

This newsletter is published by:

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[www.pkdcharity.org.uk](http://www.pkdcharity.org.uk)

Winter 2007

## World Kidney Day 2008



### Help us support the next World Kidney Day on 13 March 2008 and raise awareness of PKD in the UK

The PKD Charity would like your ideas to help make this international event, which will take place on 13 March 2008, a success for people with PKD.

We will be collaborating with other kidney charities in the UK, such as the National Kidney Federation and Kidney Research UK, to raise awareness of kidney disease generally, but we would also like to use the day to help the public understand PKD.

The last World Kidney Day took place in March 2007 and was celebrated in 66 countries. Hundreds of thousands of people, families and health care professionals took part.

World Kidney Day was launched for the first time in 2006 in response to the growth in numbers of people with chronic kidney disease. It is a joint initiative of the International Society of Nephrology and the International

Federation of Kidney Foundations.

Our kidneys, too often overlooked, have now emerged as central to global public health efforts, as the cost of renal replacement therapy for total kidney failure hits health care budgets.

### Help us make an impact

How do you think we should make use of this important opportunity? Do you have ideas for activities that will help reach more people and change perceptions?

Send us your ideas

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

Write to: Tess Harris, 91 Royal College St, London NW1 0SE

Visit [www.worldkidneyday.org](http://www.worldkidneyday.org) for more information

## Information Day a great success

The fourth PKD Information Day has been hailed as a great success. The event, a mixture of lecture, discussion and workshops, allowed plenty of time for people with PKD to meet each other and ask questions of a range of specialists.

PKD Charity chairman Tess Harris stressed her gratitude to everyone involved, 'I'd like to thank the speakers, who gave their time freely; our project manager, Justina Wilkinson; all the volunteers who helped make the day so successful and, of course, all those who attended'. *Full report on page 3.*

### Visit our website

Visit [www.pkdcharity.org.uk](http://www.pkdcharity.org.uk) for more PKD information and the latest news.



### Tell us your views

The PKD Charity is run by and for people with polycystic kidney disease, so we would like to hear from you.

- Send us an email – we may even publish it in the next newsletter
- Tell us what more we can do to help
- Give us feedback on our work

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

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## PKD support groups to be extended

Last issue we reported on the piloting of PKD support groups in Richmond and Chester. The groups, set up to provide an informal opportunity for people with PKD to meet, exchange information and swap experiences in a supportive environment, had their first meetings in April and July, so we caught up with those involved for their first impressions.

Maggie Pope, Support Group Co-ordinator and Convenor of the SW London group, explained the background, 'We started the groups because PKD is so little known. We also wanted to reach out particularly to those people with relatively few symptoms who were unable to access the more established support systems provided for those on dialysis or awaiting transplant.'

The benefits of peer support approaches within health are now well recognised. Recent research shows support groups can have a big impact on recovery rates after operations and, in the USA, organising patients with asthma into a telephone support system cut hospital admissions by 74% (source: New Economics Foundation – *Towards an Asset Based NHS: The Missing Element of NHS Reform*).

Emma Kennedy, a nurse at the Countess of Chester hospital and Convenor of the NW England group, spoke enthusiastically about the meetings, 'The feedback has been great. People really appreciated being able to compare symptoms and experiences with other people in the same boat'.

Maggie describes the meetings as informal, 'There are refreshments and we plan to invite speakers. The format is still flexible so we can respond to what people want', meaning it's an ideal time to go along.

There are plans to extend the pilots to North London and North East England so anyone in these areas who wants to be involved, or if you are interested in forming a group in your own area, please contact Maggie.

Contact Maggie Pope  
 Tel: 0845 241 0964  
 Email: [maggie@pkdcharity.org.uk](mailto:maggie@pkdcharity.org.uk)  
 Write to PO Box 368, Twickenham, TW1 9DY

Contact Emma Kennedy  
 Tel: 0845 241 0964  
 Email: [info@pkdcharity.org.uk](mailto:info@pkdcharity.org.uk)

## Coping with pain Part one: getting to grips with medication

**One of the first signs of ADPKD is pain in the back, sides or abdomen. This is usually caused by enlarged cysts, bleeding cysts and kidney stones. Effective pain management for people with PKD is therefore vital and we hope that this two part article on coping with pain helps readers gain some useful facts and tips.**

**Chris Price, a Clinical Nurse Specialist for the Acute Pain Service at The John Radcliffe Hospital, gave her expert advice on pain management at the PKD Info Day in July. And here she delves deeper into the pain medication available.**

Pain is a serious matter. It can affect quality of life, cause anxiety, depression, insomnia, prevent a person from working full-time, create financial strain and put stress on family life.

Some people and doctors are wary of over using pain-controlling drugs but as long as they are used in a logical way, there is no reason why people can't have them and enjoy a better quality of life.

### Getting the right dosage

There is a well-known medical tool, called the WHO Analgesic Ladder, which helps doctors to prescribe

the right level of medication when a patient is in pain. This chart is available on the PKD Charity's website. If a patient feels they aren't getting sufficient pain relief, they can take a print out of this diagram with them when they next see their GP.

As a rule, prescribed painkiller dosage needs to be reduced as kidney function decreases.

### Holidays and trips

If you are going to be away from home for some time, remember to plan ahead. Make sure you have enough painkillers to last.

### Other drugs that are used for pain

Anti-depressant drugs, such as Amitriptyline, and anti-epilepsy drugs, such as Gabapentin, can provide very effective pain relief and people with PKD may well be prescribed these.

Amitriptyline relaxes muscles and calms nerve endings. Sadly, some people lose faith in this drug because they find they wake up feeling hung-over, but this can be avoided. If they wake feeling heavy headed, I advise people to take this medication earlier in the evening than they were – at around 8 pm.

Both Amitriptyline and Gabapentin cause constipation but it is fine for people with PKD to use laxatives, such as Lactulose.

## Buying painkillers

### Fine

- Paracetamol (if you have liver disease, check with your GP)
- Codeine

### Avoid

- Brufen
- Diclofenac
- Ibuprofen
- Nurofen
- Voltarol

Avoid all NSAIDs. If in doubt, check the label or ask your pharmacist.

### Over-the-counter painkillers

Some popular anti-inflammatory drugs, known as NSAIDs should never be used by people with PKD as they can impair what kidney function you have. NSAIDs are a family of drugs, and Ibuprofen is just one of these. See the list of NSAID brand names and medications above for easy reference when buying over-the-counter medications.

You should consult your doctor about the use of any painkillers as they will have the overview of all your medication and conditions and can give you specific advice.

By Chris Price, The John Radcliffe Hospital

## Spirits are lifted at the PKD Information Day



Ask the experts. Left to right - Lukas Foggensteiner, Richard Sandford, Anand Saggur and Albert Ong.

### PKD Information day was held at the Queen Elizabeth Medical Centre in Birmingham on Saturday 7 July 2007.

Attended by around 60 people from all over the UK, the day was described as a great success by both organisers and participants.

PKD Charity chairman Tess Harris said, 'I'd like to thank the speakers, who gave their time freely; our project manager, Justina Wilkinson; all the volunteers who helped make the day so successful and, of course, all those who attended'.

Dr Albert Ong, Reader in Nephrology and Hon Consultant Nephrologist at the University of Sheffield School of Medicine commented, 'It was a really good day. It was great to have the opportunity to talk about medical advances and I think people found it particularly helpful to get one-to-one support from specialists, like myself, about their condition'.

Dr Ong presented an informative and optimistic update on current research with Dr Richard Sandford, Senior Fellow in Clinical Research and Genetics Consultant at Addenbrookes Hospital in Cambridge. *For an interview with Dr Ong see page 5.*

### What people got from the day

Feedback after the event highlighted how well-received this optimism was: 'The information about the drug trial was great. The day gave me so much hope.' and 'There is hope with all the research taking place. It is not all doom and gloom.'

It was satisfying too to learn that the day struck the right balance between catering for those with a limited knowledge of PKD and those who needed more detailed information. As one attendee

### 'There is hope with all the research that's taking place. It is not all doom and gloom!'

elaborated, 'It was all very useful. Although some of it was familiar, the more you hear the more you understand'.

Several people noted that the introductory talk 'More than a kidney disease – an overview of PKD' given by Dr Anand Saggur, Consultant in Clinical Genetics at St George's Hospital in London, was particularly valuable in this respect.

Dr Saggur's session, 'The Genetics of PKD – Focus on Genetic Counselling', proved particularly useful for those who wanted a clearer understanding of the genetic background to PKD, and the possible effects it could have on their children.

Other specific concerns were dealt with throughout the day. For example Dr Lukas Foggensteiner, Consultant Nephrologist at the Queen Elizabeth Hospital in Birmingham, held a workshop 'Dialysis Explained'. Many who attended this session commented how useful it was and that the level of detail and information provided was invaluable.

One person even expressed their gratitude, saying that the event had helped them come to a decision about dialysis.

### 'There was so much information that just isn't available from my GP'

Likewise Dr Sandford's workshop 'Pregnancy and PKD' provided detailed information on a specific area. Women with PKD were advised of the importance of monitoring their blood pressure during pregnancy, and warned of the additional strain it could place on the kidneys – particularly those of older mothers.

It was recommended that people with PKD who want to have children seek advice from their GP on a healthy lifestyle during pregnancy, and the possible effects on their baby.

Further well-attended workshops were run by Christine Price, Clinical

### Four tips for better GP appointments

- 1 Ask your GP for regular kidney function tests and BP checks
- 2 If you are concerned, ask your doctor to refer you to a nephrologist or renal consultant
- 3 Ask your GP to consider your family history, particularly if you are pregnant
- 4 Get to know your practice nurse – they can carry out BP checks, offer support and can be a great link to your GP

Nurse Specialist in Acute Pain at the John Radcliffe Hospital in Oxford, on 'Pain Management' (see page 2 for further information) and 'Coping with PKD' by counsellor and 'PKD husband' Martin Wilkinson.

### 'The more you hear, the more you understand'

Above all, feedback from the day suggested that people particularly appreciated the range of information available and being free to ask so many questions of specialists in an informal setting. As one woman noted, 'There was so much information that is just not available from my GP.'

### Edinburgh next for PKD Info Day

PKD Information Days are held at different venues across the UK. The next one is scheduled to take place in Edinburgh, on Saturday 26 April 2008.

If you're interested in attending, please email Tess Harris, phone Justina Wilkinson or check our website for further information and updates.

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

Phone Justina Wilkinson: 01246 823 468

Website: [www.pkdcharity.org.uk](http://www.pkdcharity.org.uk)

### Remember us

When writing a will, please consider the PKD Charity. Contact us to find out more.



## Understanding urinary tract infections

Urinary tract infections (UTIs) are common among people with PKD and they should always be taken seriously. Recurrent cystitis is very common for women, and especially difficult for PKD patients. Infections, other than one-off cystitis infections in women, need to be fully investigated.

If you suspect you have a UTI, seek treatment immediately as infection can spread to the cysts in the kidneys. Cyst infections are more difficult to treat as many antibiotics do not penetrate into the cyst fluid.

There is no need to routinely check non-symptomatic children but any child with unexplained symptoms such as tummy ache, fever or general lethargy should be checked to exclude a UTI.

### What are the signs of a UTI?

UTIs usually cause a burning sensation when you urinate, an urgent need to pass urine, fever, chills, and back pain.

### Why are infections common?

Cysts, due to their size and position, interfere with the normal flow of urine. This increases the time urine is retained in the kidney tissue and even minor delays in the flow of urine

increase the chance of an infection. It is also possible that the altered kidney tissue in ADPKD makes it easier for infections to occur.

The bacteria that cause these infections usually enter the urinary tract through the urethra. As women's urethra are shorter than men's, they are more susceptible to UTIs.

Some people have frequent infections, often from the same germ. This may be due to persistent infection in a cyst, a kidney stone or poor fluid intake. Many women can also relate the infections to recent sexual intercourse.

**How are UTIs diagnosed?** It is very important that your doctor collects a urine culture each time you have symptoms of infection. Your doctor should request the culture before you receive antibiotic treatment.

If the infecting bacteria is identified, specific treatment is prescribed or the antibiotics are modified. The germ may be different with each infection, suggesting that the bacteria are coming from outside the body. If the same germ is found each time, the antibiotics may not be

destroying a focus of infection.

**What is the treatment?** Any UTI should be treated promptly with appropriate antibiotics. PKD patients with UTIs should be treated aggressively and those with a cyst infection should be treated for longer periods.

Women with recurrent infections, who have reasonably normal kidney function, are advised to drink one to two litres of fluid every day – plain water is best – and to urinate every two hours during the day and within 30 minutes after intercourse. Evaluation by a nephrologist or urologist is also advised, as some people may be helped by a course of longer-term, low-dose, rotating antibiotics.

Always check with your doctor before drinking large amounts of fluid or high potassium drinks.

In ADPKD, aspiration of single cysts is not routinely recommended unless severe pain or refractory infection is present. Kidney stones and other more complicated problems with recurrent infections need specialist advice.

By Dr Anand Saggarr, St George's Hospital, University of London

## Aneurysms - a PKD complication made simple

ADPKD is considered a multi-system disorder. Intracranial aneurysms (ICA) are one of the more common abnormalities found outside the kidney, and potentially one of the most hazardous.

**What is an ICA?** An aneurysm is a ballooning out of a blood vessel due to weakness in its wall. An ICA occurs on the blood vessels within the head. Multiple ICA can occur in some people. Though uncommon, ICA can rupture, particularly if they enlarge, leading to a type of stroke called a sub-arachnoid haemorrhage. Many aneurysms do not rupture and the size is not necessarily related to the risk of rupture.

**How common are they?** In the general population, about 2% of people have ICA. In ADPKD, the chance of having an aneurysm depends on family history. If there is no family history of ICA, the risk is about 6%. If there is, the risk is 16-20%.

### What are the symptoms?

Symptoms are present in less than

half of people with unruptured ICA. When symptoms do occur these can be headaches, loss of vision, weakness and facial pain. A sub-arachnoid haemorrhage is a very serious condition and intervention is mandatory. Symptoms include severe sudden headache, paralysis, loss of consciousness and dislike of bright lights.

### Is screening available?

Screening is available for those individuals with a family history or symptoms suggestive of an ICA or its rupture. Some individuals with PKD who are at increased risk will be eligible for screening. The decision to recommend screening depends on the family history and the patient's own medical history and occupation.

Magnetic resonance angiography (MRA) is the preferred method of screening for ICA.

**What is an MRA?** An MRA is a form of magnetic resonance image (MRI) scan which looks at only the blood vessels. Unfortunately, some individuals may not be able to have

MRI scans due to claustrophobia, having a pacemaker or other metal object in their body, such as some of the early aneurysm clips.

**How are they treated?** The best treatment method for you will depend on your individual case details. There are three main treatments:

1. Watchful waiting – this involves monitoring the situation with regular scans for signs of increases in size of the aneurysms. The frequency of scans will depend on the number and size of aneurysms and the rate of enlargement.

2. Clipping – this method requires brain surgery and uses a titanium clip placed across the neck of the aneurysm.

3. Coiling (filling the ICA with wire coils) – this is known as endovascular embolisation. Brain surgery is not required. A small tube is passed up through an artery in the leg to gain access to the aneurysm.

By Dr Glen Brice, St George's Hospital, University of London. A longer version can be downloaded from our website.

# Tolvaptan trial - are you eligible to take part?

The launch of a worldwide trial of the new drug Tolvaptan has raised hope for people with ADPKD. The hunt is now on for eligible people to take part in the UK.

Tolvaptan is the first drug ever to be tested at a large clinical trial and is of great interest to the PKD Charity. Chairman Tess Harris said, 'We're encouraging people to come forward to take part in this trial, which is the most promising yet for people with ADPKD. Of course, it is very common for new treatments to fail at this stage of the trial process but we're cautiously optimistic.'

The hospitals involved have begun their search for eligible people to take part in the trial. This is a difficult process as the criteria for participants are very tight. If you have ADPKD, live in the UK and are between 18 and 50-years-old, you may be able to take part. Tell your consultant or GP that you want to get involved – you may like to take this article along with you to your appointment.

Research using mice with PKD initially gave scientists reason to think Tolvaptan could help with the effects of ADPKD. These tests showed the drug to be effective in halting or reversing the progression

of cyst growth. Tolvaptan has also successfully passed phase two trials with 48 people, which established the maximum safe dosage.

Tolvaptan is the first drug to show any real promise of treating ADPKD and if it does progress beyond the third and fourth trials, it will be available to benefit the next generation of people, and may possibly even benefit those living with the condition now.

Dr Albert Ong, a senior researcher at the University of Sheffield specialising in PKD, shared his perspective on the study: 'Tolvaptan is a promising compound, going by pre-clinical studies, and it has a good safety profile in non-PKD patients. It has a real chance of working but I don't want to raise hopes prematurely – it still needs to be tested through a clinical trial. Even if successful, we may find that a combination of drugs are needed to effectively treat PKD or that it works better for some people than others. For instance it may be more effective for people with PKD2 rather than PKD1, or in younger people rather than older ones.'

'This trial isn't an opportunity to get a new drug quickly. One third of those who sign up will be given an inactive compound or placebo.'

We know from past experience that the 'placebo effect' is real and so a minority of those taking it may find that their symptoms still improve. I hope many patients will volunteer to take part as that is the only way to get a clear answer as to whether the drug will work more effectively than a placebo.'

## Five facts for volunteers

- 1 The trial is called the TEMPO Study (Tolvaptan Efficacy and Safety in Management of Polycystic Kidney Disease and Its Outcomes).
- 2 The hospitals involved are listed here:  
[www.pkdcharity.org.uk/tolvaptan.html](http://www.pkdcharity.org.uk/tolvaptan.html)
- 3 If you meet the eligibility criteria but your local hospital is not taking part in the trial, your doctor or consultant can refer you to one that is, so don't take no for an answer.
- 4 The eligibility criteria are given here:  
[www.clinicaltrials.gov/ct/show/NCT00428948](http://www.clinicaltrials.gov/ct/show/NCT00428948)
- 5 See our Spring 2007 newsletter for 16 questions to ask before joining a trial. Download it here:  
[www.pkdcharity.org.uk/pkdnews.html](http://www.pkdcharity.org.uk/pkdnews.html)

## 'Of all kidney diseases, PKD is the most likely to yield a treatment in the foreseeable future,' says senior researcher

When PKD specialist and senior researcher Dr Albert Ong spoke to us in September, he shared his thoughts on the Tolvaptan trial (see above) and other promising drugs currently in smaller trials. Dr Ong is presently embarking on a piece of research himself into another potential treatment for PKD, a project that is being co-funded by the PKD Charity in memory of Peter Lockyer, a former chairman of the organisation who died in December 2006.

'I have been commissioned to research a new compound by the PKD Foundation and the PKD Charity. My personal approach has been to take a number of different scientific routes to discover new treatments for PKD. The compound we are testing works in a completely different way to Tolvaptan and the other drugs. We also hope to prove that our compound

will be effective not just for the kidney but also work on blood vessels and the liver. Tolvaptan only affects the kidneys,' Dr Ong said.

He also gave us the benefit of his optimistic if measured view of the future for PKD treatments and this makes for pleasing reading. 'Of all kidney diseases, PKD is the most likely to yield a treatment in the foreseeable future,' he said.

Dr Ong has hope for two more drugs that are currently being used in smaller clinical trials. 'Rapamycin, which is being trialled in Germany, has been proven to work in some strains of PKD in mice and it was discovered by chance that Octreotide, which is being trialled in Italy, reduced kidney size when it was being used for a different medical condition. There is reasonable optimism that both drugs could work and these studies will

be reporting in the next three to four years. If so, the next stage for both compounds would be to proceed to an international study, like the TEMPO study for Tolvaptan.'

The recent discovery that cyst growth can be plotted and predicted using periodic MRI scans is also an important development for people with PKD and could help ensure that those who are in most need can be prioritised for treatment. MRI kidney scans will be used as the main measure of the effectiveness of Tolvaptan in the TEMPO study. 'MRI scans are clearly expensive, and the procedure has not yet been incorporated as part of routine management for PKD patients. However, my colleagues and I will be pressing for this kind of assessment in the future for all PKD patients', Dr Ong said.

## Running in her father's footsteps



Left to right: Jemma, Ellen and Dilys

Ellen Griffiths ran the British Ten Kilometre Run as a personal memorial to her late father, who passed away in 2005. She completed the run in only 62 minutes, beating her personal best and raising £1,000 for the PKD Charity. 'It was a very emotional day, and exhausting! But my dad would have been proud of me,' Ellen said.

The 28-year-old HR Consultant was diagnosed with PKD three years ago; her sister Leanne was diagnosed soon after. This came as no surprise. PKD has been in Ellen's family for generations. Her father had it, his cousin had it, and it is possible Ellen's grandmother was undiagnosed with the condition.

Dealing with bereavement and accepting PKD has been hard but Ellen finds that running is the key. 'I only have to run for 15 or 20 minutes

a day and I feel so much better. Running is a great social activity, too. My friend Jemma, who's been through everything with me over the last few years, took up running to support me, and we ran the ten kilometre run together.'

Dilys Millard, Ellen's boyfriend's mother, suggested the Ten Kilometre Run and she also took part, completing it in 77 minutes.

**'It was a very emotional day, and exhausting! But my dad would have been proud of me'**

Ellen had an impressive fundraising role model in her father. John Griffiths raised thousands of pounds for Kidney Research UK, braving both the formidable London Marathon and the staggering 1,000 mile cycle ride from John O'Groats to Lands End.

'Dad got involved with one fundraising event after another,' Ellen recalled. 'Once, he roped the whole family into chaining together hundreds of ring pulls – the kind you used to get on drinks cans. The chain was 20 miles long and we got into the Guinness Book of Records!'

## 'I gave a loved one a kidney'

Three people with PKD made the British papers this summer, after receiving a kidney from a loved one.

The South Wales Echo covered the story of Bruno Bacigalupo who travelled 22,000 miles to Australia to donate a kidney to his brother-in-law Paolo Cardelli – despite his fear of needles.

Bruno said, 'Paolo has two daughters, like me. Now he can do the things I like to do, like roll around on the floor and play with them.' He added, 'If one person reads this and decides they want to donate then it has been worth it.'

The Cambridge Evening News told the story of Richard Jarvis, whose wife Lorna gave him a kidney in 2005. 'It's difficult to describe what an incredible gift it is,' he told the paper, 'Really, the only thing I can do is look after myself, look after the transplant and be healthy. That was

all Lorna wanted when she gave me her kidney.'

Andy Mudd gave his wife Maria one of his kidneys for her 45th birthday. The operations happened in July this year, and the two spoke to the Swindon Advertiser soon after. Andy said, 'I think it's a lot better than the naff necklace I bought her last year. I just don't know what I'm going to get her for her next birthday. It's going to be hard to top that!'

### Squeeze me!

**Get a kidney-shaped rubber stress ball and support the PKD Charity** £4.50 plus postage and packaging. Order form enclosed.



### Help us put PKD on the map

PKD is a little known condition yet the dominant form – ADPKD – affects more people than Down's syndrome, cystic fibrosis, muscular dystrophy and sickle cell anaemia combined. PKD has a much lower profile than these conditions. We need your help to change this.

Do you have an interesting story to tell? Newspapers love stories about families, and for those of us with PKD, there's often a lot to say.

If you're willing to talk to the media about PKD, contact Tess Harris: [tess@pkdcharity.org.uk](mailto:tess@pkdcharity.org.uk)

### Garden party fundraiser



The family of Peter Lockyer, the former chair of the PKD Charity who sadly passed away last year, held a garden party in the summer to raise funds for the charity.

Kathy Lockyer said, 'We had a very successful garden party this summer. The weather was perfect and we had lots of support.'

'We raised £750 and we plan to run a car boot sale soon to clear leftovers and raise more funds.'

### From slab to studio

Just three weeks after their living donor kidney transplant operation, Maff Potts, donor and pianist, and Andy Williamson, recipient and saxophonist, were in the studio recording 'Live Life then Give Life'.

Maff and Andy recorded the song to encourage people to sign up to the UK transplant register, and to consider being a living kidney donor. It will be released before Christmas by their band Big Buzzard and the Organ Grinders. You can hear the song at [www.myspace.com/organgrinders](http://www.myspace.com/organgrinders).