

**3RD WORLD CONFERENCE ON CDG FOR FAMILIES AND
PROFESSIONALS “UNITED SHAPING THE FUTURE FOR
CDG”**

15TH & 16TH JULY 2014
LEUVEN, BELGIUM



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“Yesterday is but today’s memory, and tomorrow is today’s dream.” – Khalil Gibran
This conference is dedicated to all CDG families and professionals, who in spite of all hurdles and challenges, are restless in pursuing their dreams and making them come true every day. All of you are improving the present and shaping the future of all CDG patients! *Commitment, Hope, Love, Work and Courage will certainly bring a brighter and dreamier Tomorrow. Thank you for sharing and investing in your dreams!*



WELCOME MESSAGE

We are happy to announce that the “3rd World Conference on Congenital Disorders of Glycosylation (CDG) for Families and Professionals “United shaping the future for CDG” is getting well into shape!

We have an amazing lineup of speakers and events. You can check them out at: <http://www.apcdg.com/events.html>

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



1. ORGANISING COMMITTEES

For more information about the different organizing committees, visit:
<http://www.apcdg.com/events.html>

2. CONFERENCE AGENDA

The full conference agenda is available [HERE](#).



3. INTRODUCTION

Following two previous successful editions, the Portuguese Association for CDG and Other Rare Metabolic Diseases (APCDG-DMR, <http://www.apcdg.com/>) coordinates the **3rd World Conference on Congenital Disorders of Glycosylation for Families and Professionals: “United shaping the future for CDG”**. Once more, this global event aims to provide opportunity and ground for all CDG experts - patients, families and professionals - to dialogue, exchange knowledge, experience and ideas.

A highly diversified and up-to-date **Agenda** is already available at <http://www.apcdg.com/events.html>. Families and health professionals are equal partners in this unique conference designed to educate and empower the CDG community. Consequently, speakers range from clinicians, researchers and other professionals to patients and parents alike. Allowing all CDG experts to have their voices heard is one of the pillars of these conferences, since only together can we effectively shape the future for CDG children and adults.

All families, patients affected by CDG together with professionals with an interest in metabolic diseases are encouraged to attend this conference. Only by sharing and discussing existing knowledge can we advance, promote and accelerate change.



4. GENERAL INFORMATION

Pre-Registration

The pre-registration forms are available [HERE](#)

After your pre-registration is fulfilled, the organisers will contact you in the next 2 weeks and will give you the information about the donation-fee payment, the 3 accommodation options booked for our conference, meals and other information of interest. We kindly request you to follow the instructions in order to have your registration completed.

Terms and conditions (Please, make sure you read all the content):

A. Registration Process and Payment Methods

1. The first step for a full registration for the Conference is to REGISTER at the event created at Eventbrite [HERE](#)

2. The second step to obtain a full registration is to respond to the confirmation email, which will be sent to you from the organizing committee, with the final requirements to validate your registration. The **registration fee is a donation that will support the overall conference**, the organization, logistics for the event, as well as the social program targeted for children and adults and so forth. In addition, the Registration fee includes Conference participation, information material and networking sessions.

* Note: Please notice that only emails from rita.francisco.28@gmail.com or sindromeqd@gmail.com are valid, any other email contact should be dismissed. Also, emails from the organizing committee will always be sent within 2 weeks after your registration at Eventbrite (máximum).

3. **Conference registrations will not be confirmed until the completed form and the correct payment are received and processed by the Registration Office (rita.francisco.28@gmail.com)**. We reserve the right to refuse admission if payment is not received on time.

4. Registrants should obtain confirmation from the Registration Office (please be sure your spam filters will allow mail from Registration Office (rita.francisco.28@gmail.com) and the conference coordinator (sindromeqd@gmail.com).

5. The deadline for registration is 1st June 2017.

6. **Accommodation**, travel and meal costs are not included in the conference registration donation fees. Attendees are responsible for making their own travel, meals and accommodation arrangements.

7. **Capacity is limited to 200 attendees. Registrations will be handled on a first-come, first-served basis.**

B. Cancellation Policy

Conference registration can be cancelled only in writing by mail seven (7) weeks before the Conference is to be held. Thereafter, the full Conference fee is non-refundable.

C. Personal insurance

APCDG-DMR cannot be responsible for healthcare, dental and ambulance services during the **3rd World Conference on Congenital Disorders of Glycosylation for Families and Professionals: "United shaping the future for CDG"**. The APCDG-DMR strongly recommends that participants take out comprehensive medical and travel insurance, which should cover the possibility of flight cancellation due to strikes and other causes. Therefore, APCDG-DMR and its local co-organizers do not accept responsibility of any nature at this level.

D. Privacy

In registering for the conference, relevant details will be incorporated into a participant list. All this information will be treated in a confidential way. The Portuguese Association for CDG and related Rare Metabolic Diseases (APCDG-DMR) may use these details to inform current participants of Conference updates or future conferences via email. **Participants are responsible for advising the Portuguese Association for CDG and related Rare Metabolic Diseases if they do not wish to have their email addresses included in the conference participant list or APCDG-DMR distribution list for future events.**

E. Copyright

All intellectual property rights in all materials produced or distributed by the Coordination in connection with this Conference is expressly reserved and any unauthorized duplication, publication or distribution is prohibited.

F. Conference Program

Conference program is subjected to change and is available at:

<http://www.apcdg.com/events.html>

Registration desk

Participants can pick up their personal Conference material at the registration desk which will be open at the venue (**Park Inn by Radisson Hotel**). The Conference secretariat will be available to assist you during the Conference at the Park Inn by Radisson Hotel.

Registration desk hour

Saturday 15th July 9.00 am to 09.45 am

Conference language

The official conference language is English.

Lunch, Breaks and Dinners

Meals will be at the restaurant of the Park Inn by Radisson Hotel.

Name Tags

Please wear your name tag at all times during the conference, including the breaks and Networking Dinner. You may be asked to present your nametag.

Note: Our Children and adults will have a specific identification: parents name and phone contact will be included to facilitate possible actions of the volunteering service.

Note to speakers

If you are schedule to present, **please ensure your PowerPoint is loaded well in advance of your presentation time**. A **central computer and technician** are available and well identified at the **Registration desk** where you may upload your presentation, which in turn will be uploaded on the computer in the appropriate room. Please visit the registration desk if you have any questions or for further details.

Adhering to this will help to ensure your presentation is available when needed, and it should also prevent confusion when loading the presentation files on to the main computer. The Day and Time for your presentation can be found in the final program, which is available, via:

<http://www.apcdg.com/events.html>

Should you have any questions related to your presentation, please do not hesitate to contact the conference general inquiries via rita.francisco.28@gmail.com

Mobile Phones, Pagers and Laptop sound

As a courtesy to presenters and colleagues, please ensure that all mobile phones, pagers and sound of your laptop **are switched off during the conference sessions**.

Currency and credit cards

Belgium's unit of currency is euro. Foreign currency can easily be exchanged at banks and money changer booths located at the international airport and throughout Leuven. Major credit cards are accepted throughout Leuven.

5. IMPORTANT DATES

To know the **Important dates** of the 3rd World Conference on CDG, visit [HERE](#).

5.1. Special Sessions

15th July 2017, Saturday

16.30-18.30: CDG Face-to-face professionals and families

16th July 2017, Sunday

From 13.00: Dancing and singing for CDG (Barbara Vulso (mom to Leo, Ireland and Italy and Morgan Webb Liddle (Australia))



6. Activity Room

3rd World Conference on Congenital Disorders of Glycosylation (CDG) for Families and Professionals
“United shaping the future for CDG”

The Activity Room is a volunteer-based action and it entails a number of different fun and entertaining activities for CDG patients (such as painting, playing, etc).

Where?

It takes place in ParkInn by Radisson Hotel (also the venue of the World Conference)

When?

The volunteer service is held from 8.30 a.m. to 18 p.m. on Saturday 15/7/2017 and from 8.30 a.m. to 13.00 p.m. on Sunday 16/7/2017.

Who?

The role of the volunteers is strictly to entertain (play, paint or carry on any other entertaining or playful activity). Thus volunteers will NOT be authorized to or in charge of feeding, giving medication, or taking the children or adults to the toilet. Families will be responsible for those chores.



CONFERENCE VENUE

Information about the venue:

Park Inn By Radisson Leuven Hotel

Martelarenlaan 36, 3010 Leuven

Belgium

Website: <https://www.parkinn.com/hotel-leuven>



Park Inn By Radisson Leuven Hotel

We are very grateful to Park Inn By Radisson Leuven Hotel for allowing us use their facilities during the the **3rd World Conference on Congenital Disorders of Glycosylation for Families and Professionals**.

7. GENERAL INQUIRIES, PUBLIC AND MEDIA INQUIRIES

Contact of Conference Coordination Office at:



Rita Francisco (APCDG Researcher and CDG community liaison and social manager, Portugal)
Portuguese Association for CDG and related Rare Metabolic Diseases.

Website: <http://www.apcdg.com/events.html>

Phone: +351 925718128

Email: rita.francisco.28@gmail.com

8. COMMUNICATION AND INFORMATION CHANNELS

Please follow us on our different communication channels to stay update with news and announcements related to this Conference:

- World Conference Page
<http://www.apcdg.com/events.html>



- RareConnect
<https://www.rareconnect.org/en/community/cdg>



- Facebook

Please follow:

“[CDG Global Alliance](#)”— Click [HERE](#)

“[Sindrome CDG](#)” – Click [HERE](#)



- Twitter
[@CDG_Portugal](#)



- LinkedIn
[Portuguese Association CDG](#)



9. OTHER ADDITIONAL INFORMATION

9.1. Advice if you are travelling with children and adults

Please be sure that you have all documentation in case that you need medical assistance.

Emergency phone numbers

Pan-European number for all emergencies: 112 (www.sos112.be). This emergency number can be called anywhere in the European Union (EU) for free.

- National Police: 101 (www.police.be)
- Local Police: 116 006
- Firefighters: 100 (www.frcspb.be)
- Medical emergency: 100/112

Medical urgency of a patient with inborn errors

In case of a medical urgency of a patient with inborn errors of metabolism the hospital:

- UZ Leuven

Leuven Centre for Metabolic Diseases

(<http://healthcarebelgium.com/index.php?id=297&L=2%5C%27%5C%27#c1368>)

Herestraat 49, 3000 Leuven

Medication

Please inform your medical doctor about the trip to Leuven and collect advices and tips directly from your CDG professional.

We want to stress that Families should not forget to take their home medication (and enough!) with them!

9.2. Transport to Leuven and to the airport and back

The Belgium national airport is located in Zaventem, Brussels, 27 kilometers from the city of Leuven city.

Connections between Leuven and the airport and back:

- National Trains (15min trip)
http://www.brusselsairport.be/en/passngr/to_from_brussels_airport/train/
- Bus numbers (616, 651 & 652)
http://www.brusselsairport.be/en/passngr/to_from_brussels_airport/bus/

For more information for people with reduced mobility:

http://www.brusselsairport.be/en/passngr/reduced_mobility/

9.3. After conference hours

Belgium Tourism website for disabled people

In the following website there is important and useful information available in english, french:
<https://visit.brussels/en/profile/reduced-mobility>

- A search engine for accessible places of interest for each type of disability: Museums, parks, monuments and guided tours.
- Lists accessible transport facilities as well as obstacles.
-

More interesting information about Accessible Tourism in Leuven and surrounding cities

<https://www.brussels.be/artdet.cfm/4226>

http://www.belgiumthelaceto.be/disabled_travellers.php

Restaurants

Full information is found at: <https://www.restocheck.com/en/default/index#!/list>

A list of restaurants (these are recommendations, you must check for detailed information):

<u>Bistro Tribunal</u>	<u>Julia en Elias</u>
<u>Zita</u>	<u>Voltaire</u>
<u>Domus</u>	<u>De Blauwe Maan</u>
<u>De Blauwe Schuit</u>	<u>New Mexico</u>

The weather forecast

<http://www.weather-forecast.com/locations/Leuven/forecasts/latest>

**"I learned a lot particularly from the
parents of these children.
Their courage, their perseverance,
their unconditional affection and love
(...) .**



PORTUGUESE
ASSOCIATION

CDG

**In my life, I have encountered many of
these heroes!" Prof Jaak Jaeken, 2016**

Portuguese Association for CDG and related Rare Metabolic Diseases disclaimer

The organizers of the 3rd World Conference on Congenital Disorders of Glycosylation for Families and Professionals: “United shaping the future for CDG” have made every effort to ensure that the conference achieves its goal of disseminating state-of-the-art and breakthrough information related to **Congenital Disorders of Glycosylation (CDG)**. Furthermore, the organizing committees have committed themselves to ensure that all participants remain comfortable and enjoy the experience of the conference. However, the organizers take no responsibility for any damage, loss or inconvenience in which participants may incur or experience during or related to the conference. In addition, the organizers cannot be held responsible for the correctness or appropriateness of the talks, papers, panels, tutorials and demonstrations included in the conference.

Moreover, in the event of industrial disruption or other unforeseen circumstances, the organizers accept no responsibility for loss of monies incurred by delegates. The organizers accept no liability for injuries/losses of whatever nature incurred by participants and/or accompanying person, nor for loss or damage to their luggage and/or personal belongings. Participants are expected to make their own arrangements with respect to personal insurance.

About the Portuguese Association for CDG and related Rare Metabolic Diseases:

Founded in 2010, APCDG (www.apcdg.com) is a patient led and centric non-profit association, whose particular goal is to stimulate new research lines that makes a difference in the lives of patients and families. APCDG initiatives are developed both nationally and internationally. APCDG is committed to finding a cure for Congenital Disorders of Glycosylation (CDG) and related disorders, improving the treatment options and giving information and support to people with CDG, through research, education, awareness programs and advocacy. APCDG top priority is to give a complete and holistic perspective of the patient as a person. Go to our website: www.apcdg.com

About [CDG & Allies-PPAIN](#): With the help of a broad network of scientists, physicians, families and patient advocacy groups, we have established a patient-led national and internationally unrivaled infrastructure for research, awareness and education for CDG. The research on Glycosylation disorders is primarily dedicated to Congenital Disorders of Glycosylation (CDG). The advances and innovations achieved for CDG through CDG & Allies - PPAIN will impact on a large number of patients, namely, all human diseases characterized by abnormal protein glycosylation such as cancer, inflammation, Alzheimer's disease and diabetes.

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