

## Focus on therapies for ADPKD

In research funded by the PKD Charity, scientists at UCL London are trying to find better ways to treat patients with ADPKD (autosomal dominant PKD) by studying new and existing drug therapies, like tolvaptan.

They want to understand why some patients do well with tolvaptan while others don't and help identify those patients who will respond to tolvaptan and other future drugs. They have developed a new, non-invasive way to quickly test whether tolvaptan is working in individual patients by looking at protein patterns in small particles found in urine samples.



The team is also working on new techniques to test the safety and effectiveness of new or repurposed drugs for ADPKD patients, using 3D organoids (tiny models of PKD kidneys in a lab dish), liquid biopsies, and novel drug delivery systems. They hope that these new techniques will accelerate the discovery of better treatments for ADPKD patients.

## Mum's the word

Inspiring mum creates book to raise awareness of her 4-year-old's battle with ARPKD.

Aria, 26, and Daniel, 29, from Cornwall, were thrilled to welcome their second child, Hazel, into the world.

However, their joy turned to fear when they discovered four months later that their little one had ARPKD, the rare form of PKD. It all started one November morning when Hazel had trouble breathing and had to be rushed to the hospital. Within hours, scans, x-rays, blood tests, and blood pressure checks revealed that she had multiple cysts covering both of her kidneys, which were also the size of a teenager's.

"We were in disbelief that our healthy baby girl had to suffer from an incurable condition that we knew nothing about," says Aria.

Unlike ADPKD, parents of children with ARPKD don't have the disease themselves and are often referred to as "carriers".

The family set about raising awareness and funds for PKD through their Facebook page, @HazelVsPKD, which has brought in messages from parents of "kidney kids" worldwide. They've organised fundraisers, raffles, and sold handmade items. Aria, who is a student and writer, even donates a portion of book sales directly to the charity.

"When a child is diagnosed with a chronic disease, it can be devastating. Raising awareness and helping others has given us a sense of purpose during



this challenging time," she explains.

Inspired by her daughter's journey, Aria decided to write and illustrate the book to help Hazel explain her condition to others. It uses child-friendly language to discuss doctor visits and tests in a way that helps to reduce fear, not only for children with kidney disease but for those with any hidden illness. The book also helps children understand the importance of treating others with kindness, even when their struggles are not apparent.

Their story is a testament to the power of positive action in the face of adversity. And Aria's book is a beautiful example of how a mother's love and creativity can help a child navigate a difficult situation with courage and understanding.

**Hazel Vs PKD is available on Amazon.**

# Information and support

## Living well with PKD

**Move better.  
Feel better.  
Live better.**

PKD exercise &  
well-being programme



### We're excited to announce the launch of a brand new PKD exercise program on Kidney Beam!

Kidney Beam is a free online service, developed in collaboration with King's College Hospital, that offers ways to improve your physical and mental health, at any time, in any place, no matter where you are on your kidney journey.

The program is designed by experienced clinical specialists to specifically cater to the unique needs of PKD patients. It includes three introductory sessions followed by on-demand movement sessions and educational classes.

No matter how much do, the most important thing is to keep moving! Even gentle exercise can boost your energy, lift your mood and make everyday activities easier.

It's quick and easy to get started and completely **FREE** until 31 July.

### Exercise sessions:

In this program, you will be taking the Get Active classes, taught by the Renal Rehab team at King's College Hospital. A gentle activity session, designed especially for you - to support you to live well with your kidney condition and to remain as happily active as possible.

In each session, you'll be coached through a circuit-style routine that'll be tailored to make sure you're working at the right intensity for your health. Each class has a slightly different focus, but includes both a strength element, and cardiovascular exercise.

### Education sessions:

The Importance of Being Active with PKD

- What Can You Do to Get More Active
- Exercise FAQs
- The Role of Exercise in CKD Personalising Exercise Plans
- Goal Setting Staying Active for the Long-Term Barriers & How to Overcome Them
- The Role of Your Kidneys
- Breathlessness & Fluid Intake
- Fatigue & Anaemia
- The Impact of High Blood Pressure Diabetes & Kidneys
- Nutrition & Diet for Your Kidney

Simply join Kidney Beam online  
[www.bit.ly/PKDBeam](http://www.bit.ly/PKDBeam)

If you are new to Kidney Beam, you will need to create a free account first. You will be asked for this research code, which you **must enter** where shown: KIDNEY-BEAM-PKD-CHARITY.

We are collecting feedback on the programme, so please complete the before and after survey. This will help us evaluate the programme.



## Nephrectomy Q&A

**Nephrectomy (nephro = kidney, ectomy = removal) is the surgical removal of one or both kidneys.**

We recently held a nephrectomy Q&A giving PKD patients, family members and carers the chance to talk directly with experts, Mr Nicholas Inston and Mr James Barnes, Consultant Renal Surgeons at Queen Elizabeth Hospital Birmingham.

**"It was really informative and easy to understand."**

**"James and Nick instil calm confidence with their knowledge and expertise and so many of my questions were asked by others which reassured me that I am not alone with my thoughts or my situation."**

*Anonymous Feedback*



To view the recording of this and talks from other events, please visit: [www.bit.ly/PKDtalk](http://www.bit.ly/PKDtalk)

Other recent recorded Q&A Sessions include Pregnancy & Family Planning and Polycystic Liver Disease (PLD).



# Information and support

## Living well with PKD



From April to June, a spring booster to top up the immunity of those most vulnerable to Covid-19 is being offered to people aged 75 years and over, residents in care homes for older adults, and those aged 5 years and over who are immunosuppressed.

We strongly encourage everyone who is eligible, to have the booster vaccine as soon as possible. Whilst no vaccine is completely effective, and some

people may still get Covid-19 despite having a vaccination, it remains an important defence against becoming severely ill from Covid-19; proven to be safe, effective and life saving for many people.

For full details of who is eligible, when and how to obtain, please see the full spring booster guide: [www.bit.ly/SpBst23](http://www.bit.ly/SpBst23)

## Coming soon!



### ADPKD Information and Support days

- London: Saturday 30 September
- Salford: Date to be confirmed
- Wales: Date to be confirmed

### ARPKD Family day

- London: Saturday 25 November

To register your interest in any of these in-person events, please email [jane.pugh@pkdcharity.org.uk](mailto:jane.pugh@pkdcharity.org.uk) or call 07866 490985

## Help at your figure tips!

We kicked off 2023 with the launch of the brand new PKD App!

Developed by the PKD Charity, clinical specialists, patients and carers for the newly diagnosed and those at the early stages of ADPKD, this free App:

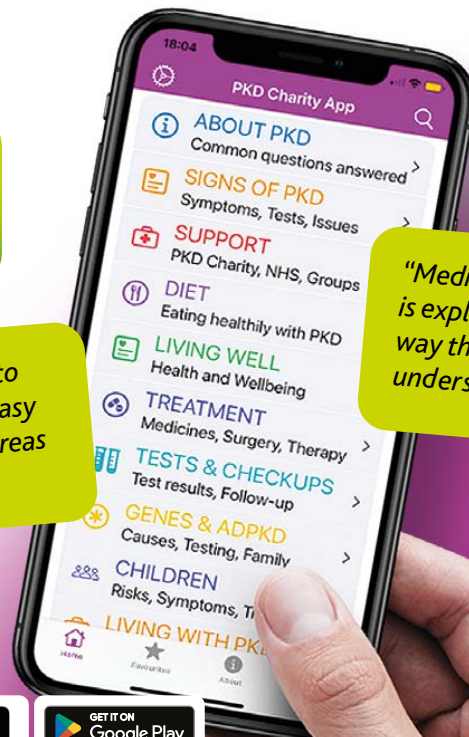
- Provides credible information and accredited health advice all in one easily accessible place
- Offers practical tips for everyday life
- Gives links to trusted further information and support

Free to download from the Apple Store and Google Play.

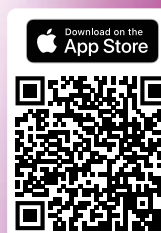


"It is clearly split into sections allowing easy access to specific areas of interest."

"Medical information is explained in a way that's easy to understand."



"Each section is covered really well and gets to the detail straight away, but if users want to delve further they can do so. As well as being a great tool for those with PKD, it can also help family members, friends and even employers gain a greater understanding of PKD."



Scan with smartphone

# Raising awareness

## PKD Voices



## Shining a light on kidney disease

The Kidney Charities Together group marked World Kidney Day this year with our biggest event yet; a new interactive pop-up aimed at educating people about kidney disease, key risk factors and ways to protect kidney health.

The pop-up, designed to resemble an everyday kitchen, invited visitors to use ultraviolet torches to reveal aspects of life with kidney disease, such as the relentlessness of frequent dialysis sessions, prohibited foods, and common symptoms. Interactive competitions were also organised to educate visitors on essential kidney facts and stats, which involved finding hidden clues or guessing the average number of pills a transplant



recipient must take annually to avoid rejection. These proved to be eye-opening for those with little to no knowledge of kidney disease.

The two-day event took place at Leicester's Highcross Centre, due to its central location and high population of Black, Asian and other ethnic minority groups. These communities are at a higher risk of developing chronic kidney disease due to diabetes and high blood pressure, than people from Caucasian backgrounds.

The pop-up was manned by team members and volunteers from each kidney charity, as well as healthcare professionals like Dr. Courtney Lightfoot and Dr. Tom Wilkinson from the Leicester Kidney Lifestyle



team, who hosted last year's "Staying Active with PKD" webinar.

The event generated significant positive attention, with people queuing up to participate in the competitions or collect information leaflets. The campaign's reach was amplified through video interviews with members of the public, patients, and healthcare professionals, which were shared widely on social media.



With a reported footfall of 61,538 people at Leicester Highcross over the two-day event, we hope to have increased awareness of kidney disease and encouraged those at risk to become more knowledgeable about kidney health.





# Raising awareness

## PKD Voices

### Happy 1st Kidneyversary!

It's been a year since Jess donated a kidney to her son, Jaxson, when he was just 2 years old.

Jaxson was born with Autosomal Recessive Polycystic Kidney Disease (ARPKD) and underwent his first surgery to insert a PD catheter for dialysis at just 24-hours-old. He relied on dialysis for the first two years of his life and had to have both kidneys removed before receiving a kidney from his mum.

Since the transplant, Jaxson has made amazing progress. He took his first steps at 2.5 years old, and he's now eating, drinking, and talking, which he didn't do before the surgery. Jess feels incredibly grateful that she was a match for Jaxson and able to give him the gift of life. She thanks the skilled surgeons, consultants, doctors, and nurses who have been involved in Jaxson's care over the past few years.

We wish Jaxson, Jess and dad, Darrell, all the best for their future.



### Care for the carer



**PKD not only impacts those with the condition, but also their caregivers, including children, partners, spouses, and parents.**

The responsibilities of caregivers can include managing medications, monitoring diet, and supporting their loved one through the physical and emotional challenges of living with a chronic illness. Some even donate a kidney or part of their liver.

As a progressive and incurable disease, PKD places a long-term burden on

caregivers, often requiring significant sacrifice and putting their own needs second, which can impact their life choices, financial security, and health and well-being.

For Carers Week in June, we want to recognise and raise awareness of the experiences of PKD caregivers. This campaign aims to highlight the challenges that unpaid carers face and recognise the valuable contribution they make. Whether your loved one is newly diagnosed, on dialysis, or has received a transplant, we would like to hear how PKD has affected your life. Patients can also share their experiences of the support they have received from a caregiver; anonymously if preferred. Please send a brief outline of your story to [jane.pugh@pkdcharity.org.uk](mailto:jane.pugh@pkdcharity.org.uk)



### Katie receives The Call

**Katie Banks from Swansea has been given a new lease of life after receiving a kidney transplant in March.**

This second chance comes after she bravely spoke out about her struggles with the 'PKD belly' that led people to often assume that she was pregnant, a common problem endured by many with PKD. Although it's still early days, the transplant has already had a profound impact on Katie's life, leaving her with immense gratitude towards her donor and their family. While Katie recovers at home under the care of the transplant team in Cardiff, she remains determined to continue raising awareness of PKD and to push for greater support for those with chronic kidney disease. We wish Katie all the best in her on-going recovery, and hope that her story can inspire others to speak out and support those in need.

**Katie's full story:**  
[www.bit.ly/KBbelly1](http://www.bit.ly/KBbelly1)





# Fundraising

## Get involved

### Sam's Head Shave for PKD raises £10k

'My name is Swetal, otherwise known as Sam. I have suffered from Polycystic Kidney Disease (PKD) for most of my life. When my father succumbed to this awful illness, there were no chances of a transplant, dialysis, and certainly no medicinal treatments.

The wonderful PKD Charity is trying to change this situation, funding research and providing support networks and initiatives so that sufferers can hope for a better future.

To raise funds for this wonderful charity, two close friends, Sujata and Tony, and shaved our heads (and beard in Tony's case!) on the 12th February.

This is a cause extremely close to my own heart. PKD causes cysts to develop in and around your kidneys, and they can grow to a size anywhere between a pea and a grapefruit. It causes the kidneys to enlarge, and in my case they were so big that I looked 8 months pregnant. As more and more cysts grew in size and weight during my late 40s and 50s, my kidney function declined rapidly, and I urgently needed help if I were to go on living as much of a normal life as possible. Ideally, this would entail a generous living donor.

After understanding and sharing this news, a few of my loved ones offered to donate their kidneys. I must say, donating a kidney is no small feat! Significant operations, risk of complication, and time off work to say the least. As you can imagine, I was overwhelmed with the love I received, and felt extremely lucky. Many others with this dreadful disease less



fortunate than I have to wait for years on dialysis, many of whom die whilst waiting for a transplant.

In June 2016, several of those who offered to donate joined me to have tests at Hammersmith Hospital to find out if any of us would be a match, and therefore appropriate for donation. We discovered that the lovely Gita was a good match to me. So, on the 15th May 2017, Gita and I powered through with our operations and were placed side by side in the ward where we were recovering. We knew we were getting slightly better when we could have zimmer-frame races round the ward! My new kidney has given me an amazing new life and Gita has saved me the worry of dialysis and even death. I am blessed to have this wonderful friend who gave me 'The Gift of Life'. We must not forget those at Hammersmith Hospital and the NHS overall for their fantastic work.

Whilst there has been progress in transplantation and dialysis, they remain the only two real treatments for this disease and its long-lasting, sometimes deadly, impacts. With your generous donations, the PKD Charity





# Fundraising

## Get involved



will continue to support sufferers of this disease, and fund research for treatments other than invasive dialysis and impactful transplants.'

Sam, Sujata and Tony have now raised an amazing £10,000 to help support people affected by PKD and fund vital research. Thank you so much to them and to their very generous friends and family for this incredible support.



## Claim your free Will with Farewill

PKD Charity has teamed up with Farewill, one of the UK's top Will writing specialists, to offer you free support with writing or updating your Will.

You can write your free Will in as little as 15 minutes with their professional help. Although PKD Charity is covering the cost, you don't have to leave us a gift to use the service.

By including a gift in your Will, you can help our scientists to build on today's discoveries and develop tomorrow's.

Write your Will for free here:

[www.farewill.com/pkd-newsletter](http://www.farewill.com/pkd-newsletter)

## Team PKD raise £27,000 at the London Marathon



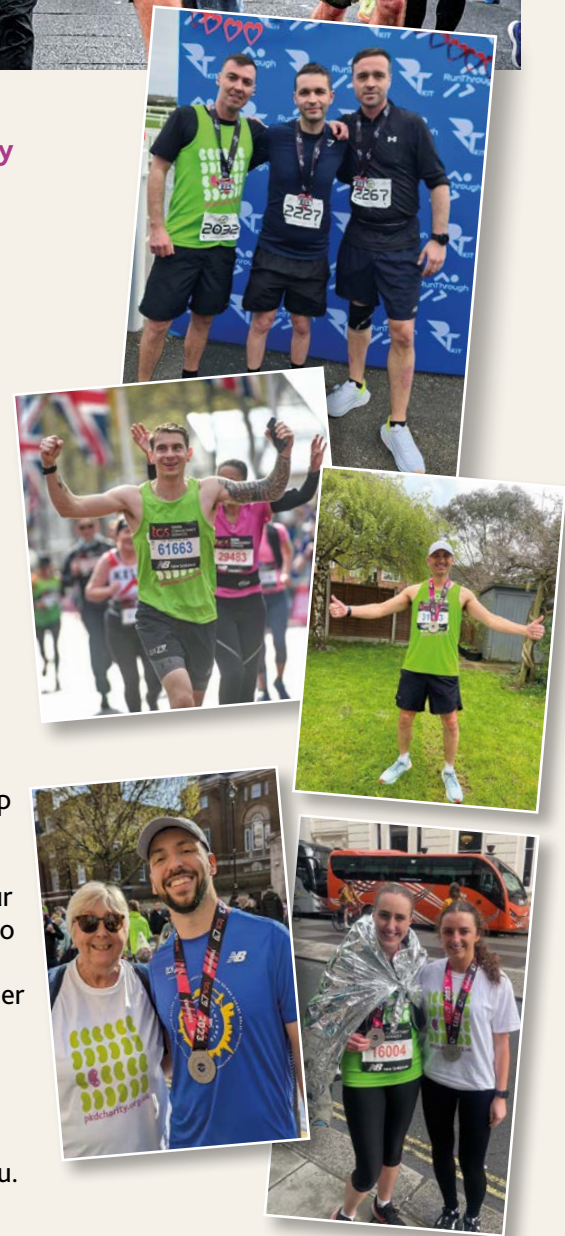
**A massive well done and thank you goes out to the PKD Charity runners who took part in the 2023 London Marathon on the 23rd April and have now raised over £27,000.**

Thank you to Sarah, Antony, Curt, Rachel, Martin, Matthew, Dan, Robin and Frances! This wonderful team of runners have worked so hard and put in so much time and effort in to training for this incredible challenge and to their fundraising for us and we are so grateful.

The support that the charity offers to anyone affected by PKD and the research that is funded to increase understanding of polycystic kidney disease and help improve the management and treatment of everyone affected would not be possible without our fabulous fundraisers. Thank you so much again to our 2023 London Marathon team and all of our other incredible fundraisers.

If you'd like to take on your own marathon challenge to fundraise for PKD Charity, please get in touch! We'd love to hear from you. Email us at

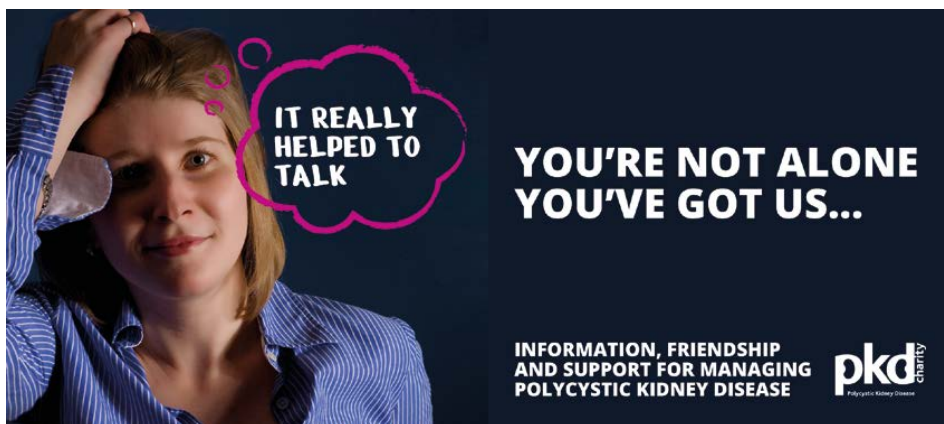
[fundraise@pkdcharity.org.uk](mailto:fundraise@pkdcharity.org.uk)



# Our support services

## Helping you cope with PKD

Whether you're looking for PKD information, practical advice or just someone to talk to, we're here to help you.



### Ring our Helpline

If you need a friendly person to talk with about your worries or are just looking for information,

ring **0300 111 1234**, our confidential helpline. Available from 9:30am to 5:00pm Mon – Fri.

"You'll never know how much I valued speaking to you."



### Find a PKD Support Group

For understanding and companionship, join one of our PKD Support Groups. Hosted by trained

volunteers with lived experience of PKD. Everyone is welcome – patients, family members and friends.

"It's great to meet others in a similar situation."



### Join a Facebook Group

For a friendly and private place to connect and share with others like you, join one of our three UK-only

private Facebook groups. There's a group for everyone affected by PKD.

For ADPKD (autosomal dominant polycystic kidney disease)

- PKD Support (PKD Charity UK)
- Parents of children with PKD (PKD Charity UK)

For ARPKD (autosomal recessive polycystic kidney disease)

- ARPKD Support (PKD Charity UK)

"I found the group on Facebook and was immediately immersed into a very friendly and welcoming environment."



### Take part in a workshop

Share your experiences and discover new coping strategies in a confidential online space with others

who understand the difficulties of life with PKD. Run by a renal psychologist and psychiatrist.

"To be able to share experiences helped me realise I am not the only one out there feeling the way I do."



### Learn more about PKD at an educational event

Want to find out more about PKD, worried for your future, or baffled by

the medical jargon? Ask the experts at one of our free educational events.

"Fantastic sessions...a very informative and interesting day."

### Visit our website for more information

How to get support, visit [www.bit.ly/pkdc-support](http://www.bit.ly/pkdc-support)

Upcoming events, visit [www.bit.ly/pkdc-events](http://www.bit.ly/pkdc-events)

## PKD Health Information

If you need reliable information about all aspects of PKD, visit our website for a range of accredited factsheets written by medical experts and checked by our lay reading panel of people affected by PKD.

Key factsheets include:

### ADPKD Basics

[www.bit.ly/adpkd-basics](http://www.bit.ly/adpkd-basics)

### Polycystic Liver Disease

[www.bit.ly/adpkd-pld](http://www.bit.ly/adpkd-pld)

### Diet and Lifestyle in ADPKD

[www.it.ly/adpkd-diet-lifestyle](http://www.it.ly/adpkd-diet-lifestyle)

### ARPKD Basics

[www.bit.ly/arpkd-basics](http://www.bit.ly/arpkd-basics)

If you don't use the internet, we can send you printed copies. Just ring our helpline: **0300 111 1234**.

## Links to other sources of help

We recommend:

UK Government Benefits Info  
[www.gov.uk/browse/benefits](http://www.gov.uk/browse/benefits)

Kidney Care UK - individual grants  
[www.kidneycareuk.org](http://www.kidneycareuk.org)

Turn2us – broad range of advice on welfare benefits and grants  
[www.turn2us.org.uk](http://www.turn2us.org.uk)

Family Fund – grants for seriously ill or disabled children  
[www.familyfund.org.uk](http://www.familyfund.org.uk)

Contact - for families with disabled children  
[www.contact.org.uk](http://www.contact.org.uk)

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