

PKD Charity & Kidney Research UK form partnership to progress PKD research

COVID-19

The coronavirus that arrived early 2020 and causes COVID-19 is still with us. We know that the threat of COVID-19 and the changes that we have made to our lives are putting every one of us under strain.

For those in a high-risk group (low kidney function, on dialysis or with a transplant) or self-isolating, this can be especially worrying and stressful.

There is nothing to suggest that people with PKD are at particular risk of being infected but some of us are at increased risk of getting seriously unwell if we get COVID-19.

Advice and guidance is available on NHS and government websites. This differs for people in England, Scotland, Wales and Northern Ireland. We recommend you visit them regularly and check how you are affected. We encourage you to support one another, staying in touch with family and friends.

Support is also available via the PKD Charity Helpline and online Facebook groups. We regularly update our blogs which have links to sources of help. Our main blog is pkdcharity.org.uk/news-events/blogs/429-covid-19-coronavirus-and-polycystic-kidney-disease and our blog on how COVID-19 might affect children with ARPKD is pkdcharity.org.uk/news-events/blogs/430-coronavirus-covid-19-and-children-with-arpkd



We have launched an ambitious partnership with Kidney Research UK to progress research in all forms of polycystic kidney disease.

Our joint vision is to significantly improve the health and quality of life in adults, children and families affected by PKD over the next 10 years and into the future.

New PKD treatments are needed now and research is vital

PKD research is critically underfunded - in the UK, less than 1% of all health research funding goes to kidney research, and a fraction of that is for PKD specifically.

We will work together to raise awareness and vital funds to increase that funding and drive more research.

Kidney Research UK is the largest charity dedicated to research into kidney disease in the UK and the

PKD Charity is the voice of people with PKD - making us a powerful partnership for change.

What we will do

We will build capacity and capability in PKD research by awarding grants to researchers for projects, studentships, or fellowships. We will bring together our research networks and share governance and programme management.

We will make PKD research a priority that benefits patients with the condition. Above all, we will ensure that PKD patients are involved throughout and that their voices and experience are embedded in everything we do.

Read more about our research partnership here and find out how you can help.

pkdcharity.org.uk/research/pkd-charity-kidney-research-uk-research-partnership

Research updates

Funding awarded to landmark research project studying chronic pain



We're delighted to announce a major award from the National Institute for Health Research (NIHR) to study pain in Autosomal Dominant Polycystic Kidney Disease (ADPKD).

A potential game-changer, EASE-PKD* is the first large-scale study aimed at identifying and characterising the chronic pain known to affect up to two-thirds of ADPKD patients and a commonly reported symptom.

Not only does pain have a significant impact on people's quality of life, but also carries grave economic and operational consequences for the NHS, due to repeated, often prolonged, hospital admissions. Yet despite the scale of the problem, to date there has been little research on the subject.

Initiated and led by the PKD Charity, and Drs Thomas Hiemstra and Ragada El-Damanawi from the University of Cambridge and Cambridge University Hospitals NHS Foundation Trust – the study has been developed in partnership with expert patients, clinicians, and researchers.

Primarily, EASE-PKD seeks to determine the - currently undefined - causes of chronic pain in ADPKD, pain intensity and how people respond to drug therapies. Pain can present in early stages of ADPKD and people often find it difficult to communicate its intensity to their doctors. Understanding the unique characteristics will help develop better, more targeted management and

treatments for resolving the burden on patients and clinicians alike.

The study includes a new, bespoke ADPKD Pain Assessment Tool (APAT), that's accessible via computer, phone or tablet. It'll enable people to log and monitor pain intensity, frequency and impact on quality of life, as well as plot - on a body map – the site of the pain they experience.

People will be invited to participate through PatientView, the Registry of Rare Kidney Diseases (RaDaR) and our website.

*Evaluating chronic pain in ADPKD using a patient-centred approach to data collection and SynthEsis

"Pain is one of the most debilitating and yet under recognised consequences of polycystic kidney disease, and yet we know very little about how best to treat it. This landmark study will allow us to understand PKD pain in great detail, providing a crucial stepping stone towards finding treatments that relieve the pain that so many suffer every day. The PKD charity and the NIHR have been instrumental in making this important research a reality."

Dr Thomas Hiemstra

ADPKD research priority setting partnership update

Earlier this year, we asked you to tell us what ADPKD research topics were most important to you. We launched a survey with 35 'unanswered' research questions, such as how to stop kidney and liver cyst growth, slow progression to kidney failure, the best diet and how to manage pain. Over 1100 people responded, including patients, carers, doctors and nurses.

Unfortunately, we had to pause the initiative in March owing to COVID-19. However, we have restarted and plan to finalise in December 2020 by holding an online workshop to debate the top 18 questions from the 35 and agree the 'Top 10' most important. In early 2021, we will publish a report and promote our research needs to funders including the government. These research priorities will also be incorporated into the research partnership programme we have launched with Kidney Research UK.

Find out more here pkdcharity.org.uk/research/proritising-adpkd-research

Would you like to be involved in projects to help improve kidney services and research in your area or the UK?

Join the Kidney Patient Involvement Network (we are founder members) who regularly send details of research projects needing feedback from patients and carers. Examples include reviewing haemodialysis patient education leaflets and a study of how best to support quality of life in people struggling with fluid intake adherence. kpin.org.uk

PKD Charity support services

Business as usual (almost)

Our personalised Support Services remain 'open' during COVID-19 to help you cope with PKD. Unfortunately, we've had to pause all face-to-face events such as our local support and information events and meetups. However, many of you have joined us online for interactive information days, webinars and our virtual meetups.

In July, we held our first virtual ADPKD Information and Support Day and are planning one more before the end of 2020. People joined from all over the UK, and even from Hong Kong and India. Using Zoom meant a large number of people could hear from leading PKD experts from the comfort of their own home and ask questions. As usual, talks on transplant, genetics and research were very popular.

"All the talks were very useful. The research talk was fantastic."

Visit pkdcharity.org.uk/news-events/events for details of future activities.

Our wonderful volunteers ran virtual meetup group sessions via Zoom. Anyone affected by PKD can join these and the meetup host will make you most welcome. Grab a cuppa and join us for a chat about how you're feeling, especially at this time of COVID-19.

Visit our website pkdcharity.org.uk/support/pkd-meetups to see the



upcoming virtual local meetup groups and details of how to join.

During March and April, our Helpline was very busy answering COVID-19 questions. We extended our hours and were able to continue offering practical, emotional, and social support - COVID and non-COVID related. If you would like to have a chat about anything ring our helpline **0300 111 1234**.

We are still providing a telephone peer support service. Our trained volunteers are people living with PKD. They have a range of experiences, so whether you're wondering about dialysis or transplant or worrying about what to say to your children, our volunteers

can help.

Topic-based group calls for up to 10 people are continuing on specific PKD topics. These are hosted by PKD staff and volunteers with PKD experience. Dial in, ask questions and listen to their experiences, from the comfort of your own home.

Email Susan

susan.muirhead@pkdcharity.org.uk, call her 07739 632836 or check pkdcharity.org.uk/support to find out more about all our support services.



ARPKD families

Recent times have seen the charity pause our face-to-face events. It has given us the opportunity to bring our small but powerful group of ARPKD patients and parents together online. It was lovely to "virtually meet" some of our community during Zoom calls.

The charity hosted an evening with experts discussing the current ARPKD research being carried out at Wolverhampton and UCL London.

Taylor Richards (see photo), the PhD student doing the research,

gave an exciting update on his findings so far.

Taylor is just starting his third year and we look forward to future talks and papers about his work.

This was followed by an informal "time to chat" with other parents. We plan to hold more of these sessions, giving families time to connect, share tips, and have a moan and a laugh with the ARPKD community from across the UK.

"Really loved meeting everyone last night. So good to speak to other parents about experiences and worries - big and small!"

"I'd never used zoom before, but it was so nice to listen and share. Hope to do it again sometime"

We also now have a UK designated ARPKD private Facebook group which you may wish to join. facebook.com/groups/arpkdUK



Raising awareness

Out but not down!

If there's one thing we learnt during lockdown, it is that our PKD community knows how to ride a storm.

Some of us used the time to reflect - perhaps welcoming a gentler pace - while others have been busy expressing their creativity in a multitude of ways.

We've seen the everyday to the more unusual. From baking, sewing and gardening, right through to running marathons indoors, to those caravanning in the back garden, to mastering the art of pet pampering, and nurturing rats!

See here just some of what your fellow PKD-ers have been up to over the past few months.

If you'd like to share your lockdown story, please contact Jane Pugh: jane.pugh@pdcharity.org.uk



"It's been so hard juggling everything during lockdown while trying to keep some semblance of 'normal' for my little one. I know many parents who're going through the same thing so we've been able to share ideas. I've tried to deal with it all by remembering this is only temporary and that I can't do everything. Some things just have to slide. Key to my keeping sane has definitely been CBeebies!"

Karen, mum to 3 year old Daniel



Sunbathing, cake baking, homemade face masks and gardening were popular.

Raising awareness

Out but not down!



"Set up by my husband when I retired, the garden is a joint passion and effort. I just love the thrill of watching things grow, especially when it goes to plan. And as the veg is organic, it's tastier too! During lockdown it's been my safe haven."

Karen Traves



When Rob and Madeleine got on their bikes!



"I kept myself busy during lockdown, mainly with sewing to keep my hands occupied and to stop me grazing all day as I need to keep my weight down to be ready for transplant."

Helen Kenny

A spotlight on events

Thank you Team PKD!

RAISED
£1,130



Robert Wheatley who walked 3k a day for 20 consecutive days.

Helen Skidmore who walked 20k from Alnmouth to Howick.

Mark, Louise, William and Emily Harris who walked 5k over four weekends.

Emma and Aiden McDonagh who walked their 20k over four weeks.

Sara K who cycled 20k a day throughout August.



RAISED
£430

And Paul Kavanagh who walked 20k over a week.

2020 marks 20 years since the PKD Charity was founded. Thank you so much to everyone who signed up and has taken on the PKD 20k Challenge! Here's to our Team PKD superstars who took on 20k their way this summer:

Angelique and Drew Tavernier, Chris P, Susan Couper, Julie Gilkinson, Natasha O'Martin, Anna Bywater and Julie Andrews.

Shannon Kent and Joe Samways, Eugene Leher, Suzzanna Heath and Mum Angela Heath who walked their 20k.

RAISED
£126



Michelle, Stuart, Kayleigh, Luke and Vikki Grant who took on the 20k as a family group 3 ways - mum and sister ran, mum and dad biked, and the two kiddies went the distance over a number of walks.

Cheryl Lear, Beth Lear and Samantha Bradley who did a 20k canal walk.

Audrey Hughes who cycled 200k on her exercise bike.

Ben, Josh and Diane Khan who walked the 20k as a family.

To date, our incredible PKD 20k Challengers have raised an absolutely incredible £7,081 to help support anyone affected by PKD whenever and however they need us, and help fund vital research into finding treatments and a cure for polycystic kidney disease.

We are so grateful and super proud of all that you did in aid of PKD Charity. Thank you all so much!



RAISED
£771

RAISED
£609



Outlanders

This summer the amazing Outlands Project – James Brannan, Dan Stephenson, Dean Regan and Gareth Bell conquered their incredible Coast 2 Coast cycle challenge.

"When we started Outlands Project we were wanting to challenge ourselves, but more importantly, we wanted to raise money for charity. Over a few months, we planned the Coast 2 Coast in a day, the 'classic/hard route', cycling 133 miles, up to 12,000 ft elevation.

We managed to raise £1,380 for the PKD Charity which was 276% of our ambitious target. We feel proud that one ride has been such a success and hopefully the start of many more to come. A huge thank you to Rum Razor Barber Shop and Abbey Heating for being our sponsors on this and enabling us to complete this challenge."

We are so grateful to you for having taken on this challenge Outlands Project! Thank you all so much for raising vital funds and awareness to support anyone affected by PKD!

RAISED
£1,380



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/donate-to-pkd

Payroll or Workplace Giving is a simple and cost-effective way to donate. We are registered with CAF, the UK's biggest scheme:

www.cafonline.org/my-personal-giving/plan-your-giving/caf-give-as-you-earn

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.

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/justgiving-virgin-money-gofundme

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/pkd-fundraising-events

'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

Pub quiz

Join us every Monday at 7pm in the PKD ARMS, either on your own or with friends and family, for just £2 for the PKD Virtual Pub Quiz!

To date they have raised over £500.

Register now at www.virtualquizevents.com, find us under 'Available Quiz Events' by searching 'PKD Charity'. Then just before 7pm login and select 'pending quiz events' to enjoy the fun. Cheers!



Virtual Balloon Race

Come fly with us on 4 December. Take part in our festive PKD Virtual Balloon Race and be in with a chance of winning £100 shopping vouchers of your choice!

100% environmentally friendly. Very competitive and huge fun for everyone. Challenge your fellow PKDers, friends, family and colleagues. Only £3 per entry - register from 1 November!



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

It's so easy to play. Visit pkdcharity.org.uk/fundraising/pkd-genetic-lottery.

Good luck and... you're helping support the PKD Charity's work!

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 meetup 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-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:

Just Diagnosed with ADPKD
pkdcharity.org.uk/about-adpkd/just-diagnosed

Symptoms of ADPKD
pkdcharity.org.uk/about-adpkd/symptoms-of-adpkd

Living with ADPKD
pkdcharity.org.uk/about-adpkd/living-with-adpkd

About ARPKD
pkdcharity.org.uk/about-arpkd

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:

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

UK Government Benefits Info
www.gov.uk/browse/benefits

Children's Liver Disease Foundation
childliverdisease.org

Board of Trustees

Jordan Adams	Karen Stapleton
Alison Carter, Treasurer	Adrian Tinsley
Alan Greenberg, Chair	Nick Tracey
Raj Johal	Elizabeth White
Rebecca Murphy-Peers	Prof Patricia Wilson

Management

Tess Harris, Chief Executive
Madeleine Martin, Fundraising Manager
Susan Muirhead, Community Support Manager
Jane Pugh, Community Engagement Manager

Research Advisory Board

Professor Patricia Wilson
Chairman
Dr Richard Sandford
Vice-chairman