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

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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 Winkelmayer, 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
<table>
<thead>
<tr>
<th>Time</th>
<th>Event Description</th>
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<tr>
<td>11:00 – 11:10 hrs</td>
<td><strong>Break</strong></td>
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<td>Location: Foyer</td>
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<tr>
<td><strong>Plenary Session #2</strong></td>
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<tr>
<td>Moderators: Detlef Bockenhauer &amp; Ron Perrone</td>
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<td>Location: Koepelzaal</td>
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<tr>
<td>11:10 – 11:30 hrs</td>
<td><strong>Patient Group: Muscular Dystrophy</strong></td>
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<td>Presenter: Elizabeth Vroom, United Parent Projects MD</td>
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<td>11:30 – 11:50 hrs</td>
<td><strong>Patient Perspective: FEDERG</strong></td>
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<td>Presenter: Daniel Renault, Chair of the Federation of European Associations of Patients Affected by Renal Genetic Diseases</td>
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<td>11:50 – 12:10 hrs</td>
<td><strong>Patient Group: PKD Foundation</strong></td>
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<td>Presenter: Julia Roberts, Roberts Resource</td>
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<td>12:10 – 12:30 hrs</td>
<td><strong>Q&amp;A</strong></td>
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<td>12:30 – 13:30 hrs</td>
<td><strong>Lunch</strong></td>
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<td><strong>Plenary Session #3</strong></td>
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<td>Moderators: Simon Day &amp; Franz Schaefer</td>
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<td>Location: Koepelzaal</td>
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<td>13:30 – 13:55 hrs</td>
<td><strong>How to Build a Reference Center</strong></td>
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<td>Presenter: Giuseppe Remuzzi, Mario Negri Institute</td>
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<td>Presenter: Ségolène Aymé, French Institute of Health and Medical Research</td>
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<td>14:20 – 14:45 hrs</td>
<td><strong>Case Study: National Organization for Rare Disorders (NORD)</strong></td>
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<td>Presenter: Marshall Summar, Children’s National Medical Center</td>
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<td>14:45 – 15:15 hrs</td>
<td><strong>Q&amp;A</strong></td>
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<td>15:15 – 15:30 hrs</td>
<td><strong>Break</strong></td>
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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)

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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 Devuyyst

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  Breakout Session 2

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