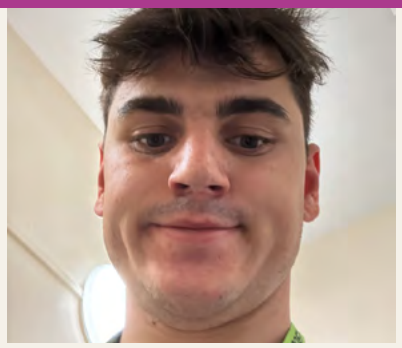
pkd charity
Polycystic Kidney Disease

newsletter

pkdcharity.org.uk Issue 33 - Autumn 2025

Get our printed or e-newsletter



From Patient to Future Surgeon

Autosomal Recessive PKD (ARPKD) is a rare form of PKD affecting about 1 in 20,000, causing breathing difficulties at birth, high blood pressure, liver complications, and kidney failure.

Sadly, outcomes can be very serious, with some not surviving the first days of life, while another third need a transplant before their teenage years. Thankfully, treatments are improving, and more children now go on to thrive.

Andy knows just how tough the journey can be, and how lucky he is. His childhood was filled with hospital visits and setbacks. There were difficult times—but also unwavering support from his family, expert doctors and surgeons, and psychological care when needed. In June 2024, just after his 21st birthday, Andy received a combined liver and kidney transplant. He calls it "the best present ever—a true gift of life."

Andy says: "I know how fortunate I've been. Living with ARPKD is hard, but there can be hope. Speak out, seek support, and believe in brighter days ahead."

Now studying medicine, Andy hopes to become a transplant surgeon, inspired by those who saved him. He also contributes to research and advocacy projects like IMPEDE and CILIAREN, helping shape the future of PKD care.

From London to Italy: Three Friends Cycle 1,700 km for PKD Charity

In May, after months of planning, lifelong friends Joff, Mark and Charlie set off on an extraordinary ride from West London to Umbria in central Italy.

Their goal: to honour a personal connection to Polycystic Kidney Disease and raise awareness for the PKD Charity. Together, they covered over 1,700 kilometres across diverse landscapes, overcoming physical challenges and weather extremes, while raising nearly £25,000!

More than a Challenge

For Charlie, this challenge was more than just a cycling trip; it was inspired by his wife, Loveday, and her battle with PKD, which she inherited from her father. Both required kidney transplants after progressing to kidney failure. Loveday's mother had donated a kidney to her husband decades ago, and after years of waiting, Charlie and Loveday entered a donor matching pool scheme.

Then, in May 2023, just before Loveday was due to start dialysis, they received life-changing news: compatible recipient and donor matches had been found. Charlie was able to donate a kidney to another recipient in the scheme, and in turn, Loveday received a compatible kidney. The transplants took place in July, transforming Loveday's life, which she describes as "like having a brand new battery fitted."

Friendship on the Road

Fast forward to 2025, now fully recovered and recently retired, Charlie saw this as the perfect moment to take on the cycling challenge. "I had been kicking the idea around for 7 or 8 years," he said, "and with Loveday and I both fully recovered, the timing felt right." After years of sketching routes, the trio finally committed together.

Joff, Mark and Charlie's friendship dates back decades. Joff and Charlie met at school aged eight, and Mark joined at 16. Though they only took

Continued on page 3

One Year On: Our CEO Alison Taylor

It's hard to believe it's already been a year since I joined the PKD Charity. When I stepped into this role, I was aware of the big boots I had to fill and hoped the team and community would bear with me as I found my feet. I need not have worried. I've been met with warmth, and encouragement.

Over the past 12 months, I've had the privilege of meeting patients, families, fundraisers, clinicians, researchers, and partners across the UK. Each has helped me understand what PKD really means, and how we can grow as a charity that listens, learns and leads with compassion.

Some of my earliest highlights were attending our PKD Information Days in Birmingham and Leicester. Meeting people face-to-face and hearing your stories — the challenges, the questions, the resilience — reminded me why we're here: to ensure no one feels alone in their journey with PKD.

That same spirit shone at the Transplant Games, a true celebration of life after adversity. Our abseil fundraiser in Northampton was unforgettable — watching people conquer fears in support of loved ones affected by PKD was inspiring.

Another standout moment was visiting Wolverhampton University, where I met young researchers in Dr Paraskevi Goggolidou's lab. Their passion for understanding PKD mechanisms and pushing science forward left me feeling incredibly hopeful. Knowing that bright, determined minds are working on solutions across the country is a real source of optimism.

I've also had the chance to represent the patient voice at events like the Genomics England meeting, the ANN UK Kidney Nursing Conference, and other research-focused gatherings. Speaking with researchers about the importance of including patient insight in trial design is something we'll continue to champion.

A major development I've been working alongside the board with this year has been the PKD Partnership — a bold, collaborative initiative with Kidney Research UK bringing together clinicians, researchers, and patient representatives to accelerate progress. We've recruited a project lead and launched the first funding round with up to £1 million available — a hugely significant and inspiring milestone.

We've strengthened how we share trusted information, by updating our website and completing our Patient Information Forum assessment. I've also enjoyed co-hosting Live Q&As on topics such as aneurysms and anaemia, helping people get answers that matter to them.

Behind the scenes, I've built relationships with national and international kidney charities, while our own team has taken time to reconnect and refocus during away days in Manchester and Birmingham. I'm proud of their dedication and kindness — qualities that keep us motivated.

As I step into my second year, I do so with gratitude and excitement. We've achieved a lot, but there's more to do. Thank you to everyone who has welcomed me, shared their stories, and supported our work. It's been a privilege to walk alongside you — and I can't wait to see what we achieve together next.

Exciting trial and research news ahead

There have not been any clinical trials in the UK for some time, but we are excited that recruitment is scheduled to begin this autumn for IMPEDE-PKD.

This international study aims to recruit 1,174 people worldwide, including 300 from the UK, and will test whether the diabetes drug metformin can help slow kidney damage in people with ADPKD.

The UK team, led by Sheffield Teaching Hospitals and the University of East Anglia, will also study chronic pain in ADPKD—how people manage it now and whether metformin can help reduce it.

The PKD Charity will host an IMPEDE-PKD webinar on 26 November, when Dr Ragada El-Damanawi, Consultant Nephrologist in Sheffield and Chief Investigator, will share details about the trial, explain what taking part involves, and answer any questions you may have.

We also have exciting developments on the horizon at the PKD Charity as we prepare to launch our Research Hub. Everyone benefits from research because it provides evidence of what works best. Our Research Hub will keep you updated on new research and trial opportunities. It will also be a place where you can get involved and help shape future research.

Various contributor roles and opportunities will be available, such as collaborating with trial teams to finalise operational protocols related to patient involvement, reviewing research documentation, representing the patient perspective, advocating for trial participants, and contributing to clinical practice recommendations.

Members of the Hub will be supported by the PKD Charity to ensure they have the necessary skills and knowledge to feel confident and empowered to contribute to the design and delivery of research based on their own lived experience.

Interested? Contact our PPIE Officer: audrey.hughes@pkdcharity.org.uk

Impact in Action
Making a Difference

Charity cycle continued from page 1.

up road cycling around 2007, they had shared mountain biking adventures before stepping up to longer European rides. This was their longest and most ambitious trip yet.

Support was crucial: Mark's daughter Ava launched and managed their social media presence, boosting donations and morale. Meanwhile, Noah and Deva, Joff's nephew and girlfriend, acted as on-the-road support crew, providing encouragement, logistics and vital care.

Peaks and Pitfalls

The journey began in London. After crossing the Channel from England, they set off from Dieppe, France, along beautifully tended cycle ways with many miles ahead.

One highlight came after crossing the Alps via the Col de Mont Cenis pass, a gruelling climb rewarded with stunning views and a warm welcome from Simone, the mountain summit café owner, before descending into Italy. Their first Italian dinner at "Rigatoni Tony's" in Rivoli marked a lively introduction to Italian culture!

The route took them through iconic towns in the Po Valley — Casale Monferrato, Piacenza, Parma and Modena — where hot weather and steep climbs pushed their limits. Throughout, Noah and Deva's support proved critical, keeping the riders hydrated and motivated.

The final day was the hardest: the longest distance and steepest climbs. Exhausted, the trio paused 10 kilometres from the finish for Coke and crisps, only for Mark to slip on gravel and fall from his bike. Luckily he escaped with minor injuries, and despite fatigue, they rode on to the finish. Friends and supporters greeted them with banners, balloons, prosecco and a medal ceremony that turned into an emotional celebration.

Tips for Future Adventurers

Reflecting on the experience, the trio emphasised the importance of preparation, careful route planning and pacing. They advise adventurers to respect limits, factor in rest days, and focus on nutrition. "I prefer real food over gels or energy bars; they work better for me. We learned the hard way what it feels like to run out of energy mid-ride, and it's not fun," said Charlie.

Booking overnight stops in advance removed stress and ensured smooth transitions. A support vehicle was invaluable, especially knowing bags were waiting at the hotel after long rides. "We couldn't have done this without Noah and Deva," Charlie says gratefully. "They kept us going with optimism and resourcefulness. We hope we didn't scare them off cycling for life!"

Charlie encourages riders to enjoy the journey as much as the cycling: "Stop regularly, take pictures, swim in lakes and rivers, make detours, and savour the scenery."

Would they do it again? The answer is a cautious no — at least not this exact route. Fifteen consecutive days on the bike was tough!

Their ride not only pushed their limits but also created incredible memories. Raising nearly £25,000 for PKD Charity is a remarkable achievement — one that will help others facing the challenges of this disease.

Decades of Dedication!

As we mark our 25th anniversary, we celebrate the people who made this journey possible. Among them is Rebecca, our longest serving trustee.

A mum of two from Manchester, she has lived with PKD since childhood — facing it all with grit, warmth and a wicked sense of humour.

Living with PKD

I was just 13 when I was diagnosed. It all began with a cystic bleed. At the time I was doing karate and thought the pain was simply part of my menstrual cycle. My mum was already a PKD patient at Manchester Royal Infirmary, so I had always known about the genetic risks. Because of that family history, I was referred to the genetics team at the hospital. A scan confirmed the diagnosis.

Loss to New Beginnings

In 2002, my mum passed away. She had run our family's construction business alongside my dad. To honour her life, and to raise money for the PKD Charity, we organised a black-tie dinner dance. My sister had a place in the London Marathon, so the event was designed to support her fundraising. We named it the Geraldine Murphy Black Tie Memorial Dinner Dance, and it quickly became a well-loved and respected annual occasion.

It was more than just a fundraiser. It was a chance to celebrate life, share laughter and raise awareness of PKD in a way that wasn't overly clinical or medical. We had Irish dancers, comedians, raffles and auctions. The highlight each year was the "star prize": a wheelbarrow! But not just any wheelbarrow—over the years we had crystal-covered ones, motorised self-tipping versions, even a bike-barrel you could ride. These brought fun to what could otherwise have been a heavy subject, and guests loved it.

We were delighted whether we made £1 or £15,000. The goal was always the same: to honour my mum and spread awareness of PKD.

Becoming a Trustee

After the first few years, we had raised so much that we became one of the charity's principal fundraisers. The board asked if a member of the family might want to become a trustee, so we had a say in how the funds were used. That's how I joined in 2003.

Since then, I've seen so much change over the years. PKD Charity has grown stronger, more diverse, more structured, and with better planning and support for the future. We now have more focus on ARPKD, more resources for patients and families, and clearer strategies to make sure we can continue to provide vital help.

Patient and Advocate

One of the challenges with genetic conditions like PKD is that your expectations are often shaped by the experience of those you've cared for. For me, that was my mum. It took time to re-write my own journey and realise my future didn't have to follow the exact same path.

In 2013, I received a kidney transplant from my aunt. Every day I am grateful that my kidney is still working. That gift gave me the chance to live life fully, and it motivates me to keep giving back.

Working alongside Tess, our late CEO, was another highlight. She was full of vision and drive and her commitment helped shape the charity into what it is today. I remember when we travelled together to the United States to attend a PKD Foundation event. Their regional fundraising groups competed fiercely, but what stood out to us was the strength of our supporters. They were, and still are, our greatest investors.

Looking Ahead

For me, the most memorable thing about PKD Charity will always be the people: those who give up their time, resources and energy to support patients and families.

I've loved seeing how the charity has evolved, and I hope it continues to be the first port of call for anyone newly diagnosed, as well as for patients and carers already living with PKD.

It has been a privilege to play a part in this journey, and I look forward to what's still to come.

After My Kidney Transplant: A Reflection

Meet Malen, a mum of three from Rugby, as she shares her journey with PKD, the resilience and love that sustained her, and its impact on her family.

Sixteen years ago, I received a kidney transplant. I've overcome the initial shock of being advised over the phone that I had a kidney failure; I have since weathered infections, long hospital stays and a long list of complications and side effects from medications. Battered by these events, I often find myself quietly stunned that I'm still here. Breathing. Functioning. Relatively intact. It is short of a miracle, and I am grateful.

I live with Autosomal Dominant Polycystic Kidney Disease (ADPKD). It causes fluid-filled cysts to form in the kidneys, which grow and multiply over time, eventually compromising kidney function and often leading to failure. It's usually inherited, though sometimes caused by new mutations. My ADPKD has been and still is, a collective project that involves the unwavering love of my family, the dedication of doctors and nurses, extraordinary advances in medicine and of course—my donor—someone I never met, who gave me the most profound gift I've ever received: time.

In recent months, my youngest daughter was diagnosed with the same condition. My eldest son has the condition too. And just recently, my middle child, an older daughter, was diagnosed with Stage 4 renal failure. It's not the news any mother ever wants to hear.

I know exactly what lies ahead for her. I've walked that road, not too long ago. The symptoms, procedures, appointments, setbacks… they're all fresh in my memory, like entries in an invisible diary. As a mother, I instinctively want to spare my children any pain, any discomfort, any fear.

But then I remember something important: this journey, as brutal as it was, also gave me something. Beneath the pain and uncertainty, it offered me a deeper understanding of life—of love, resilience, compassion, and purpose. I survived because I wasn't alone. I was carried by my husband, my father, my family, friends, community and the quiet strength that lives in all of us when we're seen, heard and held.

I won't tell my daughter, "don't worry" or "it'll be okay"—because most days, it won't be. And that is the truth. But I will walk with her and remind her of all the times she was there for me—driving me to appointments, visiting me in hospital, sitting quietly by my side at home. And now, I'll be there for her. She'll face what's ahead with courage and grit. And like I did, she'll emerge—scarred maybe, but stronger. She'll carry with her the same love and support that carried me. This is just one child's path. What the future holds for the other two, is yet to unfold. As my mother always said, "we'll cross the bridge when we get there". And our bridges—well, they're built to withstand storms, no matter how heavy the load. And I'm deeply grateful to everyone who's helped us lay each plank, bolt each beam, and keep that bridge standing strong.

This is not the story I hoped to write. But it's ours—and we will all face it... together.

The PKD Charity

In June, my daughters and I attended a PKD Charity Information & Support day. We met a room full of wonderful individuals affected by PKD, with their loved ones. It was a good day to connect and share experiences. An event that lifts some burden, offers massive support and new perspectives.

Malen is the host of our new PKD group in Warwickshire. To register your interest in joining, please email info@pkdcharity.org.uk.

Fundraising Highlights!

Congratulations to Liv Elliott who set herself the target of cycling 80km earlier this year. On her first attempt, her gear assembly sheared off at mile 19, but undeterred, a new date was set and she completed the entire distance and raised over £300.

Thank you to Lesley who once again hosted a summer coffee morning to raise funds for us. She had a fabulous turn out on a glorious day and raised an incredible £670. Lesley has been a supporter of the charity for a number of years and we truly appreciate all of her efforts.

Well done to Megan Hymer Smith and the team from CFC Healthcare, who took on the Seven Sisters Hike back in June on one of the hottest days of the year! They all completed the hike successfully, despite the heat, and raised £2,306!

Thank you to everyone at the Moors Inn who are supporting us for the second year. During that time, they have held a number of fundraising events for us, including a wine tasting evening, Bands & BBQ afternoon, a pop up dress sale, a touch of the Blues evening and a number of tombolas and raffles.

Join Graham: Be Part of a PKD Group!

Often the best support comes from people who've been there. That's what PKD Connect Groups are all about — friendly, informal meetups where you can share worries, swap tips, celebrate wins, or just listen.

Hosted by volunteers with lived experience of PKD, they create a welcoming space for patients, families, and friends. And hosting is rewarding too!

Take Graham, a married father of one from Bolton. Diagnosed with PKD at 53, he's been taking Tolvaptan for three years. After speaking about his experience at our Salford information day, and taking early retirement, he wanted to give something back. In March 2025, he launched the Greater Manchester group, which has already met twice in Kearsley, bringing people together for mutual support.

Graham says:

"I volunteer in the hope of making a positive difference — no matter how small — for those living with PKD or supporting someone who does. Volunteering also helps me come to terms with my own condition, knowing there are others I can call on for support if needed."

Interested in hosting a group? Get in touch: info@pkdcharity.org.uk

Find out more about groups on the back page.

Our Christmas Shop is open!

It's never too early to start thinking about Christmas. To help you prepare for the festive season, we have a beautiful selection of Charity Christmas cards available for you to share with friends and family.

PKD Christmas Shop

To avoid disappointment, be sure to place your order early, either by scanning the QR code to visit our online shop or by completing and sending the enclosed form directly to our suppliers.

What Will You Do in 2026?

Join TEAM PKD

Start setting your goals now with our huge range of events designed to inspire and challenge you. Whether you're up for a Tough Mudder, an inflatable run, a thrilling sky dive, or a heart-pounding bungee jump, we've got something for everyone.

Prefer something a bit more grounded? We also offer walking and running events tailored to every fitness level.

Head over to our Events Page, email fundraise@pkdcharity.org.uk or call 07715 664687

Leave a Legacy of Love and Hope This October

Farewill

This October, we're proud to once again partner with Farewill to offer our community the chance to write a will for free.

Having a will in place is one of the most important things you can do for the people you love. It ensures your wishes are clearly known, your loved ones are protected and the causes you care deeply about, like the fight against polycystic kidney disease (PKD), can carry on with strength and purpose.

By including a gift in your will, you can help fund vital research and support for those affected by PKD, creating a legacy that lasts far beyond your lifetime. It's a simple, generous act that can make a profound difference for generations to come.

The process is quick and easy, just 15 minutes to gain peace of mind. Start writing your will for free today by scanning the QR code or visiting:

www.farewill.com/pkd-freewill

Living Well with PKD

You're Not Alone. You've Got Us.

PKD Connect Groups

Our groups are springing up across the UK, with more on the horizon! Whether meeting in a cozy café, or online, you'll find understanding, encouragement and even a few laughs! Join a group: **bit.ly/PKDGroups.**

Educational Events Coming Soon

Information & Support Days:

- **Exeter:** Sat 8 Nov 2025
- **Glasgow:** Sat 28 Mar 2026

PKD Live Q&As

- **Low Clearance and Renal Replacement:** Tues 4 Nov 2025
- **IMPEDE-Research Study:** Wed 26 Nov 2025

For details, and to register, visit **bit.ly/pkdc-events** or scan the QR code.

Helpline

Confidential support & info

0300 111 1234
Mon–Fri, 9:30–5pm

PKD App

Free PKD info & advice

Scan QR code or search PKD App in the App Store / Google Play

Scan here

PKD Live Recordings

Watch past Q&As on demand:

bit.ly/PKDevtalk

Facebook Groups

Private groups to share & connect

For ADPKD (Autosomal Dominant PKD)

- PKD Support (PKD Charity UK)

For ARPKD (Autosomal Recessive PKD)

- ARPKD Support (PKD Charity UK)

Stay Updated

Sign up for e-news

Research, events & ways to get involved:

bit.ly/PKDEnews

Your PKD Hub

Trusted info online

Diagnosis, symptoms, testing, treatments, research, events & support. **www.pkdcharity.org.uk**