

7th International Cystinosis Congress – Beyond of Borders
June 28-July 1, 2012
Marriott Roissy, Paris, France

Preliminary program

Thursday, June 28 17h – 20h Welcome Reception

Friday June 29

8h30 – 9h30 : Welcome: Valerie Hotz, Daniel Renault, Patrick Niaudet

V. Hotz Hobbs Humanitarian Award

A Riggs Celebrity Spokesperson

D. Hammond Building Community

J. Braza Keynote Speaker

Plenary session

9h30 – 10h S. Cherqui Bone marrow and gene therapy for cystinosis

10h – 10h20 B. Gahl 50 years of cystinosis research and treatment

10h20 – 10h40 C. Antignac Genetics of cystinosis and prenatal counseling

10h40 – 11h Coffee Break

11h00 – 11h 20 G. Deschênes Renal disease in cystinosis

11h20h – 11h40 P. Cochat Endocrine problems in cystinosis

Parallel sessions : Panel discussions with experts

11h50 – 13h : Genetics and cystinosis

11h50 – 13h : Research and cystinosis

13h – 14h : Lunch

Plenary session

14h – 14h20 A. Servais Adults with cystinosis

14h20 – 14h40 N. Webb Transition from pediatric to adult care

14h40 – 15h N. Webb Improving compliance in patients with cystinosis

15h – 15h20 B. Cabrera Cure Cystinosis International Registry

15h20 – 15h40 P. Niaudet The European Registry

15h40 – 16h W. van't Hoff Lessons from other rare diseases

16h – 16h20 Coffee Break

Parallel sessions

16h20 – 17h30 : Workshop for grandparents and extended family

Don Hammond

16h20 – 17h30: Living with Cystinosis/patient panel discussion

16h20 – 17h30 : Session for professionals

Saturday June 30

Plenary session

9h30 – 9h 50 Ranjan Dohil Gastro-intestinal problems in cystinosis

9h50 – 10h10 D. Trauner Muscle wasting in cystinosis

10h10 – 10h30 D. Trauner Neurological complications in cystinosis

10h30 – 10h50 M. Del Monte Ocular manifestations in cystinosis

10h50 – 11h 10 Coffee Break

11h10 – 11h 30 E. Levtchenko Growth in patients with cystinosis disease

11h30 – 11h50 A Servais Pregnancy in patients with cystinosis

11h50 – 12h10 Bernard Golse Psychological help at key stages of patients life

12h10 – 13h : **Poster session**

13h – 14h : Lunch

Plenary session

14h – 14h20 F. Emma Symptomatic treatment in cystinosis

14h20 – 14h40 E. Levtchenko Cysteamine treatment and adverse events

14h40 – 15h C. Langman Long acting cysteamine

15h – 15h20 M. Del Monte New cysteamine collyriums

15h20 – 15h40 P. Niaudet Renal transplantation in cystinosis

15h40 – 16h B. Gahl Long-term outcome in cystinosis

16h – 16h20 Coffee Break

Question and answer session

16h30 – 17h30 : Workshop for Children/Parents F. Emma moderator

16h30 – 17h30: Workshop for adult patients B. Gahl moderator

16h30 – 17h30: Workshop for young adult patients W. van't Hoff moderator

16h30 – 17h30 : Group discussion on psychological support Bernard Golse,

Sunday July 1st

Question and answer sessions

8h30 – 9h30 : Neurological and psychological problems

9h30 – 10h30 : Gastro-intestinal problems, feeding and growing

10h30 – 11h30: Preserving renal function

11h30 – 12h : Concluding remarks and adjournment