

A brief history of ADPKD

ADPKD was famously first observed in the autopsy of Polish King Stefan Bathory in 1586. The kidneys of the king, who killed Ivan the Terrible, were described as "like those of an ox, with an irregular and bumpy surface".

Described pathologically in 1841, the genes responsible – PKD1 and PKD2 - were identified in the 1990s. A European consortium, directed by Prof Peter Harris in Oxford, including Prof Albert Ong, identified the PKD1 gene. Prof Ong was funded through a Kidney Research UK Fellowship.

Mutations occur in either the PKD1 or PKD2 gene. You only need to have one mutated gene copy to experience ADPKD. A person with ADPKD has a one in two (50 per cent) chance of passing the disease on to each of their children.

Global prevalence rates range from 1 in 500 to 1 in 4000, with a large number of individuals being undiagnosed during life. ADPKD can, however, be diagnosed at any time, in adulthood or in children (sometimes in utero).

ADPKD is more than a kidney disease. Cysts can grow in other organs, especially the liver. Not everyone with ADPKD will have kidney failure.



Cats can also suffer from ADPKD; about 1 in 3 Persians and 1 in 10 moggies has ADPKD.

Tolvaptan (JINARC™) approved in England & Wales

On 4 September 2015, the National Institute for Health and Care Excellence (NICE) recommended tolvaptan (brand name: JINARC®) to treat ADPKD - autosomal dominant polycystic kidney disease.

JINARC® is the first ever therapy to target the underlying disease. It is expected to slow ADPKD progression and kidney failure rate. Until now, doctors focused on managing complications, such as hypertension, pain and infections.

JINARC® is recommended for adults with ADPKD and chronic kidney disease (CKD) stage 2 or 3, with evidence of rapidly progressing disease. JINARC® was approved based on the TEMPO 3:4 trial results.

In this three-year, randomised, double-blind and placebo-controlled study, JINARC® reduced significantly the rate of increase in total kidney volume (TKV) by approximately 50 per cent compared with a placebo - 2.80% (JINARC®) vs. 5.51% (placebo) per year. JINARC® showed a statistically significant reduction in the risk of worsening kidney function and other events such as pain and infections.

The Scottish Medicines Consortium (SMC) will appraise tolvaptan in November 2015 for patients in Scotland. JINARC® is available in Canada, Japan and Germany.

Hope for the future from a breakthrough treatment

Margaret Pope is a founding trustee of the PKD Charity: "At 15, I became aware I may have inherited PKD. At 42, this was confirmed. I am now 70. A lifetime of worrying what the future may hold for myself, my children and

others affected by PKD. Tolvaptan has given us all hope of a brighter future as the rate of progression will be much reduced. Thousands of patients worldwide have taken part in tolvaptan studies and trials over the past 10 years. Many continue to participate in studies. We are grateful to them and their families."

Professor Pat Wilson, Chair of the PKD Charity Research Advisory Board, said:

"This is an important landmark decision by NICE. Not only for PKD patients but also for individual researchers and companies to provide stimulus and incentive to discover and develop complementary therapeutic compounds."

Professor Albert Ong, Professor of Renal Medicine, University of Sheffield, said: "This represents the culmination of over four decades of sustained research into the genetics and biology of ADPKD by doctors, scientists and patients. It will give hope to thousands of patients and their families in the UK and stimulate further drug discovery for this common kidney disease".

Dr Richard Sandford, Renal Genetics Consultant in Cambridge, said: "For the first time we can now discuss with individuals that there is a treatment shown to improve the long term outlook. The development of tolvaptan has told us how we may best monitor disease progression and identify those that will benefit most from treatment. It will also help some families to decide when to consider screening for this condition, often a difficult decision."

Contact Tess Harris for further information. Tel: 020 7387 0543 or tess.harris@pkdcharity.org.uk



Sign up for a Special Conference on ARPKD

Saturday 16 July, 2016, Kingston University London.

Dr Evi Goggolidou has been awarded a grant from Sparks Medical Charity to hold a one-day conference on ARPKD. This will bring together the scientists and clinicians who work on ARPKD and the patients and families who are affected.

This will be a holistic event. Scientists and clinicians will inform the patients and families about the latest developments in ARPKD, and the patients and families will discuss their experiences, to influence future research on ARPKD. This back and forth communication will allow more focused, translational research into ARPKD that will be of impact in disease diagnosis, prognosis and treatment.

Proposed programme:

10 am Welcome and Introduction

10:30 am-12:30 pm Keynote talk followed by short talks on latest developments in ARPKD.

ARPKD teenagers can opt out so that they can be involved in the "make your own movie on ARPKD" project, where they will be working with our director to create the script. Younger children will join an activity based on

reading the chronic kidney disease and transplant books provided by Medikdz.

12:30-1:30 pm Lunch break

1:30pm -4:30 pm Parallel sessions

- For ARPKD parents: Round table discussions with clinicians and scientists on various ARPKD themes (genetics, treatment, neuro-behaviour, diet, support groups). They have the option of staying on one table or circulating around.
- For ARPKD teenagers: Shooting of the movie. The edited movie will be uploaded on the PKD charity's UK YouTube channel.
- For ARPKD younger children: Draw your own experience of ARPKD. With the help of an Educational psychologist, children will be able to draw "a day in the life of an ARPKD child" and learn about their kidneys. The drawings will then be collected by the PKD charity UK and displayed on their website.

4:30-5 pm End.

Contact us to sign up!

The PKD Charity will cover reasonable travel expenses.

Would you like to join our ARPKD sub-committee?.

We're keen to have more families and adults join the PKD Charity ARPKD sub-committee.

In April 2016, we're optimistic that the NHS will commission a service for everyone with a rare ciliopathy, including ARPKD. This service should speed up diagnosis and provide those diagnosed with one-stop, multi-disciplinary clinics, better coordinated care and really help improve quality of life.

It's vital that we have patients with ARPKD and their families involved, so that the service meets your needs.

We will cover any costs, such as travel to meetings, phone conferences and childcare. For more information, contact Tess tess.harris@pkdcharity.org.uk

ESPRIT Guidance on Transplant Drugs

The ESPRIT Group has published common sense guidance for doctors regarding prescribing and switching of immunosuppression drugs. It's very useful information for patients and families too!

ESPRIT stands for Efficacy and Safety of PRescribing In Transplantation. The Group was formed in 2000 and is multi-disciplinary - transplantation surgeons, clinicians, pharmacists, and primary care representatives. Members share a common commitment to ensure the continued, effective and safe treatment of transplanted patients by educating healthcare professionals and patients.

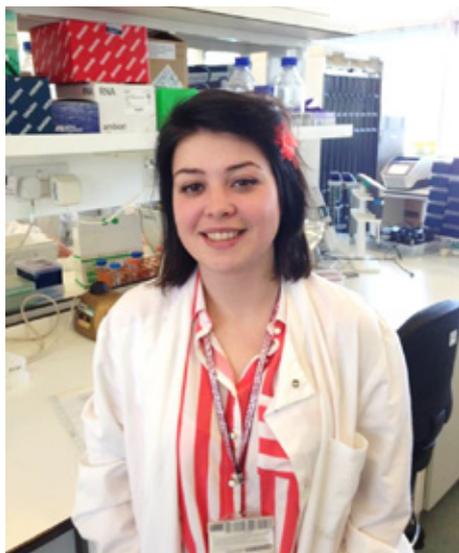
Many of you will know that immunosuppressant prescribing has been 'repatriated' or transferred from primary care (hospital level) back to secondary care (GP level). Additionally, many UK transplant units have switched from branded to generic immunosuppressants, and more will do so in the future.

Following pilot research in 2013 on patient perspectives on such switching, ESPRIT extended its research in 2014 and undertook a direct study via specialist pharmacists in transplant units, to investigate in detail both the process and outcomes of switching.

The research revealed significant variations in how different units approached the task in hand, especially in terms of patient management and monitoring during switches. Key aspects of best practice were also highlighted. The ESPRIT Group therefore convened a group of experts with direct experience of managing repatriations and immunosuppressant switches and agreed some best practice principles.

It is hoped that this informed guidance will help optimise switches going forward, in the interests of patient safety and improving the experiences of patients and healthcare professionals alike. Follow the link below to download the guidance document or visit the ESPRIT website for more info about their work and useful resources. www.esprit.org.uk

<http://www.esprit.org.uk/wp-content/uploads/2015/08/Switch-guidance-document-final-Aug-31-2015.pdf>



I am thrilled to have received a PhD studentship that is co-funded by the PKD charity and I am very excited to start my project entitled 'The composition and functional roles of exosomes in Autosomal Dominant Polycystic Kidney Disease (ADPKD)'. After completing my BSc in Biomedical Science at Queen Mary, University of London, I went on to study for a Master's degree in Cancer Therapeutics at Queen Mary's Cancer Institute. This experience stimulated my interest in research and to gain more experience and enhance my practical laboratory skills, I took a position as a laboratory technician in the Coleman lab at the University of Cambridge. Working in a research lab full-time reinforced my interest in science and particularly in research identifying potential biomarkers of disease.

This led to a growing conviction that I wanted to follow a career in research and to do a PhD. The opportunity to work on the identification of biomarkers in the progression of ADPKD is very exciting. To try and understand the progression pathway of ADPKD by identifying specific molecules in exosomes, which then have the potential to be clinically relevant is of great interest to me. Outside the lab my interests include Irish dancing and I competed internationally for a number of years. Although I no longer compete, I assist at dance classes by helping to teach dancers of all stages, levels and ages and hope to take my teacher's exams in the near future.

How you can help with PKD research

Not all medical research involves scientists in white coats or patients taking drugs in a clinical trial (CT). In advance of laboratory tests or CTs, there are plenty of opportunities for patients, relatives and carers to be involved in research projects and studies. Many of you have contributed through the years to surveys and questionnaires seeking to get your views on various topics.

Here's a few ways you can help us now.

Identifying and prioritising topics for research

You can take part in a survey to guide future research into kidney transplants. Traditional research on the effects of transplantation may overlook the shared priorities of patients, carers and clinicians. The **Kidney Transplant Priority Setting Partnership (PSP)** is working with everyone with an interest in improving transplantation outcomes to identify and prioritise the most important questions about transplant to study.

Click here to complete the PSP survey to rank what's important to you. It takes 10 minutes. Anonymous. Deadline end November 2015.

<http://www.transplantpsp.org/kidney/survey.php>

Giving your views on Innovative research ideas

New genetic technologies allow scientists to make very precise, permanent changes to the DNA of any cell. They have a number of possible applications, and difficult questions are being raised about how, when and if they should be used. It is important that the patient voice is part of the worldwide debate.

Genetic Alliance UK are inviting patients and their families to give their views on some of the issues that are raised by these new technologies by completing a short online, anonymous survey.

<https://www.surveymonkey.com/r/XPFNTD6>

Designing study and trial protocols

A study or trial protocol describes, in detail, the purpose of the study/trial and the plan that researchers will follow when carrying it out. Researchers need to explain what is being studied and the data they will collect. They must state the number of participants required, their demographics and who is eligible to take part. Organisations funding these projects require patient and/or carer involvement at an early stage.

You can help with the design of a possible trial into water as a therapy to slow the progression of ADPKD. Click here to complete a short, anonymous survey about your (water) drinking habits.

<http://water-study.questionpro.com>



Inspired By

Our Fabulous Fundraisers

As always, we are delighted to receive so much fundraising support from fundraisers up and down the country, and sometimes from overseas too! Often our supporters send in donations from their fundraising activities with a note to say 'it's only a little bit', but every little bit really is important to us. Even the smallest donation helps to support our work, from funding research, to running our supportline, to providing leaflets to the general public and medical profession. We really appreciate all your fundraising - be it large or small! Here are just a few examples of the fundraising that has been going on all around the country in the last few months. Although we cannot feature everyone, we would be delighted to see pictures of your fundraising activity and add these to our website gallery.

This year saw our inaugural Walk for PKD Event taking place around the country. Based on the highly successful September walks run by the PKD Foundation in the USA, the idea of these walks is to get people together in their local area to raise awareness and funds for PKD. This year, we focussed on raising awareness and had walks in the North West, Northern Ireland and the West Midlands. **Claire Hewitt** organised a walk in Belfast with several other PKD families attending and raised over £600 to mark her son's Birthday. The North West Support group arranged a Sunday walk and even took along a model of a polycystic kidney to

raise awareness... and probably a few eyebrows too!



Kay Turner and her family organised a 5k walk and fun run in Chasewater Park and raised over £600! The PKD Charity's **Tess Harris** also took part, as did several generations of the Turner family and Kay's brother Phil with his famous tumble dryer!

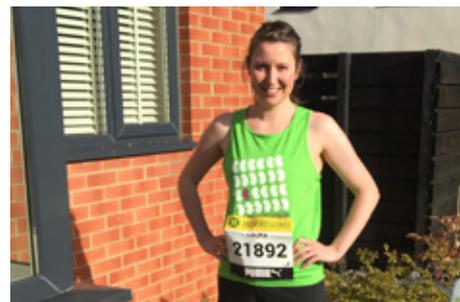


Look out for more news about Walk for PKD 2016 in our next newsletter.

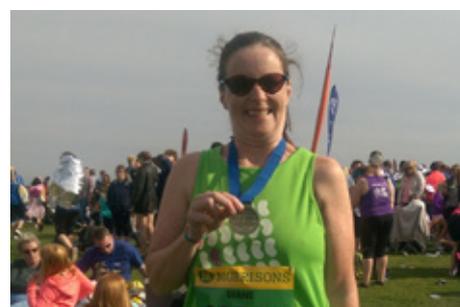
As always the famous PKD running vests have been out pounding the streets, worn by lots of PKD runners. This year's Great North Run had several PKD supporters participating and they are all working hard on collecting in their sponsorship money. **Stuart Blount** ran for his young son and raised a truly staggering £1,084. **Lynda Murray** followed up last year's Birmingham Half Marathon by taking part and raising £274.

Craig Hill ran for all his family members affected by PKD and amassed donations of £362. **Andrew Mason** laced up his trainers and ran to £322 of sponsorship from family and friends. **Alan Halmshaw** raised £365 with his fantastic run, **John Picton** raised a fabulous £855, and **Karen Stafford** ran in memory of her Dad and Aunt raising £699. Sisters **Charlotte Howe** and **Hannah Atess** ran together raising £1,266 and used the opportunity to encourage all their sponsors to sign up for organ donation too.

Inspired by her Mum donating a kidney to her Dad, **Laura Elliott** decided to run for PKD and raised an incredible £1640 from family and friends.



Despite only having been running for one year, **Laura Rosby** was determined to complete the Great North Run in memory of her mum and did so in a fabulous time, raising £595 for PKD.



Diane Yuile raised £795, far exceeding her personal target of £250. **Amy Partington** ran the Leeds 10k in July and raised £207. Also taking part was **Sarah Smith** whose family and friends sponsored her £200 to take part.

Here's a great picture of super runner **John Stone** who once again ran the Virgin London Marathon for PKD and raised £1,754.



Victoria Morgan took part in the aptly-named Liverpool Rock and Roll Half Marathon in June raising £563 along the way and **Steve Fitzgerald** raised £100 by taking part in the beautiful Lake Vyrnwy Half Marathon in September. **Sarah Dumphy** ran her way round the Windsor Half Marathon and ran her way to more than £400 in sponsorship.

Bronte Evans together with family

Do you have an idea to fundraise £100,000?

Remember the ice bucket challenge? PKD Charity and PKD International need your ideas to launch a huge pan-European awareness campaign.

£250 reward when used!

Send your ideas to

info@pkdcharity.org.uk

members **Katherine** and **Charlotte** ran the Big Sheffield Fun run, having lots of fun along the way and reaching £523 in donations from family and friends.



Fiona Davidson and her family took part in the Salford 10k in September as a team of 15 and together they raised over £1,000 for PKD.

The trend for getting muddy, scratched and scrambling over walls and ditches continues with lots of PKD supporters taking part in Tough Mudders all around the UK. **Paul McPherson** and his team known as the **Fryish Tough Mudders** have raised over £700 and are planning further challenges.



Daniel Johnson faced his own Tough Mudder challenge in September with his friend Matt and together they raised £195 for PKD. **Katerina Charalambous** represented the ladies and raised £490 from her Tough Mudder in September.

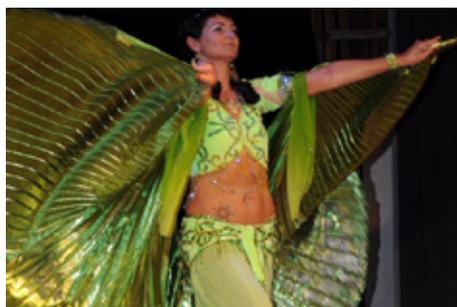
Taking things at a more leisurely pace, but challenging himself over several days and hundreds of miles was **Andy Babington** who walked Hadrian's Wall in September and so far has raised over £2650 in sponsorship from family and friends.

Valerie Lawson, Kaye Lawson and **Jayne Johns** created the team named the Hotsteppers and took on the Thames Bridges Walk in September, organised by Kidney Research UK and raised more than £500 for PKD research. **Morag Lamb** took part in the beautiful Glasgow Bridges walk with family and raised £230.



Also walking the bridges of Glasgow was **Susan Goutcher**, her husband and dog, Douglas. Together the three of them raised £287. **Nigel Webster** raised £360 by reaching the summit of Yorkshire 3 peaks in 24 hours.

Caroline and **Gavin Johnson** created their own Man v Mountain challenge and walked all the way to £720 in donations. **Paul Robinson** travelled to Austria to take part in Ironman Austria, finishing in an excellent time and raised £1,297. **Jane Duggan** participated in the Nightrider London cycling event in June and donated £182 in sponsorship. **Keve Gallagher** organised his own '1 Sister, 1 Kidney 1000 Mile Challenge' in September, cycling 1000 miles and raising a fabulous sum of £2,195 for the PKD Charity. **Vanessa Culliford** organised a brilliant Belly Dancing Night and shimmed her way to more than £600 in donations for PKD.



Beth Reeves and her family have been fundraising for the charity throughout the year in memory of **Colin Rogers** and so far have raised over £1,700.



Their fundraising has included a bake sale and donating two cars through the charity's Give a Car scheme.



Tina Procter and **Liz Procter** ran a charity stall at the Chipping show in Lancashire in August and through their fundraising they raised £500 and encouraged lots of people to sign up for organ donation too! **Paul Tyler** and his colleagues at Barclaycard Teeside organised a charity day for PKD which raised over £500. Barclays has kindly agreed to match this pound for pound! **Ollie Charles Askil** got together with his friends to have a street collection near to his home and they raised £18

Vicky Nall braved the chill of Windermere's water in September and swam her way to more than £1,772 in sponsorship. Even further north **Emma Benbow** and **Karen Alderton** braved the Great Scottish Swim raising £600 and £205 respectively. **Val Angus** organised her own 'Swim a Marathon' event and swam her way to more than £750 in donations. **Virginia Brown, Lauren Cotton** and **Matthew** decided that 2015 was the right time for the thrill and excitement of a skydive. We are really grateful to them for their

Searching for something online? If so, use Everyclick rather than Google to search and help support the charity. Just 3 searches per day would generate £3.65. If each of the 2000 subscribers to this newsletter did the same, we would raise £7,300 just by clicking! <http://fundraisers.everyclick.com>

If you would like to give a little every month to the charity you can do this quickly and easily via Charity Checkout. It takes just a couple of minutes to set up and we will give you a PKD pin badge as a regular supporter. <http://www.charitycheckout.co.uk/1085662/donate>

Inspired By

Fundraising Stories

bravery and for raising £218 and £657 respectively.



Taking on the challenge of a lifetime for PKD was **Sheena Sefiani** who trekked to the top of Mt Toubkal, North Africa's highest mountain earlier this year, raising more than £600. Here Sheena shares her experience:

"Having seen this trek advertised on the back cover of a kidney magazine in July it didn't get as far as the bin! I rang and before I knew what was

happening I was off to Gatwick to meet my fellow Trekkers (little did I know there were only three of us and they were both flying straight from Manchester) so I travelled with the Doctor and the tour-leader (very scary) as this was the first adventure I had done on my own since my husband died at 60!!!!

It was the most amazing experience to be back in Morocco to be surrounded by such friendly people - scrumptious tagines salads n fruit and of course the famous mint tea!

The trek itself was most exhilarating but at no moment was I going to be defeated - pure determination kept me going. I felt at peace with the sound of flowing streams, random butterflies, singing birds, walnut trees, orchards of crisp rosy apples, oranges, colourful carpets, pottery and SNOW!

The descent was more difficult in parts, but knowing I have raised over £700 for PKD it is definitely the way forward. Also I am pleased to say I had no blisters and was able to care for my children on Monday morning!!! Extraordinarily, the other two Trekkers were raising funds for kidney research!!!!"

If Sheena's story has got you itching to set out on your own adventure of a lifetime, then please get in touch. We have lots of challenges to choose from, cycling through Vietnam, to trekking the Great Wall of China, London to Paris bike rides and walking through the Sahara Desert!

Thank you so much to everyone who has fundraised for the charity this year, or who has sponsored a fundraiser or donated to a fundraising event. We can only do the work we do because of you!

For details on any of these events please contact our Fundraising and Events Manager - Esther Wright estherwright@pkdcharity.org.uk or call **07825 882616**.

Martin Graham's Transplant Games Success

I was three when I was diagnosed with PKD. Life was relatively normal. When I was 10, I took up running and then discovered the enjoyment of pole vaulting. After hard work and training, I became third best in the Midlands, travelling up and down the country with my sports.

I had a keen interest in road running, entered a local half marathon, trained hard and managed to PB of 1hr and 28 mins. One week after, I was involved in a motorcycle crash (not my fault). After a couple of somersaults, I had two unstable fractures in my spine followed by a six week hospital stay. During recovery, gradually I built myself up again walking, jogging and back to running - by now over 100 miles a week. I entered the half marathon where I had set my PB and was amazed to run it 5 minutes faster than the previous year.

In 2008, I started University, but something did not seem right. I was training hard, but getting slower, struggling to concentrate and feeling very tired most the time. By then, I was being closely monitored at the Newcastle Upon Tyne RVI hospital. Sadly, due to my health, I had to quit university as I just could not manage. After a few years, my creatinine reached 500. Dr Tim Goodship, my specialist, said I needed a 'pre-emptive transplant' (done before dialysis is required). That evening I called my parents, merely saying "the time has come". They already knew what the call was about. After blood and scans etc, the best match was my father. I was 28, but was strangely looking forward to the operation.

On 2 April 2003, the transplant was expertly completed by Dr Talbot and the team at Newcastle's Freeman Hospital. Wow! I felt amazing and full of beans. Prior to the transplant I had heard of the Transplant Games, and I wanted to be part of this. The first games I attended were in Norwich in 2004. It was amazing coming back with medals, I was really chuffed. To my amazement, I received a letter inviting me to represent the UK at running and swimming. The following year I attended the World Transplant Games, achieving a silver medal in the race walk.

Over time, I've changed my preference from running to swimming, achieving gold medals in swimming at the next games. Since that marvellous day in April 2003, I have not looked back and strived to improve at each British and World games I have the privilege to attend. This year I fulfilled an ambition achieving a world record time in the 200m. Along with the world record, I gained 5 gold and 2 silver medals, also beating the relay world record with my GB team colleagues. So I say "forwards and onwards and upwards to the next challenge".



Support Services

From the PKD Charity

Befriending Update

Following requests to the PKD Charity, and the responses received to the 'Support Outside of the Clinic' Survey in the last newsletter, we are committed to providing more support to adults over the age of 18 with ADPKD and ARPKD and their family members and carers. Using the information you gave us in the survey, we have been busy developing a telephone befriending and peer support service, which we hope to pilot in three areas of the UK early in the New Year. An application for funding has been submitted to the Big Lottery Awards for All England fund in September with a decision expected by the end of November. A further application is being made to the Awards for All Scotland fund.

To ensure the service PKDC develops is of the highest quality, trustee Maggie Pope and Operations Manager Julie Adams have been attending a distance learning course 'Vital Skills in Befriending Programme', which is delivered by Befriending Networks. The course is designed to provide a comprehensive grounding in befriending and covers everything from recruiting volunteers to monitoring and evaluating the service.

What is befriending and what are the benefits?

Befriending is a way of offering peer-to-peer support during pivotal or transitional times in a person's life such as periods of physical ill-health, including long term conditions like PKD. For people receiving befriending, the social and emotional support they receive from a befriender can often lead to significant and lasting improvements in their emotional health, wellbeing and quality of life. Befriending is an activity which involves the development of relationships in which one individual, usually a trained volunteer, gives time to provide informal support and encouragement to another, sometimes over a sustained period of time. Befriending relationships are based on trust, confidentiality and mutual involvement whereby both the volunteer befriender and the befriended gain from the relationships formed over time.

One of the key strengths of a befriending relationship is the unique value placed by the befriended on the voluntary nature of the befriending role, and the relationship they have with their befriender. Many see befriending as offering a distinct type of support which is uniquely different from the practical or functional day-to-day support provided by statutory services or other paid workers, who are under a professional obligation.

Befriending has evolved in recent years to include a range of different models and styles. The service PKDC is developing is telephone-based. This type of befriending can provide regular one-to-one support to people in their own home and overcomes barriers of geographical limitations. It can also be used to provide targeted support, advice and guidance to individuals or families newly diagnosed, or learning to live with, PKD.

Information and Support Days

For ADPKD - Autosomal Dominant Polycystic Kidney Disease - patients, families and care-givers, we hold several events a year in different venues around the UK. These are free to attend and patients, their families and carers are all welcome. We invite renal consultants and other healthcare professionals to talk about PKD, the genetics, management and research studies.

Our most recent Information Day was held at the Royal Free Hospital in London on Saturday 3rd October. Hosted by Dr Danny Gale, speakers included Dr Anand Saggarr, Professor Pat Wilson, Dr. Matko Marlais and Mr. Neal Banga. Talks and workshops were given on:

- The Basics of ADPKD
- Screening and Genetic Testing
- Diet and Lifestyle
- Research
- Transplants
- Tolvaptan
- Peer Support

ARPKD Family Support Days

For ARPKD - Autosomal Recessive Polycystic Kidney Disease - families and patients, we hold an annual, national



event. This year it was held at Leeds General Infirmary on Saturday 11th July. Hosted by Dr Kay Tyerman with the support of Dr Larissa Kerecuk, talks and workshops from expert doctors were given on:

- ARPKD Basics and Genetics
- The Liver in ARPKD
- Transplants
- Coping skills

Families made full use of the opportunity to talk to the experts, to meet other families and share experiences. Supervised entertainment and childcare was provided including crafts at the City Museum, which the children (and adult supervisors) enjoyed enormously.

Details are currently being finalised for our Information and Support Days in 2016 and will include:

- Birmingham
- Salford
- Northern Ireland
- Sheffield
- Kingston

To keep updated and to find out more please visit: <http://pkdcharity.org.uk/support/pkd-information-support-days/adpkd-info-support-days>

PKD Charity 2016 Calendar of Events

January (TBC) – ADPKD Information Day, Birmingham

13 March – Silverstone Half Marathon

March (TBC) – ADPKD Information Day, Belfast

24 April – Virgin London Marathon

30 May – Bupa London 10K

22 May – Great Manchester Run

Support and Information

Support available

Our Support Line is available Monday to Friday, 10 am to 4.30 pm or leave a message on answerphone: **0300 111 1234**

Join an ADPKD online support group:

- **PKD Yahoo Group**
uk.groups.yahoo.com/group/PKD_uk/
- **PKD Charity Facebook Group (UK only)**
www.facebook.com/groups/pkdcharityUK/
- **PKD Northwest Support Group**
www.facebook.com/groups/NorthwestPKD/
- **Polycystic Kidney Disease and Kidney Disease**
www.facebook.com/groups/17866443885/
- **HealthUnlocked ADPKD Community (UK only)**
www.pkdcharity-autosomalrecessive.healthunlocked.com/
- **Living with Polycystic Kidney Disease Support Group**
www.facebook.com/groups/150513068466259/

Join an ARPKD online support group

- **Facebook ARPKD Group**
www.facebook.com/groups/20526281816/
- **HealthUnlocked ARPKD Community (UK only)**
www.pkdcharity-autosomalrecessive.healthunlocked.com/
- **ARPKD/CHF Alliance**
www.facebook.com/groups/89846751499/

Insurance

Names of insurance firms and brokers specialising in PKD and other long-term conditions are on our website: www.pkdcharity.org.uk

Links to other charities and organisations

- **National Kidney Federation (NKF) - help and information to support kidney patients and their carers, in particular those on dialysis.**
www.kidney.org.uk
- **British Kidney Patient Association (BKPA) - financial support and grant aid for kidney patients.**
www.britishkidney-pa.co.uk/
- **Turn2us - helping people access money available to them through welfare benefits and grants.**
www.turn2us.org.uk/
- **Contact a Family - supporting families of disabled children**
www.cafamily.org.uk/
- **NKF Advocacy Service**
www.kidney.org.uk/advocacy-service/
- **UK Government Benefits Info**
www.gov.uk/browse/benefits
- **Back copies of PKD newsletters**
www.pkdcharity.org.uk/news-events/newsletter

Patient Information on Our Website

Just Diagnosed with ADPKD

www.pkdcharity.org.uk/about-adpkd/just-diagnosed

Symptoms of ADPKD

www.pkdcharity.org.uk/about-adpkd/symptoms-of-adpkd

Living with ADPKD

www.pkdcharity.org.uk/about-adpkd/living-with-adpkd

About ARPKD

www.pkdcharity.org.uk/about-arpkd

If you do not use the internet, ring our Support Line **0300 111 1234** and ask for printed copies.

Fundraise For PKD

Visit our website to:

Make a donation:

- Regular Giving
- Donation by Cheque
- A Gift in Your Will
- Give As You Earn
- Donate Online
- Collecting Tins and Buckets

Get our 'DIY Fundraising Tips'

www.pkdcharity.org.uk/fundraising/diy-fundraising-tips

Take part in a fundraising event

www.pkdcharity.org.uk/request-an-event-pack

Buy online at the PKD e-Shop

www.pkdcharity.org.uk/fundraising/pkd-e-shop

If you don't use the internet, ring Esther on **07825 882616** for help with fundraising.

Text us a donation

- Just text **PKDC12** followed by the amount in **£** that you wish to donate to **70070**.
- Research project 'Your Pound for a Pee'. Simply text **PKDC19 £1** to **70070**.

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