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Registered Charity in England & Wales No 1085662 | Registered Charity in Scotland No SC038279

www.pkdcharity.org.uk

Autumn 2008

Getting the most from Patient Choice



Increasing patient choice

In the past, GPs tended to make referrals to a specialist at their local hospital and, for many people, this is still the most convenient and appropriate choice. However, since April 2008, patients have been able to choose from any hospital in the country that is funded by the NHS, and this includes some private and independent hospitals. Patients can also book the appointment themselves under the new system, which is known as 'Choose and Book'.

This means you can now choose the hospital or clinic you prefer, based on the criteria most important to you – transport links, MRSA rates, reputation, waiting times or simple convenience. People who work some distance from home may decide it is less disruptive to see a specialist near their workplace. Or others may choose to be treated closer to their family or other support network. The new system is designed to be flexible enough to take such considerations into account.

Increasing flexibility

Being able to choose the time and date of your hospital visit makes it easier to juggle work, family commitments and any other appointments you may have. You can also check the status of your referral or change or cancel an appointment by phone or online. And, as the system is computerised, it should cut down on lost referral letters.

How it works in practice

Once you and your GP have decided on referral, your GP will provide you with a shortlist of the clinics or hospitals available and discuss these with you. Surveys reveal GPs are the most popular source of information about hospitals, closely followed by personal experience or that of family and friends, so you may be happy to make a decision at this stage. If you are, you can sometimes book an appointment at the surgery.

If, however, you would like some time to consider your options or need to check commitments first, or you want to talk it over with friends or family, then you can take your appointment request letter and the list of potential sites that you discussed with your doctor away with you.

Helping you choose

If you would like more information about your options, there are many websites you may find useful. For example the NHS Choices website has an easy-to-use tool that compares hospitals on a variety of criteria, from waiting times to disabled access or canteens (see box). There is also a

NHS information

Visit www.nhs.uk and go to 'compare hospitals'

Cross reference this information using:

Dr Foster – gives information on consultants and hospitals: www.drfoster.co.uk/localservices/

The Healthcare Commission – provides information on hospitals ratings: www.healthcarecommission.org.uk

Patient Opinion – gives patient feedback: www.patientopinion.org.uk

section where you can read other patients' comments – or add your own. However, none of these are perfect, so don't forget the importance of personal recommendations – your local PKD Support Group will be able to help. Visit our website or log in to the Yahoo PKD Group (see page 4) to chat to other people with PKD.

Booking your Appointment

Once you have chosen a hospital or clinic, then you're ready to book your appointment. You'll need your appointment reference number (or UBRN – Unique Booking Reference Number) which is on the referral letter from your GP, together with the password that your surgery gave you before you left.

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Family raise £5K in memory of loved one



Many of you will remember Peter Lockyer, our former Chairman, who sadly passed away in 2006. His family followed the success of their first two garden parties with another in July this year, raising an incredible £1,188.

Kathy Lockyer, Peter's mother, described the day, 'It was great fun and loads of people came. We had various games, a cake stall, a bring and buy stall, plant and book stalls, a huge raffle and tombola, plus refreshments. We don't have a particularly large garden but somehow we manage!'

All the family helped out as the games were run by Julie, Peter's wife, with the help of two of their children, Martha & Molly, and her mother

Sheila; while Julie's eldest daugher, Phoebe, ran the 'Name the Bear' and 'Guess the Number of Sweets in a Jar'.

A small entrance fee included coffee and biscuits, and Peter's godmother Teresa and her husband Andrew did sterling work in the kitchen preparing the refreshments. John, Peter's father, sportingly bore being pelted with wet sponges (which the children particularly enjoyed!) and Peter's sister, Karen, and his aunts, Velma and Ann, helped out on the stalls.

As Kathy said, 'Peter's wishes were that we carried on supporting the charity, but we wouldn't have been able to achieve this figure without the wonderful help and support of our friends and family'.

Their fundraising is fast becoming a family tradition as last year Peter's father-in-law, Peter Moody, ran a golf tournament raising about £3000, while his brother-in-law Daniel raised a further £1000 with a music festival.

All the amounts raised go to Peter's Memorial Research Grant, which last year funded its first UK research project.

Welcome to new fundraisers

The PKD Charity is delighted to announce the appointment of two part-time fundraising managers, Andrew Coutts and Esther Wright, who will work with the trustees on identifying new sources of finance to develop and expand the charity's activities.

Andrew will focus on fundraising from charitable trusts and foundations, major donors, and especially from the Big Lottery Research Fund (see page 5). He has recently been helping other medical charities, such as the Dyspraxia Foundation and ME, to raise significant sums to further their missions

Esther joins from the Stroke Association where she was Deputy Head of Regional Fundraising, responsible for over 15 major fundraising events a year. She will focus on corporate sponsorship and working with our growing supporter and volunteer base to put on a lively range of events throughout the UK.

Chairman Tess Harris said: 'We are excited by the appointment of these two talented people who will, we are confident, move us into a new growth phase and bring a professional approach to our fundraising, in addition to helping us raise much needed funds'.

Thank you for your tireless support

We'd like to extend a huge thank you to everyone who gets involved in fundraising for the PKD Charity, plus their many sponsors and those who make donations, for their time, effort and generosity. Such dedicated (and seemingly tireless!) support, really does make a massive difference. Below are just some of the people we'd like to thank – if you'd like someone to be included in future issues, please do let us know.

Last year we reported on Ellen Griffiths, who took part in the British 10K London Run as a personal testament to her father, John, who Ellen lost to PKD and who himself ran many times for kidney research raising thousands. Ellen and her sister have both been diagnosed with PKD too and, in July this year, Ellen and her friend Jemma Richardson took part in the 10k Run again, raising around £500 for the PKD Charity.

Beverley Coverdale from Bridlington, whose husband David had a kidney transplant in 2006, took part in the Leeds 10K 'Run for all' for the second time this June, adding £140 to the £300 she raised last year.

Beverley's family and friends are dedicated fundraisers – last year her parents, Mr and Mrs Hall, raised over £400 by doing the Rob Roy Way, her daughter's teacher ran the London Marathon last year, raising £200 and the Health Centre where Beverley works raised about £100 with a collection on World Kidney Day. Beverley commented, 'I would like to thank all my family, friends and colleagues for their support and generous donations. The money raised is greatly appreciated and is going to a great cause.'

Thanks to Margaret Pope (PKD Support Group Counsellor and convener of the Twickenham PKD Support Group), who held a fundraising and awareness stall at the Charity Fair on Twickenham Green in May. In torrential rain and howling gales, Margaret and her husband

Geoff not only sold over £100 of goods, but also gave out more than 50 organ donation cards and won first prize for 'Information, Colour and Presentation', with their stall, gaining a further £20 for the PKD Charity.

Also, grateful thanks for donations to: Mrs N J Lea, G E Price, Mrs C Quince, Burlington Infants School, S C Seviour, S N Longden, C M Bonney, A E Smith, A W Yates, S W O'Brien, Content online Ltd, S Smith, A Humphries, A Ballington, L V Malcolm, LAArnott, VAppleby, Mrs SM Tong, W Burgess, W D Goby, S J Marshall, M Hornsby, L Briggs, J & J Braund, S A Bewley, R F Bewley, N Thomas, J E Forrester, M A Winters, L G Tibbetts, P L Wittaker, V Wittaker, Fords (Oakham), R C & P Gall, Mrs J Holley, D Turner, Corporate Accountancy Solutions Ltd, Llandarcy Tuck Shop, Dr C Mackenzie, The Environment Agency Wales office staff, Mark & Elaine Winters.

Apologies to anyone we've missed from the above.

Information and Support

Information: just what the doctor ordered?

Information Prescriptions aim to give patients the right information at the right time

An NHS survey revealing that 88% of patients felt they needed more information to be able to make decisions and choices about their treatment and care led, in 2007, to the Department of Health funding the piloting of Information Prescriptions at 20 sites across England.

Most of our readers know from personal experience how crucial access to reliable information is in supporting those with long-term conditions - both to manage those conditions and to improve the quality of life of those affected by them. However, up to now there has been no way to ensure access to such information is systematically provided by GPs and other health professionals. It is to combat this that Information Prescriptions (IPs) have been created.

What sort of information will they provide?

IPs will be tailored to each condition to help people receive the information they need. In general they will signpost where to get advice and support, how to make contact with others with a similar condition and other vital national and local information. Information on managing conditions; treatment and medication options; care services; benefits advice and support groups will all fall into this last category. IPs will also include addresses, telephone numbers and website addresses of where to find out more.

'Information plays
a crucial role in
supporting people
with long-term
conditions to take care
of themselves and
improve their quality
of life'

Informing and empowering

IPs aim to guide those with a longterm condition or social-care need to reliable information about relevant services and treatments, which in turn will allow them to feel more in control, better able to manage their condition and retain their independence. In the words of the NHS, 'Information plays a crucial role in supporting people with long-term conditions to take care of themselves and improve their quality of life... Information prescriptions will give everyone access to the information they need, at the right time.'

Encouragingly, 76% of patients who took part in the pilots agreed that they were more confident in managing their condition and 89% agreed that the information was useful, while two thirds of professionals also said that IPs could help provide better care and gave them better opportunities to explain how to use information.

IPs are now being rolled out nationally and the PKD Charity is hoping to contribute to the development of a PKD Information Prescription in the near future.

Dialysis blogger latest

Last issue we looked at 'Life on Dialysis' in an article that focused on dialysis blogger Jeff Sheridan. Just before going to press, we were extremely happy to hear that Jeff had been lucky enough to receive a transplant, and was recovering well.

Since then, he is continuing to do well and has now returned to work. Jeff, whose philosophy is, 'Chronic illness is all in what you make it; life goes on whether you have one or not....' wrote in June that he was looking forward to this return to normality, 'It looks like I'll be going back to work on June 30. It will be eight weeks post-op by then, and I'm more than ready to return to my routine.'

After our story appeared, Jeff began using a new website and cross posted on his old site so that our readers would still have access. Now is the time to update your bookmark as Jeff will be closing the old site soon: www.chronicpositivity.com. You can also read his new, kidney-specific blog at www.mykidney.com/blog/jeff.

Freedom: have insurance, will travel

The following article refers to the UK only

As a lot of our readers already know, many travel insurers decline to include cover for pre-existing medical conditions. To help surmount this difficulty, the PKD Charity has joined forces with Freedom Insurance in a partnership that is registered with the Financial Services Authority.

Freedom is a specialist travel insurance company that offers pre-existing medical condition travel insurance. The PKD Charity has full confidence in recommending the company – they already work in partnership with many other-medically based charity and support groups, and have experience in representing many conditions. Freedom also receive referrals from Primary Care Trusts and over 100 NHS hospitals.

Donors – use Gift Aid

Please fill in a Gift Aid form when donating—the Government adds 28p to each £1 you give.

As specialists in their field, all their staff are medically aware and are therefore able to respond with sensitivity and compassion to applicants. They also, obviously, offer full confidentiality and will not pass on your details to any third parties.

Depending upon circumstances, both single trip and annual policies are available. Freedom also attempt to provide a 'one-stop-shop' where a medical screening is undertaken and premium quoted in a single telephone call.

Should you decide to take out a policy with Freedom, they will pay the PKD Charity a percentage of their commission – although this does not mean that we are endorsing them as an exclusive provider of cover.

website: www.freedominsure.co.uk phone: 01223 454 290

Information and Support

The PKD diet – low on salt, big on flavour

A PKD diet is just a normal, healthy diet with a balance of protein, carbohydrates, fats, lots of fruit and vegetables, but with the emphasis on low or no salt.

Here are some ideas for recipes to help you get started on a no/low salt routine. But remember, don't substitute regular salt for 'Lo-Salt' products as they contain too much potassium for people with kidney problems.

'Make your own stocks instead of buying salty stock cubes – and save money too!'

For a meat stock: add roughly chopped vegetables such as carrots, onions and celery to any meat bones in a pan with plenty of water. Add a bay leaf, dried herbs and peppercorns. Bring to boil and simmer for 2 hours. Strain and cool.



For a vegetable stock: omit the bones and add more vegetables such as leeks or turnips.

Lentil salad

Put 225g of brown lentils, 1 small onion and leek (chopped) plus a bay leaf into a pan. Add lots of water, bring to boil, simmer 15-20 minutes until tender. Drain and cool.

Add a dressing of olive oil, vinegar or lemon, with some mustard.

Grilled or baked stuffed fish

Chop 1 onion, 2 tomatoes plus half a lemon and stuff a whole firm fish (such as bass, mullet or mackerel). Sprinkle with fresh or dried thyme, juice of remaining half lemon and olive oil.

Grill or bake for 15-20 minutes, turning once. Alternatively, place on grill over hot water in baking tray and poach for same time.

Tandoori chicken

Skin 8 chicken legs, put in baking tray. Mix 1 chopped onion and 4 chopped garlic cloves with diced ginger root (2cm). Add 2 tsp chilli powder, 2 tsp coriander and 1tsp ground cumin. Spread over chicken, pour over 4 tsp plain yoghurt, juice of 1 lemon and 1tsp wine vinegar. Marinate if possible 4 hours.

Place in hot oven (180C/gas4), cover with foil and bake for 30 minutes. Uncover and bake a further 10 minutes.

Talk to others with PKD online

In a previous issue we introduced you to the work of our two local PKD Support Groups. The groups, in Chester and Richmond, were set up to give people affected by PKD the opportunity to meet, receive and offer information and mutual support.

However, those not lucky enough to live near either group may like to know that there is also a lively online version, open to anyone affected by the condition, or their families and carers.

Set up by the PKD Charity in 2006, the PKD_UK Online Support Group now has more than 300 members and is a great place to go to chat informally and compare experiences. Tess Harris, the group moderator, had this to say:

'The group was set up after a need had been identified for people to meet, chat and exchange news and ideas. The online group is perfect as it provides a friendly and informal way to share information and advice, exchange experiences and both offer and receive support.

'We also have access to a number of medical advisors to the charity who can supply general answers to clinical questions. However, any medical advice or suggestions received through the group should always be discussed with your doctor.'

It's quick and simple to register, meaning you are no more than five minutes away from joining and accessing the support and friendship of the rest of the group.

Visit the PKD-UK group, hosted by yahoo, here:

http://uk.groups.yahoo.com/group/PKD_uk/

Want to support PKD research?

We set aside a percentage of donations to fund research into treatments and a cure for PKD but if you want to designate an entire donation for research—just let us know your wishes at the time of giving.

PKD event near you?

The next ADPKD Information Day will be held on Saturday 11th October 2008, at the Postgraduate Medical Centre in the Royal Devon & Exeter Hospital. These Information Days, held regularly throughout the UK, offer those who attend the opportunity for talks, workshops, and to meet and exchange experiences with others.

The day starts at 9am with a series of talks, each followed by discussion and questions. Topics range from a general overview of PKD to its management and treatment. The late morning and afternoon sessions offer a choice of workshops before the day ends, after a research update, at about 4.30.

The scope of the topics covered means there is something for everyone – from the newly diagnosed to the knowledgeable.

To cover catering there is a voluntary donation of £15 per delegate or £25 per couple, although there is no charge if you are unwaged or retired.

Visit: www.pkdcharity.org.uk/pkdinfo.html
Contact: Justina Wilkinson –
Justina@pkdcharity.org.uk
Please book by 6th October
Our next PKD Day will be in Sheffield in April.

PKD Charity seeks funds for drug-free research



Although PKD is the most common inherited kidney disease, affecting an estimated 12.5 million people worldwide and over 60,000 in the UK, relatively few people with the condition have been studied for a sufficient period of time to fully understand how the disease affects people over the course of their lives.

To challenge this, the PKD Charity is applying for funding to establish a family-based ADPKD database and

DNA repository. Our aim is to create a national resource to support future epidemiological, genetic, clinical and therapeutic research.

The Big Lottery Fund has been approached as although the database potentially has great clinical significance, the fact that it is drugfree means it would be unlikely to be funded commercially.

The repository will collect data (including ethnicity, clinical, family history and previous therapy trials) from all UK centres. If the bid for funding is successful it will be the first national ADPKD database in the UK, as currently data is held in either the Renal Registry (ESRD) or individual units. This planned integration with existing UK renal databases will also facilitate the strategic planning of renal patient care throughout the UK.

The data collected will help increase understanding of PKD's possible complications, such as high

blood pressure, heart attack, and stroke; and it is hoped the information collected may help with the development of improved treatment strategies.

It is anticipated the project will last for five years (the goal is to have one thousand families with at least three affected members by the end of year three) and, if successful, the database could act as a template to be used in the study of other progressive diseases.

While individuals and their families who suffer from ADPKD will be the primary beneficiaries of the research, it will also act as an invaluable UK resource for doctors, associated health professionals and healthcare commissioners.

A national database could eventually identify larger numbers of patients for possible therapies and, in the short-term, it is hoped to assess its utility by performing a limited pilot of a water therapy that could benefit PKD patients.

Promising drug trial needs people with PKD

Last issue we reported that recruitment for the TEMPO (Tolvaptan Efficacy and safety in Management of Polycystic kidney disease and its Outcomes) Clinical study was underway.

The safety and effectiveness of Tolvaptan as a potential treatment for ADPKD is being evaluated after its efficacy was demonstrated in studies with rats with polycystic kidneys. Following these studies, scientists are hopeful that Tolvaptan could halt, or even reverse, the progression of cyst growth in PKD, slow the progression of increasing renal size, and improve related complications such as hypertension and renal pain.

'The only way to get a clear answer is through the trial – to succeed it desperately needs people to sign up'

The TEMPO trial is the first of its kind for treatment for PKD and really could provide a breakthrough. While not wanting to build false hopes, the team behind the study believes the results are extremely encouraging. However, the only way to get a clear

answer as to whether the drug really will work is through the trial – and to succeed it desperately needs people to sign up.

What participation means

The trial will involve about 1200 men and women with ADPKD, between the ages of 18 and 50, at about 100 hospitals in North and South America, Europe, Japan and other parts of the world. Those who sign up will take part for approximately three years, during which time they'll attend visits with the study doctor and have a single follow-up phone call at the end of the study. Participation is entirely voluntary and people are free to withdraw from the research study at any time, for any reason.

What to do next

If you live near any of the hospitals involved in the UK study and meet the eligibility criteria please do consider becoming involved. Or, if you live some distance away but are prepared to travel, ask your GP or Renal Consultant to contact the lead investigator for a referral. Before making a decision you can always contact the lead investigators (named below) for an informal chat – they'll

be delighted to hear from you and to answer any questions.

The hospitals involved in the UK and the lead investigator at each:

- St George's Hospital Medical School, London - Dr MacPhee
- Royal Free and University College Medical School, London - Dr Wheeler
- King's College Hospital, London Dr MacDougall
- Brighton and Sussex University Hospitals, Royal Sussex County Hospital - Dr. Stephen Holt
- Queen Elizabeth Hospital, Birmingham - Dr. Foggensteiner
- University Hospital Coventry and Warwickshire, Coventry - Dr. Zehnder
- Raigmore Hospital, Inverness Dr. Lambie
- Royal Hallamshire Hospital, Sheffield
 Dr. Wilkie

Are you an expert in building Access databases?

If so, please get in touch. The charity is looking for someone with significant Access skills to assist with helping us to develop a PKD UK clinical database

contact tess@pkdcharity.org.uk

'Team PKD' take cycle challenge



We were delighted to hear that 'Team PKD' competed in the Manchester to Blackpool Cycle Ride on Sunday 13th July, raising £420. Team Leader lan Smith from Anderton, near Chorley, takes up the story, 'The idea was a bit "onthe-spot" after a few pints, so I was a bit worried if we would get all ten who'd showed an initial interest. But seven of them did show up – a good result from the start!

'The other team members were Steve O'Brien from Prestatyn, who deserves particular congratulations. Not only was 60 miles a personal best for him, but he was the top fundraiser having persuaded his company Steria to match the amount he raised.

'Mike Yallop, from Shipston-on-Stour, very generously donated the cycling shirts after designing them himself. Hot from the Etape in the Pyrenees, Mike claimed Blackpool was warmer!

'Kathryn Yate's 'sit up and beg' bike with a wicker basket got plenty of comments, while Andy Forster's ambition is to build a multi-seat bike with a dining table and diners eating a meal served by a riding waiter. We're looking forward to that!

'My daughter Nichola Smith and her partner Ro Rubin-Mayhew also took part. It was Nikki's third time in the ride and Ro's first. However Ro looked as fresh as a daisy at the end so is a dead cert to do it again.

'We couldn't have done it without unstinting backup from my wife Ann, Steve's wife Denise and their 9-year-old son, Sam (who'd love to ride next year). Ann and Denise took the photos, fetched and carried, provided transport and ensured everyone was fed and watered at the rest area!'

lan explained his motivation for the ride, 'My wife's family have been blighted with PKD. Ann's mother Kathleen had it and subsequently died from the effects. Of her three children, two have developed the illness, but mercifully Ann has not been affected. One of her brothers has had a successful transplant (although other illnesses trouble him) and her younger brother is now preparing for dialysis.'

In conclusion, Ian summed up the team's feelings, 'A huge thank you to everybody for contributing, in particular Armstrong Watson, from Carlisle. The weather made it great, it was so sunny we even had to strip off some layers! And we all felt a huge sense of achievement once we got over the finishing line.'

Getting the most from Patient Choice

CONTINUED FROM COVER

You can book your appointment by phoning the central Choose and Book appointments line on 0845 608 8888, (textphone: 0845 8 50 22 50) or sometimes by contacting your chosen hospital direct (your referral letter will specify this). The central line is open every day from 7am to 10pm; calls are charged at the local rate and translation services are available.

Alternatively you can book online at the HealthSpace website. Go to: www.healthspace.nhs.uk and then 'Choose and Book'. Log in by giving your appointment reference number, year of birth and password. You can then book, change or cancel an appointment or simply view the status of your booking.

15-mile walk for PKD

The 15-mile Wirral Walk, organised by the North Wirral Rotary Club, is an annual event that gives walkers from Merseyside and beyond the chance to raise money for the charity of their choice.

The organisers are hopeful that this year's event, on Sunday May 18th, was a record breaker, as over 5,000 people followed the Wirral coast from Seacombe Ferry to Thurstaston Country Park, raising more than £300,000 along the way.

Among them, for the third year running for the PKD Charity, were Emma Kennedy and various friends and members of her family. Emma, a nurse, is also a PKD Trustee and Convener of the North West PKD Support Group.

Emma, together with Mike Johns, Martin Johns, Emma Drewery, Phil Starkey, Amanda Jones, Ian Dodds and Mark Johns all dressed as 118 men, while Emma's sister Dawn and



two of her friends, Christine McMahon and Emma Lambe, were more sedately dressed in PKD Charity T-shirts! Together they raised just over £1000.

Emma told us, 'It was a fantastic and really fun day, the best year yet. We had so much attention being in fancy dress, which is why we did it. Plus the weather stayed nice which really helped. We finished in under five hours – our quickest time yet. Although this did mean some very sore legs the next day, particularly

Discuss a shortlist of potential hospitals with your GP



Choose yr hospital and make an appointment once you get home

OR



Take your appointment referral letter away to think things over and make your decision later



Compare the hospitals, either online and/or through talking to family and friends



Make your choice and book your appointment

For more information about Patient Choice: www.nhs.uk/choices/Pages/ aboutpatientchoice.aspx

To book, check, amend or cancel your appointment:

www.healthspace.nhs.uk/cbintroduction.aspx