come to my attention which gives me reasonable cause to believe that in, any material respect, the trustees have not met the requirements to ensure that:</p> <p>proper accounting records are kept (in accordance with section 41 of the Act); and accounts are prepared which agree with the accounting records and comply with the accounting requirements of the Act; or to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.</p>



Ms Sarah Hutchison FCCA  
36 Epple Road  
London  
SW6 4DH

POLYCYSTIC KIDNEY DISEASE CHARITY 1085662/SCO38279

STATEMENT OF FINANCIAL ACTIVITY FOR PERIOD 1 APRIL 2008 - 31 MARCH 2009

**INCOME AND EXPENDITURE ACCOUNT**

	Unrestricted Funds Designated £	Unrestricted Funds General £	Restricted Funds Research £	Restricted Funds P Lockyer £	Restricted Funds Activities £	2008-9 Total £	2007-8 Total (15 mths) £
<b>INCOMING RESOURCES</b>							
<b>Voluntary Income</b>							
Donations and similar receipts	5,611.28	22,445.14	1,297.90	1,638.70	3,005.00	33,998.02	42,550
<b>Charitable Activities</b>							
Information Days	234.00	936.00				1,170.00	464
<b>Activities to generate funds</b>							
Abseil	30.00	120.00				150.00	
Christmas Cards	213.50	853.98				1,067.48	3,365
Merchandise	51.48	205.92				257.40	293
Interest	117.66	470.63				588.29	
<b>TOTAL INCOMING RESOURCES</b>	<b>6,257.92</b>	<b>25,031.67</b>	<b>1,297.90</b>	<b>1,638.70</b>	<b>3,005.00</b>	<b>37,231.19</b>	<b>46,671</b>
<b>RESOURCES EXPENDED</b>							
<b>Charitable Activities</b>							
Research		-				-	12,147
Patient support		10,884.55			3,005.00	13,889.55	15,166
Awareness		1,540.28				1,540.28	1,739
<b>Cost of Generating Funds</b>							
Costs of generating voluntary income		10,100.66				10,100.66	3,723
Costs of events, merchandise and other		5,004.02				5,004.02	514
Governance		768.18				768.18	1,159
<b>TOTAL RESOURCES EXPENDED</b>	<b>-</b>	<b>28,297.69</b>	<b>-</b>	<b>-</b>	<b>3,005.00</b>	<b>31,302.69</b>	<b>34,448</b>
<b>NET INCOMING RESOURCES</b>	<b>6,257.92</b>	<b>- 3,266.02</b>	<b>1,297.90</b>	<b>1,638.70</b>	<b>-</b>	<b>5,928.50</b>	<b>12,223</b>
B/F 2008		48,695.00	33,780.00	-	-	82,474.00	
C/F 2009	6,257.92	45,428.98	35,077.90	1,638.70	-	88,402.50	