

IMPROVING THE LIVES OF EVERYONE AFFECTED BY POLYCYSTIC KIDNEY DISEASE

Our year in review

Trustees' Annual Report – 1 April 2019 to 31 March 2020



ANNUAL REPORT AND ACCOUNTS 2019-2020

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REFERENCE AND ADMINISTRATIVE INFORMATION

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Polycystic Kidney Disease Charity

Registered charity in England and Wales
Number 1160970

Registered charity in Scotland
Number SC047730

A company limited by guarantee
Registered company in England and Wales
Number 9486245

Directors* and Trustees who served during the year and to the date of this report

Mr Alan Greenberg (Chair)
Mr Jordan Adams (appointed Jul 2019)
Mrs Alison Carter (Treasurer)
Mr Raj Johal
Ms Rebecca Murphy-Peers
Mrs Karen Stapleton (appointed May 2019)
Mr Adrian Tinsley
Mr Nicholas Tracey
Mrs Elizabeth White (appointed May 2019)
Professor Patricia Wilson

Research Advisory Board

Professor Patricia Wilson (Chair)
Ms Sanela Becar (Lay Member)
Professor Daniel Gale
Dr Richard Sandford

Professor John Sayer
Dr Manish Sinha
Professor David Wheeler

Management & administration

Ms Tess Harris, Chief Executive
Mrs Madeleine Martin, Fundraising Manager
Mrs Susan Muirhead, Community Support Manager
Mrs Jane Pugh, Community Engagement Manager

Patrons

Sir Vince Cable
Professor Albert Ong
Dr Anand Saggar
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*The directors of the charitable company (the charity) are its trustees for the purpose of charity law.

TRUSTEES ANNUAL REPORT & DIRECTORS' REPORT

The Trustees, who are also directors of the Charity for the purpose of the Companies Act, present their annual report and financial statements of the Charity for the year ended 31 March 2020. The accounts comply with the Charities Act 2011, Companies Act 2006 and the trust deed, and follow the recommendations in Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

The Trustees confirm that they have complied with the duty in section 17 of the Charities Act 2011 to have due regard to the public benefit guidance published by the Charity Commission in determining the activities undertaken by the Charity.

Chair's report

I am pleased to report that during the year, thanks to the generosity of our supporters and volunteers, we were able to continue our charitable work which makes a difference to patients and their families. Our focus for the 2019-20 year was to accelerate our impact, leverage our influence and bring our community together.

Our ambitions were on track until March 2020 when the arrival of the Coronavirus (COVID-19) caused a significant review of our strategy and activities.

Until the Covid-19 pandemic hit we had made significant progress in our objectives. We had increased our Income and successfully applied for a 5 year grant from the National Lottery Community Fund to help deliver and extend our PKD positive Peers programme. Very significantly we signed a Memorandum of Understanding with Kidney Research UK, to form a collaborative partnership targeting ambitious progress towards improvement in PKD patient outcomes over the next ten years, through a joint research programme.

We understand that Covid-19 will impede our progress but we are focussed on maintaining our momentum and supporting the PKD Community whilst ensuring we manage our finances in a conservative manner.

Over the next few pages you can read more about the charity's progress during 2019-20. We are unable to do our work without the generosity of those who donate money or give time: including patients and families affected by PKD, their colleagues and friends; the bereaved and those who give in memory of those who die from PKD; the healthcare professionals and researchers; our partners and foundations; our trustees and staff.

Alan Greenberg, Chair, Board of Trustees
16 December 2020



ABOUT US

The Polycystic Kidney Disease (PKD) Charity is the only UK charity solely dedicated to improving the lives of children, adults, families and carers affected by **polycystic kidney disease** (PKD).

Our charitable objects

To promote health and to relieve those persons suffering from or affected by PKD with a view to improving their conditions of life, in particular but not exclusively by:

- Funding research into determining the causes of PKD and into discovering treatments and a cure, with any useful results of such research being available to the public;
- Promoting awareness of PKD through the production and publication of authoritative information for the general public and health professionals about the medical, healthcare and related aspects of PKD; and
- Organising patient, family and carer information, education and support events across the UK and offering personal support to patients and their families.

Our mission

We want to improve the lives of everyone affected by PKD. We want to give hope for the future. We want to make PKD irrelevant and ultimately curable.

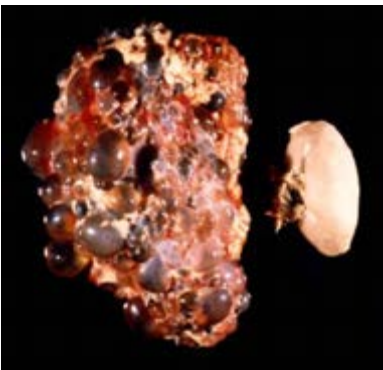
The PKD Charity was formed in 2000 by a PKD patient and a genetics consultant. Throughout the past 20 years, the majority of trustees and staff have been either PKD patients or family members. We understand the experiences and challenges of the estimated 70,000 people – children and adults – and their families in the UK coping with PKD on a daily basis.

The continuing challenge of PKD

PKD is an incurable, systemic genetic condition that causes kidney failure and damages other organs. There are two forms of PKD: **autosomal dominant polycystic kidney disease** (ADPKD), the most common inherited kidney disease and fourth cause of kidney failure worldwide; and the rare **autosomal recessive polycystic kidney disease** (ARPKD).

Of the 800,000 babies born a year in the UK, we estimate that 800 – over 2 a day - could have ADPKD (based on 1 in 1,000 prevalence) and 20-40 could have ARPKD (1 in 20-40,000 prevalence). As an inherited condition, PKD affects not only the individual but also their immediate family. It's a lifelong condition that can start to present even before birth.

ADPKD causes multiple fluid-filled cysts to develop, grow and multiply from conception in both kidneys resulting in kidney growth and progressive kidney failure. In many patients, cysts also form in



the liver, pancreas and other organs. Both kidneys can grow immensely, up to 100 times normal size (see image on left of ADPKD kidney compared with normal kidney). The brain and heart can also be damaged. Individuals with ADPKD will often have directly affected family members, parents and siblings, sometimes over several generations.

The majority of patients with ADPKD will have complete kidney failure by age 60, necessitating renal replacement therapy (RRT) to stay alive – this involves either dialysis or (if feasible) a kidney transplant. Nearly 300 kidney transplants are performed annually. Some people will require nephrectomies (kidney removal) due to organ size and frequent disabling cyst infections. Over 20 adults annually will also need a liver transplant owing to massively cystic livers. Some families are prone to brain aneurysms, which can fatally rupture if not discovered and treated. Acute and chronic pain is common throughout life. As ADPKD progresses, individuals experience complications such as high blood pressure, infections, bleeding, bowel and bone disorders, gout and kidney stones. [Read more about ADPKD on the PKD Charity website.](#)

ARPKD is often diagnosed during pregnancy. Unfortunately, 1 in 3 babies will die before birth owing



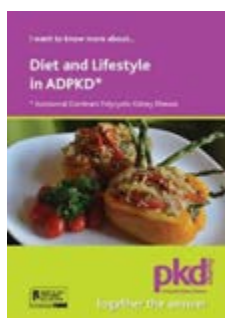
to the rapid growth of cystic kidneys preventing lung development. The babies who survive sometimes experience early kidney and liver failure. They may need life-saving dialysis before transplant and about a third have impaired growth during childhood. Some children may need kidney or liver transplants in later life. Despite this, many children do survive to adulthood with mild forms of ARPKD, although their kidneys and livers can be

impaired. ARPKD patients frequently have very high blood pressure and are prone to liver-related problems such as bile duct infections and enlarged spleens. [Read more about ARPKD on the PKD Charity website.](#)

What we aim to do

We want everyone affected by PKD to have the best quality of life, despite the complications and sometimes life-threatening nature of PKD. Being diagnosed with PKD is usually a shock, even if there are known family members with the condition. People report feeling isolated and overwhelmed by psychosocial concerns for their own future, their children and family members. ADPKD patients often feel ‘genetic guilt’ because there is a 1 in 2 risk of passing on ADPKD. Families affected by ARPKD have to cope with often devastating consequences of the disease including possible early bereavement or the long-term implications of caring for a child with potentially life-threatening kidney and/or liver failure.

We produce website content, leaflets and publications about PKD, reviewed by medical experts, to NHS Information Standard principles. These provide information and reassurance for patients and help educate medical professionals, leading to better healthcare and earlier diagnosis.



Diet and lifestyle is the number one topic on our website, viewed by 1 in 10 people who visit.

People with PKD are frequently confused about the best diet to follow. They want to know what they eat or not to help them manage their condition. Our fact sheet is written by renal dietitians who are able to provide the latest evidence-based best practice.

We fund medical research – nearly £400,000 since 2008 – to further understanding of the causes of PKD, identifies possible treatments and makes patients’ lives easier and more comfortable. This is extremely important to our community; patients and families consistently encourage and support our research work, which they hope will ultimately identify a cure for PKD.

There have been major advances in understanding the genetic and biological nature of PKD in the past 40 years. The clinical characteristics are well known, but there is a wide variability of disease expression owing to genetic heterogeneity and external factors not fully understood. For example, it is not unusual to see a significant difference between ages of kidney failure in ADPKD family members (who have the same PKD mutation). Therapies to modify and slow down progression in ADPKD are under study. However, there is only one drug (tolvaptan) which, in trials, slowed kidney cyst growth and is now licensed in the UK for a selected group of ADPKD patients. There are no disease-modifying therapies for ARPKD and very few studies worldwide owing to the small number of patients affected and disease variability. Dialysis or kidney/liver transplant are at present the only life-maintaining treatment when organs fail. Our aim is to support and fund more ADPKD and ARPKD research in the UK.

We represent the views and voices of patients, families and carers to UK healthcare professionals, NHS England and policy makers. We seek to educate pharmaceutical firms with an interest in PKD to ensure that they understand patients’ needs and the PKD burden. Where appropriate, we work in partnership with other charities and umbrella groups. We also endeavour where possible to inform the general public about PKD.

Despite being a common kidney disease, few people seem to have heard of ADPKD and awareness amongst GPs is known to be low. ARPKD is rarely seen and diagnosis can be a challenge, especially in pregnancy. We aim to raise awareness of the impact and burden of both conditions through authoritative information and targeted communications.

PERFORMANCE AND ACHIEVEMENTS DURING 2019-20

Last year, we outlined our main aims for 2019-20:

- To publish the Top Ten ADPKD research priorities in early 2020 – enabling us to set a robust patient-led long-term research agenda for ADPKD.
- To develop a collaborative research programme with Kidney Research UK to accelerate research into new treatments for both types of PKD.
- To work on developing partnerships with other organisations (UK and international) to improve patient care and health outcomes.
- To continue providing our blended range of Support Services – offering practical, emotional and social support wherever people need it, online, by phone, webinars, meet-ups.
- To continue holding Information and Support Days – in particular increasing the number of events for ARPKD families.
- To update our website and refresh the content based on input from our community.
- To grow our engagement with hospitals with the long-term aim that all PKD patients will be aware of the charity and the support we offer.
- To develop and expand our fundraising activities outside our community – in particular by applying to trusts and foundations for our support services.

ADPKD Research Prioritisation initiative

We had launched the ADPKD Priority Setting Partnership (ADPKD PSP) in 2019, in association with the James Lind Alliance (JLA).

The aim of the ADPKD PSP is to identify the unanswered questions about ADPKD from patient and clinical perspectives and then prioritise those that patients and clinicians agree are the most important. We formed a Steering Group of patients, carers and healthcare professionals, chaired by a JLA facilitator. Over 100 uncertainties were gathered from published sources which were shortlisted into 35 questions. We published a survey end 2019 and had anticipated concluding the PSP by March 2020 for a public launch in June. However, the survey was paused in early March owing to COVID-19 and completion has been rescheduled with an anticipated publication date in early 2021. Visit our website to read more <https://www.pkdcharity.org.uk/research/proritising-adpkd-research>

Collaborative research partnership programme with Kidney Research UK

In February 2020, we signed a Memorandum of Understanding with Kidney Research UK, to form a collaborative partnership targeting ambitious progress towards improvement in PKD patient outcomes over the next ten years, through a joint research programme. Our strategic aims are to:

- Increase our understanding of current and new biological pathways, develop new models and biomarkers to study the disease, and identify potential targets and therapeutic approaches.
- Explore the potential around genetics and cell therapies, genomics and use of data resources including RaDaR (UK Rare Renal Registry).
- Support the progression of evidence through to clinical application, as it develops in the coming years.

- Increase our understanding of complications and develop new approaches towards treatments.

We had intended to announce the partnership at UK Kidney Week in June 2020. However, the announcement was postponed owing to COVID-19 until September 2020. Visit our website to read more <https://www.pkdcharity.org.uk/research/pkd-charity-kidney-research-uk-research-partnership>

Support services for people and families affected by PKD

We continued to provide our ‘blended’ range of Support Services – called the PKD Positive Peers Programme - offering practical, emotional and social support wherever people need it, online, by phone, webinars, meet-ups.

In December 2019, we received a 5-year grant of £280,845 from the National Lottery Reaching Community Fund, which has enabled us to:

- employ a Community Support Manager
- fund future educational events and webinars
- develop and publish peer-reviewed, evidence-based health information
- fund helpline and peer support activities
- expand our services by reaching people unaware of the Charity and the support we offer
- implement a new ‘case management’ database to better manage and support our PKD community.



We are very grateful to the Community Fund for recognising the benefits we deliver from our programme and also for their continuing support following the major change in our operations owing to COVID-19.

During the year, we updated and created **health information factsheets**, following our established editorial process (NHS Information Standard principles), involving lay and expert readers’ panels who provide constructive feedback during the process.

These factsheets are freely available directly from the website or from links in online support groups, and distributed at educational and awareness events. Healthcare professionals download and can order printed booklets to give to their PKD patients during clinic appointments.

As in previous years, the most popular factsheets are ‘Diet and Lifestyle’, ‘Managing Pain’ and ‘Polycystic Liver Disease’



We held **ADPKD Information and Support Days** in Bristol, Exeter and London, attended by over 300 patients and family members in total. Sessions include talks by kidney doctors, nurses and patients. Each event includes workshops to allow small groups to discuss in detail matters such as coping with ADPKD, pain, diet and lifestyle.

We ask attendees 3 questions in our feedback forms to assess the impact of these events:

- Has your knowledge of ADPKD increased today?
- Do you feel more able to manage PKD as a result of attending today?
- Do you feel more positive about PKD after today?

The majority felt more informed, confident and positive. Verbatim quotes included:

“For me every bit was useful. I am a new patient with no family history of the disease so my knowledge was very limited. I have found since my diagnosis that the hospital consultants are so short on time that I never feel heard or understood or have the platform to ask or find out what I need to know. I also found finding out I had the disease quite frightening as I had just given birth to my daughter and so was a new mum. It was in the weeks following that I learnt I had PKD. Being able to speak to the speaker who specialised in maternity care of PKD patients was really great. But also the speaker on the psychological impact of the disease struck a chord with me too. It was really great - thank you. (PKD patient)

“I am very glad I came to this brilliant day. I learnt a lot and glad to see such passion and expertise on the disease.” (PKD patient)

“A better understanding of concerns of the PKD patient population/community and knowledge of the support available for patients. This will be really useful in my practice.” (Healthcare Professional)

We held an **ARPKD Family Day** at the Evelina Children’s Hospital, London for 25 families, supported

by an expert team of specialist paediatric doctors, nurses and scientists. We provided entertainment and supervised care to the children whilst the parents heard talks from the experts.



Photo permission provided

We learn from every event and use the feedback to improve subsequent events. Unfortunately, in March 2020, owing to COVID-19, we cancelled all future face-to-face events and began to plan virtual future educational events.

We continued to provide **personalised support by phone, email and our online support groups**. ‘Support’ ranges from giving non-medical information or signposting to relevant materials (on our PKD Charity site or approved 3rd party sites) to ‘listening’.

“I know you are there very much appreciated that you were there, those first few weeks was very emotional and hard and I was glad you were there ” (Newly diagnosed PKD patient)

Our Facebook groups grew during the year and became an invaluable source of mutual support, particularly in March when it became apparent that COVID-19 meant a large number of our community would be designated ‘extremely clinically vulnerable’ and have to ‘shield’. We increased our volunteer moderators to enable us to provide nearly 24/7 moderation.

“Being a member of the PKD group is like having the foundations to your home. It supports you, is always there for you and you always feel welcome”. (PKD patient)

On average, one person a day rings the **charity helpline number**. However, in March 2020, calls tripled in volume owing to COVID-19 and we extended our opening hours to include evenings and weekends.

The **webchat** on our website responds to a visitor a day, acting as a 'triage' service, handling simple requests – such as providing information about fundraising or signposting to information pages. Our closed Facebook groups are very active with an increase in 45% of message posts in last 12 months. We monitor and moderate all posts, with support from trained volunteers.

During the year, 26 local Meetups took place, including new meetups in Manchester, Reading, South Shields, Norwich, Taunton, Totnes and West Lothian in addition to the existing meets in Bristol, Elgin, Falkirk, London and Southend on Sea. Trained volunteers host the meetups. Post-meetup evaluation shows that people feel better informed and 'listened to'. In March 2020, we cancelled all future Meetups owing to COVID-19 and began to explore the possibility of virtual meetups.



We held 8 support **conference call service** on specific topics such as 'Newly Diagnosed', 'Tolvaptan', 'Dialysis'. The calls are held in the evening for up to 8 people, facilitated by trained volunteer peer supporters.

"I just want to say a massive thank you to everyone sharing their experiences & yourselves for organising it". (PKD patient)

Our trained **peer supporters** continued to support about 10 patients one-to-one by phone throughout the year.

We three **webinars** during the year: 'Living Well with Kidney Disease and the Emotional Impact of COVID', 'ADPKD in Children' and 'Ketosis & Crystals: Can Diets Help Treat PKD?'

A medical expert presented each webinar live and the recordings can be viewed for free on the PKD Charity website or [YouTube channel](#).



The PKD Charity **website** continues to attract a high number of visitors: two thirds from the UK and the remainder from around the world. During the year, the most visited pages were Diet, Pain, Urinary Tract Infections, Kidney Stones and Polycystic Liver Disease. In March 2020, we published two blogs on COVID-19: one focused on adults with PKD, the other focused on children with ARPKD. The first blog rapidly became the most visited page on our website, attracting nearly 3000 on 23 March when UK-wide lockdowns were enacted. We updated the blogs frequently, sometimes daily and will keep them active on the site for the foreseeable future.

Our volunteers are crucial. We have continued to benefit from a strong relationship with our loyal volunteers and we hugely appreciate the time and commitment they willingly give. Their sharing of

personal experiences in invaluable to others going through the PKD patient journey.

Covid-19 impacted greatly on our activities from March 2020. Many of our volunteers are clinically extremely vulnerable and were required to shield - as were 3 out of 4 staff. Likewise, many of our community were classed as clinically vulnerable. This put a huge demand on our helpline, website and webchat as people sought clarity of government guidelines or shared their concerns.

Research activities during 2019-20

Grants awarded

During the year, the Research Advisory Board recommended three projects for funding, which were approved by the trustees.

- £10,000 to Newcastle University (Dr Shalabh Srivastava) for a research project: *'Clinic to cell culture and cilia measurement – a deep phenotyping of Autosomal Dominant Polycystic kidney disease'*.
- £30,000 to UCL Centre for Nephrology Royal Free (Professor Patricia Wilson) to fund the PKD Biobank for a further 3 years. (Professor Wilson recused herself from the trustee decision.)
- £15,000 to Sheffield Kidney Institute (Professor Albert Ong) for a 2-year research project: *'Improving risk prediction for ADPKD in a multicentre European cohort (CYSTic 1)'*.

In March 2020, the trustees paused all research funding owing to COVID-19.

PKD and related research initiatives

We were delighted to hear that two research projects that we had supported through patient engagement had been funded:

- **'HIYA-PKD'**, funded by Kidney Research UK: Professor Paul Winyard and paediatric nephrology colleagues in England will study blood pressure in children and young people at risk of ADPKD (autosomal dominant polycystic kidney disease).
- **'EASE-PKD'**, funded by the National Institute for Health Research (NIHR): Drs Thomas Hiemstra and Ragada El-Damanawi from the University of Cambridge and Cambridge University Hospitals NHS Foundation Trust will seek to determine the - currently undefined - causes of chronic pain in ADPKD, pain intensity and how people respond to drug therapies. The study was initiated by the PKD Charity and developed in partnership with expert patients, clinicians, academic researchers and statisticians.

Unfortunately, at the date of this report, all research projects in the UK were suspended owing to COVID-19 and we do not yet have a date for their commencement.

The charity-funded PKD Biobank, curated by Professor Patricia Wilson at UCL Centre for Nephrology Royal Free Hospital continues to provide samples for use in PKD-related research. Over the period of 1st April 2019 to 31st March 2020 the PKD Charity Bioresource Bank provided a total of 160 samples for PKD research related for 6 different projects conducted in UK Universities and Medical Schools. This comprised 111 cell lines; 12 explant cultures; 12 tissues; 34 sections and 1 antibody.

During the year, the charity represented patients and families on two clinical study groups:

- The **ADPKD Clinical Study Group** (CSG) sits within the UK Kidney Research Consortium (UKKRC). Its members are multi-disciplinary and include patients. Its role is to stimulate ADPKD research, provide peer review to researchers and endorse worthwhile studies. The charity's CEO is the acting chair of CSG. [More information here](#). The CSG is also the RaDaR Study Group.
- The RaDaR **ARPKD Rare Disease Study Group**, chaired by Dr Larissa Kerecuk and Professor Patricia Wilson. [More information here](#)

The CEO is a member of the RaDaR Management Board.



The CEO continued to attend the monthly global **PKDOC** (PKD Outcomes Consortium) conference calls. PKDOC is seeking to establish clinical and patient reported outcomes for ADPKD research, which will be acceptable to the US FDA (Food & Drug Administration) and European Medicines Agency (EMA) regulators.

The charity participates in the **European ADPKD Forum** (EAF), a collaborative initiative launched in 2014 by PKD International, to raise awareness of ADPKD and its implications for patients, health services and economies in Europe — issues that are often under-recognised by many health stakeholders and policymakers. The CEO co-chairs the EAF with Dr Richard Sandford. In March 2019, the EAF held the first European ADPKD Summit in Brussels, attended by the PKD charity's CEO and Chair.

During 2019-20, the CEO represented the charity at conference calls and meetings of the **Kidney and Liver European Reference Networks** (ERNs). The ERNs are virtual networks involving healthcare providers across Europe, set up to address complex or rare diseases and conditions that require highly specialised treatment and a concentration of knowledge and resources. The impact of Brexit on continuing involvement is unknown.

The CEO continued to represent the charity on the international **SONG-PKD** Steering Group. SONG-PKD published a core outcome set for ADPKD for use in all research and trials during 2020.

Awareness and advocacy activities

The National Lottery Community Fund enabled the charity to part-fund a Community Engagement Manager.

During the year, we increased our engagement activities with our PKD community, primarily through online channels. We used key dates (such as Rare Disease Day) or topics (such as transplantation) to promote PKD. As a consequence, we increased our reach.



In **September 2019**, we launched **PKD Awareness Month**, inviting new and existing supporters to help raise awareness by changing and sharing their profile pictures, with 100+ agreeing to be featured on our Awareness Month gallery; 'The Faces of PKD'.



In early **March 2020**, we participated with the other leading UK kidney charities in **World Kidney Day**. This year we played a significant part in shaping the strategic and creative, direction of the campaign, working alongside the other kidney charities and for the first time, a creative agency that we helped to appoint. The outcome was a brand new campaign aimed at raising awareness of what kidneys do, what happens if they go wrong, and the emotional and physical impact chronic kidney disease and kidney failure has on your life.

The campaign branding - **'The BIG topic everyone's ignoring: Kidney's matter'** - was brought to life through a suite of digital and print assets for use in live events and across social media. In the weeks leading up to World Kidney Day we shared important kidney facts and stats on social media – achieving engagement rates from 5%-10% - with patient stories appearing in the press and on radio.

In addition, to illustrate that kidney disease is amongst us everywhere, and that for patients and their families there is no 'day off', we carried out our own unique World Kidney Day event – this consisted of several charity staff, the Chair and volunteers travelling around London landmarks and hospitals with the campaign's hero icon; a 6ft yellow kidney.



Throughout the year, we attended and participated in conferences, workshops and events relevant to kidney, liver, genetic and rare diseases.

During the year, we published and distributed two issues of the PKD Charity newsletter to approximately 3000 households.

Governance

The charity held 7 trustee meetings during the FY. Three new trustees were appointed to the board during 2019-20.

In July 2019, the charity held a General Meeting of members. A special resolution was passed amending the following articles of association of the charitable company to remove the need for an AGM:

- article number 13(1) and 13(2)
- article number 15(1)
- article number 15(3)
- article number 32
- article number 33
- article number 37(2)

The amended articles of association were submitted to Companies House.

Adult Safeguarding Courses were provided for all existing and new volunteers, including trustees.

COVID-19

It was clear in March 2020 that the pandemic would risk the charity's operations. Initial risks were assessed and the 2020-21 plan due to be signed off by trustees was reviewed. The Board implemented an emergency 6-month budget, based on revised activities plans changed notably by government guidance and national lockdown. All face-to-face events were cancelled. Fundraising was expected to be significantly affected by the cancellation of mass participation events. The Chair, Treasurer and CEO began to meet weekly to examine cash flow, review forecasts and control costs. Discussions were held with the National Lottery and will be continued during 2020-21.

Public Benefit

All charitable activities are undertaken to further charitable purposes for public benefit. The trustees confirm they have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives, and in carrying out and planning current and future activities respectively.

Fundraising

We thank all the amazing fundraisers who support the charity's work through a wide range of community activities and events: marathons, triathlons, runs, skydives, baking, school collections, etc. All fundraisers receive a pack with t-shirts and other items, plus sponsorship forms. Everyone is encouraged to sign Gift Aid declarations, an important income stream.

During the year, we employed one full-time Fundraising Manager and began to expand our fundraising activities. The majority of the charity's income is traditionally from individual donations from supporters and beneficiaries. However, during 2019-20, we hired an external consultant to assist with developing grant applications to raise funds from Trusts and Foundations.

Contribution made by volunteers

We acknowledge and thank all our volunteers for their commitment and enthusiasm in supporting the charity's activities. In particular, the trustees thank: the healthcare professionals, scientists and others who gave their time to speak at the patient information events and wrote or reviewed health information materials; supporters who proofread communication materials; and especially the phone and online peer supporters. In June 2019, we acknowledged publicly the contribution made by all volunteers during Volunteer Week.

Pro bono support

We acknowledge and thank:

- Microsoft, who provide software free of charge or at minimal cost.
- QuestionPro, who provide a free-of-charge survey platform.
- Michael Langdon, an IT consultant, who provided support for the charity's CRM database.
- Google (AdWords advertising grant).

Future plans

During 2020-2021, we intended to:

1. continue providing our blended support services by developing and scaling up the Positive Peers Programme, including implementing a new case management database/CRM system and processes
2. expand our community by engaging with and building partnerships with organisations and charities key to reaching people who are unaware of the charity
3. launch the research partnership with Kidney Research UK and form a joint research programme board
4. launch the results of the ADPKD research prioritisation initiative
5. implement a new CRM for more efficient recording of fundraising transactions
6. develop a new 3-year strategy

However, COVID-19 has severely affected all planned activities. We will use virtual channels and platforms such as Zoom and Teams to maintain our support activities as much as possible and expect to rely on digital technology and communications until it's safe for people with PKD to meet each other again.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Constitution

The Polycystic Kidney Disease Charity is a company limited by guarantee on 12 March 2015, Company

Polycystic Kidney Disease Charity | Registered charity in England and Wales (1160970) | Registered charity in Scotland (SC047730) | A company limited by guarantee

Registered company in England and Wales (9486245) | Registered address: 49-51 East Road, London, N1 6AH

Registration No 9486245 and is registered for charitable purposes with the Charity Commission, Charity Registration No. 1160970. The charity is governed by its Memorandum and Articles of Association. In the event of the Charitable Company being wound up, company members are each required to contribute an amount not exceeding £10.

Trustees

Trustees, who are also directors of the Charitable Company, are recruited and appointed by the other trustees. Most current trustees either have PKD or a family connection to PKD. They are unpaid volunteers and may claim reasonable out of pocket expenses. The charity's activities are planned and carried out by the trustees.

In 2019-20, there were 7 ordinary trustee meetings and one general meeting. The trustees make extensive use of teleconferencing and email communications.

All trustees are required to declare relevant interests and may be required to withdraw from trustee meetings.

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

PKD Research Advisory Board

During 2019-20, the PKD Charity Research Advisory Board (RAB) met to review grant applications. Members also contributed to new or updated patient information materials. Membership of the RAB was changed in April 2020.

Management and administration

The Trustees delegate the management of charitable activities and administration to a small team led by Ms Tess Harris (CEO). The trustees monitored performance at trustee meetings; the chair has regular phone and face-to-face meetings with Ms Harris.

Bookkeeping and accounts are carried out by PEM.

The charity is a member of the **Fundraising Regulator**, providing reassurance to supporters, members of the public and other donors, and promoting best practice in fundraising.

The charity is registered with the **Information Commissioner** and all supporters' and stakeholders' personal data are maintained securely according with the new GDPR (2018).

Membership of related organisations

The charity is a founder member of the **Kidney Charities Together** group of kidney charities, who meet to collaborate on campaigns such as World Kidney Day, and consider ways to work together on initiatives to improve the lives of all kidney patients.

The charity is a member of several UK umbrella organisations representing the interests of people with long-term conditions (LTC) or genetic diseases, including **Genetic Alliance, the Health and Social Care Alliance Scotland, Rare Disease UK, the Kidney Health Partnership, the Specialised Healthcare Alliance and the James Lind Partnership**. The charity engages with these organisations to ensure that the charity's aims and activities are known, recognised and taken into account. The charity regularly inputs into national consultations facilitated by these umbrella bodies.

The charity is a founder member of the **Ciliopathy Alliance**, which brings together patients, families, doctors and scientists with the aim of improving the quality of life for children and adults affected by ciliopathies – primarily genetic diseases caused by defects in the function and structure of cilia (microscopic organelles found in every human cell and vital to development). PKD is an important ciliopathy with ADPKD having the largest patient cohort. More information here: www.ciliopathyalliance.org

The charity is a member of **Befriending Networks**, the UK's leading resource on befriending whose accreditation was obtained during 2015.

The charity is a founding member of the **Kidney Patients Involvement Network (KPIN)**, which is committed to increasing the number of patients engaged with initiatives and harness enthusiasm across a wider kidney patient and carer population, improving involvement and engagement from minority and under-served groups.

The charity is a member of the **ABPI (Association of British Pharmaceutical Industry) Patient Organisation Forum**. The forum meets regularly to discuss issues such as joint working between patient organisations and pharmaceutical companies. More information here: <http://www.abpi.org.uk/our-work/patient-organisation-forum/Pages/default.aspx>

The charity is a founder member of **PKD International (PKDI)**, a global alliance of patient groups supporting people affected by all forms of PKD. These groups have similar aims to the PKD Charity. The CEO is the current President of PKDI (a voluntary role). More information here: www.pkdinternational.org

The charity is a member of **EURORDIS**, the European umbrella organisation of patient groups representing adults and children with rare diseases. More information here: www.eurordis.org

The charity is a founder member of **FEDERG**, the European Federation of Patient Groups representing rare and genetic renal diseases. More information here: www.federg.org

FINANCIAL REVIEW

Performance

During the 12 months to 31 March 2020, the charity's income was **£284,321** (2019: £237,460).

Expenditure on raising funds as a percentage of total incoming resources was 29% (2019: 25%). Research expenditure was **£63,527** (2019: £20,250). The increase in research expenditure is due to the approval of additional research grants and projects and the establishment of a priority setting partnership during the period. Research grants were funded out of restricted reserve funds and reserve funds designated for Research. The Charity's expenditure on charitable activities across Patient support, Awareness and Education was **£114,648** (2019: £89,124), which included information days, telephone support, online/chat support and expenditure on the peer support service. The increase in Patient support, Awareness and Education was driven primarily by costs incurred due to the employment of additional dedicated staff.

In total, the Charity expended **£286,089** (2019: £185,574), resulting in net outgoing resources for the year of **£1,768** (2019: net incoming resources of £51,884). Total fund balances at the year-end were **£303,458** (2019: £305,225) and all funds maintained a surplus position at the year-end (Note 15).

Public Benefit

All charitable activities are undertaken to further charitable purposes for public benefit. The trustees confirm they have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives and in carrying out and planning current and future activities.

Reserves

The Charity maintains a Reserves Policy to hold reserves equivalent to a minimum 3 months' ongoing expenditure, after covering current liabilities. As at the year end, the Charity had Undesignated Unrestricted Funds of £192,006 (2019: £150,336), equivalent to 8 months' total expenditure (2019: 9 months). The trustees considered that the Charity has sufficient reserves at the year-end and are of the view that the Charity continues to be a going concern. After year end, the trustees resolved to reallocate £96,246 from the Unrestricted General Fund to the Unrestricted Designated Research fund, to support future research initiatives (note 17). Had this reallocation been made at year end, the Undesignated Unrestricted Funds would have been equivalent to 4 months' total expenditure at 31 March 2020.

Risk Management

The trustees have overall responsibility for ensuring that the Charity is managing risk in a professional, responsible and constructive manner. This has involved identifying risks the Charity may face, assessing potential impacts and seeking to minimise them. Material risks for Charity include key person dependency on its Chief Executive, risk of loss of supporters, managing regulatory changes, and maintaining a surplus. The trustees continue to review succession plans and to survey the satisfaction of its beneficiaries and supporters, with a view to mitigating these risks. The trustees regularly review the Charity's risk management policies, which include data protection and safeguarding. The Charity is exposed to financial risks, such as loss of income, which it aims to mitigate by maintaining sufficient reserves while continuing to diversify fundraising, for example, by increasing grant funding.

Approved by the Trustees and signed on their behalf by

Alison Carter, CA, CPA, CFA

Trustee Treasurer

16 December 2020



Independent Examiner's Report to the Trustees of the Polycystic Kidney Disease Charity

Independent examiner's report to the trustees of The PKD Charity

I report on the accounts of the company for the year ended 31 March 2020, which are set out on pages 25-34.

Respective responsibilities of trustees and examiner

The trustees (who are also the directors of the company for the purposes of company law) are responsible for the preparation of the accounts. The trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) or under Regulation 10 (1)(a) to (c) of The Charities Accounts (Scotland) Regulations 2006 (the 2006 Accounts Regulations) and that an independent examination is needed. The charity is required by company law to prepare accrued accounts and I am qualified to undertake the examination by being a qualified member of Institute of Chartered Accountants in England and Wales. Having satisfied myself that the charity is not subject to audit under company law and is eligible for independent examination, it is my responsibility to:

- examine the accounts under section 145 of the 2011 Act and section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 (the 2005 Act)
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act
- to state 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 Commission and is in accordance with Regulation 11 of the Charities Accounts (Scotland) Regulations 2006. 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 no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the next statement.

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 386 of the Companies Act 2006 and section 44(1)(a) of the 2005 Act and
- to prepare accounts which accord with the accounting records, comply with the accounting requirements of the Companies Act 2006, section 44(1)(b) of the 2005 Act and Regulation 8 of the 2006 Accounts Regulations and
- which are consistent with the methods and principles of the Statement of Recommended Practice: Accounting and Reporting by Charities
- have 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

Charles Pickin
Fellow of Institute of Chartered Accountants in England and Wales
Harrison Jasper Ltd
Florance Lane
Groombridge TN3 9SH
16 December 2020



STATEMENT OF FINANCIAL ACTIVITIES - 1 APRIL 2019 TO 31 MARCH 2020

The notes on pages 27 - 34 form an integral part of these accounts.

	Note	Unrestricted funds £	Restricted funds £	2020 Total funds £	2019 Total funds £
Income and expenditure					
Income from donations, grants and legacies	2	234,478	41,548	276,026	233,651
Income from other trading activities	3	5,450	-	5,450	2,295
Investment income	4	2,844	-	2,844	1,514
Total incoming resources		242,773	41,548	284,321	237,460
Expenditure on raising funds					
Cost of fundraising	5	81,031	-	81,031	60,111
Non-charitable trading activities	5	3,020	-	3,020	1,625
		84,051	-	84,051	61,737
Expenditure on charitable activities					
Research and grants	6	48,753	14,774	63,527	20,250
Awareness and education		34,477	-	34,477	8,853
Patient support		53,674	26,497	80,171	80,271
		136,903	41,271	178,175	109,374
Other expenditure					
Governance costs	7	23,864	-	23,864	14,464
Total resources expended		244,818	41,271	286,089	185,574
Net incoming / (outgoing) resources for the year		(2,045)	277	(1,768)	51,884
Fund balances brought forward at 1 April	15	258,738	46,488	305,226	253,342
Net incoming / (outgoing) resources for the year	15	(2,045)	277	(1,768)	51,884
Transfers between funds	15	313	(313)	-	-
Fund balances carried forward	15	257,006	46,452	303,458	305,226

The statement of financial activities includes all gains and losses recognised in the year.
All income and expenditure is derived from continuing activities.

BALANCE SHEET AT 31 MARCH 2020

The notes on pages 27 - 34 form an integral part of these accounts.

	Note	Unrestricted funds	Restricted funds	2020 Total funds £	2019 Total funds £
Assets					
Fixed assets					
Tangible assets	11	-	-	-	-
Current assets					
Debtors	12	15,512	8,000	23,512	27,832
Cash at bank and in hand		252,090	119,702	371,792	396,876
Total current assets		267,601	127,702	395,303	424,708
Liabilities					
Creditors falling due within one year	13	10,596	63,750	74,346	87,482
Net current assets		257,005	63,952	320,957	337,226
Creditors falling due after more than one year	14	-	17,500	17,500	32,000
Net assets		257,005	46,452	303,457	305,226
The funds of the charity:					
Restricted funds	15	-	46,452	46,452	46,488
Unrestricted funds					
Designated	15	65,000	-	65,000	108,402
General	15	192,006	-	192,006	150,336
Total funds		257,006	46,452	303,458	305,226

These accounts are prepared in accordance with the special provisions of Part 15 of the Companies Act relating to small companies. For the year ending 31 March 2020 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies. The members have not required the company to obtain an audit of its accounts for the year in question in accordance with section 476. The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts.

Approved by the trustees on 16 December 2020
And signed on their behalf by
Alison Carter, CA, CPA, CFA, Trustee Treasurer



Notes to the Financial Statements for year ended 31 March 2020

1a Accounting Policies

The principal accounting policies adopted are as follows:

i) Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the United Kingdom and the Republic of Ireland (FRS 102) (Charities SORP FRS 102 second edition – effective January 2019) and the Charities Act 2011. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy or note.

ii) Going Concern

The trustees are of the view that the Charity holds sufficient funds to carry on for the next 12 to 18 months and that on this basis the assessment of the trustees is that the Charity is a going concern.

iii) Incoming Resources

All incoming resources are recognised once the Charity has entitlement to the resources, it is certain that the resources will be received, any performance conditions attached to the item(s) of income have been met or are fully within the control of the Charity and the monetary value of incoming resources can be measured reliably.

iv) Investment Income

Investment income is accounted for in the period in which the Charity is entitled to receipt. Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the Charity; this is normally upon notification of the interest paid or payable by the Bank.

v) Resources Expended

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably. All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category.

Governance costs principally comprise Trustees' meeting costs, accountancy costs, professional fees and an allocation of staff time.

vi) Grants

Provision is made for grants when the Trustees have made a binding commitment and this has been communicated to the applicant.

vii) Tangible fixed assets and depreciation

Depreciation is provided at rates calculated to write off the cost less the estimated residual value of each tangible fixed asset over its expected useful life. All fixed assets held currently have been fully depreciated.

viii) Current asset investments

Current asset investments represent cash investments maturing within one year and are shown at carrying value.

ix) Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid after taking account of any trade discounts due.

x) Pensions

Employees of the Charity are entitled to join The Peoples Pension, a defined contribution pension scheme. The Charity contribution is restricted to the contributions disclosed in note 8. Pension costs are allocated to activities in proportion to the related staffing costs incurred. The defined contribution pension scheme is managed by The Peoples Pension Trustee. The Charity has no liability beyond making its contributions and paying across the deductions for the employee's contributions.

xi) Creditors and provisions

Creditors and provisions are recognised where the Charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

xii) Funds Structure

Funds are established to provide financial resources for aspects of the Charity's activities. Some Funds were set up when the Charity received grants and donations that were made for specified purposes. Where conditions were made, the Funds set up are Restricted Funds. The names of most of the Funds convey the purposes for which they were established.

1b. Legal status of the Charity

The Charity is a company limited by guarantee and has no share capital. In the event of the Charity being wound up, the liability in respect of the guarantee is limited to £10 per member of the Charity.

	Unrestricted funds £	Restricted funds £	2020 Total funds £	2019 Total funds £
2. Income from donations, grants and legacies				
Donations and gifts	215,856	7,621	223,477	220,634
Trusts, foundations and grants	-	33,927	33,927	31,500
Gift Aid	18,622	-	18,622	9,516
Total:	234,478	41,548	276,026	233,650
3. Income from other trading activities				
Shop and other income	5,450	-	5,450	2,295
Total:	5,450	-	5,450	2,295
4. Investment income				
Interest income	2,844	-	2,844	1,514
5. Expenditure on raising funds				
Cost of fundraising	81,031		81,031	60,111
Cost of goods sold	3,020		3,020	1,625
Total:	84,051	-	84,051	61,736

6. Analysis of research and grants:

	2020 £	2019 £
Bio Resource Bank	30,000	-
ADPKD Research	14,774	10,000
ARPKD Research	-	10,000
Stars Together Birmingham Children's Hospital Registry	-	250
Priority Setting Partnership	6,637	-
Staff, subcontractor and other costs	12,116	-
Total:	63,527	20,250

7. Governance costs:

	2020 £	2019 £
Trustee meetings and governance	2,998	2,785
Accountancy and audit	10,330	9,625
Other professional fees	4,056	2,054
Staff costs	6,480	-
Total:	23,864	14,464

8. Employment costs:

The Charity established employment contracts during the year. Previously independent contractors were engaged. Total employment costs incurred during the year were as follows:

	2020 £
Wages and salaries	105,039
Social security costs	6,685
Pension contributions	1,506
Total:	113,229

Employment costs are allocated to the activities to which they relate in the Statement of Financial Activities. At as 31 March 2020, pension contributions of £460 were payable by the Charity. No redundancy or termination payments were made during the year. The average number of staff employed by the Charity during the year was 4. No employee received total benefits exceeding £60,000. Key management personnel of the Charity comprise the Trustees and the Chief

Executive Officer, the Support Services Manager, the Fundraising Manager and the Community Engagement Manager.
During the year, the key management personnel received total remuneration of £101,649.

9. Trustees remuneration and expenses

The Trustees were not remunerated by the Charity for their services as trustee during the year. Trustee expenses of £735 were paid by the Charity.

10. Taxation

The Charity is exempt from tax on income and gains falling within section 505 of the Taxes Act 1988 or s256 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects. No tax charges have arisen in the Charity.

11. Analysis of Movement of Fixed Assets

	2020
	£
	Office equipment
Cost	
At 1 April 2019	11,497
Additions / (Disposals)	-
At 31 March 2020	11,497
Accumulated depreciation	
At 1 April 2019	11,497
Charge for the year	-
At 31 March 2019	11,497
Net Book Value	
At 1 April 2019	-
At 31 March 2020	-

12. Debtors

	2020	2019
	£	£
Prepayments	14,649	18,197
Accrued income	8,863	8,000
Other debtors	-	1,635
Total debtors	23,512	27,832

13. Liabilities: amounts falling due within one year

	2020	2019
	£	£
Accruals and deferred income	10,596	11,005
Grant commitments	63,750	76,476
Total current liabilities	74,346	87,481

14. Liabilities: amounts falling due after more than one year

	2020	2019
	£	£
Grant commitments due after more than one year	17,500	32,000

15. Funds and reserves

Analysis of movements in restricted funds

<i>Restricted fund</i>	<i>Retained surplus 1 April 2019</i>	<i>Income</i>	<i>Expenditure</i>	<i>Transfer</i>	<i>Total funds 31 March 2020</i>
	<i>£</i>	<i>£</i>	<i>£</i>	<i>£</i>	<i>£</i>
Support Activities	-	2,000	-	-	2,000
ADPKD research	13,228	3,635	(14,774)	-	2,089
ARPKD research	24,377	1,473	-	-	25,850
Research	8,570	2,514	-	-	11,804
Royal Free Hospital biomarker	313	-	-	(313)	-
The National Lottery Community Fund – Positive Peers Programme	-	31,927	(26,497)	-	5,430
Total restricted funds	46,488	41,548	(41,271)	(313)	46,452

<i>Name of Restricted Fund</i>	<i>Description, nature and purposes of the fund</i>
Support activities	Support related activities, such as information days
Research	Research related to PKD
ARPKD research	Research related solely to ARPKD
ADPKD research	Research related solely to ADPKD
Royal Free Hospital biomarker	A project at the Royal Free Hospital for the identification of PKD related biomarkers
The National Lottery Community Fund – Positive Peers Programme	To fund a programme of face-to-face, online and telephone support for patients and families who are dealing with the traumatic and often devastating effects of PKD

Analysis of Movements in Unrestricted Funds

<i>Unrestricted fund</i>	<i>Retained surplus 1 April 2019</i>	<i>Income</i>	<i>Expenditure</i>	<i>Transfer</i>	<i>Total funds 31 March 2020</i>
	<i>£</i>	<i>£</i>	<i>£</i>	<i>£</i>	<i>£</i>
Designated research	65,000	-	-	-	65,000
Designated PKD bio-resource	13,402	-	(30,000)	16,598	-
Designated PKD registry	30,000	-	-	(30,000)	-
General fund	150,336	242,773	(214,818)	12,715	192,006
Total unrestricted funds	258,737	242,773	(244,818)	(313)	257,006

Name of Unrestricted Fund	Description, nature and purposes of the fund
Designated research	Designated to support research for PKD
Designated PKD Bio-resource	Designated to fund the Bio-Resource Bank at University College London
Designated PKD Registry	Designated to fund a project to create a PKD registry
General fund	The free reserves, after allowing for all other designated funds

16. Related Party Transactions

During the year, donations of £6,341 were received from Trustees.

Grants awarded to an institution with which a trustee is related, are as follows:

Trustee	Institution	Grant Awarded £
Professor Pat Wilson	University College London	30,000

The Charity established a casual worker contract with the daughter-in-law of a trustee. The trustee was not involved in the decision to appoint. The details are as follows:

Trustee	Employee	Total Remuneration £
Mr Alan Greenberg	Mrs Louise Greenberg	4,896

There were no other related party transactions.

17. Subsequent Event

After the year end, in July 2020, the Trustees resolved to reallocate reserves of £96,246 from the Unrestricted General Fund to the Unrestricted Designated Research fund. The reallocation was made to designate funds for future research initiatives. The table below shows the impact of the July adjustment on the year end position of the Unrestricted reserves funds.

Unrestricted fund	Total funds 31 March 2020 £	Transfer £	Total funds post July adjustment £
Designated research	65,000	96,246	161,246
General fund	192,006	(96,246)	95,760
Total unrestricted funds	257,006	-	257,006