

THE POLYCYSTIC KIDNEY DISEASE CHARITY

REPORT OF THE TRUSTEES AND STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 DECEMBER 2005

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 5 May 2006

Ms Tess Harris, Chairman
Mrs Pam Hooley,
Ms Rebecca Murphy, Treasurer
Mrs Margaret Pope
Ms Jane Pugh

Other trustees who served during 2005

Mrs Gloria Fox – resigned 1 September 2005
Professor Steve Jeffery - resigned 1 December 2005
Dr Anand Saggar – resigned 1 September 2005

Dr Peter Lockyer resigned 14 February 2006 owing to ill health.

Medical advisers

Dr Anand Saggar, Consultant in Clinical Genetics, St George's Hospital Medical School
Dr Malcolm Phillips, Consultant Nephrologist (retired 2005), Charing Cross Hospital

Scientific advisers

Professor Steve Jeffery, Professor of Human Genetics, St George's University of London
Dr Peter Lockyer, The Babraham Institute

Professional advisers

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 of Trustees. They are all unpaid volunteers and may claim reasonable out of pocket expenses. In 2005 there were five ordinary meetings of the Board of Trustees (one via telephone conference) and no special meetings. The trustees also make extensive use of email communications between meetings.

The charity's activities are planned and carried out by the trustees and other unpaid volunteers. 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 was notified and had 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 2005, three trustees resigned including the chairman. A new chairman was appointed to serve from September 2005.

In September, the trustees agreed to establish a Scientific and Research Advisory Board to identify and recommend opportunities for research. Dr Anand Sagar was appointed as chairman.

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, whether by phone, email, in writing or in person
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

During the year, the charity achieved the following:

- 1 In January 2005, the charity co-funded, with the help of the PKD Foundation (USA) and the Novartis Foundation, a **2-day conference on 'Calcium, cAMP and the pathogenesis of Polycystic Kidney Disease'**. The programme focused on the molecular basis of PKD and the potential for therapeutic intervention based on latest research in the field. Experts from around the world met to review and share data and, in particular, discuss the status of the drug **Tolvaptan**, which was due to be trialled on humans after showing good results on reducing cyst growth in rodents.
- 2 The **2nd National Patient Awareness and Information Day** was held in the Nowgen Centre, Manchester in October. **More than 60 patients, families and friends** attended the event to hear speakers on topics such as:
 - a. Genetics and pathology of PKD
 - b. Brain aneurysms
 - c. Diet
 - d. Potential treatments and drug development
- 3 A **PKD General Information Leaflet** was printed and sent to a number of renal clinics inviting people to learn more about PKD and consider a donation.
- 4 The **PKD Newsletter** was published to approximately 1000 people who had registered by phone or email. The database is growing steadily as awareness of the charity grows.
- 5 The **PKD website** www.pkdcharity.org.uk was updated and more content added.
- 6 **Continued personal support** was provided by Pam Hooley, trustee, who operates the telephone helpline providing support and information directly to callers. In addition, 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 trustees, Tess Harris and Rebecca Murphy, attended the **US PKD Foundation conference**, with financial support from the Foundation. Content from the conference has since been used to update patient information on diet, blood pressure and research. The charity has continued its relationship with the US Foundation.
- 8 One trustee, Margaret Pope, began counselling courses in order to improve the delivery of the charity's support services and assist in the process of setting up PKD support groups around the UK.
- 9 Two trustees attended a conference organised by the Department of Health on progress in implementing the National Service Framework for Renal Services.
- 10 The charity has formed 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.
- 11 The charity began a **strategic review** with a 'brainstorm' session for trustees. Drafts of a strategy were produced but not concluded. The review will be continued in 2006.
- 12 The charity installed a new database (DonorBase) which can be accessed by all trustees via a remote login. It is used to make mailings more efficient and enable better sharing of information. The charity is registered under the Data Protection Act.

5. FINANCIAL REVIEW & NOTES TO ACCOUNTS

During 2005, total **income** was £51,601.99 (£21,480 in 2004), most of which was obtained from voluntary donations.

The charity is particularly grateful to its primary donors, the Murphy family. Their annual contribution of approximately £20,000, generated through their own fundraising efforts (notably an annual dinner) enables the charity to continue.

The PKD Foundation provided a grant of £8,000 towards the January conference.

Over £7,000 was raised in the London Marathon. Family and friends of Cameron Johnston raised £5,000. St George's Hospital Student Rag donated £5,000.

Following a successful application, the D'Oyle Carte Charitable Trust awarded a grant of £2,500 towards general costs.

As a result of increased charitable activities, the charity incurred **expenditure** of £30,291 (£4,015 in 2004).

Significant expenses included:

- Costs of running the January Conference (£11,500)
- Purchase of a Marathon bond (£6,500)
- Commissioning a grants' specialist to identify and write relevant applications (£5,000)
- Purchase of office equipment (£2,915)
- Payment to a fundraiser (£1,842) for preparatory work on a charity event in 2006
- An honorarium (£1,500) to Mrs Justina Wilkinson, the sister of Tess Harris, trustee, for managing the Information Day, populating and updating the new database, mailings and book-keeping (the honorarium was approved by the Charity Commission).

During the year, the trustees voted to restrict 20% of all incoming unrestricted income to research. At present, however, the charity has insufficient funding to provide grants of appropriate sizes.

The charity had cash of £55,852 (£42,714 in 2004) at the year end with sufficient resources to fund its proposed activities during 2006.

6. FUTURE PLANS

The following activities are planned for 2006:

- 1 PKD Information Weekend in Bristol – expanded from a day to enable wider participation and greater opportunities for sharing and interaction between participants.
- 2 Re-design of the PKD logo to help with awareness generation.
- 3 Publication of new information leaflets.
- 4 2 issues of the PKD Newsletter.
- 5 Further development of the website, including a web forum.
- 6 Start local 1-2 support groups.

- 7 Increased proactive fundraising, particularly through applications to grant-making bodies and foundations.
- 8 Recruitment of new trustees.
- 9 Formal 'launch' of the Scientific and Research Advisory Board.
- 10 Continuation of the strategic review.

Approved and signed on behalf of the Board of Trustees

Tess Harris
Chairman

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

Date:

THE POLYCYSTIC KIDNEY DISEASE CHARITY
STATEMENT OF FINANCIAL ACTIVITY FOR PERIOD 1 JAN TO 31 DEC 2005

Registered Charity No 1085662

Current Trustees:

T M Harris - Chairman
P Hooley
R Murphy
M Pope
J Pugh

Independent Examiner:

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

THE POLYCYSTIC KIDNEY DISEASE CHARITY

ACCOUNTS FOR THE YEAR ENDED 31 DECEMBER 2005

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

Report on the Accounts of the Charity for the year ended 31 December 2005, set out on pages 3 and 4

RESPECTIVE RESPONSIBILITIES OF TRUSTEES AND EXAMINER

As the charity's trustees you are responsible for the preparation of the accounts. You consider that the audit requirement of section 43(2) of the Charities Act 1993 (the Act) does not apply. It is my responsibility to examine the accounts and state, on the basis of procedures specified in the General Directions given by the Charity Commissioners under section 43(7)(b) of the Act, 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 Commissioners. 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 I do not express an audit opinion on the view given by the financial statements.

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
 - * to prepare accounts which accord with the accounting records and to comply with the accounting requirements of the Acthave 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.

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 2005

INCOME AND EXPENDITURE ACCOUNT					Notes
	Restricted Funds	Unrestricted Funds	2005 Total	2004 Total	
	£	£	£	£	
INCOMING RESOURCES					
Donations, legacies and similar receipts	18,161	33,441	51,602	18,014	Note 1
Activities to further the charity's objects					
Activities to generate funds					
Investment income			0	0	
Other income				3,466	
	18,161	33,441	51,602	21,480	
<i>Less cost of generating funds</i>					
Fundraising expenses		8,658	8,658	2,265	
TOTAL INCOMING RESOURCES	18,161	24,783	42,944	19,215	
RESOURCES EXPENDED					
<i>Charitable expenditure in furtherance of objects</i>					
Charitable activities		21,895	21,895	0	
Management & admin		7,734	7,734	1,750	Note 2
Trustee Expenses		662	662	0	
TOTAL RESOURCES EXPENDED	0	30,291	30,291	1,750	
NET INCOMING RESOURCES	18,161	-5,508	12,653	17,465	

STATEMENT OF ASSETS AT 31 DECEMBER 2005			
	Restricted Funds	Unrestricted Funds	Total Funds
	£	£	£
CASH FUNDS AT 31 DECEMBER 2004	2,150	41,049	43,199
CASH FUNDS AT 31 DECEMBER 2005	20,311	35,541	55,852

Note 1: Restricted Funds consists of 20% of all unrestricted donations plus other restricted donations.

Note 2: Management & Admin costs include honorarium (£1,500) paid to sister of trustee (agreed with Charity Commission)