

THE POLYCYSTIC KIDNEY DISEASE (PKD) CHARITY

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

FOR THE YEAR ENDED 31 MARCH 2010

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

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1. LEGAL AND ADMINISTRATIVE INFORMATION

Principal address:

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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 Barry Harpham
Ms Rebecca Murphy
Mrs Margaret Pope
Mrs Alison Sanderson (Resigned June 2010)
Mrs Christine Wallach

Scientific and Research Advisory Board (SCARAB)

Chairman: Dr Anand Sagggar, Consultant in Clinical Genetics, St George's Hospital Medical School

Medical advisors

Dr Anand Sagggar, 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

Mr John Francis (J & SR Francis Partnership)
110 Gloucester Avenue
London NW1 8HX

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 part-time project manager, a part-time fundraising manager and unpaid volunteers. In 2009-10 there were five ordinary meetings of the Board and no special meetings. The trustees make extensive use of teleconferencing and 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.

During the year, the trustees considered several ways to recruit new trustees and agreed that vacancies should be filled according to the needs/skills identified in the formulation of the 3 year strategy.

PKD Charity Strategy

At a meeting in October 2009, the trustees agreed an ambitious 3-year strategy to increase income to over £400,000 by 2014, enabling the charity to award research grants totalling £100,000 and to establish the ADPKD Registry. The primary strategic goals are to develop and support local group/family fundraising activities, encourage 'reactive' fundraising by individuals, promote regular giving by standing order, and to organise more 'planned' charity events.

Management and Administration

During the year, the charity contracted with a professional fundraiser, Julia Scott, MInst.F, to support the charity's fundraising activities with targeted applications to trusts and foundations.

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.

During the year, Dalma Fulesi an accountancy student, volunteered to take over the charity's book-keeping and prepare the accounts on an accruals basis going forward.

During the year, the charity became a member of the Fundraising Standards Board, providing reassurance to supporters, members of the public and other donors, and promoting best practice in fundraising.

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 especially all the friends and families who have raised funds for the charity throughout the years.

3. REPORT OF THE TRUSTEES

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 and in extreme cases weigh up to 10-12kg each.

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 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 researchers and the charity has intentions to gather and analyse data from a significant number of ADPKD patients to further such investigative research.

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 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. 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. .

4. WHAT WE DO

Our mission – described in our charitable objects - is:

1. To relieve people affected by Polycystic Kidney Disease, in particular by providing information, advice and support to affected patients and families.

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 UK-based researchers
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 2009-10

Patient support

1 We hold regular **ADPKD Patient Information Days** around the UK; these are critical opportunities to provide advice and support to patients, their families and carers, and generate interest with local nephrologists, renal nurses and geneticists. One Information Days was held during the year at the Sheffield Northern General Hospital in April 2009. We would like to thank Professor Albert Ong (Sheffield) and colleagues for arranging the venue and speaking on the day.

Topics covered included:

- a. Genetics and pathology of PKD
- b. Progression of the disease and preventive measures
- c. Brain aneurysms
- d. Diet
- e. Potential treatments and drug development
- f. Coping with PKD

Around 80 people attended the event. 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, and learn about research into future treatments and better understanding of PKD. **One patient commented: "It has made me face the future with a more positive outlook"; another said: "I gained a better understanding than from my GP or consultant".**

2 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.

3 The **PKD website** www.pkdcharity.org.uk was updated and more content added. The site attracted over 12,000 visitors during the year. Visitors can find out information, register for the newsletter and other information, and buy PKD merchandise direct from our e-shop.

4 The **Online Support Group** membership increased to nearly 500; content is reviewed for topics of interest; personalised advice is provided where necessary or requested.

5 The **telephone helpline** was transferred to a geographically-independent 0300 number and is operated by Tess Harris, trustee; around 30 calls a month are received at present. Tess Harris also deals with **emails** received via the website.

6 Margaret Pope, trustee, operates a **Support Group helpline** with the aim of helping people who want to meet up to discuss their condition in a supportive atmosphere, and to identify potential 'champions' who can run support groups at their local hospitals.

7 Medical questions that the helpline volunteers cannot answer with general advice are forwarded to a number of **medical advisors** for specific replies. We would like to thank our medical advisors for their fast and considerate responses.

8 Our **Facebook Fan page** continued to grow and provides both a communications and fundraising channel and a platform for posting patient support information.

Research

There is no government-funded research into either ADPKD or ARPKD, and the charity is unable to fund significant research in the UK owing to insufficient resources. We are however accumulating restricted research funds given in donations and the trustees have also 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 previous year, we had prepared a submission to the **Big Lottery Research Programme** to fund a Registry at a projected cost of £500,000 over 3 years. Unfortunately, the bid was not successful. However, we are in active discussions with interested medical professionals to establish a smaller registry in 2010-11 and look for sources of matched funding.

During the year, we agreed to organise an **2-day international scientific and medical conference in September 2010** and invite the world's leading clinicians and researchers to present the latest known science and genetics, updates on worldwide research and clinical trials, current and future treatments and therapies, and the hot issues in clinical management of adults and children.

We would like to record our thanks to the following members of the conference **Steering Group** for their help with planning this conference and supporting our registry efforts:

Dr Kate Hillman, Consultant Nephrologist, Manchester Royal Infirmary

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

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

Dr Peter Harris, Professor of Biochemistry/Molecular Biology and Medicine in the Division of Nephrology and Hypertension, Mayo Clinic, Rochester, USA

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 Saggarr, FRCP, St George's Hospital

Dr Richard Sandford, PhD, FRCP, Addenbrooke's Hospital

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

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

Professor Pat Wilson, Professor of Medicine, UCL Medical School Centre for Nephrology, Royal Free Hospital

Awareness

1 In October 2009, the charity exhibited at the annual **NKF Conference** in Blackpool. We would like to thank the NKF for providing the space free of charge.

2 In March 2010, to coincide with **World Kidney Day**, the charity organised a 'Collecting Tin Day' and several volunteers raised funds in public places.

3 The charity continues to strengthen its relationships with other organisations providing services to renal patients, namely the Department of Health, NHS Kidney Care, the National Kidney Federation, Kidney Research UK and the Blood Pressure Association. We 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.

4 The charity is a member of the **National Voices** umbrella organisation (formerly LTCA) and the **Genetic Alliance** (formerly Genetic Interest Group).

5 In early 2010, the charity became a founder-member of the newly-formed **Ciliopathy Alliance UK**, established to share knowledge and understanding of diseases caused by defects in cilia function (of which PKD is one), promote awareness of ciliopathies and the respective patient organizations, encourage collaborative research and facilitate where possible and apply for research funding from government, trusts and foundations

6 In June 2009, Tess Harris and Dr Anand Saggar were invited by Novartis to attend a meeting of **European PKD patient organisations** and in August, 2009, Tess Harris was invited by Novartis to present a personal 'PKD patient story' at a pharmaceutical conference. Novartis at that time had a drug in clinical trials in France, Germany and Switzerland (this trial unfortunately failed later).

7 In October 2009, Tess Harris was invited by the **PKD Foundation** to a meeting with the European patient groups to discuss the formation of a EuroPKD Alliance to collaborate where possible on EU-wide research initiatives. Discussions are still ongoing as to the best way to cooperate.

Fundraising

The charity organised several planned events and activities in 2009-10:

1 In April 2009, we held our first major fundraising event – an Abseil the day after the Patient Information Day in April 2009.

2 10 runners applied for places in the Manchester 10k race in May 2009.

3 We held the first PKD Charity Raffle in December 2009.

4 We expanded our range of charity merchandise.

5 We formally launched our 'Friends' Scheme in Spring 2010 to stimulate regular giving.

6 We participated in the FSI UK-wide Small Car Draw.

6. OUR FUTURE PLANS

We will continue with our regular activities during 2010-11, building on experience and success with planned events, in particular, we will:

1 Hold a PKD Patient Information event at the Newcastle Royal Infirmary in April 2010

2 Hold a PKD Patient Information Day at St George's Hospital in September 2010

3 Publish two issues of the PKD Newsletter

4 Provide ongoing support by phone, email, support groups and website

5 Continue to develop and support local/family groups in their fundraising and organise more 'planned' runs and activities.

In addition, we will:

6 Hold an International Scientific and Clinical Conference on 23-24 September 2010

7 Recruit additional trustees

8 Make our first research grant award

7. FINANCIAL REVIEW & NOTES TO ACCOUNTS

During the 12 months 1 April 2009 to 31 March 2010, total income was **£63,938** (£37,231 for the 12 months ended 31 March 2009). This significant increase of 72% resulted from increased voluntary donations arising from the implementation of our new strategy.

The charity incurred expenditure of **£48,847** (£31,303 for the 12 months ended 31 March 2009).

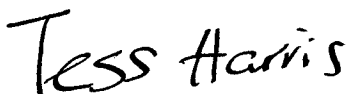
The trustees considered that the charity had sufficient reserves at the year end to fund its proposed activities during 2009-10.

Consequently, the trustees voted to restrict £32,000 from the charity's unrestricted and restricted reserves towards a 3 year research grant in support of the establishment, management, expansion and maintenance of a 'PKD Bioresource Bank'. The grant was awarded after the end of the financial year to Professor Pat Wilson, Professor of Medicine, UCL Medical School Centre for Nephrology, Royal Free Hospital.

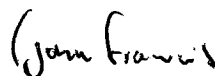
Risk Management

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
Chairman



Mr John Francis (J & SR Francis Partnership)
Independent Examiner
110 Gloucester Avenue
London NW1 8HX

25 October 2010

THE POLYCYSTIC KIDNEY DISEASE CHARITY
STATEMENT OF FINANCIAL ACTIVITY 1 APR 2009 TO 31 MAR 2010

Statement of financial activities
Year to 31 March 2010

	Notes	Unrestricted funds £	Restricted funds £	2010 Total funds £
Income and expenditure				
Voluntary income				
Activities for generating funds	1	57,157	6,330	63,487
Investment income		186	-	186
Incoming resources from charitable activities		<u>265</u>	<u>-</u>	<u>265</u>
Total incoming resources		57,608	6,330	63,938
Resources expended				
Cost of generating funds				
Cost of generating voluntary income	2	22,525	-	22,525
Fundraising trading costs	3	6,921	-	6,921
Investment management costs		<u>-</u>	<u>-</u>	<u>-</u>
		29,446	-	29,446
Charitable activities				
Research		-	-	-
Awareness and education	4	4,121	-	4,121
Patient support	5	<u>14,238</u>	<u>-</u>	<u>14,238</u>
		18,359	-	18,359
Governance costs		1,042	-	1,042
Total resources expended		48,847	-	48,847
Net incoming resources for the year		8,761	6,330	15,091
Statement of total recognised gains and losses				
Net movement in funds		8,761	6,330	15,091
Fund balances brought forward at 1 April 2009		49,580	38,822	88,402
Fund balances carried forward at 31 March 2010		58,341	45,152	103,493
Fund transfer to ADPKD Bioresource Bank Fund	-	32,000	32,000	-
Fund balances carried forward at 31 March 2010		26,341	77,152	103,493

**THE POLYCYSTIC KIDNEY DISEASE CHARITY
ACCOUNTS FOR THE YEAR ENDED 31 MARCH 2010**

Balance sheet		£
as at 31 March 2010		
Fixed assets		
Tangible assets	<u>390</u>	
	390	
Current assets		
Stocks	209	
Debtors	10,757	
Cash at bank and in hand	<u>92,137</u>	
	103,103	
Creditors		-
Net assets		103,493
Represented by:		
Funds and reserves		
Restricted funds	45,152	
ADPKD Bio-resource Bank Grant Fund	32,000	3 year award start 1/11/2010
Unrestricted funds	<u>26,341</u>	
Total funds	103,493	

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

NOTES

1 Voluntary income	£	£	£
	Unrestricted	Restricted	Total
Activities for generating funds			
Donations and gifts	25,195	5,966	31,161
Just Giving	12,521	-	12,521
Fundraising Events	4,645	-	4,645
Bequests and legacies	2,308	364	2,672
Card Aid	3,710	-	3,710
Shop income	884	-	884
New Year's raffle	1,727	-	1,727
Trusts/Foundations	1,950	-	1,950
Gift Aid	4,217	-	4,217
	<u>57,157</u>	<u>6,330</u>	<u>63,487</u>
2 Cost of generating voluntary income			
Fundraising staff	15,092		
Direct event costs	2,993		
Travel, subsistence	488		
Communication, postage	2,739		
Materials, equipment	451		
Fundraising misc.	762		
	<u>22,525</u>		
3 Fundraising trading costs			
Merchandise	2,857		
Card Aid	3,164		
Raffle	900		
	<u>6,921</u>		
4 Awareness and education			
Newsletter and website (50%)	3,919		
Administrative expenses	202		
	<u>4,121</u>		
5 Patient support			
Staff cost	7,831		
Travel and subsistence	609		
Newsletter and website (50%)	3,919		
Administrative expenses	1,879		
	<u>14,238</u>		

**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) and that an independent examination is needed.

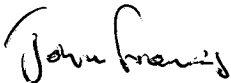
It is my responsibility to:

- 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), 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:

1. 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
2. to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.



Mr John Francis (J & SR Francis Partnership)
110 Gloucester Avenue
London NW1 8HX

25 October, 2010