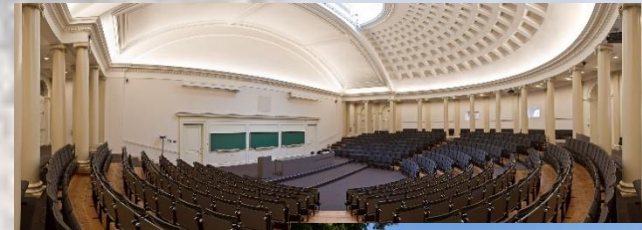


# Invitation

## 3<sup>rd</sup> 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](https://cystinosis.eu/?page_id=1027)
- Hotels: <https://cystinosis.eu/> take tab Hotel in top of home menu
- Questions: [cystinose@ziggo.nl](mailto:cystinose@ziggo.nl)



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# Program Outline

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



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# Social Program

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