

5th World Conference on Congenital Disorders of Glycosylation

The World Conference on CDG is the largest, most complete and resourceful, international conference focused entirely on Congenital Disorders of Glycosylation (CDG). The content is delivered in a patient-friendly style that can be understood by non-specialist audiences. The ultimate goal is to help people to engage with clinicians and researchers more effectively and participate actively in their healthcare decisions.

Each two years, hundreds of family members and professionals from around the world gather at our World Conference on CDG to learn the newest advances dedicated to CDG. They also gather for support, strength, hope and friendship.

This conference is a chance to gain direct access to the people fighting everyday for children and adults like yours and perhaps, most importantly, it is your occasion to meet, exchange and reunite with families on a similar journey as you. There is incredible power and strength in connecting.

The 5th World Conference on CDG took place online on 13-16 May 2021 in full collaboration with Worldwide CDG Patients advocacy Groups and advocates and CDG Professionals.

The conference was organised in 9 themes (below) composed of recorded talks, poster presentations and roundtables.

Theme 1: Actions to boost CDG research and drug development.

Theme 2: CDG Classification and Diagnosis: present, needs and solutions.

Theme 3: Well-being and resilience skills for families and professionals.

Theme 4: CDG research and drug development: updates, challenges and solutions.

Theme 5: Tools to make CDG therapies an approved reality!

Theme 6: How new technologies and tools can boost CDG basic research and therapies.

Theme 7: CDG child, teen and adult care and management

Theme 8: The impact of COVID-19 on CDG.

Theme 9: World CDG Community – Why, What and How from stakeholders views and experiences.

For all our sessions, we counted with panelists counting almost 60 family representatives, 113 professionals from 25 different countries. Among them we had Clinicians, Health Professionals, Researchers, Pharmaceutical industry, Rare disease experts from different fields than CDG and people living with CDG and their family members, so that every VOICE is heard, and every CDG Community stakeholder is effectively represented.

Find out about the <u>Program</u> and meet our prestigious panelist at https://worldcdg.org/world-conference-cdg/panelist.

We thank our supporters: SSIEM, NOVA University of Lisbon, Glycomine, Applied Therapeutics, Cerecor, Migrigrama, worldwide CDG Patient Groups