

European ADPKD Patient Summit

Saturday 16 March 2019

Novotel Brussels Airport Hotel, Brussels, Belgium

Introduction

Autosomal dominant polycystic kidney disease (ADPKD) is a complex, chronic, inherited condition that causes kidney cysts and other manifestations elsewhere in the body. People with ADPKD may need healthcare involving a range of specialist healthcare professionals, according to their individual needs.

The European ADPKD Patient Summit is a unique event designed to promote patient-centred care by providing an interactive forum for patients and experts to discuss ADPKD care, research and advocacy.

Co-hosted by PKD International and the European ADPKD Forum (EAF), the Summit aims to help, inform and empower patients and families to:

- be fully involved in the management of their own health
- talk about ADPKD with their healthcare team and participate in making decisions about their care
- make the best use of available services
- learn about ADPKD research and boost ADPKD advocacy.

The programme has been co-designed and co-delivered by patients and experts from across Europe, based on the EAF/PKD International *ADPKD Patient Route Map* (available at www.pkdinternational.org) and the *EAF Multidisciplinary Position Statement on ADPKD Care* (free online at the *Nephrology, Dialysis and Transplantation* journal).

Sessions cover topics spanning the lifetime care pathway for ADPKD, including self-care and risk reduction, predicting the progress of ADPKD, liver cysts and pain, genetics, and dialysis and transplantation. There are also sessions on current research and patient advocacy in ADPKD, and on industry perspectives.



Programme

Friday 15 March 2019

19:30–22:00 Summit Group Dinner
Opening dinner speech – Richard Sandford (University of Cambridge, EAF co-Chair)

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9:00–9:05 Welcome
Tess Harris (PKD International/ EAF, UK)

9:05–10:00 Plenary I: Developments in the international ADPKD landscape
Opportunity for patients and carers to learn about latest international developments in ADPKD research and care

SESSION CHAIR: **Tess Harris** (PKD International and EAF, UK)

PANELLISTS:

- **Albert Ong**
(Sheffield University, UK and EAF): Latest updates on the Polycystic Kidney Disease Outcomes Consortium (PKDOC)
- **Djalila Mekahli**
(KU Leuven, Belgium and EAF): Latest updates on ADPKD paediatric registries
- **David Baron**
(PKD Foundation, USA): Latest updates on the Standardised Outcomes in Nephrology – Polycystic Kidney Disease (SONG-PKD) study.

10:00–10:50 Breakout 1: Self-care and risk reduction
Opportunity for patients and carers to discuss latest studies and current advice on diet, lifestyle, blood pressure, issues in children etc – matters of key importance to daily living and self-care empowerment to help reduce progression and cardiovascular disease risk.

EAF/EXPERT:

- **Tevfik Ecder**
(Istanbul Bilim University, Turkey and EAF)
- **Djalila Mekahli**
(KU Leuven, Belgium and EAF)

PATIENT REPRESENTATIVE:

- **Flavia Galletti**
(AIRP Italy)

Breakout 2: Predicting the progress of ADPKD
Opportunity for patients and carers to learn about and discuss this increasingly important, but perhaps not widely used or understood, approach with an expert.

EAF/EXPERT:

- **Ron Gansevoort**
(University Medical Center Groningen, Netherlands and EAF)

PATIENT REPRESENTATIVE:

- **Lea Münkner**
(PKD Familiäre Zystennieren e.V., Germany)

10:50–11:10 Coffee break

11:10–12:00 Breakout 3: Liver cysts and pain in ADPKD
Focus on these particularly common and impactful complications for patients.

EAF/EXPERT:

- Liver: **Lucas Bernts**
(Radboud University Medical Center, Netherlands)
- Pain: **Ron Gansevoort**
(University Medical Center Groningen, Netherlands and EAF)

PATIENT REPRESENTATIVE:

- **Natasha O'Brien**
(PKD Charity, UK)

Breakout 4: Genetics and genetic testing
Opportunity for patients and carers to learn about and discuss genetic issues with an expert.

EAF/EXPERT:

- **Richard Sandford**
(University of Cambridge, UK and EAF)

PATIENT REPRESENTATIVE:

- **Jean-Pierre Schiltz**
(AIRG-France)

12:00–12:45

Meet the industry session

Opportunity for attendees to engage with industry representatives.

INDUSTRY: *Palladio Biosciences; Baxter; Sanofi Genzyme*

- **Carmen Walbert** (Baxter), **Neil H. Shusterman** (Palladio Biosciences), **Manish Maski** (Sanofi Genzyme)

MODERATOR:

- **Lee Baker**
(Interel European Affairs)

12:45–14:00

Lunch

14:00–14:50

Breakout 5: Renal replacement therapy

Key issue for people affected by/approaching end-stage disease. Session may touch on dialysis modalities, kidney transplantation and latest updates on artificial kidney development.

EAF/EXPERT:

- **Yves Pirson**
(Université Catholique de Louvain, Belgium)
- **Tom Oostrom**
(Dutch Kidney Foundation, Netherlands)

PATIENT REPRESENTATIVE:

- **Brenda de Coninck**
(EAF)

Breakout 6: Understanding research and getting involved

Opportunity for patients and families to discuss with an active researcher the research landscape in ADPKD, what is underway/planned, and how they can get involved.

EAF/EXPERT:

- **Albert Ong**
(Sheffield University, UK and EAF)

PATIENT REPRESENTATIVE:

- **Daniel Gallego**
(ALCER, Spain)

15:00–15:55

Plenary II: Patient engagement and disease advocacy

Panellists will present and reflect on advocacy initiatives in national/European contexts and discuss challenges, solutions and the future of ADPKD advocacy.

MODERATOR:

- **Tess Harris**
(PKD International and EAF)

PRESENTERS/PANELLISTS:

- **Clim van Daelen**
(Nierpatiënten Vereniging Nederland (NVN), Netherlands)
- **Ines Hernando**
(EURORDIS, Belgium)
- **Juan Carlos Julian**
(ALCER, Spain)
- **Ray Vanholder**
(University of Ghent, Belgium and European Kidney Health Alliance)

15:55–16:00

Closure

Richard Sandford

(University of Cambridge, UK and EAF)

16:00–17:30

Cocktail reception

Summit hosts

PKD International is a global network of patient organisations created to fight all forms of Polycystic Kidney Disease (PKD). PKD International is a non-profit, non-governmental association which carries out its activities internationally. The registered office is in Geneva, Switzerland.

The purpose of PKD International is to enhance the lives of those it affects worldwide.

PKD International achieves its purpose through the following activities:

- Supporting open communication and exchange of ideas between doctors, researchers, other health professionals and patients

- Promotion and facilitation of relevant educational programmes
- Promotion of research into PKD
- Encouraging patient involvement in global research
- Facilitating collaborative fund raising
- Supporting the creation and development of local PKD patient groups
- Communicating and lobbying international governments and other relevant organisations to promote the interests of people with PKD
- Co-operation with other related non-profits, charities, voluntary and statutory bodies.

The European ADPKD Forum is a multidisciplinary, international faculty of experts dedicated to improving the health and quality of life of people with ADPKD.

- In 2015, the EAF published a report '*Translating science into policy to improve ADPKD care*' calling for co-ordinated ADPKD care and greater multi-stakeholder collaboration. This report was formally endorsed by PKD International. The accompanying Brussels Declaration on ADPKD received support from 30 patient organisations in Europe and internationally.

- In 2016, the EAF hosted a Round Table involving representatives from European societies of medical specialists involved in ADPKD care, together with patient organisations. The resulting *EAF Multidisciplinary Position Statement on ADPKD care* is published in the peer-reviewed *Nephrology, Dialysis and Transplantation* journal (online December 2017)
- In 2018, the EAF collaborated with PKD International to produce the *ADPKD Patient Routemap* to help people affected by ADPKD throughout their lifetime care pathway. This is available at www.pkdinternational.org.

EAF experts include:

Nephrology

Prof. Olivier Devuyst
Zurich, Switzerland

Prof. Tevfik Ecdar
Istanbul, Turkey

Dr Ron T. Gansevoort
Groningen, Netherlands

Dr José Luis Górriz
Valencia, Spain

Prof. Djalila Mekahli
Leuven, Belgium

Prof. Albert Ong
Sheffield, UK

Prof. Yves Pirson
Brussels, Belgium

Prof. Vicente E. Torres
Rochester, MN, USA

Hepatology

Prof. Joost P.H. Drenth
Nijmegen, Netherlands

Genetics

Dr Richard Sandford
Cambridge, UK

Patient advocacy

Brenda de Coninck
Bussum, Netherlands

Tess Harris
London, UK

Alastair Kent
London, UK

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