



Helping families with GSD to better treatment and connecting healthcare professionals

Scandinavian Association for Glycogen Storage Disease 6th GSD Conference, May 3 to 4, 2024 in Ängelholm, Sweden

Friday May 3 – Scientific Day

- 10.00 **Opening ceremony of the conference**
Entry march by the GSD kids
- 10.15 **Welcome and presentation of the SAGSD**
Marcus Landgren, President SAGSD
- 10.30 **Experience and evidence on Empagliflozin for GSD Ib patients**
Dr. Terry Derks, UMCG, Groningen, Netherlands
- 11.00 **Ketotic types GSD III, VI and IX – Treatment goals and complications**
Dr. Thomas Casswall, Astrid Lindgren Children's Hospital, Stockholm, Sweden
- 11.30 **Aspects on fructose and galactose intake in patients with GSD Ia**
Camilla Carøe, dietitian, Children Nutrition Unit, Rigshospitalet, Copenhagen, Denmark
- 12.00 **Lunch**
- 13.00 **Innovations and novel GSD treatments**
Dr. David Weinstein, Consultant, USA
- 13.30 **Early learnings from the GSD Value Project**
Dr. Ruben Overduin, UMCG, Groningen, Netherlands
- 14.00 **Monitoring in liver GSDs – aspects and considerations**
Dr. Andrea Schreuder, UMCG, Groningen, Netherlands
- 14.30 **Lifestyle and wellness in GSD**
Dr. Damian Cohen, research coordinator, Miller School of Medicine, Miami, USA
- 15.00 **Ultragenyx presentation**
Dr. Richard Collis, Senior Medical Director, New York, USA
- 16.00 **Q & A session – patients to doctors**
Moderator Marcus Landgren
- 17.00 **Mingle party and try GSD friendly tapas and snacks**
Fredrik Karlsson, dietitian, Key Account Manager, Navamedic
- 18.00 **Dinner**



Helping families with GSD to better treatment and connecting healthcare professionals

Saturday May 4 – Interaction Day

Patient meeting

Conference room: **HAVET**

Moderator: Marcus Landgren
President SAGSD

Open session – All participants welcome

- | | |
|-------|--|
| 09.00 | SAGSD General Meeting
General meeting |
| 09.45 | Workshop – Fundraising
Jessica Andersson
Secretary SAGSD |
| 10.00 | Driving research and building a community through patient advocacy – Sophie's Hope Foundation & Cure GSD1b
Blair Stone-Schneider,
Executive Director
Sophie's Hope Foundation, USA |
| 10.30 | Coffee break |
| 11.00 | Patient story: feelings and GSD
Birgit Sivertsen, Chairwoman,
GSD Association, Faroe Islands |
| 11.15 | Travel and GSD – assisted by a new international GSD network
Birgit Sivertsen, Faroe Islands
Sabine Sarnighausen, Germany
Iris Ferrecchia, USA |
| 11.45 | Feedback about the conference |

Meeting for doctors, dietitians and nurses

Conference room: **UTSIKTEN**

Moderator: Dr. Domniki Papadopoulou
University Hospital, Lund, Sweden

Closed session – Doctors, dietitians & nurses only

- | | |
|-------|---|
| 09.00 | Case discussions
Type I, III, VI and IX |
| 10.30 | Coffee break |
| 11.00 | Discussion continues
Type I, III, VI and IX |
| 11.45 | Feedback about the conference |

12.00 Lunch

13.30 Closing remarks and the conference ends



Helping families with GSD to better treatment and connecting healthcare professionals

- Venue** **Klitterhus hotel, Klittervägen 45, 262 62 Ängelholm, Sweden**
The hotel is situated on the beach in the beautiful bay in Ängelholm.
- Getting here** Flights to Copenhagen, Denmark is the most convenient. From Copenhagen Airport direct trains to Ängelholm every hour: www.skanetrafiken.se or www.oresundstag.se
- Prices**
- 1) Scandinavian GSD patients and family, pay a reduced fee:
500 DKK for adults and 250 DKK for children up to 13 years old (younger than 2 free)
Covers meals (lunch x 2 and dinner x 1) and beverages are included.
 - 2) International GSD patients and families, pay a slightly reduced fee, price 1000 DKK for adults and 500 DKK for children up to 13 years for children up to 13 years old (younger than 2 free). Covers meals (lunch x 2 and dinner x 1) and beverages are included.
 - 3) Doctors, dietitians, and industry/sponsors are invoiced the full conference fee 1500 DKK.
The conference fee includes meals, and beverages.
A single room with sea view 1995 SEK
A single room with no sea view 1695 SEK
A double room with sea view 2195 SEK
A double room with no sea view 1895 SEK
- All 14 hotel rooms are reserved for health care professionals and can be booked by contacting Klitterhus
- Accommodation** **Patients and families**
A 30% discount on the cottages can be obtained by using the booking code:
"LANDGREN2024"
Destination Råbocka, Råbockavägen 101, 262 63 Ängelholm, Sweden
Telephone number: +46 706 84 22 44
www.rabocka.se
- Health care professionals**
Contact the hotel for booking: Telephone number: +46 43 11 35 30
www.klitterhus.nu
- Registration** Send an email to Marcus Landgren: landgrenmarcus@gmail.com
- Deadline for registration: **April 26, 2024**
Transfer the total amount in DKK to our bank account in Denmark.
- Jyske bank, Østergade 23, 9800 Hjørring, Denmark
IBAN number DK1873600001573055
Swift JYBADKKK

Scandinavian Association for Glycogen Storage Disease
A non-profit association registered in Sweden with an organization number of 802461-2312
C/O Marcus Landgren
Lotshusgatan 43
216 41 Limhamn
Sweden

