

THE POLYCYSTIC KIDNEY DISEASE CHARITY

REPORT OF THE TRUSTEES AND STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 DECEMBER 2006

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

Charity Registration Number 1085662

2. TRUSTEES AND ADVISERS

Board of Trustees as at 30 June 2007

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

Medical advisors

Dr Anand Saggar, Consultant in Clinical Genetics, St George's Hospital Medical School
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 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 and other unpaid volunteers. In 2006 there were four ordinary meetings of the Board and no special meetings. The trustees make extensive use of email communications between meetings.

The charity does not employ any full or part-time staff. 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.

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

During 2006, the trustees determined to recruit additional trustees to fill skills' gaps on the Board and agreed a recruitment process involving contacting everyone on the PKD database and promoting via the newsletter, through medical contacts, and by word of mouth. Candidates were issued with a recruitment pack and those interested were interviewed by the Board in September 2006. Consequently, five new trustees were appointed and a trustee induction day was held in December 2006. (One trustee resigned in June 2007 owing to family commitments.)

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

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 **3rd National Patient Awareness and Information Event** was held at Bristol Southmead Hospital. This year we decided to hold the event over a weekend and invited people to join trustees and volunteers to a user-pay supper on the Saturday evening. **Approximately 90 patients, families and friends** attended over the weekend 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 The **PKD logo** was changed during the year following a tender. The new logo was designed for maximum awareness – using eye-catching colours of purple and green around the PKD letters – and to be easy to reproduce in all media. All communications materials were subsequently updated.
- 3 A new **PKD Leaflet** was produced aimed at the newly-diagnosed. This was mailed to every renal clinic in the UK and other interested persons. Several people have since contacted the charity to ask for information on specific aspects of PKD, such as blood pressure, infections etc, and new leaflets are planned as a result for 2007 on these topics.
- 4 The **PKD Newsletter** was published during the year to those registered on the PKD database and other interested persons.
- 5 The **PKD website** www.pkdcharity.org.uk was updated and more content added. The site attracts nearly 5,000 visitors per month, an increase of approximately 20% compared with last year.
- 6 A new **online support group** was established (following the closure last year by the service provider of the original forum) and currently has over 150 active members.
- 7 **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.
- 8 The Board approved the launch of local **PKD Support Groups** and a charter developed by Margaret Pope, trustee.
- 9 The charity continues to develop its **relationships** with other organisations providing services to renal patients, namely the Department of Health, 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.

At the end of the year, the trustees were very saddened by the death of a former chairman and treasurer of the charity, Dr Peter Lockyer. Peter was dedicated to the work of the charity and gave unstintingly of his time and energy. He organised the

charity's first Patient Information Day and its first scientific conference in 2005 in Cambridge. Given his particular interest in PKD research in the UK, the trustees agreed to honour him with a Fellowship in his name (planned for 2007).

5. FINANCIAL REVIEW & NOTES TO ACCOUNTS

During 2006, total **income** was £44,285 (£51,702 in 2005).

The principal source of income is voluntary donations.

In addition:

- St George's Hospital Student Rag donated £15,000
- Awards for All awarded a grant of £5,000 to cover the costs of the July Patient Information event
- Otsuka Pharmaceuticals provided £2,610 towards the July event which was carried forward (with their permission) to the 2007 event.

We would like to thank all the individuals, their families, friends and colleagues for their generosity. 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 restrict 20% of all incoming unrestricted income to research. Consequently, funds carried forward for research at the year end were £29,460.

The charity incurred **expenditure** of £29,886 (£30,291 in 2005).

The charity had cash of £70,251 (£55,852 in 2005), which includes £32,304 total restricted funds, at the year end with sufficient resources to fund its proposed activities during 2007.

6. FUTURE PLANS

The following activities are planned for 2007:

- 1 4th annual PKD Patient Information event at the Queen Elizabeth Medical Centre in Birmingham
- 2 Launch of local Support Groups in Chester, Richmond and Moodiesburn
- 3 Publication of leaflets on specific PKD topics
- 4 Two issues of the PKD Newsletter
- 5 Re-development of the website (subject to grant funding)
- 6 Contribution from restricted funds towards a research grant awarded to Dr Albert Ong of Sheffield University by the PKD Foundation, named in honour of Dr Peter Lockyer

Approved and signed on behalf of the Board of Trustees

Tess Harris
Chairman

Date:

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

**THE POLYCYSTIC KIDNEY DISEASE CHARITY
STATEMENT OF FINANCIAL ACTIVITY 1 JAN TO 31 DEC 2006**

Registered Charity No 1085662

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
Ms Jane Pugh
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 DECEMBER 2006**

***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 1085662
STATEMENT OF FINANCIAL ACTIVITY FOR PERIOD 1 JAN TO 31 DEC 2006

INCOME AND EXPENDITURE ACCOUNT	Restricted Funds Research £	Restricted Funds Activities £	Unrestricted Funds £	Period Total £
INCOMING RESOURCES				
Donations, legacies and similar receipts			26,087.98	26,087.98
Donations, legacies and similar receipts - research	9,148.88			9,148.88
Grants		7,610.97		7,610.97
Activities to further the charity's objects			0.00	0.00
Other income			110.88	110.88
Activities to generate funds:				
Christmas Cards			993.88	993.88
Merchandise			332.80	332.80
TOTAL INCOMING RESOURCES	9,148.88	7,610.97	27,525.54	44,285.39
RESOURCES EXPENDED				
<i>Charitable expenditure in furtherance of objects</i>				
PKD Conference Costs		2,784.65		2,784.65
PKD Conference Planning & Speakers		1,982.14		1,982.14
Newsletter			1,941.48	1,941.48
Information leaflets			2,342.60	2,342.60
Design costs			356.87	356.87
Other Subscriptions			727.00	727.00
Database			337.00	337.00
Phone/Website			512.50	512.50
Equipment			0.00	0.00
Stationery/Consummables			490.76	490.76
Postage			281.82	281.82
Travel (Non Trustees)			270.23	270.23
Management & admin			1,500.00	1,500.00
Trustee Expenses			1,372.47	1,372.47
Other			338.95	338.95
<i>Cost of generating funds</i>				
Research	0.00			0.00
Fundraising			9,374.44	9,374.44
Christmas Cards			1,999.38	1,999.38
Merchandise			3,062.64	3,062.64
Just Giving			211.44	211.44
TOTAL RESOURCES EXPENDED	0.00	4,766.79	25,119.58	29,886.37
NET INCOMING RESOURCES	9,148.88	2,844.18	2,405.96	14,399.02
B/F 2005	£20,311	£0	£35,541	£55,852
C/F 2006	£29,460	£2,844	£37,947	£70,251