

ARPKD Research News

The PKD Charity has awarded a grant of £24,000 over 3 years towards a PhD Studentship at the University of Wolverhampton, matched by a grant from the Arran Brown Foundation. Dr Evi Goggolidou, who will supervise the student, said: "Autosomal recessive polycystic kidney disease (ARPKD) is a rare form of PKD with variable disease severity and progression. We have identified a novel modifier gene called ATMIN. This award will enable us to study more thoroughly the genetic mechanisms of ARPKD and could help develop treatments that reduce its severity". More on this research in the next issue.

The Charity has also awarded £10,000 to fund a research nurse to enter data to the ARPKD RaDaR registry. Professor Pat Wilson said: "This will greatly enrich the depth of clinical information in the registry. We are also developing a standardised protocol and training to collect ARPKD patient samples for storage in the PKDC biobank. The protocol and enhanced data should expand and accelerate clinical research into ARPKD, increasing the potential for significant patient studies". Find out more about RaDaR here: pkdcharity.org.uk/about-arpkd/arpkd-patient-registry



Stephen Hancock received a kidney from a deceased donor

Organ Donation Opt-out Consultation

The UK government plans to change organ and tissue donation to an 'opt-out' system. Early in 2018, they invited the public, patients and health care professionals to give their opinions about this momentous change and to make suggestions about how the new system will work.

The consultation ended on 6 March. The government and the Department of Health are analysing the thousands of responses they received and will publish a report later in the year.

Below we give some background information about the current system.

Background on the organ donation system (at December 2017)

In England and Scotland, deceased organ donation is organised through a legal system of 'opt-in'. A person has to register their consent on the NHS Organ Donor Register (NHS ODR) to donate their organs in the event of their death. If a person dies with a suitable organ but is not on the ODR, specialist nurses in hospital ask the person's next of kin for explicit consent to donate.

In Wales, in December 2015, the Welsh government started a new

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Organ Donation Opt-out Consultation

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system with two forms of legal consent: 'deemed' or 'presumed' consent to donate from people who have not registered to opt-out of donating an organ; and 'express' consent by those who have registered to say they wish to be a donor. Next of kin and families are asked if they know whether the deceased would not have consented and families may object. However, the law should take precedence. This form of consent is also called 'soft opt-out' and is operated across Europe. It's believed that this system will increase the

numbers of donations and transplants in Wales but at present the system is too new to draw conclusions.

In July 2017, 23.6 million people were on the NHS ODR, more than one third of the UK's population. About 500,000 people die in the UK each year. However, only 1 in every 100 people die in circumstances where they can donate. NHS Blood and Transplant (NHSBT), who manage the ODR, discovered in 2016/17 that 177 families – 3 per week – of potential donors refused consent because "they were not sure whether the patient would have agreed".

The UK, for a number of reasons, has one of the lowest consent rates in the world. One reason seems to be that people don't discuss organ donation with their families. NHSBT surveys show more than 8 in 10 people support organ donation but only around 1 in 2 people have ever talked about it. The deceased's wishes aren't known and families refuse to consent

because they didn't know what their relative wanted.

The low consent rate and a national shortage of organs for donation means that there are more people waiting for transplants than organs available. Some people will die therefore before a suitable organ becomes available.

The public are supportive of an opt-out system. A poll by the British Medical Association (BMA) in early 2017 found that 2 in 3 members of the public supported the BMA's calls for the opt-out system in Wales to be extended to other parts of the UK. The government in Scotland has announced its intention to move to soft opt-out.

Sign up to the PKD Charity eNewsletter for regular updates.

<http://eepurl.com/R2Ssn>



The PKD Charity's Position.

The PKD Charity supports children, adults and families affected by polycystic kidney disease (PKD), a range of incurable, systemic genetic conditions. One form of PKD (autosomal dominant PKD) is the most common inherited and fourth leading cause of kidney failure, affecting an estimated 12.5m worldwide and 70,000 people in the UK. The other form of PKD is the rare ARPKD (autosomal recessive PKD), which is often diagnosed in pregnancy.

In the UK, about 1 in 8 adults and 1 in 20 children with a kidney transplant have PKD as the primary reason for kidney failure. We also think that about 1 in 16 adults on dialysis has ADPKD - many awaiting a transplant. In March 2017, there were about 5,000

adults and 80 children on the national waiting list for a kidney. The average waiting time for an adult is 870 days and about 260 days for children. We estimate that about 500 people on the waiting list (1 in 10) has PKD.

Furthermore, adults with ADPKD (autosomal dominant PKD) may experience longer waits owing to a lack of living organ donors caused by close relations also being affected by ADPKD and unable to donate.

Some children and adults with ADPKD and ARPKD will also require a liver transplant. In March 2017, 490 adults and 43 children were on the national waiting list for a liver transplant. We estimate that over 20 adults with PKD are currently waiting for a liver, with average waiting times of 1,000 days and up to 2,000 days. Unfortunately, adults with ADPKD have good liver functionality and

are not prioritised for transplant. Owing to the long waiting times and low probability of receiving a transplant, it's believed that many adult ADPKD patients are not even put forward for liver transplantation.

Additionally, those in black and minority ethnic (BAME) communities generally experience longer waiting times and lower consent rates from next of kin than in the white population. Although some are able to receive a transplant from a white donor, for many, the best match will be an organ donated from someone with the same ethnic background.

The PKD Charity will be an active stakeholder in the opt-out consultation. We will provide the government with information about the economic and psychosocial burden of ADPKD and ARPKD, to help with their decision making.

The PITHIA Trial

Aiming to increase the number and quality of transplanted kidneys



Over 5,200 people are actively waiting for a kidney transplant (March 2017) but only about 3,300 transplants took place during 2016-17. About two-thirds of transplants are from deceased donors. The majority of these donors are over 60 years old and kidneys from older donors are associated with poor function and early transplant failure. If 'good quality' kidneys from older donors can be easily identified, it's believed that transplant numbers will increase and outcomes for recipients will improve.

The PITHIA trial is a UK-wide trial designed to evaluate the use of pre-implantation biopsies to check for age-related damage and identify good kidneys to transplant. PITHIA is short for 'Pre-Implantation Trial of Histopathology In renal Allografts'. Surgeons will carry out a kidney biopsy on donor organs before transplantation, using a thin needle to extract tissue samples. The samples will then be urgently tested by a dedicated 24 hour National Biopsy Service – a process known as histopathology. The process takes about 4 to 5 hours and the samples are scored using an internationally recognised system. Surgeons will use

the results to help them and patients decide whether to go ahead or not with the transplant.

Hopes for PITHIA

The trial will demonstrate the value of pre-implantation histopathology in increasing number and quality of transplants. It will also test other aspects of transplantation which are of value. For example, if there is an increase in cold ischaemic times (CIT) as a result of waiting for the biopsy results. CIT refers to how long a kidney is chilled or cold and not receiving a blood supply after removal. There may be complications from the biopsy procedure and this will be assessed. More kidneys may be discarded than at present and close attention will be paid to this aspect.

Mr Gavin Pettigrew, one of the transplant surgeons leading the trial, explains that PITHIA has been designed to enable the researchers to compare results at each centre, before and after the introduction of the urgent histopathology service. The PITHIA team are hopeful of a modest increase in acceptance rates of donor organ of 10% which would result in an additional 150 transplants a year.

Novel trial design

PITHIA is the first ever randomised transplant trial to use the national NHS registry which stores all information about donors, recipients and transplants from the 22 UK transplant centres. The trial uses a novel 'stepped-wedge cluster' design. This approach aims to reduce the costs of running the trial dramatically, as well as reducing the burden of taking part, for both patients and clinicians.

Timetable and how to get involved

PITHIA launched in January 2018 and will roll out across the UK. Look out for meetings being held at your local transplant centre and join in to give your input. If you are likely to need a kidney transplant from a deceased donor in the next few years, it's even more important to be involved as the findings of this trial will help you and your surgeon decide whether to accept a kidney or not.

Find out more about the trial at <http://www.pithia.org.uk>.

Follow on Twitter @PITHIA_trial https://twitter.com/PITHIA_trial.

The Dawn of the Artificial Kidney

From wearable devices to kidneys grown in the laboratory



Artificial kidneys may sound like something from a science fiction movie, but these ground-breaking new treatments are currently being designed and tested across the globe. These scientific advances offer patients with kidney failure the hope of more prompt or less burdensome treatments in the future, but can they become a reality?

Today, patients with kidney failure have two main options: a kidney transplant or dialysis. Either treatment can replace some lost kidney function and prolong life, but each comes with drawbacks. People opting for a transplant may face long waiting times due to donor organ shortages and need lifelong immunosuppression treatment.

On the flipside, those receiving dialysis can begin treatment more promptly, but often feel tied down by the demands of regular dialysis sessions and dietary restrictions.

Meet the innovative dialysis and transplant technologies being developed for the future:

The wearable artificial kidney

These coffee-cup sized devices would potentially allow a patient to receive blood-filtering dialysis (haemodialysis) during the day or night. This would mean more frequent or continuous removal of wastes and fluids, and improved quality of life. The devices are lightweight and will rely on long-lasting batteries, advances in miniaturisation, new filtering materials and highly permeable membranes.

One of the best-known artificial kidneys is the Wearable Artificial Kidney (WAK) depts.washington.edu/givemed/magazine/2015/10/full-circle-revolutionizing-kidney-dialysis, being developed at the University of Washington. It weighs about 5 kg and is worn on the waist like a toolkit belt, with a catheter connecting it to the bloodstream. It's the only device so far tested in humans.

Patients taking part in trials in Italy and the Royal Free Hospital, London, wore the WAK for up to 8 hours. The next clinical trials will take place in the USA. The US body that approves new drugs and devices (the FDA) sees

such potential in the WAK that they selected it for a 'fast track' innovation programme, meaning the developers can get expert advice on trial design and commercialisation.

The Dutch Kidney Foundation has also invested in the development of a portable artificial kidney called the Neokidney. This is a small haemodialysis device for nighttime use. It's much smaller and more portable than current home haemodialysis machines.

There are important technical and safety issues to solve before wearable artificial kidneys become a reality. We don't expect them to be available for many years. Moreover, before use in the UK, regulatory approval and appropriate professional and patient training and monitoring needs to be in place.

The bioartificial or 'cyborg' implantable kidney

This small, surgically implanted device consists of a highly permeable filtration unit and human kidney cells. Because the device contains live cells, it can theoretically not only filter

Second Tolvaptan Trial

In later-stage ADPKD

the blood, but also perform other important functions of a real kidney, such as releasing hormones to control blood pressure.

The best-known bioartificial kidney is being developed by The Kidney Project (pharm.ucsf.edu/kidney), at the University of California, San Francisco: youtu.be/hc5e5cYdshl.

The team is currently raising money to finish preclinical studies and build prototypes. Safety trials could start in 2018, followed by human trials of the prototype as early as 2020. Technical challenges include being able to keep the device working long-term.

Laboratory-grown living kidneys

Several researchers around the world are attempting to grow a complete human kidney using kidney cells from embryos, stem cells from adults or cloned tissue.

A team from Manchester University is the first in the world to have grown the parts of the kidney that filter blood (nephrons) in a laboratory dish using human stem cells (www.manchester.ac.uk/discover/news/scientists-create-functioning-kidney-tissue). Stem cells are early cells that usually lie dormant in the body, but that can develop into many different cell types when needed. The laboratory-grown nephrons were then implanted into a mouse and were able to filter the animal's blood and produce urine, similarly to how a normal kidney works.

With healthy kidneys having an estimated 1 million nephrons each, the process would need scaling up to grow whole organs ready for transplantation. The beauty of using a patient's own stem cells is that this could help to avoid their body rejecting the laboratory-grown kidney (which can happen with today's kidney transplants).

This research is in the early days and a lot more work is needed, but the ability to grow nephrons in the lab is an exciting development.

The first clinical trial of Tolvaptan showed that it was effective in slowing the growth of the total kidney volume (TKV*) and in slowing the decline in eGFR* in ADPKD patients. However, that trial focussed on patients in the early stages of their disease process. Now there is evidence that Tolvaptan also works in patients at the later stages of ADPKD.

Results of a second trial called 'REPRISE' were announced in November 2017. In this trial, patients started taking Tolvaptan and then, after a period, were randomly selected to take either a placebo in its place or to continue with Tolvaptan.

This type of trial is called a 'placebo-controlled, double-blind trial'. Neither doctors nor patients knew whether they were taking the active drug or the placebo which avoids bias. For each patient who continued to receive Tolvaptan there was one who was on the placebo. They continued with the treatment for 12 months. The study was carried out in several centres across US, UK and Europe.

The patients in REPRISE were between 18 and 65 years old and results were analysed in two groups (18–55yrs and 56–65yrs.)

The younger group had an eGFR from 65 down to 25 (ml/minute/1.73 m²).

The older group had an eGFR from 44 to 25. The important end point measurement was the change in eGFR from the baseline at the start of the trial to the end of the trial.

For those patients taking Tolvaptan the drop in eGFR was significantly smaller than for those patients on the placebo.

Over the year the controls, or placebo group, had an average drop in eGFR of 3.61 ml/minute/1.73 m², while in the Tolvaptan group the

drop was 2.34 ml/minute/1.73 m². This difference is statistically significant.

From the safety aspect a few patients had slight rises in liver enzymes, but they returned to normal on stopping Tolvaptan. Indeed some of the people in the placebo group also had rises.

The conclusion from this trial is that

Tolvaptan results in a slower decline in the eGFR for patients in the later stages of the disease process. So it is effective even for patients who already have a reduced eGFR, as low as 25.

It may take a while for the study results to be implemented into clinical practice and currently Tolvaptan is limited in its licence to certain patients with higher eGFR. This is however certainly good news for all ADPKD patients.

Explanation of terms:

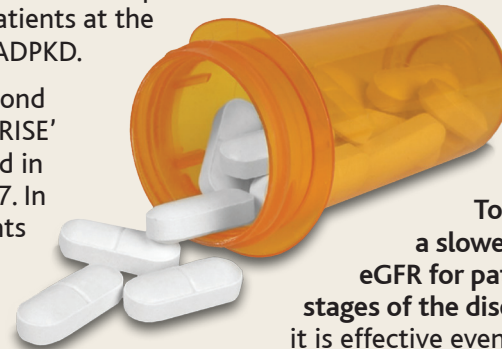
* **Total Kidney Volume (TKV)** is calculated from measurements made at an MRI scan and is known to relate to kidney function. As the TKV increases so the function falls, or larger kidneys tend to have lower function.

* **Estimated glomerular filtration rate (eGFR)** is calculated from measurements of the creatinine in the blood and it is an approximation of how well the kidneys are working – a low eGFR equates to a low kidney function. It is measured in units ml/minute/1.73 m².

Vasopressin is a hormone that causes cyst cells to increase in number and to secrete more fluid into the cyst. It does this through a messenger called cAMP.

Tolvaptan is a drug that blocks the actions of vasopressin.

Link to the paper: www.nejm.org/doi/pdf/10.1056/NEJMoa1710030



PKD and Employment

Know your rights

Polycystic kidney disease (PKD) may affect your working life. You may need to take time off work for medical appointments and clinical procedures as well as unplanned leave due to your illness. This article, written by a PKD patient, considers the equality laws and how you might discuss employment issues with your employer.

You might be classed as having a disability due to:

- Reduced kidney function causing extreme tiredness, affecting your normal daily activities, e.g. you're unable to concentrate in long meetings, you need to write important documents, or you can no longer work full time.
- Anxiety. You need more time to respond to questions or solve problems, and struggle to think clearly under pressure.
- Pain from enlarged kidneys, meaning you can no longer carry out manual tasks, or sit in one position for any length of time.
- Medication so you need to visit the toilet frequently.

How is your right to work protected?

The Equality Act 2010 protects people from discrimination, harassment and victimisation in the UK, including those with a disability due to long-term illnesses such as PKD. The definition of disability in the act is: *"a physical or mental impairment that has a substantial and long-term negative effect on your ability to do normal daily activities"*. 'Substantial' is explained as being more than minor or trivial, and 'long-term' means 12 or more months.

Under the Equality Act 2010, employers must make 'reasonable adjustments' to support people to manage their illness at work. Examples of reasonable adjustments are altering your working environment or letting you come back to work gradually.

Many employers are aware of their obligations under the Equality Act. Others might be less aware or fail to support employees as needed. If you

feel that your employer is failing to understand or meet your needs, here are some points to help:

Explain your health condition

Your employer cannot support you and consider reasonable adjustments if they don't understand how PKD affects you. For example, if you have a 'return to work' meeting following a PKD-related absence, mention that you have PKD and explain what it is. Would you attend an Occupational Health Assessment? If so, let your employer know or ask for a meeting.

Get medical reports

Medical reports from your GP or Occupational Health can help you to demonstrate how PKD is affecting your daily work life. When your employer gets the report, it's good practice for them to arrange a meeting with you to discuss the content.

Ask for reasonable adjustments to be made

Once your employer is aware of your disability, they must consider what reasonable adjustments they can make to avoid you being at a disadvantage when doing your job. What's 'reasonable' will depend on your role and organisation size. For example, a large corporation may be able to offer you an alternative role with better-suited duties, but a small company might not have the flexibility to do this.

Reasonable adjustments an employer could include:

- allowing you to reduce your hours or work from home
- altering your working patterns
- adjusting your duties to remove heavy lifting or bending
- providing a more comfortable chair
- allowing home working when you're experiencing pain

PKD and sick leave

There may be times when you're on sick leave due to PKD. You may be invited to a meeting to discuss your

absences. To help you prepare for a meeting and explain your absence:

- Make sure that any absence related to PKD is reflected in your self-certificate/medical certificate.
- Check your company's sickness policy. Does sickness related to disability count in terms of the sickness procedure?
- Be aware how many days you have had off for reasons other than your PKD.

If your employer issues a warning to you for PKD-related absence, it's a good idea to seek union support if you're a member, or contact the Advisory, Conciliation and Arbitration Service (ACAS) www.acas.org.uk.

It's illegal for companies to discriminate or mistreat an employee who is covered by the Equality Act. But, an employer may feel that you're not fulfilling your contract of employment and could take steps to dismiss you on grounds of, for example, needing to run a profitable business, business efficiency and reducing costs, or for health and safety reasons.

Your employer must demonstrate that your dismissal is fair. This is a complex area of law and we advise you to seek advice.

What about a new job?

A potential future employer can only make limited enquires about disability. They can ask whether you have a disability that would affect your ability to do an assessment test that is part of the selection process (e.g. a test at a computer) and what reasonable adjustments they can make to help or whether your health meets standards needed for safety reasons.

If you think you have been unfairly treated by a recruiting employer or your current employer, you can lodge a claim with the Employment Tribunal. To find out more, see the Gov.uk website.

A longer version is on our website: pkdcharity.org.uk/about-adpkd/living-with-adpkd/pkd-and-employment.

Support Our Work

Fundraising ideas

Thank you for supporting our work in 2017. The PKD Charity is almost entirely funded by donations from people and families affected by PKD, and we are very grateful to everyone who has raised funds or given time during the year.

There are many ways to help us continue our work.



Donations

Single or regular donations can be made online via our website. If you are a

UK taxpayer, we can also reclaim Gift Aid on your donations:

pkdcharity.org.uk/fundraising/donate-to-pkd.

Payroll or Workplace Giving is a simple and cost-effective way to donate. We are registered with CAF, the UK's biggest scheme:

www.cafonline.org/my-personal-giving/plan-your-giving/caf-give-as-you-earn

Leaving a gift in your will to the PKD Charity can help us continue our long-term research activity - such as funding the PKD bio-bank used by many researchers in the quest for new therapies.

You can donate in memory of a loved one online or set up a tribute fundraising page on one of the 3rd party platforms we use: pkdcharity.org.uk/fundraising/justgiving-virginmoney-btmydonate.

If you are arranging a funeral collection, we can send you printed envelopes to make the collection easier. Just email esther.wright@pkdcharity.org.uk letting us know how many you need.



Facebook Fundraisers

Facebook has made it super easy to raise money – to celebrate your birthday or a special anniversary. Visit the PKD Charity Facebook Page www.facebook.com/pg/pkdcharity/fundraisers to start a fundraiser and share the link with family and friends.



Take part in an event

We advertise places in runs, walks and other challenges on our

website and on our Facebook page: www.facebook.com/pkdcharity.

Check back regularly pkdcharity.org.uk/fundraising/pkd-fundraising-events.

'DIY Fundraising' is a great way to involve your family, friends or work colleagues and friends in raising money for our cause. Baking, knitting, making crafts are all popular with our supporters. Email esther.wright@pkdcharity.org.uk for an ideas pack.

When you're doing a fundraising event, ask your employer if they have a Matched Giving Scheme where they will match the amount you fundraise up to a certain level.



Online Shopping

We're updating our own PKD e-shop in 2018, to offer you greater variety of PKD

branded goods and other products. pkdcharity.org.uk/fundraising/pkd-e-shop

An easy – and free – way to raise money by shopping is to use the Give as You Live or Easy Fundraising portals. Every time you shop online at over 4,200 stores they receive commission which is donated directly to the PKD Charity. Sign up at www.giveasyoulive.com/join/pkdcharity or www.easyfundraising.org.uk/causes/pkd/?u=96OIY1

Amazon has a new charity shopping scheme called Smile, launching in the UK in March 2018.

Visit smile.amazon.co.uk.

Need help with fundraising? Email esther.wright@pkdcharity.org.uk or call her on 07715 664687



Registered with
**FUNDRAISING
REGULATOR**

The PKD Charity is registered with the Fundraising Regulator.

This means that we commit to carry out fundraising in accordance with the Code of Fundraising Practice and will ensure that our fundraising is legal, open, honest and respectful at all times.

We make the following promise to all our supporters:

- We will comply with the law as it applies to charities and fundraising.
- We will do what we say we are going to do with donations we receive.
- We will give a clear explanation of how you can make a gift and change a regular donation.
- We will explain our fundraising costs and show how they are in the best interests of our cause.
- We will not put undue pressure on you to make a gift. If you do not want to give or wish to cease giving, we will respect your decision.
- We will manage our resources responsibly and consider the impact of our fundraising on our donors, supporters and the wider public.

Find out more: www.fundraisingregulator.org.uk

Make a difference with your gift

- **£5** pays for refreshments for a patient or family member attending one of our regular Information & Support Days
- **£10** will help us send 100 PKD health information leaflets to a renal unit for doctors and nurses to hand to patients
- **£20** enables us to offer 60 minutes of telephone support to an anxious person who rings our our helpline

Our Support Services

Helping you cope with PKD



In Person/Face to Face Support

Meet Ups

We help organise regular social meetings for adults living with PKD, their family members or friends. An informal way to share experiences, offer friendship and signposting to other sources of support and information. Check our website for details.

pkdcharity.org.uk/support/pkd-meetups

ADPKD Information and Support Days

Hosted by leading PKD renal consultants in venues around the UK. Providing an opportunity to find out more about ADPKD, treatments, ask questions, meet with others and share experiences. Check our website for the next event.

pkdcharity.org.uk/support/pkd-information-support-days/adpkd-info-support-days

ARPKD Family Day

Annual event for children with ARPKD and their families. Whilst the adults attend information sessions and meet other parents, children are provided with supervised entertainment.



Telephone Support

0300 111 1234
Helpline

Confidential personal support from an experienced PKD volunteer. Available from 10am–4:30pm Monday to Friday.

Telephone Peer Support Service

Our trained volunteers are people living with PKD. They have a range of experiences, so whether you are wondering about dialysis or transplant, or worrying about what to say to your children, our volunteers

can help. Call **07739 632836** to find out more and be matched with someone who understands what you are going through.

Topic Based Teleconference

Monthly conference call on a specific topic for up to 10 people. Hosted by a professional and a volunteer with experience of PKD. An opportunity to dial in, ask questions and listen to others experience, from the comfort of your home.



Online Support

Facebook Groups

We moderate a dedicated PKD Charity UK-only closed group.

A safe place to ask questions, share experiences and offer mutual support to those diagnosed with PKD, their families, and loved ones.

www.facebook.com/groups/pkdcharityUK

HealthUnlocked Communities (linked from NHS Choices)

We moderate two HealthUnlocked communities, one for ADPKD:

healthunlocked.com/pkdcharity-autosomal dominant.

The other for ARPKD
healthunlocked.com/pkdcharity-autosomal recessive.

Topic Based Webinars

For people who can't attend an Information and Support Days. Webinars are led by a medical expert, are easy to access from a PC or smartphone or can be viewed later.

The 2018 series will cover PKD in children, tolvaptan, pain, diet and lifestyle.



PKD Charity Health Information



The PKD Charity's health information is

accredited by the NHS Information Standard.

All factsheets are written by medical experts and checked by our lay reading panel of people affected by PKD.

Key factsheets include:

Just Diagnosed with ADPKD

pkdcharity.org.uk/about-adpkd/just-diagnosed

Symptoms of ADPKD

pkdcharity.org.uk/about-adpkd/symptoms-of-adpkd

Living with ADPKD

pkdcharity.org.uk/about-adpkd/living-with-adpkd

About ARPKD

pkdcharity.org.uk/about-arpkd

If you do not use the internet, ring our Support Line **0300 111 1234** and ask for printed copies.

Links to Other Sources of Help

Links to other sources of help:

Kidney Care UK - for individual grants

www.kidneycareuk.org

Turn2us – broad range of advice on welfare benefits and grants

www.turn2us.org.uk

Family Fund – grants for seriously ill or disabled children

www.familyfund.org.uk

UK Government Benefits Info

www.gov.uk/browse/benefits

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