

THE EVOLUTION OF THE SSIEM-DIETITIANS GROUP (SSIEM-DG)

Link R., Chair of SSIEM-DG, Wiesbaden, Germany

Introduction

While doctors and scientists working in the field of inherited metabolic disorders (IMD) as well as parents and patients with IMD are organised on an European level nothing existed so far for dietitians working in this field. Therefore, it was agreed at the SSIEM Meeting in Hamburg in 2007 to form a networking group for IMD dietitians. Only 6 months later this group was founded in London, 2008 with a group of enthusiastic dietitians as the European Metabolic Dietitians Group (**EMDG**), chaired by Reinhild Link, Germany. In 2010, it was established as the first SSIEM specialist interest subgroup and was named SSIEM-Dietitians Group (**SSIEM-DG**), which will have representation on the SSIEM Council. It is the goal of SSIEM-DG to continue to develop IMD dietetics to a highly scientific and professional level for the benefit of all SSIEM dietitians and their countries. SSIEM-DG aims to promote the important role of metabolic dietitians as key members of all IMD teams.

The group will be co-ordinated by a committee with corresponding members from represented countries. Currently SSIEM-DG has 26 corresponding members representing 14 countries (see fig. 1). Communication will be through meetings and the newly developed web page on the SSIEM website (www.ssiem.org/dg/). The group will have its annual meeting at the SSIEM Symposium.

The group has already started evaluating the provision of metabolic dietetic training in its member countries. This work was presented at the ICIEM 2009. As a consequence of the limited IMD dietetic training opportunities and wide differences in training standards the SSIEM-DG plans to develop core IMD training standards and validate the training of IMD dietitians.

Aims of SSIEM-DG

- Coordination of the Group by a committee with corresponding members from represented countries
- Communication and sharing knowledge through meetings and the newly developed web page on the SSIEM website www.ssiem.org/dg/
- Development of training standards for IMD dietitians and validation of existing training
- Organisation of educational (training) courses for IMD dietitians
- Evaluation of treatment practices for different IMD among its member countries. A chosen topic will be presented at the annual meeting to start the exchange and discussion. During the following year data and opinions will be collected and finalised in a publication or report (website) on the dietary practice. This years topic is >pyridoxine non-responsive Homocystinuria<
- Publication of best practice to ultimately improve the nutritional management and long-term outcome of IMD patients
- Provide advice to SSIEM Council on dietetic issues

SSIEM-DG Annual Meeting 2010

Members presentations will include: An evaluation of treatment of >pyridoxine non-responsive Homocystinuria< in different European countries; Dietary treatment of urea cycle disorders in the UK; The need for supplementary dietary guidelines for extended neonatal screening; The body composition and markers of metabolic syndrome in adults with PKU.

Fig.1: Corresponding members of European countries

Each country is represented by a maximum of 3 delegates. Currently the group has 26 members from 14 countries representing their national IMD dietitians associations

Country	Corresponding members
Austria	Anna Fekete, Doris Mayr
Belgium	Martine Robert, Kristel Van de Kerckhove, Karin Luyten
Denmark	Kerstin Ahring, Helle Vestergaard
France	Joelle Wenz
Germany	Katharina Dokoupil, Reinhild Link
Ireland	Anne Clark
Netherlands	Margreet van Rijn, Heidi Zweers
Norway	Rina Lilje, Linn H. Stolen
Poland	Agnieszka Kowalik
Portugal	Manuela Almeida, Julio Rocha, Anna Faria
Switzerland	Peter Jacobs, Delphine Egli
Sweden	Elisabeth Sjöqvist, Carina Heidenborg
Turkey	Hulya Gokmen
United Kingdom	Marjorie Dixon, Anita MacDonald



SSIEM-DG, London 2010

Membership of SSIEM-DG

- SSIEM-DG membership is open to dietitians or nutritionists who are paid members of SSIEM
- Prospective SSIEM members should process their annual subscription payments online
- All memberships begin 1 January each year.

SSIEM-DG Website



www.ssiem.org/dg/