



ESPGHAN

European Society for Paediatric Gastroenterology, Hepatology and Nutrition Rue De-Candolle 16 1205 Genève, Switzerland www.espghan.org

ESPGHAN Coeliac Disease Special Interest group **Terms of Reference** (Version September 2018) Carmen Ribes-Koninckx, M.Luisa Mearin, Steffen Husby

Definition of the group:

The Coeliac Disease (CD) Special Interest Group (CD-SIG) is an open group of ESPGHAN, the goals of which are to generate collaborative international research and to provide a leadership role concerning current diagnosis and management of CD in children and adolescents. It will include all ESPGHAN members who wish to participate in all activities generated inside the CD-SIG by a Steering Committee such as collaborative studies and guidelines' preparation.

Aims:

- 1. To improve medical care for children with CD worldwide, by promoting good clinical practice via various professional educational tools, lectures and publications.
- 2. To develop management guidelines and statements on behalf of ESPGHAN regarding paediatric CD.
- 3. To perform collaborative **research** of all types in the field of CD as agreed within the group.
- 4. To develop educational activities in the field of CD, in agreement with the Education Secretary and the Council.
- 5. The SIG may contribute to the Scientific Program of the Annual Meeting, by request of the GIC, as agreed within the group.
- 6. To provide experts' opinion and advocacies on behalf of paediatric CD patients when needed. Specifically advice can be offered scientific societies, regulatory bodies, non-governmental organizations, industry and other interested parties.
- 7. To participate in the European research initiative, ESSCD, with council and working group members.
- 8. To arise and extend awareness on Coeliac disease in the European lay society.

Rules and Regulations

- 1. All ESPGHAN members with a proven interest in Coeliac disease, confirmed by a short CV and verified by the Executive Committee, may apply to become a **Member** of the SIG. They are invited to attend open meetings and to propose working groups and/or research projects to the Executive Committee. They can be invited to collaborate in ongoing or new activities and will then become temporarily members of the Core group. An open call will be advertised on the ESPGHAN website 2 months before the Annual Meeting. New members will be welcomed during the open SIG meeting at the Annual ESPGHAN meeting. An updated member's data base (SIG-MDB) will be maintained by the CD-SIG secretary.
- **2.** The Core Group: Members involved in specific Working groups or research programs will compose the SIG Core group for the duration of their activities. They will participate in the close meetings related to their activity inside the SIG. An updated members' data base will be the responsibility of the EC secretary.
- 3. The <u>Steering Committee</u> of the CD-SIG is an Advisory board composed of a closed group of paediatric CD experts from ESPGHAN elected among the CD-SIG members. The number will not exceed 6 (plus the Executive Committee members). No time limit for serving in the Steering Committee. Together with the Executive Committee they will decide on the new working strategies and working groups. Close contact with Patients organization is also under their responsibility.
- 4. The Executive Committee: Liaison with Council will occur through an Executive Committee composed by the chair of the CD-SIG, a Secretary and a Treasurer (financial liaison). Each committee member will be elected by secret ballot for a term of 3 years among the members of the Core group applying as candidates. One of these members will be elected specifically for the role of Chair of the group. No member may serve more than two consecutive terms on the Executive committee. Members of the Executive Committee will be part of the Steering committee.

The Executive Committee supported by the Steering Committee has the duty **to promote and empower** the specific active working groups. Additional duties of the Executive Committee are: the day to day management of the SIG, maintenance of updated Members data base, updated registry of the SIG activities and publications, regular updating (at least once a year) of the CS-SIG area on the ESPGHAN website, to report to the GIC on an annual basis both on activities and budget.

5. Budget: an annual budget will be allocated by the GIC upon presenting an annual action plan.

Working organization and Meetings

- 1. At least one <u>closed annual meeting</u> will be held where ongoing activities are reviewed. This can eventually be scheduled during the ESPGHAN Annual meeting. Active core members will be asked to participate.
- 2. One **Open meeting** of the CD-SIG during ESPGHAN Annual Meeting for all ESPGHAN members with an interest in CD.
- 3. Additional ad hoc meetings could be scheduled according to needs and work development for specific activities such as guidelines or position papers. Attending costs will be partially covered provided the CD-SIG budget allows it.



- 4. On-line meetings and Teleconferences will be held to promote and facilitate the working group's activities.
- 5. On-line meetings and Teleconferences between the Executive Board and the Steering Committee will be held on a regular basis (once every 3 months) to discuss the progress of the WG, to discuss new proposals, and to deal with overall management issues of the CD-SIG.
- 6. New WG / research projects, once approved by the Executive Committee and the Steering Committee, will be advertised in the ESPGHAN website (CD-SIG area); applications to participate from SIG regular members will be encouraged and accepted after evaluation by the EC and the Steering Committee.

