

German Association for Glycogen Storage Diseases



Selbsthilfegruppe
Glykogenose
Deutschland e.V.

Presentation for the European Meeting
of GSD Organizations

Ute Stachelhaus-Theimer

Milano, 02.10.2010

1. Our Organization in Germany

- **SHG Glykogenose** founded on the 25th of November 1989 by seven families with children affected by GSD type I
- Membership increase by addressing patients with GSD types I, II, III, V, IX and others
- Celebration of the 20th anniversary of our organization last year

2. Photo SHG Glykogenose Deutschland



Duderstadt 2009

3. Statistics of the SHG Glykogenose

- Members: 378, where 333 are affected by GSD
- GSD I: 145
- GSD II: 110
- GSD III: 9
- GSD V: 21
- GSD IX: 7
- Others: 15

4. Administration of the SHG Glykogenose

- President: Thomas Schwagenscheidt (type II)
- Vice-president: Gerhard Eckstein
- Youth representatives:
 - Elena Welling (type Ib)
 - Laura Pauels (type Ia)
- Treasurer: Michael Kautsch (type I)
- Director: Gerda Kalle-Menne (mother of an adult daughter with type I)

5. Leader for Different GSD Types

- Type I: Ute Stachelhaus-Theimer
- Type II: Thomas Schaller,
Thomas Schwagenscheidt
- Type III: Katrin Schwenterly
- Type V: Norbert Eckelmann

6. Publication («Rundschreiben»)

- Two or three times per year
- Responsible persons: Andreas Wiemeler
Thomas Hornsteiner

7. Contacts to Other GSD Organizations

- France: Ute Stachelhaus-Theimer
- Great Britain: Norbert Eckelmann
- Spain: Elena Welling
- Italy: vacant
- United States: vacant

8. Scientific Council

- Type I: in preparation
- Type II: Dr. Mengel (Mainz)
Dr. Hahn (Gießen)
Dr. Kirschner (Freiburg)
Prof. Müller-Filber (München)
Prof. Winterholler (Schwarzenbrück)
- Type V: in preparation

9. Contact

- Selbsthilfegruppe Glykogenose e.V.
Gerda Kalle-Menne
Birkenbusch 11
45770 Marl
- Tel: +49 2365 931406
Fax: +49 2365 931401
Email: shg@glykogenose.de
- Web page: www.glykogenose.de
(with »forum» for discussions among members)

10. How to Become Member of the SHG

- Annual cost of membership: 25 € per person
- Family membership does not exist, only personal one
- Children: No memberships fees until they are 18

11. Partners

- **ACHSE** Alliance of rare chronic diseases in Germany



- **BAG** Working group of all patient organizations in Germany



- **DGM** German association against myopathies



- **IPA** International Pompe Association



12. Objectives

- Exchange of patients and their families
- Provide practical help for the daily life
- Share experiences
- Learn from success stories in other families or organizations
- Provide information
- Defend interests of the association
(e.g. raise our voice in the public health system)
- Initiate GSD-related research

13. Activities

For all members:

- General assembly once per year
(next one will take place **15th – 17th April 2011** in Duderstadt in the center of Germany)
 - With scientific presentations for the types I/III, II and V
 - Especially the youngsters and children urge their parents to participate
- Family vacations
- Weekends for parents (studies, exchange and relax time, ...)

14. Photos (1/5)



General assembly at Duderstadt

14. Photos (2/5)



General assembly at Duderstadt

14. Photos (3/5)



Berchtesgaden 2005

14. Photos (4/5)



Berchtesgaden 2005

14. Photos (5/5)



Berchtesgaden 2005

15. Activities for GSD type I (1/2)

- Created a « guide for all families »
- Wrote cookbook with recipes for type I
- Collected tables for fructose and galactose
- Organize dietetic weekends
- Educate children and young adults how to treat GSD I (together with physicians, dieticians and psychologists)



15. Activities for GSD type I (2/2)

- Give practical help
 - Information on tubes, nutrition pumps, systems to monitor glucose levels
 - Information for responsible persons in the kindergarten or school
- Exchange among the young people
 - A weekend for teenagers with type I per year, organized by themselves
- Contact physicians, medical centers for GSD and the commission of pediatricists for the metabolic diseases
- Contact industry

16. Education for Children (1/3)



16. Education for Children (2/3)



16. Education for Children (3/3)



17. Dietetic Weekend (1/6)



Schloss Gehrden, 02 – 04 October 2009

17. Dietetic Weekend (2/6)



17. Dietetic Weekend (3/6)



17. Dietetic Weekend (4/6)



17. Dietetic Weekend (5/6)



17. Dietetic Weekend (6/6)



18. Activities for GSD type II

- Organize weekends focusing on type II
- Learn about the enzyme therapy for type II (Thomas Schwagenscheidt)
- Contact other organizations (representing patients, research and industry)
- Start projects together with IPA
- Participate in international conferences

19. Activities for GSD type V

- Started some years ago
- Contact physicians to establish a medical reference center specialized for the treatment of type V (like the McArdle clinic in Great-Britain)
- Contact other associations for the mutual exchange (like in Great-Britain in September 2009)
- Organized a neuromuscular seminar with the physiotherapist Dr. John Buckley (Great-Britain) in November 2009

20. Contacts to Other GSD Organizations

Participations in general assemblies of GSD organizations:

- France: 2008 and 2009 (Ute Stachelhaus-Theimer)
- Great-Britain: 2008 and 2009 (Norbert Eckelmann) and also in 1997, 1998
- Spain: 2009 (Elena Welling)
- Italy: in 2002(?) – relationship exists via an Italian-German family

Thank You



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