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

01 CDG IMPACT ON FAMILIES
02 RESEARCH
03 GOAL: CURE CDG
04 UNITED TO OVERCOME CHALLENGES
05 WHY YOU SHOULD ATTEND WORLD CONFERENCE ON CDG (WCCDG)
06 OUTCOMES FROM THE CONFERENCE?
07 HOPE FOR PATIENTS AND THEIR FAMILIES

WORLD CONFERENCE CONGENITAL DISORDERS OF GLYCOSYLATION

This and other resources available at:
www.apcdg.com
How a liver transplant changed my life

Before

After
8 jaar
Problems as a child

- Liver fibrosis
- Periods of vomiting, diarrhoea and fever
- Chronic diarrhoea
- Enlarged abdomen
- Protein-losing enteropathy

- Low sugar levels
- Lack of energy
- Drumstick fingers and toes
- Opiates and local anaesthetics didn't work
Problems that disappeared as an adult

- Periods of vomiting, diarrhoea and fever
- Chronic diarrhoea
- Enlarged abdomen
- Sugar problems
Problems as an adult

- Liver cirrhosis
- Opiates and local anaesthetics still didn't work
- Lack of energy
- Often feeling really cold
- Constipation
- Hepatic encephalopathy
- Oedema
- Gall stone attacks
- Intestinal ulcers
- Thrombosis
- Oesophageal bleeding

Spider naevi
Drumstick fingers and toes
Shortness of breath
Cramps
Liver transplant

03:45 1st of January 2012
Liver transplant complications

- Severe pain after the operation
- Bleeding
- Spleen infarction
- Sepsis
Improvements after the liver transplant

- No more gall stones
- No more chance of oesophageal bleeding
- Spider naevi are gone
- No longer intensely cold
- No additional oxygen necessary
- No cramps any more
- Oedema has gone
- Constipation has gone
- Local anaesthetics work
- More energy
- Drumstick fingers and toes have gone
- Transferrin is normal
Drumstick fingers and toes
Transferrin tests

← 2 weeks stop of mannose therapy

Mannose therapy →

← After liver transplant
Immunosuppressants

- Psychological symptoms
- Symptoms depending on type of medication and dosage
- CDG related?
In conclusion

Before

After
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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