The Netherlands
31 MAY 2014
Vol. 48

THE OTSUKA WHATS & WHOS

Otsuka
people creating
new products
for better health
worldwide

Formation of the European ADPKD Forum

The Forum is a newly formed group of physicians and advocates in Europe dedicated to improving the health and quality of life of people with autosomal dominant polycystic kidney disease (ADPKD). The formation of the European ADPKD Forum (abbreviated as EAF) coincided with the 51st European Renal Association-European Dialysis and Transplant Association Congress that was held in Amsterdam, the Netherlands. The Forum is supported by Otsuka Pharmaceutical Europe Ltd.

The original seeds of Otsuka's engagement on ADPKD can be traced back to research done at Otsuka labs in Tokushima, Japan in the late1980s on vasopressin, a hormone that increases water reabsorption in the kidneys. Otsuka shared the findings with university-based researchers around the world, and subsequent R&D has created significant scientific insights into ADPKD.

The EAF initiative is co-chaired by Tess Harris, President of PKD International, and Dr. Richard Sanford, Consultant Clinical Geneticist at Addenbrooke's Hospital, Cambridge, UK.

Click to learn more about autosomal dominant polycystic kidney disease (ADPKD)

Tess Harris, (left) EAF co-chair and ADPKD patient commented: "ADPKD places a great emotional and physical strain on people with the condition and their families. ADPKD patients experience a diminished and sometimes impoverished quality of life and are at risk of dying prematurely. Healthcare professionals and the wider public simply aren't as aware of ADPKD as they should be and this must be urgently addressed. The EAF initiative will do this by identifying areas for improvement in care inequalities and by establishing a framework in which expertise and learnings can be shared to tackle the ongoing concerns faced by the ADPKD patient and care-giving community throughout Europe."

The EAF is currently developing an expert report that will feature new evidence from the largest-ever survey of ADPKD patients. The report will draw attention to the emotional and physical burdens of living with the disease, as well as explore the potential barriers to the development of innovative treatments for ADPKD.

"This EAF report will provide the most robust overview yet of the wide-ranging impact of ADPKD, how health services are currently set up to meet this challenge, and what changes are needed to improve care development and delivery," says Dr Richard Sandford. The EAF report will be published in late 2014.

The co-chairs and faculty of the EAF do not receive fees for their roles in the initiative and the opinions expressed in EAF publications are solely their own and are not necessarily shared by Otsuka.

The EAF initiative aims to:

- Increase awareness of the impacts of ADPKD on patients and health services
- Recommend health policy strategies to improve ADPKD care, based on the latest scientific evidence and expert insight
- Encourage and facilitate collaboration between the individuals and groups involved in the care and support of people with ADPKD.

What is ADPKD?

ADPKD is a disease arising from one of two possible genetic mutations in which innumerable cysts (sacs in which fluid accumulates) form in the kidney, leading to gradual diminution of renal function. In most cases symptoms begin to show up in the third or fourth decade of life in the form of complaints such as blood in the urine, abdominal or low back pain, and abdominal distention. Also, hypertension may occur before the damage done to the kidneys by ADPKD becomes apparent.

Approximately.50% of ADPKD patients experience end-stage renal disease by age 59 and 75% reach ESRD by age 70.*[1] The disease occurs relatively frequently among genetic disorders and approximately 200,000 people have been diagnosed with ADPKD in Europe, 120,000 in the U.S. and 30,000 in Japan.*[2,*3,*4]

1. Parfrey PS, Bear JC et al. The diagnosis and prognosis of autosomal dominant polycystic kidney disease. *The New England Journal of Medicine*. 1990; 323:1085-1090
2. European Medicines Agency. EU/3/13/1175.2013
3. Data on File. TOLV-002. Otsuka America Pharmaceuticals, Inc.
4. Higashihara E, et al. "Prevalence and renal prognosis of diagnosed autosomal dominant polycystic kidney disease in Japan. Nephron."1998;80:421-7

To further explore ADPKD, here are two useful links:
https://www.pkdcure.org/
http://pkdcharity.org.uk/