



**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\*

8.00 h

**Registration open**

9.00 h – 15.00 h **Novel therapies for cystinosis**

Meeting of E-Rare consortium

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

14.00 h – 18.00 h **Child Care open**

15.00 h – 15.30 h **Welcome and Opening\*\*** Erik Harms

15.30 h – 16.15 h **What is cystinosis?\*** William Gahl

The basics for everybody

16.30 h – 18.00 h **Discussion in smaller groups\*\***

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

**Panel:** Gema Ariceta, Paul Goodyer, Paul Grim, Galina Nesterova, Neveen Soliman, Rezan Topaloglu, Alexei Tsygin and others  
**All groups are chaired by a medical specialist and experienced patients. We will split into adults, adolescents, parents.**

18.30 h

**Welcome meet and greet**

Drinks and snacks, no dinner

### Saturday, July 14\*

8.00 h

**Registration open**

Please sign in today at the info desk for the group you want to join on Sunday morning.

8.15 h – 13.00 h **Child Care open**

8.30 h

**Welcome again and information\*\***

8.40 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.

## Programme 3

### Saturday, July 14\*

8.40 h – 9.20 h

**Eyes** Rachel Bishop

General overview on eye problems

9.30 h – 10.10 h

**Neurological problems** Liesbeth de Waele

General overview / Particular Adult problems

10.20 h – 11.00 h

**Muscles** Craig Langman

Overview, problems and therapy

11.10 h – 11.50 h

**Orthopedic Problems** Nadine Herzig

Overview – physiotherapy – sports – surgery

12.00 h – 12.40 h

**Growth / Growth hormone** Dieter Haffner

Introduction and discussion

12.40 h – 13.00 h **Introduction Poster Session**

13.00 h – 14.00 h **Lunch and Poster Session Visit**

14.00 h – 18.00 h **Child Care open**

14.00 h – 14.40 h

**Pharmacology** ETH Zürich

Overview on drugs and medications / Interactions between medications / Side effects  
New drugs to come

14.50 h – 15.40 h

**Hormones** Julia Rohayen

General overview on hormone substitution in children, adolescents, adults

15.40h – 16.20 h

**Fertility / Pregnancy** Martine Besouw

News and hope for men and women

16.40 h – 18.00 h

**News from research**

**Ongoing projects and newly planned research**

Achim Treumann, Elena Levtchenko, Francesco Emma, Katharina Hohenfellner and others

19.00 h

**Dinner (please register at the info desk)**

## 4 Programme

Good to know 5

### Sunday, July 15\*

**8.00 h**            **Registration open**

**8.45 h – 11.30 h** **Child Care open**

**9.00 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.

Feeling healthy is not only visit the doctor and take your medication but also other domains like: 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  
William Gahl
- for adolescents (ca. age 12 – 18)  
Katharina Hohenfellner
- for adults  
Graham Lipkin
- for parents of adolescents and adults  
Elena Levtchenko

All groups will be led by professionals and experienced patients.

**Please register on Saturday at the info desk for the group you want.**

**11.30 h**            **Final meeting for fare well and good bye**

### Translation

**The sooner you register the better. We will order translators for simultaneous or whisper-translation according to number of registered participants in April 2018.**

### Information Desk

The cystinosis information desk in the main hall of the hotel will be open **every day from 8.00 h to 18.00 h** for your convenience.

Please go there to get all final informations about the conference and your package (one per family). This is the place to register for dinner on Saturday and to sign in for your chosen topic when it comes to round table talks.

Please don't hesitate to ask anything you need to know there, starting with bus tickets or restaurant recommendations not to finish with good ideas for a small touristic program. If you lost something (or someone) this again is the place to go.

### Child Care / Adolescents

**Child care** in different groups will be provided.

**Friday: 14 h - 18 h**

**Saturday: 8.15 h – 13.00 h; 14 h – 18 h**

**Sunday: 8.45 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 programme not finally decided before printing this. More information will soon be available on our website <https://www.cystinosis-conference-berlin-2018.eu>

\*The program might slightly change.

\*\*Translation or whisper-translation to German will be available. Other languages available depending on number of registered participants.

### 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](mailto:info@cystinosis-europe.eu) or call us: Tel. +49 / 2102 / 69627

#### Conference venue

Hotel Movenpick,  
Schöneberger Str. 3  
D-10963 Berlin

Tel. : +49 / 30 / 230060

recommended **Airport**: Berlin-Tegel (TXL) or Berlin-Schönefeld

recommended **Railway station**: Berlin Hauptbahnhof

The closest underground- or busstation is:

Anhalter Bahnhof (200 m to walk)

**Taxi** from Airport Tegel to the hotel is about 25.- €

Please book your room at a special price using the link given on our conference website:

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

There you can book for a special price until May 28,2018.

Single room: 109.- € / Double room: 119.- €, some rooms can be booked with a third bed: 158.- € - all incl. breakfast.

### Registration and Hotel

#### Other hotels or accommodations

You don't want to stay in a hotel? Or in another one than the conference hotel?

There are a lot of possibilities in a big city like Berlin, not only hotels, but apartments for tourists or private guest rooms, camping sites or youth hostels. Please feel free to find something convenient to you online.

But remember: Berlin is a big city and even if the underground is fast and easy to use and busses are available everywhere, it might take some time to get to the conference hotel in the morning.

Do you need help in looking for a hotel, please send a mail to [info@cystinosis-europe.eu](mailto:info@cystinosis-europe.eu).

### Pictures and Video

Yes, pictures will be taken and we will try to get at least some of the presentations as video clips on our website.

Therefore we ask you to sign that you know this and are aware you could by accident be seen on one of the pictures. As long as these show „crowds“ with more than 7 people this can happen and has to be allowed.

Please tell us if you don't want to show up anywhere and watch yourself not to stand right in the middle when it comes to a photo shooting (like all participants' pictures).

When we take care of each other this should work very well.

Please be aware that we are not responsible and can not guarantee for pictures taken for private use by guests and participants of this conference.

## Funding

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



Das Europäische Cystinose-Konferenz 2018 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.

## BARMER

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

### Cystinosis Network Europe

Cystinosis Ireland  
 Cystinosis Foundation UK  
 Cystinose Groep Nederland  
 Cystinosis Group Belgium  
 AIRG France

Cystinose France  
 Asociación Cistinosis España (ACE)  
 AIRG-España  
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 Cystinose-Selbsthilfe e.V.

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