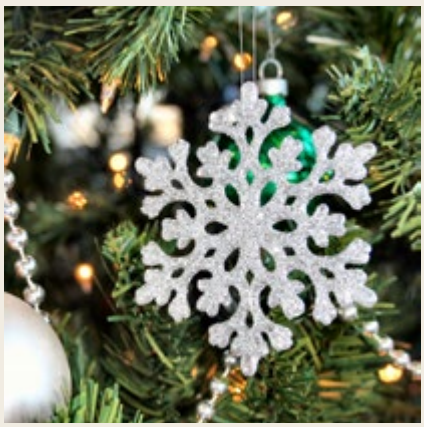
pkd charity
Polycystic Kidney Disease

newsletter
pkdcharity.org.uk Issue 14 - Autumn 2014

Xmas Cards 2014



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ARPKD International Recommendations

ARPKD (Autosomal Recessive Polycystic Kidney Disease) is a rare, 'early-onset' form of PKD. However, there are no consistent guidelines for care and management of the babies and children born with ARPKD.

In 2013, expert doctors and scientists from 5 countries met to review the medical literature to develop recommendations for diagnosis, surveillance and clinical management.

The first part of the recommendations have just been published – read them here: http://www.pkdcharity.org.uk/about-arpkd/international-recommendations The next part will cover specialist care of ARPKD complications, dialysis, transplant and management of severe portal hypertension.

Update On Tolvaptan

In our last newsletter, we wrote about what happened after the publication in 2012 of clinical trial results of Tolvaptan, a drug that may delay the development of kidney cysts.

Otsuka, the pharmaceutical company who sponsored the trial, had applied for official product licensing from the drug regulatory agency in the US (the Food & Drug Administration or FDA) and we were eagerly awaiting a decision.

In August 2013, the FDA Advisory Committee met to review the Tolvaptan licensing submission. After hearing presentations from researchers, clinicians, ADPKD patients and the public, the Advisory Committee voted against approval of Tolvaptan at that time. The FDA required more data and had some safety concerns.

In December 2013, Otsuka Pharmaceutical Co Ltd submitted an application to the European Medicines Agency (EMA) for marketing authorisation of Tolvaptan for the treatment of ADPKD in Europe. At the date of this newsletter, the EMA has not yet arrived at a decision. In the meantime, Tolvaptan has been licensed in Japan where it is being prescribed to some ADPKD patients. Otsuka is also conducting another trial, which has started in the US and in Europe soon.

If the EMA gives a license to Tolvaptan, it will be assessed in the UK for clinical and cost effectiveness by NICE – the National Institute for Health and Care Excellence. NICE will look at the balance of benefits and risks, and will take into consideration the effect of Tolvaptan in potentially delaying kidney failure and alleviating ADPKD symptoms (eg pain and infections) against the cost of dialysis, transplant, hospitalisation, infection treatments, pain-relief etc.

NICE has asked the PKD Charity to prepare a 'submission' in anticipation of Tolvaptan being assessed in 2015 (subject to EMA licensing). The submission is a short document that contains clear facts, information and summaries of patients' and carers' experiences of ADPKD. The purpose of the submission is to identify important aspects of ADPKD that are not well presented in clinical or scientific literature, and may not be understood by the people who will assess Tolvaptan.

To help us with this submission, we have prepared a questionnaire and will shortly post a copy to you as well as circulating links to an online version.

This is a momentous time for all of us affected by ADPKD as we witness, potentially, the prescribing of the first-ever licensed drug to slow down the effects in patients. One day, we hope, there will be similar excitement around a therapy for those affected by ARPKD.

Find out about other ADPKD research studies

At the date of this newsletter, there are over 30 open research studies into ADPKD around the world.

No treatment studies are taking place in the UK. However, the pan-European Eurocyst Registry is invited patients attending clinics in Sheffield and Cambridge to join this study and patients attending the Royal Free in London are being recruited to the biomarker study funded by the PKD Charity (see page 6).

To find out what other studies are taking place or are being planned in the rest of the world, visit the international Clinical Trials website www.clinicaltrials.gov and search for ADPKD.

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ADPKD – a Nephrologist's Perspective

Interview with Dr Danny Gale

Tess Harris (TH): I interviewed Dr Danny Gale (DG) at the Royal Free Hospital in London to find out more about him and the PKD Clinic that he manages. The Royal Free is a large teaching hospital. It provides specialist renal services, including transplant, and is one of the UK's leading academic and research nephrology centres.

TH: What attracted you to nephrology and PKD?

DG: As a junior doctor, I did a nephrology job for six months and enjoyed working with the doctors, nurses and the patients. I also enjoy the academic side of nephrology - understanding the biological mechanisms and how it translates to clinical practice, which I find very satisfying.

My interest in PKD comes from an interest in genetic kidney disease. Technological advances over the last 15 years mean it's now possible to find the gene responsible in families where previously there wasn't a diagnosis. That's really important because genetics gives you a clue about the disease mechanism and enables you to better understand how to care for patients and provide effective treatments.

TH: Tell me about the PKD clinic at the Royal Free.

DG: Kidney patients at the Royal Free are increasingly being looked after by disease specialists. There was a small genetic kidney disease clinic but now it's expanded and we are seeing PKD patients who previously attended general nephrology clinics in local district general hospitals. Currently we have over 200 adult PKD patients, from early to late stage, mostly with ADPKD. I expect numbers to grow as the clinic becomes better known.

TH: I asked our PKD forums for questions to ask you. Many were about testing and especially genetic.

DG: PKD is usually diagnosed by an ultrasound scan to demonstrate the presence or absence of cysts. However, cysts sometimes don't develop until adulthood and in some people even quite advanced adulthood. So a normal, cyst-free ultrasound scan - particularly in children and young people – doesn't exclude the possibility that they might carry the abnormal PKD gene and might develop PKD in the future.

It's technically possible to carry out a genetic test in a person with proven PKD and identify the specific change or mutation in the PKD gene that has caused the disease in them. Not in every person but in more than 80% of those tested, we can find the gene mutation. This won't give any more significant useful information for that person but it does mean the same gene mutation can be looked for in their children. If the genetic test shows the child hasn't inherited the PKD mutation then one can be certain that they are not at risk of developing PKD. And, conversely, if they do have the same gene change, you can predict that they will go on to develop PKD.

TH: What is the cost of genetic testing at the moment?

DG: At the moment, the cost is around £2,000. If we were testing a family, the first test would cost that amount and testing other family members will cost less. But it depends, of course, on finding the genetic mutation.

TH: What is your advice about being tested for PKD?

DG: An important consideration is whether this is a diagnostic or a predictive test. A diagnostic test occurs when a patient has a clinical problem, say pain, which makes them go to their doctor. The question here is "what's the cause of that pain?" It might be PKD-related or something completely different that needs investigating. A doctor can't really provide the best treatment unless they know the cause. If someone of any age has a clinical problem, with a parent with PKD, and problems consistent with PKD, it is sensible to investigate.

A predictive test is when a completely fit and well person, who may be worried about PKD but has no symptoms, wants to know if they at risk of developing clinical problems from PKD in the future. There are many reasons why someone would want to know, for instance, family or career planning. Some would find it helpful, some not. It depends on the individual.

TH: What about screening children?

DG: Once a child is diagnosed, labelling them as having a disease may prevent them doing things they otherwise would do, which may not be in their best interests. Importantly, by performing the test on a child you have taken away the opportunity to decide for themselves whether they want to be tested.

However, this is an evolving area because now we don't have a treatment for children or young people so the reasons for screening are more psychological than medical. If there is an effective treatment that is going to change the progression of PKD, doctors might want to give it to pre-symptomatic people to reduce their risk of disease – and then we would test because the whole risk/benefit would shift.

TH: What advice can you give to parents who have undiagnosed but at-risk children?

DG: First, it's important to check blood pressure (BP), because it's recognised that high BP and indeed kidney damage can occur in childhood. So, BP must be checked properly. No guidelines exist, but we think checking the BP every 1-2 years is probably sufficient.

If there are other symptoms such as unexplained tummy pain, this might require a diagnostic ultrasound test. However, the absence of cysts in childhood does not take away the risk of PKD. It just means that the problem presenting is not caused by a cyst visible on ultrasound.

TH: What about genetic therapies or is that too futuristic?

DG: Do we need a genetic cure? If we can understand the things that make someone with PKD go on to develop cysts and kidney failure and other problems, we may not need much to change it from being a serious condition to one that is very controllable. In that context, heroic interventions on the genome are probably not needed.

Information Day Stories

PKD Info Day at Addenbrooke's Hospital

I was recently diagnosed with polycystic kidney disease in November 2013, I had visited my GP for what I had thought was a routine check-up as I was feeling dizzy and had an earache. After a few tests and a scan I was told I had PKD, both in my liver and kidney.

Since childhood I was dreading the day I may find out that I too will be diagnosed with PKD. I was aware whilst growing up that PKD was a genetic chronic condition having lost many family members to this disease.

After the initial consultation I was in shock and denial. The news finally started to sink in and I felt as if I was sitting on a time bomb about to explode; I didn't want to live my life in this way as I had so much more to do and see.

So, I began researching into this condition on the internet for any relevant information which would be beneficial for my family as we were all coming to terms with the fact that I now have PKD.

I found out through a family member that Addenbrooke's Hospital in Cambridge was running an AKPKD Information and Support Day for patients, families and carers. At first I was reluctant to go as I was still in denial deep down and didn't want to accept that I had the condition.

My family and I set off early and travelled up to Cambridge. I was feeling slightly nervous and sat quietly throughout the journey.

On arrival we were met by Tess Harris and her volunteers, we were shown how to register and were made welcome; this helped to put me at ease.

The day was hosted by Prof Fiona Karet who gave us a short introduction and then introduced us to the following expert speakers:

- Dr Richard Sandford - who described to us the basics of PKD and later in the day he spoke of the exciting research currently being undertaken.
- Dr Roz Simms and Dr Paul Winyard - explained the genetic screening, the what, who and why scenarios.
- Mrs Clare Parslow and Mr James Perry - gave us information relating our diet or a better lifestyle for PKD patients.
- Mr Andrew Butler - a transplant surgeon from Addenbrooke's Hospital who gave us an insight into transplants and showed us footage from an operation.

The day was split with two breakout sessions which we could attend. The following choices of topics were available:

- Sharing stories - groups, facilitated by two renal counsellors from Addenbrooke's Hospital.
- 'My Mum/Dad has PKD'... for the young attendees
- My partner has PKD - but I don't...
- PKD genetics The PKD charity - what it can it can do for you and vice versa.

Both my family and I found this day to be of extreme value, it also gave me a chance to gain further insight and an opportunity to meet with the experts whilst networking with fellow PKD patients of all ages. By meeting PKD patients and carers in the discussion groups we were able to learn from each other's experiences. Equally important was to hear positive stories after growing up and seeing the worst case scenarios.

Written by a patient, who attended the Information Day

Next ADPKD Info Days

Meet the PKD Charity in:

- **Dorchester**
  Saturday, 8 November 2014
- **Edinburgh**
  Saturday, 24 January 2015
- **Newcastle**
  Saturday, 7 March 2015

Hear about ADPKD from the experts. Share your experiences.

Visit http://pkdcharity.org.uk/support/pkd-information-support-days/adpkd-info-support-days for more details

Get Involved

In Fundraising

With your help, the last year has been tremendously successful for PKD Charity fundraising. Your support has helped to raise more voluntary income than ever and we want to say a huge thanks to each and every one of you that has organised an event, run, swam, cycled, baked, sold and much, much more to support the charity. Although we cannot feature everyone, we would be delighted to see pictures of your fundraising activity and add these to our website gallery.

The past year has seen a big increase in the number of people organising their own events.

Jo Gray held a charity night at Ashton-on-Mersey Golf Club and raised £2002. Tickets were sold for £10 and this included a quiz, two tombolas, a photo booth and a raffle with some fabulous prizes kindly donated by local businesses. Stacie and Ryan Jones continued their fundraising for the PKD Charity throughout 2013, with the help of their friends at the Bulls Head in Shrewsbury. They raised an amazing £1000 in April 2013 with a St George's Day event and another £500 in June!

Judith Hurst held her second tea and driftwood party in December and raised £306. Vicky Foster followed up on her 2013 Alice in Wonderland themed fundraising evening with a Night at the Races themed event in February of this year.

Rhonda Thomas from Mid-Glamorgan held her own fundraising event and raised £628. Ashley Cooper and Lynette Lewis got together to hold a party to celebrate Lynette's 50th Birthday with donations from all of Lynette's family and friends. Also combining celebrating and fundraising was Debbie Davies who helped organised a Glitz and Glam Ball for her friend's 50th Birthday. The party-goers split the donations with two other charities and donated £185 to the PKD Charity.

Jen Stoneman held a house sale and car boot sale last autumn which raised £172.50 and no doubt tidied up the house and garage!

Lesley Smith continues to bake and sell and donated proceeds from a soup and scone lunch and coffee morning totalling £548. Mahisha Shahjahan held a cake sale at school which completely sold out before too long and raised £100 for PKD.

Susan Searle and colleagues at Sir Robert McAlpine once again held a fundraising evening to benefit the PKD Charity. The event was a huge success and raised £1250. Emma Jayne Black held two fundraising events at The Boulevard in Wigan in October 2013. The first event was a Mediumship Evening followed by a Halloween Rock & Metal Extravaganza with no less than three Bands, two DJ's and a raffle with some amazing prizes! Emma-Jayne and her team of supporters raised a total of £1000 for the charity with help from Moorhouses Brewery who donated a nine gallon cask of real ale.

As always, lots of you have been taking on big sporting challenges to raised funds for the PKD Charity.

Those taking on Triathlons in 2013 included David Jessop in the Warwickshire Triathlon raising £235, Paul Shaw in the Helvellyn Triathlon raising £748 and Martin Cockerham in the Ilkley Triathlon raising £153.

Ryan Springett participated in the aptly named 'Nuts Challenge' and raised £175 in sponsorship. Sophie Fisher took part in the Reading Half Marathon with several of her family. Several PKD supporters took on the Great South Run in October 2013.

Joanne Jackson raised £460, Nicky Milford raised £1279, and Adam Hill raised £297 in sponsorship. Lucy Baille took part in one of the first running events of this year, the Silverstone Half Marathon and raised over £1000 by running the famous course at the Silverstone race track.

Claire Vickery raised £386 running the world famous Great North Run and Phillipa Harpham raised £626 by running the Perkins Great Eastern Run. Martin Paterson was sponsored £326 to do the Liverpool Half Marathon earlier this year and Chris Carrington took on the Brentwood Half Marathon in March raising more than £350 and completing the 13 mile course in 1hr 52 minutes.

Kenny Fraser was a participant in the Baxter's Loch Ness marathon raising an incredible £2576. Chris Shaw took on the Silverstone Dualthon, Holly Watkins ran the Bupa Birmingham Great Run raising £97 and Sophie Tostevin took part in Jersey Relay Marathon raising £133 in sponsorship.

The more unusual sporting challenges, all undertaken in the name of the PKD Charity, included the Two Towers

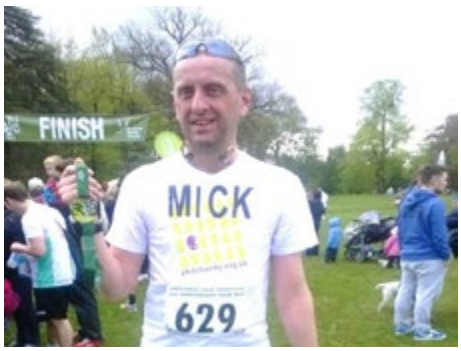
cycling challenge which **Richard MacLean** used to raise £314, and a skydive by **Scott Phillips** raising £294. Young **Calum Graham** was brave enough to take on a shark dive and raised more than £660 last summer.

Steve Hill, a teacher at St Joseph's Roman Catholic Primary School took on the most exotic challenge, trekking through Borneo and to the summit of Mount Kinabalu. He combined this with other fundraising throughout the school all to support Mark Holden who was given a kidney last year by Liz Whitworth. Steve and his students raised an amazing £2,300.

TextAnywhere Foundation supported the PKD Charity. Photo above shows **Adrian Harris** handing a cheque for £6,233.50 to Tess.

March 13th marked World Kidney Day and this year the focus was on raising awareness of kidney health with everyone being encouraged to 'raise a glass' by posting a picture of themselves drinking a glass of water. Amongst those using the opportunity to fundraise for PKD was **Melanie Wild**, who together with family and friends held an afternoon tea at her village hall and raised a staggering £1051. **Marie Grant** held an awareness raising event and many other people took part by giving out leaflets and sharing the key message of the day with family and friends via social media.

In January of this year we challenged you to take a £20 stake from the charity and grow it into a larger donation! Lots of you took up the challenge and by the closing date of the challenge at the end of March, the total raised was over £3700! The ideas for growing the £20 into something larger were varied and innovative. **Maria Boehne** and her colleagues held a work quiz night raising £914. Elizabeth Wood created an 'exploding' box of chocolate and raffled it off, selling tickets to customers, family and friends and raising £210. **Karen Webster** used her £20 to buy wool and has been crocheting all sorts of wonderful items to sell to family and friends. **Michael Bardell** held a series of local history talks and asked his audience members to donate, raising an incredible £659 in the process. **Shelley Morley** raised £220 by taking part in a half marathon and both **Debbie Sadler-Watson** and **Gina Basi** are organising sponsored walks later in the year. The prize for the most money raised from a £20 stake went to **Janet Curry** who organised a fabulous fundraising event complete with DJ, bouncy castle, cake sale, children's party bags and sweet stall and a raffle which included items donated by Next, Arsenal and Tottenham Football Clubs and Wembley Stadium. With lots of help from her family, Janet raised an amazing £1870.23! Huge thanks to everyone that took part in the £20 challenge and look out for details of the 2015 £20 Challenge at the end of this year.



In April of this year, **Mick Worsfold** signed up for the Bracknell Half Marathon in Berkshire. In his customised and personalised PKD Charity T-shirt, Mick received lots of support on the day and raised £407 for the charity.

Trading her hair for donations, **Rebecca O'Brien** very bravely agreed to shave off all her hair for the benefit of the PKD Charity. Watched by a large group of family and friends, Rebecca quickly went from shoulder-length locks to the shortest of crops! Thanks to incredibly generous support from all those that watched, Rebecca raised a hair-raising £1778. We're hoping Rebecca's hair grows back in time to keep her warm this winter!.

At the start of the summer, **Helen Gould** ran the Sutton Fun Run in Sutton Coldfield. With sponsorship from her family and friends, Helen donated £117 to the charity.

Do you have one of these?

If you've been collecting your loose change in one of these little collection boxes since Christmas, now is the time to take a look inside! You might just be surprised by how those coins add up. Please send in the donations you've raised in your collection boxes by sending a cheque for the total amount (made payable to 'The PKD Charity') to 91 Royal College Street, London NW1 0SE, or send an email to esther.wright@pkdcharity.org.uk for our bank details to deposit the coins directly into the PKD account.

PKD Charity Research Update

How we spend your donnations

People often ask what we do with money donated to the PKD Charity for research. The first thing we do is to 'tag' it in our accounts as 'restricted'. This means that the money is 'ring-fenced' specifically for spending on research and cannot be used for any other purposes, for example to pay postage on this newsletter.

Since the foundation of the charity in 2000, money has steadily accumulated in our restricted research funds and at the end of 2013, we had £80,000 in the bank. Medical research can, however, cost millions, so the trustees decided to wait until there was sufficient money to make a difference with the research funds entrusted to them.

In 2007, the charity jointly funded a research project with the US PKD Foundation. A £40,000 grant was awarded to Professor Albert Ong in Sheffield. It was named in honour of Dr Peter Lockyer, a co-founder of the charity, who sadly died in the middle of a promising scientific career. His family contributed half of the £20,000 the charity committed, by fundraising.

In 2010, the charity awarded a grant to Professor Patricia Wilson to support the maintenance of a unique PKD Bio-resource Bank at the UCL Centre for Nephrology, Royal Free Hospital in London.

Above: Professor Patricia Wilson and PKD Charity Trustees

This was initially £10,000 a year for 3 years but last year the charity trustees agreed to continue the funding, as it is a valuable resource to UK researchers. We have also funded some equipment for Prof Wilson's lab and obtained that funding from an external philanthropic trust.

The Bio-resource Bank is essentially some very high-tech and ultra cold freezers with more than 8,000 cell, tissue, and fluid samples of autosomal dominant polycystic kidney disease (ADPKD), autosomal recessive polycystic kidney disease (ARPKD), plus age-matched control samples suitable for research purposes. To date, researchers from University and Kings' Colleges London, the Institute of Child Health/Great Ormond Street Hospital, the Royal Free London, and Addenbrooke's Cambridge, have submitted successful applications for Bio-resource Bank materials in frozen, live cell and/or fixed sectioned states to use for PKD research projects. A number of people in the UK have donated their kidneys to the bio-resource and we welcome more!

Also in 2013, the trustees awarded Prof Wilson a grant of £10,000 to kickstart a 'biomarker' research project. The goal of this research is to develop a simple urine test to predict when the kidneys of people with ADPKD would be likely to fail. The rate at which ADPKD progresses in patients causes changes in proteins that are released into the urine. By analysing these "biomarker proteins" from ADPKD patients at different stages of disease severity, characteristic patterns or "fingerprints" will be determined that represent minimal, moderate and severe disease.

Urine and blood samples are being collected from around 300 ADPKD patients attending the UCL/Royal Free specialist ADPKD clinic. They will be processed in the laboratory, divided into multiple replicates, barcoded and stored frozen in the PKD Charity-sponsored Bioresource Bank and data included in the ADPKD database at the Royal Free. The combination of protein biomarker patterns identified with the clinical data will facilitate the basis and proof-of-principle for development of a new predictive test. Large-scale funding is now being sought from the NHS National Institute of Health Research (NIHR) or the Medical Research Council (MRC) to bring this biomarker test into clinical practice.

In 2014, the trustees agreed to award £30,000 to what we call 'pump priming' projects. We hope to attract applications in the region of £10,000 each from UK researchers in the areas of dietary modification as potential therapies for ADPKD and Autosomal recessive polycystic kidney disease (ARPKD).

You can help contribute towards the biomarker project by donating to the £ for a Pee Fundraising Campaign. Just text PKDC19 to 70070 with the amount you wish to donate in £. Or make a donation online here: https://www.charitycheckout.co.uk/1085662/Page1

More more information about the PKD Charity's research, please contact Tess at tess.harris@pkdcharity.org.uk or ring 020 7387 0543.

Better transplant outcomes for ADPKD patients

Patients with kidney failure from ADPKD (autosomal dominant polycystic kidney disease) are more likely to receive a kidney transplant and live longer, according to an American study. Researchers looked at the records of over 1m patients who had kidney failure and needed renal replacement therapy (RRT), which means either dialysis or a transplant. Over 23,000 of these had ADPKD.

The rate of being listed was higher for ADPKD patients than for other types of kidney conditions, as was the rate of receiving a transplant. Survival rates were higher too.

Interestingly, less than half of the ADPKD had seen a nephrologist in the year before RRT. The researchers were disappointed by that figure as people with ADPKD are usually diagnosed before they reach complete kidney failure and more should have been receiving nephrology care before RRT. However, this may be due to the nature of the American healthcare system.

Ian's kidney

A PKD Patient's Transplant Story

The title is incorrect as it should be called Abby's kidney as she is my wonderful daughter who forced me into accepting her kidney!

My kidney story began around 26 years ago ironically, as that was when Abby was born. I needed my Wisdom teeth removed, and so I arrived at Guys Hospital in London, and began my long term relationship with that place.

After coming round from the operation, I could hear alarms ringing and thought that there was a fire practice taking place. It was only when staff came rushing to my bed that I realised that I was the cause of the alarm. It turns out that I had broken the machine monitoring my blood pressure which had risen to the heights of 280/220 which is not a healthy place to be. I only had a slight headache which I thought came from the anaesthetic, so was not unduly worried, but the staff would not let me go home! I was admitted while they tried to discover why someone so young (27) had such high blood pressure.

I spent several weeks being tested and medicated, and it was eventually found that I had polycystic kidney disease, PKD.

Not really understanding much about PKD, I was not unduly perturbed as I only felt a bit ill due to the pills they were pumping me with to keep my BP down. It seems that I had high BP for some while and my system had got used to it, but it took some while for me to get used to having a more normal BP again as various medications were tried before we arrived at a stable cocktail.

I learnt that PKD is normally hereditary in 85-90% of cases, but my parents and brother were tested and they were clear, so it seems that I am one of the 10-15% in which it occurs sporadically.

For the first few years I visited Guys Hospital every year as my kidneys deteriorated slowly, and tried to learn as much as I could about the condition. I adjusted my diet to avoid salt, red meat, etc., and started a determined approach to make my kidneys last as long as possible.

With the arrival of the internet I was able to correspond with people all over the world who had similar problems. I have learnt so much by researching my condition and am very grateful to the many correspondents and websites. Around ten years ago I was told that I would be on dialysis within five years!

Over the years I have managed to slow the deterioration of my kidneys as much as possible, only dropping functionality during particularly stressful times in my life. It had taken around six years to drop from 20% functionality to around 10%. As fellow kidney patients will know, 10% is the usual threshold when the medical staff start taking a serious interest and look at options for the future. If there is not the possibility of a live donation, then it would be a case of preparing for dialysis and joining the long wait on the transplant list with no guarantee of finding anything approaching a good match.

I have always been lucky to have the support of good family and friends during the PKD process. My wife wanted to donate but is on medication for breast cancer so is not suitable, but Abby was very insistent that she would be tested. It turns out she is a very good match (1-1-1 for those of you aware of the figures) and her kidneys are working at 113% capacity! This raised the emotional decision of whether I could accept her donation, despite the fact that she was adamant that if I did not agree she would turn up on my doorstep with it in a box! How could I put her through an operation that she did not need and when she is at such a young age?

Of course if it were my parent who needed a kidney I would agree to donate immediately, but it is very different when it is the other way round. So began a long period of soul searching and trying to get my head around the situation.

After considering my limited quality of life, and the prospect of dialysis I eventually gave in and on 10th April this year Abby and myself were being prepared for transplant. Abby started surgery at 8.00am and I followed at 11.30. Abby returned at 3.00pm and I did not get back on the ward until 9.30pm. Much to my surprise there was no dressing on my wound, as it was glued together at skin level. I was attached to many tubes for pain killing drugs, fluids, wound drain, catheter, and a three line tube in my neck to take blood samples and administer other medicines.

I had two days of hourly monitoring day and night, which decreased over the following days. Abby left hospital after 3 days and I followed after 7 days. Amazing progress considering the major surgery, so all credit to the staff of Guys.

After a couple of setbacks including a nasty experience with the catheter removal, I am doing very well. I still have some soreness and swelling but it gets better each day. I lost 4kg of excess fluid in four days after the operation and have lost a couple of kg since so am feeling better as a result. More details are at a blog I started www.ianskidney.wordpress.com if you are interested or wish to contact me. Many thanks to all the wonderful staff at Guys for their continued help and support. These people do some life changing work!

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

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

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

Fast Facts 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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