
Agenda EGS/GalNet-MEETING 2017

Friday, 16.06.2017

- 13.00 General meeting EGS – Welcome *by the chairman*
- 13.05 Lunch
- 14.00 1. Minutes of the last meeting
- 14.15 2. Board and task issues
- 14.30 3. Members/ Members Scientific Committee
- Adds or changes needed?
- 14.45 4. Input from country reports: Best and new practices and ideas.
- 15.30 5. Website
- A small group is going to work on the content. Others continue with rest of the agenda
- 15.45 Coffee break
- 16.00 6. Financials *by the treasurer*
- Results 2016
 - Approval of the accounts
 - Budget 2017/2018
 - Decide on contribution per country for 2017 meeting in order to build up EGS reserves
- 16.45 7. EGS/GalNet meeting, preparations for Saturday
- 10 minutes presentation by the EGS
- 17.45 8. EGS-meeting 2018
- Date and location
 - Skype-meeting schedule
- 18.15 Miscellaneous
- 18.30 Closure general meeting
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- 19.30 Drinks and Dinner at the Dorint Airport hotel

Saturday, 17.06.2017

08.30 Breakfast

09.15 **Welcome**

by Jeroen van Kempen, chair EGS

1. **Patient perspective**

by Jeroen van Bruggen, chair GVN

2. **International guidelines**

Availability, translation, dissemination, implementation

by Dr. Annet Bosch

3. **International patient registry**

Workshop, Data entry and analysis

by Dr. Estela Rubio

13.00 **Lunch**

13.45 **Group picture**

4. **Collaborative research**

Roads to an effective treatment for Galactosaemia beyond the neonatal period

- GALK1 inhibitors, ER stress inhibitors, and other modalities,

*by Dr. Kent Lai, PhD
University of Utah, USA*

- GALT structural characterization and implications for pharmacological chaperone design

*by Wyatt Yue,
SGC University of Oxford, UK*

- Workshop
Aims, priorities and ideas
Discussion, conclusions and action points

by Jeroen van Kempen

17.15 **Closure**

20.00 Dinner in Amsterdam

Sunday, 18.06.2017

08.30 Breakfast and checkout of the hotel

09.30 Surprise program in Amsterdam (finish \pm 12.00h)

List of participants

Participants GalNet:

Austria	Dr. Sabine Scholl-Bürgi, <i>Innsbruck</i> Dr. Barbara Lanthaler, <i>Innsbruck</i>
Estonia	Dr. Katrin Õunap, <i>Tartu</i>
Germany	Prof. Dr. Dirk Müller-Wieland, <i>Aachen</i> Susanne Mansfeld, <i>Aachen</i>
Ireland	Prof. Dr. Eileen Treacy, <i>Dublin</i> Dr. Peter Doran, <i>Dublin</i> Asta Agasarova, <i>Dublin</i>
Lithuania	Birute Burnyte, PhD student, <i>Vilnius</i>
Netherlands	Dr. Annet Bosch, <i>Amsterdam</i> Dr. Estela Rubio, <i>Maastricht</i> Liesbeth van der Ploeg, <i>Maastricht</i> Ana Coelho, <i>Maastricht</i> Dr. Jörgen Bierau, <i>Maastricht</i> Wendy Poot, student, <i>Maastricht</i> Minela Haskovic, student, <i>Maastricht</i> Joost van Heukelom, student, <i>Maastricht</i> Dr. Lindsey Welling, <i>Amsterdam</i> Mendy Welsink, student, <i>Amsterdam</i>
Portugal	Prof. Dr. Isabel Rivera, <i>Lisboa</i>
Spain	Dr. Maria José Coll, <i>Barcelona</i>
Switzerland	Dr. Matthias Gautschi, <i>Bern</i>
UK	Dr. Elaine Murphy, <i>London</i> Prof. Wyatt Yue, <i>Oxford</i>
USA, Utah	Dr. Kent Lai, <i>Utah</i>

Participants EGS:

Austria	Sabine Ebner Else Tanner Susanne Gierlinger
Denmark	Gitte Østergaard Brigitte Schmidt Astrup
Estonia	Hiie Taks
France	Elise Bertrand Clementine Bry
Germany	Anton Fuchs
Netherlands	Maaïke van Kempen Jeroen van Kempen
Spain	Rosa Olivé Antonio Vazques
Switzerland	Andreas Kilchör
UK	Sue Bevington Laura Bevington

Guests Dutch patient society (GVN):

Netherlands	Jeroen van Bruggen Bart van der Stoep Karen 't Hooft Kerstin Haase Raymond Verkade Maaïke Verkade Christina Powell Scott Powell
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