

Grant to promote PKD treatment research

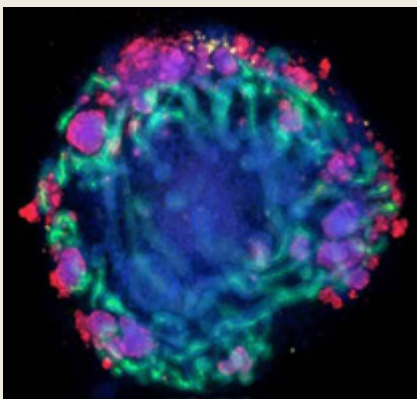
We urgently need new ways to treat polycystic kidney disease. At present, there is only one disease-modifying drug for ADPKD and none for ARPKD. The only other treatments are standard symptomatic care and/or surgical interventions such as nephrectomy (kidney removal) and kidney/liver transplantation.

The PKD Charity has just awarded a £45,000 grant to the UCL Division of Medicine at the Royal Free Hospital London to part-fund a 3-year PhD Studentship.

The PhD student will undertake a research project on 'Drug Therapy in 3-dimensional Human Polycystic Kidney Disease (PKD) Organoids'.

These PKD organoids (see image below) are made from human stem cells in a lab dish and have the same genetic faults that cause PKD in people. They can be used to test potential therapeutic drugs.

The ultimate aim of the research is to inform future clinical trial developments in paediatric and adult ADPKD and ARPKD patients.



Fresh hope on the horizon with launch of new PKD research awards



In September, we welcomed the exciting launch of the brand-new PKD research awards round, as the next pivotal step of our ambitious research partnership with Kidney Research UK.

Formed earlier in 2021 but delayed by the pandemic, this ground-breaking partnership combines the might of Kidney Research as the largest charity in the UK dedicated to kidney disease research, with our 21-year history as the voice of PKD.

By working together to accelerate PKD research, which to date has been vastly underfunded in the UK, we aim to significantly improve PKD patient outcomes over the next ten years.

"Research is critical to improving the lives of people blighted by PKD. Yet, the amount spent on PKD research is miniscule compared with amounts spent on cancer, whilst the burden and cost of healthcare for PKD patients and the social burden and costs on their families is disproportionately high.

Now, we can make research happen much faster." Explains Tess Harris,

CEO of the PKD Charity.

The awards round invites researchers to apply for grants to fund their research into PKD, focussed on - but not restricted to - the top research priorities for ADPKD. The priorities, which were identified by the PKD Charity in conjunction with the James Lind Alliance, patients, family members, carers and healthcare professionals, can be viewed here: bit.ly/3frI9Pf.

Applications focussing on autosomal recessive polycystic kidney disease (ARPKD) were also welcomed.

The next steps, following the closing date on October 4 2021 is for applications to be reviewed by a panel of experts and patients before research grants are awarded in Spring 2022.

Watch this space for details of the successful applicants and the projects we hope will prove to be life-changing for current and future generations of people affected by PKD.

Information and research

COVID-19 vaccine update



3rd dose vs booster: the differences explained

3rd (primary) dose: is for people who are severely immunosuppressed, such as transplant recipients, who may not have had a sufficient immune response to the first 2 doses. The 3rd dose forms part of a 'standard course' and is separate to the booster programme. It should be given at least 8 weeks after your 2nd dose. An mRNA vaccine is advised.

We're aware however that some people, who're eligible for the 3rd dose, are being (wrongly) advised to wait for the booster dose. The latest NHS guidance here bit.ly/GP3rdOct should be shown to your health care

provider if required. And whilst the 3rd dose is reassuring for kidney transplant patients, we await further advice for those on dialysis or with advanced kidney disease.

Booster: is for the wider group of people whose initial immune response to their first 2 doses is likely to have weakened over time, and is therefore designed to help maintain your level of immunity for longer. It can be given 6 months after your 2nd dose.

How to obtain the 3rd dose or booster: You'll be invited to book an appointment by letter, phone call or text from your GP or renal team.

For further advice, please contact your GP or consultant.

Confused by antibodies?

There are many ways your immune system fights off infection, but 2 important ways are by B cells, which produce antibodies, and T cells, which attack and kill infected cells.

Some people have been tested for antibodies but testing is not yet considered to be useful to provide information on your risk of infection following vaccination, because antibody levels don't tell the whole story.

Get your guide on how the COVID-19 vaccine helps to protect you and why you shouldn't interpret the results of an antibody test as an indication of protection from infection:

bit.ly/AntiC19

ADPKD aneurysm risk study

People with autosomal dominant polycystic kidney disease (ADPKD) are known to be at high risk of intracranial aneurysms (IA). IAs occur in about 3 in 100 of the general population but in between 10-12 in 100 of individuals with ADPKD.

If you have an IA, it can rupture and cause Subarachnoid Haemorrhage (SAH), a devastating type of bleed on the brain which unfortunately results in disability or death in most patients.

However, very little is known about how frequently IAs rupture in ADPKD and whether this is the same as IAs in general or not. Without knowing what risks their IAs pose, it is impossible to make rational decisions for individual patients with ADPKD about whether to treat their aneurysms or not.

Mr Diedrik Bulters, neurosurgeon at University Hospital Southampton, is leading a national study to validate an IA risk score. This will include individuals with ADPKD to see if ADPKD fits the risk score or if it needs adaptation to include



ADPKD and family history in the model.

The PKD Charity has awarded a grant of £10,000 towards this important study which affects many ADPKD families.

PKD Charity support services

Living well with PKD – a series of online workshops



This summer Louise Hankinson, Clinical Psychologist, and Rachael Williams, Psychotherapist, created a unique series of four online workshops for people affected by ADPKD.

The 'Living Well with PKD' workshops covered pain, diagnosis, anxiety and relationships.

Following the success of the initial pilot series, we are delighted to announce more workshops will be available.

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

- Pain workshop attendee, June 2021

"A lovely, relaxed event, nice to interact with people with similar health problems."

- Anxiety workshop attendee, July 2021

Each workshop lasts 90 minutes and is limited to 10 participants. There is a waiting list if the workshop is fully booked.

Visit pkdcharity.org.uk/support/workshops to find out more and for details on the next workshops.

We are grateful to the National Lottery Community Fund for supporting these workshops.



Let's talk about...

Living with PKD can sometimes feel like a lonely road. 'Let's Talk About' is a series of PKD Charity Zoom meetings where you can safely chat about specific topics with others. Topics include:

- Dialysis
- Transplant
- Polycystic Liver Disease
- Nephrectomy (kidney/s removal)
- Tolvaptan

We host these small group online meetings with the assistance of trained volunteers with lived experience of the topic.

Note that these are not medically-led conversations and no medical advice can be given. These meetings are designed to give you the opportunity to log in, listen to others' experiences, ask questions and join the discussion from the comfort of your home.

Visit pkdcharity.org.uk/support/pkd-meetups for dates and details, including information on how to register.

ARPKD Time to Chat

Time to Chat connects those affected by ARPKD (Autosomal Recessive Polycystic Kidney Disease) in an informal, friendly meetup on Zoom. You'll have the opportunity to chat, share moments of joy, frustration, and everything in between with others.

You don't need to prepare and there's no pressure to share anything at all - it's fine to come along and just be amongst people who understand!

Everyone is welcome no matter



what the issue, and whether you're a social butterfly or more of a listener. Parents of children and adults with ARPKD are all invited.

Visit pkdcharity.org.uk/support/pkd-meetups for future dates.

ARPKD workshop

2 November 2021, 7 pm

The PKD Charity invites ARPKD parents to join an exclusive online workshop which will be led by Louise Hankinson, Clinical Psychologist and Rachael Williams, Psychotherapist.

This 2 hour online Zoom workshop will cover the topic – The future, coping and anxiety about what's next.

Book now at bit.ly/LWARPKD or email Susan Muirhead (susan.muirhead@pkdcharity.org.uk) for more information and future dates.

Raising awareness

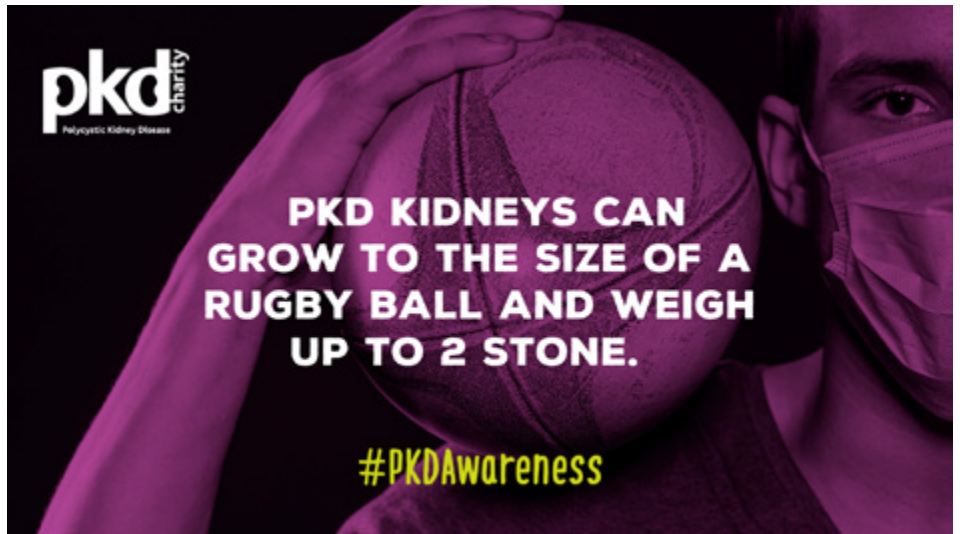
PKD Voices

September was PKD Awareness month - our time to unite, educate and take action to help improve the lives of the estimated 70K men, women and children in the UK who're affected by polycystic kidney disease.

With the lifting of restrictions, many of you donned vests and dusted off your running shoes to take part in live events such as the Hackney Marathon, Great Manchester and North runs and the London to Brighton cycle ride.

Others took to the hills, and even the skies, whilst the more vulnerable amongst us spread the word from the safety of home.

You told your touching stories in PKD Voices, from transplants to nephrectomies, some triumphant, others tragic.



You liked and shared important PKD facts, tested family and friends' knowledge in the quiz, donated, golfed, walked... and crawled to raise awareness and funds for our research

efforts and patient and family support services.

Thank you team PKD for raising the bar this awareness month! Visit PKD Voices: bit.ly/PKDVoices



Martin and his 'angel' donor, great-niece Alex.



Angel Donor cake

Raising awareness

PKD Voices



Helen, bravely tells the story of her painful journey with polycystic kidney disease that has left her battle scarred, but not without fight.



Good things come in 3s! Unique story of 3 brothers who received kidneys from living donors... by 3 different routes... within 3 years of each other!



A big thumbs up from Kayla (left) who, after a double nephrectomy in May received a kidney from sister Becky!



Brothers Justin and Josh receive transplants within 10 days of each other.



Hawden MEP team tackling the 3 Peaks for PKD

Hazel vs PKD



Hazel is one of our youngest supporters and was diagnosed with ARPKD shortly after birth. Aria, Hazel's mum, set up a Facebook blog to raise awareness of PKD, which has over 500 followers. Visit 'Hazel vs PKD' to follow Hazel and her family's journey of living with ARPKD.

facebook.com/HazelVsPKD

Kay



Kay has been raising funds and awareness of PKD for over 7 years.

She recently persuaded her company HiB Bathrooms to hold a charity auction and next year, she's taking on the Birmingham Marathon - again!

Well done Kay!

A spotlight on events

Thank you Team PKD!



A big thank you to all our wonderful supporters that have taken part in an event or have plans to fundraise for us this year. Here's a snippet of your Team PKD activities!

Sisters **Lynette Pickett** and **Nicky Baker** took part in the London Landmarks Half Marathon in August and raised £1,470! Four generations of their family have been diagnosed with PKD and they have been fabulous supporters. They also ran the London Marathon in October wearing hand-made tutus bearing the names of PKD patients past and present. Thank you!

A BIG thank you to all our wonderful



supporters that took part in the 21k Challenge in April and May 2021 and raised a whopping £8,300 for PKD Charity. Our largest amount of money raised in this challenge yet!

Mark, Vicky, Chris, Brian and **Adam** cycled the South Downs Way in August, it was a tough ride of 100 miles across the most beautiful countryside of Hampshire, West Sussex and into East Sussex with a total elevation of 11,640feet.



Together they raised £1,380, thank you!

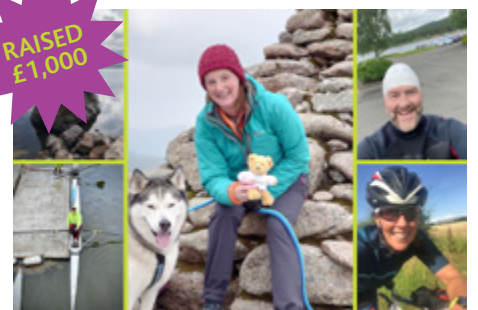
In June, PKD patient - **Domenico Sprovieri** - took on a challenge of lifetime this Summer by cycling from London to Calabria, Italy in support of PKD Charity and AIRP - Associazione Italiana Rene Policistico. Thank you Dom for raising awareness across Europe!

Diane hosted a Garden party in June with the wonderful support



from her husband and sister. Diane was diagnosed in 2016 aged 54 and continues to support PKD by raising awareness in the community. She raised £301 in her garden party in the beautiful sunshine, thank you!

PKD Charity would like to thank **Pulsant** and their staff for taking part in a Chimu (Olympic) Challenge and for their kind donation of £1,000! Collectively the teams travelled over 25,000km by running, walking, swimming, cycling and rowing as far as they could! You're inspirational, thank you!



Jenny's Story

Jenny Fullard inherited ADPKD from her father who died when she was 7. Now in her mid-seventies, Jenny has written a memoir of her adventurous and interesting life. She published this in a book '*Jenny's Story*' and donated all the book profits to the PKD Charity - raising £5,000.

Jenny enjoyed a happy childhood and trained in nursing and midwifery. She joined the Flying Doctor service in Zambia, delivering babies and running

vaccination clinics. Back in the UK, she opened and ran a residential home for the elderly. She travelled widely with her husband Richard. In 2011, she received a kidney transplant and despite other health issues, she continues to enjoy exercising and looks forward to more travels post-COVID.

If you feel inspired by Jenny's Story or other PKD Superstars, and want to do some fundraising for us, please email fundraise@pkdcharity.org.uk and our fundraising manager will be in touch to support you.



Support our work

Fundraising ideas

The PKD Charity is almost entirely funded by donations from people and families affected by PKD, and we are very grateful to everyone who has raised funds or given their time.

There are many ways to help us continue our work.



Donations

Single or regular donations can be made online via our website. If you are a

UK taxpayer, we can also reclaim Gift Aid on your donations:

pkdcharity.org.uk/fundraising/make-a-donation

Payroll or Workplace Giving is a simple and cost-effective way to donate:

pkdcharity.org.uk/fundraising/make-a-donation/payroll-giving

Leaving a gift in your will to the PKD Charity can help us continue our long-term research activity - such as funding the PKD Bio-resource Bank used by many researchers in the quest for new therapies:

pkdcharity.org.uk/fundraising/make-a-donation/leave-a-gift-in-your-will

You can donate in memory of a loved one online or set up a tribute fundraising page on one of the third party platforms we use:

pkdcharity.org.uk/fundraising/give-in-memory/tribute-fundraising

If you are arranging a funeral collection, we can send you printed envelopes to make the collection easier. Just email fundraise@pkdcharity.org.uk letting us know how many you need.



Facebook Fundraisers

Facebook has made it super easy to raise money – to celebrate your birthday or a special anniversary.

Visit the PKD Charity Facebook Page www.facebook.com/pg/pkdcharity/fundraisers to start a fundraiser and share the link with family and friends.



Take part in an event

You can read all about the places we have in challenge events on

our events page:

pkdcharity.org.uk/fundraising/take-part-in-an-event

'Your fundraising, your way' is a great way to involve your family, friends or work colleagues in raising money for our cause. Baking, knitting, making crafts are all popular with our supporters. Email

fundraise@pkdcharity.org.uk for an ideas pack.

When you're doing a fundraising event, ask your employer if they have a **Matched Giving Scheme** where they will match the amount you fundraise up to a certain level.



Online shopping

An easy – and free – way to raise money by shopping is to use online shopping portals.

Easyfundraising and Give as you Live® pay commission every time you shop online at over 4,200 stores. Sign up at www.easyfundraising.org.uk/causes/pkd/?u=96OIY1 or www.giveasyoulive.com/join/pkdcharity

Amazon has a charity shopping scheme called Smile.

Visit smile.amazon.co.uk and login with your usual Amazon account.

Need help with fundraising? Email fundraise@pkdcharity.org.uk or call 07715 664687.



Donate your car

Do you have a car to dispose of? Giveacar is a UK based fundraising organisation that

organises car donation for good causes in the UK.

giveacar.co.uk/charities/polycystic-kidney-disease



Christmas Virtual Balloon Race

Come fly with us on 6 December in the PKD Charity Christmas Balloon Race with a chance to win a £100 shopping voucher. Only £3 per entry. 100% environmentally friendly. Very competitive and huge fun for everyone. Challenge your fellow PKDers, friends, family and colleagues.

Visit pkd.rentaballoonrace.com to enter.

2022 – year of Ultra Challenges

Kick start the new year with one of many Ultra Challenges you can take on during 2022. Walk, jog or run, and push yourself further. Ultra Challenges range from the London Winter Walk at end January to navigating the Isle of Wight coastal path to tackling the mighty Peak District. There's different sponsorship options and we can support your efforts with t-shirts and running vests. For more information visit: ultrachallenge.com



Play today & support those affected by PKD

Join the PKD Charity Genetic Lottery® and win up to £25,000!

It's so easy to play. Visit pkdcharity.org.uk/fundraising/make-a-donation/play-the-genetic-lottery.

Our support services

Helping you cope with PKD



In person support

We remain committed to offering support. However, for now, no events will be

available face-to-face.

Meetups

We're working with our wonderful meetup hosts to run virtual meet-up group sessions via Zoom. These sessions are for anyone affected by PKD and the group host will make you most welcome. This is an informal way to share experiences, offer friendship and signposting to other sources of information and support.

pkdcharity.org.uk/support/pkd-meetups

ADPKD information and support days

Events hosted by leading PKD renal consultants. Currently held as live webinars via Zoom. Providing an opportunity to find out more about ADPKD, treatments, and ask questions.

ARPKD information and support days

Events for parents, carers, family members and adult patients affected by ARPKD, we are looking forward to welcoming you to our first ever virtual information day soon.

Check our website for the next event. pkdcharity.org.uk/support/pkd-information-and-support-days/upcoming-information-support-days



Telephone support

0300 111 1234
Helpline

Confidential personal support from an experienced PKD volunteer. Available from 9:30am to 5:00pm Mon - Fri.

Telephone peer support service

Our trained volunteers are people living with PKD. They have a range of experiences, so whether you are won-

dering about dialysis or transplant, or worrying about what to say to your children, our volunteers can help. Call **07739 632836** to find out more and be matched with someone who understands what you are going through.

Topic based teleconference

Monthly conference call on a specific topic for up to 10 people. Hosted by a professional and a volunteer with experience of PKD. An opportunity to dial in, ask questions and listen to others' experience, from the comfort of your home.



Online support

Facebook groups

Join our dedicated PKD Charity, UK-only private groups

on Facebook. Ask questions and share your experiences with others diagnosed with PKD, their families, and loved ones. There's always someone who knows what you are going through and can give you mutual support.

For everyone affected by PKD
www.facebook.com/groups/pkdcharityUK

For parents of children affected by PKD
www.facebook.com/groups/parentsofchildrenwithpkd

For everyone affected by ARPKD
www.facebook.com/groups/arpkdUK

Topic based webinars

For people who can't attend Information and Support Days. Webinars are led by a medical expert, are easy to access from a PC or smartphone or can be viewed later.

The topics include PKD in children, tolvaptan, genetics and pain, diet.

Visit our **Events page** for all upcoming events:
pkdcharity.org.uk/news-events/events

PKD Charity Health Information

We have adopted the NHS Information Standard - a quality standard that supports the production of health and care information which meets the needs of all patients, carers and families.

All our factsheets are written by medical experts and checked by our lay reading panel of people affected by PKD.

Key factsheets include:

ADPKD Basics

pkdcharity.org.uk/adpkd/what-is-adkpd/adpkd-basics

Polycystic Liver Disease

pkdcharity.org.uk/adpkd/symptoms/polycystic-liver-disease

Diet and Lifestyle in ADPKD

pkdcharity.org.uk/adpkd/life-with-adpkd/pkd-diet-and-lifestyle

ARPKD Basics

pkdcharity.org.uk/arpkd/what-is-arkpd/arpkd-basics

If you do not use the internet, ring our Support Line **0300 111 1234** and ask for printed copies.

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

Board of Trustees

Alan Greenberg, Chair	Jordan Adams
Jade Raymond, Treasurer	Karen Stapleton
Prof Patricia Wilson	Adrian Tinsley
Rebecca Murphy-Peers	Nick Tracey

Jon Rees
Raj Johal

Staff

Tess Harris, Chief Executive
Kerry Thomas, Fundraising Manager
Susan Muirhead, Community Support Manager
Jane Pugh, Communications and Events Manager

Research Advisory Board

Professor Patricia Wilson Chairman
Dr Richard Sandford Vice-chairman