

SSIEM Official Satellite Symposia

**“The 2nd World Conference on Congenital Disorders of Glycosylation (WCCDG) for Families and Professionals: a challenging story of sugar trees”,
28 to 30 August 2015, in Lyon (France)**



**CONGENITAL
DISORDERS OF
GLYCOSYLATION
WORLD CONFERENCE**

The power of advancing patient-oriented research united
FAMILIES AND PROFESSIONALS

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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THE POWER OF ADVANCING PATIENT-ORIENTED RESEARCH UNITED

FAMILIES AND PROFESSIONALS

PORTUGUESE ASSOCIATION



01

CDG IMPACT ON FAMILIES

- PATIENTS & CAREGIVERS ARE OVERLOOKED FOR CONSIDERING THERAPEUTIC AND INFORMATION TO ADDRESS COG.
- DELAYS IN DIAGNOSIS AND MEDICATIONS MAY HAPPEN.
- LACK OF EFFECTIVE TREATMENT OPTIONS, AND EMOTIONAL, FINANCIAL AND LOGISTICAL QUALITY OF LIFE OR SOCIAL RELATIONSHIPS.
- INSUFFICIENT FINANCIAL SUPPORT OF CLINICAL RESEARCH.

02

RESEARCH

- LACK OF FUNDING
- LIMITED AWARENESS OF SCARCE RESOURCES
- LACK OF DISCOVERY AND TRIALS METHODS, RESEARCH PROGRAMS
- LACK OF BASIC RESEARCH TOOLS
- ONLY ANNUAL MEETINGS

04

UNITED TO OVERCOME CHALLENGES

- COLLABORATION
- COMMUNITY
- SUPPORT
- SUCCESS

03

GOAL: CURE CDG

- SUCCESS
- RECOVERY
- SUPPORT
- COMMUNITY

07

HOPE FOR PATIENTS AND THEIR FAMILIES



06

OUTCOMES FROM THE CONFERENCE?

- INCREASED AWARENESS
- COMMUNITY BUILDING
- SHARING KNOWLEDGE
- FOSTER COLLABORATION

05

WHY YOU SHOULD ATTEND WORLD CONFERENCE ON CDG (WCCDG)?

- INCREASING AWARENESS
- COMMUNITY BUILDING
- SHARING KNOWLEDGE
- FOSTER COLLABORATION



WORLD CONFERENCE CONGENITAL DISORDERS OF GLYCOSYLATION

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Evolution and potentiality of sibling relationships

Talking about déficiency with children, listening to them, letting them talk to each other

Functions of the brother

group imposed by the parents, created by the children

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- creations of Pacts of loyalty and rules of to live together between peers,
- flexible and evolutionary games,
 - ▣ hatred/love,
 - ▣ alliance/break,
 - ▣ complicity/rivalry,
 - ▣ aggressiveness,
- favour the processes of separation parent-child,
- introduced the child into the logic of the chain of the generations.

Links parents/sibling

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- Every parent passes on to his children the "psychic cards" of his own brotherhood

The child with disability is “brother of”
and not only “son of”.

I have two children and
a child with a disability.

My brother, it is not as a real brother, I do not do what we
do with a “normal” brother, he is not a friend because I
would have not chosen him

I have three mothers and no sisters.

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Build itself always with and in the glance of the other one.

process

of identification/
differentiation

Each of the children is differently affected by disability at the various moments of its life

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- according to the singular links to the parents and the parental projections on each of the children
- according to the dynamics of the group sibling and singular links in the subgroups of the sibling.

The handicap comes into effect and take meaning according to the intrapsychic and intersubjective problems of the moment : moments keys

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- announcement of the handicap,
- when the younger child overtakes the elder brother,
- worsening or the cure of the pathology,
- Inclusion
- integration in a specialized institution
- adolescence,
- marriage and the first pregnancy of sibling
- death of the parents.

The disability comes into effect and take sense according to the links and to the problem of the subject

Why, how I was born ?

Why he and not me, me and not him ?

Who is he ? Who am I ?

Why this feature does she make cry adults

Should we have disability to become important to the parents, adults

Why the parents, the doctors cannot protect, be better cured.

Effects of Parental trauma on the children

- modification of the glance and the interest of the parents for their non-handicapped child
- fear/desire of being or to become handicapped to be loved
- the child with a disability feels guilty for making sad her parents and depriving her siblings of parental attention.

- do not be a good son, a good brother :
identification at the parental guilt,
- handicap as realization of the desires of
aggression : disturbing omnipotence of
the thought.

shame of the other one : I am ashamed to have a link with this other one shameful,
shame for the other one : if I was him, I would be ashamed of me,
shame to be ashamed : if I was a "good" brother, I shall not have to be ashamed.

Think of the handicap to transform the traumatic reality into a convertible object by the thought

the child must be able to think without being afraid of hurting those who he loves : “they do not ask questions, for him his brother, it is his brother, he always saw him like that, then“.
(dénégative pact, Kaes, 1998)

Which helps for the children

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- ▣ group word,
- ▣ be allowed go to listen to them,
- ▣ favour the structuring game of construction of pact between them, rivalry, complicity, jealousy, not prevent that the handicapped child takes his place there,
- ▣ favour time of exchange between them outside the glance and outside the control of the adult,
- ▣ let the handicapped child take the risk of the brotherly link without the protection of the adult.

Support the parents

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- they are not "handicapped parents", professionals have to show themselves not "too good", "too knowing", helping be just what is needed when it is needed.
- help them to spot the positive aspects and the negatives of the brotherly experience,
- their children form before any a sibling, the handicap is only one of the explanatory elements of their links.

- do not interpret systematically the brotherly problem in the light of the only handicap,
- think of the importance that the child with disability can live an experience of brotherhood,
- support the professionals in their skills to be spoken in and with the children of the deficiency and its consequences.

Conclusion

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- help the children to create of sense in the handicap,
- allow him, her, to say what he knows, what he wants to know (*via* words, carry out in act, somatization),
- help him, her to clarify his, her, knowledge, its feelings for the other one for one,
- make the children of what benefit that the adults know and feel to authorize them to build their own manners to appropriate this reality.

Perspectives

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Better take into account the subjectivity of every children of the family so that they build themselves with the reality of the deficiencies and their consequences.

Estimate the impact of the multiple interventions of the professionals with the baby handicapped on the brotherly links and the social development of the skills.

Improve the knowledge of the intra-brotherly ill-treatments in the situations of vulnerabilities of a child (differentiate ill-treatments and structuring aggressiveness's)

Publications

- Scelles R. (2010) Liens fraternels et handicap. De l'enfance à l'âge adulte. Erès.
- Scelles R. ; Bouteyre E. ; Dayan C. ; Picon I. (2011) Support groups for sisters and brothers of children with intellectual and developmental disabilities. *Early Child Development and Care*, 180(06), 743 - 752.
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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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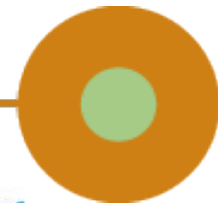
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