

## European ADPKD Patient Summit - **DRAFT PROGRAMME**

Date: Saturday 16 March 2019

Location: Brussels, Belgium (Novotel Hotel, Brussels Airport).

### Background information

The Summit is joint venture between PKD International and the European ADPKD Forum (EAF).

Sponsorship has been secured from Otsuka and Palladio Biosciences. Discussions are on-going with Sanofi-Genzyme and Baxter.

The Summit content is based on the [EAF/PKD International ADPKD Patient Route Map](#), to help bring to life the Route Map as a tool to help patients and families navigate the ADPKD research and care pathway.

More specially, 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 to participate in making decisions about their own care
- make the best use of available services so that everyone affected by ADPKD gets the care, support and information they need, at the right time
- learn about ADPKD research, and how to participate
- help boost ADPKD advocacy.

### Summit Programme

- Session topics are based on the ADPKD Patient Route Map
- For each session, explanatory 'Rationale' notes in blue explain the main theme to be covered
- Sessions are to be co-led by EAF members and PKDI patient representative. Co-leads are to jointly develop specific content outline / objectives

### Draft Programme

Friday 15 March 2019	
19:30 -22:00	<b>Summit Group Dinner</b> Opening dinner speech – <b>Richard Sandford</b> , Cambridge University, EAF co-Chair - <b>confirmed</b>
Saturday 16 March 2019	
9.00–9.10	<b>Welcome:</b> <b>Tess Harris</b> (PKD International/EAF, UK) - <b>confirmed</b>
9.10–10.00	<b>Plenary I: Developments in the international ADPKD landscape</b> <i>Rationale: Opportunity for patients to learn about latest international developments in ADPKD research and care. Topics to be covered will include: latest updates on the Polycystic Kidney Disease Outcomes Consortium (PKDOC), global paediatric registries, and the Standardised Outcomes in Nephrology—Polycystic Kidney Disease (SONG-PKD) study.</i> Session chair: <b>Tess Harris (PKD International/EAF, UK)</b> Presenter/panellist:

	<ul style="list-style-type: none"> <li>• <b>Albert Ong</b> (Sheffield, UK) - <b>confirmed</b></li> <li>• <b>Djalila Mekhali</b> (UC Leuven, Belgium) - <b>confirmed</b></li> <li>• <b>David Byron</b> (PKD Foundation, USA) - <b>confirmed</b></li> </ul>	
10.00–10.50	<p><b>Breakout 1: Self-care and risk reduction</b></p> <p><i>Rationale: Opportunity 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 CV disease risk.</i></p> <p>EAF/Expert:</p> <ul style="list-style-type: none"> <li>• <b>Tevfik Ecdar</b> (Istanbul, Turkey) - <b>confirmed</b></li> <li>• <b>Djalila Mekhali</b> (Leuven, Belgium) - <b>confirmed</b></li> </ul> <p>Patient representative:</p> <ul style="list-style-type: none"> <li>• <b>Flavia Galletti</b> (AIRP Italy) - <b>confirmed</b></li> </ul>	<p><b>Breakout 2: Predicting the progress of ADPKD</b></p> <p><i>Rationale: Opportunity for patients to learn and discuss this increasingly important, but perhaps not widely used/understood approach, with an expert.</i></p> <p>EAF/Expert:</p> <ul style="list-style-type: none"> <li>• <b>Albert Ong</b> (Sheffield, UK) - <b>confirmed</b></li> </ul> <p>Patient representative:</p> <ul style="list-style-type: none"> <li>• <b>Lea Münkner</b> (PKD Familiäre Zystennieren e.V. , Germany) - <b>confirmed</b></li> </ul>
10.50–11.10	<i>Coffee break</i>	
11.10-12.00	<p><b>Breakout 3: Liver cysts and pain in ADPKD</b></p> <p><i>Rationale: Suggestion to focus on these particularly common and impactful complications for patients.</i></p> <p>EAF/Expert:</p> <ul style="list-style-type: none"> <li>• Liver: <b>Lucas Bernts</b> (Radboud university medical center, Netherlands) - <b>confirmed</b></li> <li>• Pain: <b>Ron Gansevoort</b> (Groningen, Netherlands) - <b>confirmed</b></li> </ul> <p>Patient representative:</p> <ul style="list-style-type: none"> <li>• Name <b>name tbc</b></li> </ul>	<p><b>Breakout 4: Genetics and genetic testing</b></p> <p><i>Rationale: Great opportunity for patients/family members to learn about and discuss genetic issues with an expert. The predicting prognosis session might mention genetic testing too, but among aspects. This session allows all aspects of genetic testing to be explored in detail.</i></p> <p>EAF/Expert:</p> <ul style="list-style-type: none"> <li>• <b>Richard Sandford</b> (Cambridge, UK) - <b>confirmed</b></li> </ul> <p>Patient / community representative:</p> <ul style="list-style-type: none"> <li>• <b>Jean-Pierre Schiltz</b> (AIRG-France) - <b>confirmed</b></li> </ul>
12.00-12.45	<p><b>Meet the industry session</b></p> <p><i>Rationale: Unique opportunity for attendees to engage with industry representatives. Format and content to be developed further, strictly subject to relevant codes of practice.</i></p> <p>Industry: <b>Otsuka</b>; <b>Palladio Biosciences</b>; <b>Sanofi-Genzyme tbc</b> ; <b>Baxter tbc</b></p> <p>Proposed co-moderators: Lee Baker (Interel, EU) – <b>confirmed</b></p>	
12.45–14.00	<i>Lunch</i>	

14.00–14.50	<p><b>Breakout 5: Renal Replacement Therapy</b></p> <p><i>Rationale: key issue for people affected by/approaching end-stage disease. Session will touch on dialysis modalities, kidney transplantation and latest updates on artificial kidney development.</i></p> <p>EAF/Expert:</p> <ul style="list-style-type: none"> <li>• <b>Yves Pirson</b> (Brussels, Belgium) - <b>confirmed</b></li> </ul> <p>Patient representative:</p> <ul style="list-style-type: none"> <li>• <b>Brenda de Coninck</b> (Patient Representative, NVN) - <b>confirmed</b></li> <li>• <b>Tom Oostrom</b> (Dutch Kidney Foundation) - <b>confirmed</b></li> </ul>	<p><b>Breakout 6: Understanding research and getting involved</b></p> <p><i>Rationale: Unique opportunity for patients/families to discuss with active researchers the research landscape in ADPKD, what is underway/planned, and how they can get involved (registries, trials, understanding and disseminating results, national advocacy on research, etc).</i></p> <p>EAF/Expert:</p> <ul style="list-style-type: none"> <li>• <b>Olivier Devuyst</b> (Zurich, Switzerland) - <b>confirmed</b></li> </ul> <p>Patient representative:</p> <ul style="list-style-type: none"> <li>• <b>Daniel Gallego</b> (ALCER, Spain) - <b>confirmed</b></li> </ul>
15.00–15.50	<p><b>Plenary II: Patient engagement and disease advocacy</b></p> <p><i>Rationale: Boosting advocacy is an aim of the meeting. Speakers/panellists to present and reflect on advocacy initiatives/campaign in national contexts, then a panel debate to discuss challenges, solutions, future of ADPKD advocacy.</i></p> <p>Moderator:</p> <ul style="list-style-type: none"> <li>• <b>Tess Harris</b> (PKD International and EAF) - <b>confirmed</b></li> </ul> <p>Presenters/panellists:</p> <ul style="list-style-type: none"> <li>• <b>Clim van Daelen</b> (Policy Advisor, NVN) - <b>confirmed</b></li> <li>• <b>Ines Hernando</b> (ERN and Healthcare Director EURORDIS) - <b>confirmed</b></li> <li>• <b>Juan Carlos Julian</b> (ALCER, Spain) – <b>confirmed</b></li> <li>• <b>Representative from the European Kidney Health Alliance (EKHA)</b> - <b>confirmed</b></li> </ul>	
15.50–16.00	<p>Closure: <b>Richard Sandford</b> (Cambridge, UK; EAF co- Chair) - <b>confirmed</b></p>	
16:00-17:30	<p><i>Cocktail reception</i></p>	

## Appendix 1. European ADPKD Forum members

- Tess Harris, PKD International, London
- Richard Sandford Academic Department of Medical Genetics, University of Cambridge School of Clinical Medicine, Cambridge, UK (EAF co-chair)
- Brenda de Coninck, Dutch Kidney Patient Association (NVN), Bussum, Netherlands
- Olivier Devuyst, Institute of Physiology, Zurich Center for Integrative Human Physiology, University of Zurich, Zurich, Switzerland
- Joost PH Drenth, Department of Gastroenterology and Hepatology, Radboud University, Nijmegen Medical Centre, Nijmegen, the Netherlands
- Tevfik Ecdar, Department of Internal Medicine, Division of Nephrology, Faculty of Medicine, Istanbul Bilim University, Istanbul, Turkey
- Alastair Kent, Patients Network for Medical Research and Health (EGAN), London, UK
- Ron T Gansevoort, Department of Nephrology, University Medical Center Groningen, University of Groningen, Groningen, the Netherlands
- José Luis Górriz, Department of Nephrology, Hospital Clínico Universitario, Valencia, Valencia, Spain
- Djalila Mekahli, PKD Lab, Department of Development and Regeneration and Department of Pediatric Nephrology, University Hospitals Leuven, Leuven, Belgium
- Albert CM Ong, Academic Nephrology Unit, University of Sheffield Medical School, Sheffield, UK
- Yves Pirson, Division of Nephrology, Cliniques Universitaires Saint-Luc, Université catholique de Louvain, Brussels, Belgium
- Vicente E Torres, Division of Nephrology and Hypertension, Department of Internal Medicine, Mayo Clinic, Rochester, MN, USA