News from CDG USA Patient Group!

Presentation Prepared for:

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www.cdgs.com *(no longer active!)*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

www.cdgcare.com
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

www.cdgcare.com
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

*www.cdgcare.com*
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

www.cdgcare.com
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!

www.cdgcare.com
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

www.cdgcare.com
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

www.cdgcare.com
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!

Presented by:
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