

New Support Services Planned

In response to an increasing number of requests to the charity, we want to provide more support services outside of the clinic to adults over 18 with ADPKD and ARPKD.

Although there are several friendly, active online groups on Facebook, many of you say you want to meet up with others locally. Some renal units do have peer support services, but these are often only for those on dialysis and transplant. Another suggestion is to set up a telephone befriending service.

We have decided to pilot different peer support, group support and befriending ideas in 3 areas: London, the North West and Scotland. To fund the pilot, we are applying to the Big Lottery for a grant. We need to include figures about 'demand', so we created a short survey. You can complete it online by visiting this website link: <http://pkdc-support-survey.questionpro.com>. It should take about 3 minutes, is anonymous and confidential.

If you have questions, please contact Julie Adams on 07739 632836 or by email julie.adams@pkdcharity.org.uk



Julie Adams joined the PKD Charity in February as Operations Manager. She has worked in the charity sector for

the past eight years, most recently at Alzheimer's Society.

Latest news on Tolvaptan (JINARC™)

Since our last newsletter, we had positive but also very disappointing news about Tolvaptan. In February, Tolvaptan – now called by its brand name JINARC™ - was approved in Canada and is now being prescribed to adults with ADPKD.

On 28 May, we heard that the European Commission had granted 'marketing authorisation' to JINARC™. In other words, the drug is now – officially – the first-ever licensed therapy to treat adults with ADPKD in Europe.

Tolvaptan represents a significant medical breakthrough in the management of ADPKD. For the first time, progression of the disease can be modified with the potential to delay kidney failure.

However, the same day (28 May), we were shocked to hear that the National Institute for Health and Care Excellence (NICE) had initially rejected JINARC™ in England and Wales.

The NICE Appraisal Committee (which met on 1st April) concluded that the relative benefit of the drug compared with placebo (as reported in the TEMPO 3:4 trial) is associated with some uncertainty and that it is not a cost-effective use of NHS resources.

This is hugely disappointing. In December 2014, we made a submission to the NICE Committee about the impact of living with ADPKD on overall health, wellbeing and quality of life. This was based on a specially-designed survey we conducted in November. Many of you reading this will have completed this survey. Thank you!

A total of 651 people responded to our

survey, 513 were ADPKD patients, and 138 relatives/carers. A summary of the results was presented at the European Renal Association and European Dialysis and Transplant Association (ERA-EDTA) Congress in May and attracted a great deal of attention. We will publish a comprehensive report soon, so as many people as possible can understand the physical and emotional burden of living with ADPKD.

NICE published the report of the Appraisal Committee report on 5 June, for wider consultation.

The PKD Charity, clinical experts and members of the public made responses and on 7 July, 2015, the NICE Committee will meet again to review the comments.

Unfortunately, we will have to wait until September for their final decision. If this again is negative, we will appeal immediately and begin a campaign for access.

If that appeal fails, NICE will review JINARC™ again in 3 years, by which time the results of a second trial will be known together with the results of long-term observation of ADPKD patients who are still taking Tolvaptan around the world.

Please note that there is a separate appraisal process in Scotland, which will be carried out by the Scottish Medicines Consortium. We don't have the SMC date.

Contact Tess Harris on 020 7387 0543 or tess.harris@pkdcharity.org.uk for help with commenting on the NICE consultation.

First-ever Grant from the PKD Charity for ARPKD Research

Exploring the potential of genetic modification

The PKD Charity has awarded £10,000 to Dr Evi Goggolidou of Kingston University for a study on a gene which is believed to influence the development and progression of Autosomal Recessive Polycystic Kidney Disease (ARPKD).

This is the first grant from the charity focusing solely on ARPKD, which is the rare form of PKD. It occurs in about one in every 20,000 live births and results from abnormalities –

ARPKD Patient Registry (RaDaR)

Until recently there was no national database of ARPKD patients. The Renal Association of kidney doctors has now developed the National Registry of Rare Kidney Diseases (RaDaR), which is gathering information on children and adults with a range of rare kidney diseases, including ARPKD.

By bringing together all the knowledge about ARPKD patients in one place, we hope this will improve understanding of how ARPKD affects your children and adults. With larger numbers of known patients on a single database such as RaDaR, this will encourage research and speed up studies or clinical trials into treatments. RaDaR collaborates with a number of international doctors, researchers and registries. By joining forces with those groups, we can all work together, faster, to help improve the lives of those affected by ARPKD.

If your child attends one of the 13 UK hospitals that specialises in Paediatric Nephrology, you may have been asked to register your child or yourself. If you have not been asked, please speak to the renal doctor or nurse on your next visit. If you are an adult with ARPKD, you can also be registered. Speak to your renal consultant.

Find out more about RaDaR here <http://rarerenal.org/radar-registry/>

called mutations - in a gene which controls how kidneys develop in the womb.

ARPKD mostly affects children around birth, but a wide range of severity is observed. Sadly, about one baby in three with ARPKD dies from breathing problems during the first four weeks after birth and some will die during pregnancy. However, about 8 to 9 in ten babies (80-90 per cent) who survive the first four weeks of life are still alive at five years old. Some children will need dialysis and a kidney transplant (such as 5 year-old Will in this photo) but encouragingly, a good number of children have a milder form of ARPKD and survive into adulthood with full and productive lives.

One possible reason for the variation in disease severity is that other genes might modify the clinical symptoms of ARPKD.

Enlarged cystic kidneys are a major problem in ARPKD. It is known that cysts can arise because of the abnormal arrangement of cells in the kidneys and that several genes 'control' this arrangement by sending special chemical signals through antenna-like cilia which stick out of every kidney cell.



ATMIN gene might control effects of ARPKD genes.

Dr Evi's research group is working on a gene called ATMIN which they believe plays a role in modifying ARPKD severity.

In this PKD Charity funded grant, they will investigate how ATMIN could determine ARPKD severity by looking

at how ATMIN interacts with kidney cells and relating them to the severity of ARPKD. Better understanding of such interactions could help develop treatments that reduce the severity of ARPKD.



Will, aged 5, has ARPKD. He had a kidney transplant when he was 2, from his dad.

ARPKD Family Day Saturday, 11 July 2015

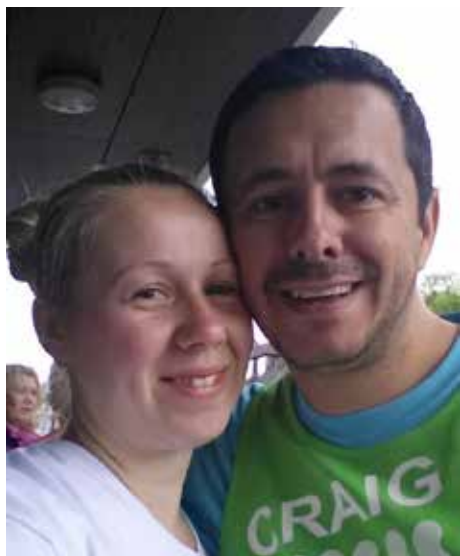
The next ARPKD 2015 Family Support & Information Day will be held at Leeds General Infirmary, Education Centre, Great George St, Leeds LS1 3EX. 10am to 4pm.

Hosted by Dr Kay Tyerman with the support of Dr Larissa Kerecuk (Birmingham Children's Hospital). Talks from expert doctors on ARPKD basics, genetics, transplants and liver aspects. Workshops on benefits, bed-wetting and coping skills. Chance to meet other families to share experiences. Supervised entertainment and childcare for all ages, including crafts at the City Museum. Free to attend. Free parking. Includes lunch and refreshments.

Register at <http://bit.ly/arpkd-2015> or contact Esther Wright on 07825 882616 or esther.wright@pkdcharity.org.uk

Why I Run For PKD

Kay Turner talks about what inspires her



Hi I'm Kay, 33yrs old, married to Craig and we have 3 boys, Evan 11, Kian 9 and Charlie 3. Craig was diagnosed with ADPKD 6yrs ago in 2009 during an ultrasound check to see if he could be a donor for his sister who also had PKD and was waiting for a transplant. The news was a complete shock to us all and got me researching PKD which is when I found the PKD charity.

A year later we found out I was pregnant with Charlie and we knew he had a 50/50 chance of having PKD. At my 20 week scan, Charlie's kidneys were showing up as echogenic (meaning that something might be abnormal in his kidneys). I went home and searched the meaning of echogenic kidneys but deep down felt I knew our baby would have PKD. On May 13th 2011 Charlie was born healthy and well.

When he was 6 weeks old, however, he had an ultrasound and was diagnosed then with ADPKD, 2 cysts on one kidney and 1 on the other. This news sent me into a whirlwind of emotions; anger, sadness, guilt and upset. I was told I had post-natal depression when Charlie was 6 months which my health visitor believes is due to dealing with my baby with PKD. I was prescribed medication but soon came off them after just 5 months.

Now, my anti-depressant is running! One evening I was going through the PKD charity site and found the fundraising section, clicked on Great Birmingham Run event knowing full

well I can't run 3 miles let alone 13.1 miles. Undaunted, I signed up for the half marathon! In June I began my journey to train for the run and found my local running club. I went from not running a mile to running 3 miles then went further and further.

I then set up my own run event for people to participate whilst donating £5 each and in return they run 10k and receive a medal. My life very quickly got taken over by fundraising and running. I was throwing myself into all this fundraising and found coping with having a husband and a toddler with PKD became easier. Charlie recently had several blood tests and scans due to some findings in the kidneys and he now has more than 10 cysts on each kidney. I find it hard to see him go through the tests. It's not nice for him or anybody else. My focus is on getting more awareness and more money to help Craig, Charlie and all other patients.

My husband and my brothers have jumped on board with fundraising and joined in with my [#letsgetthisdiseaseontherun](#) journey.

They have run half marathons, full marathons, and my younger brother Phil Box - is now running marathons

with a tumble dryer on his back.

It gets people's attention and they see the PKD signs all over it. Between me, my husband and my brother we've raised over £2000.



I will continue to battle through more run events and raise more money. I will continue to support my husband with his health and I will continue to help Charlie through his years being healthy. If you want to join us in our runs, we're holding a Fun Run on 27 September at Chasewater Country Park, Pool Lane, Burntwood, Staffordshire, WS8 7NL. Get in touch via the PKD Charity info@pkdcharity.org.uk or find me on the PKD Charity UK Facebook group!

If you are inspired to run by Kay's story, visit our website and challenge yourself! Not only running but you can walk, swim, cycle or skydive for PKD.

<http://www.pkdcharity.org.uk/fundraising/pkd-fundraising-events>

Get Involved

In Fundraising

Thanks to you and all your fantastic support, fundraising income for the charity continues to grow year on year. We want to say a heartfelt thank you to everyone who has helped to raise funds for the charity, to those that have sponsored someone taking part in an event right through to people organising their own events.

We are constantly surprised by the variety of fundraising activities from writing competitions, to bake sales; from Firewalks to running with a tumble dryer strapped to your back. Although we cannot feature everyone, we would be delighted to see pictures of your fundraising activity and add these to our website gallery.

This year's £20 Challenge took place from January to March and saw lots of creative fundraisers taking a £20 stake from the charity and growing it into a larger donation to give back to the charity at the end of March.

This year's winners were **Claudia** and **Robert Bell** for their brilliant PKD quiz raising £543 and to **Louise Manfredi**

who raised £750.01 from her £20 stake.

World Kidney Day 2015 on March 12th was marked by lots of PKD Charity supporters baking kidney shaped cookies to sell at work or at school. There were some delicious cookie pictures posted on our Facebook page and the challenge was won by both the **Craven family** and **Jessica Latham** who continues to raise funds in memory of her sister.

Running is now the fastest growing sport in the UK and nowhere is this more evident than with the number of supporters running for PKD.

Bronte, Catherine and Carrie ran the Big Fun Run Sheffield in August 2014 and raised more than £500. **China Kearns** and **Reece Unwin** ran the Colchester Half Marathon at the end of March raising £1,124 for PKD. **Chris Locke** took on the huge Isle of Wight Ultra Marathon finishing in a great time, when many did not complete the event and raising £609 for PKD. **David Turner** and a team of friends got together to do the Great Birmingham 10k in May and donated more than £460 in sponsorship.

Debbie Munroe donated £257 in sponsorship from her run. **Shirley Camfield** ran the Southampton 10k last autumn and raised over £361. **Michael** and **Andrew Hau** ran the Chester Half Marathon earlier this year raising £379. **Sam Allen** took part in the Godalming Run in March and donated £453. **James Gourlay** raised £267 running the Yorkshire Half Marathon and **Ryan Springett** survived London's Survival of the Fittest to raise £218.



Annie Broe took part in the Brighton Marathon and despite a fall managed to complete the event within her target time and raise over £900 for PKD.



Phil Johnson decided one run was simply not enough and decided to take on 8 runs and over 1000 miles in 2014. Phil raised an incredible £1,150 which he donated to PKD.

We had several runners in the Great South Run in October including **Jon Rolland** and two ladies putting their best foot forward, with **Jane Turnham** raising £541 and **Louise Allcock** raising £330.



Lynda Murray took part in the Great Birmingham Run last October and raised £501 as did **Hollie Watkins** and also **Devon Sherlock** who raised £1,304.

In the Great North Run last September **Cameron Jefferies** raised £684 taking part for the second year running as did **Jonathan Latcham** and **Claire Vickery** who raised over £220.

Catherine Russell-Jones and **Katie Hubball** ran in the Great Manchester Run as did **Shane** and **Mark Bunce** who reached £631 in donations.



In the Bupa London 10k in May PKD's Fundraising and Events Manager,

PKD Charity 2015 Calendar of Events

July 4 – Great Manchester Swim, Salford Quays

July 11 – ARPKD Family Information Day, Leeds General Infirmary

July 18 – Great Newham London Swim, Royal Victoria Dock

August 1-2 – British Transplant Games, Newcastle/Gateshead

September – PKD Charity Virtual Walks, UK wide

September 13 – Great North Run, Newcastle

October 3 – ADPKD Information Day, London

October 9-11 – NKF Conference, Reading

October 18 – Great Birmingham Run

October 25 – Great South Run, Portsmouth

Esther and her sister **Jess Wright** took part in their first ever run and raised over £500. **Izzy Bradshaw** also took up the challenge and raised a whopping £1,061.



We had a number of people sporting the lime green PKD running vests in this year's Virgin London Marathon. **John Bloomfield** raised £1,126 by taking part and **Lee Whitfield** also participated raising £458. **Veronika** and **Stefan Javarova** raised £1,186 with their run, **Vince Jobson** raised £538, **Cameron Edwards** raised £315 in sponsorship and **John Stone** raised £1,754.



The PKD Charity's single guaranteed entry in the marathon was awarded to **Tim Dennis** who with the help of family and friends raised a staggering £2,587 and lots of awareness in the Watford area.

Lots of people were pounding the pavements in Scotland too. **Douglas Connelly** ran the Edinburgh Marathon and raised £75 and **Jolisa Drummond** ran Edinburgh Marathon Festival 10k and donated £131. **Jodie Johnstone** took on the Silverstone Half Marathon and raised £115. **Alison Williams** also took on a Scottish event running the Great Scottish Half Marathon in October and raising £312.

James and **Owen** took on the challenge of a Bungee Jump in May and bounced all the way to £638. **Philippa Harpham** joined the Rat Race Dirty Weekend in May, and donated £540 in sponsorship. **Leigh Anscombe** threw himself into the Rat Race Full Mucker in May raising £1,080. **Eve Walker** showed she was tough enough in the Tough Mudder Midlands in May and raised £457.

Martin Wickham organised the West London United Walk and together with family and friends raised in excess of £2,200. **Ben Groucott** donated the tremendous sum of £951 from his sponsored bike ride. **Rehanne White** braved the cold in November to raise £408 from taking on The 3 Peaks Challenge.

Lesley Smith continues to bake, sew, make and sell for the charity and has so far raised over £2,000. **Julie Perry** donated a number of beautiful handmade cushion covers which are now available on our e-shop, whilst stocks last. **Sammie Sands** organised a writing competition and donated £95 as part of the £20 Challenge. **Ian Ramage** decided to deny himself any chocolate as part of Choctober and was sponsored £271 by family and friends. **Teresa Williams** went Sober for October raising an incredible £560.

November proved to be a popular time for cake sales with **Debi Rice** holding a 12 hour coffee and cake event which raised £635 and **Sheena Sefiani** once again baking up a storm to donate £370. In December regular supporter **Judith Hurst** held another fundraising evening and donated £500 from the event.

Sarah Carpenter organised a Charity Golf Day with her employer, Sellafield in September and raised an incredible £2,000.

Leah Walsh and her fellow students at St Albans College raised more than £1,200 for PKD in March with a fun run, auction and dinner.

Jo Gray held her second charity night in April with fantastic support from local businesses family and friends and donated over £2,100 as well as £400 sponsorship from the Manchester Santa Run which she completed in December.

Simon Phillips got together with family and friends to organise a charity night in March and raised over

£3,000 with live music, and a raffle.

Joe Arazi and his family held another fabulous Magic Night at the Radlett Centre in September. Through ticket sales, an auction and tremendous support from family friends and colleagues they raised more than £8,100.



Apple Ivory's daughter raised £20 from her handmade cards.

The Turner/Box family from the West Midlands continue to find new and ingenious ways to raise funds for the PKD Charity through their love of running. **Kay Turner** completed the Great Birmingham Run last October raising £1,267, **Craig Turner** ran the Silverstone Half Marathon in February raising £486. **Matthew Box** and **Philip Box** both took on the Manchester 10k and Philip aka 'Phil The Tumble Dryer' decided to run it with a tumble dryer strapped to his back raising £730! It's one of several runs he plans to do this year with the tumble dryer in situ so, look out for him! Kay and her family are organising a **Family Fun Run** at Chasewater Country Park, West Midlands on 27 September 2015.

If you would like to take part then please contact esther.wright@pkdcharity.org.uk

Lizzi Young is organising a **Firewalk in the Scottish Borders** to benefit the PKD Charity on 23rd October 2015. So, if you would like to show your support for PKD by literally walking over hot coals, contact Lizzi on bordersfirewalkchallenge@hotmail.com.

A heartfelt thank you to all our fundraisers.

Looking for something on the internet? If so, use Everyclick to search and help support the charity. Just 3 searches per day would generate £3.65. If each of the 2000 subscribers to this newsletter did the same, we would raise £7,300 just by clicking! <http://fundraisers.everyclick.com>

If you would like to give a little every month to the charity you can do this quickly and easily via Charity Checkout. It takes just a couple of minutes to set up and we will give you a PKD pin badge as a regular supporter. <http://www.charitycheckout.co.uk/1085662/donate>

PKD Charity Research Update

How we spend your donations

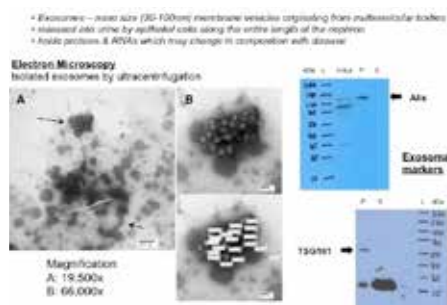
Development of clinical biomarkers of ADPKD progression

We present the final report from the investigators on their research.

Our hypothesis is that the proteins contained in the small vesicles (called exosomes) contained in the urine of ADPKD (Autosomal Dominant Polycystic Kidney Disease) patients reflect the disease stage and severity and can be used to identify biomarkers and evaluate risk of progression.

Aim 1: Isolation of urinary exosomes has been completed

The laboratory methodology for optimising the isolation of urinary exosomes has been finished. Membrane vesicles (30-100nm diameter) have been characterized by scanning electron microscopy and marker protein profiling by Western blot (illustrated below).



Aim 2: Collection and storage of at least 200 urine and blood samples from ADPKD patients has been completed and exceeded

More than 350 urine and blood samples have been collected at 6-monthly intervals from ADPKD patients visiting the Royal Free Hospital specialist ADPKD clinic. This cohort of patients includes those at all pre-dialysis stages of progression (i.e. CKD stages 1, 2, 3, and 4). Total urine samples and aliquots suitable for exosome analysis have been processed, archived and stored at -80°C in the PKD Charity-sponsored Bioresource Bank. Sample archiving details have been incorporated into our linked ADPKD clinical information database (Vital Data). Ethics, R&D and LCRN branding NIHR (National Institute for Health Research) applications are being pro-

cessed for approval to allow for the addition of Royal London and Evelina ADPKD patient sample collection and addition to the Royal Free sample set to provide a confirmatory cohort and to add childhood onset ADPKD to our area of study.

Aim 3: Proteomic profiling of urinary exosomes has started and proof-of-principle established

A pilot analysis of proteomic profiling has been conducted on a control set of urine samples demonstrating the feasibility of unbiased, comprehensive protein 'fingerprinting' analysis in our NHS (NIHR)-supported UCL/GOSH/Biomedical Research Centre state-of-the-art biological mass spectrometry facility (Dr Mills). A total of 200 patient samples are now ready for analysis for Phase 1 of our cross-sectional study, subject to availability of machine time. This will provide a profile and comparison of early- (stages 1 and 2) and late- stages (3 and 4) of ADPKD. Subsequent prospective samples collected longitudinally every 6 months will be collected and analysed over the next 3 years. Combination of the final results with patients' clinical data and validation in an independent cohort (from Royal London Hospital) will provide an individual progression risk score assessment and the basis for a predictive test.

Principal Investigator: Dr Jill Norman, UCL/Royal Free Centre for Nephrology, London

Co-Investigators: Dr David Wheeler, Prof Pat Wilson, Dr Danny Gale

Grant to investigate blood pressure in children and young people with ADPKD

The PKD Charity has awarded £10,000 to UCL Institute of Child Health/Great Ormond St Hospital for a study investigating the optimal blood pressure level in children and young people with ADPKD.

High blood pressure (BP) or hypertension is a common problem in adults with ADPKD. Some patients develop

major complications of hypertension in the vessels, resulting in a heart attack and stroke, before they have significant kidney issues. There is increasing evidence that hypertension may start in childhood but there is very little research on BP in children and young people with ADPKD.



This is a pilot study to investigate the optimal BP level in children with ADPKD at two major UK children's hospitals: Great Ormond Street and the Evelina London Children's Hospital. The researchers will measure BP in 3 ways (i) in the normal way using a standard arm cuff in clinic, but also (ii) check it repeatedly over 24 hours at home using a portable device around the size of a smartphone and (iii) using a home BP monitor measured by parent/ young person.

They will also assess the health of the heart and blood vessels using a new device similar to a small, unobtrusive ultrasound machine. Urine and blood samples will be collected at the same time as normal clinic tests, and stored as a children's ADPKD biobank for later investigation.

The project will comprehensively document BP and its effects in children and young people with ADPKD. They are aiming for 50 patients which will already be the largest study in such detail, but hope to roll this out across the country in future studies if, as expected, they find evidence of early hypertension that needs treatment. Diagnosing BP problems early in the disease may be the key to long term health benefits.

Principal Investigator: Dr Matko Marlais (Academic Clinical Fellow in Paediatrics)

Co-Investigators: Dr Paul Winyard (Reader in Paediatric Nephrology), Dr Manish Sinha (Consultant Paediatric Nephrologist)

To help fund PKD research, just text PKDC12 followed by the amount in £ that you wish to donate to 70070.

Abby's story

A daughter donates to her dad

In our last newsletter, we told Ian's story of receiving a living kidney transplant from his daughter Abby. Now Abby tells the story of the transplant in her own words:

"I'm up early at 6am, not that I got a wink of sleep anyway, and seem to be the only one in the hospital foyer besides the bored-looking girl at the coffee bar. I was not due on the ward until 7am and nil by mouth so no coffee for me. I try not to think about the coming day.

I find myself counting every minute until it's unbearable. I head to dad's ward to see if he's awake yet. He's had as much trouble sleeping as me and is wide eyed and full of emotion.

He's prepped with a cannula in the hand so I sit with him. It all still feels a bit surreal. Neither of us is actually sick but we are here, about to change our lives and make a huge impact on the lives of those around us. Years of preparation, tests, information, all seem meaningless and lost to this very moment. All that matters now is us, me and dad. We hold hands as I'm taken off to theatre.

People ask me if I ever thought of backing down, withdrawing my decision to donate, but the question doesn't even exist to me. I've been given the chance to do something amazing, to give back life to the one person who gave so much to me. Me and my dad always faced life as it came, dealt with problems as they arose and did the best we could, why change now.

So the tranquilliser goes in and..... and that's it! 4 hours later it's all over.... or just begun!

I woke up feeling like the biggest loser of a hard boxing match. Oxygen tubes across my face and a blood pressure cuff continuously crushing and releasing my left arm. 2 cannulas in my right hand and one in my left. The left one attached to a giant button supplying a nice surge of morphine when required. Lovely, you'd think, but each press of this darn button threw a cold sensation through my veins and made me feel like I'd just eaten 10 Big Macs and then jumped on a Big Dipper!

The tubes running across me and the stabbing pain in my belly made sure I wasn't going anywhere! I fiddle around with the adjustable hospital bed and nuzzle myself into a relatively comfortable position. I think about my dad and how he is. Familiar faces arrive to comfort me but my emotions are high and my impatience pushes through.

Eventually I'm told of his condition and how well he is coping, reiterating his remarkable and admirable strength. I shed a tear, not for sadness but for relief and joy that my best friend and my inspiration is proving what I already knew and smashing through the battles ahead.

Day 1, post op.....

I'm tube free :). No more machines or cables, although I still have the bruises and scars to show for it. I master my technique of wiggling out of bed, rolling sideways to prevent using belly muscles and wedging myself upright on one elbow, perfection! I manage the slow waddle across the ward to see dad. I conjured up fearful images in my head. How will I cope seeing the man who is my rock and my inspiration, tied up to machines and covered in tubes? As I approach him, I feel a huge sense of relief rush over me. He looks much healthier and brighter than anticipated, he casts me a smile and the look in his eyes tells me 'we got this.'

Day 2, post op.....

I'm told I can go home! I'm nervous about leaving the hospital and leaving my dad. I gather my mountain of medication and now the time has come to negotiate the terrifying world outside hospital. I grasp my best friend's hand and say an emotional goodbye to my dad.

As we stepped into the outside world, a flush of cold fresh air ran over me. I was anxious about the journey home but knew I was in safe hands. I noticed people judging my composure which resembled that of a weekend alcoholic staggering home from a lunchtime bender! If only they knew I was far from drunk!



Day 3, post op....

The pain is slowly subsiding and I've reduced my pain killers. I've taken great comfort in microwave bean bags, and arrange pillows and cushions to position myself. I'm shocked at my recovery speed and how little pain I've experienced.

Dad tells me he should be out of hospital tomorrow. Although I am ecstatic, I am also filled with fear and hopelessness. Removal from intense clinical care is frightening, I know he is one tough cookie but it's still a huge step.

Day 4, post op.....

Being isolated from the world has made me appreciate and comprehend so much. This pain, frustration, discomfort, these medicines and pain killers, this is all temporary for me. But for dad.....this is how he must have felt the majority of his life with ADPKD. I'm here moaning about my recovery, when dad had to endure this pain and anguish, with no certain end. I've changed that, I've given him hope and opened doors he may never have imagined existed. I've handed him a life line, a new energy, a window of opportunity, the pain I feel right now is more than worth every hour, every minute, every second I've given him. People are praising me, telling me how wonderful I am for what I've done, I don't want their praise, I don't need it, seeing my dad live life the way he should, the way he deserves, seeing his world turn upside down, that's all I need.

Find the latest UK statistics for Organ Donation and Transplantation:
www.organdonation.nhs.uk/statistics

Support and Information

Support available

Our Support Line is available Monday to Friday, 10 am to 4.30 pm or leave a message on 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/

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

- **National Kidney Federation (NKF) - help and information to support kidney patients and their carers, in particular those on dialysis.**
www.kidney.org.uk
- **British Kidney Patient Association (BKPA) - financial support and grant aid for kidney patients.**
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/
- **NKF Advocacy Service**
www.kidney.org.uk/advocacy-service/
- **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 **07825 882616** 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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