

Take part in our ADPKD Research Priority Setting Partnership (PSP)

Identifying and funding the research that is most important to people with ADPKD is the Charity's priority this year. One way to do this is to bring together the clinicians, patients and carers who know most about ADPKD to jointly discuss the unanswered questions and unmet needs that we all have. For example: what is the best diet, how to manage pain, should I have my child scanned, is gene therapy possible? In future months, we will be asking you to help by responding to a series of surveys designed to rank and prioritise the most important areas of research in ADPKD. Prioritising ADPKD research in this way offers three important benefits: increasing awareness, funding and translation into policy. We hope that our ADPKD priority setting partnership will give a voice to your most important research questions that will be heard by researchers, funders and policy makers.

If you would like to have a say in how the ADPKD PSP is organised, please contact us at:
tess.harris@pkdcharity.org.uk



PKD Charity 2017 Calendar of Events

- 13 May** ADPKD Information Day
Hammersmith, London
- 22 July** ARPKD Family Day
Birmingham

PKD Charity Research Update

Since 2008, the PKD Charity has funded over £200,000 of research in the UK. The money has helped support many projects. For example: a unique bioresource of samples – kidneys, blood and urine – donated by ADPKD and ARPKD patients which are used to identify 'biomarkers' of disease progression. We have also given grants for an investigative study on an ARPKD modifier gene, research into high blood pressure in children and young people, and a pilot clinical trial into water in ADPKD. We have also supported the education of an early-career researcher and a doctor – the next generation of PKD experts. Find out more on our website www.pkdcharity.org.uk/research/pkd-charity-research/grants-awarded

This research would not be possible without the incredible individual and family fundraising efforts of our supporters. We also receive donations to be used specifically for research, called restricted funds. Sadly, some of these are gifts made in memoriam of adults and children with PKD.

All research grant applications are thoroughly assessed by our Research Advisory Board of experienced PKD doctors and scientists.

How you can help research

Apart from donating and raising funds, there are a number of ways you can help with PKD research.

Ask your doctor or your child's doctor about RaDaR, the National Registry of Rare Kidney Diseases. RaDaR is collecting information from PKD patients across the UK. The aim is to give researchers a deeper understanding of how PKD really affects us and speed up research. If sufficient patients can be registered, studies

and trials can start on new treatments. If you agree to join RaDaR, relevant medical information is put onto your record which is updated at every clinic visit. Over 2,400 ADPKD and 130 ARPKD patients have already registered. We'd like everyone with PKD to have the opportunity to join.

www.pkdcharity.org.uk/about-arpkd/arpkd-patient-registry
www.pkdcharity.org.uk/about-adpkd/adpkd-patient-registry

At your next appointment, ask your doctor or nurse about any research studies you could be involved in. If there's nothing happening in your hospital at present, let them know you are interested in future research.

Look on Patient View for a new Research tab. Some of you will have access to Patient View (formerly Renal Patient View). A new Research tab will be added for you to register your interest in research – not just into PKD but also kidney research. Find out more about Patient View: www.patientview.org.

Sign up for the 100,000 Genomes Project. Genomics England is analysing – known as 'sequencing' – the genomes of 100,000 people in the UK with rare diseases and cancer. A genome is an entire set of all your genes plus a lot of other DNA found in human cells. The aim is to stimulate innovative research, deliver greater medical insights and transform the genetics health services. ARPKD and ADPKD patients and family members are eligible to sign up, if you haven't had a prior diagnosis by traditional molecular testing.

www.pkdcharity.org.uk/about-adpkd/100-000-genomes-project-adpkd
www.pkdcharity.org.uk/about-adpkd/100-000-genomes-project-arpkd

Health Information

Understanding Pain in ADPKD

How common is pain in patients with ADPKD?

Pain is common in patients with ADPKD. Nearly 1 in 10 (7%) suffer an episode of severe pain a year. These painful episodes are usually related to infection, stones or bleeding into cysts and subside after treatment. However, about 2 in 3 (60%) suffer constant pain, which may be related to enlarged kidney cysts. These cysts can distort the kidney and compress internal organs. Their sheer size can cause abnormal body posture, which may lead to musculoskeletal pain.

Not everyone with large polycystic kidneys experiences chronic pain. Research has shown that the severity of pain does not correlate with kidney size. But it may be that pain depends on where the cysts are within the kidney, rather than the size of the kidney. Or that only cysts over a certain size cause pain.

How do we normally sense pain?

We should also remember that pain is a sensation that is generated by the nervous system. The scientific word for 'pain nerves' is nociceptors. 'Noci' comes from the Latin 'nocere', which means to injure. Nociceptors detect damage to the body and send signals up to the brain, which generates the feeling of pain.

The brain isn't just a passive receiver of nerve signals. It can amplify or dampen the signals coming up from the nerves. For example, the brain can dampen the nerve signals to decrease

pain despite damage to the body to give athletes the winning edge during sports. When the competition is over, the brain switches from dampening to amplifying nerve signals to increase pain, which enforces rest to promote recovery.

What might be happening to the nervous system in chronic pain?

Damage to the body causes nociceptors to fire off strongly. Scientists have discovered that strong and frequent signals from nociceptors increase the sensitivity of the central nervous system – called central sensitisation. Central sensitisation causes areas surrounding the injured part of the body to feel painful. For example, stroking normal skin around or near a knife cut will feel uncomfortable or even painful for up to a few inches away from the cut.

Central sensitisation is useful because it causes increased pain and tenderness, which protects the damaged body part. The increased sensitivity should fade away with healing. If that doesn't happen, pain is likely to continue or get worse. That's what researchers suspect happens in some patients with chronic pain (www.painscience.com/articles/central-sensitization.php).

Is central sensitisation relevant to chronic pain in patients with ADPKD?

We don't know whether central sensitisation is relevant to chronic pain in patients with ADPKD.

However, we know that central sensitisation contributes to chronic pain from nerve damage, for example in patients with diabetes or shingles. Pain from nerve damage is called neuropathic pain, which has distinct qualities. Patients with neuropathic pain often describe their pain with words like 'burning', 'electric shocks', 'tingling', and even 'numbness'.

There are drugs for neuropathic pain but all have side-effects. But they may be worth trying if there's some aspect of pain in an ADPKD patient that is neuropathic.

Can we detect neuropathic pain in ADPKD?

At a recent PKD Charity Information and Support Day, issues of pain were explored in a workshop and a neuropathic questionnaire called PainDETECT completed by 34 participants.

The graph shows a number of participants for each neuropathic score. Scores in the green zone indicate pain without neuropathic qualities, and in the red zone pain with neuropathic qualities. Only two patients we surveyed had a definite neuropathic quality to their pain.

This small survey gives a glimpse into the nature of pain in patients with ADPKD. What we really want are tests proven in research studies that tell us where the pain is coming from for a particular patient. For example, is pain related to large kidney cysts, or poor posture, or abnormal nerves for that patient? Such knowledge will help tailor treatments for individual patients.

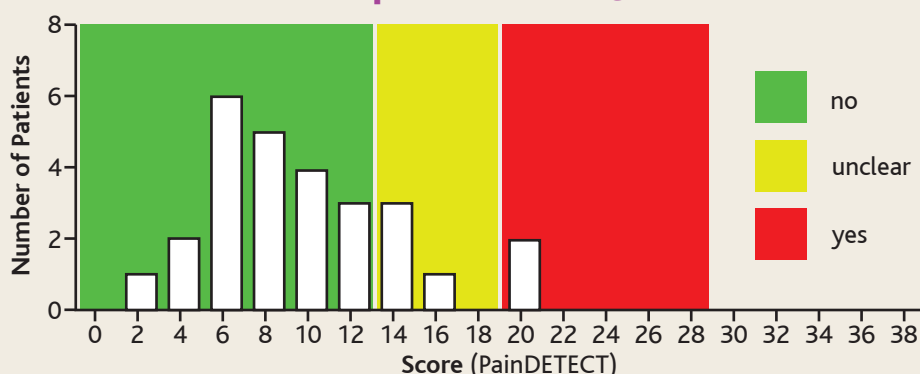
The PKD Charity is supporting a larger research study into pain in ADPKD. More about this in later newsletters.

Written by:

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Link to PainDETECT questionnaire:
www.specialistpainphysio.com/wp-content/uploads/2010/07/painDETECT-Questionnaire-01.pdf

Neuropathic-like Qualities



Health Information

New Leaflets Published

Three new health information leaflets have been published on the PKD Charity website. These are accredited by the NHS 'Information Standard'. We are very grateful to the patients, families and medical experts who helped us.

Genetic Counselling and Testing in ARPKD and Genetic Counselling in ADPKD were written by Dr Christine Patch, King's College London. They cover the genetics of both conditions, describe the difference between genetic counselling and testing, how useful they are in family planning, and provide information on how to access these services.

Links:

www.pkdcharity.org.uk/about-arpkd/diagnosis/genetic-counselling-and-genetic-testing-in-arpkd

www.pkdcharity.org.uk/about-adpkd/just-diagnosed/genetic-counselling-and-genetic-testing-in-adpkd

Diet and Lifestyle in ADPKD is an updated leaflet, reflecting some recent changes to dietary advice from the NHS. This leaflet includes an illustrative urine chart you can use to check if you are sufficiently hydrated by looking at the colour of your pee.

Note that this leaflet is for people with ADPKD who are not on dialysis and have above 30% function. If you are on dialysis, have low kidney function or have been given specific dietary or lifestyle advice from a healthcare professional, the advice in the leaflet might be wrong for you.

www.pkdcharity.org.uk/about-adpkd/living-with-adpkd/diet-and-lifestyle

If you don't have access to the internet, please contact us for a printed copy.

Our health information is for people in the UK. We try to ensure it is correct and up to date. It is not a substitute for professional medical advice or a medical examination. We do not promote or recommend any treatment. Always consult your GP, pharmacist or other medical professional if you have any concerns.

Appointment Tips

Prepare well

Plan your travel, follow instructions given by the clinic, collect all information requested, write down any important questions you have, and ask a friend/relative along if you want.

Give clear information

Give your doctor a clear picture of your symptoms and concerns – be honest and brave!

Check you understand

Ask about the benefits, risks and practicalities of treatments or procedures. If you don't understand, ask your doctor to explain it again, or differently. Write down key

information, and ask for copies of reports and letters. Ask who you can contact if you have questions later.

Pause for thought

Don't fall into a trap of feeling rushed in your appointment. If you need a moment to think things through or make a decision, ask for this. Check your notes – have you covered everything you wanted to discuss?

Follow up

If you have new questions, new symptoms or side effects from your treatment, get back in touch with your doctor. If you're waiting for test results or an appointment, call up if these don't arrive when expected.

Check the colour of your urine to see if you are hydrated



Clear to light yellow

You're hydrated.
Drink as you get thirsty.



Dark yellow to dark amber

You're dehydrated.
Have a drink of water.

Why is my urine an odd colour?

Strange coloured urine can be caused by some foods or medicines. It can also signal a health problem. See your doctor if your pee has changed colour and you haven't had foods or medicines to explain this.



Cloudy (milky)

You might have a urinary tract infection, especially if you have other symptoms, like a burning sensation when you pee, needing to pee more often or smelly pee. Kidney stones can also cause cloudy pee.



Pink, red or light brown

This can be caused by some medicines or food (e.g. beetroot, blackberries or rhubarb). If you're female, it could be vaginal blood. Sometimes, a urinary tract infection causes blood in pee. Or if you have ADPKD, it could signal a cyst infection, bleeding cyst or kidney stone.



Dark brown

This can be caused by some medicines or food (e.g. broad beans, rhubarb or aloe). It might also signal a urinary tract infection or kidney or liver problem.



Green or blue

This can be caused by some medicines or food colours. It can also be a sign of a urinary tract infection or a liver problem.



Dark yellow or orange

You might be dehydrated. Orange pee can also be caused by some medicines, laxatives, B vitamins or carotene (found in carrots and some other fruit and veg) or a liver problem.

These urine colours are for illustrative purposes only and may not match the colour of your urine.

We are inspired by

Our Fabulous Fundraisers

Giving PKD the Bump

Lots of people got involved with our first Europe-wide awareness campaign by 'Giving PKD the Bump' and sharing it on social media, buying our 'bump' pin badges and fundraising in very novel ways! **Josh Askwith** and his partner organised a Guess the Weight of the Baby competition, giving a new meaning to the Give PKD the Bump campaign! They raised £60 and the prize was the weight of the newborn baby in chocolate! **Dan Craven** took up the bump challenge and raised £186. **Sheena Sefiani** once again baked and sold yummy treats raising £70. **Vanessa Culliford** and the Superstition Belly dancers raised over £739 at their belly dancing concert in October.



Further afield, **Debs Roebuck** took part in the Amsterdam Half Marathon and raised £402.

Running

In the 2016 London Marathon **Lindsay Brown** raised £137. **Kathy Bergh** also ran and **Esther Wright** from the PKD Charity raised £3,448. **John Stone** once again completed the tough course and continued to fundraise for PKD. **Phillip Box** ran the marathon with a tumble dryer strapped to his back! By the time he had completed the London Marathon (including an interview on the BBC prior to the race) he had raised over £2,773 for PKD and narrowly missed out on a Guinness World Record!

Also in April, **Charlotte Roshier** raised £831 for PKD in the Great Manchester Marathon. In May's Great Manchester Run, **Kevin Button** raised £567, **Tilly Robinson** raised £698, David Salt raised £100 and **Natasha Costello** raised £280. **Erika Couling** and 6 of her friends also took part raising more than £2,300. Also in

May, **Megan Freeborn** ran the Vitality 10,000m and donated more than £800 of sponsorship to PKD. **Jagdeep Gill** ran the Two Castles Run in June between Warwick Castle and Kenilworth Castle and raised £305. **Sarah Smith** raised £237 by running the Leeds 10k. In June **Sherie Lovering** entered the Swansea Half Marathon and raised £122. **Steven Burnside** took on the mammoth 8 day Cape Wrath Ultra, in the Scottish Highlands in May and raised more than £2,000 for PKD. **Barry Davies, John Kennedy** and **Stuart Donald** competed in the Spartan Beast raising £431 for the charity. **Nikki** ran the Baxter's 10k and raised £348.75. **Caron and Megan Barr** raised £125 in the Great Scottish Run in October. **Donna Bennett** took part in the big Coventry Fun Run in September with her two children and together they raised £195.



Graeme Hamlett ran the Vitality Reading Half Marathon and raised £111. **Claire Smith** raised £360 in the Moonlight Colourthon. **Michael and Helena Rees** ran the Cardiff Half Marathon together and raised £828 for PKD. **Rebecca Fisher's** Cardiff Half Marathon in October saw her raising £176 for PKD. **Susan Dunne** ran two back-to-back events in November; the Helvellyn 10k Saturday the Ullswater 10k Sunday. Susan raised over £388 in sponsorship from family and friends.

In the Great North Run, **Iona Bergin** raised £468 and David Heath-Whyte raised £1,700. Andrew Mason ran the Great North Run as well as the Yorkshire Marathon raising £360 in the process. Also hitting the streets of the North East were **David Neal** and **Jonathan Read** who raised £392. **Matthew Todd** ran for PKD and raised £215 and **Rosalyn Wilde** completed the challenge to raise £170. **Josh Watson** ran the junior Great North Run for his friend Ethan and raised £383.

In the annual Great South Run, **Kate Barfoot** raised £1,141, **Laura Topping** raised £209 and **Emma Hyslop** raised £265. **Caroline Kingshott** also ran with her husband and sister, **Emma Ewens** and they raised £402.



Gordon and Sara Bailey have continued their 'Winston's Wings' fundraising in memory of their little boy, Winston. A team of 30 runners took part in the Lochness Marathon Festival in September. As well as some personal bests, the team have raised more than £6,000. In the same event, **Hayley Allardice** took on the 10k distance raising £80 for PKD in the process.

Swimming

Taking to the water, **Jenny Max** swam the lidos of London and raised over £2,800. **Kirsty Neal** also braved outdoor water temperatures to participate in the Great London Swim in July and raised £605.

Walking

Gemma Higgs was part of a team who organised a Prom Walk for **Harry Mara** in August and they raised more than £400 in sponsorship. **Sian Marshall** also took part and fundraised for the event, raising £60 for PKD. **Paul Foster** and his wife, **Helen Foster** planned to do the Thames Bridges Trek in September. Unfortunately, Helen was unable to take part, but her sponsors still donated and together Paul and Helen raised more than £700 for PKD. In May, **Alice Page** and her friend **Caroline** decided to take part in the Isle of Wight 106k walk and donated £1,729 of sponsorship to the PKD charity. **Clare Parrott** organised a sponsored walk to celebrate 20 years of her Mum, Wendy's, kidney transplant. With the support of family and friends they raised more than £1,500 for PKD. **Nigel Atkins, Steve**

Bown and **Sharron Atkins** took on the Yorkshire 3 Peaks Challenge in June and raised £1,092. **Lori-Anne Desmond** walked the Thames Bridges Path Challenge raising £388.

Tina Procter and the team who organise the annual LUMPS walk, featuring 20 miles and 20 pubs, decided to donate this year's fundraising to the PKD Charity and a local boy named Wilf in need of specialised eczema treatment. The **LUMPS team** raised over £10,000. Fortunately, Wilf's condition improved over the year and his treatment was not required. At his own request the funds that had been raised for **Wilf** were also donated to the PKD Charity.



Cycling

The **Rt Hon Mr Fabian Hamilton** MP organised a cycle ride from Leeds to Brighton in July, stopping at the Houses of Parliament along the way. With incredible support from constituents, friends, family and colleagues more than £3,700 was raised for PKD.



In September, **Paul Sims** cycled from Land's End to John O'Groats with **Mark Allen** and **Beau Ormrod** and they raised £6,464.70. **Mark Barnard** and friends organised the 'The Big Ride in September' in memory of **Aimi Lawson** and raised over £1,000. **Tomas Katafiasz** and friends **Jack** and **Gareth** cycled from Land's End to John O' Groats in September and raised £2,000.

Overseas

Further afield, **Jennifer Lees** struck out on the challenge of a lifetime and trekked the Great Wall of China in April. Jennifer's incredible walking and

fundraising efforts led her to donate more than £3,700 of sponsorship to the PKD Charity. Continuing the overseas theme, **Georgina Bream** trekked up Mt Kilimanjaro with her Dad and raised more than £1,000. Georgina is now planning further challenges to continue her fundraising.



Amy Pemberton decided February 2017 was her time to trek to the top of Mt Kilimanjaro and in doing so she raised £465. Heading to the USA for their fundraising, **Neil McLean** and his friend **Alastair** ran the New York Marathon for several charities and raised the tremendous sum of £1,716 for PKD. **Paul Reeves** and a team of 3 friends decided to cycle the 208 miles from London to Paris in August enduring temperatures of 33 degrees once they reached France. Together they raised over £600 for PKD. Also taking to the continent was **Alex Smith** who walked the Haute Route Pyrenees route, unaided, for his Grandmother who has PKD. Alex raised sponsorship of more than £1,700. **Caroline Somerset** took on another incredible challenge and trekked across the Canadian Rockies in September raising more than £3,700 in sponsorship.

Other Fundraising Activities

Simon Heywood organised a Dryathlon in August and donated £272 to PKD. In October, **Roy Turner** strapped himself in for the Ageas Bowl Zip Wire Challenge and raised £165. **Seamus Mulready** was in a boxing match in December and raised £1,293. **Lisa Tilley** got together with fellow quiz enthusiasts to put their brains to the test and raised £332 from her quiz night. **Sarah Vaughan** and the **Cardiff University Archery Club** organised a 24-hour archery shoot in April and raised over £900. **Cameron Roberts** organised an event for PKD at his local community centre and raised more than £200. **Simon Said** organised the Alley Cats Variety Show in June and with his performers donated over £300 to

PKD. **Dave Thomas** created a unique challenge by completing a 50k bike ride followed by a 10k run, rounded off by climbing all 1,000 steps at the Madejski Stadium. Dave raised over £190 for PKD and his Vodafone Big Bold Challenge in October raised £231.25. **Steven Cassidy** took part in the Strathclyde Triathlon Festival in June and raised £1,282. **Jenny Lewis** and the **Dunnington Fayre** team very kindly used the event to fundraise for PKD. With the help of a team of volunteers led by **Peter Buckley** and his family, the event raised £300 for the PKD Charity. **Nicholas Corry's** wedding guests donated £678 to the PKD Charity in lieu of gifts at his wedding to **Jen** in August. **Samantha Macdonald** didn't let the fact that she had never sailed before prevent her from sailing from Plymouth to Eddystone Lighthouse in June. Samantha was supported by sailor **Andrew Patrick** and raised £1,600. Getting muddy for PKD were several Tough Mudders. **Kingsley Ikemeh** raised £94 by taking on the London Tough Mudder. **Nicky Patch** organised a team of colleagues to take on the same event in September and together they raised £1,562. The team included **Dave Mahoney**, **Andy Ogier**, **Chet Pohl**, **Anthony Williams**, **Ed Blewett**, **Nicky Patch**, **Michelle Schofield**, **Libbie Law**, and **Charlie Ward**. **Dom McKenzie** entered the Yorkshire Tough Mudder and raised £130 in sponsorship from family and friends. **Tara Edwards'** haircut in April from very long to short raised £572. Also going for the chop was **Felix Grady** who braved the scissors and donated more than £900 to the PKD Charity.



We don't have space to thank everyone who has fundraised for us, but we say a heartfelt thank you to everyone who has fundraised, run, swam, walked, cycled, boxed, quizzed, trekked, baked, sailed and so much more for PKD in the last year. Our work simply would not happen without your support.

Moderate Salt Restriction is Beneficial

In ADPKD

What we know already

It has long been recognised that people with ADPKD have raised blood pressure. Kidneys are central to regulating blood pressure (BP) and they do this through the Renin-Angiotensin-Aldosterone-System (RAAS) which involves a delicate balance of blood volume, renal blood flow, aldosterone and sodium (Na).

In the general population it is accepted that moderate sodium restriction has a beneficial effect on BP and cardiovascular events. Most sodium is eaten as salt (NaCl or sodium chloride). But defining the optimum salt/sodium intake for people with chronic kidney disease has been controversial, with some studies producing unexpected results.

Reducing sodium intake has been shown to slow the progression of renal diseases where protein excretion in the urine (proteinuria) is common. However, proteinuria is not a major feature of ADPKD, so would sodium restriction have the same effects?

The gold standard for assessing dietary sodium intake is to measure the sodium output, that is the urinary excretion of sodium (UNaE). This is more accurate than asking people to keep food diaries or extrapolating from single measurements of urine sodium content. The UNaE test entails a 24-hour urine collection.

The CRISP study in 2011 found that UNaE was associated with the rate of total kidney volume (TKV) increase. CRISP stands for the Consortium for Radiologic Imaging Studies of Polycystic Kidney Disease - not the salty snack. This suggests that dietary intake of sodium may be related to the

growth of the kidneys.

It has previously been shown that increase in total kidney volume (TKV) can be used as a measure of progress of the disease, even in early stages. In later stages, disease progress is measured by the fall in the glomerular filtration rate (eGFR).

Dr Vicente Torres and colleagues carried out a sub-analysis of the HALT-PKD trial data. HALT-PKD was a large trial which set out to examine the effects of BP control in ADPKD. Because it involved several hundred people with ADPKD it provides a valuable data resource for further analyses¹. The researchers used the data from HALT-PKD to investigate whether sodium restriction slows the progress of ADPKD.

What this sub-analysis of HALT-PKD adds to our knowledge

The conclusion of the study is that moderate salt restriction in the diet could slow the progression of the disease.

It is worth a closer examination of the validity of this claim, bearing in mind that HALT-PKD was not specifically designed to examine sodium intake and disease progression.

HALT-PKD had two 'arms' or groups of patients in the trial, one in early stages with good kidney function (A), the other patients in later stages of ADPKD and moderately reduced kidney function (B). These two groups were sub-analysed separately. Both

¹ Torres, Vicente E., et al. "Dietary salt restriction is beneficial to the management of autosomal dominant polycystic kidney disease." *Kidney International* (2016).

demonstrated a relationship between urinary sodium output (UNaE) and progression of the disease. In A, the early stages, the rate of increase in total kidney volume was associated with the averaged UNaE. In B, with less kidney function, the greater the urinary sodium excretion the larger the fall in kidney function, as measured by the estimated glomerular filtration rate (eGFR).

All of the patients involved in HALT-PKD were given advice on reducing their dietary salt intake. Although long-term compliance with a low salt diet can be quite hard to achieve, the measurements of the urinary excretion of sodium did fall during the study showing that on the whole, patients in the study did manage to keep to a sodium-restricted diet.

It is important to note that the effect of sodium restriction was noticed regardless of which BP treatment the patients were on.

This study has clearly suggested a causal relationship between dietary sodium and increase in kidney size, irrespective of age, gender, race, BMI or BP treatment.

Dr Torres et al have added a single note of caution: that overzealous sodium restriction for patients on ACE inhibitors for blood pressure medication could theoretically lead to some damage to the interstitial tissue (the tissue between the tubules) of the kidney. This has been shown in studies on rat models, but this is probably an unlikely situation given the modern diet. On average, the general population consumes a third more salt daily (8g for adults) than is recommended (6g).



Stephen's Story

Cycling on Peritoneal Dialysis (PD)

What does this mean for ADPKD patients?

A low salt diet in this instance was set as no more than 2.4g salt per day. If higher sodium intake is associated with faster decline in kidney function then it is clearly going to help if we take steps to reduce our salt intake.

This is no easy task and we need both knowledge of the salt content of foods and frequent reinforcement of the low salt message in order to comply with this advice.

There is always a rider to any study, that individuals should only make dietary adjustments in consultation with their own medical advisors. But it is very likely that most of us would benefit from a low salt diet.

Thanks to Katie Law for reviewing this study and summarising these results.

Tips for reducing dietary salt

Do not add salt to your food at the table. Use herbs, spices, lemon or vinegar instead.

Make your own stock instead of buying salty stock cubes – and save money too! For a meat stock: add roughly chopped vegetables such as carrots, onions and celery to any meat bones in a pan with plenty of water. Add a bay leaf, dried herbs and peppercorns. Bring to boil and simmer for 2 hours. Strain and cool. For a vegetable stock: omit the bones and add more vegetables such as leeks or turnips. Simmer for 30-40 minutes.

Read the food labels. Look for the red, amber, green symbols, and the table showing salt content.

Find out more in the new Diet and Lifestyle leaflet on the PKD Charity website:

www.pkdcharity.org.uk/about-adpkd/living-with-adpkd/diet-and-lifestyle



Download the free FoodSwitch app for IOS and Android phones.

play.google.com/store/apps/details?id=uk.co.bupa.foodswitch

itunes.apple.com/gb/app/foodswitch-uk/id804442303?mt=8

I had dreaded this for months, but finally my renal consultant said: "It's time to start dialysis". Sleeping badly, poor appetite, feeling lethargic and rotten, I was facing peritoneal dialysis or PD - meaning the end of a normal, pleasurable life. In an act of bloody-minded belligerence, I bought a bike.

My first ride was soon after fitting the PD catheter. A wobbly 3 minutes 400m, but with 100m downhill where I felt the same 'whooshing' sense of freedom I did as a child.

After cycling a few months, I felt much fitter and healthier. A bit concerned about overdoing it, I spoke to my nurse and consultant. They said 'do as much as you like'. I could get on with life!

I live in the beautiful Lake District and used the hilly terrain to my advantage. Cycling can be tough, but only as tough as you want it to be. I cycled when I felt like it. I dialysed overnight and carried no fluid during the day, so PD didn't restrict my cycling - other than needing to be home each night.

My fitness returned. I'm 54 and rarely get serious PKD pain. Cycling alleviated the pain and helped with other symptoms. I felt better, had more energy and reduced bouts of restless legs (heck, they really make life miserable). But mainly, it's the sheer fun and emotional wellbeing that kept me on my bike. It gave me new purpose and new friends - I set up a cycling group catering for those of 'a certain age'. I set myself the target of 100km in a day, which I achieved on a charity ride in Cumbria.

Fast forward...

The above was written last year. Just before Christmas I got 'THE CALL' leading to a quick drive to the Freeman Hospital for a kidney transplant. It went well and I was out of bed the day after. Unfortunately, 4 days post transplant, I had a massive cardiac arrest, leading to me being in a coma for a few days, along with the fitting of an internal defibrillator in my shoulder and wires in my heart. The medical team couldn't find the cause of my heart trouble, it was just 'one of those things'. However, the physios



got me on my feet the day after being released from intensive care and soon I was back cycling. They put a stationary exercise bike at the bottom of my bed so I could hop on and gently pedal for 10 minutes at a time.

I am now home and it's tremendous to no longer be on dialysis, to eat and drink what I want, and feel so unbelievably grateful for each day. I've been back on the bike for relatively sedate rides. I have to return to fitness at a steady pace, largely because of the heart issue but each day I get a bit stronger. I know I am extremely lucky to survive a cardiac arrest. I am very, very lucky that a generous donor family gave me a kidney and I am very lucky the kidney survived my time in ICU - in summary I am the luckiest person I know! I also know the surgeons and countless others who helped me through the transplant didn't put that effort in so that I sit on my behind for the rest of my life. The Freeman specialists said that one reason for my good recovery from transplant and cardiac arrest was my initial level of general fitness. Cycling and being fit when on PD may well have saved my life (in the UK the survival rate for cardiac arrests is only about 8% - and the hospital crash team worked on me for 40 minutes before my heart was properly going again). For me to survive, and to keep the kidney working and not to suffer brain damage...well...let's just say I had medics visiting me in hospital as my speedy recovery was indeed a rarity for them.

Yes I have a heart issue, yes I have PKD, yes I have a transplanted organ - but I will regain my fitness and yes I will enjoy the future.

Support and Information

Support Available

Our Support Line is available Monday to Friday, 10 am to 4.30 pm or leave a message on the answerphone: **0300 111 1234**

Join an ADPKD online support group:

- **PKD Yahoo Group**
uk.groups.yahoo.com/group/PKD_uk/
- **PKD Charity Facebook Group (UK only)**
www.facebook.com/groups/pkdcharityUK/
- **PKD Northwest Support Group**
www.facebook.com/groups/NorthwestPKD/
- **Polycystic Kidney Disease and Kidney Disease**
www.facebook.com/groups/17866443885/
- **HealthUnlocked ADPKD Community (UK only)**
www.pkdcharity-autosomalrecessive.healthunlocked.com/
- **Living with Polycystic Kidney Disease Support Group**
www.facebook.com/groups/150513068466259/

Join an ARPKD online support group

- **Facebook ARPKD Group**
www.facebook.com/groups/20526281816/
- **HealthUnlocked ARPKD Community (UK only)**
www.pkdcharity-autosomalrecessive.healthunlocked.com/
- **ARPKD/CHF Alliance**
www.facebook.com/groups/89846751499/

Join a PKD Meetup Group

- www.meetup.com/PKD-UK/

Insurance

Names of insurance firms and brokers specialising in PKD and other long-term conditions are on our website: www.pkdcharity.org.uk

Links to Other Charities and Organisations

- **NKF Kidney Care UK - help and information to support kidney patients and their carers, in particular those on dialysis**
www.kidney.org.uk
- **The British Kidney Patients Association Advocacy Service**
www.britishkidney-pa.co.uk/
- **Turn2us - helping people access money available to them through welfare benefits and grants**
www.turn2us.org.uk/
- **Contact a Family - supporting families of disabled children**
www.cafamily.org.uk/
- **Grants for help with seriously ill or disabled children**
<https://www.familyfund.org.uk/>
- **UK Government Benefits Info**
www.gov.uk/browse/benefits
- **Back copies of PKD newsletters**
www.pkdcharity.org.uk/news-events/newsletter

Patient Information on Our Website

Just Diagnosed with ADPKD

www.pkdcharity.org.uk/about-adpkd/just-diagnosed

Symptoms of ADPKD

www.pkdcharity.org.uk/about-adpkd/symptoms-of-adpkd

Living with ADPKD

www.pkdcharity.org.uk/about-adpkd/living-with-adpkd

About ARPKD

www.pkdcharity.org.uk/about-arpkd

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

Fundraise For PKD

Visit our website to:

Make a donation:

- Regular Giving
- Donation by Cheque
- A Gift in Your Will
- Give As You Earn
- Donate Online
- Collecting Tins and Buckets

Get our 'DIY Fundraising Tips'

www.pkdcharity.org.uk/fundraising/diy-fundraising-tips

Take part in a fundraising event

www.pkdcharity.org.uk/request-an-event-pack

Buy online at the PKD e-Shop

www.pkdcharity.org.uk/fundraising/pkd-e-shop

If you don't use the internet, ring Esther on **07715 664687** for help with fundraising.

Text us a donation

- Just text **PKDC12** followed by the amount in **£** that you wish to donate to **70070**.
- Research project 'Your Pound for a Pee'. Simply text **PKDC19 £1** to **70070**.

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