

News from CDG USA Patient Group!

Presentation Prepared for:



**CONGENITAL
DISORDERS OF
GLYCOSYLATION
WORLD CONFERENCE**
The power of advancing patient-oriented research united
FAMILIES AND PROFESSIONALS

**Presented By:
Andrea Berarducci
President, CDG CARE and
Mother to Bianca, 5 yrs old, CDG 1a**

History of CDG USA Efforts...

- **The CDG Family Network** (1996-2014)
 - Founded in 1996
 - USA nonprofit founded by parents
 - Mission
 - Exchange information with families and physicians, locate new families and raise awareness
 - Strategy
 - Internet, family conferences and email listserv

www.cdgs.com *(no longer active!)*



Current CDG USA Efforts...

- **CDG CARE** (2014 – current)
 - Founded in 2014
 - USA nonprofit founded by parents
 - After 18 years of committed leadership and expertise, the CDG Family Network restructured and merged into the new nonprofit organization, **CDG CARE**

www.cdgcare.com *(New and Active website!)*



CDG CARE

Community Alliance and Resource Exchange

- *CARE Grows...* with every new patient who is properly diagnosed
- *CARE Grows...* as donor commitment broadens to support new educational and research opportunities
- *CARE Grows...* with every medical and therapeutic advancement that leads to improved care
- *CARE Grows...* as global collaboration and partnerships raise awareness and strengthens the future for our Community



CDG CARE Mission

- Provide information and support to individuals diagnosed with CDG, their families, and the professionals who work with them,
- Increase public awareness and understanding of CDG
- Develop a resource of programs and services to help individuals build strengths and meet challenges from early childhood through adulthood
- Encourage and support research into a wide range of issues related to CDG



CDG CARE Strategy

- Website – www.cdgcare.com
- Global Collaboration
- Semi-Annual E-Newsletter
- USA Conference
- Email Listserv



CDG CARE Governance

- **Board of Directors**
 - Provide overall governance, oversight and direction to ensure that all values, goals and laws are upheld
- **Medical Advisory Board**
 - Share experience and expertise on behalf of patients and families affected by CDG
 - Contribute to the CDG CARE semi-annual newsletter and ensure availability for consultation and support for medical, scientific and research materials published on the organization's website



CDG CARE Board of Directors

- Andrea Berarducci
 - Acting Chair
 - Colorado, USA
- Lori Rodriguez
 - Secretary
 - Colorado, USA
- Duncan Webster
 - New Brunswick, CANADA
- Kathleen Amaral
 - Acting Vice Chair
 - Massachusetts, USA
- Alex Conner
 - Oregon, USA
- Michelle Heim
 - Pennsylvania, USA
- ***Currently Recruiting for 3 Open Board Positions***



CDG CARE Medical Advisory Board

- Canice E. Crerand, PhD
 - The Research Institute at Nationwide Children’s Hospital
 - Ohio, USA
- Bradley S. Miller, MD, PhD
 - University of Minnesota, Masonic Children’s Hospital
 - Minnesota, USA
- Lynne A. Wolfe, MS, PNP, ACNP, BC
 - NIH/National Human Genome Research Institute
 - Maryland, USA
- Hudson H. Freeze, PhD
 - Sanford-Burnham Medical Research Institute
 - California, USA
- Eva Morava, MD, PhD
 - Tulane University Medical School
 - Louisiana, USA
- Can Ficicioglu, MD, PhD
 - The Children’s Hospital of Philadelphia
 - Pennsylvania, USA

CDG CARE is continually looking for professionals with an interest in joining our Medical Advisory Board!



CDG CARE Initiatives

➤ 2016 USA Conference!!

➤ 7th Annual Rare Disease Symposium

- Scientific Conference, at Sanford-Burnham, CA
✓ Feb 26-27, 2016
- CDG Family Conference, at Clarion Del Mar, CA
✓ Feb 27-29, 2016

➤ Semi-Annual E-Newsletter

➤ Email Listserv

➤ CDG Awareness Day

CDG Social Network Community



Facebook

- CDG Family Network Facebook Group
 - A GLOBAL ALLIANCE formed by worldwide parents and family members seeking to build a unique voice to fight against the impact of CDG in patients and families lives

CDG Family Network Facebook Group



Objectives

- To give support to families,
- To facilitate connection within families,
- To promote sharing of information,
- To boost and conduct patient-initiated research
- To raise global awareness, and
- To build robust and trustful relationships with CDG professionals

CDG Family Network Facebook Group



Membership

- 527 Members (as of 8/24/2015)
- Closed Group
 - Membership is open to the following family members only: affected individuals, parents, grandparents, siblings of affected individuals
 - CDG experts/professionals
 - Professionals who serve the global CDG Community for the greater good of all individuals with CDG and their families

CDG Family Network Facebook Group



Administration

- Consists of a group of volunteer family members who work together in a team effort to ensure the safety, confidentiality and respect in the group's members, children and the global CDG community
 - Brea McClain - USA
 - Vanessa Ferreira- France
 - Merell Liddle - Australia
 - Rana Atwi – Dubai
 - Michaela Specianova – Czech Republic
 - Andrea Berarducci - USA



THANK YOU!

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