

ADPKD Information & Support Day

Hosted by:

**Professor John Sayer,
and the PKD Charity UK**



Programme

Date: Saturday 2nd March 2024

Venue: Institute of Transplantation,
Freeman Hospital, Newcastle upon Tyne NE7 7DN

09.30: ARRIVAL & REGISTRATION

10.15 – 10.30: Introduction to the day – John Sayer, Consultant Nephrologist, and The PKD Charity

10.30 – 11.15: ADPKD Basics (what it is, and progression), including Paediatrics and ADPKD – John Sayer, Consultant Nephrologist, and Vincent Tse, Consultant Paediatric Nephrologist

11.15 – 11.45: Tolvaptan and ADPKD – Rachel Fraser, Renal Pharmacist

11.45 – 12.00: BREAK

12.00 – 12.45: Surgical and transplant aspects – David Talbot, Consultant Surgeon, and ADPKD patient Phil Thornton

12.45 – 13.30: Genetics and Research opportunities/Clinical Trials in ADPKD – Shalabh Srivastava, Consultant Nephrologist and Holly Mabillard, Clinical Training Fellow

13.30 – 14.30: LUNCH

WORKSHOPS

SESSION 1: 14.30 – 15.20

1a. Diet & Lifestyle, plus Barriers to Change – Amita Godse and Ekta Chheda, Renal Dieticians, and Susan Rowley, Renal Nurse & Trainee Health Psychologist

1b. Psychological aspects of ADPKD – Dr Penny Wilmott, Clinical Psychologist

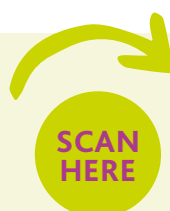
15.20 – 15.30: BREAK

SESSION 2: 15.30 – 16.20

2a. Diet & Lifestyle, plus Barriers to Change – Amita Godse and Ekta Chheda, Renal Dieticians, and Susan Rowley, Renal Nurse & Trainee Health Psychologist

2b. Psychological aspects of ADPKD – Dr Penny Wilmott, Clinical Psychologist

Stay in the loop! Get PKD Charity e-news or printed newsletter, visit:
<https://bit.ly/Stayuptodate>

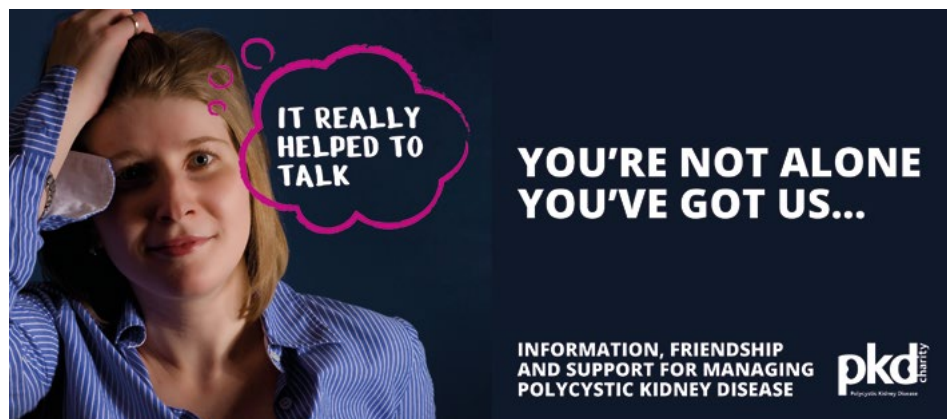


Contact: Jane Pugh – jane.pugh@pkdcharity.org.uk – 07866 490985

Our support services

Helping you cope with PKD

Whether you're looking for PKD information, practical advice or just someone to talk to, we're here to help you.



Ring our Helpline

If you need a friendly person to talk with about your worries or are just looking for information, ring **0300 111 1234**, our confidential helpline. Available from 9:30am to 5:00pm Mon – Fri.

"You'll never know how much I valued speaking to you."



Find a PKD Support Group

For understanding and companionship, join one of our PKD Support Groups. Hosted by trained volunteers with lived experience of PKD. Everyone is welcome – patients, family members and friends.

"It's great to meet others in a similar situation."



Join a Facebook Group

For a friendly and private place to connect and share with others like you, join one of our three UK-only private Facebook groups. There's a group for everyone affected by PKD.

For ADPKD (autosomal dominant polycystic kidney disease)

- PKD Support (PKD Charity UK)
- Parents of children with PKD (PKD Charity UK)

For ARPKD (autosomal recessive polycystic kidney disease)

- ARPKD Support (PKD Charity UK)

"I found the group on Facebook and was immediately immersed into a very friendly and welcoming environment."



Take part in a workshop

Share your experiences and discover new coping strategies in a confidential online space with others

who understand the difficulties of life with PKD. Run by a renal psychologist and psychiatrist.

"To be able to share experiences helped me realise I am not the only one out there feeling the way I do."



Learn more about PKD at an educational event

Want to find out more about PKD, worried for your future, or baffled by the medical jargon? Ask the experts at one of our free educational events.

"Fantastic sessions...a very informative and interesting day."

Visit our website for more information

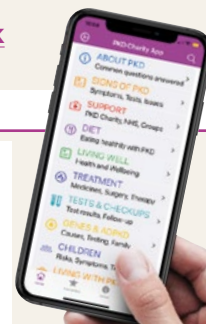
How to get support, visit bit.ly/pkdc-support

Upcoming events, visit bit.ly/pkdc-events

PKD app

Download our **FREE App**, created to inform and educate people who are newly diagnosed or at early stages of PKD.

Scan here



PKD Health Information

If you need reliable information about all aspects of PKD, visit our website for a range of accredited factsheets written by medical experts.

Key factsheets include:

ADPKD Basics

bit.ly/adpkd-basics

Polycystic Liver Disease

bit.ly/adpkd-pld

Diet and Lifestyle in ADPKD

bit.ly/adpkd-diet-lifestyle

ARPKD Basics

bit.ly/arpkd-basics

If you don't use the internet, we can send you printed copies. Just ring our helpline: **0300 111 1234**.

Links to other sources of help

We recommend:

UK Government Benefits Info

www.gov.uk/browse/benefits

Kidney Care UK - individual grants

www.kidneycareuk.org

Turn2us – broad range of advice on welfare benefits and grants

www.turn2us.org.uk

Family Fund – grants for seriously ill or disabled children

www.familyfund.org.uk

Contact - for families with disabled children

contact.org.uk