

Report of Annual SSIEM-DG Members Meeting

Innsbruck, September 3rd 2014, 14:00-15:30 am

Honorary Secretary`s Report 2013 - 2014

1. Business: Report from SSIEM-dietitians group

Reinhild Link, Chair, SSIEM-DG

SSIEM-DG is a subgroup of dietitians within the SSIEM, managing patients with inherited metabolic disorders (IMD). The group was founded in 2010. The group is represented at SSIEM Council by Marjorie Dixon.

SSIEM-DG Committee: Reinhild Link (Chair), Karin Luyten (Secretary), Marjorie Dixon (Council member), Anna Fekete, Anita MacDonald, Margreet v. Rijn, Júlio César Rocha, Peter Jacobs.

AIMS of SSIEM-DG are to provide a network to facilitate communication amongst dietitians working with inherited metabolic disorders (IMD) through meetings, website and e-mail: www.ssiem.org/dg. To increase awareness of SSIEM-DG to doctors & parent groups in the EU with posters and flyers (available on the website). To be an information source for dietary management of IMD. Work together on research projects (see below).

WEBSITE

Is the main conduit by which the Group corresponds with members. We encourage the members to announce job offers in the EU and international meetings, *The Group is grateful to Michael McConnell for helping with the webpage*. Reinhild Link is updating the website.

MEETINGS AND TRAINING

Representatives of our Group provide education and training for dietitians looking after IMD patients at the annual symposium at the:

- Nutrition and Dietetic Meeting - (this is organized by the SSIEM hosts, in conjunction with SSIEM-DG)
- Parallel session on 'Nutrition & Dietetics' (from submitted abstracts)
- SSIEM Dietitians Group Members Meeting with presentation of challenging cases from Colleagues in the member countries

Many thanks to our committee for the organization!

Annual Training Courses are offered regularly in Germany and the UK

Next: Paediatric Dietetic Course: Inherited Metabolic disorders, 4-7th November, 2014, London. From January to May 2015 in Germany. See website !

FUTURE SSIEM and ICIEM SYMPOSIA

SSIEM symposia Lyon, France, 2015

SSIEM symposia Rome, Italy, 2016

ICIEM/SSIEM symposia Rio de Janeiro, Brazil, 2017

RESEARCH

The Group promoted research in the dietetic treatment of IMD. Five Surveys among European SSIEM-DG Members took place:

- **Dietary practices in non-responsive homocystinuria: A European survey:**
 - Adam S, Almeida MF, Carbasius Weber E, Champion H, Chan H, Daly A, Dixon M, Dokoupil K, Egli D, Evans S, Eyskens F, Faria A, Ferguson C, Hallam P, Heddrich-Ellebrok M, Jacobs J, Jankowski C, Lachmann R, Lilje R, Link R, Lowry S, Luyten K, MacDonald A, Maritz C, Martins E, Meyer U, Müller E, Murphy E, Robertson LV, Rocha JC, Saruggia I, Schick P, Stafford J, Stoelen L, Terry A, Thom R, van den Hurk T, van Rijn M, van Teeffelen-Heithoff A, Webster D, White FJ, Wildgoose J, Zweers H. Dietary practices in pyridoxine non-responsive homocystinuria: A European survey. **Molecular Genetics and Metabolism (2013):110(4):454-59.**
- **Dietary management of urea cycle disorders: European practice**
 - Adam S, Almeida MF, Assoun M, Baruteau J, Bernabei SM, Bigot S, Champion H, Daly A, Dassy M, Dawson S, Dixon M, Dokoupil K, Dubois S, Dunlop C, Evans S, Eyskens F, Faria A, Favre E, Ferguson C, Goncalves C, Gribben J, Heddrich-Ellebrok M, Jankowski C, Janssen-Regelink R, Jouault C, Laguerre C, Le Verge S, Link R, Lowry S, Luyten K, MacDonald A, Maritz C, McDowell S, Meyer U, Micciche A, Robert M, Robertson LV, Rocha JC, Rohde C, Saruggia I, Sjoqvist E, Stafford J, Terry A, Thom R, Vande Kerckhove K, van Rijn M, van Teeffelen-Heithoff A, van Wegberg A, van Wyk K, Vasconcelos C, Vestergaard H, Webster D, White FJ, Wildgoose J, Zweers H. Dietary management of urea cycle disorders: European practice. **Molecular Genetics and Metabolism (2013):110(4):439-45.**
- **Nutrition education tools used in phenylketonuria: clinician, parent and patient perspectives from three international Surveys**
 - Bernstein LE, Helm JR, Rocha JC, Almeida MF, Feillet F, Link RM, Gizewska M. Nutrition education tools used in phenylketonuria: clinician, parent and patient perspectives from three international surveys. **Journal of Human Nutrition and Dietetics (2013) Apr 23. doi: 10.1111/jhn.12065. [Epub ahead of print].**
- **Questionnaire for dietitians managing diet in adults with galactosaemia** in cooperation with the European Galactosemia Support Group
- **New!** Questionnaire on protein substitutes used in PKU patients
- **New!** Dietary treatment of Organic Acidaemias: A European Survey

Many thanks to Anita MacDonald and her team for initiating and circulating the various questionnaires. Thanks also to all dietitians who participated

COLLABORATION WITH European IMD (E-IMD)

We are asked by Prof.Dr. Häberle from University in Zürich and coordinator of guidelines of UCD to prepare practical guidelines in form of diet plans for different age groups. Marjorie is a member of the guideline group. The guidelines are undergoing first revision.

MEMBERSHIP OF SSIEM-DG

The membership increased last year and continues to rise from countries worldwide; currently we have 300 members (dietitians and doctors); 110 are dietitians. We encourage younger dietitians to join our Group. The benefit of membership is members receive the Journal of Inherited Metabolic Diseases (JIMD) which is extremely important despite only a few dietetic papers are published. Reduced cost to attend annual SSIEM symposium. The attendance of nutrition meetings at SSIEM symposia. SSIEM financially support these meetings by (ie speakers, room costs etc). Travel scholarships are available to attend the SSIEM symposium, dietitians are actively encouraged to apply for these (see website). Single day tickets are available which keeps cost down for dietitians members. The greatest benefit is meeting other colleagues and being part of a group of dietitians.

To become an SSIEM-DG member contact the SSIEM Office (admin@ssiem.org) and SSIEM-DG Secretary (Karin Luyten - karinluyten@hotmail.com). All members have to be SSIEM members.

CORRESPONDING MEMBERS

Currently, we have 29 corresponding members in 17 European countries. They act as a link between SSIEM-DG and the country's National Dietetic Group and IMD dietitians.

We have 2 new corresponding members for Greece since 2014 and a second member of Switzerland. We still need representatives for the following countries (e.g. Spain, Lithuania, Slovenia, Russia).

E-mail contact to the corresponding members via : www.ssiem.org/dg

Country	Corresponding members
Austria	Anna Fekete, Doris Mayr
Belgium	Martine Robert, Kristel Vande Kerckhove, Karin Luyten
Croatia	Valentina Uroic
Denmark	Kirsten Ahring, Helle Vestergaard
France	Joelle Wenz
Germany	Katharina Dokoupil, Reinhild Link, Carmen Rohde
Greece	Christina Katsagoni, Rania Zerva
Hungary	Erika Kiss
Ireland	Anne Clark
Italy	Anna M. Lammardo
Netherlands	Margaretha van Rijn, Heidi Zweers
Norway	Rina Lilje, Linn Stolen
Poland	Agnieszka Kowalik
Portugal	Manuela Almeida, Júlio César Rocha, Ana Faria
Sweden	Elisabeth Sjöqvist, Carina Heidenborg
Switzerland	Peter Jacobs, Cornelia Maddalon
Turkey	Hulya Gokmen
United Kingdom	Marjorie Dixon, Anita MacDonald

CHANGES IN SSIEM-DG COMMITTEE

Marjorie Dixon resigned as member of SSIEM Council. She was actively involved in Council meetings for the last 6 years (2008-2014). She was also founder of the Group and received our sincere thanks for her continuous support.



We received one nomination: **Annemiek van Wegberg**, Dietitian in paediatric unit at University Medical Centre Nijmegen; Project assistant of European PKU guidelines. She was accepted by the committee and by the Council at the AGM in Innsbruck for the next 3 years. Congratulations on Annemiek's election and very best wishes.

Also **Reinhild Link** resigned as Chair of SSIEM-DG who was founder of the Group and leading the Group from start (2006-2014)

We received one nomination from our representatives for: **Lesley Robertson**,



Paediatric Metabolic Dietitian at Royal Manchester Children's Hospital.

Lesley Robertson was accepted by the Committee and the participants of the Annual Members Meeting in Innsbruck and elected for the next 3 years. Congratulations on Lesley's election and very best wishes.

A new **representative for Germany** was accepted by the Committee: **Carmen Rohde** from University Children's Hospital in Leipzig. Congratulations and very best wishes.

ADDENDUM: we regret to announce **Karin Luyten**, our secretary for the last 2 years has resigned for personal reasons. Many thanks for her continuous support and help. Nominations for the secretary's post are being invited.

Management of IMD cases with challenging dietary treatment issues & other issues

Chair: Chair: Annemiek van Wegberg, Nijmegen and Terry Derks, Groningen

Infantile Refsum Disease: the influence of dietary management on plasma levels of phytanic acid	Julio Rocha ,Porto
What is the optimal dietary treatment of asymptomatic VLCADD ?	Karin Luyten and An De Meyer, Antwerp
Glycogen Storage Disease Type III: Atkins Diet as therapeutic option	Uta Meyer, Hannover
The challenge of introducing a low lysine diet in an asymptomatic child with GA1	Rachel Skeath , London
A screened infant with MSUD, the home office and immigration: all in a days work for the metabolic dietetic team	Satnam Chahal, Birmingham
How low can we go? Low Amino acids in PKU patients on diet - tolerate or treat?	Corrie Timmer, Amsterdam
Thank YOU !	Heidi Zweers Reinhild Link

At the end of the Meeting, Heidi Zweers is thanking in name of all representatives of the member countries both Marjorie and Reinhild for their support in launching and running the Group. A big bag full of presents from each member country was handed over to both of them. A very friendly gesture of our network.

Karin Luyten (secretary) and Reinhild Link (chair)

25-10-2014