



**Cystinosis
Network Europe**

European Cystinosis Conference

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

**From innovative science
to better clinical care**

2 Program

Friday, July 13*

8 h Registration open

9 h – 15.00 h Preliminary Program

Novel therapies for cystinosis

Specialists' meeting for members of this workgroup. The meeting is open for all professionals and patient representatives to listen. (English only, no translation)

14 h – 18 h Child Care open

15 h – 15.15 h Welcome and Opening

15.15 h – 16 h What is cystinosis?

The basics for everybody

16.15 h – 17.45 h Discussion in smaller groups

All groups are chaired by a medical specialist and experienced patients

Kidneys before transplantation / Fanconi syndrome
Feeding problems in cystinosis
and any other upcoming questions

18.30 h Welcome meet and greet

Drinks and snacks

Saturday, July 14*

8 h Registration open

8.15 h – 13 h Child Care

8.30 h Welcome again and information in plenum

9 h – 13 h Talks and discussions in plenum

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

*The program might slightly change.

Saturday, July 14***9 h – 9.50 h Eyes**

General overview on eye problems

All you should know about eye checks and therapy

Late onset cystinosis

10 h – 10.50 h Neurologic problems

General overview / Special Adults' problems

11 h – 12.50 h Muscles / Orthopedic Problems / Growth

Muscles: Overview, problems and therapy

Orthopedic problems: General questions – physiotherapy -- Sports

Problems to be discussed: knock-knees, joint pain, bone pain

Growth / Growth Hormone: Introduction and discussion

13 h – 14 h Lunch & Poster Session**14 h – 18 h Child Care****14 h – 14.50 h Dialysis / Transplantation**

Overview: What does dialysis mean?

Different kinds of dialysis, life under dialysis

Overview: What is transplantation?

Precondition, donors, immunosuppressive therapy – all upcoming questions will be answered as good as possible.

15 h – 15.50 h Pharmacology

Overview on drugs and medications

Interactions between medications, new drugs to come, side effects

16 h – 16.50 h Hormones / Fertility / Pregnancy

General overview on hormone substitution in adolescents

News and hopes

17 h – 17.45 h News from research

Ongoing projects and newly planned research

19 h Dinner (please register at the info desk)

*The program might slightly change.

4 Program

Sunday, July 15*

8 h Registration open

9 h – 11.30 h Child Care

9 h – 9.45 h Positive health

How to live with a chronic disease in a positive way? See the problems but stick to the good moments in your personal life. Just come and test it, it is worth a try!

10 h – 11.30 h Workshops with roundtables

Discuss with others knowing your condition!

All groups will be led by professionals and experienced patients. Please register for one group on Saturday already.

- for parents of young children
- for children (if wanted)
- for adolescents (ca. age 12 – 18)
- for adults
- for parents of adolescents and adults

11.30 h Final meeting for fare well and good bye

Specialists and Speakers

Gema Ariceta

Rachel Bishop

Federico Emma

William Gahl

Paul Goodyer

Paul Grim

Dieter Haffner

Erik Harms

Nadine Herzig

Katharina Hohenfellner

Machteld Huber

Craig Langman

Elena Levtchenko

Graham Lipkin

Galina Nesterova

Aude Servais

Neveen Soliman

Rezan Topaloglu

Achim Treumann

Alexander Tsygin

Liesbeth de Walle

*The program might slightly change.

Good to know

Child care in different groups will be provided.

Friday: 14 h - 18 h

Saturday: 8.15 h – 12.50 h; 14 h – 18 h

Sunday: 9 h – 11.30 h

Please give your children's age when registering to the conference. This is easier to plan. Depending on the weather there will be inside and outside activities (no swimming!).

Please note that child care will be closed in lunch-time and after 18.00 h

Adolescents

There will be some special program not finally decided yet before printing this. Please ask at the info desk while the conference.

Registration and Hotel

Registration

The easiest way is using this link:

<https://www.cystinosis-conference-berlin-2018.eu/english/registration/>

Conference fee is € 50 / person or € 100 / family.

This contains entrance, beverages, lunch and dinner on Saturday, child care, conference package with lots of information.

the information desk will be open all three days to your convenience.

The bank account is given on the website. For any questions please mail to: **info@cystinosis-europe.eu** or call us: Tel. +49 / 2102 / 69627

Conference venue

Hotel Movenpick, Schöneberger Str. 3, 10963 Berlin

Tel. : +49 / 30 / 230060

recommended Airport: Berlin-Tegel (TXL)

recommended railway station: Berlin Hauptbahnhof

The closest underground- or busstation is:

Anhalter Bahnhof (200 m to walk)

Please book your room at a special price using the link given on our conference website **www.cystinosis-conference-berlin-2018.eu**

Funding

Without funding and donations this conference could never take place. We would like to thank all our donors.



BARMER Das Projekt wird im Rahmen der Selbsthilfeförderung nach § 20 h Sozialgesetzbuch V finanziert durch die BARMER. Gewährleistungs- oder Leistungsansprüche gegenüber der Krankenkasse können daraus nicht erwachsen. Für die Inhalte und Gestaltung sind das Cystinosis Network Europe und die Cystinose-Selbsthilfe e.V. verantwortlich.

This conference is organised by Cystinosis Network Europe and Cystinose-Selbsthilfe e.V., Germany

Cystinosis Network Europe:

Cystinosis Ireland
 Cystinosis Foundation UK
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 Cystinosis Group Belgium
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