

## Your £ for a Pee

£1



Help raise £5000 for PKD research to develop a simple urine test to predict when kidneys might fail. The test looks for protein

patterns in pee - called 'biomarkers' - that form a unique fingerprint of each patient.

Simply text **PKDC19 £1** to **70070**  
<http://bit.ly/pound-for-a-pee>

## A walk of love for Abdul (Abs) Sefiani

by Lis Saks and Stephen Moss

*Stephen and I decided to walk part of the Camino de Santiago in the Northern Mountains of Spain for lots of reason, but the main reason was for Abs. He had Polycystic Kidney Disease and was in pain for far too many years. Despite his pain he was an inspiration of love and radiance to everyone he came into contact with.*

*When walking the Camino and when it was tough going, I just thought of Abs and that nothing was as tough as the pain he had to endure – it spurred me on to walk the 165 km from Irun to Bilbao.*

*Stephen and I were so glad to have done it when we did, as Abs passed away on 16 June 2012, 3 weeks after we came back.*

*He has taught us both the humbling part of life, that pain can transcend us from fear to love.*

*It was a privilege to know him. It is a privilege to help his charity.*

## Organ Transplantation to 2020

NHS Blood and Transplant (NHSBT) has issued a new strategy 'Taking Organ Transplantation to 2020' which aspires for the UK to 'match world-class performance in organ donation and transplantation'.

The strategy focuses on increasing the numbers of people who donate their organs after death, and ensuring NHS clinical practice can support this increase. When consent has been given, it aims to ensure donation will happen, all suitable organs are transplanted and survive as long as possible. It emphasises the need for societal changes so people accept organ donation as normal and expected of themselves and loved ones.

The next stage is for the four UK Health Departments to work in partnership with stakeholders to develop detailed operational plans. Work to implement the strategy should start in September 2013.

The PKD Charity welcomes the NHSBT strategy and its aims. Organ donation and transplantation is a key issue for our patients and their families - one in eight people with a kidney transplant has ADPKD, 10 people a year with enlarged polycystic livers receive liver transplants and many children with ARPKD undergo kidney and liver transplants.

We support the need for a change in attitudes to organ donation, particularly because pledging to donate requires a voluntary, positive expres-

sion of intent by the individual. We believe it is extremely important to reduce the numbers of families who object to donation even though their loved one has given consent in life. We welcome proposals to address this through effective support. Given the proposed introduction in Wales of an opt-out consent scheme, we call for collection of evidence on the impact to inform future debate on changing legislation in other parts of the UK.



Whilst we acknowledge that increasing transplant numbers is vital to improving UK performance in line with the world leaders, the quality and

effectiveness of transplants carried out is equally important. For this reason we welcome the proposed research into donor organ/recipient compatibility. It is believed this will improve graft survival and reduce the need for later transplantations.

Finally, we note the strategy does not detail the resources for its implementation. Although these are financially difficult times, we argue that there are significant economic benefits to increasing rates of organ donation and transplantation, not least returning economically active individuals to the workplace. We therefore call for appropriate funding to be identified as a priority.

Find out more: [www.nhsbt.nhs.uk/to2020](http://www.nhsbt.nhs.uk/to2020).

Send your comments on the NHSBT Strategy to: [info@pkdcharity.org.uk](mailto:info@pkdcharity.org.uk)

# Tolvaptan

## First ever drug to show a benefit in ADPKD

The eagerly awaited results of the global Tolvaptan clinical trial were reported in November 2012, by Dr Vicente Torres, Professor of Medicine at the Minnesota Mayo Clinic, at the American Society of Nephrology Conference. The results were positive. ADPKD patients who took Tolvaptan for 3 years had a slower increase in their kidney volume, a slower decline in kidney function, less pain and fewer infections, compared with those who were given a placebo (inactive substance).

For the first time, a drug had been shown to modify significantly the course of ADPKD in a group of patients. Otsuka, the pharmaceutical company who sponsored the trial<sup>1</sup>, has applied for official product marketing authorisation from the drug regulatory agencies in the US (FDA), the EU (European Medicines Agency) and Japan.

Tolvaptan works by blocking the action of an antidiuretic hormone called vasopressin, which is implicated in kidney cyst cell secretion and growth. These cells form the fluid-filled cysts in ADPKD. Dr Torres and his research team had first shown in 2003 that Tolvaptan (then called OPC31260) slowed cyst formation in mice, but it took 10 years of further study and trials to demonstrate, safely, an effect in humans. (See infographic on next page).

### Who will benefit from Tolvaptan?

The drug was tested on a subgroup of people diagnosed with ADPKD in early stages of disease development. We do not know which patients or what stage of their disease could be considered for treatment - if Tolvaptan is granted a marketing authorisation to sell the drug in the EU.

To enter the trial, participants had to be between 18 and 50, with eGFR<sup>2</sup>

<sup>1</sup> The Otsuka sponsored trial was called TEMPO - Tolvaptan Efficacy and Safety in Management of Autosomal Dominant Polycystic Kidney Disease and its Outcomes. People with ADPKD were recruited from many countries, including the UK.

<sup>2</sup> eGFR = estimated Glomerular Filtration Rate, a number calculated from serum creatinine

over 60 and a kidney volume more than 750ml. At the start of the 3 years, the average age was 40 and there were slightly more men than women (52% to 48%). Ethnicity was self-reported and the majority was caucasian. 8 in 10 had hypertension (high blood pressure). Around half had experienced pain. Results of genetic testing were not reported, so it is not known how many had PKD1 or PKD2 mutations. (See sidebar for more on genetic differences.) No children were included in the trial.

The trial results showed that patients on Tolvaptan benefited from slower rate of increase in kidney volume and a slower decline in renal function. However, the positive effect on renal function was nominally greater among people over 35 years, those with hypertension, and those with kidney volumes over 1500 ml. The change in kidney volume was greater in the first year and decrease in pain was observed early on.

Additional three years, however, is too short to assess fully the impact of a drug on ADPKD, which is usually a long-term, often slowly progressing condition. It is understood that Otsuka is continuing to observe trial participants to see if the positive benefits persist.

### What are the side-effects?

Tolvaptan makes you pee more! The drug triggers thirst which means that those taking it drank more fluids/water and consequently urinated more, day and night. About 1 in 12 stopped taking Tolvaptan in the first month because of the burden of thirst, fluid intake and frequent loo visits. This raises questions around long-term tolerability, impact on lifestyle and work.

Overall, nearly 1 in 4 of the Tolvaptan group never completed the trial for a number of reasons including thirst/urination effects. By comparison, about 1 in 8 in the placebo group also failed to complete the trial for various reasons. But of those taking Tolvaptan

(measured by blood tests), age, sex, and race. eGFR gives an estimate of kidney function, for example, an eGFR of 60 is roughly 60% remaining kidney function across both kidneys.

## Genetic ADPKD differences

More than 8 in 10 (85%) people affected by ADPKD have genetic alterations or mutations in the PKD1 gene, with the remaining (15%) having PKD2 mutations.

PKD1 mutations are associated with faster progression than those in PKD2. Future research studies and clinical trials may include genetic testing.

who did complete the 3 years, 9 out of 10 adhered to the dosage given.

A side-effect was observed in that levels of a liver-enzyme increased resulting in 3 participants withdrawing. Liver function monitoring would be required for all patients taking Tolvaptan if prescribed.

### Will the NHS prescribe Tolvaptan in the UK?

The price of Tolvaptan is known as the drug is licensed for a rare condition called Hyponatraemia. We do not, however, know the likely cost to the NHS of prescribing Tolvaptan for ADPKD. Using the list price on the internet, in trial doses, the cost could be over £200,000 a year. This cost compares with about £30,000 for yearly dialysis.

New drugs in the UK are assessed for clinical and cost effectiveness by NICE – the National Institute for Health and Care Excellence. They look at the balance of benefits and risks, so 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, pain-relief etc. It is not clear whether the socio-economic and psychological burden will be factored into the NICE 'formula' that will determine whether Tolvaptan is affordable by the NHS (England, Scotland, Wales and NI inclusive.)

NICE initiated a review of Tolvaptan in July 2013, anticipating (perhaps) that the drug could receive a marketing authorisation from the European Medicines Agency (EMA). The PKD Charity is participating in

this process, representing affected patients and families. More to follow on this in the next few months as we learn more. In the meantime, doctors are not allowed legally to prescribe Tolvaptan to ADPKD patients.

### Could water work as well as Tolvaptan?

The group of people with ADPKD in the trial who took a placebo had a 'relatively milder' renal progression than might have been expected. They also increased their fluid intake during the 3 years. This observation has further stimulated a continuing discussion about whether drinking large volumes of water could be as effective as Tolvaptan (or any other vasopressin inhibitor).

A number of researchers have previously looked at conducting clinical trials with water but whilst appearing easy, such trials are difficult to carry out scientifically. However, the UK ADPKD Study Group (chaired by the PKD Charity) is developing a protocol for a study in the UK. More to follow on this exciting development!

### The enduring unmet need for ADPKD drugs and treatment

The Tolvaptan (TEMPO) trial has

shown a disease-modifying effect of a drug on the most common inherited and the fourth most common overall cause of kidney failure worldwide. It took at least 10 years of laboratory work and millions of pounds spent on clinical trials. We congratulate our friends at the PKD Foundation (PKDF) in the US for their early support and continual advocacy.

Yet, the unmet need for PKD drugs and treatments endures. There are a few other trials underway looking at different approaches to slowing cyst growth and renal decline, but compared with cancer and AIDS, ADPKD remains a highly neglected disease. There has been no UK or EU government funding of PKD research for decades. All previous UK research (apart from Tolvaptan) has been basic laboratory projects, funded by academics and charities.

In early 2004<sup>3</sup>, Dr Vicente Torres said this about the promise shown for OPC31260 (Tolvaptan) in treating ADPKD: "We would hope it slows down the disease enough that it becomes irrelevant." Having an irrelevant disease remains a hope still for many of us in 2013.

<sup>3</sup> New Scientist, 6 March 2004

## Search for PKD trials

Publicly and privately supported clinical trials on human participants are registered on an international database managed by the US National Institutes of Health. This site lists the trials and results. To find out where both ADPKD and ARPKD trials are taking place, just enter those terms in the search box. <http://clinicaltrials.gov/>

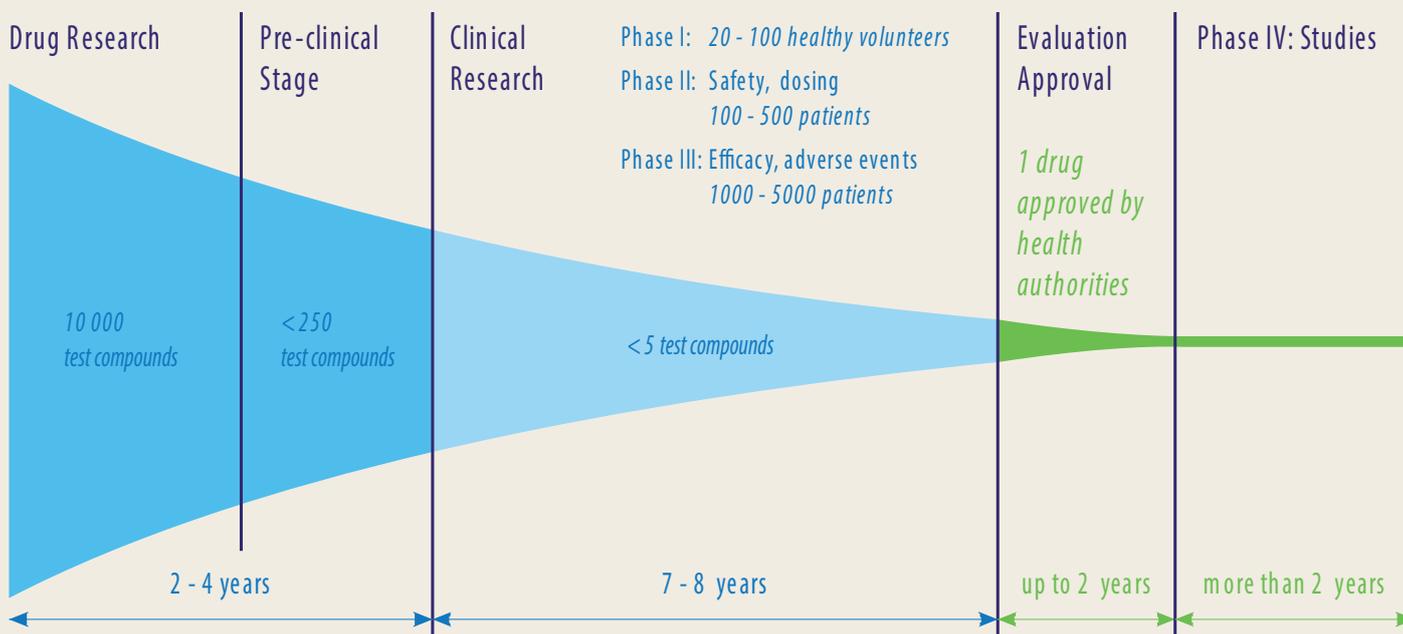
The EU has recently developed an EU Clinical Trials Register which allows you to search for information on clinical trials in European Union (EU) member states and the European Economic Area (EEA). Visit [www.clinicaltrialsregister.eu](http://www.clinicaltrialsregister.eu).

### Read more about Tolvaptan

Keep up to date with Tolvaptan on our website [www.pkdcharity.org.uk/research/key-clinical-trials/tolvaptan](http://www.pkdcharity.org.uk/research/key-clinical-trials/tolvaptan). To request a printed copy ring our Support Line **0300 111 1234**, or email [info@pkdcharity.org.uk](mailto:info@pkdcharity.org.uk).

## How long does drug development take?

It can take up to 10 years and many millions of pounds to develop a drug, from innovation and basic research to clinical trials on patients with a condition or disease. The figure below shows the drug development process. After the regulatory authorities have approved a drug and given it marketing authorisation, the drug's effectiveness on the condition continues to be monitored.



# Get Involved

## In Fundraising

Thank you for your energy, enthusiasm and support over the past few months. Together you have raised more than ever for the benefit of people with PKD.

Here's just a sample of your latest fundraising activities. Sorry we can't feature you all but if you have a favourite photo of your fundraising event or activity, please send it to us for the PKD Charity website gallery or the next newsletter, with info about what you did. High resolution please! See below for email details.

This year we have seen huge demand for our running events, and runners were pounding the pavements for PKD all over the country.

**Jonathan Read** ran the Peterborough Half Marathon in October raising £150 and **Ben Judge** ran a 10k event in February raising £273 plus gift aid. At opposite ends of the UK, **Steve Green** raised £346 running the Great North Run and **Ian Beavis** ran his way to £207 of sponsorship at the Great South Run.

**Raminder Dosanjh** completed the tough 13 miles of the Great Birmingham Run in October in an impressive time of 1hour and 50 minutes.



Raminder had fantastic support from family and friends and raised over £5,000.

The most arduous run on behalf of PKD was out of the UK – in the heat and dust of the Moroccan desert. After 2 years of training, **Simon Greenwood** and **Fred Laboroi** ran the famous Marathon des Sables, 151 miles over 6 days, carrying all their own food and equipment on their backs! They finished in 100th position out of 1024 participants. Congratulations both and well done on raising over £8,000.



The Great Manchester Run is always popular and this year we had a record 42 runners. Lime green PKD vests were everywhere! Over £11,000 was raised. Thank you to the cheering friends and families who helped make this a fantastic day. If you fancy taking part next year, it's on 8 May 2014.



In the London Marathon in April, **Ed Porter** led the way and raised over £2,000 with his company providing some matched funding.

**Steve Garland** got together with his colleagues at Sky and raised £210 in August 2012.

**Sarah Carpenter** used the happy occasion of her son's christening to collect donations from family and friends for the PKD Charity.



In June, the Northallerton Lionesses Club raised £1000 in memory of the chairperson's husband. Sandra and Peter Buckland attended on behalf of the charity and collected the cheque.



New and innovative fundraising ideas are always exciting to hear about.

**Vicky Foster** organised an Alice in Wonderland themed evening in February. The event raised over £1,100 and featured raffle, fancy dress and a fantastic Alice in Wonderland cake.



**Judith Hurst** held a Driftwood and Light party in the run up to Christmas and raised £175 from selling beautiful items made from driftwood.

**Lori-Anne Desmond** at The Nutri Centre in Milton Keynes continues to sell hundreds of PKD trolley coins each month in the shop. If you would like to follow her lead, have a look at our e-shop at [www.pkdcharity.org.uk](http://www.pkdcharity.org.uk) to purchase trolley coins, badges, wristbands and much more.



**Andrea Sutton** held an Open Garden at her mother-in-law's stunning garden in September and raised £140 from family and friends.



Opting for a more challenging way to fundraise, **Alick Davis** took on a skydive for PKD and after several postponements due to bad weather he finally took the plunge in October 2012 and raised £700 in the process.

Hope you enjoyed the view, Alick!

Regular PKD fundraiser, **Linda Howell** held a PKD evening event raising more than £2,203 and **Avril Ainscough** raised £252 from the sale of her home made cards in the lead up to Christmas.

It's always a pleasure to open an envelope from **Lesley Smith**. She's always fundraising for us and sends her cheques with a handwritten note about the event she's organised.

Her homemade Pea & Pie suppers and bread baked with her garden herbs are renowned, and she's planning more suppers for the winter months.

Proving that it's possible to fundraise with just about anything, the **Blue Skies Montessori Nursery** in Whitefield, Manchester has been recycling old pairs of shoes.



The Nursery, managed by **Karin McKenzie** and her staff **Angela, Andrea, Jo** and **Lorraine** then sell the shoes to a recycling company, donating all the proceeds to the PKD Charity. To date, they have raised over £200!

That's a lot of unwanted shoes!

**Sacha El-Labany** rode from London to Paris in July, 4 days and over 300 miles, to arrive before the end of the Tour de France.



The Roach family got together with friends and family for a weekend of fundraising in April and raised nearly £2,000. We love this photo of everyone in their PKD t-shirts.

PKD supporters got cooking on World Kidney Day in March, by baking kidney shaped cookies to sell and by holding their own events.



**Felicity Webb** at Park Resorts held at fundraising event at the company headquarters in Hemel Hempstead and **Sheena Sefiani** baked lots of homemade cakes and goodies to sell at a her local deli in London, in memory of her late husband Abdel.

But you don't have to don your trainers, dive from the skies or bake cakes. There are lots of other ways to get involved. For example, if you have a printer at home or in an office, collect your used cartridges and post them back in a prepaid envelope – donations go directly to the charity. Mobile phones and even cars can be recycled too.



Get more ideas from our **DIY Fundraising Tips** on the PKD website, or request the Tips plus an event pack by emailing Esther. You

can also ring her for suggestions and support directly. (See contact details below).

### Gift Aid

Gift Aid helps charity donations go further. If you or the person giving money pays UK tax, we can reclaim 25p for every £1 donated from HMRC

– at no cost to the person making the gift. Last year, we received about 10% of our income from HMRC Gift Aid rebates. However, we need the name and address of the donor, plus confirmation they are happy to have the donation gift-aided.

We have **Gift Aid Forms** which you can hand out to individuals. Or you might prefer to use our small donation envelopes – donors can easily pop cash or a cheque into the envelope and there's space for them to write their Gift Aid details on the front. The envelopes can be really helpful at an event where you would like to ask people to make a private donation and are often used at funerals to make donations in memory of a loved one. Ask Esther for Gift Aid Forms or envelopes (See contact details below).

### Future events to get involved in

We also have places in the **Great South Run** on 27 October 2013. Email Esther (see below). All we ask is that you pledge to raise a minimum of £200 in sponsorship and in return you will receive a fundraising pack, training t-shirt and one of our famous lime green PKD running vests!

If you would like to run the **2014 Virgin London Marathon** to raise funds for PKD, please contact Esther (see below) and we will enter you into our ballot for the places we have. Ballot closes on 30 September 2013 with winners notified on 1 October.

Without your amazing fundraising efforts, we are unable to carry out our work. Thank you to everyone who has supported the charity. We appreciate every penny that you raise for PKD.

How to get more information on fundraising:

Email [esther.wright@pkdcharity.org.uk](mailto:esther.wright@pkdcharity.org.uk)

Ring Esther on **07825 882616** (leave a message and she will ring you back)



Visit our website to request an Event Pack [www.pkdcharity.org.uk/request-an-event-pack](http://www.pkdcharity.org.uk/request-an-event-pack)

# Overview of Surgical Procedures

## Related to ADPKD

Not everybody with ADPKD (Autosomal Dominant Polycystic Kidney Disease) will need surgery but for those who do, here is a brief overview of the main renal surgical procedures related to ADPKD.

### Peritoneal dialysis catheter

When kidney function is insufficient to support your health, dialysis might be required. One form of dialysis, peritoneal dialysis or PD, uses the peritoneal cavity (the bit between your organs and the abdominal cavity). Fluid is put in the cavity until it removes the toxins and then emptied out. This is done via a tube that is inserted through a small incision just below the navel/belly button (umbilicus). The tube is passed into the abdominal cavity and under the skin to exit the abdomen. This moves the tube away from the scar and makes it easier to use. In ADPKD, as space is limited, the procedure is usually done under general anaesthetic.

### Fistula

This surgery – known as an arterio-venous or AV fistula - is done to join an artery to a vein or to a plastic graft to allow haemodialysis (HD). This is the most common type of dialysis, requiring access to the blood stream multiple times a week. Whilst operations on arteries and veins sound complex the majority are performed under local anaesthetic (injection) and are often quick and straightforward. A fistula needs about 6 to 8 weeks to 'mature' and become sufficiently thick and strong enough for successful dialysis.

### Nephrectomy

If a kidney transplant is being considered or the kidneys are very big or causing problems such as cyst infections, one or both may need to be removed. Removal of one kidney is called a nephrectomy; removal of both is called a bilateral nephrectomy.

The decision to remove a kidney is often difficult. If you are not on dialysis and both kidneys are removed, you will require dialysis after – needing either a PD catheter or AV fistula surgery. When the kidneys are removed, this may result in fluid restriction and

blood pressure (BP) may fall. A low BP may seem beneficial but can be a problem with dialysis and transplantation if it's too low.

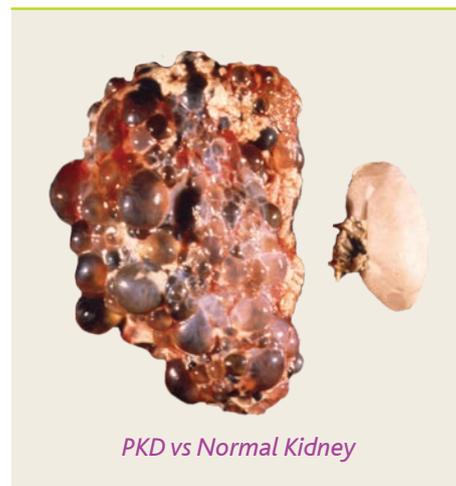
Kidneys can be removed by different techniques but due to the large size of ADPKD kidneys, surgery can be challenging. (See photo of typical polycystic compared with normal kidney). Multiple infections and cyst bleeds can also make the kidneys stick to neighbouring organs. The traditional approach is through a generous incision (open procedure) either across the abdomen or up and down the abdominal midline. To safely get to the kidneys, which lie behind the other organs, is technically demanding for the surgeon and requires considerable expertise.

As big incisions are not desirable, some specialist surgeons have developed techniques that allow a more minimally invasive approach. Laparoscopic or 'keyhole' surgery involves using telescopes and instruments through small incisions in the abdomen to mobilise the kidney and divide it from its internal attachments. The problem of getting the enlarged kidney out still remains though! To do this a small cut can be used and the cysts drained before removing the kidney. This approach is not possible in everyone. Even when attempted, some laparoscopic operations will need 'converting' to a bigger cut and an open approach.

A polycystic nephrectomy is a major operation and whilst most people do recover well afterwards (which may take weeks) it needs careful consideration. A thorough discussion with the surgeon is required about whether one or both kidneys are removed and which technique will be used.

### Kidney transplantation

Kidney transplants have been performed successfully in the UK since the 1960s and offer the opportunity for a better quality and length of life over dialysis. About 6 in 10 transplanted kidneys come from deceased donors, with the remainder from living donors (who may be related or unrelated). Transplanted kidneys are always recognised as slightly different



PKD vs Normal Kidney

or 'foreign' by the body and the recipient will require lifelong medication (immunosuppression) to suppress the cells which would otherwise attack the transplant.

A kidney transplant is performed through an incision in the lower abdomen. The reason for this is because the lower abdomen gives access to blood vessels and to the bladder. If polycystic kidneys are very big, however, they might not allow access to these structures and this is why surgeons sometimes remove one or both for space reasons. Nephrectomies are either done before or after, never during transplantation surgery.

During the operation, the blood vessels are joined together and the ureter (the draining tube from the kidney) is joined to the bladder. When operating on blood vessels the concern is blood clots forming which result in the kidney failing. Fortunately this occurs in less than 1 in 20 (5%) of patients. Transplantation is usually very successful and over 9 in 10 (90%) of transplanted kidneys will be working a year after the operation.

### Summary

If you have ADPKD, any or all the surgical procedures above may occur. In general, however, the outcomes are good. The timing of surgery and the technique used, particularly for removing kidneys and for transplantation, are important decisions. Careful consideration and thorough discussion between patient and surgeon are essential to allow sufficient time to understand what's involved and allow an informed choice about surgery to be made.

*Article by Mr Nick Inston, Surgeon at the Queen Elizabeth Hospital, Birmingham*

# What Your Blood Tests Tell You

## The importance of your blood in kidney health

Your kidneys filter the blood flowing through your body 20 to 25 times each day and excrete toxins in your urine. Kidneys also control blood pressure (BP), balance salt and water, regulate calcium and haemoglobin. Below is a simple overview of what your blood tests tell you about kidney health.

**eGFR** is short for **estimated Glomerular Filtration Rate**, which shows roughly how well kidneys work. Creatinine is produced by muscles. Normal kidneys filter about 100 ml every minute. eGFR reduces and creatinine rises as kidneys start to fail. eGFR figure gives approximate percentage kidney function and is used to monitor trends.

If you know your eGFR, you know your 'stage' of kidney disease – ranging from 1 (normal) to 5 (kidney failure). Eg, eGFR of 60 is Stage 2 or mildly reduced kidney function. eGFR is based on age, sex and ethnicity as well as creatinine. Check your eGFR on the Renal Association site: [www.renal.org/eGFRcalc/GFR.pl](http://www.renal.org/eGFRcalc/GFR.pl). Remember that this figure is only an estimate. A more accurate way of measuring Glomerular Filtration Rate is to inject a tiny amount of a radioactive substance and measure how quickly it disappears from the blood, or appears in the urine.

**Potassium (K)** is in food, mainly fruit and vegetables. When you eat more potassium than needed, the kidneys excrete the extra amount. Potassium rises with kidney failure. High levels

of potassium can be very dangerous, causing serious heart rhythm abnormalities. Some patients with severely damaged kidneys, or on dialysis, may need to limit fruit and vegetables. Potassium levels can also rise with some BP drugs. Ask to speak to a dietitian if you have been advised to reduce dietary potassium.

**Urea** is produced from protein and excreted by the kidneys. Urea is low if you do not eat enough protein and it rises when kidneys fail and if you are dehydrated.

**Sodium (Na)** comes mainly from salt (sodium chloride). Sodium increases in the body when the kidneys do not work properly, and can cause high BP, oedema (swelling), and even fluid on the lungs (pulmonary oedema). You won't see a change in the blood, because sodium makes you thirsty, making you drink more until the sodium level becomes normal again. Most people with PKD need to reduce dietary sodium they eat, in particular less salt in food, and may also need to take diuretic drugs to increase the sodium excreted in urine.

**Calcium (Ca)**. As kidneys fail, calcium levels in bones can either rise or fall. Low levels occur when the kidneys stop converting **vitamin D** from food (helped by sunlight) into an active form. This can lead to bone thinning, weakness and tingling. Special types of active vitamin D will be prescribed to prevent renal bone disease and raise blood calcium.

Increased **phosphate** ( $\text{PO}_4$ ) levels may result in itching and calcium deposits, especially in arteries. Kidney patients often have to limit the amount of phosphate in diet, or take tablets called phosphate binders that stop dietary phosphate getting out of your gut into your blood. Some phosphate binders contain calcium, so can raise blood calcium too.

Longer-term, **PTH** or parathyroid hormone levels can also rise resulting in high blood calcium levels. If PTH cannot be controlled by drugs such as active vitamin D, the 4 parathyroid glands behind the thyroid gland in the neck may need removing.

**Haemoglobin (Hb)** is a red protein found in blood which carries oxygen around the body. Kidneys produce **erythropoietin (EPO)**, which stimulates bone marrow to produce red blood cells. Loss of EPO production as kidneys fail causes anaemia. Treatment with artificial EPO has been a huge advance for patients with kidney failure.

**White blood cells (wbc)** fight infection in the body. Their level is often raised in the presence of infection. They consist of different types, but the most important ones are called neutrophils.

**Albumin** is an important protein in the blood that is made in the liver. It may be low if you are severely malnourished or seriously ill. Albumin binds calcium, so calcium levels seem lower when albumin is low.

**Table Of Reference Ranges For Blood Tests** (Note: Average values fall a little with age)

Creatinine	60–120 $\mu\text{mol/l}$	Goes up as kidney function goes down
Urea	2.5–6.6 $\text{mmol/l}$	Accumulates in blood in kidney failure
Potassium	3.6–5.0 up to 6.0 $\text{mmol/l}$	May sometimes be acceptable, but higher is dangerous
Sodium	135–145 $\text{mmol/l}$	Rarely changed
Phosphate	0.8–1.4 $\text{mmol/l}$	Keep around 1.8 $\text{mmol/l}$ or less
Calcium	2.1–2.6 $\text{mmol/l}$	Keep as normal as possible
Parathyroid hormone	According to laboratory	Less than 2–3 times normal level
Haemoglobin	130–180 $\text{g/l}$ (men) 115–165 $\text{g/l}$ (women)	Around 110 $\text{g/l}$ to normal with erythropoietin (note that 110 $\text{g/l}$ = 11 $\text{g/dl}$ )
White blood cells	4–11 x 10 <sup>9</sup> /l	Keep as normal as possible
Albumin	35–50 $\text{g/l}$	Keep as normal as possible

# 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/](http://uk.groups.yahoo.com/group/PKD_uk/)
- **PKD Charity Facebook Group (UK only)**  
[www.facebook.com/groups/pkdcharityUK/](http://www.facebook.com/groups/pkdcharityUK/)
- **PKD "CYSTERHOOD"**  
[www.facebook.com/groups/PKDCYSTERHOOD/](http://www.facebook.com/groups/PKDCYSTERHOOD/)
- **Polycystic Kidney Disease and Kidney Disease**  
[www.facebook.com/groups/17866443885/](http://www.facebook.com/groups/17866443885/)
- **HealthUnlocked ADPKD Community (UK only)**  
[www.pkdcharity-autosomalrecessive.healthunlocked.com/](http://www.pkdcharity-autosomalrecessive.healthunlocked.com/)
- **Living with Polycystic Kidney Disease Support Group**  
[www.facebook.com/groups/150513068466259/](http://www.facebook.com/groups/150513068466259/)

### Join an ARPKD online support group

- **Facebook ARPKD Group**  
[www.facebook.com/groups/20526281816/](http://www.facebook.com/groups/20526281816/)
- **HealthUnlocked ARPKD Community (UK only)**  
[www.pkdcharity-autosomalrecessive.healthunlocked.com/](http://www.pkdcharity-autosomalrecessive.healthunlocked.com/)
- **ARPKD/CHF Alliance**  
[www.facebook.com/groups/89846751499/](http://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](http://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](http://www.kidney.org.uk)
- **British Kidney Patient Association (BKPA) - financial support and grant aid for kidney patients.**  
[www.britishkidney-pa.co.uk/](http://www.britishkidney-pa.co.uk/)
- **Turn2us - helping people access money available to them through welfare benefits and grants.**  
[www.turn2us.org.uk/](http://www.turn2us.org.uk/)
- **Contact a Family - supporting families of disabled children**  
[www.cafamily.org.uk/](http://www.cafamily.org.uk/)
- **NKF Advocacy Service**  
[www.kidney.org.uk/advocacy-service/](http://www.kidney.org.uk/advocacy-service/)
- **UK Government Benefits Info**  
[www.gov.uk/browse/benefits](http://www.gov.uk/browse/benefits)
- **Back copies of PKD newsletters**  
[www.pkdcharity.org.uk/news-events/newsletter](http://www.pkdcharity.org.uk/news-events/newsletter)

## Patient Information on Our Website

### Just Diagnosed

[www.pkdcharity.org.uk/about-adpkd/just-diagnosed](http://www.pkdcharity.org.uk/about-adpkd/just-diagnosed)

### Symptoms

[www.pkdcharity.org.uk/about-adpkd/symptoms-of-adpkd](http://www.pkdcharity.org.uk/about-adpkd/symptoms-of-adpkd)

### Living with ADPKD

[www.pkdcharity.org.uk/about-adpkd/living-with-adpkd](http://www.pkdcharity.org.uk/about-adpkd/living-with-adpkd)

### Fast Facts about ARPKD

[www.pkdcharity.org.uk/about-arpkd](http://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](http://www.pkdcharity.org.uk/fundraising/diy-fundraising-tips)

### Take part in a fundraising event

[www.pkdcharity.org.uk/request-an-event-pack](http://www.pkdcharity.org.uk/request-an-event-pack)

### Buy online at the PKD e-Shop

[www.pkdcharity.org.uk/fundraising/pkd-e-shop](http://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**.
- New research project 'Your Pound for a Pee'. Simply text **PKDC19 £1** to **70070**.

### Board of Trustees

Barry Harpham  
Chairman

Judith Dignum  
Treasurer

Margaret Pope  
Support Group Counsellor

Edwina Graham

Raj Johal

Sarbjit Johal

Rebecca Murphy

Christine Wallach

### Fundraising

Esther Wright

[esther.wright@pkdcharity.org.uk](mailto:esther.wright@pkdcharity.org.uk)

### Management

Tess Harris

Chief Executive

[tess.harris@pkdcharity.org.uk](mailto:tess.harris@pkdcharity.org.uk)

### Scientific, Clinical and Research Advisory Board

Professor Pat Wilson  
Chairman

Dr Anand Saggar MBBS FRCP  
Vice-chairman