

THE POLYCYSTIC KIDNEY DISEASE CHARITY

REPORT OF THE TRUSTEES AND STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 MARCH 2008 (15 months)

**Please note that this Report and SOFA cover the 15 month period
1 January 2007 to 31 March 2008**

1. LEGAL AND ADMINISTRATIVE INFORMATION

Principal address:

The PKD Charity
PO Box 141
County Durham
DL14 6ZD
Tel: 01388 665004
Email: info@pkdcharity.org.uk
www.pkdcharity.org.uk

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

2. TRUSTEES AND ADVISERS

Board of Trustees as at 31 August 2008

Ms Tess Harris, Chairman
Mr Chris Butler-Donnelly
Mr John Eatough
Ms Emma Kennedy
Mrs Pam Hooley
Ms Rebecca Murphy, Treasurer
Mrs Margaret Pope
Mrs Alison Sanderson
Mrs Christine Wallach

Medical advisors

Dr Anand Sagar, Consultant in Clinical Genetics, St George's Hospital Medical School and Chairman of the PKD Charity Scientific, Research and Advisory Board
Dr Malcolm Phillips, Consultant Nephrologist (retired 2005), Charing Cross Hospital
Dr Richard Sandford, Senior Fellow in Clinical Research & Genetics Consultant, Addenbrooke's Hospital

Scientific advisors

Professor Steve Jeffery, Professor of Human Genetics, St George's University of London

Professional advisors

Bankers: Lloyds TSB Bank, Twickenham, TW1 4AW
Independent accounts examiner: Sarah Hutchison, FCCA

3. The PKD Charity 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. 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 and unpaid volunteers. In 2007-8 there were five ordinary meetings of the Board 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.

During 2007-8, one trustee resigned owing to family commitments and one new trustee was appointed at the Trustee Meeting on 28 March 2008.

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

Governance

At the **Trustee Meeting of 19 October 2007**, it was noted that the charity had registered with the Office of the Scottish Charity Regulator with the number SC038279.

At the **Trustee Meeting of 7 December 2007**:

- Tess Harris was re-elected Chair of trustees
- It was agreed to change the financial year end to 31 March from 31 December to better align with the Inland Revenue year for Gift Aid reclamation – consequently this report covers a 15 month period from 1 January 2007 to 31 March 2008
- It was agreed that one other person who is not a trustee would be authorised to sign cheques

As the last two decisions required an amendment to the charity's Governing Document, the Charity Commission was asked if consent or authority to amend the Document was required. In an email of **25 February 2008**, the Charity Commission stated that they had "considered the proposed amendments, together with the amendment provisions within the charity's Governing Document" and that they were "satisfied that no consents or authorities were required from the Commission". They asked that a Supplemental Deed be signed, dated and returned for inclusion on the charity's file.

During the year, the trustees determined to change the charity's bank account from Lloyds and establish separate accounts for restricted research funds that would yield higher interest. At the **Trustee Meeting on 28 March**, it was agreed to open an account with CAF (Charities Aid Foundation) Bank.

Management and Administration

At the Trustee Meeting of **19 October 2007**, it was agreed that the charity should hire a part-timer fundraiser to support the charity's fundraising activities and identify sources of funds for developing patient support and medical research. (Update: On 1 September 2008, the charity appointed two part-time fundraising managers.)

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.

4. OBJECTIVES, ACTIVITIES AND ACHIEVEMENTS OF THE PKD CHARITY

The PKD Charity's 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, the charity aims to:

1. Ensure that anyone who contacts the charity receives the support they need - in person, by phone, email or in writing
2. Keep up to date with the latest research into a cure and treatment for PKD in order to better inform patients and interested others
3. Find ways to bring PKD to the attention of the media
4. Build up a research fund through fundraising and by setting aside a percentage of all incoming unrestricted resources

Achievements during the year:

1. The **4th National PKD Patient Awareness and Information Event** was held at the Queen Elizabeth Medical Centre, Birmingham. **Approximately 50 patients, families and friends** attended to hear speakers on topics such as:
 - a. Genetics and pathology of PKD
 - b. Brain aneurysms
 - c. Diet
 - d. Potential treatments and drug development
 - e. Coping with PKDAs in previous years, those who attended found the event to be helpful and informative. In particular, the opportunity to talk to other people with PKD and with renal specialists was highly appreciated.
2. **Information leaflets** were produced on aneurysms, family planning, urinary infections and pain; these were uploaded to the website.
3. Two issues of the **PKD Newsletter** were published and mailed to around 500 people registered on the PKD database, all the UK Renal Units and the UK Kidney Patients' Associations, plus other interested persons.
4. The **PKD website** www.pkdcharity.org.uk was updated and more content added. The site attracted nearly 6,000 unique visitors during the year, an increase of approximately 20% compared with last year. Feedback from

- visitors is very positive, with people finding it "extremely useful" and easy to navigate.
- 5 The **online support group** membership has doubled to over 300; content is reviewed for topics of interest; personalised advice is provided where necessary or requested.
- 6 **Telephone personal support** was provided by Pam Hooley, trustee, who operates the telephone helpline providing support and information directly to callers. Tess Harris, trustee, deals with **emails** received via the website. The charity would like to thank its **medical advisors** for their fast and considerate responses to questions raised.
- 7 Two active local **PKD Support Groups** were established under the stewardship of Margaret Pope, trustee. One in Chester is organised by Emma Kennedy, trustee; the other in Richmond is run by Margaret Pope who also provides telephone support via a dedicated Support Group helpline.
- 8 On 14 March 2008, to coincide with World Kidney Day, the charity held a **PKD Awareness event** at the BodyWorlds exhibition held at the Manchester Museum of Science & Industry. Around 60 people attended and viewed a 'plastinated' polycystic kidney from the exhibition; the head of Renal Services UK spoke; local press coverage was obtained.
- 9 On 29 March 2007, the trustees approved the payment of a grant of **\$25,000** to the PKD Foundation (US) towards a **research project run by Dr Albert Ong in Sheffield**. The project is named in honour of the late Dr Peter Lockyer (former trustee) and the Lockyer family members, through personal fundraising, contributed 50% of the money. The research will continue to end 2008.
- 10 Margaret Pope, trustee, attended an NHS Workshop and presented on the "PKD Journey" to an audience of DOH personnel including the Head of Renal Services UK.
- 11 The charity continues to develop its **relationships** with other organisations providing services to renal patients, namely the Department of Health/NHS, the National Kidney Federation, Kidney Research 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.

We would like to record our thanks to all the **volunteers** who made our achievements possible, in particular, those who gave their time to speak at the Patient event, those who proofread our written materials and helped mail out leaflets.

We should also like to thank Jellymould (who edit the newsletter on a voluntary basis) and Orbit Internet (who host the website free of charge).

5. FINANCIAL REVIEW & NOTES TO ACCOUNTS

During the 15 months 1 January 2007 to 31 March 2008, total **income** was £46,671 (£44,285 in 2006).

The principal source of income is voluntary donations.

In particular:

- The family of Dr Peter Lockyer raised £6,254 towards the Research Project awarded in his name by the PKD Foundation
- Sales of Christmas Cards generated £3,365
- The Patient Information Day generated £463

- Sales of merchandise (wristbands, t-shirts, stress kidneys) generated £293

We would like to thank all the individuals, their families, friends and colleagues for their generous donations and purchase of merchandise. Without their personal fundraising efforts throughout the year, we would not be able to carry out our charitable activities.

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

The charity incurred **expenditure** of £34,448 (£29,886 in 2006).

In particular:

- On 29 March 2007, the trustees approved the payment of £12,147 (\$25,000) to the PKD Foundation (US) towards a research project run by Dr Albert Ong in Sheffield.

At the Trustee Meeting of **19 October, 2007**, the trustees agreed to designate **£40,000** towards the 2-year cost of a Clinical Research Nurse at St George's Hospital, Tooting, to assist with an initiative to establish a UK-wide PKD clinical and patient database for research purposes.

The charity had cash of **£82,474** (£70,251 in 2006) at the year end with sufficient resources to fund its proposed activities during 2008-9.

6. FUTURE PLANS

The following activities were planned for 2008-9:

- 1 PKD Patient Information event at the Edinburgh Royal Infirmary in April 2008
- 2 PKD Patient Information event at the Royal Devon and Exeter Hospital, October 2008
- 3 Two issues of the PKD Newsletter
- 4 Re-development of the website (subject to grant funding)
- 5 Application to the Big Lottery to fund a UK-wide PKD Clinical Database and Repository
- 6 Appointment of part-time Fundraising Managers and development of 5-year fundraising strategy

Approved and signed on behalf of the Board of Trustees

Tess Harris

Tess Harris
Chairman

Date: *26 Sep 2008*

Sarah Hutchison

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

Report of the Trustees and Statement of Financial Activities 1 January 2007–31 March 2008

**THE POLYCYSTIC KIDNEY DISEASE CHARITY
STATEMENT OF FINANCIAL ACTIVITY 1 JAN 2007 TO 31 MAR 2008**

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

Current Trustees:

Ms Tess Harris, Chairman
Mr Chris Butler-Donnelly
Mr John Eatough
Ms Emma Kennedy
Mrs Pam Hooley
Ms Rebecca Murphy, Treasurer
Mrs Margaret Pope
Mrs Alison Sanderson
Mrs Christine Wallach

Independent Examiner:

Ms Sarah Hutchison, FCCA
20 Sandringham Rd
London NW11 9DP

**THE POLYCYSTIC KIDNEY DISEASE CHARITY
ACCOUNTS FOR THE YEAR ENDED 31 MARCH 2008**

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

**Respective
responsibilities of
trustees and examiner**

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.

It is my responsibility to:

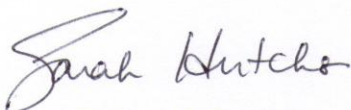
- examine the accounts (under section 43 of the Act, as amended),
- to follow the procedures laid down in the General Directions given by the Charity Commission (under section 43(7)(b) of the Act, as amended), and
- to state whether particular matters have come to my attention.

**Basis of independent
examiner's statement**

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.

**Independent
examiner's statement**

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:
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.



Ms Sarah Hutchison FCCA
20 Sandringham Rd
London
NW11 9DP

POLYCYSTIC KIDNEY DISEASE CHARITY No 1085662/SC038279

STATEMENT OF FINANCIAL ACTIVITY FOR PERIOD 1 JAN 2007 TO 31 MARCH 2008

Covering a 15 month period

INCOME AND EXPENDITURE ACCOUNT

	Restricted Funds Research £	Restricted Funds P Lockyer £	Restricted Funds Activities £	Unrestricted Funds £	Period Total £
INCOMING RESOURCES					
Donations, legacies and similar receipts				26,084.10	26,084.10
Donations, legacies and similar receipts - research	2,660.40	6,254.04	0.00		8,914.44
Grants			0.00		0.00
Activities to further the charity's objects				463.60	463.60
Other income				0.00	0.00
<i>Activities to generate funds:</i>					
Christmas Cards				3,364.78	3,364.78
Merchandise				292.96	292.96
Income designated from donations by Trustees for research	7,551.36				7,551.36
TOTAL INCOMING RESOURCES	10,211.76	6,254.04	0.00	30,205.44	46,671.24
RESOURCES EXPENDED					
<i>Charitable expenditure in furtherance of objects</i>					
Charitable activities				408.20	408.20
PKD Conference Costs			2844.00	2,783.86	5,627.86
Awareness Events				1,739.06	1,739.06
Newsletter				3,418.90	3,418.90
Information leaflets				284.41	284.41
Design costs				621.27	621.27
Other Subscriptions				357.00	357.00
Database				424.99	424.99
Phone/Website				377.03	377.03
Equipment				0.00	0.00
Stationery/Consummables				235.00	235.00
Postage				171.64	171.64
Travel (Non Trustees)				288.45	288.45
Support Groups				664.04	664.04
Management & admin				1,750.00	1,750.00
Other				537.39	537.39
Trustee Expenses				1,158.50	1,158.50
Research		12,146.51			12,146.51
<i>Cost of generating funds</i>					
Fundraising				513.48	513.48
Christmas Cards				2,399.42	2,399.42
Merchandise				810.46	810.46
Just Giving				514.30	514.30
TOTAL RESOURCES EXPENDED	0.00	12,146.51	2,844.00	22,301.40	34,447.91
NET INCOMING RESOURCES	10,211.76	-5,892.47	-2,844.00	7,904.04	12,223.33
B/F 2006	£23,568	£5,892	£2,844	£37,947	£70,251
C/F 2007-8 (15 months)	£33,780	0	0	£48,695	£82,474