



KDIGO Controversies Conference on Common Elements in Uncommon Kidney Diseases

**June 16 – 19, 2016
Amsterdam, Netherlands**

--- CONFERENCE AGENDA ---

Thursday, June 16
18:00 – 20:00 hrs

18:00 hrs **Welcome Reception**
Location: 2B Bar

Friday, June 17
09:00 – 18:30 hrs

06:30 – 09:00 hrs **Breakfast Available**
Location: Scossa Restaurant

Meeting Overview
Location: Koepelzaal

09:00 – 09:10 hrs **Welcome & Introductions**
Presenters: John Davis, KDIGO CEO, David Wheeler & Wolfgang Winkelmayr, KDIGO Co-Chairs

09:10 – 09:20 hrs **Conference Overview & Objectives**
Presenters: Olivier Devuyst & Lisa Guay-Woodford, Conference Co-Chairs

Plenary Session #1
Moderators: Nine Knoers & Jon Klein
Location: Koepelzaal

09:20 – 09:45 hrs **Impact of Rare Diseases on Health Economics**
Presenter: Aris Angelis, London School of Economics

09:45 – 10:10 hrs **Responsible Implementation of Genomic Testing for Rare Kidney Disorders**
Presenter: Martina Cornel, Professor of Community Genetics & Public Health Genomics, VU University Medical Center

10:10 – 10:35 hrs **Regulatory Agencies: Perspectives from FDA & EMA**
Presenters: Bruno Flamion, University of Namur & Segundo Mariz, European Medicines Agency

10:35 – 11:00 hrs **Q&A**

11:00 – 11:10 hrs **Break**
Location: Foyer

Plenary Session #2

Moderators: Detlef Bockenhauer & Ron Perrone
Location: Koepelzaal

11:10 – 11:30 hrs **Patient Group: Muscular Dystrophy**
Presenter: Elizabeth Vroom, United Parent Projects MD

11:30 – 11:50 hrs **Patient Perspective: FEDERG**
Presenter: Daniel Renault, Chair of the Federation of European Associations of Patients Affected by Renal Genetic Diseases

11:50 – 12:10 hrs **Patient Group: PKD Foundation**
Presenter: Julia Roberts, Roberts Resource

12:10 – 12:30 hrs **Q&A**

12:30 – 13:30 hrs **Lunch**
Location: Upper Foyer

Plenary Session #3

Moderators: Simon Day & Franz Schaefer
Location: Koepelzaal

13:30 – 13:55 hrs **How to Build a Reference Center**
Presenter: Giuseppe Remuzzi, Mario Negri Institute

13:55 – 14:20 hrs **Orphanet 20 Years Later: Lessons About Information Needs and Value of Data**
Presenter: Ségolène Aymé, French Institute of Health and Medical Research

14:20 – 14:45 hrs **Case Study: National Organization for Rare Disorders (NORD)**
Presenter: Marshall Summar, Children's National Medical Center

14:45 – 15:15 hrs **Q&A**

15:15 – 15:30 hrs **Break**
Location: Foyer

Plenary Session #4

Moderators: Ségolène Aymé & Julie Ingelfinger

Location: Koepelzaal

- 15:30 – 15:50 hrs **Diagnostic Challenges in Rare Kidney Diseases**
Presenter: Nine Knoers, University Medical Centre Utrecht
- 15:50 – 16:10 hrs **Pediatric Management of Renal Function Decline**
Presenter: Rémi Salomon, Hôpital Necker - Enfants Malades
- 16:10 – 16:30 hrs **Adult Management of Renal Function Decline**
Presenter: Ron Perrone, Tufts Medical Center
- 16:30 – 16:50 hrs **Challenges in Clinical Study Design in Rare Diseases**
Presenter: Simon Day, Clinical Trials Consulting & Training
- 16:50 – 17:20 hrs **Q&A**

Plenary Session #5

Moderators: Julia Roberts & Vicente Torres

Location: Koepelzaal

- 17:20 – 17:40 hrs **Translation from Research to Clinical Care**
Presenter: Tim Goodship, University of Newcastle
- 17:40 – 18:00 hr **Practical & Integrated Patient Support**
Presenter: Dwight Odland, PKD Foundation
- 18:00 – 18:20 hrs **Q&A**
- 18:20 – 18:30 hrs **Closing Remarks**
Presenters: Olivier Devuyst & Lisa Guay-Woodford, Conference Co-Chairs
- 18:30 hrs **Adjourn** (evening on own)

Saturday, June 18
08:00 – 18:30 hrs

- 07:00 – 08:00 hrs **Breakfast Available**
Location: Scossa Restaurant

Breakout Session: Group Discussions

Location: Koepelzaal

08:00 – 08:15 hrs **Recap from Day 1**
Presenter: Lisa Guay-Woodford

08:15 – 08:30 hrs **Breakout Session Remit**
Presenter: Olivier Devuyst

08:30 – 12:30 hrs **Breakout Session 1**

Group 1: Diagnostic Challenges

Discussion Leaders: Jon Klein & Nine Knoers
Location: Amsterdam

Group 2: Management of Renal Function Decline

Discussion Leaders: Detlef Bockenhauer & Ron Perrone
Location: Haarlem - Eindhoven

Group 3: Challenges in Clinical Study Design in Rare Diseases

Discussion Leaders: Simon Day & Franz Schaefer
Location: Rotterdam

Group 4: Translation from Research to Clinical Care

Discussion Leaders: Ségolène Aymé & Julie Ingelfinger
Location: Den Haag

Group 5: Practical & Integrated Patient Support

Discussion Leaders: Julia Roberts & Vicente Torres
Location: Koepelzaal

12:30 – 13:30 hrs **Lunch**
Location: Upper Foyer

Breakout Group Preliminary Reports and Discussion

Location: Koepelzaal

13:30 – 13:50 hrs **Group 1: Diagnostic Challenges**

13:50 – 14:00 hrs **Q&A**

14:00 – 14:20 hrs **Group 2: Management of Renal Function Decline**

14:20 – 14:30 hrs	Q&A
14:30 – 14:50 hrs	Group 3: Challenges in Clinical Study Design in Rare Diseases
14:50 – 15:00 hrs	Q&A
15:00 – 15:20 hrs	Group 4: Translation from Research to Clinical Care
15:20 – 15:30 hrs	Q&A
15:30 – 15:50 hrs	Group 5: Practical & Integrated Patient Support
15:50 – 16:00 hrs	Q&A
16:00 – 16:15 hrs	Break Location: Foyer
16:15 – 18:30 hrs	<u>Breakout Session 2</u> Group 1: Diagnostic Challenges Discussion Leaders: Jon Klein & Nine Knoers Location: Amsterdam Group 2: Management of Renal Function Decline Discussion Leaders: Detlef Bockenhauer & Ron Perrone Location: Haarlem - Eindhoven Group 3: Challenges in Clinical Study Design in Rare Diseases Discussion Leaders: Simon Day & Franz Schaefer Location: Rotterdam Group 4: Translation from Research to Clinical Care Discussion Leaders: Ségolène Aymé & Julie Ingelfinger Location: Den Haag Group 5: Practical & Integrated Patient Support Discussion Leaders: Julia Roberts & Vicente Torres Location: Koepelzaal
19:30 hrs	Group Dinner Location: Restaurant de Silveren Spiegel (Meet in lobby at 19:30 to walk to the restaurant)

Sunday, June 19
08:00 to 12:30 hrs

07:00 – 08:00 hrs **Breakfast Available**
Location: Scossa Restaurant

Breakout Group Final Reports and Discussion

Location: Koepelzaal

08:00 – 08:30 hrs **Group 1: Diagnostic Challenges**

08:30 – 08:50 hrs **Q&A**

08:50 – 09:20 hrs **Group 2: Management of Renal Function Decline**

09:20 – 09:40 hrs **Q&A**

09:40 – 10:10 hrs **Group 3: Challenges in Clinical Study Design in Rare Diseases**

10:10 – 10:30 hrs **Q&A**

10:30 – 10:45 hrs **Break**
Location: Foyer

10:45 – 11:15 hrs **Group 4: Translation from Research to Clinical Care**

11:15 – 11:35 hrs **Q&A**

11:35 – 12:05 hrs **Group 5: Practical & Integrated Patient Support**

12:05 – 12:25 hrs **Q&A**

12:25 – 12:30 hrs **Conference Summation & Next Steps**
Presenters: Olivier Devuyst & Lisa Guay-Woodford