KDIGO Controversies Conference  
Nephropathic Cystinosis  

December 11-13, 2014  
Lisbon, Portugal

--- CONFERENCE AGENDA ---
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 Levchenko, Conference Co-Chairs

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 Levchenko, Conference Co-Chairs

Plenary Session: Overarching Lectures
Location: Room I

09:15 – 9:45 hrs  Basic and Translational Science
How does cystinosin 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 Levchenko, Conference Co-Chairs
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
Plenary Session: Breakout Group Reports
Location: Room I

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

SATURDAY, DECEMBER 13
 09:00 – 16:00 hrs

07:00 - 09:00 hrs  Continental Breakfast Available
                   Location: Saldanha Mar Restaurant

09:00 - 09:15 hrs  Brief recap from Day #1
                   Presenters: Craig Langman & Elena Levchenko, Conference Co-Chairs
                   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
12:00 – 13:00 hrs  Lunch  
Location: Bonsai Restaurant

13:00 – 13:45 hrs  Breakout Group 3: Management of Infants and Children with Cystinosis

13:45 – 14:30 hrs  Breakout Group 4: Adolescent Issues

14:30 – 14:45 hrs  Break  
Location: Foyer

14:45 – 15:30 hrs  Breakout Group 5: Adult Issues and Management of Extra-Renal Manifestations of Cystinosis

15:30 – 16:00 hrs  Final Prioritization & Conference Summation

16:00 hrs  Adjourn