European Cystinosis Conference

July 13 – 15, 2018
in Berlin / Germany

From innovative science
to better clinical care
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.
<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
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<tbody>
<tr>
<td>9 h – 9.50 h</td>
<td><strong>Eyes</strong>&lt;br&gt;General overview on eye problems&lt;br&gt;All you should know about eye checks and therapy&lt;br&gt;Late onset cystinosis</td>
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<td>10 h – 10.50 h</td>
<td><strong>Neurologic problems</strong>&lt;br&gt;General overview / Special Adults' problems</td>
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<td>11 h – 12.50 h</td>
<td><strong>Muscles / Orthopedic Problems / Growth</strong>&lt;br&gt;Muscles: Overview, problems and therapy&lt;br&gt;Orthopedic problems: General questions – physiotherapy -- Sports&lt;br&gt;Problems to be discussed: knock-knees, joint pain, bone pain&lt;br&gt;Growth / Growth Hormone: Introduction and discussion</td>
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<td>13 h – 14 h</td>
<td><strong>Lunch &amp; Poster Session</strong></td>
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<td>14 h – 18 h</td>
<td><strong>Child Care</strong></td>
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<tr>
<td>14 h – 14.50 h</td>
<td><strong>Dialysis / Transplantation</strong>&lt;br&gt;Overview: What does dialysis mean?&lt;br&gt;Different kinds of dialysis, life under dialysis&lt;br&gt;Overview: What is transplantation?&lt;br&gt;Precondition, donors, immunosuppressive therapy – all upcoming questions will be answered as good as possible.</td>
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<td>15 h – 15.50 h</td>
<td><strong>Pharmacology</strong>&lt;br&gt;Overview on drugs and medications&lt;br&gt;Interactions between medications, new drugs to come, side effects</td>
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<td>16 h – 16.50 h</td>
<td><strong>Hormones / Fertility / Pregnancy</strong>&lt;br&gt;General overview on hormone substitution in adolescents&lt;br&gt;News and hopes</td>
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<td>17 h – 17.45 h</td>
<td><strong>News from research</strong>&lt;br&gt;Ongoing projects and newly planned research</td>
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<td>19 h</td>
<td><strong>Dinner (please register at the info desk)</strong></td>
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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  Galina Nesterova
Rachel Bishop  Aude Servais
Federico Emma  Neveen Soliman
William Gahl  Rezan Topaloglu
Paul Goodyer  Achim Treumann
Paul Grim  Alexander Tsygin
Dieter Haffner  Liesbeth de Walle
Erik Harms
Nadine Herzig
Katharina Hohenfellner
Machteld Huber
Craig Langman
Elena Levchenko
Graham Lipkin

*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/](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 bustation 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](http://www.cystinosis-conference-berlin-2018.eu)
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
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Without funding and donations this conference could never take place. We would like to thank all our donors.