3RD WORLD CONFERENCE ON CDG | 2017
FOR FAMILIES AND PROFESSIONALS

15 / 16TH JULY 2017
LEUVEN (BELGIUM)

UNITED SHAPING THE FUTURE FOR CDG

Congenital Disorders of Glycosylation
AGENDA

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DREAMS DON'T WORK UNLESS YOU DO!
WHY A WORLD CONFERENCE ON CDG FOR FAMILIES AND PROFESSIONALS?

The 3rd World Conference on Congenital Disorders of Glycosylation (CDG) for Families and Professionals “United shaping the future for CDG” aims to raise awareness for Congenital Disorders of Glycosylation (CDG) worldwide, to promote education and to act as knowledge, experience and information platform exchange. It welcomes and joins patients, family members, researchers and physicians, as well as CDG experts from all areas.

This conference is organized by the Portuguese Association for CDG (APCDG), in partnership with several associations and/or country CDG patient advocates: CDG Denmark, Foundation Glycosylation (the FoG) Canada, GlycoKids, CDG UK, Les P’tits CDG France, CDG Spain, CDG Sweden, CDG USA, and CDG Netherlands.

It does not matter how slowly you go, so long as you do not stop

REGISTRATION

The registration process will begin on the 1st January 2017.

For more information and updates, please visit: www.apcdg.com/events
ORGANIZATION

APCDG and Local Co-Organisers: Pf Dr Eva Morava, Pf Dr David Cassiman and Pf Dr Jaak Jaeken.
Dear families, professionals, colleagues and friends:

“Alone we can do so little, Together we can do so much!”. This quote by Helen Keller sums up the organization and development process of the World Conference on CDG.

It is with great pleasure that we invite you to the **3rd World Conference on CDG: United shaping the future for CDG** planned to be held in **Leuven, Belgium - 15 and 16 July 2017**.

This World Conference on CDG will provide a patient-tailored program which will highlight important information in the clinical and research area, as we progress to our goal of better care and improvement of the quality of life of people living with CDG and related metabolic rare diseases.

The Scientific-Medical and Family organizing committee is sure that this unique event will be unforgettable and look forward to welcoming you to this Third World CDG conference.

We would like to express our thanks to all experts, professionals and families for their outstanding contributions and in particular to the members of the committees for their contribution and helpful support. Likewise we would also like to express our appreciation to the speakers, as well as to the invited moderators for their careful preparation of the invited sessions.

**CDG families together with professionals can make the difference!**

Laying the groundwork for future stages of research and development based on families’ needs is the most rewarding aspect of this World Conference. Boosting translational research will be a dream that becomes true!

We are looking forward to seeing you in Leuven!
With our warmest regards.

On behalf of the organizers,
**Vanessa Ferreira**, PhD, MBA
Volunteer and founder APCDG
All are important but some make a difference...

Gold Generosity

glycomine

Silver Generosity

Bronze Generosity
Andrea Berarducci, JD, MHA, FACMPE
Mother to Bianca CDG CARE (USA)

Richard Waddell, Father to Fiona Waddell.
As a father to Fiona, he has been part of the CDG Family for about eighteen

Vanessa Ferreira, PhD
Sister to Princess Lili
Portuguese Association CDG

Lut De Baere, PhD
BOKS Belgium Association for Children and Adults suffering for Metabolic Diseases

Andrea Berarducci, JD, MHA, FACMPE
Mother to Bianca CDG CARE (USA)

Duncan Webster, MA, MD, FRCPC
Father to Mimi and physician on infectious diseases FoG (Canada)

Konstantin Feinberg, PhD
Father to Ethan and molecular neurobiology researcher (Canada)

Richard Waddell,
Father to Fiona Waddell. As a father to Fiona, he has been part of the CDG Family for about eighteen
ORGANIZING COMMITTEES

Local volunteer Medical and Scientific organizing committee

Pf Eva Morava, MD, PhD
USA and Belgium

Pf David Cassiman, MD, PhD
Belgium

Pf Jaak Jaeken, MD, PhD
Belgium

Dr Dulce Quelhas
Portugal

Dr Mercedes Serrano, MD, PhD
Spain
THE POWER OF ADVANCING PATIENT-ORIENTED RESEARCH UNITED
FAMILIES AND PROFESSIONALS

01 CDG IMPACT ON FAMILIES
- Patients are scattered and isolation occurs;
- Few community-friendly resources and information to address CDG;
- Delays in diagnosis and misdiagnosis may happen;
- Lack of effective treatments/curatives;
- Big emotional toll and lower quality of life on patients/caregivers;
- Significant financial burden of care.

02 RESEARCH
- Lack of funding;
- Limited maximization of scarce resources;
- Scarce discovery and translational research programs;
- Lack of basic research tools;
- Few animal models;
- More research and development for CDG is sorely needed.

03 GOAL: CURE CDG

04 UNITED TO OVERCOME CHALLENGES

05 WHY YOU SHOULD ATTEND WORLD CONFERENCE ON CDG (WCCDG)?
- Increasing awareness;
- Community building;
- Sharing knowledge;
- Fostering research.

06 OUTCOMES FROM THE CONFERENCE?
To address the challenges faced by CDG families and professionals through:
- Networking;
- Mutual editorial dialogue among stakeholders;
- Stimulation of ideas and exchange of latest information;
- Sharing experiences;
- Improve holistic CDG patient care.

07 HOPE FOR PATIENTS AND THEIR FAMILIES

WORLD CONFERENCE CONGENITAL DISORDERS OF GLY COSYLLATION

WWW.APCDG.COM
INFORMATION

The official website to disseminate information and materials elaborated to the 3rd World Conference on Congenital Disorders of Glycosylation (CDG) for Families and Professionals “United shaping the future for CDG” is:

www.apcdg.com/events.html

We are not responsible for any information posted in other websites. If you have further questions please write to Rita Francisco, CDG community liaison manager and researcher at:
rita.francisco.28@gmail.com

PRE-PROGRAM AT A GLANCE

The following Family and Scientific program was elaborated by the local organisers in full collaboration with the Portuguese Association for CDG (APCDG, www.apcdg.com). All speakers and moderators will contribute in an altruistic manner.

The different sessions, initial program, invited speakers and moderators are listed below. Please note that this is only a preliminary version; thus last minute changes may occur.
**DAY 1 | SATURDAY, 15th JULY 2017**

Please see the released Draft of our Conference Agenda HERE.

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
</tr>
</thead>
<tbody>
<tr>
<td>09.00-09.45</td>
<td>Registration desk</td>
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<tr>
<td>10.00-10.30</td>
<td><strong>Topic 1</strong>&lt;br&gt;Session Moderators: Francois Foulquier and Romain Peanne&lt;br&gt;<strong>CDG history and clinical presentation</strong>&lt;br&gt;Jaak Jaeken, (Centre for Metabolic Diseases, University Hospital Gasthuisberg Leuven, KU, Belgium)</td>
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<td>10.30-11.00</td>
<td><strong>Biochemical aspects</strong>&lt;br&gt;Dirk Lefeber (Nijmegen Center for Disorders of Glycosylation, Netherlands)</td>
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<td>11.00-11.30</td>
<td><strong>Coffee Break</strong></td>
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<tr>
<td>11.30-12.00</td>
<td><strong>Topic 2</strong>&lt;br&gt;Session Moderators: Uwe Kornak, Monique VanScherpenzeel (To be confirmed soon) and Marisa Girós&lt;br&gt;<strong>Diagnostic tools</strong>&lt;br&gt;Christian Thiel (Department I, Center for Child and Adolescent Medicine, Center for Metabolic Diseases Heidelberg, Germany)</td>
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<tr>
<td>11.30-12.00</td>
<td><strong>Session Moderator: Paula Videira</strong> (Glycoimmunology group, Faculty of sciences, Lisbon University, Portugal)</td>
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<td>12.00-12.30</td>
<td><strong>Gastrointestinal problems</strong>&lt;br&gt;Stephanie Grünewald (Great Ormond Street Hospital for Children NHS Foundation Trust, London, UK)</td>
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<td>12.30-14.00</td>
<td><strong>Lunch Break</strong></td>
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<tr>
<td>14.00-14.30</td>
<td><strong>Topic 3</strong>&lt;br&gt;Session Moderators: Belen Perez Gonzalez and Rita Barone (To be confirmed soon)&lt;br&gt;<strong>CDG neurology: What you need to know</strong>&lt;br&gt;Mercedes Serrano (Hospital San Joan de Déu, Barcelona, Spain)</td>
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<tr>
<td>14.30-15.00</td>
<td><strong>The role of the cerebellum in cognition and behavior: beyond coordination in the Central Nervous System</strong>&lt;br&gt;Marc Patterson (Mayo Clinic, USA)</td>
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<tr>
<td>15.00-15.30</td>
<td><strong>Coffee Break</strong></td>
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<tr>
<td>15.30-16.00</td>
<td><strong>Topic 4</strong>&lt;br&gt;Session Moderator: Thorsten Marquardt (Germany)&lt;br&gt;<strong>CDG Adults: main symptoms and management</strong>&lt;br&gt;David Cassiman (Department of Clinical and Experimental Medicine, University Hospital Gasthuisberg- KU Leuven, Belgium)</td>
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<tr>
<td>15.30-16.00</td>
<td><strong>Moderator: Dulce Quelhas</strong> (Centro Hospitalar do Porto, Portugal)</td>
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<tr>
<td>16.00-16.15</td>
<td><strong>Genetic aspects of CDG</strong>&lt;br&gt;Gert Matthijs (Department of Human Genetics, KU Leuven, Belgium) - To be confirmed soon&lt;br&gt;<strong>Moderators: Giuseppina Andreotti</strong> (Institute of Biomolecular Chemistry (ICB), Consiglio Nazionale delle Ricerche (CNR), Italy) and <strong>Agnes Rafalko</strong> (Glycomine, USA)</td>
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<tr>
<td>16.15-16.30</td>
<td><strong>Treatment</strong>&lt;br&gt;Eva Morava (Tulane University Medical School Hayward Genetics Center, USA and KU Leuven, Belgium)</td>
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<tr>
<td>16.30-18.30</td>
<td><strong>CDG Face-to-face professionals and families</strong></td>
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</table>
Day 2 | Sunday, 16th July 2017

Please see the released Draft of our Conference Agenda HERE.

<table>
<thead>
<tr>
<th>Topic 1</th>
<th>Session Moderators: Miski Mohamed and Carla Asteggiano <em>(To be confirmed soon)</em></th>
</tr>
</thead>
</table>
| 09.00-09.30 | Physical therapy  
Chantal Verhille (*Physio therapist at the Metabolic Unit at KU Leuven, Belgium*). |
| 09.30-09.50 | Psychomotor Therapy and Body Experience  
*Dolores Viegas Gamito* (Special Education Teacher specialized in Psychomotricity, Lisbon, Portugal) |

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<tr>
<th>Topic 2</th>
<th>Session Moderators: Barbara Vulso (CDG mother and advocate, Ireland &amp; Italy) and Ágata Fiumara <em>(To be confirmed soon)</em></th>
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</table>
| 09.50-10.10 | Educational digital resources for CDG  
*Joana Peixinho* (CDG mother and Special Education Teacher, Porto, Portugal) |
| 10.10-10.25 | Overall strategies to improve communication in CDG  
*Merell Liddle* (CDG mother and patient advocate, Australia) |
| 10.25-10.55 | Coffee break |
| 10.55-11.15 | Tips for home adaptation and accessibility  
*Sandra Pereira Pinto* (CDG mother and Architect specialized in design for universal accessibility, Porto, Portugal) |

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<tr>
<th>Topic 3</th>
<th>Session Moderator: Richard Wadell (CDG father and advocate, The Netherlands)</th>
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*Luísa Barros* (Professor at Faculdade de Psicologia e de Ciências da Educação. Universidade de Lisboa, Portugal). |
| 11.40-12.05 | Patient Reported Outcomes for CDG  
*Liz Forbat* (Faculty of Health Sciences, Australian Catholic University of Canberra, Australia). |

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<tr>
<th>Topic 4</th>
<th>Session Moderators: Rita Francisco (APCDG, Portugal) and Andrea Berarducci <em>(To be confirmed soon)</em></th>
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| 12.05-12.30 | Advocacy tool kit to integrate rare diseases into social services and policies  
*Raquel Castro* (Social Policy Senior Manager, EURORDIS, Paris, France) - *To be confirmed soon* |

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<tr>
<th>Topic 5</th>
<th>Session Moderators: Eva Morava and David Coman (Department of Paediatrics, The Wesley Hospital, Brisbane, QLD, Australia)</th>
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</table>
| 12.30-13.00 | Natural History of CDG, and envisioning the future.  
*Lynne Wolfe* (National Human Genome Research Institute (NHGRI), Office of Rare Diseases, Undiagnosed Diseases Program) and *Hudson Freeze* (Director of the Human Genetics, Sanford Burnham Institute, USA) |
| 13.00 | Dancing and singing for CDG (Barbara Vulso (mom to Leo, Ireland and Italy and Morgan Webb Liddle (Australia)) |
THE HISTORY OF THIS UNIQUE EVENT

The 1st World Conference on Congenital Disorders of Glycosylation for Families and Professionals: “A booming story of sugar trees” (2013) was fruitfully designed in a collaboration with leading experts in the field of CDG: families and professionals worked together to exchange knowledge, experiences, needs and perspectives. Our “First World CDG Conference (2013)” has welcomed more than 200 participants, comprising:

- 42 CDG families from 18 countries,
- 70 professionals from all continents and 23 countries.

The oral presentations are available HERE.

The 2nd World Conference on Congenital Disorders of Glycosylation (CDG): “A challenging story of sugar trees” (2015) was the product of intensive cooperation among CDG Key Opinion Leaders (KOLs). It counted with the attendance of over 200 participants and resulted in the participation of and interaction between the CDG community members: Families, Physician and Researchers. Among our participants were:

- 55 CDG families from 18 countries
- 85 professionals from all continents.

The oral presentations are available HERE.
RESOURCES
