

### The Paediatric IBD Porto and Interest Groups of ESPGHAN

## **CHARTER**

- First charter approved in the annual meeting in Porto April 2013
- Version #2 approved following the annual Porto meeting in March 2015. Main changes from version #1 are the inclusion of the interest group, the need for reelection after 5 years and other general
- Version #3 approved after the annual Porto meeting in 26.2.16. Main changes from #2 are adding criteria how to initiate research projects, changing the voting system for new members and voting on guidelines
- Version #4 approved in a secret web-based voting in 09.2016. Main change included the introduction of the concept of a senior member
- Changes of version #5 were approved unanimously during the annual Porto meeting on 17.3.17. Main changes from version #4 included removal of the clause requiring at least 1/3 of Porto group members in every Porto project and shortening membership period from 5 to 3 years
- Changes of version #6 define the role and mandate of the research committee (approved at the annual meeting March 2018)
- Changes of version #7 change the voting system and mandate at least 3 new members every year (of 12 of stand for re-election), remove the specific role of the executive committee and define research projects that can be defined as Porto group projects.

#### Overview

The "Paediatric IBD Porto Group" is a group of paediatric IBD experts from ESPGHAN whose goals are to generate collaborative international research and to provide a leadership role with regards to current diagnosis and management of IBD in children.

The aims of the group are:

- 1. **Research:** To facilitate, and perform collaborative research of all types as agreed within the group, including ongoing registries
- 2. **Guidelines:** To develop management guidelines and position papers on behalf of ESPGHAN regarding paediatric IBD
- 3. Advocacy: To provide experts' opinion and advocate on behalf of paediatric IBD patients when needed
- 4. **Education:** To improve medical care for children with IBD worldwide, by promoting good clinical practice via various educational tools, lectures and publications

This research collaboration in combination with provision of leadership in international guidelines and other activities requires intense commitment and hard work with restricted timelines. This necessitates opening the group to new collaborators with required expertise,





while defining a mechanism to exclude members that are not capable of fulfilling these obligations to ensure keeping the group dynamic and productive.

#### General

- 1. Members of the Porto and the Interest Groups must be members of ESPGHAN.
- 2. When a site or center has one Porto member, no other person from this site can join the Porto group as a new member. Membership is not transferable to other colleagues from the same institution or other institutions, nor can observers vote by proxy for members. Sites that have had two members prior to April 2013 when this clause has been agreed upon, will continue to have two members until one steps down or is not re-elected.
- 3. Every member has one vote during ballots (voting for positions, new members, new initiatives etc). Every site has one vote (i.e. only one vote will be accepted from sites with two members).
- 4. Membership requires <u>active</u> participation in group activities. Members who have been absent for more than two consecutive annual meetings (three or more), and who have not participated in group activities for over two years (collaborative research, guidelines development etc), will no longer remain members, but may reapply like other nominees.
- 5. Attendance of meetings and activities by observers may be allowed if cleared by the executive committee. These may include participants and research coordinators in relevant studies or historical members. The fee for observers will be decided by the executive committee and host as they are expected to cover their expenses. Observer status does not confer membership with the resulting rights and obligations as stated above. The arrangement of a meeting before/after the Porto meeting (e.g. the launch of a new study) is allowed if cleared by the executive committee, but finances have to be covered by the organizers of this meeting.

#### Elections

- 1. Three members of the Porto group will serve as an executive committee. Each committee member will be elected by secret ballot for a term of 3 years. 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 committee.
- 2. The term of all elected (or re-elected) members will be for a period of 3 years only.
- 3. Total number of Porto group members will remain 36.
- 4. Each year 12 members will stand for re-election.
- 5. New members will be elected from the open IBD Interest Group of ESPGHAN.
- 6. Nominees are required to submit a CV, a personal statement why they should be elected to the Porto Group (1-2 paragraphs) and a statement what they would like to promote within the group if elected (1-2 paragraph).
- 7. Each eligible Porto group member will indicate which of the nominees (new and existing) should be elected according to the number of available slots (e.g. if 10 people



compete for 5 slots, each member will indicate only 5 names). Nominees will be elected based on the cumulative points achieved by all voting members.

- 8. Members are expected to vote primarily according to the perceived merit to meet and promote the goals of the group. Geographic diversion will be also considered but as a secondary point.
- 9. Existing Porto members who are standing for re-election are allowed to vote for other nominees but not for themselves in order to leverage chances with nominees from the interest group.
- 10. Porto members will become "senior members" after the age of 65 to allow new member to take their place. Senior members are welcome to participate in the Porto group meetings as observers and are expected to cover all expenses related to their stay. Senior members reserve all rights as members of the open interest group.
- 11. At least three new members will join the Porto group each year. In cases where there are no 3 Interest group members selected, of the one third of the Porto group (12 members) standing for re-election each year, the three lowest ranked will step-down to the Interest group and the highest three ranked from the Interest group will be invited to the Porto group. Members of the Porto group who stepped down for other reasons (e.g. voluntarily or for seniority) will be included in the count of three members; For instance- if one became a senior member than only the lowest two will be forced to step down to the Interest group. The same will apply if there are less than 3 candidates from the interest group.

#### **Open IBD Interest Group of ESPGHAN**

- 1. The Open IBD Interest Group of ESPGHAN offers a forum to contribute to Paediatric IBD within ESPGHAN, even for those who are not members of the Porto group.
- 2. The Porto Group will hold an annual meeting with the Interest Group during the ESPGHAN annual meeting.
- 3. Registration to the Interest Group and its management will be through the executive committee of the Porto Group, to allow complete and useful coordination of activities.
- 4. ESPGHAN members who wish to join the IBD Interest group will register with the executive committee of the Porto group, using the same template as for the Porto group (CV, personal statement and planned activities). The membership will be then automatic.
- 5. Members of the IBD Interest group are expected to participate in the activities.
- 6. All Porto Group activities (except of the annual Porto group meeting) will also be open to the interest group, such as guidelines, statements, position papers and collaborative research. An open call to participate in all Porto Group projects will be issued to the interest group.

#### Research

The Paediatric IBD Porto Group



- Five members of the Porto group will serve as a research committee, including a chair, elected by the executive committee for 3 years (with the exception of the first term, which will be 2 years for 2 members, 3 years for the chair, and 4 years for 2 members to allow continuity). The main goal of the research committee is to promote, review, advise, and facilitate collaborative research, while ensuring excellence and impact.
- 2. Any member of the Porto and the Interest group may propose a research project to both groups by email and/or frontal presentation during the annual meeting; all proposals must be reviewed by the research committee prior to presentation/dissemination to the group.
- 3. The executive committee must ensure that every manuscript carrying the name of the Porto group is of sufficient merit, value and scientific rigor. This will be verified both at the time of the proposal submission and at conclusion of the study. Manuscripts will be approved by the executive committee for including the Porto group name prior to submission.
- 4. In order to be considered as a 'Porto project', the project must be initiated as such and follow the criteria outlined in the instructions sheet.
- 5. Each research project will be discussed in an annual meeting (at Porto or during ESPGHAN meeting) to allow the entire group to vouch for the study as a Porto group paper. If such presentation is not feasible (e.g. desire to start the project prior to the meeting or unavailability of the authors to present), the executive committee may decide, based on recommendations from the research committee, on behalf of the group and the group's approval will be obtained by email.
- 6. The Research Committee will review all research proposals submitted by Porto and Interest Group Members and will:
  - a. Provide a critical review with specific comments on the protocol.
  - b. Assess resubmissions, addressing comments by point-to-point reply (if needed), and submit final recommendation (accept, resubmit revised proposal, reject) to the Executive committee to determine if the proposal can be a Porto group project.
  - c. Proposals must be submitted to the secretary and research committee chair at least one month before the annual meeting for it to be discussed then, but proposals can also be approved throughout the year.
  - d. To review the final manuscript prior to submission, provide comments, and submit a recommendation to the executive committee if the paper can carry the name of the Porto group and if it follows the rules outlined in this charter.
- 7. The proposal must include the following:
  - a. Subheadings: background and rationale, hypotheses, aims, explicit methods (design, eligibility criteria, outcomes, power calculation, statistical approach), and importance.
  - b. Authorship plan (in general balancing scientific merit, invested effort and number of included patients/samples from each site). In any case, each Porto group publication will include a full list of contributing members in an addendum to be listed as much as possible in Pubmed.



- c. The anticipated reporting standard of the final manuscript (e.g. CONSORT, STARD etc- see last clause of this section).
- 8. Surveys and narrative reviews cannot typically be considered as Porto group projects.
- Governed by the above restrictions (#3-5; all of which must apply), all manuscripts arising from the Porto group will have the name of the group in the title (<u>Paediatric</u> <u>IBD Porto group of ESPGHAN</u>). Author's list will include as a suffix "<u>on behalf of the</u> <u>Paediatric IBD Porto group of ESPGHAN</u>".
- 10. Research projects may be published in any journal according to the discretion of the co-authors.
- 11. All manuscripts carrying the name of the Porto group will be reported according to accepted standards to ensure that the final reports are of highest possible quality. Examples:

CONSORT statement - checklist and flow diagram for reporting RCT

SPIRIT statement - protocol items for intervention trials (good checklist for other studies also)

<u>STROBE</u> statement – reporting observational studies (cohort, case-control and cross-sectional)

CARE - checklist and flow diagram for reporting case reports and series

STARD statement – checklist and flow diagram for reporting diagnostic accuracy

TRIPOD statement – reporting diagnostic or prognostic modelling

<u>RECORD</u> statement – reporting routinely-held health administrative data observational studies

PRISMA - checklist and flow diagram for reporting SR and MA

<u>SQUIRE</u> statement and checklist – reporting quality improvement studies

# Position papers and guidelines

- 1. Position papers and guidelines will be established according to ESPGHAN guidance following an open call to all members of the Porto and the Interest group.
- 2. Selection of members to participate in the projects will be decided (based on merit only) by the ad-hoc committees nominated by the Porto Group.
- 3. The final voting reported in the manuscript will include the writing group and Porto group members. However, a pre-final version will be sent to the open Interest group members for comments.
- 4. Position papers and guidelines will be published in JPGN unless explicitly required otherwise (e.g. joint guidelines with ECCO).