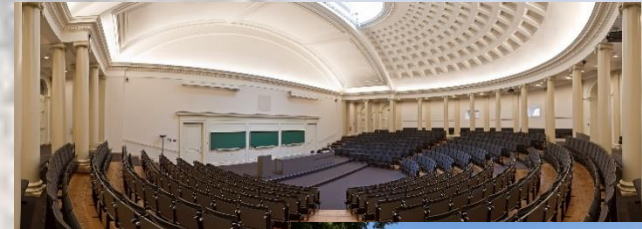


Invitation

3rd CNE International Cystinosis Conference

- Date: July 7-10, 2022
- Venue:
 - Maria-Theresia College
 - Sint-Michielsstraat 6, 3000 Leuven
- Conference website: <https://cystinosis.eu/>
- Registration: https://cystinosis.eu/?page_id=1027
- Hotels: <https://cystinosis.eu/> take tab Hotel in top of home menu
- Questions: cystinose@ziggo.nl



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Program Outline

Day	Date	Time	Description	Attendance
Thursday	July 7, 2022	13:00-17:00	Research Meeting	Researchers, Medical Doctors, CNE members
		13:00-17:00	Paramedical Meeting	Nurses, Social workers, Psychologists, Dieticians
		17:30-19:30	Welcome Reception	All participants
Friday & Saturday	July 8 & 9, 2022	08:30-18:00	Main Conference & Poster Sessions	All participants
Sunday	July 10, 2022	09:00-12:30	Workshops	Patients & families



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Social Program

Day	Date	Time	Description	Attendance
Thursday	July 7	17:30-19:30	Welcome Reception	All
Friday & Saturday	July 8 & 9	08:30-18:00	Childcare (Excl. Lunch)	Age 4-12
Sunday	July 10	09:00-12:30	Childcare	Age 4-12
Friday	July 8	19:00-22:00	Percussion Workshop & Dinner	Patients & Siblings 13-18 only
		19:00-22:00	Cooking Workshop	Adult Patients only
		20:00-21:30	Walking tour Leuven	Who wants to join
Saturday	July 9	09:00-12:45	Cartoon Workshop	Patients & Siblings 13-18 only
		13:45-14:45	Motivational Speaker	Patients & Families
		19:00-21:00	Conference Dinner	All
Sunday	July 10	10:15-12:00	Graffiti tour Leuven	Patients & Siblings 13-18 only

Research Meeting

Sessions:

1. Novel disease models for cystinosis
 - In vitro and In vivo models
2. Towards innovation in the treatment of cystinosis
 - Gene therapy
 - Fertility
 - Eye treatment

Paramedical Workshop

Sessions (preliminary):

1. How to fit the intake of cysteamine with the food & drinks schedule
2. Transitioning from tube to oral feeding
3. Therapy compliance
4. Transition from paediatric to adult care



Main Conference

Sessions:

1. Cystinosis: a global view
2. How to monitor cysteamine treatment?
3. How to improve current treatment?
4. Cystinosis as a multi organ disease
5. Future perspectives: from newborn screening to gene therapy
6. Quality of life & Workshops



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