



Final Conference Report

2026 CDG Scientific & Family Conference

Submitted to the Society for the Study of Inborn Errors of Metabolism (SSIEM)

Conference Overview

The **2026 CDG Scientific & Family Conference**, *"Pathways to Progress: Uniting Science, Support, and Solutions for CDG,"* was held April 24–26, 2026, in Orlando, Florida, USA. Hosted by CDG CARE, the conference brought together 330 participants from across the global Congenital Disorders of Glycosylation (CDG) community, including clinicians, researchers, laboratory scientists, industry partners, patient advocates, and families united by a shared commitment to advancing research, improving clinical care, and accelerating therapeutic development.

As the largest international meeting dedicated exclusively to CDG, the conference provided a unique forum where scientific discovery, clinical expertise, industry innovation, and lived patient experience were intentionally integrated. The meeting fostered meaningful collaboration among stakeholders while promoting patient-centered approaches to research, standards of care, therapeutic development, and clinical trial readiness.

CDG CARE is sincerely grateful to the **Society for the Study of Inborn Errors of Metabolism (SSIEM)** for its generous support, which helped facilitate international participation and contributed significantly to the success of this global scientific meeting.





Conference Highlights

- 330 conference participants
- Three-day international scientific and educational conference
- 16 countries represented
- 21 scientific and educational presentations
- 25 scientific poster presentations
- International faculty representing leading academic institutions, clinical centers, research laboratories, industry partners, and patient organizations
- Interactive "Ask Me Anything" roundtable discussions promoting direct dialogue between families and international experts
- Official launch of the first international CDG Biorepository
- Professional recording of all presentations to create the permanent 2026 CDG Education & Research Miniseries

Scientific Program

The conference featured a comprehensive multidisciplinary program spanning the full continuum of CDG research, clinical care, and therapeutic development.

Scientific sessions highlighted advances in glycobiology, disease mechanisms, biomarkers, diagnostics, natural history studies, newborn screening, precision medicine, clinical trial readiness, drug repurposing, gene therapy, gene editing, and emerging therapeutic strategies.

Clinical education focused on multidisciplinary care across numerous specialties, including neurology, endocrinology, nutrition, bone health, ophthalmology, psychology, rehabilitation, gastroenterology, and supportive care. Presentations emphasized translating scientific discoveries into meaningful improvements in patient outcomes while identifying remaining knowledge gaps to guide future research priorities.



A distinguishing feature of the conference was the integration of patient and caregiver perspectives throughout the scientific program, reinforcing the importance of patient-centered research and meaningful partnerships between families, clinicians, researchers, and industry.

Scientific Exchange and Global Collaboration

The conference provided exceptional opportunities for collaboration across the international CDG community.

The scientific poster session featured 25 research presentations, showcasing ongoing investigations across multiple CDG subtypes and related glycosylation disorders. Poster sessions encouraged discussion between investigators, clinicians, trainees, families, and industry representatives while fostering new collaborations and future research partnerships.

Interactive "Ask Me Anything" roundtable discussions further distinguished the meeting by allowing families to engage directly with internationally recognized experts in an open and collaborative environment. These sessions facilitated meaningful conversations surrounding diagnosis, clinical management, research priorities, therapeutic development, and quality of life.

The conference strengthened existing international partnerships while establishing numerous new collaborations that continue to support ongoing research initiatives, educational programming, standards of care development, and future therapeutic efforts.

Lasting Educational Impact

One of the primary objectives of the conference was to ensure that the educational value extended well beyond the three-day meeting.

To accomplish this, every scientific presentation was professionally recorded and transformed into the **2026 CDG Education & Research Miniseries**, a permanent educational resource now freely available through the CDG CARE YouTube channel.

The miniseries features 21 expert-led presentations organized into curated educational playlists covering:



- [CDG Therapeutics](#)
- [Biology, Biomarkers & Disease Mechanisms](#)
- [Clinical Care & Disease Management](#)
- [Patient & Family Support](#)
- [Living with CDG](#)

Presentations were delivered by internationally recognized clinicians, researchers, industry leaders, psychologists, patient advocates, and families representing leading institutions worldwide. Topics include gene therapy, gene editing, drug discovery, drug repurposing, clinical trials, biomarker development, newborn screening, glycobiology, artificial intelligence, psychosocial care, sibling support, and patient-led research.

To maximize worldwide accessibility, every presentation includes professionally prepared English subtitles with automatic translation into **more than 130 languages**, ensuring that clinicians, researchers, families, and patient advocates around the world can benefit from this enduring educational resource.

Launch of the Global CDG Biorepository

A landmark achievement of the 2026 CDG Scientific & Family Conference was the official launch of the **CDG Biorepository**, the first coordinated international biospecimen resource dedicated specifically to the global CDG community.

Through the extraordinary participation of conference attendees, biospecimens were collected from individuals representing 14 distinct CDG types, creating a foundational research resource to support biomarker discovery, disease modeling, natural history studies, translational research, and future therapeutic development.

During the conference:

- 59 individuals participated in biospecimen collection
 - 30 affected participants
 - 23 healthy control participants
 - 6 carrier family members



Collectively, the initiative generated 673 biospecimens, including:

- 58 whole blood samples
- 239 plasma samples
- 187 serum samples
- 70 peripheral blood mononuclear cell (PBMC) samples
- 55 nasal epithelial samples
- 48 urine samples
- 16 dried blood spot cards

Importantly, **467 biospecimens were collected directly from individuals living with CDG**, representing an unprecedented resource for the international research community. The collection of multiple specimen types from individual participants substantially enhances opportunities for biomarker validation, cellular studies, natural history investigations, therapeutic development, and future clinical trials.

The CDG Biorepository has already become a cornerstone of CDG CARE's research infrastructure and will continue to expand through regional Biorepository Roadshows, collaborations with clinical centers, and partnerships with investigators worldwide. This initiative establishes a lasting scientific resource that will continue accelerating CDG research well beyond the conference itself.

Conference Outcomes

The 2026 CDG Scientific & Family Conference successfully achieved its objectives by:

- Bringing together **330 participants** from **more than 16 countries** for the largest international conference dedicated exclusively to Congenital Disorders of Glycosylation.
- Delivering **21 scientific and educational sessions** alongside **25 scientific poster presentations** spanning basic science, translational research, clinical care, and therapeutic development.



- Strengthening collaboration among clinicians, researchers, laboratory scientists, industry partners, patient organizations, and families through multidisciplinary scientific sessions, networking opportunities, and interactive discussions.
- Launching the **first international CDG Biorepository**, resulting in **673 biospecimens** collected from participants representing **14 types of CDG**.
- Creating a permanent educational legacy through the **2026 CDG Education & Research Miniseries**, providing free worldwide access to all conference presentations with translation capability into more than **130 languages**.
- Supporting new international collaborations that continue to advance standards of care, patient-centered research, therapeutic development, clinical trial readiness, and future educational initiatives.
- Empowering patients and families to become active partners in research through direct engagement with international experts and participation in new research infrastructure.

Acknowledgement

CDG CARE gratefully acknowledges the generous support of the **Society for the Study of Inborn Errors of Metabolism (SSIEM)**.

SSIEM's contribution played an important role in the success of the 2026 CDG Scientific & Family Conference by supporting an international forum dedicated to advancing education, research, collaboration, and clinical care for individuals living with Congenital Disorders of Glycosylation.

The impact of SSIEM's support extends well beyond the conference itself. Through the launch of the global CDG Biorepository, the creation of the 2026 CDG Education & Research Miniseries, and the international collaborations established during the meeting, the conference has generated lasting resources that will continue to advance scientific discovery, improve patient care, and strengthen the global CDG community for years to come.

CDG CARE sincerely appreciates SSIEM's continued commitment to supporting education, innovation, and collaboration within the international inherited metabolic disease community.