



INVITATION

Nordic CDG meeting

September 1–2, 2018 in Malmö, Sweden



Welcome!

On behalf of the Organizing Committee, we warmly welcome you to the Nordic CDG meeting on September 1 until September 2, 2018 in Malmö, Sweden. The event is co-organized between the Swedish CDG association and Dr Erik Eklund, MD, PhD, Associate professor of Experimental Paediatrics at Lund University. We are pleased to present a program that represents a variety of clinical, investigational, therapeutic and community experts from around the World.

The purpose of this event is to facilitate the meeting and the collaboration between medical professionals and families, to share knowledge and experience and discuss common issues of patients living with CDG. This creates a unique opportunity to develop and create a community that enables medical professionals and families to unite and enhance CDG research, knowledge, therapeutic and alternative treatment strategies.

We would like to thank all our speakers who kindly accepted our invitation to par-

ticipate in this unique and educational program. Without their willingness to share their time and expertise, this conference had not been possible.

The conference is organized and run by members of the Swedish CDG Association, and is funded by donations, grants and a participant registration fee. A big thank you to all who contribute, without whose efforts this had not been possible.

Together we can make a difference in the fight against congenital diseases of glycosylation (CDG). On our behalf, thank you for joining us.

Kind regards

Anne-Kristin Ottosson
Swedish CDG Association

Erik Eklund, MD, Ph.D.
The scientific program

Organizing a meeting of this kind requires a lot of resources. It requires money as well as time. The members of the Swedish CDG Association do not require any compensation for their time put in. However, it costs money and this is nothing an association based on voluntary work has a lot of. If you feel that you can and wish help support this event, we are grateful for donations to bank account in the name of Svenska CDG föreningen 5905-4940. (IBAN nr: SE75 8000 0831 3950 3017 2869. The banks BIC is SWEDSESS).

Welcome on behalf of the Swedish CDG Association:

Anne-Kristin Ottosson
chairman

Anna Lund
member of the board

Eva Rubin
secretary



Program

The scientific program has been developed by Erik Eklund, in cooperation with the Swedish CDG Association (cdgforeningen.se). Please note that some of the lectures will be held in English and some will be held in Swedish (SWE) / Scandinavian (SCA). Please also note that this is only a preliminary version. Changes can thus be made at the last minute.

SATURDAY SEPTEMBER 1

08.00 Registration

09.15 **Welcome and information**

Anne-Kristin Ottosson, Chairman Swedish CDG association

09.30 **An exposé of my life with CDG**

Professor Jaak Jaeken, MD Ph.D., Em. Professor of Pediatrics, Centre of Metabolic Diseases, University Hospital Gasthuisberg, Belgium



10.20 **CDG – a review in Scandinavian language** (SCA)

Dr Erik Eklund



11.40 LUNCH

13.10 **CDG and the hormones** (SWE)

Dr Maria Elfving

14.00 **The nervous system and CDG**

Professor Marc C. Patterson, MD, Professor of Neurology, Pediatrics and Medical Genetics, Mayo Clinic Children's Center, Minneapolis



14.50 BREAK

15:30 **The role of advocacy in CDG**

Dr Vanessa dos Reis Ferreira



16.10 Lecture or time for individual sessions

19.00 DINNER

SUNDAY SEPTEMBER 2

09.15 **The natural history data study at the NIH** RN Lynne Wolfe, NIH

10.10 RN Carlos Ferreira, NIH

10.40 PAUS

11.20 Agnes Rafalko, Founder & CEO at Glycomine, Inc

12.00 **The basics of CDG – sugar n'genes**

Professor Hudson Freeze, Ph.D. Professor and Director, Human Genetics Program, Sanford Children's Health Research Center, Sanford-Burnham-Prebys Medical Discovery Institute, California



13.15 Estimated finishing time



Registration

Registration must be made by mail to svensk-acdgforeningen@gmail.com by June 15, 2018. Enter your name and phone number in your mail. At the time of registration, a registration fee per family is required at the minimum amount of 250 SEK. We are also grateful for larger donations as this is an ideally arranged event with many outstanding lecturers. The

amount is paid to the Swedish CDG association bank account 5905-4940 a.s.a.p. (IBAN nr: SE75 8000 0831 3950 3017 2869. The banks BIC is SWEDSESS)

If you join as a represent from the medical profession or for research purposes, the registration fee is 495 SEK. The amount is paid to the Swedish CDG association bank account 5905-4940 (IBAN nr: SE75 8000 0831 3950 3017 2869. The banks BIC is SWEDSESS) by June 15, 2018.



Practical information

Venue

As venue for this meeting, we have chosen Quality Hotel View in Malmö, Sweden with the address Hyllie Stationstorg 29. The hotel is located in Hyllie with excellent communication facilities.

Rooms are reserved at Quality Hotel View at the price of;

Single room; 850 SEK / night

Double room; 950 SEK / night

The rooms are paid directly by the participants to the hotel.

The rooms can be booked directly by mail to the hotel at q.view@choice.se and state the booking code Svenska CDG association, alternatively, indicate the reservation number; 2110GR009936

Distance to airports:

- Copenhagen Airport: 24 km, 12 min by train, about 20 min by car
- Malmö Airport: 30 km, about 25 min by car

Distance to public transport:

- Less than 50 meters to Hyllie train station
- 50 meters to bus stops for city and regional traffic

Meals

Friday August 31: Since everyone is expected to arrive at different times, you are welcome to let us know if you are interested in attending a mutual dinner on Friday evening. Mail us regarding interest to svenskacdgforeningen@gmail.com. Dinner is paid by each participant on site.

Saturday September 1: Lunch is best on your own as there are several restaurants available. Lunch time will be 90 minutes

Dinner; A mutual dinner is offered on Saturday evening. This is ordered and paid for no later than August 1 to the Swedish CDG association (svenskacdgforeningen@gmail.com). A 3 course meal is planned at price of 450 SEK / pers (excluding drinks).

Payment for Saturday night's meal must be available to the Swedish CDG Association no later than August 1 at bank account 5905-4940. (IBAN nr: SE75 8000 0831 3950 3017 2869. The banks BIC is SWEDSESS)

Welcome!