



**CDG FAMILY CONFERENCE
Tentative Agenda**

February 27, 2016

1:00 – 4:00 PM	“Doctor-is-in” Sessions Location: Sanford Burnham Prebys (SBP) Medical Discovery Institute, La Jolla, CA *Pre-Registration is required by November 2, 2015 at http://www.sbpdiscovery.org/research/programs/genetics/symposium/Pages/2016.aspx
4:00 PM	Social Reception Location: Sanford Burnham Prebys (SBP) Medical Discovery Institute, La Jolla, CA

February 28, 2016

8:00 – 8:15 AM	Welcome and Opening Program Andrea Berarducci – CDG CARE
8:15 – 9:00 AM	CDG Discovery, Diagnosis and Outreach Hudson Freeze, PhD – Human Genetics Program, Sanford Children’s Health Research Center
9:00 – 9:45 AM	Intellectual Disability in CDG Marc Patterson, MD – Pediatrics and Medical Genetics Department at Mayo Clinic College of Medicine
9:45 – 10:30 AM	Hormone Abnormalities in Children with CDG Bradley Miller, MD, PhD – Pediatric Endocrinology, University of Minnesota Masonic Children’s Hospital
10:30 – 11:15 AM	The Clinical Spectrum of the CDG Rainbow Donna Krasnewich, MD, PhD – NIGMS, National Institutes of Health Christina Lam, MD – NHGRI, National Institutes of Health
11:15 – 12:00 PM	Coping with CDG: Challenges and Opportunities for Parents and Families Canice E. Crerand, PhD – Department of Pediatrics and Plastic Surgery The Ohio State University College of Medicine and Center for Biobehavioral Health, The Research Institute at Nationwide Children’s Hospital
12:00 – 12:45 PM	Understanding the Roadmap Toward Therapies in CDG Matthew Might, PhD – Department of Biomedical Informatics, Harvard Medical School and NGLY1.org
12:45 – 1:45 PM	LUNCH



1:45 – 2:30 PM	NGLY1: The 1st Disorder of De-glycosylation Lynne Wolfe, MS, CRNP, BC – NIH Undiagnosed Diseases Program, National Institutes of Health
2:30 – 3:15 PM	Application of Glycomics Analysis for Diagnosing Congenital Disorders of Glycosylation Miao He, PhD – Metabolic Disease Laboratory, Children’s Hospital of Philadelphia
3:15 – 4:00 PM	Dietary Therapies in Different Types of CDG Eva Morava, MD, PhD – Hayward Genetics Center, Tulane University Medical School
4:00 – 4:45 PM	Effective Therapy Plan for Children with Significant Developmental, Physical and Sensory Challenges Becki Cohill, PhD – University of St. Augustine San Diego
4:45 – 6:00 PM	“Doctor-is-in” Sessions *Sign up will be available on-site at Registration Booth

February 29, 2016

8:00 – 8:45 AM	Going on a Diagnostic Journey: Tools and Tales Mary Elizabeth Parker, PT, PhD, NCS, PCS – Department of Physical Therapy, Texas State University and Medical Liaison, U.R. Our Hope
8:45 – 9:30 AM	A Look at Alternative Therapies and an Update on Funding Challenges and Successes of Salon Gianna David and Natalie Dragotto – CDG Parent Representative
9:30 – 10:15 AM	Cutting Edge Treatments and Therapies for Children and Adolescents Living with Physical, Developmental and Sensory Disabilities Lynette LaScala – NAPA Center
10:15 – 10:45 AM	Rarecommons Project North America: Sharing to move ahead Andrea Berarducci – Coordinator and Parent Researcher
10:45 – 11:30 AM	Issues to Identify and Address in the Aging Adolescent with CDG LaRae Mercer-Wise – CDG Parent Representative
11:30 – 12:15 PM	Speech-Language and Communication Therapies, Introduction to Augmentative & Alternative Communication Devices and Applications <i>Speaker TBA</i>
12:15 – 12:30 PM	Closing Remarks
12:30 PM	LUNCH

***Please Note that this is a Tentative Agenda and that Speakers and Times are subject to Change.**