

A multidisciplinary scientific forum to advance and disseminate knowledge in the field WITH and FOR CDG families and professionals

AGENDA

5th World Conference on CDG



May 14-16, 2021 | Auditorium CAIXA
GERAL DE DEPÓSITOS, FACULTY OF
SCIENCES AND TECHNOLOGY OF
NOVA UNIVERSITY OF LISBON (FCT-
UNL), Caparica, Portugal



**WORLD CDG
ORGANIZATION**
Awareness, Research, Education and Empowerment United
FAMILIES AND PROFESSIONALS

*****4th Official Announcement *****

5th World Conference on CDG for families and professionals

The multidisciplinary scientific forum to advance and disseminate knowledge in the field WITH and FOR CDG families and professionals

*****DRAFT PROGRAM*****

Conference Theme: “#StandUnited4CDG Patient Centric approach that drives CDG therapeutic development: Impossible, Is Possible!”

When: Friday 14 to Sunday 16 May 2021

How: This edition, will exceptionally be a hybrid event, due to the COVID-19 pandemic. Thus, we will combine "live" in-person event for those that can join us at Faculty of Sciences and Technology of Nova University of Lisbon (FCT-UNL) (Monte da Caparica, Portugal) and conference sessions will ran "virtually".

Where: For those in-person Auditorium Auditório Caixa Geral de Depósitos

Programme is scheduled according to Lisbon time. Please check the corresponding times in your time zone [HERE](#)

Poster session: On Sunday 16th May 2021 & World CDG Awareness day 2021 will be a live Q&A poster session.

12th April 2021 is the due date for poster submission in order to participate in a poster exhibition during the 5th World Conference on CDG for families and professionals.

For the submission the following information is required:

- Title of the poster
- Presenter details (name and title)
- contact email
- Abstract
- PDF of the poster (resolution for printing on A0 format)

Major Novelty: The majority of the conference sessions enter under the scope of the “Think Metabolic, Think CDG” Academy for families, academia, medical doctors and industry.

The “Think Metabolic, Think CDG” Academy aims to provide CDG stakeholders the knowledge and skills needed to become experts in CDG medicines research and development. Thus, by securing your attendance and actively participating during the

conference, you will be able to achieve the “CDG Expert Level 2”. Further details, **SOON!**
Stay tuned!

Day 1: Friday 14th May 2021

11:00 – 12:40	Registration for those in-person
12:40 -13:00	Open session and Welcome to Day 1 of our the 5th CDG World Conference CDG & Allies PPAIN and World CDG Organization team
Theme I	CDG Diagnosis: present, hopes and future
13:00 – 13:20	Keynote speech: CDG a growing family – New CDG types and update on CDG classification. Moderator: CDG professional and CDG patient group/family member Panelists: • Clinician Perspective: TBC • Diagnostic researcher Perspective: TBC • Clinician Perspective: TBC • Parent Perspective: TBC • Patient Group Perspective: TBC
13:20 –13:40	Q&A & Discussion
13:40 - 14:00	Break
14:00 - 14:40	Panel Discussion: CDG diagnosis from different perspectives: challenges and hopes. Brief description: The session aims to explore what is important to professionals and to patients regarding their potential diagnosis (or lack thereof) and future care pathways; to discuss innovative ways of working with health professionals and patients to develop interventions which support these care pathways; and discuss potential new approaches to improve care for people living with CDG and their family members. Join this panel to hear their experiences and to deciphering solutions united. Moderator: CDG professional and CDG patient group/family member Panelists: • Diagnostic researcher Perspective: TBC • Clinician Perspective: TBC • Parent Perspective: TBC • Patient Group Perspective: TBC
14:40 -14:50	Q&A & Discussion

14:50– 15:30	Interactive session: What’s next after the announcement of CDG diagnosis? • Overview of current educational resources to reduce the CDG diagnostic odyssey within medical doctors and to empower families. • Exploring role behaviour and its impact on patient–physician interaction. • What to do and to say when a CDG patient is at Hospital emergency? Moderator: CDG professional and CDG patient group/family member Panelists: • Diagnostic researcher Perspective: TBC • Clinician Perspective: TBC • Parent Perspective: TBC • Industry Perspective: TBC • Patient Group Perspective: TBC
15:30 – 15:40	Key take away points & closing remarks
15:40– 16:00	Break
Theme II	CDG Care: Spotlight to Immunological involvement in CDG
16:00 – 16:40	Keynote speech: Immunological Involvement in Congenital Disorders of Glycosylation (CDG): learnings and hopes from a people-centric PhD research. Moderator: CDG professional and CDG patient group/family member Speaker: Rita Francisco
16:40 – 17:00	Q&A & Discussion
Closing plenary session Day 1	
17:00 – 18:00	Keynote speech: Building Resilience: Overcoming compassion, fatigue and burnout. Brief description: A CDG diagnosis affects the entire support network, including family and healthcare providers. In this session, parents and experts discuss the importance of self-care so that you can ultimately be the best care provider for your family. Moderator: CDG professional and CDG patient group/family member Panelists: • Clinician Perspective: TBC • Clinician Perspective: TBC

	• Parent Perspective: TBC • Parent Perspective: TBC • Parent Perspective: TBC • Patient Group Perspective: TBC
Social hour	
Social moment! Attendance is limited, so be sure to join early to ensure you have a spot in our Social Hours!	

Day 2: Saturday 15th May 2021

09:30 -10:00	Registration for those in-person
10:00 – 12:00	Workshop I: How to communicate and disseminate research results effectively? Brief description: Dissemination is now acknowledged as an important component of the research process. Effective communication is an important aspect of dissemination. However, because the audience for health promotion research is heterogeneous, dissemination has to meet the various requirements of different users. There are many barriers to effective communication between researchers and wider audiences including the general public. Join this workshop where several best practices and ready to use examples will be shared and discussed. How: will be held in-person for those that can join the event and online for those Moderator: CDG professional and CDG patient group/family member Speakers: representatives from different rare diseases will share transferable best practices applicable to any research area. Audience: wider audience with genuine interest to hear first hand best practices to communicate and disseminate research results effectively. Note: Due to the fact that this is planned as to be a very interactive workshop, the number of participants will be limited to 15 people. So be sure to ensure you have a spot at the earliest!
12:00 – 13:00	Lunch
Theme III	CDG therapies
13:00 – 13:05	Welcome to Saturday: Our Day 2 of our 5th CDG World Conference
13:05 – 14:00	Keynote speech: Overview of current emerging therapeutic strategies for CDG (e.g. acetazolamide, epalrestat, sugar supplementation, liposomes among others) Moderator: CDG professional, pharma and CDG patient group/family member Panelists: • Clinician Perspective: TBC • Clinician Perspective: TBC • Clinician Perspective: TBC • Parent Perspective: TBC • Parent Perspective: TBC • Parent Perspective: TBC

	• Patient Group Perspective: TBC
14:00 - 14:30	Q&A & Discussion
14:30 - 15:00	Break
15:00 - 15:20	Panel Discussion: Dietary management in CDG: What (and what not) to eat? Moderator: CDG professional and CDG patient group/family member Panelists: • Clinician Perspective: TBC • Clinician Perspective: TBC • Parent Perspective: TBC • Parent Perspective: TBC • Parent Perspective: TBC • Patient Group Perspective: TBC
15:20 – 15:30	Q&A & Discussion
15:30 - 16:00	Break
Theme IV	Accessing CDG clinical trials and medicines
16:00 – 17:00	Interactive session will focus on: • What do patients expect from CDG therapy development? • How to stimulate clinical trials to meet patients' needs? • How can patients access clinical trials and medicines? Brief description: Delivering access to new rare disease medicines can be one of the biggest challenges in the development pathway. In this panel we will talk to principal CDG investigators leading clinical studies, CDG pharma and CDG families and get a complete overview of different experiences of these access challenges and identify solutions united. Join this panel to hear useful open eye experiences. Moderators: CDG professional and CDG patient group/family member Panelists: • Clinician Perspective: TBC • Clinician Perspective: TBC • Pharma Perspective: TBC • Parent Perspective: TBC • Parent Perspective: TBC • Patient Group Perspective: TBC

17:00 – 17:10	Key take away points & closing remarks Day 2 of our 5th CDG World Conference
17:10 – 17:30	Break
Closing plenary session to end Day 2	
17:30 – 17:50	Keynote speech: What's the matter with you?" to "What matters to you?: a CDG families and professionals think tanks approach. Moderator: CDG professional, pharma and CDG patient group/family member Panelists: • Clinician Perspective: TBC • Clinician Perspective: TBC • Clinician Perspective: TBC • Parent Perspective: TBC • Parent Perspective: TBC • Patient Group Perspective: TBC
17:50 – 18:00	Q&A & Discussion
Social hour	
Social moment! Attendance is limited, so be sure to join early to ensure you have a spot in our Social Hours!	

Breakout Sessions Day 2: Saturday 15th May 2021

Think Tank 1:	Tools to make CDG therapies an approved reality!
18:00 – 20:00	Topic: Clinical Outcome Assessments (COAs) for CDG. Brief description of the Think Tank 1: Including patients in the selection and development of Clinical Outcome Assessments (COAs): an area of clinical development where the patient perspective is becoming more and more relevant. Clinical Outcome Assessments (COAs) is an essential component of clinical trials to collect patient (caregiver, clinician) perspective on treatment benefits and risks. Results from the CDG Patient preference study and Clinical Outcome Assessments (COAs) tool for CDG will be shared. How: will be held in-person and online Moderators: Luísa Barros, and other TBC Speakers: Carlota Pascoal, Alison Slade, Michelle Cardoso Participants: Medical doctors, pharma and CDG patient advocates

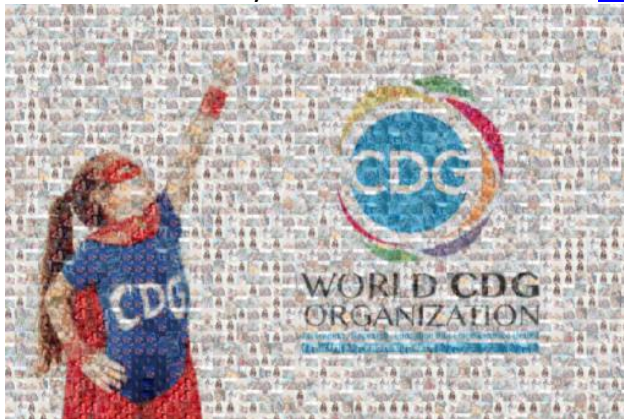
Breakout Sessions Day 2: Saturday 15th May 2021

Think Tank 2:	Tools to make CDG therapies an approved reality!
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18:00 - 20:00	Topic: Mapping the CDG clinical, emotional and digital journey to improve CDG care and management Brief description of the Think Tank 2: The value of developing a Patient Journey Map adds clarity for both patient and healthcare provider. There are further benefits in identifying areas that require extra support, such as information for healthcare professionals, patients, family members and/or caregivers. Overlaying the CDG journey allows better understanding of unmet needs, drivers and barriers for change along the journey. It is possible then to develop interventions tailored to patient, healthcare professional or stakeholders' individual needs, helping the patient experience and, hopefully, leading to improved patient outcomes. How: will be held in-person and online Moderators: Vanessa dos Reis Ferreira, and other TBC Speakers: Carlota Pascoal, Alison Slade, Michelle Cardoso Participants: Medical doctors, pharma and CDG patient advocates
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Day 3: Sunday 16th May 2021 & World CDG Awareness day 2021

09:00 - 09:30	Registration for those in-person
09:30 – 11:30	Workshop II: People, not statistics: The Why's and How's of efficiently and creatively capture and integrate the voice and experience of people living with a certain condition throughout the drug development: rare diseases as models. Brief description: Finding new and creative ways to share the rare disease patient and family experience and cutting through the noise to highlight the unmet need within rare diseases communities is a constant struggle. CDG & Allies PPAIN and related rare diseases have been at the forefront of some of the most creative approaches to telling impactful patient stories. Join this workshop and listen to (1) The ways you can reach a wider audience with your stories and experiences, (2) How to maintain an authentic patient voice, (3) How to use storytelling to drive meaningful communication in rare disease and (3) listen to successful industry and patient groups led awareness campaigns. How: will be held in-person and online Moderator: CDG professional and CDG patient group/family member Speakers: representatives from different rare diseases will share transferable best practices applicable to any research area. Audience: wider audience with genuine interest to hear first hand best practices to efficiently and creatively capture and integrate

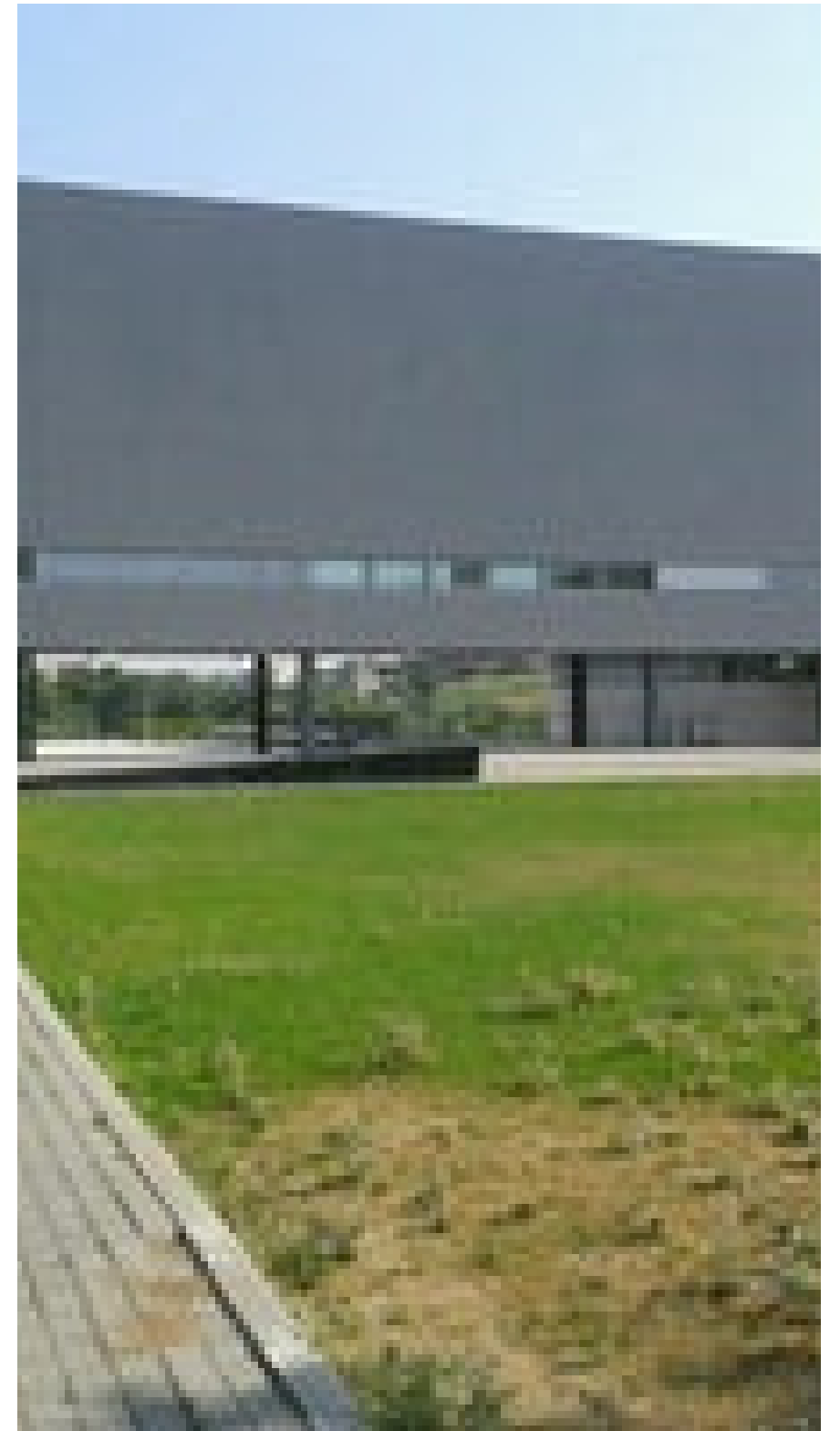
	the voice and experience of people living with a certain condition throughout the drug development. Note: Due to the fact that this is planned as to be a very interactive workshop, the number of participants will be limited to 15 people. So be sure to ensure you have a spot at the earliest!
11:30 -12:00	World CDG Awareness day 2021 celebrations We will unravel the #CDGMosaic May 16, 2021, during the World CDG Awareness day celebrations. Read more HERE 
12:00 – 12:30	Live Q&A poster session
12:00 – 13:00	Lunch
Theme VI	How new technologies can transform CDG landscape
13:00 -13:05	Welcome to Sunday: Our Day 3 of our 5th CDG World Conference
13:05 – 13.40	Keynote speech: Artificial Intelligence (AI) and Bioinformatics in rare diseases: Is the future brighter? Brief description: The amount of data collected and managed in (bio)medicine is ever-increasing. Thus, there is a need to rapidly and efficiently collect, analyze, and characterize all this information. Artificial intelligence (AI), with an emphasis on deep learning, holds great promise in this area and is already being successfully applied to basic research, diagnosis, drug discovery, and clinical trials. Rare diseases (RDs), which are severely underrepresented in basic and clinical research, can particularly benefit from AI technologies. During this session we will discuss how existing Artificial Intelligence (AI) and Bioinformatics can progress drug development and how patient expertise can help cut through the noise when AI interrogates big data. Moderator: CDG professional, pharma and CDG patient group/family member Speakers: Sandra Brasil, Gonçalo Valadao and Tatiana Rijoff
13:40 -13:50	Q&A & Discussion

13:50 – 14:00	Break
14:00 – 14:40	Keynote speech: Going digital to shape better CDG care and management: addressing the digital challenges and opportunities from families and professionals' views. Moderators: CDG professional and CDG patient group/family member Panelists: • Researcher Perspective: TBC • Clinician Perspective: TBC • Clinician Perspective: TBC • Parent Perspective: TBC • Parent Perspective: TBC • Patient Group Perspective: TBC
14:40 – 14:50	Q&A & Discussion
14:50 – 15:00	Break
Theme VII	CDG child, teen and adult care and management
15:00 – 15:40	Keynote speech: Overview of standards of care and management for CDG children, teens and adults. And challenges when navigating the healthcare system. Moderator: CDG professional and CDG patient group/family member Panelists: • Clinician Perspective: TBC • Clinician Perspective: TBC • Parent Perspective of a CDG child: TBC • Parent Perspective of a CDG teenager: TBC • Parent Perspective of a CDG adults: TBC • Patient Group Perspective: TBC
15:40 – 16:00	Q&A & Discussion
16:00 – 16:30	Break
Theme VIII	Impact of COVID-19 among CDG
16:30 – 17:00	Interactive session: The impact of COVID-19 on drug development for CDG and within family's day to day life. Brief description: COVID-19 has forced everyone in the rare disease world to think and work in new and innovative ways and has created profound challenges for drug developers, patients and carers to overcome. We will discuss what life looked like for CDG and look ahead to steps we can take united to move forward in a world that still presents uncertainties.

	Moderator: CDG professional and CDG patient group/family member Panelists: • Clinician Perspective: TBC • Pharma Perspective: TBC • Parent Perspective: TBC • Parent Perspective: TBC • Patient Group Perspective: TBC • Patient Group Perspective: TBC
17:00 – 17:30	Interactive session: How to best serve the CDG medical doctors and families from undeserved countries in the world? Moderator: CDG professional and CDG patient group/family member Panelists: • Clinician Perspective: TBC • Clinician Perspective: TBC • Pharma Perspective: TBC • Parent Perspective: TBC • Patient Group Perspective: TBC • Patient Group Perspective: TBC
17:30 -17:40	Key take away points Day 3 of our 5th CDG World Conference
Closing plenary session Day 3	
17:40 – 18:00	Keynote speech: Blue sky is the limit: looking ahead for CDG? Moderator: CDG professional, pharma and CDG patient group/family member Panelists: • Clinician Perspective: TBC • Clinician Perspective: TBC • Pharma Perspective: TBC • Parent Perspective: TBC • Patient Group Perspective: TBC

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