

PKD Charity Welcomes New CEO

Alison Taylor joins as our new Chief Executive Officer, bringing over 22 years of senior leadership experience in health and research-related charities.

Her previous roles include CEO of the Children's Liver Disease Foundation and Head of Services, Education and Research for Meningitis NOW. She is passionate about working alongside patients, families, clinicians, research teams, and partners to develop support services, campaign for improved care, and support research to develop new treatments.



"I feel very privileged to be joining the PKD Charity team. My career has been focused on the leadership of small but mighty charities that put the patient at the centre of all they do. During my 9 years as CEO of CLDF, I enjoyed working closely with Tess Harris on several initiatives, and it is an honour to become the new Chief Executive as we build on her incredible legacy. I'm looking forward to working with the board, team, patients, clinicians, partners, and supporters as we plan for the future to further develop the charity and the work we do to improve the lives of all those affected by PKD." Alison Taylor, CEO.

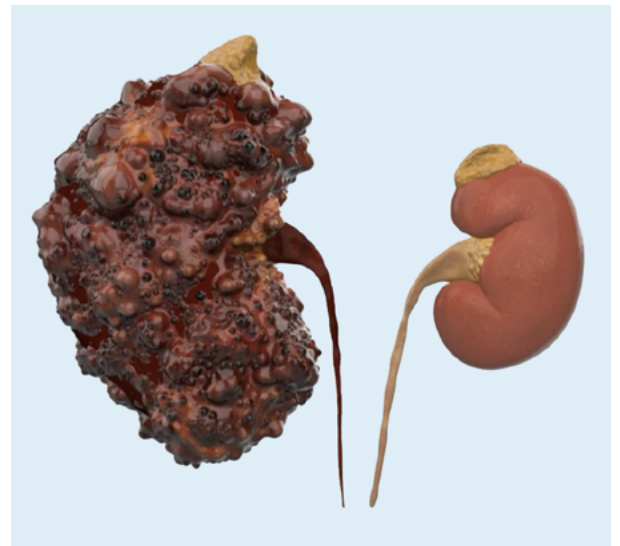
New Hope for PKD Patients: IMPEDE-PKD Study Launches

A ground-breaking research study is underway to investigate whether the diabetes drug metformin can slow the progression of Autosomal Dominant Polycystic Kidney Disease (ADPKD).

Marked by the growth of fluid-filled cysts in the kidneys, ADPKD is the 4th leading cause of kidney failure with over 70% of people affected requiring kidney replacement therapy by age 58 (UK RaDaR data).

With limited treatment options currently available, finding ways to slow cyst growth early is crucial to preventing irreversible kidney damage. Metformin, commonly used to treat diabetes, has shown promise in initial studies by potentially blocking signals that drive cyst growth. Recent clinical trials have also confirmed that metformin is safe for use in ADPKD patients.

The IMPEDE-PKD trial will involve 1,174 participants from the UK, USA, Australia, and New Zealand, with 300 patients being recruited from the UK. In the first phase of the study, all participants will be gradually adjusted to an optimal metformin dosage. Afterwards, they will continue taking either metformin or a placebo for two years. Throughout the study, kidney function, pain levels, and quality of life will be closely monitored.



Medical Illustration: Aimee Hutchinson

As a double-blind trial, neither participants nor researchers will know who is receiving the medication or the placebo. The study's goal is to assess whether metformin can delay the progression of kidney disease and reduce the need for kidney replacement therapy in ADPKD patients. If successful, this research could transform the treatment landscape for those living with this challenging condition.

Information and support

Living well with PKD



Writing to Your Donor's Family

After your transplant, your main focus will be on recovering and adjusting to your new life. At some point, you may feel ready to write a thank you letter to your donor's family. This is entirely optional, and it's okay if you choose not to.

What's the Process?

1. Write your letter, card, or email without including personal details (like your last name, address, or workplace).
2. A coordinator will review your message to ensure it doesn't reveal your identity.
3. A copy is kept on file.
4. Your message is matched with your donor.
5. The donor's family is notified that a message is available.
6. If they wish, the message is forwarded for them to open at their discretion.

Sometimes, donor families may reply to your letter, but they might also choose not to. Either way, your gesture is meaningful.

What to Include

- Share details about your life, hobbies, or family if you wish.
- You don't need to explain why you needed a transplant unless you want to.

Where to Send Your Letter

By Post: Mail your letter to:

Donor Family Care Service
NHS Blood and Transplant
14 Estuary Banks
Speke
Liverpool
L24 8RB

Include a separate sheet with:

- **Your full name**
- **Your date of birth**
- **The date and type of your transplant**
- **The hospital where your transplant took place**

By Email: Send your letter as an attachment to:

transplant.recipientcare@nhsbt.nhs.uk

Include the same details as above in the body of the email. This information is only used to match records and will not be shared further.

We Need Your Voice!

Help shape the future of the PKD Charity by sharing your thoughts in our quick survey. Your feedback is crucial for us to enhance our services, plan future initiatives, and secure essential funding. Whether you're living with PKD, caring for someone with it, or a dedicated supporter, your input matters.

Participating is easy and confidential - simply scan the QR code or click here <https://bit.ly/PKDCSurvey2024> to complete it online.

Your responses will directly influence our work and make a real difference in the PKD community.

Thank you for helping us make a bigger impact!



What do you think?



Information and support

Living well with PKD



Our Groups Are Growing!

PKD Connect meetups are now available in Bedfordshire, Derbyshire, Hampshire, Herefordshire, Liverpool, London, Newcastle, and Norfolk! We also offer online groups such as PKD Connect Wales, ARPKD Time to Chat, and a Low Clearance Group for those facing dialysis or transplant. Plus, there's a group for young people aged 16-30.

These groups provide a welcoming and supportive space for anyone affected by PKD to come together, share experiences, and find mutual support. Whether you're celebrating successes or facing challenges, our informal meetups offer an environment to be yourself - no pressure, just understanding faces.

Meet Tina, founder of our Hampshire Group:

"Hi, I'm Tina, 57 years old and a PKD patient. Although I've known about my polycystic kidney disease since my teens, I didn't think much of it until recently when my kidney

function declined, and my consultant recommended Tolvaptan.

This prompted me to seek support, which led me to the PKD Charity website. While the site was informative, I felt a need to connect with others going through similar experiences. With no local support group, I volunteered to start one, and in June 2024, the Hampshire Support Group was born. So far, we've held two meetings, with a third scheduled for November.

Nine people attended the first meeting, six of whom were at different stages of PKD. The atmosphere was incredibly positive, with attendees eager to share their experiences. Though some discussions were difficult, everyone was grateful by the end and excited for future sessions.

I'm thankful to the PKD Charity for their support and hope the group continues to grow, helping more PKD patients find the support they need."

Interested in starting a group? Contact susan.muirhead@pkdcharity.org.uk.



New Consortium Boosts Efforts in PKD Research

We are proud to launch the PKD Research Consortium, a crucial step in addressing the severe underfunding and stagnation in PKD research.

PKD, the most common inherited kidney disease globally, receives a disproportionately small share of the UK's health research budget.

This lack of funding has resulted in minimal progress in treatment over the past 50 years, with many patients still receiving outdated care.

The emotional and physical toll on patients and their families is immense, compounded by the disease's significant burden on the NHS, which costs £750 million annually. PKD is responsible for 1 in 8 kidney transplants and dialysis cases in the UK, underscoring the urgent need for progress.

In partnership with Kidney Research UK, the consortium will bring together leading experts to advance research. By utilising innovative models like organoids and biosamples and leveraging data from the UK Rare Kidney Disease Registry (RaDaR), the consortium aims to uncover new insights and drug targets.

As we move towards 2025, the collaboration is poised to overcome past research limitations and pave the way for significant breakthroughs in the years to come.

Raising awareness

PKD Voices

A 'wee' inconvenience, but worth it!

Nicola Moore opens up about the shock of discovering she had PKD after treatment for a knee injury, and the challenge of managing tolvaptan's frequent bathroom trips - all while continuing as a secondary school teacher.

When I seriously injured my knee exercising in 2017, my main concerns were who was going to cover my lessons as a biology teacher and whether I would make the school trip I had committed to – kidney disease could not have been further from my mind. An MRI scan revealed I had torn my anterior cruciate ligament (ACL) and meniscus and would need surgery. During this time, my GP prescribed a non-steroidal anti-inflammatory drug (NSAID) for pain relief.

Discovery of cysts

After taking the NSAID for a year, my GP requested a blood test to check my kidney function. I had never had a kidney infection, had no family history of kidney disease, so was shocked when the test revealed my kidney function was lower than it should be.

During an ultrasound scan of my kidneys, the sonographer mentioned something about cysts, so I casually asked where it was – only to learn there were hundreds of cysts in my kidneys, liver, pancreas and spleen. An MRI scan and genetic testing then confirmed I had Autosomal Dominant Polycystic Kidney Disease (ADPKD). With no family history, I am a genetic mutant or de novo, which is the more delicate medical term for about one in 10 of ADPKD patients with this background.



Photography by Peter Flude: www.peterflude.co.uk

Learning about tolvaptan

I started to see a kidney consultant in February 2019, who told me about the drug tolvaptan, which could slow down the progression of my disease. I was keen to give it a go, as there were no alternative treatments. However, tolvaptan is an expensive drug and NICE guidelines restrict it to patients with evidence of rapidly progressing disease, which means not everybody with ADPKD qualifies for treatment. Despite my new diagnosis, the lack of historical data meant, initially, there wasn't enough evidence to qualify me for the drug.

Just can't wait!

I finally qualified for tolvaptan in February 2022, but felt daunted by managing the drug's side effects. It works by blocking a hormone called vasopressin, which normally causes the kidneys to reabsorb water back into the blood; without it, you feel more thirsty, need to drink more water and pass urine more often.

I was worried about whether I would drink enough water, as I often didn't feel thirsty and whether I'd wet myself! Through the Polycystic Kidney Disease Charity, I discovered the tolvaptan Facebook group and it was useful to hear other people's experiences and recommendations,

which included the Bladder and Bowel UK's 'Just Can't Wait Card' which gives access to toilets not normally available to the public.

Living (and sleeping) with the side effects

The first couple of months were hard. I was so thirsty all the time, particularly at night, gulping down lots of water only to wake up an hour later to go to the loo. I quickly realised it helped if I took the second tablet earlier in the day and stayed away from anything salty and big meals in the evening.

And, I did not wet myself – turns out I still have bladder control, just like before, which is quite a relief, as I spend my day standing in front of teenagers! I do, however, go to the loo far more often (about 10-12 times a day) or about every hour and a half in the day and twice during the night. At school, accessing drinking water is not



Raising awareness

PKD Voices

always easy, so I take four, 750ml water bottles with me. Fortunately, my classroom is close to a staff toilet and I time my loo breaks with lesson changes. So far, I have found it manageable. I've also explained the basics to our HR department and now have the added bonus of not having to invigilate exams or go on long, coach trips!

After my first month on tolvaptan, the dose was titrated up, which is usual, but my eGFR dropped by 11. I had read on the Facebook group that a slight drop in eGFR was normal and nothing to worry about, but my consultant stopped my tolvaptan for a month – and I will not lie, I was so ready for the extra sleep! He then put me back on the lower, starting dose of 45mg in the morning and 15mg in the afternoon and thankfully, my eGFR came back up.

I have now been on that dose for just over a year and my eGFR is stable.

Benefits

Tolvaptan's benefits are greater the earlier you take it, so I am not sure how much extra time it will buy me before my kidneys fail. But I find the side effects manageable (even though I drink about four to five litres a day now!) and, like many women, I am used to being aware of where the nearest toilets are.

On balance, I feel continuing with tolvaptan is my best option for the moment.

Useful Links:

Read the full article on "Tolvaptan & PKD" in the Kidney Care magazine

<https://bit.ly/KM24Tolv>



Get a Just Can't Wait Card: Bladder and Bowel UK

www.bbuk.org.uk

British Transplant Games 2024: Celebrating PKD Heroes

The British Transplant Games in Nottingham this August was an inspiring event for all involved.

A special shoutout goes to Darren from Leicester, who won two Gold medals in swimming and a Bronze in volleyball. Just over a year ago, Darren received a kidney from his wife, Donna, following his PKD diagnosis 13 years earlier. Their story is a beautiful reminder of how organ donation can transform lives.

Mark, also known as Maid Marian, hit the 5k Donor Run with his son Christopher and wife Gaby, dressed as Robin Hood and Friar Tuck. They ran to raise money for the PKD Charity and Guy's Hospital Transplant Team, boosting awareness with their fun costumes.



Claire, an ARPKD patient, who is 44 years post-transplant won Bronze in the cricket ball throw, proving her enduring strength. Andy continued his success by winning Gold in Doubles Badminton and Silver in Table Tennis, following his recent wins at the European Championships.

These stories, along with many others, highlight the power of organ donation and the incredible resilience of the transplant community. Congratulations to all who participated - whether you won a medal or not, your spirit and strength are truly inspiring.



Fundraising

Get involved

How can you support PKD?

Could we be your charity of the year for 2025?

Are you part of a sports club, a choir, or perhaps your workplace is looking to select a charity of the year?

By nominating us as your charity partner, you will be helping us to spread the word about PKD and the importance of the charity. It will also help us to raise vital funds so we are able to continue with our charitable aims.

If you know of an opportunity but would like to discuss it further, please get in touch with the fundraising team at fundraise@PKDCharity.org.uk

Easyfundraising

Did you know you can raise money for PKD by doing your online shopping? From weekly shops, insurance renewals or a cheeky takeaway at the weekend, every time you do your shopping through the app, we receive a donation. The best thing is, it won't cost you anything!



To create your account scan the QR code or [click here](#), sign up and get shopping!

You have to be in it to win it!

Did you know that every week, one lucky person will win £25,000 playing the Genetic Lottery? For as little as £1 a week, your number will be entered into the weekly draw, which takes place on Friday. Better still, you'll be raising money for the PKD Charity, so everyone is already a winner. Don't delay - sign up now by scanning the QR code or [click here](#)! You can even buy an entry as a gift for the person in your life who has it all!



What will you do in 2025

Although we are still firmly in 2024, it is never too soon to start planning your next big adventure.

We offer charity places in a number of events throughout the year up and down the country so whether you are a walker, runner or fancy a go at skydiving, we have something for everyone.

Whatever you decide to do for PKD Charity, you will not be alone. Our fundraising team are always on hand to offer support and guidance on how to make the most of your fundraising.

These are just a few ideas on what you could be a part of, so if you can't see anything that tickles your fancy, or you have an idea about doing your own thing get in touch at fundraise@PKDcharity.org.uk



Christmas Cards

The nights have started drawing in and there is a definite chill in the air. That can mean only one thing. It must be nearly Christmas! Well not quite, but it is never to soon to be prepared.

The PKD Christmas shop is now open where you can find a wonderful selection of Charity Christmas cards that are sure to be a big hit with family and friends.

To place your order, simply scan the QR code or click here <https://bit.ly/PKDXmas24> to order online.



Create Your Free Will Today

We offer a free will-writing service through Farewill, one of the UK's top specialists. Only around 60% of UK adults have a will, and even fewer leave a charitable gift.

You can write or update your will in just 15 minutes with professional help. While there's no obligation to leave a gift, including one could support vital research and services for those affected by PKD.

October is free wills month, so now is the perfect time to plan your legacy. Start writing your will for free today by scanning the QR code or visiting:

www.farewill.com/pkd-freewill



Fundraising Highlights



Thank you to Luke and Jordan who raised over £5000 by organising a charity football match in memory of their mum Lisa.



Thank you to Lesley who hosted a coffee morning in July and raised £650. Just look at those goodies!



Congratulations to Balazs who paddled an incredible 300km in August and raised £1455.



Well done to Cherry and her husband William who completed the Long summer Walk last month to celebrate her 15th Kidneyversary and raised £590.

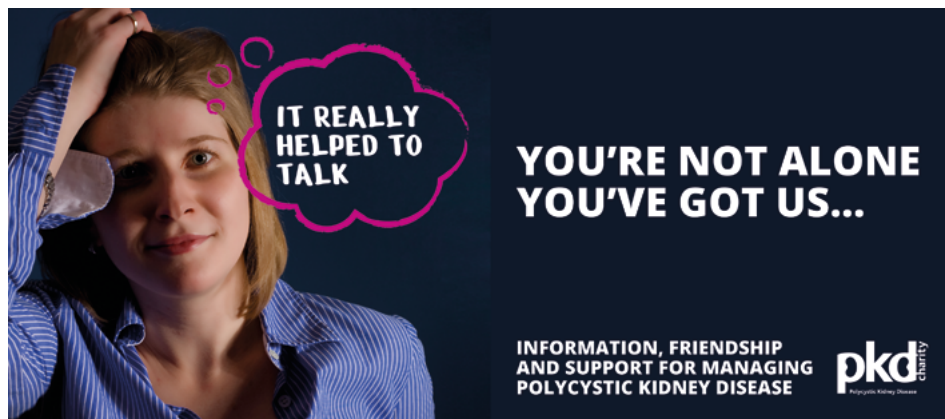


Congratulations to Lee Imrie on completing the West Highland Way 24 hour challenge and raised £2700.

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.

"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/pkd-support

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

PKD app

Download our **FREE App**, created to inform and educate people who are newly diagnosed or at early stages of PKD.

Scan here



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.

Key factsheets include:

ADPKD Basics

www.bit.ly/adpkd-basics

Polycystic Liver Disease

www.bit.ly/adpkd-pld

Diet and Lifestyle in ADPKD

www.bit.ly/adpkd-diet-lifestyle

ARPKD Basics

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

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

Contact - for families with disabled children
www.contact.org.uk