

European Working Group on Gaucher Disease: the EWGGD

History: The European Working Group on Gaucher disease (EWGGD) was launched as an affiliate of the European Study Group on Lysosomal Diseases (ESGLD). At the ESGLD meeting in Delphi in 1993, the founding of the Group was proposed by Prof. Dr. J.M. Tager, professor of Biochemistry and Prof. dr. R. Goudsmit, professor of Haematology and supported by the president of the ESGLD, Prof. K. von Figura. The EWGGD had its first workshop in 1994 in Trieste. Following meetings were in Maastricht 1997, Lemnos 1999, Jerusalem 2000, Prague 2002, Barcelona 2004, Cambridge 2006, and Budapest 2008. The next meeting is planned for December 2009 in Amsterdam.

Missions: The aim of the EWGGD is to promote clinical and basic research into Gaucher disease for the ultimate purpose of improving the lives of patients with this disease; it brings together clinicians, scientists and patients in an open forum for discussion on all aspects of the condition. The opportunity for presenting unpublished scientific data as well as free discussion is a central premise of the Group. For the dissemination of information a two yearly workshop is organized. Although a limited number of representatives from industrial partners are invited to attend the meetings, the Working Group has always been an independent organization with a charitable purpose.

Representatives: The EWGGD represents clinicians and researchers with an interest in Gaucher disease. The EWGGD is affiliated to the European Gaucher Alliance (EGA), representing the interests of the patients. This alliance was formed shortly after the founding of the EWGGD and reached a more formal status in 2008, when during the EGA meeting patient representatives of 24 countries unanimously agreed to incorporate the EGA into a formal charitable body, to speak for Gaucher patients on a Pan European level.

Funding: There is no general funding for the EWGGD. Hitherto, the management in between meetings has been informal and conducted on a voluntary basis. For the workshops, held every two years, funding is requested through grants from the European Union as well as unrestricted funds from pharmaceutical companies. These companies (Genzyme, Shire Human Genetic Therapies, Actelion, Amicus, Protalix) can in turn exhibit their products in between sessions and, when considered important for the Gaucher community, may be invited to present new developments as part of the scientific program. Industrial partners do not contribute to the work of the international or local scientific committees – the latter convened to assist with the programme development for individual Workshops.