pkd charity

Polycystic Kidney Disease

RaDaR

National Registry of Rare Kidney Diseases

25 years of PKD Charity & 15 years of RaDaR

Polycystic Kidney Disease

The PKD Charity

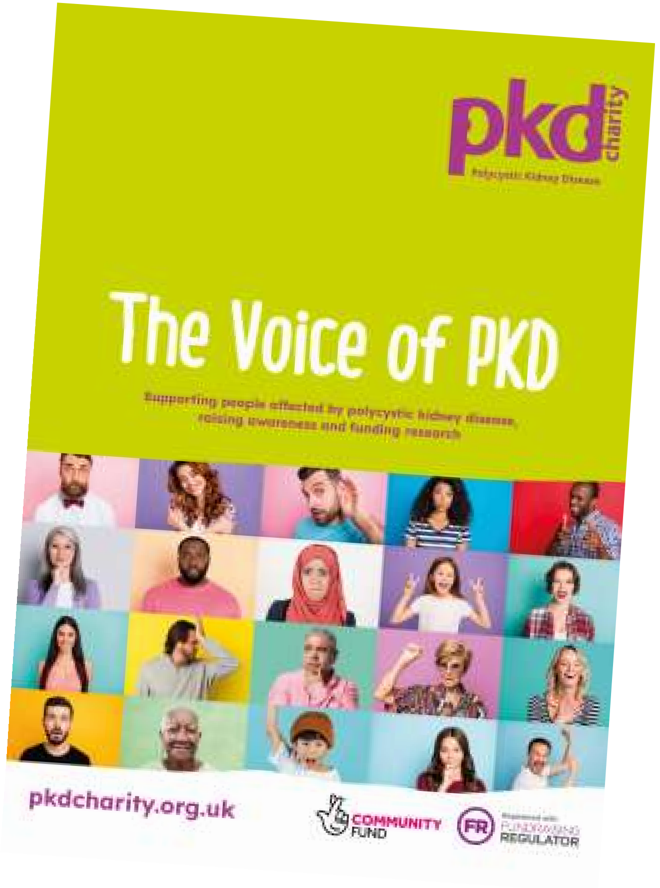
……together the answer

- The charity founded by Prof Anand Saggar in partnership with patient Pam Hooley was registered as a charity in 2000.
- Support individuals and families affected by PKD, generate national awareness campaigns, finance research initiatives to bring about change.
- From the beginning the need to campaign for funds and drive research forward in partnership with patients was a key focus.

pkd charity
Polycystic Kidney Disease

The Voice of PKD Today

- Only UK charity dedicated to improving the lives of PKD families
- Raise awareness of the burden of PKD, clinical and psychosocial
- Alleviate the fear and isolation felt by those affected by PKD by providing support services
- Provide up-to-date, accessible information on PKD
- Forge strong relationships with patients & healthcare professionals working together for the best outcomes
- Drive research advancements for better PKD treatments and care



The Voice of PKD

Supporting people affected by polycystic kidney disease, raising awareness and funding research

pkdcharity.org.uk

Informing Patients

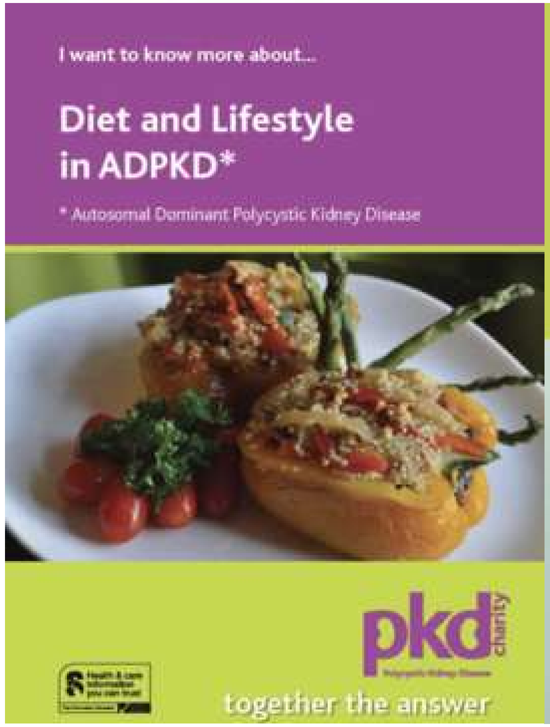
pkd charity
Polycystic Kidney Disease

- Since our first Information day held in Cambridge in 2004 we have held over 100 information events both in person and online
- Our website features information on 40 PKD related topics & receives165,000 visitors per year – co production
- Live Q&A evening sessions are run 6 x per year – 100 attendees + 100s of views of recordings
- In 2021 we launched our PKD app to make information even more accessible

PKD Information & Support Day

Saturday 2 March 2024
10:00 AM - 4.30 PM
Newcastle upon Tyne

Professor John Sayer



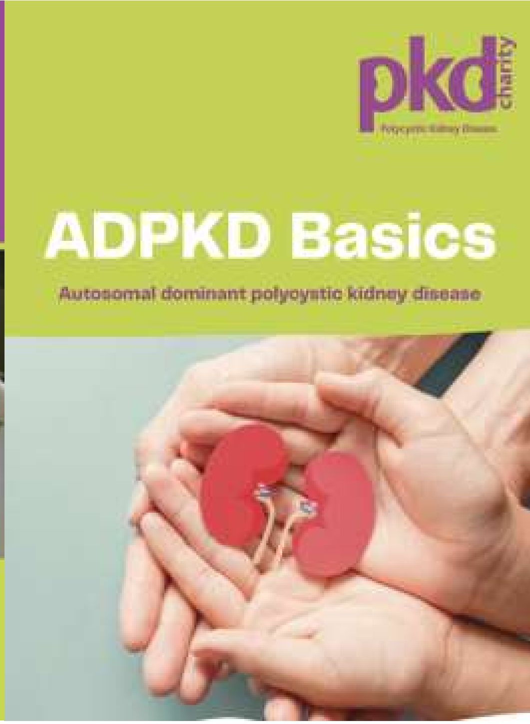
I want to know more about...

Diet and Lifestyle in ADPKD*

* Autosomal Dominant Polycystic Kidney Disease

pkd charity

together the answer



pkd charity

ADPKD Basics

Autosomal dominant polycystic kidney disease

Supporting Patients

- Helpline and email support is provided directly to patients.
- Since our first regional support group was set up in 2007 we now have 8 in person groups and others online.
- Closed Facebook groups are used by 4,000 patients for online peer support moderated by the PKD team
- Workshops and ‘time to talk’ on requested issues are delivered as required

pkd Connect

Friendship & Support for people living with Polycystic Kidney Disease

GROUPS MEETING IN JUNE:
In-person meetup
Derbyshire
London
Newcastle
Norfolk
Staffordshire
Wiltshire

Northern Ireland
Low Clearance
Wales
zoom

> “I joined the low clearance group around a year ago. Sharing experiences about PKD-specific issues is so helpful. You are with people who truly understand our day-to-day lives. Nothing is off the table from transplant, dialysis, itching and holidays. It’s great”

pkd charity
Polycystic Kidney Disease

Research Focus

- Providing funds important but only a part of the work with £771,000 paid in grants to some amazing projects and early career researchers supported
- Understanding the power of researchers, the charity and patients working together to improve the likelihood of advances taking place central to the mission.
- Harnessing the patient voice to draw attention to the inequities of funding into PKD.
- Informing patients of the latest developments and treatments on the horizon, highlighting opportunities to get involved with research, bringing research and patients closer together.

Worldwide experts meet to discuss PKD

Bringing leading scientists from across the globe to discuss a possible breakthrough on drug therapy for PKD was the first financial undertaking by The PKD Charity to promote research into the disease.

New Scientist

‘Hope for inherited kidney disease’

New Scientist magazine ran a story on March 6th 2004 highlighting the progress of a new drug that halts the growth of kidney cysts in rodent models of PKD. Dr Richard Sandford, University of Cambridge, offered his views of the research. You can hear more about the drug, and listen to Dr Sandford talk about PKD, at the Patient Meeting in September.

PKD charity demands action on UK and European research spending

research career opportunities

Medical Research Council MRC

So where are the opportunities for British scientists to work on PKD?

OPC 31260 Tolvaptan clinical trials are underway

Bringing patients and research together

- Involvement in many research initiatives/ projects and bringing the patient perspective to enable better design and outcomes
- Managing PPI and patient involvement in research initiatives and forums
- Making our 6,000 strong patient community aware of opportunities to get involved. Consistently through surveys they tell us how eager they are to do so.
- Informing and educating on research processes, with new projects on the horizon ‘trail ready community’
- Finding out what matters most to the community in terms of research questions – James Lind PSP 2019

ADPKD Chronic Pain Study

HIYA PKD STUDY

Hypertension in Children & Young People at Risk of PKD

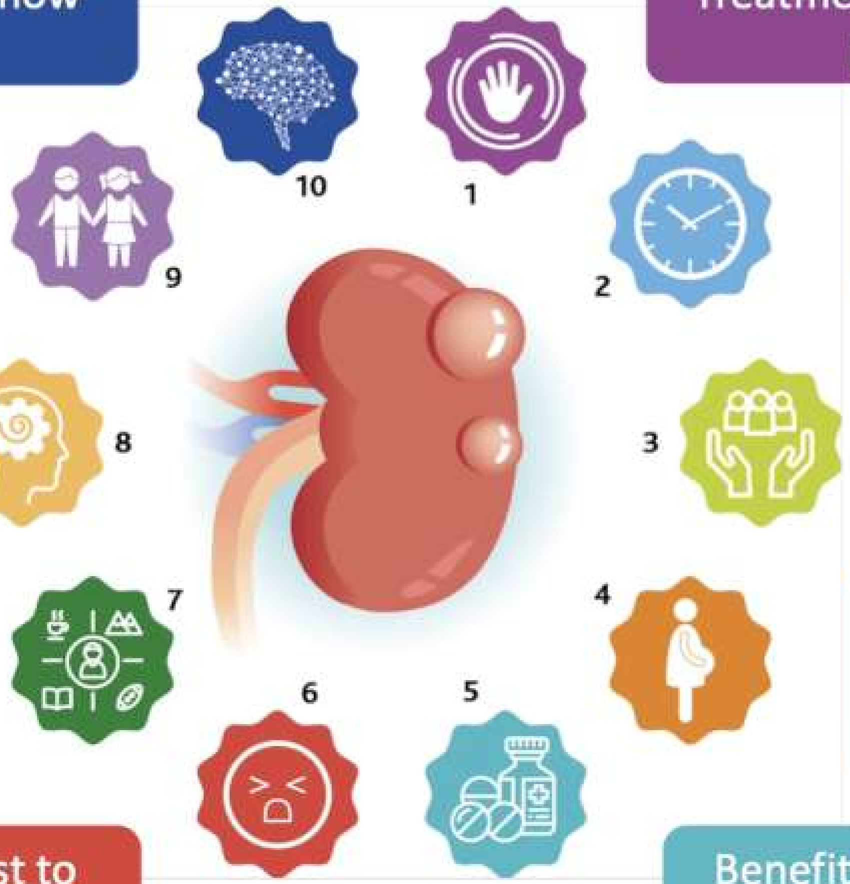
The IMPEDE-PKD trial

AKTN 16.01

pkd charity

Polycystic Kidney Disease

The Top 10 ADPKD research priorities



1. Treatments to slow/prevent progression
2. Who benefits from early treatment and how identified?
3. How should care be organised to improve outcomes?
4. Effect of pregnancy on women including pregnancy health, kidney function, and liver cysts?
5. Benefits and harms of drugs for ADPKD including PLD?
6. What treatments work best to reduce ADPKD pain?
7. What lifestyle, exercise and/or dietary changes are beneficial?
8. How does diagnosis affect people psychologically / impact lives?
9. Benefits and harms of screening / diagnosing ADPKD in at-risk CYPS?
10. What causes aneurysms & how best to screen/treat?

In association with
James Lind Alliance
Priority Setting Partnerships

pkd charity
Polycystic Kidney Disease

Supporting Research Data Infrastructure

- The need for registry for PKD was a key strategic aim of the charity from 2005 onwards.
- 2008 the charity made a 500k bid for funds to set a PKD registry – unsuccessful
- In 2011 a grant was awarded to establish the PKD Charity Bioresource Bank at UCL and subsequently provided additional resources for a research nurse and ongoing annual funding
- In 2012 the charity commissioned a review of ADPKD registries and databases in the UK and the development of technical requirements with appropriate datasets and indicative costing for an ADPKD Charity Registry.
- It was in hindsight wonderful that the charity decided not to go ahead, but the review outcomes fed into the development of RaDaR. The charity financially supported its development and continues to do so.
- Our relationship with RaDaR is much prized, we know how important its role will be, alongside bio resources in getting treatments to our patient community.

pkd charity
Polycystic Kidney Disease

Collaboration is Key

- Researchers, patients, charities and research infrastructure are integral to the journey to treatments.
- Over the last 7 years the charity has been exploring ways to speed up that journey.
- In 2019 we embarked on our first joint funding round with Kidney research UK and began talks on forming a joint approach to making change happen. Together we are stronger.
- The need to find a way to bring together the key people and infrastructure into a central hub was established.
- With a fantastic steering team, links to researchers and clinicians and feasibility study undertaken, the project planning gained great traction.

"Myself and my 2 brothers were diagnosed in our 40s. Both my brothers died in their early 70s. I have 30% kidney function as I approach 75. I try to keep positive and try to live healthily and hope to have a few years left yet. I hang on to hope that a cure or treatment is discovered soon."

"It is an impending dread of what's to come after seeing my mum suffer the pain, breathlessness, haemodialysis and finally passing away from PKD."

"It sucks. At 54, I am in stage 5 kidney disease with an EGFR of 11, I am always exhausted and I'm only half the man I should be."

"My PKD journey began when I was 16. My father died at the age of 40 from PKD therefore the fear of what to expect was constantly with me."

"Living with PKD is hard. It feels unseen and not understood."

"PKD has cast a long shadow over my family. I was diagnosed as a teen. I know that kidney failure is in my future. I am only 30 now but every year I get closer to the age that my Dad's kidneys failed. I am doing my best to keep healthy but every day it feels like that black cloud in the distance of an uncertain future comes that little bit closer. I hope something changes for when I hit kidney failure"

PKD Partnership

Advancing treatments, transforming lives

- PKD Charity and Kidney Research UK have formed a partnership to boost research and development in PKD.
- Our mission is ‘to understand the key drivers of progressive PKD, identify new therapies and improve patient outcomes within 10 years’.
- Our vision is to stop PKD patients needing dialysis and transplantation (kidney/liver).