



First Information Day held for families affected by ARPKD*

We held the first ARPKD Family Information Day in June at the Birmingham Children's Hospital (BCH). Around 40 parents with children came from all parts of the UK, along with doctors and scientists from the UK, USA and Germany. Dr Larissa Kerecuk (Paediatric Nephrologist BCH) had organised the venue and obtained some sponsorship. The PKD Charity funded activities for the children and with the Arran Brown Foundation arranged for Prof Lisa Guay-Woodford to travel from the US to give the keynote talk.

Prof Guay-Woodford gave the first talk on the basics of ARPKD. She is an international expert in all forms of PKD and ARPKD in particular. She practised as a paediatric doctor and nephrologist for many years, whilst conducting major scientific research.

Unlike ADPKD, ARPKD is a 'Rare' genetic condition. It affects 1 in 20,000 to 1 in 40,000 people, compared with the 1 in 400-1000 affected by ADPKD. Unfortunately, ARPKD affects mostly babies and children, and some pregnancies fail. ARPKD can also cause major problems in both the kidneys and liver from an

early age. However, the problems can vary widely – in terms of timing and severity - even in the same family. Hypertension is however common and requires lifelong medication but not every person affected will experience kidney or liver failure.

Dr Pat McKiernan (BCH) gave a talk about the liver aspects of ARPKD followed by a talk on liver and kidney transplantation by the BCH surgeon, Mr Khalid Shariff. Dr Joanna Jarvis (BWH) gave a talk on genetics. Prof Pat Wilson and Prof Guay-Woodford finished with talks on research and future therapies.

The families enjoyed the day, especially meeting other parents going through similar "ups and downs" of coping with ARPKD.

It was agreed to hold a second Information Day in 2013 and make this an annual event. If you weren't able to attend and would like to know about future ARPKD events and activities, please send your contact details to Tess Harris at info@pkdcharity.org.uk

Download the talks from our website pkdcharity.org.uk

* ADPKD = Autosomal Dominant PKD
ARPKD = Autosomal Recessive PKD

PKD Charity News

We are sad to announce the death of Justina Wilkinson from PKD complications. Many of you knew Justina from her work with the charity, in particular organising the Information Days. Justina was also Tess Harris' oldest sister and on behalf of the charity, we extend our deepest sympathies to Justina's family and friends.

We also send condolences to supporters of the charity who have lost loved ones during the past year.

We are pleased to announce that trustee Barry Harpham has taken on the chairman's role for the next 12 months. The trustees have contracted Tess Harris, who has chaired the PKD Charity for 6 years, as part-time Chief Executive to lead the development and implementation of a 5-year growth strategy.

1st PKD Charity Family Fun Day

On Sunday 16 September the PKD Charity held its first ever Family Fun Day at Campbell Park in Milton Keynes. The event featured 10k and 5k runs and a 1m stroll for families and pushchairs in the morning. These were followed by live music and entertainment on the park's main stage, stalls, refreshments, bouncy castles and much more throughout the afternoon. The event raised £4,000 and was attended by more than 500 people throughout the course of the day. Special thanks go to the wonderful team of local volunteers who helped to plan and run the event and all the service providers and stall holders that contributed to the day. We hope to run similar events next year in several parts of the country, so if you would like to get involved, please let us know.

Calendar

2013

26 January PKD Charity ADPKD Info Day. Nowgen Centre Manchester

3 March Silverstone Half Marathon. Places still available contact esther@pkdcharity.org.uk

14 March World Kidney Day

16 March PKD Charity ADPKD Info Day. Birmingham

21 April Virgin London Marathon. Support our PKD London Marathon Runner. Name to be announced 1 November 2012

26 May Great Manchester Run. Places still available contact esther@pkdcharity.org.uk

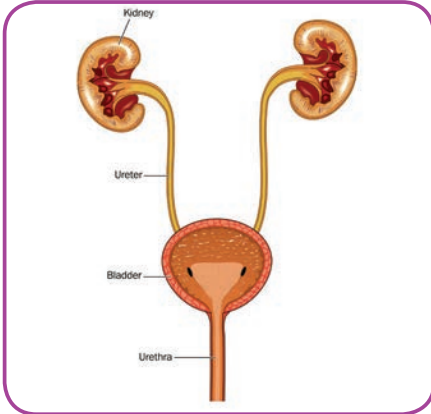
27 May Bupa London 10k. Places still available contact esther@pkdcharity.org.uk

7 July 7 Stanes Bike Ride for PKD Charity. To sponsor Team Knight rider PKD visit www.justgiving.com/teamkrcharideepkd

Urinary tract infections

Urinary tract infections (UTIs) are common among people with ADPKD, and particularly for women. These infections should always be taken seriously and fully investigated, because frequent UTIs may worsen kidney function.

A UTI occurs when bacteria infect the urinary tract. The urinary tract consists of



The bacteria that cause UTI enter the urinary tract through the urethra. This explains why UTI are more common in women. The urethra is shorter in women than in men, so it is easier for bacteria to enter the urinary tract from the outside—for example, after a bowel movement.

Some people with ADPKD can have frequent UTIs, often from the same germ. This may be due to:

- Persistent infection in a cyst
- A kidney stone
- Not drinking enough fluid
- For women, re-infection during sexual intercourse.

Symptoms of UTIs

The most common symptoms of UTI include:

- Pain or a burning sensation when you urinate
- An urgent need to pass often small amounts of urine
- Fever, chills, and back pain (when the infection is in the kidneys).

If you suspect you have a UTI, seek treatment immediately from your doctor. The infection usually starts in the bladder, but can spread to the cysts in the kidneys. Cyst infections are more difficult to treat because many antibiotics cannot penetrate into the cyst fluid.

Diagnosing UTIs

It is very important for your doctor to collect a urine sample from you for diagnosis. This is to enable the laboratory to grow or 'culture' any bacteria in your urine sample to make sure that you can be given the right antibiotic.

If the germ is different with each infection, this suggests that the bacteria are coming from outside the body. If the same germ is found each time, the antibiotics may not be destroying the infection, and you need another treatment.

Treating UTIs

Any UTI should be treated promptly with appropriate antibiotics. People with ADPKD may need to take a higher dose of antibiotics, and an infection in a cyst is likely to need a longer course of treatment.

Review by a nephrologist or urologist is also advisable, as some people may need a longer course of low-dose, regularly switched (rotating) antibiotics.

Preventing UTIs

People with PKD can reduce the likelihood of frequent UTIs by:

- Drinking at least two litres of water every day (but first check with your doctor in case you are on restricted fluids because of your kidney function).
- Avoiding fluids that can irritate the bladder (e.g. pure fruit juices, alcohol and caffeine-containing drinks such as tea, coffee, cola).
- Urinating every two hours during the day.

Women with PKD who have frequent UTIs should:

- Choose underwear made of natural materials such as cotton, and do not wear thongs, which can irritate the urethra.
- Drink a glass of water before intercourse and urinate within 30 minutes afterwards to flush out any bacteria that may have entered the urethra.
- Wipe from front to back after urinating or a bowel movement to reduce the chance that bacteria will be transferred to the urethra.

Need financial help?

If you're struggling with the impact of PKD on your life, like covering the costs of your domestic bills, hospital travel, education and holidays, you could qualify for a grant from the British Kidney Patient Association.

More info: www.britishkidney-pa.co.uk/grants.html

If you have to stop work or work part-time because of PKD or if you are caring for someone with PKD, you may find it hard to cope financially. There are several types of financial support available from the state but it can be difficult to identify and then apply for the appropriate benefits. Also, unlike in some conditions, kidney failure is not always regarded as a 'disability' by those administering the benefit system.

We learnt recently about an organisation called Disability Rights UK, formed in January 2012 through a unification of Disability Alliance, Radar and National Centre for Independent Living. They aim to be the largest national pan-disability organisation led by disabled people. They have a wide range of factsheets on their website www.disabilityrightsuk.org

If you have children with either AD or ARPKD, please also visit the Contact a Family website for up to date information on disability rights for families. www.cafamily.org.uk

- Wash the genital area before sexual intercourse.

UTIs in children

There is no need to routinely check for UTIs in children who have no symptoms. But a doctor should investigate and rule out a UTI in any child with unexplained symptoms such as tummy ache, fever or lethargy.

More information

The Bladder and Bowel Foundation has helpful, general information on UTIs
www.bladderandbowelfoundation.org/bladder/bladder-problems/urinary-tract-infection.asp

Exercise Q&A for people with kidney disease



We all know the benefits of regular exercise. Yet many people with kidney disease do not exercise enough because they are concerned about the type of exercise they can do and how often they should exercise. Here are some Q&A tips from the National Kidney Foundation in the US.

Q: What types of exercise can I do?

A: Anything that moves large muscle groups continuously, such as walking, swimming, bicycling (indoors or out), skiing and aerobic dancing. Incorporate some low-level strengthening exercises, using light weights and high repetitions. Avoid heavy lifting.

Q: How often and for how long should I exercise?

A: Exercise at least three days a week, on non-consecutive days. Build up gradually until you can exercise for 30-minutes.

Q: How hard should I work while exercising?

A: This is difficult to answer without knowing your own exercise capacity. However, the following is helpful:

- Your breathing should not be so hard that it prevents you talking with someone exercising with you.

- You should feel completely normal within one hour after exercising. If not, slow down.
- Your muscles should not feel so sore that it stops you exercising the next session.
- The intensity should be a “comfortable push” level.
- Start each session with a slow warm up, then pick up your pace, and slow down again when about to finish.

When should I exercise?

- Either morning or evening.
- Wait one hour after a large meal.
- Do not exercise less than an hour before bedtime.

Q: When should I stop exercising?

A: Stop exercising if you feel any of the following:

- Very tired
- Short of breath
- Chest pain
- Irregular or rapid heart beats
- Sick
- Leg cramps
- Dizzy or light-headed

Q: Are there any times when I should not exercise?

A: Don't exercise without talking with your doctor if any of the following occurs:

- You have a fever
- If on dialysis, you have changed your schedule
- You have changed your medicines
- Your physical condition has changed
- You have eaten too much
- The weather is very hot and humid
- You have joint or bone problems that become worse with exercise

The above is for information purposes only. Always consult your doctor if you have any concerns about exercising with kidney disease.

NBTA launch

The National BAME (Black, Asian and Minority Ethnic) Transplant Alliance – NBTA - was launched in July. The NBTA's mission is to bring together “people, passion and resources to address the barriers faced by those from a Black, Asian or Minority Ethnic genetic heritage needing a whole organ or stem cell transplant”.

People with BAME and mixed parentage backgrounds face difficulties finding appropriately matched organ donors. Black and Asian people are three times more likely to need a transplant than the general population but donation rates are lower. Less than 2% of people on the NHS Organ Donor Register (ODR) are from the BAME community. Consequently, BAME people may wait significantly longer for a kidney transplant than the current average of 3 to 4 years.

The NBTA aims to increase by 15% the numbers joining the ODR by 2015 by making a significant change in attitude to donation and transplantation. They also aim to increase consent rates from families of potential deceased donors and increase the numbers of living organ donors.

Quick Baked Apple

Perfect for chilly Autumn nights

Apples are a genuine 'superfood': high in fibre and anti-inflammatories, and known to protect against heart disease. Autumn is the perfect time to enjoy our delicious British apples.

For each person:

1 medium apple (Bramley or regular)
1-2 teaspoons honey (depending how sweet your apples are)
Grated nutmeg and cinnamon

Preparation:

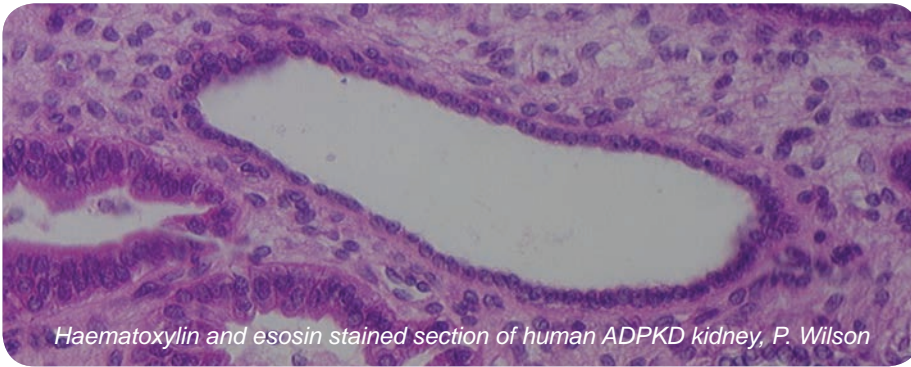
Wash and core apple. Place in a high-sided bowl.

Pour honey into centre of cored apple. Sprinkle on nutmeg and cinnamon.

Cover with plastic wrap. Microwave on high for about 6 minutes.

Serve immediately, topped with low fat yoghurt or crème fraiche.

Adapted from DaVita recipe. For more kidney-friendly recipes, visit www.davita.com



Haematoxylin and eosin stained section of human ADPKD kidney, P. Wilson

Update on the PKD Bio-resource Bank

The PKD Bio-resource Bank was established at UCL Centre for Nephrology at the Royal Free London NHS Foundation Trust in 2011, supported by a grant from the PKD Charity – our first solo research grant in the UK. We want this unique bio-resource to become a crucial component in laboratory research, in the UK and internationally. The acceleration of PKD research depends on well-characterized human PKD and age-matched normal control tissues, cell lines and animal models that faithfully recapitulate the genotypic and phenotypic characteristics of PKD.

Currently, the PKD Bio-resource Bank contains 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.

If you are a researcher and want more details of samples available, or if you have PKD and may require a cystic kidney to be removed by nephrectomy and wish to donate that organ to the Bio-resource Bank, please send an email to Tess Harris tess.harris@pkdcharity.org.uk

ESPRIT - Advice for transplant patients

The **Efficacy and Safety of Prescribing In Transplantation (ESPRIT) Group** is an independent, not-for-profit, multidisciplinary group dedicated to the safety and wellbeing of transplant patients. Given that a significant proportion of people with PKD will go on to have a transplant, we thought it important for you to be aware of the Group and its offerings.

A key focus for the Group has been on the drugs prescribed post-transplant to suppress the immune system and so help prevent rejection of the transplanted organ by the body. It is important that these drugs are both prescribed and dispensed by brand name. This is the only way to ensure that the patient receives a consistent formulation and is especially important now that various

generic immunosuppressants are available.

The Group has produced in-depth reviews of the evidence surrounding appropriate brand prescribing, and associated recommendations. It has then developed various educational resources for healthcare professionals and patients, including communication packs for hospitals, patient leaflets and cards. It also liaises and collaborates with various official organisations regarding recommendations and guidelines on appropriate brand prescribing, with a view to effecting change where that is in the interests of transplant patients.

Further details about the Group, its members, activities and resources can be found on the website - www.esprit.org.uk - where queries can also be posted.

The human and financial cost of kidney disease – including ADPKD

NHS Kidney Care recently published a health economics report on the burden and impact of chronic kidney disease (CKD) in England.

Its key findings were that the annual cost of CKD to the NHS in England is estimated at £1.45 billion. This is more than the combined annual cost of breast, lung, colon and skin cancer. More than half this goes on RRT or renal replacement therapy (dialysis or transplantation), even though people needing RRT account for only 2 per cent of all people diagnosed with CKD.

Care for a patient on dialysis costs the NHS around £27,000 a year. There are approximately 7,000 extra strokes and 12,000 extra heart attacks each year among people with CKD, which cost an estimated at £174-£178 million in healthcare a year. Social care for people who have had strokes adds an extra £130 million to the total bill.

The financial burden of ADPKD

We believe that ADPKD accounts for about 10% of that £1.45 billion 'price tag'. 1 in 10 people on dialysis has ADPKD and 1 in 8 people with a kidney transplant has ADPKD – meaning that ADPKD could cost the NHS (England) around £145 million a year.

This is a huge sum of money. Moreover, if you factor in the other costs of lost employment, lost tax revenue, disability benefits and so on, we estimate that ADPKD could cost up to one third of a billion pounds a year.

Yet, the UK government has not spent a penny on ADPKD research – ever. Meanwhile, the average age of renal failure in ADPKD recorded on the Renal Registry was 55 years for decades. Not everyone with ADPKD will experience renal failure, of course, but we are the youngest group of CKD patients needing dialysis and/or transplantation. This situation is unlikely to change without new drugs or therapies – which require state recognition and funding as our small charity will never raise sufficient money to fund research.

In July, we presented to the All Party Parliamentary Kidney Group of MPs and Peers. As a consequence, we have brought the financial and human burden and cost of PKD to the attention of policy makers. We hope to bring you more news in later editions about the outcome.



Lucy Moore, Emily Prejac and Kim Murphy all took on the challenge of the 2012 Virgin London Marathon and between them raised more than £6,000 for the charity!

Linda Cooke and a team of colleagues from Lloyds TSB raised over £2,000 in the Cardiff Half Marathon in October. **Diana Philipson** also took up the Cardiff Half Marathon and raised £120.

Alison Laksey organised a big charity gig in April 2011 with the help of her family. Alison spent the day making a buffet for hundreds of people before running the event that evening and raised more than £850.

Aaron Bennett ran the Plymouth Half Marathon in May 2011 and raised over £305.

Fiona Charles took part in the Liverpool Half Marathon in March and **Lee Fitzsimmons** took part in the Tatton Park Triathlon in September 2011 raising £185.

Susan Searle at Sir Robert McAlpine raised £850 through a staff charity evening for the second year running. Also holding a fundraising evening was **Laura Stephenson** who held an ARPKD evening earlier this year which raised more than £4,500.

A special garden party was held by **Alison Gibbons** and her family to mark the Diamond Jubilee featuring old time music, champagne, stalls and delicious food. To mark the occasion, 3 friends cycled from Barmouth to the party in Bloxwich helping to make the total for the day more than £4,300.

Mark Ulyett organised a Golf Day and one of his family did a sponsored silence helping them to raise more than £500. **Samantha Wood** organised a company dress down day with colleagues at Arval in February. The day raised over £711 which we think may be a record for a PKD dress down day!

The Stafford Local Fundraising Group is going from strength to strength. Established for just over a year they've done a variety of fundraising activities including writing to companies for donations, placing collection boxes in shops in the local community, raffles and talks to students.

On World Kidney Day, **Sanela Becar** baked some delicious kidney-shaped cookies and sold them at work, raising more than £130 in the process. **Jackie Ellis** and family had a cake sale raising over £60. **Jon McCaig** decided to forgo the cakes and cookies and did a sponsored slim in the first half of this year. His sponsorship from family, friends and colleagues is still coming in but he has raised more pounds than he lost.... more than £2500 in total!

Mr & Mrs Brian Berry celebrated their Golden Wedding Anniversary in December and very generously asked for PKD donations in lieu of presents raising £540. £110 was donated by the family and friends of **Kevin and Elaine Harris** to mark their 30th Wedding Anniversary. **Tracey Firth** asked for donations in lieu of Birthday presents in September and raised £600 from very generous family and friends.



Caroline Kingshot and her husband climbed the iconic Sydney Harbour Bridge in October, sponsored by family and friends, raising £325.



Anne Duncan completed the Hull Marathon.



You Could Win a Small Car! The PKD Charity is once again taking part in the Small Car Draw, organised by the Foundation for Social Improvement. Tickets are just £2 and the winner receives a brand new Kia Picanto. The draw takes place on 19th February 2013, but tickets must be purchased before 4th January. 92% of each ticket sales goes directly to the PKD Charity. To buy a paper ticket or books of tickets, contact esther@pkdcharity.org.uk or to purchase an online ticket visit <http://www.smallcharitycardraw.org/> and click on the PKD Charity link. Good luck!

Simon Greenwood completed the Berlin Half Marathon and **Becky Pykett** ran the Silverstone Half Marathon. Both events were part of their training for the amazing Marathon des Sables in 2013.

In January **James Voce** and friends trekked to the top of Mount Kilimanjaro to raise funds for the PKD Charity. **Fiona McLeod** took on the Liverpool Half Marathon in spring and **Ashleigh Hopps** raised over £600 cycling Scotland's 12 mile way.



Dave Loveridge continues to run around the country for PKD clocking up 4 runs for the charity in the last six months; the Great South Run and Milton Keynes 10k last year and the Silverstone Half Marathon and the incredible Tough Mudder event in the spring of this year, in which his finishing time gave him automatic entry into the World Tough Mudder Championships next year.

Our sincere thanks to the Great Manchester runners, particularly **Ryan Deering** who raised over £600 and to **John Stone** who raised £1585.

In January we organised our first ever PKD Fundraising Workshop,

attended by enthusiastic fundraisers from around the country. The workshop produced some great fundraising ideas, many of which are being put into action this year with the help of our supporters, such as the Family Fun Day.



If you want to fundraise for the PKD Charity, we've written an 'A-Z of Fundraising' which has lots of ideas on fundraising events and activities, from the really small, right through to big events. Copies are available on our website or from Esther esther@pkdcharity.org.uk.



Esther Wright at the Family Fun Day

Quick ways to raise money for PKD this Christmas

Easyfundraising

is a shopping directory with over 500 of the UK's top retailers. All you have to do is use the links on their site whenever you shop online and, at no extra cost to you, we'll receive a free donation of up to 15% from every purchase you make.

It's free to register and use. Visit www.easyfundraising.org.uk/pkd and when you register, select Polycystic Kidney Disease Charity as the organisation you wish to support.

Give As You Live

is an online shopping portal from Everyclick.

Thousands of stores, including John Lewis, iTunes and British Airways, have signed up to donate money to the PKD Charity when you shop with them.

Visit the PKD Charity Give As You Live page:

www.giveasyoulive.com/join/thepkdcharity and join today.

Do you own a vehicle that you want to dispose of?



Then you can make a real difference for the PKD Charity this year!

Giveacar is a UK based fundraising organisation that organises car donation for good causes in the UK.

They provide a FREE service, which is available throughout the UK. They can arrange the collection of your vehicle at no cost to you and, depending on its age and condition, they can either recycle it at a green facility, or send it to a salvage auction.

Scrap donations raise an average of £100 for the charity, with auction cars often raising much more. Since Giveacar was set up in 2010, the organisation has raised over £700,000 for over 800 charities!

To arrange donation of a car to the PKD Charity, visit giveacar.co.uk/charities/polycystic-kidney-disease or call 020 0011 1664, quoting 'PKD Charity' as your preferred charity.

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