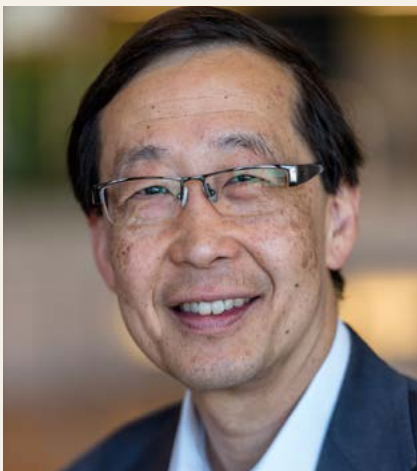


2022 Kaplan Award Winner

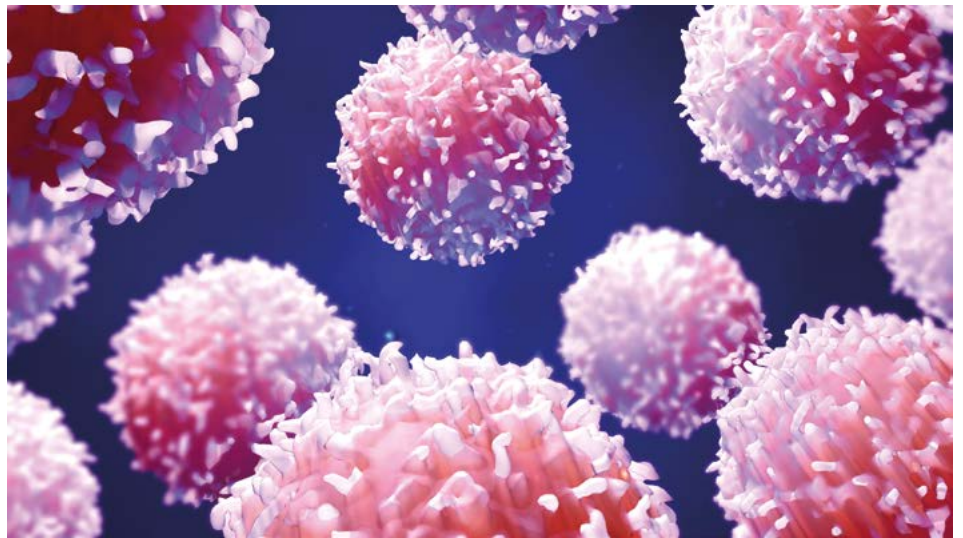
Professor Albert Ong, consultant nephrologist at the Sheffield Kidney Institute and professor of renal medicine at the University of Sheffield, has received the prestigious Lilian Jean Kaplan International Prize for Advancement in Polycystic Kidney Disease.

Prof Ong trained as a doctor in Oxford and later joined the Oxford genetics research lab at an exciting time for PKD. It was 1995, and Dr Peter Harris was about to publish the first paper on the PKD1 gene. At that time, not much was known about the gene, other than it caused ADPKD when mutated. The lab studied its mechanism and developed new genetic techniques, such as isolating mutations in families with unusual forms of PKD.

Prof Ong moved to Sheffield and set up a dedicated PKD clinic at the Northern General Hospital whilst continuing his research. For 20 years, he has focused on identifying genetic and non-genetic factors influencing PKD variability, testing novel treatments, and helping improve patient care.



New research uses kidney recipients' own T cells to prevent organ rejection



Immunosuppressive drugs after kidney transplant may no longer be needed by some people. Researchers are testing new treatments to help stop the immune system rejecting a donated kidney from a living donor.

One new research treatment involves modifying the recipient's regulatory T cells. These are a specific type of white blood cell that help protect your body from harm. Think of them like 'peacekeepers', directing other white blood cells to stop your immune system mistakenly attacking healthy organs such as a new kidney.

In a transplant, your immune system uses a protein called 'human leukocyte antigens' (HLA) in your cells to distinguish yours from your donor's. If your HLA is 'mismatched' to your donor's, your immune system will start to attack your new kidney. Immunosuppressants help prevent the attacks. But the drugs can affect the health of your new kidney and can have unpleasant side effects.

One new research study (STEADFAST) is recruiting people hoping to have a living donor transplant but who have been told they and their selected donor have an HLA-A2 'mismatch'. They are HLA-A2 negative (no HLA-A2 proteins in their body), and their donor is HLA-A2 positive (their kidney has HLA-A2 proteins on it).

Researchers collect T cells from the recipient's blood before the transplant. They engineer the T cells in a lab to form a Chimeric Antigen Receptor (CAR) protein on the cell surface. Three months after transplant, the recipient is given the modified T cells which target the new kidney's HLA-A2 protein. The T cells help prevent an immune response. Oxford University Hospital is currently recruiting for the STEADFAST trial. Visit www.steadfastclinicalstudy.com for more information.

Information and support

Living well with PKD

Staying Covid-safe

Vaccination is still our best line of defence against COVID-19, proven to be safe, effective and life saving. It's vital that you and eligible household members stay up-to-date with vaccinations to maintain protection levels.

Yet with primary doses and boosters, it's no wonder some of us are finding it hard to keep track!

A spring booster is now being offered



to those over 75, those living in care homes and those aged over 12 who are immunosuppressed. All eligible groups can access this now as long as it is at least 3 months since their last dose, although for some people the gap will be closer to 6 months.

If you're unsure which vaccination to have and when, see the full Kidney Charities Together guide:

bit.ly/KCTVac422



Shake your salt habit!

Almost everyone in the UK (and the rest of the Western world) eats too much salt, often far exceeding the recommended daily amount.

For those with or at risk of having PKD, this can have a serious detrimental effect on our health. In fact, there is growing evidence that reducing your salt intake can slow down disease progression in PKD. But how much salt is too much salt, which foods are the most harmful, and how do you ensure your food packs a flavoursome punch without relying on salt?

If you missed or would like to revisit our recent Shake Your Salt Habit webinar, the talk from Renal Dietitian, Fiona Hunter, is now available. To view this and talks from our other online educational events take a look here:

bit.ly/ADPKDvid

Vaccination	Who			When	How (England) See below for devolved nations
	Chronic Kidney Disease (CKD) stages 1-5	Dialysis patients	Transplant patients/people who are severely immunosuppressed		
1st primary dose	✓	✓	✓	ASAP	<ul style="list-style-type: none"> Book online Walk in vaccination site
2nd primary dose	✓	✓	✓	From 8 weeks after previous dose	<ul style="list-style-type: none"> Book online Walk-in vaccination site Under 18s need to take proof of eligibility if less than 12 weeks from previous dose, or contact GP surgery
3rd primary dose	✗	✗	✓	From 8 weeks after previous dose	<ul style="list-style-type: none"> Book online Walk-in vaccination site with proof of eligibility
1st booster	✓ "3rd dose"	✓ "3rd dose"	✓ "4th dose"	From 3 months after previous dose	<ul style="list-style-type: none"> Book online Walk-in vaccination site (with proof of eligibility if "4th dose")
Spring booster	✗	✗	✓ "5th dose"	From 3-6 months after previous dose	<ul style="list-style-type: none"> Book online Walk-in vaccination site with proof of eligibility
Autumn booster (2022)	TBC	TBC	TBC	TBC	TBC

Being fully vaccinated can reduce your risk of becoming seriously ill, hospitalisation or death from Covid-19

Change to organ donation law in Northern Ireland passes final hurdle!



In a move that brings Northern Ireland in line with the rest of the UK, legislation to bring in an opt-out system passed its final stage earlier this year.

The law change, first debated in the Assembly as far back as 2012, is a long overdue victory for organ donation campaigners that brings fresh hope to those in need of a transplant.

To be known as 'Dáithí's Law' the bill is named after the five-year-old boy who has been waiting most of his life for a new heart, and whose family campaigned for the change.

It means that from spring 2023, all adults will become potential donors unless they specifically opt out or fall into exempted categories. The consent of the person's family will still be required for the donation to be carried out.

More about organ donation in Northern Ireland:

www.organdonationni.info

Information and support

Living well with PKD



Dealing with anxiety

Anxiety is a normal and natural emotion. We can't avoid it or indeed turn it off completely. In real life-and-death situations, it can help keep us alive as part of our fight-or-flight response. The trouble is our minds cannot tell the difference between real or perceived danger. We label anxiety as 'negative', rather than a 'protective emotion' and are unwilling to accept it.

Anxiety is usually triggered by something we are thinking about or an external event such as a hospital visit. The adrenalin in our bodies rises. Our heart rate goes up, we get shallow breathing, dilated pupils, sweaty palms, and wobbly legs. Our stomachs ache and we can't think straight.

Look for the early signs that anxiety is showing up. All emotions are first felt in the body. You need to calm your body first to give your mind time to realise there is no real danger. The adrenalin level will then fall and as your mind calms down, you can start to problem solve or even ask for help.

The following exercises can help to reduce your anxiety symptoms, calm your body and mind, and help you feel rested and safe:

- Blow bubbles! Take a pot of bubbles with you. Blowing bubbles

through pursed lips slows down the breathing.

- Change your breathing pattern. Breathe in through the nose for a count of 4, hold for 4 and exhale through pursed lips for a count of 8.
- Try a breathing app. Download from:



- Hum! Humming stimulates the vagus nerve and slows down your out breath.
- Hug yourself. The body responds to touch by releasing oxytocin, the body's natural opiate.
- Try a simple grounding exercise to bring your mind back to the present situation. Look around and notice 5 things around you that you can see, hear, or touch.
- Adjust your posture. Try a superhero pose in the toilet. Hands on hips, shoulders back. Release any trapped breath and tell yourself "I've got this!"
- Don't fight your anxiety. Ask yourself where you feel it in your body and what it feels like when we drop its grip on us.

LIVING WELL

with PKD

Following the launch of 'Living Well with PKD' in 2021, Clinical Psychologist, Louise Hankinson, and Psychotherapist, Rachael Williams, return for a 2nd series of these popular online workshops!

Each free 90-minute workshop provides a unique opportunity to learn new techniques to help you care for your emotional wellbeing, alongside others who understand the difficulties of life with PKD.

17 May: ANXIETY and other emotions - An opportunity to look at the different ways in which anxiety might show itself.

25 May: RELATIONSHIPS - PKD impacts our relationships on many levels, both at home, at work, and beyond.

8 June: DIAGNOSIS - Diagnosis may come out of the blue, or you may see it coming.

Find out more and register: bit.ly/LWPKD22



Raising awareness

PKD Voices



Despite all he has to endure, Luke never complains!

Luke's story

It's every parent's worst nightmare to have a poorly child. For Tori and Carl Amos, when 11-week-old Luke began to scream and turn blue while playing happily in his rocker one day, little could they have known what lay ahead.

Yet within hours of being rushed to Alder Hey Children's hospital Luke was diagnosed with Autosomal Recessive Polycystic Kidney Disease (ARPKD), the rare form of PKD usually diagnosed in babies and young children. On noticing his abdomen was slightly swollen, doctors carried out an ultrasound scan to discover Luke's kidneys were covered in small cysts. "They resembled frog spawn," recalls Tori, who had never heard of PKD.

Unlike ADPKD, parents of children with ARPKD don't have the disease themselves because they have one normal copy of the gene and one faulty copy. They're often called 'carriers'.

ARPKD can cause a range of problems, including underdeveloped lungs, an enlarged liver and progressive loss of kidney function, resulting in 1 in 3 needing dialysis or transplant by the age of 10. Luke's blood pressure was also dangerously high, and it took several weeks in hospital and 5 different types of medication to get it under control.

Once stabilised, Tori and Carl took doctors' advice to let him live as normal a life as possible. They enjoyed holidays and days out as Luke grew into a fun loving, sporty little boy who is always smiling. Aged 10 however, his kidney function had declined significantly, leading to severe headaches and tiredness. Although she knew this day would come, Tori couldn't help but to burst into tears when doctors explained he needed dialysis "I just didn't want his life to stop" she explains.

And whilst dad Carl had agreed to donate a kidney, Luke's kidneys would need removing before a

transplant could go ahead - by then they were twice the size of healthy kidneys. With no other option in the meantime, Luke started dialysis 3 times a week. With travel this takes 6 hours each time, which is a lot for anyone let alone a child. Tori and Carl, who are constantly "on the go", fit Luke's dialysis sessions around their jobs and caring for their 5-year-old 2nd son, who does not have ARPKD.

Thankfully Luke - who wants to be a Youtuber when he grows up - adapted well to dialysis and despite being unable to do the things his friends can do "never moans, he just gets on with it" says the proud mum.

She also has nothing but praise for the team at Alder Hey; "They are rushed off their feet all the time, yet nothing is ever a bother". When Luke got MRSA in November and was very poorly for 3 weeks, they bent over backwards to help him".

The next step for Luke is the transplant, and in preparation for this, on 7 February he underwent the 7-hour operation to remove both his kidneys, a long stressful day for the whole family. Although it's been a painful time for Luke, Tori is pleased to report that he's bounced back, and even seems to have more energy than before. With a date for the surgery due soon, hopefully it won't be long before his dad can give him a new kidney and the chance to live life to the full. Meanwhile, the family celebrated Luke's 11th birthday in April!

Luke and the family at Christmas



Raising awareness

PKD Voices

Kidneys matter

In March we marked World Kidney Day, the big annual campaign aimed at raising awareness of kidneys and the devastating consequences of kidney failure.

This year, as we begin to emerge from the Covid-19 pandemic, the spotlight was on kidney patients and their loved ones who still live with fears for the future. Not only worries for physical health, but the lasting financial and emotional impacts of the pandemic, including job loss and increased loneliness.

Kidney patients candidly shared their stories, along with family members who also feel these pressures as their loved one receives a diagnosis, begins dialysis or waits for a kidney transplant.

Lindsey, a 30-year-old wife and mum told of her heartbreak and fears for the future after it was suddenly discovered that her husband has PKD and faces a transplant in the very near future. Read the full story here: bit.ly/WKDLind

With many kidney patients reluctant to share their diagnosis for fear of losing their job, and the employment rate for dialysis patients coming in at a shocking 26%, the campaign also called for a change to workplace attitudes: urging employers to improve their knowledge and provide better support to employees with kidney disease, including making the



necessary workplace adjustments.

Whether you're an employee or employer, you can still help make your workplace more kidney aware by sharing this World kidney Day guide with colleagues: bit.ly/WKDwork

And if you've a story to tell about your experience of living and working with PKD, we'd love to hear from you. It's too big to ignore! (Please email jane.pugh@pkdcharity.org.uk).

Stay tuned!

Receive our free e-newsletter for details of PKD educational and support events, what's new in research, and fundraising opportunities direct to your inbox. Head here to add your contact details: bit.ly/Stayuptodate

STAY TUNED!



Fundraising

Thank you Team PKD!



Sue (left) and Helen.

Sue & Helen's story

Sue Norris is taking on the Jurassic Coast Marathon Challenge in May and fundraising for PKD Charity in memory of her sister Helen. Here, Susan tells us what prompted her to take on this challenge:

"I lost my dearest sister Helen to Covid 19 on 13 January 2021. She was everything to me, like a Mum, friend, confidante, as well as my precious sister. Helen was 10 years older than me and she suffered from PKD. She had suffered terrible pain when it was first diagnosed, and on 10 Jan 2011, I donated one of my kidneys to her.

The kidney started to reject after a few months, and to save it, she had a plasma exchange. Unfortunately, that September she caught shingles, then she caught a rare form of pneumonia and because her immune system was now impaired, she became terribly ill. She had to be put in a coma because her lungs, respiratory system and kidney all went into failure.

She was in a coma for weeks. We thought we were going to lose her so many times, but she was so strong and just kept fighting all the time. She loved her girls so much; Laura, Lindsey and Megan, they helped to keep her going. Then her Grandchildren, Charlie, Ivy and Alexander gave her even more reason to fight. She loved them with all her heart.

Throughout everything Helen remained positive, even when so ill, she would still say there are people worse off than her. The donated kidney only lasted 3 years and then she had to go on to acute dialysis. She had to have both her kidneys removed during a short interval when she was well enough to, due to the cysts causing infections.

When she contracted Covid we still thought she would be ok, even when they put her on a ventilator, we all thought as always, she would fight it and pull through. On that awful day last year, her husband, Martin received a phone call from the Dr, who said that he needed to go be with her. She passed away just before midnight.

Martin gave me Helen's new walking boots (luckily, I'm the same size) that she never had a chance to wear. I have chosen to do the Jurassic Coast Challenge as a real personal challenge for me. I know Helen would be proud of me, and it helps me knowing that. Getting out in the countryside and nature does help me to cope with losing this miraculous woman, she really was a walking, living miracle.

I had a knee replacement a couple years ago and I love challenging myself to do things. 'Can't' is not in my vocabulary (my big sis taught me to be that way) I have been training every day for about 3 or 4 weeks

now. I'm really determined, and because it's for Helen I know I'll do it. I am taking part in the event with my friend Graham Hill, he has only just had a hip replacement, so we are like the titanium kids.

I want the world to know about my one-in-a-million sister and I want her to be remembered forever. How unselfish and how brave. She made everyone who knew her feel loved and important. So, here's to my beautiful sister Helen, the strongest and bravest person I have ever met."

Inspired by Sue's challenge?

Why not take on your own fundraising challenge to support PKD Charity? For fundraising advice and support, email:

fundraise@pkdcharity.org.uk



Fundraising

Get involved

Needle felting workshop

Join us on Wednesday 18 May at 7pm for a needle felting workshop streamed live online with needle felting expert Steffi Stern from The Makerss.

During the 90-minute workshop, you'll learn how to make an adorable poseable mouse with her party outfit of balloons and tutu skirt. The project is needle felted, an increasingly popular craft which is suitable for total beginners. It involves stabbing a sharp needle into wool (**please be aware and we recommend children age 10+ complete with a responsible adult supervising**) which causes the wool to become firmer and shrink in the process. This means that you can sculpt shapes to your liking. For this project you will also learn how to wrap wool around pipe cleaners before felting it into shape.

To register for the event, purchase a needle felting kit from our online shop: pkd-charity.square.site/

The kits are £18 (plus £2 postage and packaging) and contains everything you will need to make the mouse, balloons and the tutu skirt.

£10 from the sale of every kit sold will go towards helping to support people affected by polycystic kidney disease, raising awareness and funding research.



Support PKD Charity

We couldn't provide the support that we do to anyone affected by polycystic kidney disease without our wonderful fundraisers. If you would like to take on some fundraising for the PKD Charity then please get in touch. Whether you have a fully-fledged master plan, or an idea on a napkin, we'd love to hear about it. Email fundraise@pkdcharity.org.uk.

You can support the PKD Charity today by making a donation. When you donate to us you are making a huge difference to the lives of anyone affected by polycystic kidney disease, helping to raise vital awareness and fund life-changing research into finding treatments and a cure for PKD. Donate today: pkdcharity.org.uk



Spring into March 2022 raises £6,000

Earlier this year we launched our Spring into March fundraising event. Asking our wonderful PKD Charity supporters to get active and move your way, every day for 31 days in March whilst raising funds to help support people affected by polycystic kidney disease and boost funds for PKD research.

We would like to say a massive thank you to everyone who took part; from windswept walks in the park, workouts in the gym, silent discos, Parkruns in the Peak District, muddy dog walks and aqua aerobics by the pool – you all did amazing and helped to raise £6,000. Well done Team PKD!



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 bit.ly/pkdc-support

Upcoming events, visit 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

bit.ly/adpkd-basics

Polycystic Liver Disease

bit.ly/adpkd-pld

Diet and Lifestyle in ADPKD

bit.ly/adpkd-diet-lifestyle

ARPKD Basics

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 contact.org.uk

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