

Euro Awareness Campaign Launches Autumn 2016 – Save the Dates!

PKD patient groups around Europe have united to launch the first-ever Euro Awareness Campaign on **Friday 30 September** and **Saturday 1 October 2016**. Instead of having just one day devoted to our PKD kidneys, we decided to run the campaign over two days.

We're keeping the campaign logo and strapline a secret until nearer the date but we're confident that you will be as excited as we are when you see it. The campaign will be mostly online with viral videos, a social media wall and plenty of creative ways to raise awareness of all forms of PKD – just like the famous ice bucket challenge last summer! There'll be 'offline' ways too, so you can be involved in helping to get our PKD message across. So, save the dates and be prepared to join with us all across Europe! **Friday 30 September** and **Saturday 1 October 2016**.



Are you registered for the PKD Charity eNewsletter?

In addition to our twice-yearly printed newsletter, we also have an eNewsletter that's published more frequently. It contains breaking news and hot topics, plus seasonal fundraising ideas. To register your email or check if you are registered, visit <http://eepurl.com/R2Ssn>

PKD Charity Telephone Befriending Service

The Befriending Service came about after feedback from Patient Information Days and helpline calls showed a clear need for more personalised and regular support by phone. Research was carried out and supporters affected by PKD were surveyed. We made successful applications to the Big Lottery Awards for All, and received funding to pilot a Telephone Befriending service in London, the North West of England and Scotland.

The North West pilot was launched at an evening event at Salford Royal Hospital on 3 March. Dr Grahame Wood, Consultant Renal Physician, gave a talk on PKD followed by an insight from Rebecca Murphy as a PKD Charity trustee and patient. On World Kidney Day, 10 March, we launched at Guy's Hospital in London. Speakers included Eleri Wood, King's College London, who discussed the benefits of peer support for renal patients. Nicki James gave a PKD patient perspective and Maggie Pope, founder PKD Charity trustee, described the journey to telephone befriending. At both events, Julie Adams (PKDC Operations Manager) gave an overview of how the pilot would work in each area. A similar event is being organised for Scotland.

If you are interested in joining our volunteer befriending team in these areas or would like more details on getting befriending support, please email julie.adams@pkdcharity.org.uk or ring **0300 111 1234**.

From Trustee to Trainer

Maggie Pope, the PKD Charity's longest serving trustee, is stepping down after 16 years. The good news is that Maggie will be staying with the charity and continuing to support those affected by PKD.



Maggie has been with the charity since 2000, when Dr Anand Saggar, her renal consultant at St. George's Hospital, asked if she would become a trustee. Maggie was also taking part in Dr Saggar's research programme and felt confident she could contribute positively.

The PKD Charity was formed with three main objects: 1) To promote awareness; 2) To fund research; 3) To provide support for patients, families, carers and all those affected by PKD. These aims continue today.

Maggie had various roles as a trustee but with a background in nursing, health visiting, teaching and training, her main area of interest was always patient and family support. From the first Patient Information Day in 2004 to piloting and supporting PKDC's face-to-face support groups and answering helpline calls, Maggie has always been actively involved.

Whilst the remaining trustees are very sorry to see Maggie step down, they are delighted she is taking on a new role at the charity - as a Telephone Befriending Trainer. Maggie has completed an accredited Befriending Training Course, and with Operations Manager Julie Adams, she will be training volunteer telephone befrienders in person and by distance learning.

Autosomal Dominant Polycystic Kidney Disease (ADPKD)

In Children and Young People

We recently revised our information leaflet 'ADPKD in children' which is available as a printed booklet or can be downloaded from the PKD Charity website. This leaflet provides information and guidance aimed at parents and carers of children who are diagnosed or may be at risk of ADPKD. It considers some of the pros and cons of testing children for ADPKD and explains how ADPKD can be diagnosed in childhood. It also covers some of the symptoms of ADPKD in children, as well as how the disease can be monitored and treated in childhood. We are grateful to all the individuals affected by ADPKD who contributed to this leaflet by reviewing and reading drafts.

In addition, the PKD Charity is funding a clinical research study focused on children with ADPKD. High blood pressure is a common problem in adults with ADPKD, but it is less common in children with ADPKD. This study aims to develop our understanding of high blood pressure

in children with ADPKD and what effect this high blood pressure may have on individual children. Children that take part in the study are also having a full assessment of their heart and blood vessels. We hope that this will provide valuable information about how we should monitor and treat high blood pressure in children with ADPKD. The study has already recruited 26 children from Great Ormond Street Hospital for Children and Evelina Children's Hospital. Recruitment is still ongoing and we aim to recruit 50 children with ADPKD in total.

Professor Paul Winyard, paediatric nephrologist, is an expert in managing children and young people who are at risk of ADPKD or have been diagnosed: "High blood pressure is said to affect up to a third of children with ADPKD, but many are not being diagnosed or treated at present because they don't have regular blood pressure checks. Our study offers a comprehensive blood pressure and cardiovascular check for children at Great Ormond



Street Hospital and the Evelina Children's Hospital. We want to find the true percentage with blood pressure issues so that we can develop national guidelines to deliver better quality care around the country".

Parents of children with ADPKD are involved in the development of these guidelines, to ensure that patients' and parents' experiences and opinions are truly accounted for.



We will publish more on the guidelines in a later issue.

Guidance on the Use of Tolvaptan in the UK

The first ever licensed medicine to treat autosomal dominant polycystic kidney disease (ADPKD) - tolvaptan (Jinarc®) - is now available in the UK. Tolvaptan is taken as tablets. It can slow the rate at which your kidneys grow and can help to protect kidney function.

Tolvaptan is not available for all patients with ADPKD. The organisations that recommend which medicines the NHS uses (the National Institute for Health and Care Excellence [NICE] in England and Wales, and Scottish Medicines Consortium [SMC] in Scotland), have set the following guidelines:

- In England and Wales, tolvaptan can be prescribed to people with ADPKD, chronic kidney disease stage 2 or 3 and evidence that the disease is progressing rapidly*
- In Scotland, tolvaptan can be prescribed to people with ADPKD, chronic kidney disease stage 1, 2 or 3 and evidence that the disease is progressing rapidly*

Your kidney specialist can let you know whether tolvaptan is suitable for you, and explain the benefits and risks. As with every drug, tolvaptan has side effects. These include being thirsty and passing more urine day and night. Professional guidelines are being developed to help doctors identify patients who may be suitable.

How does tolvaptan work?

Tolvaptan works by blocking a hormone called vasopressin in your body. Vasopressin has a few roles in your body, including controlling the amount of water you retain and narrowing your blood vessels. By counteracting vasopressin, tolvaptan can reduce your kidney growth and protect your kidney function. It does this by reducing the speed at which cysts grow and by reducing fluid excretion.

If you think you may be suitable and meet the criteria for tolvaptan, please ask your GP to refer you to a nephrologist. Alternatively, if you already regularly see a nephrologist, s/he may ask you to come for an appointment to discuss tolvaptan.

Contact Tess if you need more information. tess.harris@pkdcharity.org.uk or 0300 111 1234.

Autosomal Recessive Polycystic Kidney Disease (ARPKD)

In Memory of Aimi



We were profoundly sad to hear about the death of Aimi Bella, just before her 3rd birthday. Aimi was born with ARPKD – autosomal recessive polycystic kidney disease – the rare form of PKD. Shortly after birth, Aimi's massive cystic kidneys were removed and she started haemodialysis at Great Ormond Street Hospital (GOSH). Aimi's mother, Zara, travelled with Aimi 3 times a week from their home in Essex so that Aimi could receive the life-saving treatment.

Despite some setbacks since birth, Aimi was thriving and it was hoped that she would soon be old enough and sufficiently large enough to receive a kidney transplant. Sadly, she had a final health problem from which she never recovered.

Aimi was an inspiration to everyone who met her. She was loved by all nurses and doctors on the GOSH Eagle Ward.

Aimi's parents started a blog when she was born with the aim of raising awareness of ARPKD and funds for research. Since her death, they have continued to fundraise, most recently raffling signed shirts and boots donated by Chelsea footballers.

To find out more about Aimi, visit www.hope4aimi.co.uk

To find out more about ARPKD, visit <http://pkdcharity.org.uk/about-arpkd>

ARPKD Patient Registry

The natural history and progression of ARPKD is poorly understood and there are currently no preventive treatments. Also, patients are scattered around the UK, making it difficult to get sufficient numbers of individuals to take part in research.

RaDaR

Until recently there was no national database of ARPKD patients, so the Renal Association RaDaR group of kidney doctors has developed the first-ever National Registry of ARPKD children and adults. To date, about 80 patients are registered. By bringing together all the knowledge about ARPKD patients in one place, we hope this will improve understanding of how ARPKD affects your child or yourself.

If your child attends one of the 13 UK hospitals that specialises in Paediatric Nephrology, you may have been asked to register your child. If you have not been asked, please speak to the renal doctor or nurse on your next visit.

If you are an adult with ARPKD and see an adult nephrologist, you can also be registered. Speak to your doctor or nurse on your next visit.

The PKD Charity has provided a grant to RaDaR to assist with the development of the ARPKD Registry. Find out more about RaDaR here <http://rarerenal.org/radar-registry/>

ARPKD Family Conference

Saturday 16 July, 2016, Kingston University, 10am-4pm



Learn, share and have fun!

Join us in Kingston for talks about ARPKD from the expert doctors and scientists. Take part alongside other parents in roundtable discussions about the future of ARPKD research.

We will have supervised entertainment & activities for younger children and movie-making for the teenagers.

FREE to attend. Lunch included. Travel bursaries available.

Visit <http://bit.ly/arpkd-2016> to register today.

Inspired By

Our Fabulous Fundraisers

As in previous years everyone at the PKD Charity has been astounded by the number of people who sign up for the most demanding physical challenges to raise funds for PKD.

Leigh Anscombe took part in the Burreigh Rat Race in May last year consisting of a mammoth 200 obstacles over 20 miles and raised more than £1000 in doing so. **Barry Davies** completed the challenging Spartan Scotland event in July and raised £200. Regular fundraiser **Melanie Arazi** raised £858 by completing the Blenheim Palace triathlon which took place in June 2015. Committed fundraiser **Ian Beavis** was one of several PKD runners in the Great South Run at the end of October last year. Ian raised £559 in sponsorship for PKD. **Toni Vogel** also took part and raised £803. Joining the PKD runners in his PKD lime green vest was **Craig Kingshott** who donated more than £347 from his sponsors. **Ellie Belfield** ran the Yorkshire 10k last summer and donated £357 from her generous sponsors. **Susan Dunne** bravely took on the challenge of the Clumber Half Marathon in June and raised more than £750 in sponsorship from her family and friends. **Andrew Cooper** was inspired to run for PKD having seen **Kay Turner's** story in his local paper. Kay, whose son Charlie is

affected by PKD, has taken part in numerous runs and even organised her own fun run for PKD. Andrew was so taken with what Kay was doing for PKD that he decided to run the Cannock Rotary 10k in November and donated sponsorship of £226 to the charity. **James and Diane Helsby** decided to test themselves with a series of events in 2015 including several Tough Mudders, Born Survivor and the St Helens 10k.



Ashleigh O'Keefe persuaded a team of friends to climb Mount Snowdon on a cold March day this year and together, in their striking green PKD t-shirts, they raised £824. The team consisted of: **James Izzo, Ria Knight, Tiana Cann, Karis Cook, Laura Hastings, Dominic Biggs, Anna Sharp, Olly Sandall, Nathan Fitzgerald** and of course **Ashleigh. Chris Cooper** completed Stroud's Half Marathon in October and raised £140 by doing so.



Also in October **Jen Stoneman** completed the Bath to Bristol Half Marathon, coming 40th in her age category and securing an astounding £2202 in sponsorship. **John Carrington** chose to take part in the Brentwood Half Marathon earlier this year to raise funds for PKD and donated £716. Also this year **Charlotte Hutchison** raised £288 in the Brighton Half Marathon. **Maxine Lamb** and her brother **Alex** raised more than £1,000 by choosing to run the Cambridge Half Marathon together at the end of February. A little further afield **Barry Issacson** and **Charles Kenton** raised £1800 to be split between the PKD Charity and another charity by running the Las Vegas 10k in November.



Even further away from our shores, **Emma Black**, who lives in Western

Holly Mae Florence Skydiving Experience

Have you ever wondered what it would feel like to jump out of a plane? Well, Holly Mae Florence did just that and here she shares her story.

"My Mum and Dad underwent ten years of IVF before conceiving me, during this time, my Mum was also diagnosed with PKD aged 24. Aged 35, after toing and froing to London three times a week for dialysis, with a 1 year old child, my Mum's kidney function was now at 5% and she was reliant on these machines.

On 21st June 1998, my Mum received the call to come in as they had a match for her. By the early hours of the 22nd, my Mum was a new woman with a fully functioning kidney, all that was left to do was remove the two polycystic ones. However, my Nan had also discovered she was a carrier of PKD and became reliant on dialysis until her match was found too. Within the last year, my Auntie has also undergone a kidney transplant and found that her husband was a match. She is also recovering, and all three ladies now have fully functioning kidneys.

Unfortunately the chance of me developing PKD is 50/50 and I will have tests in the future to find out whether I have been affected or not. In the meantime, I decided I wanted to raise as much money for PKD charity as possible and booked a skydive. I managed to raise over £1100! However I suffered an asthma attack on the way down. But that does mean that I now have the funniest photos to look back on and I hope to do more fundraisers for such an amazing charity in the future."



Australia, took on one of Australia's famous Ironman Challenges and raised £276 for PKD. We now have places in even more sporting events from 5k fun runs through to Bear Grylls 50k Survival Challenges! Have a look at our website for more details and if there is an event you would like to take part in and you don't have a place, please do contact us as we may be able to get a place for you. But it's not all about sport and sweat! We are constantly surprised by the novel fundraising ideas of our supporters all around the country. **Hertfordshire Bowling Club** have made the PKD Charity their Charity of the Year and have been fundraising at a series of events. They have already donated £200 from loose change placed in their collection tins. **Tina Barron** and her daughter **Leanne Dare** had a craft stall in October and donated the proceeds to PKD. **Beth Murrell** has previously swum Stanborough Lake to raise funds and awareness for PKD. This year she decided to ask for sponsorship to have her hair cut off and raised £315 by having the chop. **Luke Gledhill** and a team of friends took part in a car rally to Italy in October and took on lots of fundraising activities. Together with team members **Chris Clark**, **Ade Hairsine** and **Guy Gledhill** they donated over £900 to PKD. **Nicola Thomas** organised her own event at Dickens World and the owners, **Britannia Entertainments Ltd** very kindly donated £127. Cat lover and regular supporter **Natasha O'Brien** donated raffle items to this year's London Cat Show and in return the organisers kindly donated the proceeds of the Cat Show raffle to PKD. A great idea as cats have PKD too! **Holly Graham** organised a dress down day at Badenoch and Clark and together they donated £244 to the PKD Charity.

Judith Hurst fundraises for the charity every December and this year she raised £388 by holding a series of Christmas Teas at a local tearoom and by writing a Christmas play for **Comeli Nursery Class**. In return the nursery held a raffle and raised £89 for PKD. **Ros Baillie** literally walked over hot coals to raise funds for PKD with a Firewalk in November. She raised more than £100 and walked the coals five times! This year's World Kidney Day took place on 10th March and we were delighted to see so many people flying the flag

for PKD. **Diane Shaw** raised £20 for PKD on World Kidney Day. **Alison Hyssop** manned an information stand giving out leaflets about PKD and **Jo Hopkins** had an information stand in her local shopping centre. Always raising awareness, **Marie Grant** and her team of awareness-raisers attended several information events in the local area. **Bonnie Kensit** used World Kidney Day to do a personal 5k walk in memory of her son Ezra and raised £778. Each year the PKD Charity holds a challenge to coincide with World Kidney Day.



Elizabeth Cooke and her family decided to participate in the £20 for 2 Months Challenge, by organising a raffle and fundraising events which included a Bake Off competition judged by the Local WI. **Elizabeth** and her family also sold a number of items via eBay and have raised in excess of a staggering £3,207 from the £20 cheque given to them by the charity. They truly have found a way to grow money!



Winner of the most novel fundraising idea in the challenge was **Katie Cameron** who made and sold Easter sweetie cones turning her £20 stake into £223. **Louise Manfredi** once again took on the PKD Charity's £20 for 2 Month's Challenge as she did in 2015 and held a delicious cake morning and cake sale which turned her £20 stake into an incredible £551. A Spring Ball held at Tern Hill Hall, Shropshire in March raised almost £2,000 for the PKD Charity. The event was organised by Fundraising and Events Manager, **Esther Wright** as part of her London Marathon fundraising. The event was really well supported with Trustees from the

charity, friends, family and guests enjoying a great evening with a live band and some fabulous prizes donated by local businesses.



We've been delighted that so many brides and grooms have wanted to remember the PKD Charity on their big day. **Caitlin Duncan** was married in October and decided to use the happy occasion to raise funds and awareness for PKD by using PKD Charity badges as the wedding favours. Not only did **Amy Partington** decide to run the Leeds 10k for PKD last year, she also choose to have PKD wristbands as her wedding favours donating £187 to the charity. **Carole and Brian Jennings** were married in 2015 and donated £780 in lieu of gifts from their wedding guests. **Danny Robinson** and his wife celebrated their wedding with a barn dance and asked guests to donate to PKD via a Wishing Well at the event. Their family and friends kindly donated more than £900 to the charity. We are always moved by so many kind hearted people who chose to fundraise for the PKD Charity in memory of someone very special to them. **Claire Stibbard** bravely took on Mud Mania in March to support her dear friend, whose daughter Aimi had ARPKD and died in early 2016. Claire beat the mud and raised £20 in Aimi's memory. Many of Aimi's family and friends have chosen to raise funds in her memory and they have already donated more than £1,300 to the charity and have many more fundraising activities planned. **Gordon Bailey** and his partner **Sara** have set up Winston's Wings in memory of their little son Winston. Together with family and friends in Scotland they have raised over £1,800 in just a few months with lots more activities planned including entering a team in the Lochness Marathon later this year.

We are so grateful to everyone who has fundraised for PKD, for people who continue to donate via direct debit and standing order and to families who so kindly donate in memory of their loved ones.

The Latest Statistics

Kidney (and Liver) Transplantation and Donation

Every year, NHS Blood and Transplant (NHSBT) invites patient support groups and renal physicians (surgeons, nephrologists, immunologists) to the Renal Transplant Services Meeting (RTSM).

NHSBT is part of the Department of Health and is responsible for two NHS agencies: Blood Donation and Organ Donation and Transplantation (ODT).

ODT runs a website www.odt.nhs.uk with up to date statistics on organ donation and transplantation as well as information for patients.

At the RTSM, NHSBT present the latest statistics on kidney transplantation and organ donation, and there are talks on studies and initiatives to increase and improve the number and quality of transplants. In this article, we give some highlights of the 2016 RTSM. Links to all the presentations can be found at the end.

Kidney transplants and organ donation statistics

The 2014-15 detailed activity report shows annual data from 2005-6 and it's a very useful source of information, for example if you are talking to media or schools etc about kidney and other organ transplantation.

Note that data from 2015-16 is available on the ODT website but only top level numbers.

Kidneys are donated from individuals who are either deceased or living. Deceased organs are classed as either DBD (Donation after Brain-stem Death) or DCD (Donation after Circulatory Death). DBD means that the person experienced 'brain stem death', when there is no activity in their brain stem due to a severe brain injury. DCD refers to the retrieval of organs for the purpose of transplantation from patients whose death is diagnosed and confirmed using cardio-respiratory criteria.

Living donations are from healthy individuals who have consented to give one kidney to someone who needs a transplant. This could be a family member – related or unrelated – or a friend. Living donors can also donate anonymously.

In 2014-15, 2,793 adult kidney transplants took place in the UK, 3% fewer than in 2013-14. Of these, 1,832 were from deceased donors and 961 from living donors (see bottom box for donor definitions). We do not know the exact number of PKD transplants but approximately 1 in 8 to 1 in 10 of people with a kidney transplant have PKD, so that might suggest around 200. There were 139 paediatric transplants, 48 from deceased donors and 91 from living donors. A number of these will be for ARPKD children.

Kidney transplants have increased by about 60% since 2005-6. However, the increase is from living donors (nearly twice as many) and more recently DCD organs (see bottom box for definitions). The number of DBD organs has remained fairly static owing to improvements in neurosurgery and falls in deaths from traumatic injuries.

Overall data for the 2015-16 year shows an increase from 2,793 transplants to over 2,900. Whilst positive, this is a modest increase, and the number of transplants per year has barely increased in 3 years. The number of people on the active kidney transplant list is still over 5,000 and although this has fallen, the reduction has come from an increase in the number of people on the suspended transplant list. Suspensions are usually due to infections or other illnesses, or when an individual no longer fulfils the transplant criteria.

Increased use of DCD organs across the UK

Until recently, DCD organs were less used and mostly locally. The donor's kidneys spent more time without blood flow than from a DBD donor, resulting in delayed graft function and higher rejection risk. However, long-term outcome data has shown that DCD transplant survival is as good as DBD.

Following a London trial, a national DCD Kidney Allocation Scheme was introduced in September 2014. There are now four DCD donor kidney sharing regions in the UK, designed to provide equity of access at the same time as realising acceptable time to transplant. One organ is offered locally, the other regionally, and this has resulted in the increase in DCD transplants and wider use in longer waiting patients.

Kidney transplant unit statistics and waiting list

There are 24 transplant units in the UK. In 2014-15, Manchester performed the most transplants (215) followed by Leeds (191) and Guys (185). Plymouth has the least (58).

Regarding the waiting list, Manchester has the highest number (537) followed by Birmingham and West London.

The median (average) time on the waiting list has fallen for all patients but there are wide variations. Across the UK, the median wait for white patients is 995 days but 1,200 days for BAME (black and Asian) patients. Cambridge has the shortest waiting time (around 500 days), and Birmingham the longest (around 1,500 days).

Living donor transplant paired scheme

In recent years, the number of paired living donor transplants has increased. In 2014-15, there were 62. This type of transplant occurs when a potential donor and recipient are biologically incompatible (blood group or tissue type) and they join a list of others in the same situation hoping that an exchange of kidneys between them

News from PKD Charity

Strategy and New Trustee

can lead to a compatible living donor transplant. The scheme also includes compatible pairs who would like a better match.

Most exchanges are between two pairs (i.e. two donors and their respective incompatible recipients), or between three pairs. There are very few countries outside the UK that offer this scheme. NHSBT is encouraging all nephrologists to talk to their patients about the paired scheme as well as other living donor options, as it increases the number of transplants and the outcomes are good for recipients.

How long do kidney transplants last?

The survival of a kidney transplant – or graft is as it's known – is measured by number of years since transplant. At present, more than 9 in 10 people still have their graft 2 years after a transplant, and 7-8 people in 10 have their graft after 10 years. We don't know what the figures are for PKD patients. However, studies have shown that PKD patients have better graft and overall survival rates than other kidney transplant recipients.

Liver transplants

We think that about 10 people a year will have a liver transplant owing to severe PLD (polycystic liver disease). There are 9 liver transplant centres for adults and children. Unfortunately, the ODT data doesn't show transplants by diagnosis.

In 2014-15, liver transplants fell to 842 and the waiting list increased. Unlike kidney patients, liver patients are prioritised as super-urgent if they require a new liver due to rapid failure of the native organ. This rarely happens in PLD and sadly many people with PKD and PLD have to wait many years before getting a liver transplant.

You can read or download all the presentations from the 2016 RTSM here: www.odt.nhs.uk/transplantation/advisory-groups/kidney/RTSM_2016/ or contact Tess Harris tess.harris@pkdcharity.org.uk if you have specific questions.

The PKD Charity needs your input to its future strategy

The PKD Charity trustees are reviewing the charity's current strategy which was developed in 2013.

We need your input! Some of you will receive a printed copy of a short survey with this newsletter, which you can complete and return to the charity by post.

You can also take part in the survey by using this online link to answer the same questions.

pkd-charity-2016.questionpro.com

All answers are completely anonymous. The written surveys will be destroyed after processing online.

The trustees will meet in September to review the survey answers and agree a revised or new strategy.

Thank you very much for your help! Note that the survey closes on 8 July 2016.



Nick Tracey – new Trustee Treasurer

"I am delighted to have been appointed Treasurer of the PKD Charity and particularly enjoyed meeting patients, professionals and members of families affected by PKD at one of our recent PKD Information Days.

I've already been impressed by the energy and care with which our trustees, chief executive and staff pursue the charity's aims to promote awareness of PKD, funding research and supporting patients and their families. It is an exciting time to be joining the charity as a treasurer. The recently announced Befriending pilot, funded by a successful Lottery 'Awards for All' Grant, demonstrates what we can achieve through grant funding - I'm sure it will be well received. And the survey we've shared this month will be an invaluable source of feedback on what you feel we should focus on when we come to plan our priorities over the next few years - please let us know your thoughts.

I'm looking forward to supporting the



planning, funding and delivery of PKD Charity's good work."

Nick Tracey is currently Vice President, Barclays Treasury, with responsibility for planning, forecasting and stress testing of Barclays Treasury's multi-billion pound balance sheet.

He has experience within risk management, corporate governance and risk culture and is a subscribing member of the ICAEW Financial Services Faculty and Charity and Voluntary Sector Group.

He is a Lay Member of Marie Curie's Research Expert Voices panel and in his spare time enjoys cooking, running and skiing.



www.giveasyoulive.com/join/pkdcharity

PKD Charity 2016 Calendar of Events

16 July ARPKD Family Conference

17 Sep ADPKD Information and Support Day, Sheffield

Nov (TBC) ADPKD Information and Support Day, Salford

Support and Information

Support Available

Our Support Line is available Monday to Friday, 10 am to 4.30 pm or leave a message on the 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
- **The British Kidney Patients Association Advocacy Service**
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/
- **Grants for help with seriously ill or disabled children**
<https://www.familyfund.org.uk/>
- **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 **07715 664687** 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**.

Board of Trustees

Judith Dignum, Chair
Nick Tracey, Trustee Treasurer
Barry Harpham
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