

Pregnancy and PKD



Rebecca and Sonny

Issues concerning PKD and pregnancy always receive a lot of interest at our Information Days and, sadly, we still hear some horror stories of people's experiences. It's heartening, therefore, to be able to share a first-hand account of when things go right from PKD supporter and trustee Rebecca Murphy.

Although some people are only diagnosed with PKD when a scan during pregnancy reveals the presence of cysts, Rebecca's mother had registered both her and her siblings with the genetic unit at St Mary's Hospital in Manchester when they were young. As adults both Rebecca her sister Melissa decided to attend the unit for counselling, "to find more out about what being diagnosed with PKD meant and the implications for pregnancy", Rebecca explains.

Some years later, after the death of her mother through PKD-related complications, Rebecca became involved with the PKD Charity as a

trustee specialising in fundraising. In 2005, the Charity held a patient awareness event at the Nowgen Centre in Manchester and Dr Diana Scotcher, the geneticist at St Mary's Hospital, attended with some of her students.

I wanted others to know that although it can be a worrying time, particularly if you have PKD, the level of service and care I received was excellent

Diana was moved by the personal accounts relating to the family impact of this genetic disease, and she asked Rebecca and a former trustee to come and talk to the genetics students to help raise awareness of PKD across the health sector. We hope this strategy is starting to pay off, at least

Continued on page 2

In this issue



Tess Harris, PKD
Charity Chairman

A very warm welcome to our Spring 2010 newsletter. We hope you enjoy the mix of information and support together with the latest research

and heart-warming and inspiring stories. However, if there's something you'd like to see included then please do get in touch – we'd love to hear from you.

I'm sure you will have seen the recent 'Prove It' advertisements, part of the organ donation campaign which aims to promote awareness and convert people's good intentions into action by encouraging them to sign up to the donor register. The encouraging response to the campaign adds to the good news we reported last issue of the increase in 'living kidney donations'. This issue, therefore, we've decided to take a closer look at one of the remarkable individuals behind the 'living kidney' statistics. You can read about what prompts such a decision and take a glimpse at the process they undergo on page four.

There is happy news too, from PKD Charity trustee Rebecca Murphy, of how smoothly things can go during an NHS-pregnancy; plus information from the Renal Tsar, Dr Donal O'Donoghue on page three. Donal has offered to make this a regular column, so please do write in with any questions or comments that you'd like him to address.

There's news, too, about the setting up of our Friends scheme, the first local fundraising groups, the launch of overseas challenges and the usual round-up of the efforts of all our hard-working supporters. Thank you to you all!

If you have any feedback or contributions please email me at tess@pkdcharity.org.uk

Board of Trustees

Tess Harris
Chairman
tess@pkdcharity.org.uk

Rebecca Murphy
Treasurer
rebecca@pkdcharity.org.uk

Margaret Pope
Support Group Counsellor
maggie@pkdcharity.org.uk

Barry Harpham
Alison Sanderson
Christine Wallach

Scientific, Clinical and Research Advisory Board

Dr Anand Saggar MBBS FRCP
Chairman

Administration
Justina Wilkinson
justina@pkdcharity.org.uk

Fundraising

Esther Wright
esther@pkdcharity.org.uk

Pregnancy and PKD Continued from front cover

at hospital level, as Rebecca couldn't speak highly enough of the care she received during her recent pregnancy. "I wanted others to know that although it can be a worrying time, particularly if you have PKD, the level of service and care I received was excellent. Basically, I want to give a huge thank you to all the team and especially to the midwives at St Mary's Hospital."

As Rebecca's renal consultant is based at the MRI, she was encouraged to attend St Mary's Hospital for her pregnancy care as the two hospitals have close links. "Although I had every confidence in my local hospital, had there been any pregnancy-related problems, St Mary's had a higher level of dependency care. It also made it easier to share medical information from the genetic unit and my renal consultant. I'm sure the input from different teams was key to the care I received. Basically, St Mary's gave me an extra level of confidence."

Although I was made aware of the worst-case scenario the stress was very much focusing on a normal delivery

Her gynaecologist, Dr J Gillham of the fetal management unit, ran a pregnancy clinic for people with a wide variety of complications. "She was lovely – really personable. She explained the potential problems and how these could be monitored and dealt with. Although I was made aware of the worst-case scenario the stress was very much focusing on a normal delivery."

One warning Rebecca found particularly useful was her partner,

Andy, being told to look out for symptoms of aneurysms softening or a bleed occurring as both can be caused by the hormonal changes common to pregnancy. "Things such as not paying attention, excessive sleeping, blurred vision, loss of balance or dropping things. Although," Rebecca laughed, "many of the symptoms – being exhausted and vague - were those of a normal pregnancy so he did worry whether he'd notice!"

Rebecca also had a scan every three to four weeks with regular tests to check for raised blood pressure and signs of pre-eclampsia. "Although it was a pain to have to go into Manchester so often it was definitely worth it. Hypertension can affect the baby's growth so they checked the foetus was following the correct growth-acceleration pattern – I'd have been extremely perturbed if I'd had to wait till week 40. They also put the onus on me to keep an eye on things, and gave me information on who to call if I noticed anything abnormal."

At week 33, Rebecca had to put this into practice when she noticed her blood pressure (BP) was high. She rang the number she'd been given and was told to come straight in. "I was obviously worried but everyone was fantastic. They were so calm and thorough it really set my mind at rest. They checked the baby wasn't distressed and put me on Labetalol to lower my BP*. I had to go in every other day until they were happy with the dose, then weekly until the birth. Their thoroughness was really reassuring."

During the last three to four weeks the pros and cons of opting for an induced or natural birth were fully explained. "Some of the most useful

advice the team gave me was to have an open mind. Ante-natal classes can tend to emphasise patient choice, but it's not always realistic for those at increased risk of complications. Having an open mind meant I didn't have unrealistic expectations, so wasn't disappointed when they didn't work out." After weighing up her options, Rebecca finally opted to be induced a week early. "I was pleased to have got as far as I had with no complications and didn't want to push my luck. It also meant I could choose a time when Dr Gillham would be around in case she was needed."

"The birth itself was a bit traumatic as the ward was at full capacity. Twice I got as far as the second (of three) applications of induction gel before they had to stop as there was no dedicated midwife available. Luckily there were four of us in the same boat and the camaraderie helped!" Finally, in a definite case of third time lucky, Rebecca gave birth to Sonny, a beautiful 7lb baby boy.

The level of aftercare she describes was also impressive. "Before discharge the paediatrician saw me to discuss the implications for Sonny and to check I was happy for the information to be passed to the genetic team so they can keep an eye on him, and an appointment was made for me with my renal consultant. My health visitor was also fully briefed to check my levels – there's been some fluctuation but essentially they're normal. My BP was back to normal ten minutes after birth and I'm off the medication. I'm just very relieved that there's been no deterioration in function and I had such a fantastic level of care."

* NB Certain BP medications can cause foetal abnormalities so if you are on medication and find you are pregnant, or are trying for a baby, contact your GP immediately.



PKD Charity is using Facebook & Twitter!

Do you Tweet? Or use Facebook? If so, please follow us on Twitter and our Facebook fan page. You can follow the links on our website to get you started.

Twitter is a free service that lets you keep in touch with people through the exchange of quick, frequent answers to one simple question: What's happening? Join today to start receiving PKD Charity's tweets!

Join up now and follow 'PKDCharity'!

Your questions answered by the Renal Tsar, Dr Donal O'Donoghue

This issue: paid sick leave for live donors

Below is the first in what Donal has very kindly offered to make a regular column, so please do write in with any questions or comments that you'd like him to address.

NHS statistics reveal living donor kidney transplants now represent more than one in three of all kidney transplants, increasing from 589 in 2005-2006 to 927 in 2008-2009. Although fabulous news, this also raises some interesting questions, such as the question of paid sick leave for live donors.

In response to this Dr Donal O'Donoghue, the Government-appointed Renal Tsar for England, has kindly allowed us to use the following Q&A from his blog, which you can find at: <http://renaltsar.blogspot.com>.

Q: Dear Dr O'Donoghue, I have a kidney policy type question/thought that might help a little with the situation with donors.

As some background, my sister has PKD and I am a prospective donor for her. We're at the stage where we're waiting for her to be sick enough for the transplant to take place and I'm cleared for surgery. However, my questions/thoughts are not concerned with the medical side, which is mostly logical.

I work for a large multinational company and approached the HR team to explain I was donating my kidney and needed clarification of cover for a) testing days as normal treatment-type leave and b) post-operation as normal sick leave. Their response was "no" until after further discussion - where I pointed out cover is allowed for blood donors, normal accidents, pregnancies etc - when they finally agreed that absences related to the kidney donation would be covered as normal sick leave.

It would help donors if it was made law for firms to effectively treat the above as a normal condition - much as normal sick leave. As Renal Tsar, would you be in a position to carry this thought forward at a national level?

My sister and I are currently chasing around our various health insurers to see how we're covered. I suspect that the answer initially will

be no - since I'm not technically sick (in fact the opposite) but hope to point out the error of their policies and get it changed, otherwise she could be in one hospital, whilst I am operated on in another and the kidney transported between them.

Any thoughts on the above would be great. Thanks in advance.

A: Thank you for your email about your discussions with your company to support your living donation of a kidney to your sister. I'm delighted that they have agreed to continue to pay your salary.

From your description, it appears you are employed by a large company that runs a "contractual" sick leave scheme (i.e. you receive so many days, weeks or months at full pay, half pay etc as long as medical certificates are provided).

I understand that under employment law, there is no obligation for firms to pay contractual sick pay (probably many very small firms cannot afford to do so). However, employers do have a duty to pay statutory sick pay (SSP) for the first 28 weeks if an employee is absent due to sickness in any period of three years.

Therefore, I suspect that it would be difficult to make legislation forcing employers to pay employees for the period of absence due to live organ donation as they are not obliged to pay anything other than SSP for any type of sickness absence. One avenue to explore might be with the Department of Work and Pensions (DWP) on the criteria for SSP, to clarify that someone in your circumstances (who would presumably get medical certificates) would qualify for it and to ensure that this is communicated to employers. A change in legislation might not therefore be necessary.

We are also discussing with trade unions how they could work with us to raise the profile of organ donation with their members. This seems an issue that they could raise to encourage organisations to agree to meet salary costs when absent from work as a live donor.

My best wishes to you and your sister for a successful transplant.

Now booking ADPKD Patients' Information Days

- Put your questions to our medical experts
- Learn about the latest research
- Share your experiences with others

Saturday 17 April, 2010
9:30am - 4:30pm

Freeman Hospital
High Heaton
Newcastle upon Tyne
NE7 7DN

And save this date if you live in or around London
Saturday 25 September 2010

See our website
www.pkdcharity.org.uk for more details

A reader's letter

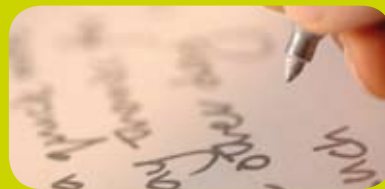
Dear Friends,

We have PKD in our family and in February this year I gave my eldest son one of my kidneys. The hospital concerned has just sent me a cheque for my expenses and so, making the sum up to a nice round number, I am delighted to be able to send you the enclosed cheque, together with your completed Gift Aid form.

I picked up one of your newsletters on a recent visit to the Churchill Hospital in Oxford with my wife and was pleased to learn of the TEMPO trials. Also with Vince Cable MP as your new patron, you must be an alright organisation!

Seriously, I hope that the enclosed helps you with your work and that ultimately my children and grandchildren will not have to worry about their PKD.

R W Heath-Whyte



A look behind the scenes of altruistic kidney donation

Last issue we reported heartening news of a rise in the number of 'altruistic non-directed' (where donor and recipient are unrelated, either genetically or by marriage) living kidney donations. 22 people in the UK, with three more awaiting surgery, have donated a kidney to a stranger since it first became possible in late 2006.

This issue we're focusing on one of these remarkable individuals - although I know they would be uncomfortable with such a description. In their words "I feel I am doing very little and I almost feel uncomfortable when people say how great I am. I have total faith in the medical profession and the fact that I can live happily with one kidney, so to offer one takes little effort... The heroes are the surgeons and medical teams and the recipient - that takes far more courage."

Below, we've generously been allowed to use edited excerpts from their blog, giving a snapshot of what prompted their decision and the process - both physical and emotional, from initial consultation and tests through to final acceptance - they undergo. We hope you find it as moving and inspiring as we have.

February [first visit]: "I was struck by the assortment of people that had kidney problems ... young, old, mothers, fathers, youngsters. It was a reminder that anyone, any age, can be seriously ill and need help. I had time sitting there to think about the struggles some people have to try and lead a normal life. It made me realise I have been very lucky as regards my health... I am so glad I made this decision to donate."

I almost feel uncomfortable when people say how great I am... The heroes are the surgeons and medical teams and the recipient - that takes far more courage

"The surgeon made sure I knew exactly what it was I was offering to do. I would go through a very thorough medical assessment, including a psychologist and a psychiatrist. If I pass, the details are sent for approval to an independent assessor, who I also meet and who presents a report to the Human Tissue Board, seeking their permission for the donation to go ahead. Once this is given, I'm put on the database and when a suitable recipient is found, arrangements will be made for the transplant. The evaluation process can be between three and six months, but they anticipate that once accepted it will be a very short time before they locate a suitable match."

It made me realise I have been very lucky as regards my health... I am so glad I made this decision to donate

April: "Had several more blood tests including a fasting one [and] a renal ultrasound. I saw the consultant nephrologist who checked blood pressure, weight, height and general fitness."

June: "Met with the psychologist today, a very nice lady, felt immediately comfortable. She needed to know I fully understood the risks involved and that I was not under any pressure to go through with this. She asked why I wanted to donate to a stranger [and it] was explained to me that after the operation some people can feel a bit down and "neglected" - suddenly after the months of evaluations and attention, it is all over."

"Still to come are the DMSA, where they check the anatomy of each kidney to help decide which to remove and the GFR (Isotope Glomerular Filtration Rate) test which assesses the capability of the kidney to 'clear' the blood. A small amount of dye is injected into a vein and blood samples are taken at hourly intervals for three/four hours, to measure renal clearance of the dye."

It can only help people to give the full picture and to have someone to contact who will give "as is" information

July: "I was challenged recently to try to explain what drives me to donating to a stranger and what is in it for me. If I were paid a large sum of money, then that could be understood as the motive. But with no apparent benefit - why do it?"

"Very good question and not always easy to answer. Why do we do anything? Emotions drive us to do something or not do something... I had a desire to offer one of my kidneys to someone who desperately needed one. That desire just grew over time. I knew it was something I wanted to do."

"I have had some stress. Evaluation started in February and it's now July... the wheels turn so slowly. There's not much support as altruistic kidney donation is very much a new development so finding people to chat to about it is not easy. This was one of the reasons I started the blog. Four people have contacted me who want to donate (three to relatives and one to a stranger) but who are finding it hard to get first-hand information from the donor perspective. Reading my blog has put to bed most of their concerns. It can only help people to give the full picture and to have someone to contact who will give 'as is' information."

Read the full blog, with links to many useful sites, here: <http://livingkidneydonation.co.uk/>



Fundraising

2009 was a busy year for PKD Charity fundraising, and judging by the number of fundraisers and supporters who have already been in touch with us this year, 2010 looks set to be even busier.

PKD Fundraising Initiatives

September walk

To coincide with the tenth Anniversary of the PKD Charity, September 2010 sees a major scientific conference hosted by the charity, and the bi-annual Information Day follows this in London. To mark the end of this significant weekend in the charity's history, we are holding our first ever sponsored walk on Sunday 26th September. The route will take in some of London's most famous sites and will offer two route lengths, so there is sure to be something to appeal to everyone. Details of the event are still being finalised, so please make sure you log onto our website regularly for all the latest information. Put the date in your diary now and get ready to walk with us for PKD.

Friends Scheme

We are proud to be launching the PKD Friends Scheme in 2010. This new scheme allows you to become a Friend of the charity by donating

a regular amount. By setting up a standing order direct from your account every month, quarter or year, you can help us to raise even more to fund research, support and treatment for PKD. Regular giving is easy, simply set up a standing order direct from your bank account, and in return we will send you one of our PKD pin badges and a list of the charity's Friends will be available in each issue of this newsletter. To launch the scheme, the PKD Standing Order Form is available within this newsletter and on our website or you can request a copy by contacting our fundraising manager, Esther Wright, on 07825 882616 or email esther@pkdcharity.org.uk.

Local fundraising groups

In 2009, the PKD Charity began to set up a series of Local Fundraising Groups around the UK. The Charity receives many calls from people who feel isolated and don't know anyone in their area with PKD so we wanted to try to put people in touch with other PKD patients in their local area, to share stories and experience and to fundraise at the same time. If you are interested in creating your own local group, it couldn't be easier. Simply get in touch with us for your local group starter pack. You can set your own aims for the group, and decide how much you want to try to raise each year. The charity will then support your group with fundraising materials, ideas, telephone and email support as well as media coverage and will put you in touch with other local groups to share ideas. You can name your group whatever you like; perhaps in memory of a loved one, the family name, or even the town/village that you are based in. You can make it as personal as you like with the fundraising aims as small or as grand as you like.

Overseas challenges

Move over skydives! We now have something even more exciting which could help you to achieve a lifetime's ambition whilst raising funds for the charity at the same time. We have a series of exciting overseas challenges which really do offer the experience of a lifetime. They are available all year round and are provided by fully qualified instructors, with flights, meals, tuition and equipment being



Sarah Gurr after successfully completing the Blythe Valley Run in September 2009

provided. All you need to do is pick your challenge, pay a deposit and raise a certain level of sponsorship according to the challenge. These fabulous experiences are:

- Cycle Vietnam
- Cycle London to Paris
- Cycle Paris to Geneva
- Trek Costa Rica
- Trek Iceland
- Trek Peru
- Trek China
- Kilimanjaro Trek
- Sahara Trek

To find out more about any of these amazing experiences, contact us for an information pack or give us a call to discuss your ideal challenge. Don't forget, you can still take up the challenge closer to home by doing a skydive for the PKD Charity. These take place 365 days of the year at numerous locations around the country and include tandem, solo and static line jumps.



Grand New Year Draw – Our Patron, Vince Cable MP, pulls out the winning numbers together with Maggie Pope, Support Group Counsellor

The Great South Run

This year, we are entering our first ever team in this fabulous event on 24th October. We already have several keen runners signed up, several of whom have participated independently in this event in previous years. At the time of going to press, we do still have a couple of places available. All we ask is that you raise a minimum of £200 in sponsorship and we'll send you a fabulous fundraising pack to help you on your way.

Raffle

The start of the new year saw the draw for our first ever raffle taking place. Tickets were sold by supporters all around the UK for our Grand New Year Draw. Pulling out the winning tickets was our Patron, Vince Cable MP, and we thank him for giving up his time. The winners were:

- First prize of £500 won by Julie Lockyer
- Second prize of £250 won by David Ainscough
- Third prize of £100 won by D Williams.

Your fundraising

The last six months has seen an ever increasing number of supporters fundraising for the PKD Charity in a huge variety of ways. To mention just a few: Sarah Gurr took part in the Blythe Valley Run in September, Jennifer Byson raised an incredible £650 from a coffee morning in September, proving that there must have been some fantastic cakes, and Nahida Godchild held a 'Jamie Oliver' style event in October to raise funds for PKD.

The start of 2010 has seen a real explosion in fundraising for the charity. So many of you have been in touch to tell us about your forthcoming fundraising activity and the variety has been truly astounding. Here are the details of just some of them:

- Denise Allan – Collection at local M&S store for World Kidney Day in March.
- Karit Banks - Walking Snowdon in 2010
- Francesca Lockett – coast to coast bike ride in Spring
- Claire Bayly – Bath half-marathon in April
- Charlie Douglas – bungee jump in May
- Sam Clackson – South Downs Run
- Rob Thomas, Matthew Johnson and Dean Fitzpatrick – London Marathon April 2010
- Amanda Craven – Family Fun Day on 26th June in Stewartby
- Andrew Homes – Dingle Marathon in September

If you are thinking of holding your own fundraising event, want to get involved in another event and raise funds for the charity, or if you just want to discuss ways in which you want to help the charity, please do contact Esther, our Fundraising Manager, on 07825 882616 or email: esther@pkdcharity.org.uk

Volunteer needed

The PKD Charity is looking for a volunteer to help with organising our international scientific and medical conference in September 2010. The work will be based in London with flexible hours, and we'll be able to cover reasonable expenses.

If you're interested, please contact Tess Harris, PKD Charity chairman, for more details:

tessharris@pkdcharity.org.uk

Be our friend!

Become a friend of the PKD Charity by giving a regular donation to help fund our work.

The PKD Friends scheme allows you to become a Friend of the charity, by setting up a standing order and donating on a regular basis.

You can donate as much or as little as you like, monthly, quarterly or even annually – whatever suits you.

As a Friend of the Charity, you will receive a PKD pin badge and all new Friends will be listed in the charity's newsletter.

Becoming a Friend is easy. Simply complete the Standing Order form enclosed with this newsletter, download a form from our website, or contact our Fundraising Manager for more details.

By donating to the PKD Charity regularly, you will be helping us to provide support for people affected by PKD, conduct research into new treatments and work towards finding a cure.

Contact Esther Wright, Fundraising Manager on 07825 882616 or email esther@pkdcharity.org.uk.