

Help spread the word about England's new 'opt out' organ donation law

In Spring 2020, a new law for organ donation will come into force in England. All adults will be considered to have agreed to be an organ donor when they die unless they 'opt out' or are in an excluded group.

Also known as 'Max and Keira's law', this radical change aims to help save and improve more lives by increasing the availability of donated organs. Currently, more than 6 out of 10 families agree to organ donation. To meet the needs of patients this proportion needs to increase to 8 out of 10 families.

The change comes about thanks to campaigning begun by Max Johnson and his family while he awaited a heart transplant, later donated by Keira Ball when she tragically passed away aged 9.

The law has been passed through parliament and formerly agreed by the Queen (Royal Assent). The health system is preparing for the change and a public awareness campaign over the next 12 months will help people to understand the new law.

The change mirrors a similar opt-out system brought into Welsh law in 2015. Northern Ireland chose to keep using an 'opt-in' system in 2016, while in Scotland a bill for an opt-out style law has been put to parliament for consideration.

The new English law will not apply to under 18s, those lacking mental health capacity, and those living in England for less than 12 months.

You can learn more on the NHS Blood and Transplant website:
www.organdonation.nhs.uk/uk-laws/organ-donation-law-in-england.



From spring 2020 the law around organ donation in England is changing

Unless you choose to opt out, you will be considered to have agreed to be an organ donor when you die.

Whatever you choose, let close family or friends know to help ensure your decision is honoured.

To find out more about your choices, including how to opt out:
visit organdonation.nhs.uk
or call 0300 303 2094

PASS IT ON

Research Updates

PKD Bioresource Bank supports over 90 research projects in UK



The PKD Charity sponsors a collection of samples from people with polycystic kidney disease (PKD) that researchers can use to better understand the disease. This Bioresource Bank is kept at the Royal Free Hospital in London and is overseen by curator Professor Pat Wilson from University College London.

Professor Wilson is also the chair of the charity's Research Advisory Board.

The samples donated by people with ADPKD and ARPKD include kidney tissue, kidney cells, urine, and fluid from cysts. Once approved, researchers are able to use the samples for free in studies that can help us to better

understand the biology of PKD and how it can be treated.

The Bioresource Bank also helps researchers by providing methods for research studies, similar to tested recipes!

Since it began in 2010, the PKD Bioresource Bank has provided over 2,500 samples and methods to over 90 projects in the UK.

Become a Bioresource Bank Donor

However, the collection only has so many samples. So that we can continue to help researchers in the future, more samples from PKD

patients are needed.

Some hospitals can collect samples from you during routine clinic appointments. With your permission, some blood and urine from your regular tests can be put in separate test tubes and stored in a freezer. Being a sample donor this way doesn't mean any extra visits or procedures for you.

One project at the Royal Free has identified a possible 'biomarker' by analysing blood and urine samples donated by patients at their regular visits to the PKD Clinic. We believe this has potential to be a simple and practical method of identifying ADPKD patients at risk for rapid progression and to help with selecting patients suitable for drug therapy.

Or if you have a planned nephrectomy and wish to donate a kidney or some cells from a kidney, that may be arranged through contact with your surgeon. Samples are never taken without the consent and knowledge of patients or, in the case of children's kidneys, their parents or guardians.

If you would like to find out more about donating samples to the Bioresource Bank, contact Tess at the charity by email to info@pkdcharity.org.uk.

Are kidney cilia the key to understanding ADPKD?

The PKD Charity has awarded £10,000 to Newcastle University to analyse the cilia in kidney cells from ADPKD patients. Cilia are tiny antenna-like structures inside the kidney, which are important in understanding cyst growth in ADPKD (autosomal dominant polycystic kidney disease).

The specialist renal genetics clinics in Newcastle and Sunderland have over

400 patients with ADPKD. Professor John Sayer and Dr Shalabh Srivastava will aim to match detailed clinical, biochemical, genetic and radiological data from about 60 patients with information about the cilia from cells grown from patients' urine samples. Urine is simple and easy to collect at clinic appointments.

Newcastle is a leading centre for the development of kidney cell cultures from urine, and this cutting edge technique will allow new insights to be made. The technique has already been used by the researchers in other rare conditions where the cilia go wrong and cause cystic kidneys.

This pilot project will run for 12 months and will provide important



Cilia under the microscope

data to support a larger application for a nephrology trainee to undertake a clinical research training fellowship at Newcastle. The longer-term aim is to develop and offer patients more effective targeting of therapies.

PKD Charity Support Services

Susan Muirhead explains how you can get help and advice

Did you know the Charity offers support through many forms?

On the back page of the newsletter we list all our support services. As more people discover they have PKD they are contacting the charity in greater numbers. As a result, we are increasing the number of Information and Support Days for patients and families affected by PKD. Our national helpline (03000 111 1234) is now available 9:30 to 5pm, Monday to Friday. Remember, there is no such thing as a silly question and if we don't have an immediate answer, we can nearly always find an expert who can help.

In recent years, we've added new services, such as our growing network of Meetups (hosted by trained volunteers), web chat messaging (on our website www.pkdcharity.org.uk) and teleconferences for small groups to discuss a specific PKD topic in confidence. People have particularly enjoyed the teleconferences for 'Newly Diagnosed'.

As Martin, one of our volunteers, discovered when he learnt he'd inherited PKD from his mother:

"It's overwhelming to suddenly hear you have PKD. You feel alone. Although I discussed my concerns with my partner, friends and family they don't have

the knowledge and experience those with PKD do. I found it really helpful, both for information and helping me to deal with the new diagnosis."

Having seen his mother suffer from kidney failure and dialysis, together with his own experience of falling kidney function, which led to a transplant two and a half years ago, he was keen to help others. Today, after undergoing training to become a befriender for the charity, he is able to talk sympathetically to those who are affected by PKD.

"I volunteer because I've been lucky to receive a transplant and want to give back."

The phone befriending/peer support service that we launched 3 years ago is now well established. One to one calls give you the opportunity to speak directly with someone who gets it! They will have experienced the PKD journey you are going through.

Don't suffer in silence. If you are feeling anxious, afraid or alone, pick up the phone and ring us, or send an email to support@pkdcharity.org.uk. The PKD Charity was set up by PKD patients and family members and is run by people with PKD who know what you are going through and can help.



Susan Muirhead is the Community Support Manager at the PKD Charity, since joining us in March 2019. She coordinates a programme of personalised, non-medical support services for individuals and families affected by PKD. These include online PKD Forums, nationwide telephone peer support; topic based conference calls, meetups and PKD information and support days.

Susan has experience of PKD, having seen personally the effects of it as a PKD wife, mother and kidney donor. Over six years ago Susan discovered the closed UK PKD support Facebook page which she started to promote and make more active. It has grown from 40 members to 1,750.

Do you know your facts about kidney stones?

These crystals of salts and minerals are common in people with ADPKD, occurring at least twice as often as in the general population. On our website, you can find new information about kidney stones, including symptoms, how they are diagnosed and treated, and what you can do to prevent them.

It is thought that the slower flow of urine through the kidney and imbalances in its content make

stones more likely to form in people with ADPKD: pkdcharity.org.uk/about-adpkd/symptoms-of-adpkd/kidney-stones.

Most stones are small and can be passed in 1–3 weeks at home.

However, if you develop a larger stone you might need a procedure to break it up so you can pass it.

Usually, this doesn't involve surgery.

In extracorporeal shockwave lithotripsy for example, a special machine can break up the stone using shockwaves.

Avoiding dehydration, adding fresh lemon juice to drinking water, and eating only a healthy amount of salt and calcium can help to reduce your chance of getting kidney stones.



6 mm

Kidney stone

Fiona Davis

Living life to the full after her kidney transplant



I was diagnosed with autosomal dominant polycystic kidney disease in 1999 when I was 17 years old. I assumed that I would be in my 60s before I would have any issues, so carried on life as normal. When I was 26, I started getting a lot of pain in my abdomen. This turned out to be from some of my cysts bursting.

I had my son in 2012 when I was 30 years old. My kidney function dropped suddenly 3 months after his birth. It fell from roughly 75% (eGFR of 75) to 43% (eGFR of 43), putting me in stage 3 chronic kidney disease.

My kidney function never recovered and dropped steadily over the next few years. Each time a cyst burst, I would have terrible pain and vomiting and would lose a little bit more kidney function. Then in September 2016, I had a significant cyst burst which shifted my kidney function from 22% to 10% overnight: I was suddenly in kidney failure.

As it was unexpected, I was very quickly referred to the low clearance clinic where we began discussing dialysis. I couldn't get peritoneal dialysis as a scan showed my kidneys

were too big to allow my abdomen to accommodate the dialysis tube and fluid. I therefore began preparations for haemodialysis, which would filter my blood.

In March 2017, I had a small operation to have a fistula created in the bend of my arm. This would allow the haemodialysis tubing to be easily connected to my bloodstream. The operation was successful, and I was told the next step was to build up the fistula until it was mature enough to be used.

I was very lucky that my dad offered to be my live donor, and 3 friends plus my manager also came forward to be tested to see if they could be suitable donors for me. As my kidneys were so large, it was agreed that once I had started having dialysis I would have an operation to remove them both (a bilateral nephrectomy). Then 3 months later when I was fully recovered, I would have my transplant with my dad as my donor.

I was very fortunate to have a great relationship with my renal team. As my son was only 4 years old, they were very flexible with me. I tried my

best to keep pushing the dialysis start date further and further back, aiming to wait for him to start school in August. However, towards the end of May I was told we couldn't wait any longer: I agreed to start haemodialysis the following week. I visited the unit, tried out my chair and had my bloods taken to prepare for my first session the following Wednesday.

That weekend was my son's birthday party. As the party ended and I waved goodbye to everyone, I had a call from the transplant team to say that a donor had been found who was a better match than my dad. I went into hospital that night and the surgeon confirmed that, with the removal of a few cysts, the donor kidney could be squeezed into the left side of my abdomen.

My transplant was carried out on my son's birthday. I recovered very well from the operation and felt like a new person. I had energy again and I looked so healthy, with glowing skin and soft, shiny hair. It was incredible! I struggled with some of the side effects of the immunosuppressants, but they subsided and became more manageable as time passed.

I was monitored very carefully after my transplant. My donor kidney was doing an incredible job and my kidney function sat at around 70%.

Discussions continued regarding the removal of my own kidneys, and in August 2018 I was added to the waiting list. By this point, I was struggling with the size of my abdomen: I found it difficult to bend and lift things and was unable to do most exercises. I had a lot of pain and discomfort. My confidence was badly affected as at least once a week someone would mistakenly ask when my baby was due. In addition, my bladder had been pushed out of place by my enlarged kidneys and was under a lot of pressure, meaning I was up 5–6 times every night to go to the toilet. My bowel was also being pushed flat against the wall of my abdomen.

Insurance

Getting cover that's right and affordable

In November 2018, I had my bilateral nephrectomy to remove both enlarged kidneys. This operation was very big, but I had a great team around me who were very supportive. The operation took 5 hours. Although my kidneys had become attached to most of my other organs, the surgeon removed them without causing any damage.

There were no complications, and I was returned to the ward to recover. I was given effective pain relief – I had a spinal anaesthetic, 2 local anaesthetic pumps at either end of the wound, plus a morphine pump. I am grateful that my surgeon agreed to try internal glue and stitches for the wound, instead of staples, which worked incredibly well. All of this meant I was up on my feet 3 days later and went home a week after the operation.

My new kidney was affected by the severity of the operation and its function reduced. However, after 2 days it was functioning as before and is now functioning better than ever.

The recovery from my second surgery was much harder than I expected, being a lot slower than my recovery from my transplant. I was a lot less mobile and also had significantly more pain and discomfort. For the first 4 weeks, I was able to do very little, but I started to feel a lot better as time went on. I returned to work 8 weeks after my operation.

I feel so much better. My body shape has returned to normal – the 'PKD belly' and baggy clothes are gone! I have returned to cycling and yoga: activities I'd had to stop previously. I have a good appetite, feel less sick, can breathe better and have much more self-confidence.

I feel incredibly lucky to be where I am today. A few years ago, I felt that my normal life was gone forever as I was so unwell that I couldn't see an end point. I am incredibly grateful to my donor and his family who, through agreeing to donation, gave me back a normal life. They have allowed me to be the mother I wanted to be and to live my life to the full.



It can be difficult to find affordable insurance if you have polycystic kidney disease (PKD).

Nevertheless, there are a number of specialists who offer all types of insurance to those with pre-existing conditions such as PKD - but be prepared to pay higher premiums because of the high risk of claims. And always read the small print of any insurance policy to understand the level of cover and the exclusions.

The following refers to insurance in the UK only. You must declare that you have PKD if you are asked. Insurers may or will refuse to payout otherwise, or may cancel your policy and keep your premiums.

Life Insurance

Some insurers will just turn you down immediately, while others will exclude PKD from the policy. Your premium will vary depending on the type of life insurance, the size of the sum insured and also the risk of a claim – which may also be related to your job as well PKD.

Remember that life insurance premiums rise with age and is more expensive for an older person. But it is still possible to take out life insurance when you are in your 50s, and some firms will accept without medical or health questions.

Travel Insurance

There are insurers who will insure you whilst travelling if you have PKD. It's important that you understand what the cover provides and ensure that you are getting the right policy for your needs.

UK Insurance Companies

We do not and cannot recommend any insurer or financial services provider. However, we are confident that the companies listed below can help you. They have access to a large panel of leading insurers so that you can compare prices and choose the policy that best suits your needs.

For every policy sold, some firms will give a donation directly to the PKD Charity at no additional cost to you. These firms already work with a number of charities like us on the same basis. But please note that we are not endorsing them as exclusive providers of cover.

- The Insurance Surgery - all types of insurances: www.the-insurance-surgery.co.uk/?ref=6200
- Freedom Insurance Services - travel only: www.freedominsure.co.uk/Polycystic-Kidney-Disease-Travel-Insurance

A spotlight on events

Are you up for a challenge?

RAISED
£3,262



Susan shares what completing the 2019 London Marathon meant to her:

"I was diagnosed with PKD about 25 years ago, at the age of 14, I was scanned as my Mum had just been diagnosed.

I have been in good health since my diagnosis, my GFR started to make a slow decrease about four years ago and so I thought it was time to start looking after myself a little better. With the encouragement of my husband who had become a keen runner, I took it up too, enjoying time out running. I ran my first half marathon back in 2015 which I did on behalf of the PKD Charity, and ran with pride wearing my green vest, raising over £750. In 2016 I ran a 'dirty double', (two 10 km races back to back) in the Lake District, again, on behalf of PKD Charity and raising a similar amount.

The London Marathon is the best-known marathon and I loved running it for the charity that means so much to me and my family. In March I turned 40 and was proud to complete the London Marathon in my 40th year raising as much as I could for PKD – I was delighted to raise £3,262 in total!

Thanks for letting me share my story".

The PKD community regularly comes together in support of the charity, and each time we're humbled by the dedication and determination of so many. This was especially true in April when a team of four runners took part in the London Marathon in support of the PKD Charity. Susan Dunne, Terry Lapkns, Rob Gilder and Shelly Wilson – we all send you our biggest thanks.

If you feel inspired to take on the London Marathon in 2020, or a 10k or half-marathon, please do get in touch as we are lucky enough to have places in many sought-after events.

RAISED
£4,539



Amar Parmar took on the popular London Landmarks Half Marathon in March this year.

A team of eleven take on three peaks for PKD

Earlier this month a team of 11 **Scottish Water Horizons employees** aimed to climb the highest peaks in Scotland, England and Wales in 24 hours. **Patrick** and **Frances Stakim** share their story:

"Every year we challenge ourselves to raise money in memory of our friend and colleague Keith Winstanley who sadly passed away in 2017.

Keith was a keen hillwalker and a very good friend and colleague who was taken too soon and is sorely missed by all that knew him. We chose the charity PKD due to it being close to the heart of one of our team.

We had a great, if tiring, time and in the process have raised £4,539 plus Gift Aid for the charity.

Here is a photo of the team at the start of Ben Nevis!"



Our biggest thanks to the team for taking on this mighty challenge and raising such an incredible amount of money for the charity in memory of their dear friend, Keith.



Velocity 2 – the fastest zip line... In the world!

How would you like to take on a truly unique and exhilarating challenge? Velocity 2 – the fastest zip line in the world awaits. Soar over Penrhyn Quarry, located near Bethesda in North Wales, where you could travel at speeds of over 100mph while taking in the breathtaking views and feeling the freedom of flight.

The PKD Charity has 36 places in this adrenaline-fueled event on Sunday 22nd September 2019.

- How fast?
You can go over 100mph
- How far?
1555 metres
- How many?
Up to 4 people at any one time
- How many zips?!
2 - the little & big zipper!
- Duration?
2 hours



There is plenty for spectators to do too, enjoy the view of zippers flying by from the Blondin Restaurant, experience the Penrhyn Quarry Tour on its famous red trucks, or take in the sights from the viewing platform!

Please do get in touch if you're keen to take part – please note, age, height and weight restrictions apply.

fundraise@pkdcharity.org.uk

Support our work

Fundraising ideas

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 their time.

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 third 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 fundraise@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

You can read all about the places we have in challenge events on

the previous page, or visit pkdcharity.org.uk/fundraising/pkd-fundraising-events

'Your fundraising, your way' is a great way to involve your family, friends or work colleagues in raising money for our cause. Baking, knitting, making crafts are all popular with our supporters. Email fundraise@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

An easy – and free – way to raise money by shopping is to use online shopping portals.

Easyfundraising and Give as you Live® pay commission every time you shop online at over 4,200 stores. Sign up at www.easyfundraising.org.uk/causes/pkd/?u=96OIY1 or www.giveasyoulive.com/join/pkdcharity

Amazon has a new charity shopping scheme called Smile.

Visit smile.amazon.co.uk and login with your usual Amazon account.

Need help with fundraising? Email fundraise@pkdcharity.org.uk or call 07715 664687.



Donate your car

Do you have a car to dispose of? Giveacar is a UK based fundraising organisation that

organises car donation for good causes in the UK.

giveacar.co.uk/charities/polycystic-kidney-disease



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



**THE
GENETIC
LOTTERY**

**Join the PKD Charity
Genetic Lottery® and
win up to £25,000!**

It's so easy to play. Visit pkdcharity.org.uk/fundraising/pkd-genetic-lottery.

Good luck and you're helping support the PKD Charity's work!

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 9:30am to 5:00pm 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 with 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 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 topics will include PKD in children, tolvaptan, genetics, pain, diet and lifestyle.

Visit our **Events page** for details of upcoming webinars, information days, meetups and support group calls:

pkdcharity.org.uk/news-events/events

PKD Charity Health Information

We have adopted The NHS Information Standard - a quality standard that supports the production of health and care information which meets the needs of all patients, carers and families.

All our 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 - 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

Children's Liver Disease Foundation
childliverdisease.org

Board of Trustees

Alison Carter
Alan Greenberg, Chair
Elizabeth White
Raj Johal
Sarbjit Johal

Rebecca Murphy, Peers
Nick Tracey, Treasurer
Adrian Tinsley
Harriet Rimbault
Prof Patricia Wilson

Management

Tess Harris, Chief Executive
Susan Muirhead, Community Support Manager
Jane Pugh, Community Engagement Manager

Scientific, Clinical and Research Advisory Board

Professor Patricia Wilson
Chairman
Dr Anand Saggar MBBS FRCP
Vice-chairman