

PKD International

Milestones

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PKD International
United Nations for polycystic kidney disease

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We are a global alliance of patient organizations dedicated to a cure for Polycystic Kidney Disease (PKD).

PKD International

Our mission is to improve the lives of an estimated 12.5 million affected by PKD worldwide, and their families and care-givers. We will do this by uniting patients, families, scientists, and healthcare professionals committed to ending PKD.

Sign Up to Our Newsletter

Email Address *

Idea of PKD International was born June 22, 2007 during national convention

- The international PKD community was initiated by the PKD Foundation in 2007. The idea was to **unite the national patient groups** who already fund and organize very successful activities (patient support, research, conferences, awareness ...) in their home countries.
- There were PKD-members from Canada, US, Germany, Switzerland, France,



WG: AW: German participation at Nat Convention and Coordinator Training



info@zystenniere.de
An: 'Morgan Perry'
Cc: 'Uwe Korst (ukorst)'

↩ Antworten

↩ Allen antworten

→ Weiterleiten

Mi 23.05.20

Von: GaryDeGrande [<mailto:pkdmnchapter@comcast.net>]

Gesendet: Samstag, 21. April 2007 17:08

An: Morgan Perry

Cc: Uwe Korst; Tara Fitzgerald

Betreff: German participation at Nat Convention and Coordinator Training

Hi Morgan

We are fortunate this year in having Uwe Korst from Germany joining us at the National Convention and Coordinator Training in Florida. Mark Stone and I have discussed the broad picture with Uwe recently by phone. Uwe has made his plane reservations for arrival June 20th and departure June 24th. Please contact Uwe directly regarding hotel reservations, and any other info that is appropriate. Uwe in particular could use some assistance with travel info from airport to hotel, etc. I just received my packet of info for Florida today and perhaps you could send a similar packet to Uwe. Uwe can be contacted at the above email address. Sorry, but I don't have a postal address yet for Uwe. Thanks for your help.

Gary De Grande



2007

First meeting
PKD International
In Orlando



2008

MoUs between
PKD US and
patient groups

MoU = memorandum of understanding

2009

Agreement on
basic principles
(Paris meeting)



2010

Study on PKD
International
completed

2011

Setup of
PKD International

First European PKD Patient Group Meeting – Basel – June 22, 2009

- Participants from France, Germany, Italy, Switzerland and UK took place.
- See Executive Summary

EXECUTIVE SUMMARY

June 22, 2009, the first European PKD Patient Group Meeting was held in Basel. Participants from France, Germany, Italy, Switzerland and the UK with the following objectives:

- Learn about activities / issues / plans of the national PKD organizations in the field of PKD
- Evaluate possibilities to cooperate in the fields of disease awareness and information campaigns
- Exchange experiences of successful (and less successful) campaigns
- Evaluate opportunities to cooperate in the PKD website expansion
- Learn about Novartis and its activities in PKD

The meeting consisted of short introductory lectures by all participants followed by extensive discussions. The format proved successful in generating discussions and collecting input from the patient group representatives.



Meeting of PKD groups in Paris on behalf of PKD Foundation US

In 2009, a working group set up the guidelines for an international patient organization

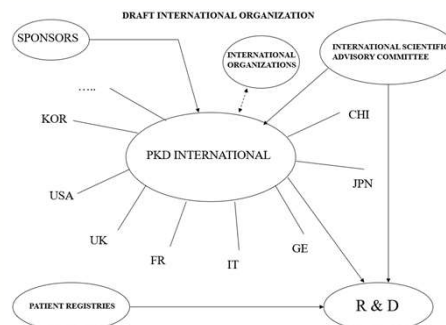
Meeting of European PKD Patient Groups

Saturday, October 17th
Hotel Ibis Paris Tour Eiffel Cambronne 15eme, Paris, FRANCE

Meeting Schedule

Saturday, October 17

9:00am – 6:00pm	Meeting of European PKD Patient Groups (Breakfast & Lunch will be served during this time)
7:30pm	Dinner at a local restaurant



PKD Foundation, Mark Stone (Vize President)
PKD Fam. Zystennieren e.V., Uwe Korst (Vorsitzender)
PKD Charity, Tess Harris (President)
Association Polykystose France, Corinne Lagrafeuille (President)
Association Polykystose France, Richard von Dobenik (Vize President)
AIRP, Prof. Marco Soria (President)
Novartis, Stephan Korste (Direktor Global Advocacy)

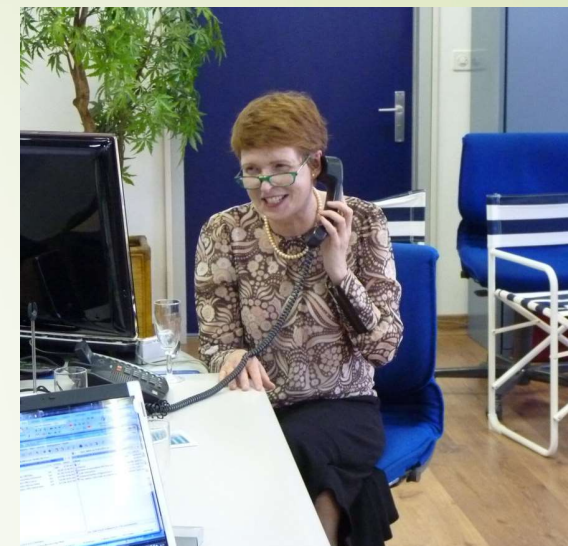
ERA-EDTA 2009 – meeting in Munich

- In 2009, a working group set up the guidelines for an international patient organization and during the International ERA-EDTA (worldwide meeting of nephrologists) in Munich 2010 a strategic plan was worked out.
- Frank Servais / Uwe Korst / Richard von Dobenik and Mark Stone (PKD Foundation)



PKD I – Founding meeting 2011 April 07

- In April 2011, PKD patient groups from Austria, France, Germany, Italy, Switzerland and the UK met in Geneva to establish **PKD International** in Geneva



General Assembly of PKD International 2011 – April 07

Uwe Korst

Draft (Feb 08)

x	TH Tess Harris -UK	X	UK Uwe K
X	RvD Richard von Dobenik - F	X	FS Frank
-	MS Marco Soria	X	CL Corinn
X	BH- Barry Harpham -UK	X	Karine Ha
x	MS – Marina Servais- CH		
X	OD – Prof. Oliver Devuyst – BE		
X	SuS Sussanne Schmidinger OE		
X	DM- Daniel Mundwyler CH	X	Gabriele I
X	CW- Christoph Willi CH		

KDIGO – Controversies Conference in Edinburgh - 2014

- The Conference was held in Edinburgh, United Kingdom on January 17-19, 2014.
- Drs. Vicente E. Torres (Mayo Clinic, USA) and Olivier Devuyst (University of Zurich, Switzerland) co-chaired this conference.
- The objective of this conference was to assess the current state of knowledge
- [Visit the KDIGO website](#) or directly download:
- [Conference Overview & Objectives](#)

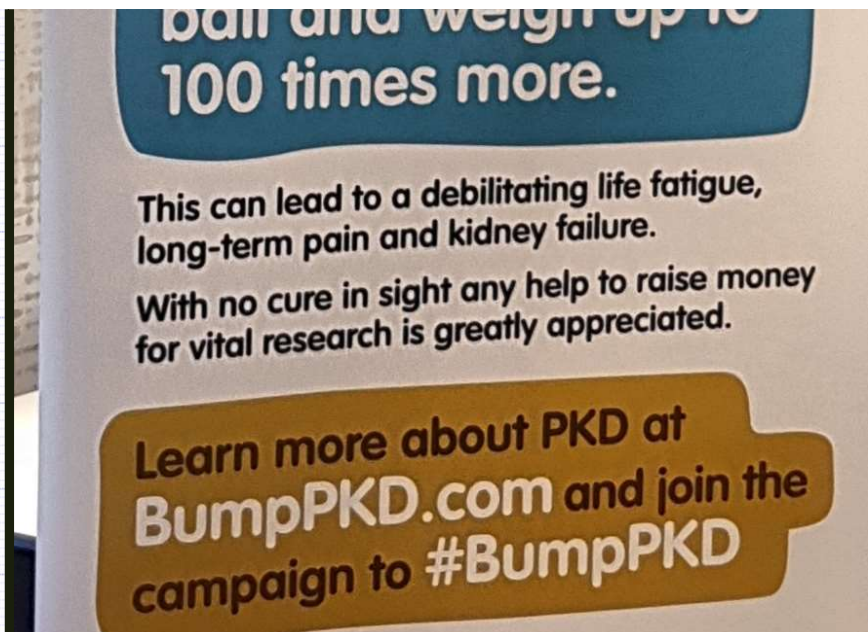


European wide ADPKD awareness campaign Give PKD the bump



- Participants shared and discussed their countries' ADPKD priorities, challenges and developments, discussing opportunities to learn and share information within the patient community
- Social, cultural and economic factors impacting patient healthcare were highlighted, as well as country and pan-European initiatives in ADPKD, including peer support initiatives, patient registries, new research, awareness events and patient days
- Feedback was sought on the ADPKD route map, in development by the European ADPKD Forum (EAF), to ensure its relevance and ease of use by national advocacy groups
 - A follow-up session to gain specific patient perspectives and develop the tone of the route map is to be scheduled
- PKD International (PKDI) reflected on the 2016 Give PKD the Bump campaign and there was consensus to run the campaign again in 2017

ADPKD Patient Advocacy Group London - June 2017



PKD European Patients Day 2019

- On Saturday 16 March 2019, PKD International and the European ADPKD Forum (EAF) hosted the hugely successful 1st European ADPKD Patient Summit – 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.
- [The ADPKD Summit agenda](#)
- [View/download the slides of the ADPKD Summit in one PDF file.](#)



Cilia Cologne 2022 – Representing also PKD International



IVIS TESS HARRIS

Secretariat

Tess is the General Secretary of the Ciliopathy Alliance.

She is also CEO of the Polycystic Kidney Disease (PKD) Charity UK. Tess has autosomal dominant polycystic kidney disease (ADPKD) and received a kidney transplant in 2020. She's a patient representative in several research programmes and networks in the UK and internationally, including the UK ADPKD and ARPKD Clinical Study Groups and ERKNet (European Kidney Reference Network). She is the international patient representative on SONG (Standardised Outcomes in Nephrology Group) and has a particular interest in patient reported outcomes and registries.

RESEARCHGATE

LINKEDIN



ERKNET AD Structural Disorders - 2023

September 2023 Tess asked me to chair the ePAG „AD structural disorders“ group.

