



Helping families with GSD to better treatment and connecting healthcare professionals

Scandinavian Association for Glycogen Storage Disease

4th Biannual Conference, April 28th and 29th 2018 at Klitterhus Hotel in Ängelholm, Sweden

Saturday 28th April

- 08.00 **IGSD PSP Steering group meeting (by invitation only)**
Katherine Cowan, Senior Adviser, James Lind Alliance, London, UK
- 12.00 **Lunch and arrival**
- 13.00 **About the SAGSD**
Marcus Landgren, President SAGSD
- 13.15 **Overview GSD I, III, IV, VI and IX**
Prof. David Weinstein, Connecticut Children's, University of Connecticut, USA
- 14.00 **Ketonemia and hypoglycemia in GSD III, VI and IX**
Dr. Terry Derks, University of Groningen, UMCG, Beatrix Children's Hospital, Netherlands
- 14.30 **The role of optimal metabolic control in GSD Ia**
Prof. David Weinstein, Connecticut Children's, University of Connecticut, USA
- 14.45 **Research study protocol: Fructose and galactose in patients with GSD Ia**
Dietician Camilla Caroe, Children Nutrition Unit, Rigshospitalet, Copenhagen, Denmark
- 15.00 **Break**
- 15.30 **A patient story – the long and winding road to diagnosis**
Parents to Elliott 3 years, GSD IXa2, Sweden
- 15.45 **Psychological challenges for GSD patients, parents and health care providers**
Psychologist Peter Burgard, Dietmar-Hopp-Metabolic Centre, Heidelberg, Germany
- 16.15 **Parents experience and perspectives – discussions**
Nurse Iris Ferrecchia, Connecticut Children's, USA
- 16.30 **Break**
- 16.45 **Priority Setting Partnership – What's it all about?**
Katherine Cowan, Senior Adviser, James Lind Alliance, London, UK
- 17.00 **International GSD Priority Setting Partnership survey – Interim results**
MD-PhD-student Fabian Peeks, University of Groningen, UMCG, Beatrix Children's Hospital
- 17.15 **Lifestyle and wellness in GSD**
Dr. Damian Cohen, Director Glucolatoino, Rosario, Argentina
- 17.30 **Gene therapy for GSD patients**
Prof. David Weinstein, Connecticut Children's, University of Connecticut, USA
- 18.00 *A 30 min run or walk – a fundraising for SAGSD (put your jogging shoes on)*
- 19.00 **Dinner**





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Sunday 29th April

After the morning exercise and breakfast two parallel sessions will be offered

07.30-08.15 *Tabata wake up with Lea Thuesen - optional
(put your sports outfit on)*

07.30-09.15 **Breakfast**

Patient meeting

Conference room: **HAVET**

Moderator: *Marcus Landgren*

09.15 **SAGSD General Meeting**
A formal general meeting

10.00 **Workshops (three groups)**
Introduction to workshops
Suggested topics:
-safety
-exercise
-diet
-mental health
-independent living

10.30 **Coffee break**

10.45 **Presentation of the workshops**
Group A: Marcus Landgren
Group B: Peter Burgard
Group C: Iris Ferrecchia

11.45 **SAGSD conference survey 2018**

Meeting for doctors and dietitians

Conference room: **UTSIKTEN**

Moderator: *Dr Terry Derks*

09.15 **Disease specific discussion**
Type I
Type III
Type IV
Type VI
Type IX

10.30 **Coffee break**

10.45 **Research and clinical
collaboration**

11.45 **SAGSD conference survey 2018**

12.00 **Lunch**

13.00 **Conference ends and departure**

13.00–16.00 **IGSD PSP Steering group follow-up meeting (by invitation only)**
Katherine Cowan, Senior Adviser, James Lind Alliance, London, UK





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About the conference

- Venue** **Klitterhus hotel, Klittervägen 45, 262 62 Ängelholm, Sweden**
The historic hotel Klitterhus built in 1922 is situated literally on the beach in the beautiful bay of Skälderviken in Ängelholm.
- Getting there** Flights to Copenhagen, Denmark is the most convenient. From Copenhagen Airport direct trains to Ängelholm every hour: www.skanetrafiken.se
- Invited** All with interest in GSD are welcome, national and international. Scandinavian members/patients/families and health care professionals have priority.
- Prices**
- 1) GSD patients and family:
450 DKK adults and 250 DKK children up to 13 years old
(conference fee, meals, beverages and accommodation in camping cottages)
 - 2) Health care professionals:
750 DKK dietitians and doctors
(conference fee, meals, beverages but **not** accommodation)
- Accommodation** **Patients and families**
The SAGSD has booked 14 cottages for 2 or 4 persons in each at Råbocka Camping, Råbockavägen 101, 262 63 Ängelholm
www.rabockacamping.se
- Health care professionals**
Rooms are pre-reserved for Saturday. Please contact the hotel for booking:
Hotel Klitterhus, Klittervägen 45, 262 63 Ängelholm
www.klitterhus.com
- Registration** Send an email to Marcus Landgren:
postmaster@sagsd.org
Deadline for registration: **March 31, 2018**
Transfer the total amount in DKK to our bank account in Denmark
- Jyske bank, Østergade 23, 9800 Hjørring, Denmark
IBAN number DK1873600001573055
Swift JYBADKKK
- Cost Funding** **The estimated cost for the conference approx. 75 people is 110000 DKK.**
The budget for the conference is divided according to the following funders:
35000 DKK donation from the SAGSD
30000 DKK conference fee from doctors/dietitians/families
15000 DKK donation from Society for the Study of Inborn Errors of Metabolism (SSIEM)
21000 DKK sponsorship Vitaflo Intl Ltd
14000 DKK sponsorship Navamedic AB

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