



Global Action. Local Change.

# **KDIGO Controversies Conference Nephropathic Cystinosis**

**December 11-13, 2014  
Lisbon, Portugal**

**--- CONFERENCE AGENDA ---**



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**THURSDAY, DECEMBER 11**

**18:00 – 20:00 hrs**

- 18:00 hrs      **Welcome Reception & Introductory Videos**  
Location: Room I
- 19:00 – 19:15 hrs      **Opening Remarks**  
Presenter: John Davis, KDIGO CEO
- 19:15 – 20:00 hrs      **Conference Overview**  
Presenters: Craig Langman & Elena Levtchenko, Conference Co-Chairs
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**FRIDAY, DECEMBER 12**

**09:00 – 18:30 hrs**

- 07:00 – 09:00 hrs      **Continental Breakfast Available**  
Location: Saldanha Mar Restaurant
- Introduction: Meeting Overview**  
Location: Room I
- 09:00 – 09:15 hrs      **Recap of Conference Overview and Objectives**  
Presenters: Craig Langman & Elena Levtchenko, Conference Co-Chairs
- Plenary Session: Overarching Lectures**  
Location: Room I
- 09:15 – 9:45 hrs      Basic and Translational Science  
**How does cystinosis deficiency leads to cell damage & how can it can be repaired?**  
Presenter: Francesco Emma



- 9:45 – 10:15 hrs      Diagnostics and Biochemical Follow-Up  
**Genetics, prenatal diagnosis, WBC cystine measurements**  
Presenter: Bruce Barshop
- 10:15 – 10:45 hrs      **How can we build on existing registries? Would a global registry improve patient outcomes?**  
Presenter: Rick Kaskel
- 10:45 – 11:15 hrs      Management of Infants and Children with Cystinosis  
**Growth, feeding, treatment of renal Fanconi syndrome. Does early treatment with substrate depletion therapy prevent late complications?**  
Presenter: Katharina Hohenfellner
- 11:15 – 11:30 hrs      **Break**  
Location: Foyer

**Plenary Session: Overarching Lectures (cont'd)**

Location: Room I

- 11:30 – 12:00 hrs      Adolescent Issues  
**Kidney transplantation, recognition of systemic disease needs; transition to adult clinics**  
Presenter: Julian Midgley
- 12:00 – 12:30 hrs      Adult Issues and Management of Extra-Renal Manifestations of Cystinosis  
**Neurological complication, ocular involvement, endocrinologic issues**  
Presenter: Aude Servais
- 12:30 – 12:45 hrs      **Review of Breakout Group Questions & Remit**  
Presenters: Craig Langman & Elena Levtchenko, Conference Co-Chairs



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12:45 – 13:45 hrs     **Lunch**  
Location: Bonsai Restaurant

**Breakout Session: Group Discussions**

13:45 – 15:45 hrs     **Breakout Group 1: Basic and Translational Science**  
Discussion Leaders: Francesco Emma & Jess Thoene  
Location: Room II

**Breakout Group 2: Diagnostics and Biochemical Follow-Up**  
Discussion Leaders: Bruce Barshop & Chris Ottolenghi  
Location: Room V

**Breakout Group 3: Management of Infants and Children with Cystinosis**  
Discussion Leaders: Paul Goodyer & Neveen Soliman  
Location: Room IV

**Breakout Group 4: Adolescent Issues**  
Discussion Leaders: George Deschênes & Julian Midgley  
Location: Room III

**Breakout Group 5: Adult Issues and Management of Extra-Renal Manifestations of Cystinosis**  
Discussion Leaders: Graham Lipkin & Aude Servais  
Location: Room I

15:45 – 16:00 hrs     **Break**  
Location: Foyer



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**Plenary Session: Breakout Group Reports**

Location: Room I

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| 16:00 – 16:30 hrs | <b>Breakout Group 1: Basic and Translational Science</b>  |
| 16:30 – 17:00 hrs | <b>Breakout Group 2: Diagnostics and Biochemical Follow-Up</b>  |
| 17:00 – 17:30 hrs | <b>Breakout Group 3: Management of Infants and Children with Cystinosis</b>   |
| 17:30 – 18:00 hrs | <b>Breakout Group 4: Adolescent Issues</b>  |
| 18:00 – 18:30 hrs | <b>Breakout Group 5: Adult Issues and Management of Extra-Renal Manifestations of Cystinosis</b>                          |
| 18:30 hrs         | <b>Adjourn</b>  |
| 19:30 hrs         | <b>Reception &amp; Group Dinner</b><br>Location: Panorama Restaurant<br>Meet in hotel lobby @ 19:15 to walk to restaurant |

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**SATURDAY, DECEMBER 13**

**09:00 – 16:00 hrs**

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| 07:00 - 09:00 hrs | <b>Continental Breakfast Available</b><br>Location: Saldanha Mar Restaurant  |
| 09:00 - 09:15 hrs | <b>Brief recap from Day #1</b><br>Presenters: Craig Langman & Elena Levtchenko, Conference Co-Chairs<br>Location: Room I |



**Final Breakout Session: Discussions & Preparation of Recommendations Presentation**

09:15 – 10:15 hrs

**Breakout Group 1: Basic and Translational Science**

Discussion Leaders: Francesco Emma & Jess Thoene

Location: Room II

**Breakout Group 2: Diagnostics and Biochemical Follow-Up**

Discussion Leaders: Bruce Barshop & Chris Ottolenghi

Location: Room V

**Breakout Group 3: Management of Infants and Children with Cystinosis**

Discussion Leaders: Paul Goodyer & Neveen Soliman

Location: Room IV

**Breakout Group 4: Adolescent Issues**

Discussion Leaders: George Deschênes & Julian Midgley

Location: Room III

**Breakout Group 5: Adult Issues and Management of Extra-Renal Manifestations of Cystinosis**

Discussion Leaders: Graham Lipkin & Aude Servais

Location: Room I

10:15 – 10:30 hrs

**Break**

Location: Foyer

**Plenary Session: Final Breakout Group Reports**

Location: Room I

10:30 – 11:15 hrs

**Breakout Group 1: Basic and Translational Science**

11:15 – 12:00 hrs

**Breakout Group 2: Diagnostics and Biochemical Follow-Up**



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12:00 – 13:00 hrs	<b>Lunch</b> Location: Bonsai Restaurant
13:00 – 13:45 hrs	<b>Breakout Group 3: Management of Infants and Children with Cystinosis</b>
13:45 – 14:30 hrs	<b>Breakout Group 4: Adolescent Issues</b>
14:30 – 14:45 hrs	<b>Break</b> Location: Foyer
14:45 – 15:30 hrs	<b>Breakout Group 5: Adult Issues and Management of Extra-Renal Manifestations of Cystinosis</b>
15:30 – 16:00 hrs	<b>Final Prioritization &amp; Conference Summation</b>
16:00 hrs	<b>Adjourn</b>