

Top 10 priorities for ADPKD research

COVID-19 Vaccination update

To date, over 50 million doses of the COVID-19 vaccine have been administered in the UK, with over a quarter of adults having received both doses – and data from a Public Health England study shows the vaccines are already having a significant impact, reducing hospitalisations and saving more than 10,000 lives in England alone by the end of March.

Meanwhile, the Joint Committee on Vaccination and Immunisation (JCVI) has advised that adult household contacts of adults (aged 16 and over) with severe immunosuppression are now eligible for the COVID-19 vaccination. They have asked all GP practices to identify and write to all severely immunosuppressed adults on their patient lists informing them of this decision. For more information, contact your GP or see here: bit.ly/JCVI-Covid

We regularly update our blogs on COVID-19 and PKD. Our main blog is pkdcharity.org.uk/news-events/blogs/429-covid-19-coronavirusand-polycystic-kidney-disease.

For information on how COVID-19 might affect children with ARPKD visit pkdcharity.org.uk/news-events/blogs/430-coronavirus-covid-19-and-children-with-arpkd

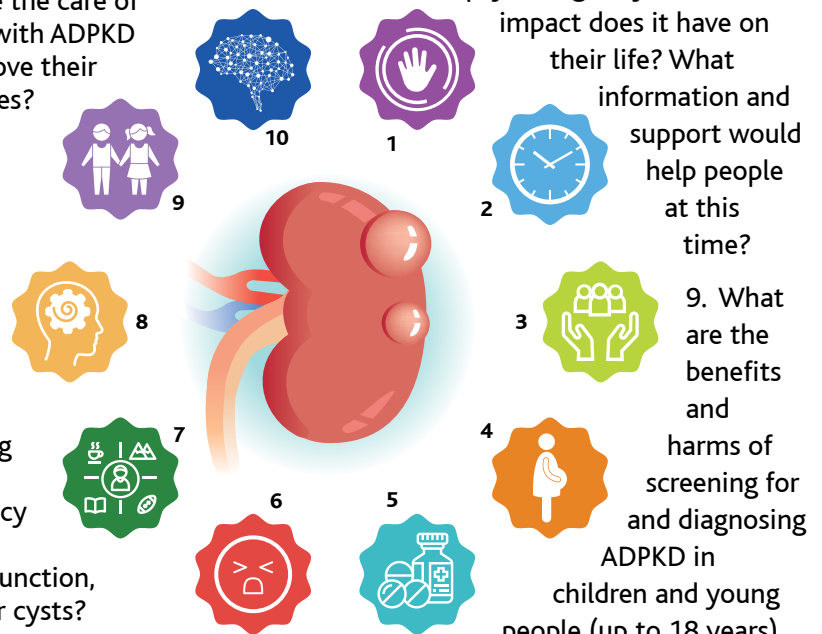
About 18 months ago, we asked what you think is most important to research in ADPKD (autosomal dominant polycystic kidney disease). Last year, we brought together the clinicians, patients and carers who know most about ADPKD to jointly discuss the unanswered questions and

unmet needs that we all have. Then we asked you to vote on your top 10 research questions. The results are in!

Thank you to everyone who took part. Read more about how we decided on the Top 10 and why they matter. pkdcharity.org.uk/research/prioritising-adpkd-research

1. What treatments can be developed that slow or prevent progression of ADPKD and improve patients' quality of life?
2. Which people with ADPKD would benefit from early treatment and how can doctors identify them?
3. What are the best ways to organise the care of people with ADPKD to improve their outcomes?
4. What effect does pregnancy have on women with ADPKD including their pregnancy health, kidney function, and liver cysts?
5. What are the benefits and harms of drugs that can be used for the management of ADPKD including polycystic liver disease (PLD)?
6. For people with ADPKD experiencing pain, what treatments work best to reduce this pain?

7. What changes to lifestyle, exercise and/or diet (including amount of water drunk) benefit people with ADPKD and polycystic liver disease (PLD)?
8. When people are newly diagnosed with ADPKD, how does this affect them psychologically and what impact does it have on their life? What information and support would help people at this time?
9. What are the benefits and harms of screening for and diagnosing ADPKD in children and young people (up to 18 years) at risk of having inherited this condition?
10. What causes enlarged blood vessels (aneurysms) in some people with ADPKD and what is the most effective way to screen for and treat aneurysms?



Information and research

More flavour, less salt!



Pour on flavour



not salt

#SaltAwarenessWeek

This year's Salt Awareness Week was all about More Flavour, Less Salt! - the ideal theme by Action on Salt for these unusual times.

With restrictions put in place due to the pandemic, we now spend more time at home recreating much-loved dishes. While some have enjoyed flexing their culinary muscles, it's a big challenge for those unsure how to achieve flavour without relying on salt. However, many of you know that too much salt increases your blood pressure, which can damage your kidneys. Reduced salt may also help slow the progression of ADPKD.

Thankfully, there are many ways to limit your salt intake and still ensure your food packs a flavoursome punch,

once you know how!

Action on Salt provides a few simple tips to help, including:

- Replacing salt with chilli, citrus, fresh herbs, garlic, black pepper and spices
- Cutting back on sauces such as soy sauce, ketchup and salad dressings which can contain lots of hidden salt
- Using lower salt-stocks, or making your own low-salt stock

Remember that ALL salt is salt (even the posh sea, rock and pink salt!). There are 'low salt' alternatives but be careful. Manufacturers have replaced the sodium with potassium, which can be harmful if you have

low kidney function or are taking certain medications.

Action on Salt have developed delicious recipes to help you cook low salt meals without compromising on flavour: www.actiononsalt.org.uk/resources/recipe-books

It also pays to develop good habits as early on in life as possible. Action on Salt's Food Flips is a terrific new card game that helps children learn to read food labels and practice maths and reading in a light and fun way. www.actiononsalt.org.uk/resources/food-flips-game



Have your say!

Parents, and mum's to be, Liverpool University invite you to take part in an online focus group as part of an important research study into NHS maternity and children's services.

You'll be asked to talk about your experiences of using services during and since things returned to 'normal' following the initial COVID-19 lockdown - For example, how involved you felt in decisions made by the Trusts regarding limitations on visitors or the use of video consultations.

As a thank you for your time, you'll receive a £25 shopping voucher!

Ideally, the university would love to hear from those in any of the following NHS Trust areas:

- Liverpool
- Birmingham
- Lewisham and Greenwich
- Morecambe Bay and South Lakes
- Sheffield

(Or anyone else who's interested!)



If you'd like to get involved please contact Dr Carol Gray
Carol.Gray@liverpool.ac.uk

Ref: 'Exploring ethical issues arising in routine maternity and paediatric care during the covid-19 pandemic'

PKD Charity support services

PKD connect meetups



Living with PKD can sometimes feel like a lonely road - perhaps you're Covid weary, newly diagnosed, worried or generally feel misunderstood, even by those who mean well.

PKD Connect gives you the chance to chat, share moments of joy, frustration and everything in between in an informal friendly meetup.

PKD Connect meetups are for anyone affected by PKD. The meetup host will make you most welcome – just grab a cuppa and join us for a chat about how you're feeling at this time.

Plus, it's free and easy to attend from the comfort and safety of your own home, via Zoom.

Below is a list of upcoming virtual

local meetups:

Biggleswade, Central Scotland, London, North Scotland, Norwich, Southend on Sea and South Shields.

Register on our website PKD Meetups (pkdcharity.org.uk/support/pkd-meetups).

If a meetup isn't available in your area, please join our PKD Community Meetup held at 11am on the first Wednesday of each month.

We also plan to establish new regional PKD Connect meetups in Northern Ireland, Birmingham and Wales.

For more information, email Susan at susan.muirhead@pkdcharity.org.uk or call/text her on 07739 632836.

Save the date

PKD diet webinar 2 June 2021

Evidence is growing that plant-based diets may help slow kidney disease progression, reduce cardiovascular risk of heart disease and stroke, and benefit the gut microbiome.

The patient-centred plant-dominant low-protein diet (PLADO) proposes a protein intake of 0.6–0.8 g/kg ideal body weight/day, with over half of the protein from plant-based sources. It is considered a heart-healthy, safe, flexible, and feasible diet for people with chronic kidney disease who are not yet on dialysis or with a transplant.

On Wednesday 2 June, we are delighted that Dr Kamyar Kalantar-Zadeh will join us for a webinar to explain more about PLADO and answer your questions. Register here:

bit.ly/PLADO-webinar

Please note that this will be an informational webinar only and you should always discuss dietary changes with your doctor or a dietitian.

ARPKD events

PKD Connect 'Time to Chat' events are for parents of children, and adults affected by ARPKD.

They are informal, virtual meetings held on Zoom which give everyone time to connect, share tips, and have a moan and a laugh with the ARPKD community from across the UK.

Our next Time to Chat is on Wednesday 7 July, 6.30pm. If you would like to join, contact Susan at susan.muirhead@pkdcharity.org.uk or call/text her on 07739 632836.



If you can't join us in July, don't forget you can chat with others affected by ARPKD on our UK ARPKD private Facebook group. facebook.com/groups/arpkdUK

ARPKD info day

26 June 2021

Exclusive to parents of children with ARPKD, plus adult ARPKD patients. Dr Manish Sinha of Evelina Children's Hospital, and Dr Tassos Grammatikopoulos of King's College Hospital give an update on ARPKD, dialysis/transplant and liver complications, in this informal, friendly, half day Zoom event. To register head here bit.ly/ARPKD-12621 or visit News and Events (Events) at www.pkdcharity.org.uk.

Raising awareness

World Kidney Day 2021

It's the topic that's too BIG to ignore. On 11 March, patients, family, friends and medical professionals united to shine a light on kidney disease for World Kidney Day.

Never was there a more important time to act. The pandemic has badly impacted kidney patients, with many having to shield at home for the past year, the pause on transplants, and sadly - for some - illness or worse. It's also led to more people with otherwise healthy kidneys to develop problems, including acute kidney injury in those with serious Covid-19 infections.

Thankfully, despite restrictions it didn't stop the community shouting from the rooftops, up to and on World Kidney Day. Thousands of people coloured their world yellow with the free campaign video backgrounds and colouring packs, superb



entries to the BIG Picture competition, while others helped spread the word by sharing their stories, and important kidney facts on social media!

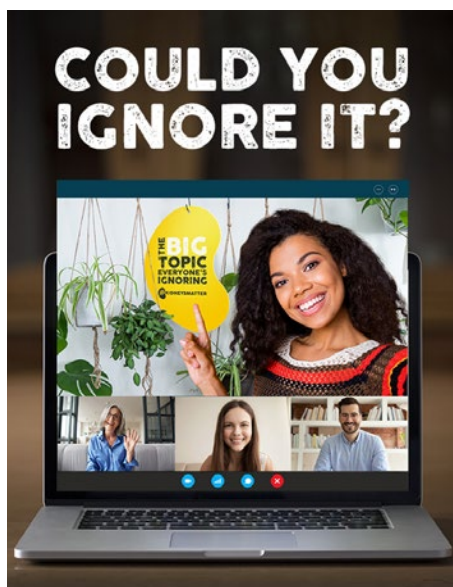
A Picture Paints a Thousand



With so many brilliant entries to the World Kidney Day Big Picture competition, it was a tough choice for the judging panel (PKD Charity, Kidney Care UK, Kidney Research UK, National Kidney Federation, British Renal Society, the Renal Association and Kidney Wales).

It was unanimous however to award 1st place to 28 year old Rachel for illustrating just how big a problem kidney disease is with this humorous yet very touching entry.

The photo, taken by Rachel, is of her mum Wendy moments before going to theatre to donate a kidney to a stranger as part of the UK paired donation scheme; an amazing sacrifice she made so that Rachel's dad and PKD patient, Peter, could receive a new kidney! Paired donation is often used when the donor and



Peter and Wendy walk to a new future

recipient are incompatible - as in Peter and Wendy's case - and are matched to another couple in a similar situation so that both people in need of a transplant receive a matched organ.

The transplant marked the start of a positive new phase for this PKD family who've experienced their share of starting afresh.

Peter was just 23 and a serving police officer when he learnt he had PKD, which he believes he may have inherited from his dad. Sadly, this meant he was retired from the police force on medical grounds and had to carve out a whole new career.

dialysis, which he could fit in around work. Before long though, he simply didn't have the energy to carry on with a business that's demanding even for a healthy person. The couple were forced to make the tough decision to sell the hotel they'd run with such pride for 13 years.

Eager to help her husband, Wendy was screened as a living donor but wasn't a match for him. It was then doctors' introduced the idea of paired donation, which Wendy and Peter jumped at. Living donor kidney matching runs are carried out quarterly, but are not always successful first time round. Indeed on the 4th attempt, 18 months after



Peter, Wendy, Rachel and Ben together again post-surgery.

Along with Wendy, he began working in hospitality before they headed north from their home in Sheffield to picturesque Lochcarron in the Scottish highlands, where they bought and ran a hotel. By 2015 however doctors' told Peter he must begin dialysis and needed a transplant. Although it was expected, Rachel was distressed by the news. Along with worrying about her dad, it was perhaps also a glimpse into her future too - Rachel and older brother Ben had known since childhood that they too have inherited PKD.

With the nearest hospital 64 miles away, Peter opted for peritoneal

being added to the list, the 57-year-old couple were finally matched.

Their operations took place at the Royal Infirmary of Edinburgh in October 2018, while Rachel and brother Ben anxiously waited in the wings. To record this special time, Rachel captured many photos of her parents before and after surgery. And we're so pleased she did!

Today, Peter and Wendy - who celebrated their 36th wedding anniversary on April 13 - are enjoying this second chance of life. Peter's kidney function has increased to an amazing 70% and he can hardly believe how energised he feels



compared to before the transplant.

While her parents' experience has made Rachel more conscious of her disease, she is equally more determined to live life to the full, and take good care of her kidney health - Wendy instilled in her from an early age the importance of drinking lots of water and limiting her salt intake. As a big thank you to her generous mum, she gave the competition prize of £250 Amazon vouchers to Wendy on Mother's Day!

Congratulations Rachel and all the family!

The Kidney Charities Together Group co-ordinates the UK World Kidney Day activity. This consists of the PKD Charity, British Renal Society, Kidney Care UK, Kidney Research UK, National Kidney Federation, the Renal Association and Kidney Wales.

PKD 21k Challenge!

Do something amazing this Spring, Summer or Winter and take on the 21k Challenge whilst raising awareness of PKD Charity!

Take on 21k, your way, and make a difference on our 21st anniversary. Whether that's cycling or running 21k over a weekend, walking or running a kilometre a day for 21 days - you decide how!

For more information visit: pkdcharity.org.uk/fundraising/pkd-fundraising-events/challenge-events/170-21k-pkd-challenge

A spotlight on events

Thank you Team PKD!

RAISED
£1,654



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!

Nancy Kennils took part in the 10,000 kettlebell swing challenge in February. Nancy completed 100 swings a day building up to the BIG finale of 5,000 swings on the final day! Through Nancy's strength and dedication, she completed her challenge and raised a whopping £1,654!

Joanna McWeeney walked 201km in March in memory of her Dad and raised £876 in total.



RAISED
£876

The Gutteridge Family did a fantastic job selling hampers last year and raised fantastic £930 for PKD Charity. It goes to show that family and friends can be a great support with your fundraising. A big thank you to the Gutteridge Family!

Jonathon McCreadie took part in running 31 days of 10ks in January for his grandmother who was diagnosed 20 years ago. Thank you Jonathon for raising a fantastic £800.

RAISED
£800



A big thank you to our April 21k Challenge participants, **Sarah D, Louise E, Kevin, Catherine, Kate, Janet, Melissa, Gemma, Emily, Maliha, Zoe, Louise D, Sarah A, Lucy, Chelsea, Nicola, Laura, Russel, Zoe, Polly, Faye, Alison, Simon, Marie, Vicky, Louis, Allison, Georgina, Corale and Janette** for taking part in the 21k Challenge! So far the 21k challenge has raised nearly £6,500!

Skydiving Superstars **Amanda Gabrielli** and **Laura Robinson** for



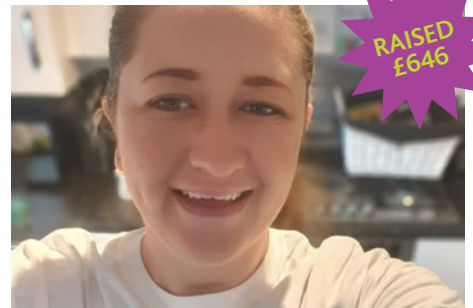
RAISED
£1,365

taking part in a skydive in April! They raised a fantastic £1,365 for PKD Charity!

We are so grateful and super proud for all your support. Thank you so much!

If you feel inspired by our PKD Superstars and want to take part in a fundraising event for PKD Charity, please contact fundraise@pkdcharity.org.uk.

Our corporate partner, **oneninefive** is hosting a Golf Day at the Aldenham Golf Club, Hertfordshire on 2nd July. If you're a keen golfer and would like to get a PKD team together, we are selling tickets via our website.



RAISED
£646

Good luck

Adrian Mapp is taking on a challenge of a lifetime by riding John'O Groats to Lands' End in May.

Adrian is taking part in this challenge as he witnessed his inspirational Mum go through her PKD journey.

Adrian says "Although affecting me and my family personally, by carrying out this adventure we can hopefully raise some more money to go towards vital research and

funds to help contribute to the fight against this disease which I know can eventually be beaten!"

A big thank you to Adrian for supporting PKD Charity and we wish him the best of luck.

So far he has raised £1,050!

We also want to use this opportunity to wish good luck to Laura Mapp (Adrian's Sister) who is taking part in the Virtual London Vitality 10,000 and Terry Lapins (Laura's partner) who is taking part in the London Marathon this year. You're a family of PKD superstars!



RAISED
£1,050



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

London to Brighton Cycle Ride



PKD Charity have a number of places in the London to Brighton Cycle Ride on Sunday 19th September. Take the 55-mile picturesque route through the English countryside followed by the climb up Ditchling Beacon before you glide down to the vibrant Brighton Seafront. With a buffet lunch stop at the halfway point, this ride is a fantastic day out in the sun. For more information visit: pkdcharity.org.uk/fundraising/pkd-fundraising-events/cycling-events/165-london-to-brighton-cycle-ride

Virtual Balloon Race

Come fly with us on Monday 21st June and take part in the PKD Charity, Summer Solstice Balloon Race and be in for a chance of winning a £100 shopping voucher. Only £3 per entry, register online from 31st May.



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/pkd-genetic-lottery. Good luck!

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

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