

Swine Flu

With swine flu in the news, we thought a few renal-specific pointers might help you find your way through all the information. A guidance paper prepared by the Renal Association Clinical Affairs Board stated that although there is little good evidence kidney patients face an increased risk from influenza, 'patients with pre-existing chronic kidney disease (CKD) are at risk of pre-renal exacerbation through pyrexia, poor fluid intake from anorexia and sore throat, diarrhoea...and NSAIDs used by patients for treatment of myalgias and headaches.'

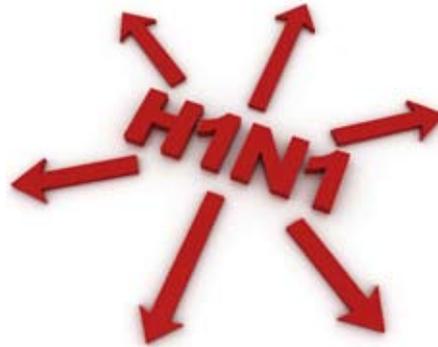
It is important, therefore, that a fever of 38C/100.4F or above and a sudden cough, or other symptoms such as headache, limb or joint pain, stomach upset, sore throat and loss of appetite, are responded to quickly.

Patients on dialysis

If you are on dialysis contact your Renal Unit who can confirm whether you should follow the procedure outlined below to receive antiviral drugs. They will also tell you if you should take these to your next session to take after dialysis and, if necessary, will make isolation arrangements.

Patients not on dialysis

In Scotland, Wales and Northern Ireland, where demand is not yet as high, kidney patients not on dialysis should call their GP from whom they will continue to receive antiviral drugs. In England, however, patients should contact the National Pandemic Flu Service (launched by the government to relieve pressure on GPs and provide fast access to antiviral drugs) via the website: www.direct.gov.uk/pandemicflu, or phone-line: 0800 1 513 100 (textphone 0800 1 513 200).



The service will check your symptoms and, if swine flu is confirmed, will give you a unique number to obtain antiviral drugs, which must be picked up at a collection point by a non-symptomatic 'flu-friend'.

Patients who call the service will be asked whether they have chronic kidney disease and whether they attend a specialist clinic for the care of renal or kidney failure. If they answer yes and are older than five they will be authorised Zanamivir (Relenza), which is inhaled. As Relenza is poorly systemically absorbed and after use is entirely excreted in the urine, it is not necessary to adjust the dose for those with renal impairment. Patients younger than five will be authorised Oseltamivir (Tamiflu) and their parents advised to give the first dose and then to contact their renal specialist for advice on the second dose.

Relenza or Tamiflu?

If patients find Relenza difficult to use, however, they should seek further advice and can be given Tamiflu tablets at a reduced dose. Whilst the antiviral actions of Relenza and Tamiflu are equivalent and any patient aged over five with CKD 1-3 can use Tamiflu at the standard dose, it was felt unlikely that everyone would reliably know their GFR. Relenza requires no dose adjustment according to GFR whereas the dose

of Tamiflu must be reduced in patients with a GFR <30ml/min/1.73m². It is this that makes Relenza the preferred choice.

Anyone (even if they are not displaying symptoms) who has been in close contact with someone diagnosed with swine flu should also contact the Flu Service to explain the situation and that they are a kidney patient. If preventive treatment is thought necessary they will be authorised antivirals.

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In this issue



Tess Harris, PKD
Charity Chairman

Welcome to the latest issue of the PKD Charity newsletter – packed with heart-warming stories to keep any autumn chills at bay! This time,

along with useful tips concerning swine flu, we've got heartening news about a rise in the number of living kidneys donated altruistically by strangers, plus information on how to get involved in an exciting new 'green' healthcare campaign directly affecting kidney patients. It's hoped the campaign will not only create more sustainable care but improve the patient experience too. There's useful advice from Martin Wilkinson on the psychological aspects of coping with PKD and an incredible range of fundraising stories. As ever, I am moved by the stories that inspired our fundraisers. On behalf of everyone at the Charity and our beneficiaries, many thanks to you for giving your time and energy to raise awareness and funds.

Get involved!

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

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esther@pkdcharity.org.uk

A great summer of fundraising for the PKD Charity

Summer 2009 has proved to be an excellent time for fundraising up and down the UK, with lots of money being raised for the Polycystic Kidney Disease Charity.

Abseiling the Abyss



April saw the first ever PKD Abseil at the Abyss in the magnificent Magna Centre in Sheffield. More than 20 abseilers took on a stomach-churning 130-foot drop into darkness inside this former steel foundry, cheered on by family and friends. The event was 'launched' by our Chair, Tess Harris, who took one of the first leaps off the purpose-built abseil platform, amid cheers of support. In fact, Tess enjoyed the event so much, that she

abseiled again later in the day. In total 25 abseilers followed in Tess's footsteps and raised an incredible £7,168. Our thanks to everyone involved - the brave abseilers, their family and friends and our army of volunteers who supported us on the day. We are planning another abseil in 2010 in a 'high' profile location, so watch this space!

Great runners

In May, the PKD Charity had its first ever team in the Great Manchester Run. Fourteen runners took on the 10k challenge to raise funds at the event on 17th May, which attracted more than 40,000 runners, making it the largest 10k run in the UK. The PKD team ranged from running novices through to those with running experience and established race runners. As well as several months of training on cold and wet nights, the PKD runners also found time to raise funds for the PKD Charity and raised a staggering £7197! This is an incredible feat and the charity would like to extend its deepest thanks to each of the runners and to everyone who sponsored them. In 2010, we are hoping to extend our participation in the Great Run series and will have places for the Great North Run, Great

South Run and Great Manchester Run. If you would like to reserve a place, please contact our Fundraising Manager at esther@pkdcharity.org.uk or 07825 882616.

Our thanks to the 2009 PKD Team:

- Phillip Lea
- Sara Meakin
- Paul Meakin
- James Irving
- Victoria Wilson
- Dawn Gabay
- Louise McGealey
- Ryan McGealey
- Jonathan Black
- Steven Thacker
- Geoff Hope
- Gemma Barlow
- Bridie Milner
- Mark Adams

Swine Flu

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Statement by DoH

In response to the National Kidney Federation's request for specific advice for renal patients, the Department of Health stated "it is essential that renal patients alert any person prescribing or providing a vaccine or other medicine in relation to swine flu to the fact that they are a renal patient". So it is vital to make this clear should the Flu Service or other prescriber fail to ask. The advice, given by Dr Colin Hardisty, Consultant Clinical Advisor in Pandemic Flu Planning, also made clear that although the preferred antiviral is Relenza "there is clear agreed guidance on the use of Oseltamavir (Tamiflu) for renal patients should the necessity arise."

Altruism on the rise...

A remarkable 22 people in the UK (with three more awaiting surgery) have donated a kidney to strangers since it first became possible two years ago. In late 2006, in response to the serious shortage of donor organs (about 7000 people in the UK are waiting for a kidney), the Human Tissue Authority (HTA) changed the rules so that people who were unrelated – either genetically or by marriage – could become living donors.

"We expected to see a small number of cases when we first started approving this type of transplant, but we did not expect to see the number rise so significantly after just one year," said Vicki Chapman, director of policy and strategy at the HTA.

Ten people came forward the first year, rising to 15 in the second. The rates of living donations among relatives also increased, with 1,008 such donations approved in

2008/2009 compared with 961 the previous year.

Peter Rowe, Consultant Nephrologist at Plymouth Hospitals NHS Trust which carried out three of the 22 altruistic transplants, commented "The donors I have come across are genuinely altruistic, they decide that, on balance, donating is unlikely to do them any harm but will transform someone else's life."

Your fundraising events

2009 has certainly been the year for crossing the country by one means or another!

In May, Victoria McCaig took part in the Glasgow Women's 10k and raised a fantastic £365 in sponsorship from her family and friends. As you can see from the picture that Victoria sent us – she was ready to cross that finishing line!



On 7th May, Mike McDonnell-Brookes took on the Three Peaks Challenge in aid of the PKD Charity and lived to tell the tale! The trip was full of unexpected changes, hazards, poor weather and smelly wet clothes, but Mike completed the event in one piece and has raised a staggering £1,300 for the charity. Mike and his team completed the event in 23 hours, 51 minutes and 40 seconds, but had to stop just short of the Ben Nevis summit (about 55 metres) as they were caught in a blizzard with gale force winds that caused a 'white out'.



Mike has kindly shared his photos and video footage with us, which really give an idea of just how hard the challenge was, and how bad the conditions were.

To see more, have a look at our website: www.pkdcharity.co.uk

Or on our new YouTube channel: www.youtube.com/user/polykids



You may recall from our Spring Newsletter that we shared the story of Jon Kennard who was planning to ride his motorbike from England's most easterly point, up to John O' Groats, down to Lands End and back to Lowestoft to raise funds for PKD – a distance of some 2300 miles! Jon and a team of friends set off on 11th July and, despite the rain, thoroughly enjoyed the whole event, completing the gruelling ride in just seven days. Jon reports that the team only experienced two mechanical problems during the trip, which makes it a great success. Jon has managed to raise around £3000 for the Polycystic Kidney Disease Charity. Our thanks go to Jon and everyone who supported him for helping to raise a magnificent sum of money for the charity.

For more details of this unusual and epic journey, have a look at: www.jonkennard.co.uk

Continuing the travelling theme, Peter Harris from Cardiff decided to cycle from North to South Wales to raise funds for the PKD Charity. The route of just over 250 miles was expected to take five days, but Peter managed to beat his own target by one day, completing the whole event in just four days and passing some stunning scenery on the way! Peter set up his own Justgiving page and managed to raise an incredible £690 whilst training for the event. Well done Peter! / Llongyfarchiadau Peter!

Your logo could be here

The PKD Charity Newsletter reaches over 2,000 people and costs £1,600 to produce and mail. We are looking for a sponsor to help us maintain this important resource.

Contact tess@pkdcharity.org.uk



Keeping her feet firmly on the ground was Jina Davis, who earlier in the year raised over £1000 for the PKD Charity by holding an all-day music event at the Hobbit pub, which included live bands and a raffle. Continuing in her mother's footsteps, Jina's six-year old daughter, Jasmine, also collected donations for lollies in a bucket. Both Jina and her mum are affected by PKD and Jina was determined to do something to help her mum, Caryl. Our thanks to Jina and Jasmine for their creative fundraising!



We were delighted to receive correspondence from Michael and Carmella Murphy telling us that they were recently married and had asked guests to donate to PKD in lieu of wedding gifts. Michael is the father of PKD Trustee Rebecca Murphy and organised a pre-wedding reception with family and friends. Guests made very generous donations to the charity which exceeded the expectations of both Michael and Carmella. Our sincere thanks go to Mr and Mrs Murphy for helping to raise funds and awareness for the charity on their very special day.

This year, the PKD Charity is participating in the Small Car Raffle for the first time. The draw is organised by the Foundation for Social Improvement and charities are encouraged to sell their own tickets with £1.96 of every £2 ticket sold going directly to the charities themselves. PKD supporters Avril Ainscough and Sandra Phillips took up the challenge, with Avril raising £60, despite dashing off on her holidays, and Sandra raising an incredible £320. First prize is a Fiat 500 and the draw takes place on 1st October. Good luck to everyone who has purchased a ticket!

Future fundraising

There are a number of exciting new fundraising plans swinging into action this autumn. So, if you've never been involved with fundraising, now is your chance!

Christmas cards

Our Christmas cards are once again on sale, with two beautiful new designs to choose from. The cards are available to view on our website and you can also download and complete an order form there. Just go to: www.pkdcharity.org.uk. Alternatively you can email Justina@pkdcharity.org.uk. The proceeds from the sale of each and every card goes to the charity to help us support people and families affected by PKD and work towards finding a cure. So stock up early and get ahead this Christmas.

Christmas raffle

This Christmas will also see the launch of our first ever Christmas raffle. With some excellent prizes and tickets priced at just £1, this is a great opportunity to raise funds for the charity. Perhaps you could help to sell just a few raffle tickets to your family and friends or perhaps you could take a couple of books of tickets into your place of work. However you feel you can help, please contact Esther Wright at esther@pkdcharity.org.uk or phone her on 07825 882616. Please help us to make our first Christmas raffle a real success.

PKD on YouTube

Calling all you 'YouTubers'. We have now established our own channel on YouTube - www.youtube.com/user/polykids. We are looking to you to help us make this channel exciting and informative for people with PKD and their families. The channel will hold videos, messages and lots of other useful information and could really help to raise awareness of the condition. If you feel strongly about how PKD is perceived, have ideas about how people with PKD can be helped, or just want to share your tips and experience, then this is the forum for you. All you need to do is record your own message or video and then send to tess@pkdcharity.org.uk for uploading. Remember it should be no longer than 10 minutes. It's also a great place to share your exploits. Have a look at the channel

to see amazing footage from Mike McDonnell-Brookes' recent Three Peaks Challenge. We need your help to make this a success and really put PKD on the map.

Skydiving success

Have your got a milestone birthday coming up? Maybe an anniversary or perhaps you've always wanted to do something to stun your family and friends? Now you can take on the challenge of a lifetime and raise funds for the charity at the same time, by taking on a Skydive! We have teamed up with professional event organisers, Skyline, and through them we are able to offer parachute jumps around the country, 365 days of the year!

There are three types of jump available:

- 'Accelerated Freefall' where you can experience the thrill of skydiving solo from up to 12,000 feet
- 'Tandem Skydive' from 10,000 feet attached to a professional instructor
- 'Static Line' jump which is performed solo from up to 3,000 feet.

You can choose to jump from any one of over 20 British Parachute Association approved airfields across the UK. No experience is necessary as all training is given and if you raise £365 (depending on the type of jump you choose) you will receive your jump for free. So if you would like to make a thrilling skydive from 10,000 feet or an exhilarating solo jump from up to 3,000 feet contact our Fundraising Manager, Esther Wright on 07825 882616 or email esther@pkdcharity.org.uk and we will send you a full information pack and everything you need to take part in the experience of a lifetime.

World Kidney Day 11th March 2010

Preparations are starting early for a series of collections to mark World Kidney Day 2010. The event takes place on 11th March and will see the kidney community uniting to raise awareness and funds for kidney diseases. The PKD Charity will be holding a series of collections that week at various sporting venues around the UK. If you think that you can spare a couple of hours to join our friendly team and help collect at a sports venue close to you, then please

do get in touch, we would love to hear from you.

If you are planning to do your own fundraising in the next few months, then please don't go it alone. We are here to help you and can provide you with help, advice, leaflets, stickers, badges, t-shirts and anything else you may need to help your fundraising go with a bang. For help and advice, or an informal chat about your fundraising idea, please do get in touch.

Local fundraising groups

Would you like to meet people in your local area who are affected by PKD and raise funds for the charity at the same time? This autumn, the charity is launching its local fundraising group scheme, to give you the chance to fundraise in the way you want, with who you want, and when you want. It's a very simple system that allows you to set up a fundraising group in your home town, village or city and then fundraise as often as you like in whatever way you like. You could choose to hold a collection in your local High Street once a year, or to hold a summer fête, or sponsored walk. You could even decide to hold regular coffee mornings for supporters of PKD, contact your local mayor to become Charity of the Year or ask your local Rotary or Lions Club to support you. However you choose to fundraise, you determine the amount you want to raise, and we will support you with everything from leaflets, badges and t-shirts through to media support, fundraising advice and prizes.

Each group will be listed on our website, and you could even set up your own Facebook page to encourage more members to get involved. In each newsletter, we will be focusing on one group, and how they've been fundraising throughout the year. This is a great way to make new friends, get in touch with local people who have PKD and raise funds at the same time. To find out more, go to our website, or contact our Fundraising Manager on 07825 882616. We will then send you your own starter pack and everything you need to get your group started.

Coping with PKD

A fascinating new article by Martin Wilkinson on the psychological aspects of managing a long-term illness is available on the PKD website. As the partner of someone with PKD and a background in Human Relations, Martin is particularly well placed to provide insights into the difficulties that a long-term illness can cause.

PKD affects people in different ways and the article emphasises how each individual can develop as an 'expert patient' i.e. someone who chooses to become well informed about managing their illness. Such patients are empowered to work with doctors as partners rather than as passive recipients - the article warns against succumbing to the belief that

only doctors can control your life or, in the case of chronic long-term illness, that no one can. As Martin points out, research reveals those who cope best with long-term illness are those who focus upon what they can still control and/or do and avoid grieving too much over what they can't.

The factors that shape illness are biological (the disease itself), psychological (thoughts/moods) and social and interpersonal (support/attitudes). This leaves many areas those diagnosed with PKD can control and develop to make them feel better without changing the disease itself. Martin's inspirational article examines some of the challenges and suggests practical strategies for meeting them.

Read the full article at:
www.pkdcharity.org.uk/copingwithpkd.html



Financial support for carers

Following last issue's focus on financial issues, this time we're looking at what's available for carers. You can find further information on the government website at: bit.ly/1138vd

Carer's Allowance (CA)

This is a taxable benefit to help people aged 16 or over who spend at least 35 hours a week looking after someone who is disabled. You do not have to be related to or live with the person you care for, but they must receive either attendance allowance (AA) or disability living allowance (DLA) at the middle or highest rate for personal care.

As the 'caring week' runs from Sunday to Saturday, if you provide care only over weekends you could still be eligible. And, for carers of kidney patients, the hours include not only helping with dialysis but all other times when the carer has to be available – for example to help with getting in and out of bed or when the patient is not well enough to be left alone.

CA is not means tested and does not depend on national insurance contributions (NICs) so you may qualify even if you've never worked, or if you also get AA or DLA. However, you are not eligible if you are in full-time education (21 hours or more a week of supervised study) or earn more than £95 a week after certain

deductions (such as income tax) have been made.

The standard rate received is £53.10 per week, although the final amount is affected by individual circumstances. For example, if you receive certain other benefits such as state pension, incapacity benefit or contribution-based jobseeker's allowance, the 'overlapping benefits rule' will subtract the value of these from your rate of CA. However, even if you won't be better off financially it may still be worth applying as you might then qualify for a carer premium (included in your overlapping benefit); NIC credits (which help satisfy the conditions for incapacity benefit and jobseeker's allowance); or a £10 Christmas bonus. The free Benefits Enquiry line (details below) will be able to advise you on this.

Carer premium

Carers who receive CA or who, although they qualify, do not receive it due to the overlapping benefits rule, may be eligible for the carer premium. This is an extra sum of money (currently £27.15 a week) paid to a carer getting income support, jobseeker's allowance, housing benefit and/or council tax benefit. The premium is also used in calculating housing benefit or council tax benefit and in many cases will increase their value.

Please note, however, that if you do qualify for CA the person you care for may lose money if they live alone, or if they live only with other people who get AA or DLA, and if they get income support, housing benefit or council tax benefit. If this is the case they could lose the severe disability premium part of these benefits. Again, contact the Benefits Enquiry line if you need specialist advice.

How to claim

You must claim on form DS700 which you can get from a Jobcentre Plus office or Pension Centre, or from the Benefits Enquiry line (0800 882200; 0800 220674 in Northern Ireland) who can also give you advice on how to fill it in.

Alternatively claim online at:
<http://bit.ly/assIR>

Further information and support

- Carers UK
www.carersuk.org
- Carers Direct (NHS)
Tel: 0808 802 0202
www.nhs.uk/carersdirect
- The Princess Royal Trust for Carers
www.carers.org

Green Nephrology programme

Dr Frances Mortimer, Medical Director of the Campaign for Greener Healthcare (CGH), has called on patients to champion sustainability in their local units in response to news that the NHS is responsible for around 3% of UK emissions.

The contribution by kidney care is likely to be disproportionately large given that most kidney disease is life-long and care is concentrated in regional hubs (there are fewer renal centres per head in the UK than most other developed countries) resulting in considerable patient travel. Haemodialysis and peritoneal dialysis also have a high use of disposable equipment and packaging.

In May 2008 talks on improving sustainability began when the Renal Association responded positively to CGH's approach and Baxter Healthcare, a major supplier of dialysis equipment, agreed to support the work. A number of projects such as dialysis water recycling, heat exchangers, reduction of packaging and virtual nephrology clinics were identified for the Green Nephrology programme to build on.

Benefits

Sustainability not only benefits society, but patients and clinicians too. Getting involved empowers patients and will lead to more patient-centred care – a major priority for increase of sustainability in kidney care is to minimize travel to hospitals. Solutions include virtual clinics, tele-

consultations, blood testing in local rather than regional laboratories, and home-based therapies. An improved focus on prevention, and better integration of related specialist clinics and primary care, will also improve the quality of care and reduce waste.

The programme will benefit clinicians too. As the first specialty to address its environmental impact, nephrology is creating a model of best-practice. A reduction in travel and consumption of material resources also reduces the vulnerability of kidney care to rising costs and the renal community is strengthened by care providers and suppliers working together to develop and realise a common vision for care.

First steps...

The first Green Nephrology summit took place in February 2009 with another planned for 2010. Areas addressed included commissioning and payment by (sustainable!) results, tele-clinics and home or near-patient treatments. NHS Kidney Care is also funding a one-year Out of Programme Experience for a Specialist Trainee in renal medicine, Andrew Connor, who will be seconded to the Campaign for Greener Healthcare.

The SHEBA website, www.sustainabilityforhealth.org, was launched in June 2009 to provide a central resource for sustainability in the health sector. The first specialty to have its own clinical area, the renal pages display resources to support local units in taking action and enable

online networking and discussion – you can help by visiting and posting comments.

Get involved!

Local kidney units are encouraged to undertake a sustainability audit and develop a green action plan. However, patients are often best placed to notice potential improvements: where care by different teams could be combined, transport routes streamlined, and waste or packaging reduced. Your ideas are needed so take a look at the CGH website (bit.ly/zfPHc) and talk to staff at your hospital and to other patients – ask if they know about the campaign and make suggestions.

Actions such as encouraging patients to bring their own blankets to dialysis to cut down on laundry, reducing food waste, and using email to save unnecessary visits do make a difference. As Andy Williamson, Chair of Guys & St Thomas' Kidney Patients' Association comments "As a kidney patient, I'm acutely aware of my own vulnerability to climate events, and my dependence on drugs and dialysis equipment which rely on cheap oil for their availability. We need to lead the way now in reducing emissions drastically, or my soon-to-arrive baby isn't going to stand a chance. I want to be able to look him/her in the eye and say I tried."

Hospital champions

The PKD Charity is looking to build on the success of its local support groups by establishing 'hospital champions' – people to create a three-way relationship between the charity, their local hospital and patients. To do this we need to find people who, in liaison with their local Renal Unit and Renal Social Worker, can set up and run a hospital-based volunteer support group that meets several times a year, offering informal advice and support to PKD patients and their families in a relaxed, friendly environment.

Hours are entirely flexible and, although the position is voluntary, expenses will be paid and advice and training can be provided. If you think you have the necessary skills and experience - an understanding of PKD, empathy, strong listening and communication skills - and would like to find out more then please contact Maggie Pope:

Maggie@pkdcharity.org.uk
Tel: 0845 241 0964.

PKD 10th Anniversary Conference

London 23rd – 25th September 2010

The PKD Charity celebrates its 10th Anniversary next year and to celebrate we'll be holding a special Conference. Look out for more details next issue, but put the date in your diaries now!