



SAGSD

*Helping families with GSD to better treatment and connecting healthcare professionals
A non-profit association registered in Sweden 802461-2312 and Denmark CVR 35 93 87 10*

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 of 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 **Ultragenyx presentation**
Dr. Richard Collis, Senior Medical Director, New York, 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 **Coffee break**
- 15.00 **Lifestyle and wellness in GSD**
Dr. Damian Cohen, research coordinator, Miller School of Medicine, Miami, USA
- 15.30 **Innovations and novel GSD treatments**
Dr. David Weinstein, Consultant, USA
- 16.00 **Q & A session – patients to doctors**
Moderator Marcus Landgren
- 17.00 **Mingle party and taste GSD friendly tapas and snacks**
Fredrik Karlsson, dietitian, Key Account Manager, Navamedic
- 18.00 **Dinner**



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Saturday May 4 – Interaction Day

07.30 **“Footsteps for GSD”** – join us for a walk or run along the beach in front of Hyttstigen 6
You can also donate for to fundraise for the SAGSD: <https://gofund.me/95aad72d>

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 **A patient story**
Kamille 19 years old has GSD Ia
She will share her journey
- 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
Skåne 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 end of the conference**



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- 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. Trains run directly from Copenhagen Airport to Ängelholm
www.skanetrafiken.se or www.oresundstag.se
- Prices The two-day conference includes meals (lunch x 2 and dinner x 1) and beverages
- 1) Scandinavian GSD patients and family, pay a very reduced fee of 500 DKK for adults and 250 DKK for children up to 13 years, (younger than 2 are free)
 - 2) International GSD patients and families, pay a slightly reduced fee of 1000 DKK for adults and 500 DKK for children up to 13 years, (younger than 2 are free)
 - 3) Doctors, dietitians, and industry/sponsors pay the full conference fee of 1500 DKK
- Accommodation **Patients, families, and industry/sponsors are recommended to stay at:**
The Best Western Hotel - Hus 57 - in the town of Ängelholm
To book a room write the booking code "MLAND" in an email to: bokning@hus57.se
By the SAGSD the negotiated reduced prices are:
- | | |
|---|----------|
| A single or a double room including breakfast for | 1200 SEK |
| A 3- or 4-person room including breakfast for | 1400 SEK |
- www.hus57.se
- Health care professionals can book rooms at Klitterhus:**
This is a small hotel with 14 rooms that are reserved primarily health care professionals
To book a room send an email to the hotel: info@klitterhus.nu
- | | |
|---|-----------------|
| A single room including breakfast for with / without sea view | 1995 / 1695 SEK |
| A double room including breakfast for with / without sea view | 2195 / 1895 SEK |
- www.klitterhus.nu
- Registration Email Marcus to register to the conference: 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
- (Danske patienter kan overføre til Jyske Bank, Reg. Nr. 7360 og Konto Nr. 1573055)

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