SSIEM Official Satellite Symposia
28 to 30 August 2015, in Lyon (France)

This conference is part of the Educational Program of Excellence on CDG created by the Portuguese Association for CDG (APCDG, www.apcdg.com).

It is organized in partnership with several associations and/or country CDG patient advocates: CDG Australia, CDG Brazil, CDG Czech Republic, CDG Denmark, Foundation of Glycosylation (the FoG) Canada, CDG Denmark, CDG Italy/Ireland, CDG Israel, Les ptits CDG France, CDG Spain, CDG Sweden, CDG USA, CDG UK charity and CDG The Netherlands.

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My name is Barbara Vulso
I’m the mother of Leonardo CDG1a
CDG Challenges and Choices

or

How difficult it can be to raise a Superhero
(and being one at times)
Leo’s Story

• Normal pregnancy
• Born breech
• Hypotonia
• MRI Scan
• Diagnosis
• CDG
Diagnosis and choices

Our present was full of grief and questions

- What are we going to do?
- How will the future be?
- Is there any cure?
- Will he be ok?
- Should we move?

Fear, Frustration, Powerless, Isolation
There is a crack in everything, that's how the light gets in.

-Leonard Cohen
Challenges:
1 - What is it going to happen?
or
Understanding CDG

FUTURE

Diagnosis CDG1A

Understanding CDG
How can we get information?
How can we help Leo?
Is there anybody out there?

Our thoughts and roles:
Parents
Therapists
Caregivers
Challenges:
2 - Will we be able to cope?
or
The pressure of being a “Rare” family

Diagnosis
CDG1A

Pressure on our family
Hopes and Dreams

Our feelings:
Emotionally broken
Feeling isolated and frustrated
High level of stress and tiredness

PAST
Challenges:
3 - What can we do now?
or
Making the right choices for Leo

Diagnosis
CDG1A

Making the right choices
Priorities

Our actions:
- Reaching out for information and knowledge
- Understanding and fighting for Leo’s rights and needs
- Financial pressure of being a caregiver

PRESENT
WHEN SOMETHING GOES WRONG IN YOUR LIFE, JUST YELL, "PLOT TWIST!" AND MOVE ON.

A New Hope
A New Hope

or

What do we need to make things happen and to overcome challenges and difficulties
Awareness and Advocacy

• How can we help?
• Creating awareness
• Give a voice to Leo
• Finding ways to tell our kids’ stories

Make Sure That Leo's Voice Is Heard!
Knowledge and connections

• From having a diagnosis to becoming an expert
• How can we gather the important information
• The importance of knowing every aspect of CDG
• Monitoring
• Updates
Going places or
The importance of connecting to other CDG families and reaching out
Identity

“To look deep into your child's eyes and see in him both yourself and something utterly strange, and then to develop a zealous attachment to every aspect of him, is to achieve parenthood's self-regarding, yet unselfish, abandon. It is astonishing how often such mutuality had been realized - how frequently parents who had supposed that they couldn't care for an exceptional child discover that they can. The parental predisposition to love prevails in the most harrowing of circumstances. There is more imagination in the world than one might think.” – Andrew Solomon, Far from the Tree: Parents, Children, and the Search for Identity
Solsbury Hill

“...it’s about being prepared to lose what you have for what you might get...it’s about letting go”

“...it’s not like a clever rhythm, just a bit odd. It’ll be interesting to see how people dance to it”

This is our story. We have now new hopes, dreams and expectations, and although sometimes they are a little odd, all we can say is: let’s go with it and dance.
Foundation Glycosylation (FoG) is the official sponsor of the videos targeted to the “SSIEM Official Satellite Symposia – Second World Conference on Congenital Disorders of Glycosylation (CDG): a challenging story of sugar trees”:

The Foundation Glycosylation (FoG) founded by Duncan Webster (Canada), is the official sponsor of the videos of all oral session that will be given during the conference. This material will be available in the Youtube channel dedicated to “SSIEM Official Satellite Symposia – Second World Conference on Congenital Disorders of Glycosylation (CDG): a challenging story of sugar trees” at:

For more information about the work of this organization which is focused on research to ALG9 -CDG (CDG-1L), visit the following link: http://www.thefog.ca/main.html

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