



**Cystinosis
Network Europe**

European Cystinosis Conference

**July 13 – 15, 2018
in Berlin / Germany**

**From innovative science
to better clinical care**

2 Programme

Friday, July 13*

9.00 h – 13.00 h **Novel therapies for cystinosis**

Meeting of E-Rare consortium

The meeting is open to all professionals and patient organisation representatives (English only, no translation)

15.00 h – 15.10 h **Welcome and Opening****

15.10 h – 15.30 h **Where do we come from?***

What are our visions for the future?

Prof. Dr. Erik Harms

15.30 h – 16.15 h **What is cystinosis?** Prof. Dr. William Gahl

The basics for everybody

16.30 h – 17.45 h **Discussion in smaller groups**

e.g. Kidneys health and failure prior transplantation
Fanconi syndrome / Dialysis and transplantation
Any other kidney related questions

**Groups are chaired by a medical specialist and experienced patients.
We split in language groups if necessary.**

16.30 h – 17.45 h **Cystinosis facts I** PD Dr. Katharina Hohenfellner for adolescents and young adults only

Saturday, July 14*

8.30 h – 13.00 h **Talks and discussions in plenary session****

All topical subjects are presented by a medical specialist and put into a non-medical perspective by a patient/parent.

8.30 h – 9.10 h **Eyes** Dr. Rachel Bishop MD MPH General overview on eye problems **Questions and discussion**

9.15 h – 9.55 h **Neurological problems** Dr. Liesbeth de Waele MD, PhD General overview / Particular Adult problems **Questions and discussion**

Coffeebreak

*The program might slightly change.

Saturday, July 14*

- 10.10 h – 10.40 h Muscles** Craig Langman MD
Overview, problems and therapy
- 10.40 h – 11.10 h Orthopedic Problems** Dr. Nadine Herzig
Overview – physiotherapy – sports – surgery
- 11.10 h – 11.30 h Questions and discussion**
- 11.10 h – 12.20 h Cystinosis facts II** PD Dr. Katharina Hohenfellner
for adolescents and young adults only
- 11.40 h – 12.20 h Growth / Growth hormone** Prof. Dr. Dieter Haffner
Introduction and discussion
- 12.30 h – 13.00 h Introduction Poster Session** (extra Flyer)
- 13.00 h – 14.00 h Lunch and Poster Session Visit**
- 14.00 h – 14.40 h Pharmacology** Prof. Dr. Michael Arand
Overview on drugs and medications / Interactions between medications / Side effects
New drugs to come
Questions and discussion
- 14.50 h – 15.20 h Sexual hormones in male patients**
PD Dr. Julia Rohayem
- 15.30h – 15.50 h Fertility / Pregnancy** a case study
Martine Besouw MD, PhD, Dr. Graham Lipkin
- 15.50 h – 16.30 h Questions and discussion** Chair: Dr. Aude Servais
- Coffeebreak**
- 16.45 h – 18.00 h News from research**
Ongoing projects and newly planned research
Dr. Achim Treumann, Prof. Dr. Elena Levchenko
and others
- 18.45 h Final meeting** (Please be in time not to miss this special meeting!!)
Dinner will start right after that.

**Translation or whisper-translation will be available: English, German, French, Spanish, Italian, Dutch.

4 Programme

Sunday, July 15*

9.00 h – 9.45 h Positive health Wibo Drijfhout, Marjolein Bos
How to live with a chronic disease in a positive way? See the problems but stick to the good moments in your personal life.
Social participation, mental well being, friendship and relations, work etc

10.00 h – 11.30 h Workshops with roundtables
Discuss with others who know what it's like to live with cystinosis!

- for parents of young children
- for adolescents and adults
- for parents of adolescents and adults

All groups will be led by professionals and experienced patients.

11.30 h Final meeting for fare well and good bye

Experts in place

This conference would not be possible without specialists spending their time and sharing their knowledge. We appreciate very much the participation of these professionals not mentioned in the entire programme: **Dra. Gema Ariceta, Dr. Florian Eichler, Dr. Marcella Greco, Dr. Paul Goodyer, Paul Grimm, Dr. Mohamed Ibrahim, Dr. Manoe Janssen, Prof. Dr. Neveen Soliman, Prof. Dr. Rezan Topaloglu MD, Alexey Tsygin MD, Koenraad Veijs MD**

This conference is organised by Cystinosis Network Europe

Cystinosis Ireland	Cystinose France
Cystinosis Foundation UK	Asociación Cistinosis España (ACE)
Cystinose Groep Nederland	AIRG-España
Cystinosis Group Belgium	Associazione Cistinosi, Italy
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