pkd charity
Polycystic Kidney Disease

newsletter

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HIYA PKD STUDY

Hypertension in Children & Young People at Risk of PKD

HIYA-PKD is a new study exploring how common high blood pressure is in children and young people aged 12–17 who are at risk of Autosomal Dominant Polycystic Kidney Disease (ADPKD). This includes those with a parent or sibling diagnosed with the condition but who haven't yet been tested themselves.

High blood pressure can be a silent danger in the early stages of ADPKD, with an estimated 1 in 5 children affected. If left untreated, it can lead to kidney damage over time. Early detection and treatment of high blood pressure are therefore vital for managing disease progression and improving overall health.

The aim of the study is to measure blood pressure and examine its potential impact on the heart, arteries, and other organs.

As part of the study, participants will undergo MRI scans of the kidneys and heart, have their blood pressure assessed, and be tested for ADPKD via a genetic test. Participation typically involves two hospital visits.

If you're interested in participating or would like to learn more, please contact the study coordinator, Louise Keehn, at gstt.hiya.pkd@nhs.net.

From Small Acorns Grow

Though the PKD Charity was officially registered in 2000, our roots go back further. As we celebrate 25 years, co-founder and adviser Professor Anand Saggar, shares his journey into genetics and the story of how the charity began.

The Beginnings of a Mission

"The first thing to say is that I'm truly honoured to be part of the PKD Charity and incredibly proud of how far the organisation has come. More so because my intention always was that it shouldn't survive and thrive by my efforts alone. I always wanted it to be for the patients and run by the patients. I saw myself as a catalyst to get it going."

Anand acknowledges the significant contributions of Tess Harris, who served as CEO until her passing in 2024 and played a crucial role in advancing the charity. "If I had to pinpoint two defining moments that took the charity to the next level, the first would be when we became a national charity in 2000, and the second was when Tess took the helm. Her dedication and vision were instrumental in shaping what the PKD Charity is today."

But how did it all begin?

From Nephrology to Genetics

Anand started his medical career as a general physician specialising in nephrology—the medical study of kidney function and disease. He trained as a doctor, later conducting nephrology research at the Karolinska Institute in Stockholm under Jonas Bergström, a pioneer of modern dialysis.

"I worked in the blood gas laboratory, running tests and relaying results to intensive care units. I didn't speak Swedish at the time, so I often faced resistance from staff who were surprised to receive results in English. It was an interesting time!"

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Celebrating 25 YEARS Polycystic Kidney Disease Charity

Funding The Future

Meet Jay, who recently joined us in our newly created role as Grants Officer.

"My job is to help the charity secure funding from trusts and foundations to support the work we do. That includes things like support groups, Information Days, and online Q&A sessions.

Most people don't realise that these services don't just happen automatically. We often need to apply for funding to make them possible, and each application requires care and evidence to show why the support is needed and how it helps people.

One of my favourite parts of the role is pulling together stories, feedback, and insights from both healthcare professionals and people living with PKD. Hearing how the charity's support is helping them and seeing the real difference it makes brings everything to life. That's the part funders really connect with, too. If you're ever asked for feedback after an event, please do!—it helps us show the impact of our work and strengthens our funding applications.

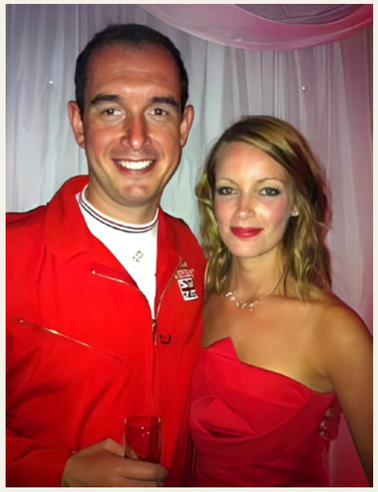
I've been blown away by the PKD community. The honesty, strength, and generosity in the stories people share have made a huge impact on me. It has also made me even more determined to make sure their voices are heard, as they are at the heart of every funding application we write.

Trusts and foundations come in all shapes and sizes. Some are small, family-run charities, while others are large national funders like the National Lottery. Each one has different priorities, processes, and expectations. That means I am constantly adapting how I write, but PKD is always at the centre of the story.

One thing I've learned quickly is that there is a huge amount of competition out there. Most funders receive far more applications than they can support. So, part of my job is to help PKD Charity stand out. I try to do that by keeping our funding applications grounded in real experiences, showing the impact of what we do, and highlighting the difference it makes to people's lives.

Trust fundraising can be challenging. There is no guarantee of success, and every funder is looking for something slightly different. But every successful grant helps us keep going.

I'm really glad to be part of the team at PKD Charity. It's a privilege to help secure the funding that allows us to keep showing up for the community—now and in the future."



Jay lives in Buckinghamshire with her two children and husband, David, a BA pilot and former Team Pilot for the Red Arrows.

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After returning to the UK, Anand applied for a research position with Professor Graham McGregor, a renowned academic who later established CASH, Consensus Action on Salt and Health. "I got this very prestigious fellowship called the Williams Fellowship of the University of London, which funded research into diseases affecting humans."

Anand and Tess Harris

This research led Anand to study polycystic kidney disease (PKD) and its link to high blood pressure. "At the time, we had about 50 to 100 PKD patients and were investigating whether high blood pressure was due to sodium retention or the cysts aggravating the renin system. We conducted a study, which became part of my thesis."

Through his clinical work, Anand encountered patients from multiple generations—siblings, parents, and children—who had PKD. "I suddenly realised there was this whole world of clinical genetics that hadn't existed as a formal specialty just five years earlier. My mentor, Professor Mike Patton, encouraged me to explore it. I finally felt like I had found something I truly wanted to do."

A Gap in Patient Support

While training under Professor Patton, Anand recognised a major gap in patient support. "PKD was the most common inherited kidney disease and the fourth leading cause of dialysis, yet patients would come into the clinic saying they had never met another person with PKD. Meanwhile, they were sitting next to three others in the waiting room."

Raising awareness
PKD Voices

It was then that he realised the need for a dedicated patient organisation. "There was a strong PKD organisation in the U.S., but nothing in the UK. That's when I decided to take action."

Anand brought together a group of patients and launched the PKD Charity. "At first, it was very much led by me. We operated out of the medical school and produced the UK's first patient information booklet on PKD—the little blue booklet!"

The First Steps

Funding was a challenge in the early days. "Money was needed to print the booklet, so I reached out to a patient who connected me with a Greek shipping tycoon. He generously donated £2,000, which became our first funding!"

Further support came serendipitously. "I approached the art department to design the booklet, and they helped as a favour. Then I found a printer through a PKD patient's recommendation. When I met the printer, he revealed that his brother had PKD. He printed the booklets for free."

These early efforts laid the foundation for the PKD Charity. "At this point, we weren't a registered charity, but we had charitable status. We were very London-centric, organising meetings and gatherings."

In the late 1990s and early 2000s, access to information was limited. "There was no internet as we know it today, no local support groups, and no national organisations providing PKD families with the resources they needed. Our booklet filled that void, becoming highly sought-after across the UK. Eventually, it was even translated into Japanese."

Expanding the Vision

As awareness of his work grew, Anand met Pam Hooley, who joined him on his mission and later became Chair of the PKD Charity. "Pam was diagnosed with PKD at age 32. With no family history of the condition, she was eager to learn more and seek out support. At the time, the only significant organisation she came across was the PKD Foundation in the U.S."

Pam and Anand connected with Dan Larson, then-President of the PKD Foundation in Kansas. "Their website was impressive, emphasising both information and community. They had chapters across the U.S., in France, and Japan—but not in the UK."

Encouraged by their work, the PKD Charity UK continued to grow, providing patients with a network of support and resources that had never existed before.

Breakthroughs in Research and Support

One of the biggest milestones in PKD research was the discovery of the PKD genes in 1996, which significantly advanced our understanding of the disease and led to the development of the first treatment—tolvaptan. "In the midst of growing the charity, the gene was identified, which was a pivotal moment. It meant we could better understand PKD, develop treatments, and offer more accurate genetic counselling."

Alongside this, the charity expanded its activities. "We started offering small grants and received lottery funding, allowing us to revisit and validate our booklets. We also launched patient information days, our first being in 2004 in Cambridge."

Fundraising efforts grew too, including the Geraldine Murphy Black Tie Irish Dinner Dance, organised by her daughter Rebecca, which raised over £10,000 annually. Geraldine sadly passed away in 2002, and Rebecca remains a dedicated trustee of the charity to this day.

Over the years, the charity has expanded its support, holding over 100 combined face-to-face and online events, including information days, educational webinars, nationwide support groups, Facebook communities, a helpline, and even launching a dedicated PKD app.

Challenges Ahead

Despite these successes, challenges remain. "Funding is always an issue for charities, and kidney disease doesn't have the same emotional pull as other conditions. As one nephrologist put it, 'It's hard to raise money for kidney disease because no one likes wee.'"

Raising awareness of the multi-system nature of PKD is also crucial. "PKD isn't just about kidney failure. It can cause heart murmurs, brain aneurysms, infections, and high blood pressure. Educating doctors and the public remains a key focus."

Proud Past, Bright Future

From its humble beginnings, the PKD Charity has become a vital organisation supporting patients, advancing research, and raising awareness about polycystic kidney disease. Anand's vision and dedication, alongside the contributions of countless others, have helped create a lasting impact on the lives of those affected by PKD.

"Looking back, I'm very proud of what we've built. The PKD Charity started as a small group of patients coming together, and today, it's a thriving and successful organisation that continues to make a difference. And that, for me, is the greatest achievement of all."

Professor Anand Saggar, Professor of Medical Genetics and Consultant in Clinical Genetics

New Guidelines Set to Transform PKD Care

The first-ever KDIGO guidelines focusing on autosomal dominant polycystic kidney disease (ADPKD) have landed!

KDIGO is a global organisation that creates evidence-based guidance to improve kidney care. These guidelines were developed over ten years by clinicians, researchers, and patient groups – including PKD Charity – to tackle real challenges faced by people with PKD and their families.

What This Means for UK ADPKD Patients

The guidelines aim to help healthcare teams provide more consistent, high-quality care. People with ADPKD can expect clearer advice on treatment options, including therapies like tolvaptan, which help slow disease progression. Care should be more tailored, with patients more involved in decisions. The guidelines also support better management of blood pressure, pain, and complications such as aneurysms. There's a strong focus on fair, respectful care for everyone, whatever their background.

A Call for UK Implementation

Professor Albert Ong, member of the KDIGO ADPKD Guideline Working Group, says:

"These guidelines result from years of high-level discussions among global experts, patients, and scientists to harmonise standards of care for PKD patients. I very much hope they will be adopted and fully implemented in the UK."

Honouring Tess Harris

The guideline is dedicated to Tess Harris, former CEO of PKD Charity, whose commitment to improving PKD care was key to shaping this initiative.

View and download guidelines
https://bit.ly/PKDKDIGO25

PKD Live Q&As: Your Questions Answered

Our PKD Live Q&A series continues to grow, offering expert guidance, practical tips, and an informal space to get your questions answered!

Here's a look back at the most recent sessions.

Topics Covered:

- **ADPKD Basics** – How ADPKD is diagnosed, its stages, and causes.
- **Genetics and Genetic Testing** – The benefits of genetic testing, how to interpret results, and IVF pre-implantation testing.
- **PKD and Hypertension** – Causes of high blood pressure and available treatments.
- **PKD and Aneurysms** – Symptoms, treatments, and prevention strategies.
- **Pain in PKD** – Causes of PKD-related pain and management options.
- **Anaemia in PKD** – Symptoms, treatment, and management approaches.

Access the Recordings

Missed a session? You can watch the recordings and explore more valuable resources at **https://bit.ly/PKDevtalk**

What You Told Us

"These sessions are SO helpful. It's not always easy to ask questions during rushed appointments. I trust the information given and always leave feeling better informed."

Anon, PKD & Anaemia Session

"Thanks so much for these webinars! I appreciate that you cover not only the obvious topics but also the less-discussed issues that affect many of us with PKD."

Anon, PKD & Aneurysms Session

"I have learned so much from these sessions and from the questions others have asked. It's such a helpful and safe environment."

Anon, Pain in PKD

These sessions remain a valuable resource for the PKD community, providing expert insights and shared learning. See "Coming Soon" for future events!

Travel Smart with PKD: Why Insurance Matters

With holiday season fast approaching, it's important to be prepared. Travel insurance is essential, providing peace of mind and financial protection if your trip doesn't go to plan.

A good policy can cover unexpected cancellations, lost baggage, missed connections, and most importantly, medical emergencies abroad. Without insurance, costs can quickly run into thousands. Avoid being stranded without financial or logistical support.

What to Look for in a Policy

- **Medical Cover:** Always declare pre-existing conditions like PKD to ensure your policy is valid.
- **Comprehensive Protection:** Look for cover that includes trip delays, personal injury, and lost or stolen items.
- **Compare Policies:** Don't just choose the cheapest—compare what's included and look into insurers who specialise in medical conditions.

Top Tips

- If you're travelling in Europe, carry a Global Health Insurance Card (GHIC) alongside your travel insurance. It offers basic healthcare access, but is not a substitute for full cover.

Apply here: **https://bit.ly/nhsGHIC25**

- Use comparison sites or specialist providers to find a policy that suits your health needs. Some companies even donate to the PKD Charity with each policy sold—at no extra cost to you.

Explore your options:
https://bit.ly/PKDinsurance25

By law, we cannot recommend any insurer or financial services provider, but the companies listed on our site offer access to a wide range of providers. Stay covered, stay safe—and enjoy your trip with confidence.

PKD Research Needs You

"When I was diagnosed with ADPKD in the late 1980s, I was told there was no cure. I'd likely need dialysis or a transplant one day, and there was a 50% chance I could pass it on to my children. I was only 23. It was a lot to take in."

"Years later, in 2007, I heard that research had started on a treatment to slow kidney damage. That treatment turned out to be Tolvaptan, which became available in 2015. It's still the only approved medicine for ADPKD. I often wonder—where would I be if people hadn't taken part in those trials?

There has never been a more exciting time for PKD research. Thanks to the new **PKD Partnership with Kidney Research UK**, there's a significant commitment to accelerating research efforts.

If you've ever thought about getting involved, now is the time. Taking part in research is a personal decision, but it can be incredibly rewarding. You're helping yourself—and helping others in the future.

And it's not just about clinical trials. Sharing your story helps researchers understand what it's really like to live with PKD. More and more, they're listening to what we think matters most.

Getting involved also helps you feel more informed and supported. You may build stronger connections with your care team and learn more about managing your condition.

Crucially, all studies are reviewed and approved before they begin. Your safety, rights and wellbeing always come first.

We'll soon be launching a new **PKD Patient Research Panel and Hub**—a place to share your insights, shape future research and stay updated on new trial opportunities.

This is a hopeful and promising time for our community. Be part of the progress."

Audrey Hughes
Patient Involvement & Engagement Officer, PKD Charity

Coming soon!

Live Q&A (Zoom):

Newly Diagnosed with PKD: Questions and Next Steps – Dr Matthew Gittus. Tuesday 24th June, 6.30pm.
Register: **https://bit.ly/PKDqa25**

Kidney Transplant in PKD – Mr Hussein Khambalia. Tuesday 3rd June, 6.30pm.
Register: **https://bit.ly/PKDTX2025**

In-person event:

Leicester PKD Information and Support Day. Dr Osasuyi Iyasere. Saturday 28th June.
Register: **https://bit.ly/LeicPKD25**

Drink tea for PKD

Who doesn't love getting together for a cup of tea, or coffee and cake. This year to celebrate our 25th anniversary we are inviting you to host your own tea party. It could be at your local community group, at work with your colleagues or in your garden with friends.

We have everything you need to get you started on our website from invites and posters to cake flags and games to play on the day. And, if you are stuck for some inspiration on what to make, we have even got a recipe book full of our communities favourite cakes and bakes!

Scan the QR code to head to our website and start downloading everything you need to host your big event!

Blooming lovely!

This year, PKD Charity turns 25! We're celebrating the amazing community we've built and the lives we've touched. Join us by adding a leaf to our online Celebration Tree.

Whether you're thanking a medical professional, remembering a loved one, or honouring a life-saving donor, your tribute matters. It's quick and easy—just visit our tribute page, pick a leaf, add a message or photo, and donate if you can.

Each leaf is a story. Let's grow the tree together and celebrate the people who make a difference— leaf by leaf, story by story.

Share your tribute now

Scan the QR code or visit:**https://bit.ly/PKD25Tree**

How far will you go for PKD?

This year, let's go big and celebrate the charity's 25th anniversary in style. We have loads of ways for you to test your stamina and nerve – all whilst supporting PKD Charity.

Northampton express Tower Abseil.

This is not for the faint hearted and will take nerves of steel to step over the edge of the imposing Express Tower in Northampton. An incredible 418ft high it is the largest abseil tower in the world, and we are looking for fearless individuals to join us in July to be a part of this event. Be quick though, we only have a limited number of places!

Northampton Tower Abseil

Three Peaks Challenge

Arguably the toughest challenge in the country, the Three Peaks Challenge involves scaling Ben Nevis, Scafell Pike and Snowdon, covering a total of 22 miles and ascending around 9500ft. It will push you to your limits, but you won't be alone. The excellent team from Global Adventure Challenge will be with you every step of the way, with words of motivation and snacks to get you up and down each mountain. Interested?

GLOBAL ADVENTURE CHALLENGES

Ultra Challenge Events

With events up and down the country, throughout the year there is something for every fitness level and ability. These incredibly popular events are set in some of the most spectacular countryside England has to offer and whichever event you choose to be a part of, it is sure to be memorable. Take a look now and see where your next adventure will take you.

ULTRA CHALLENGE SERIES

Take part in an event

If you haven't seen anything that takes your fancy so far, head over to our brand new events page where you will find lots of ways you can be a part of Team PKD. From 5ks to Marathons, fun inflatable runs to Tough Mudders. Take a look and join the team today. Scan the QR code, email **fundraise@pkdcharity.org.uk** or call 07715 664687.

Take part in an event

Fundraising
Get involved

Team PKD Kicks Off Event Season in Style!

The start of April was a busy and inspiring one for Team PKD as event season officially launched with both the London Landmarks Half Marathon and the Brighton Marathon taking place on the same day!

In London, Oliver, Maisey, Emma, and Evie all lined up at the start, ready to take on the 13.1 miles through the capital. They were spurred on by amazing crowds, live bands, and show choirs as they powered through the city streets. Each of them rose to the challenge and crossed the finish line to proudly collect their medals.

Among them was Oliver, one of our youngest runners, who was running in honour of his dad's journey with PKD.

"After years of challenges, he was given a second chance at life thanks to a selfless kidney donation from his sister—a testament to love, resilience, and the power of organ donation. This race is my way of giving back, raising awareness, and helping fund vital research so that more families can have hope for the future. Every step I take is for those still waiting, for those navigating PKD, and for the breakthroughs that can change lives."

At the same time, down by the sea in Brighton, Mya and Michael were preparing to take on the full marathon distance.

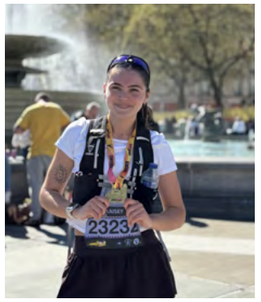
Mya shared her experience:

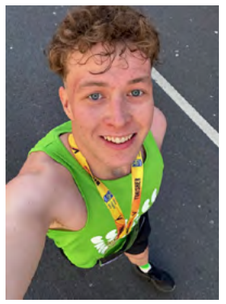
"I did it! I finished my first marathon. Running in the heat was awful, my body hurts, and I could never do it again—but I am so proud of myself for completing it. I raised £3,201 for PKD!"

Each one of our incredible runners has their own personal reason for joining Team PKD, and we are so grateful for their dedication and heart.

Want to be part of Team PKD?

Whether you're a first-timer or a seasoned runner, we've got loads of exciting events you can take part in. To find out more scan the QR code 'take part in an event' on the opposite page.



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 to 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.
https://bit.ly/PKDGroups

"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 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)

For ARPKD (autosomal recessive polycystic kidney disease)
- ARPKD Support (PKD Charity UK)

"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

Curious about PKD, worried about the future, or baffled by medical jargon? Get clear answers from experts at our free educational events – whether it's a full-day, in-person session or a 'PKD Live' topic-specific online event.

You can also watch recordings of many of our events online. Take a look here:
https://bit.ly/PKDevtalk

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

Help at Your Fingertips

Get the FREE PKD App for credible information and health advice, all in one place. Scan the QR code or search "PKD App" on the App Store or Google Play.

Scan here

Be the First to Know!

Sign up for our e-news to stay up to date with the latest on PKD research, events, inspiring supporter stories, and ways to get involved. We only send the important stuff—and you can unsubscribe anytime.
https://bit.ly/PKDEnews

Your PKD Hub

The PKD Charity website is a fantastic source of trusted information on all aspects of PKD, both ADPKD and ARPKD. Learn about diagnosis, symptoms, genetic testing, treatment options, and the latest in research.

You'll also find details of educational events, support groups, and how to get involved through fundraising and awareness.

www.pkdcharity.org.uk

How to get support, visit
www.bit.ly/pkd-support

Upcoming events, visit
www.bit.ly/pkdc-events