

ISSCD Committee – Terms of Reference

B4 CeD: Before Celiac Disease Diagnosis

The ISSCD Board will appointment a Chair who, along with the ISSCD Board will convene a Committee of experts in the field with broad epidemiologic and translational expertise in population health as it relates to the pre-diagnosis phase of celiac disease. In addition, expertise in cutting edge methodologies as well as tools that could elucidate the mechanisms and processes that underlie or explain the earliest phases including but not limited to the triggering and escalation of celiac disease to the point of diagnosis.

Remit

Specifically the Committee will:

- Recommend research priorities to advance the study of the earliest phases of celiac disease, particularly as it relates to studies of birth cohorts, population studies, and incidence cohorts of individuals who have potential celiac disease.
- Promote collaboration through data sharing and multicenter studies.
- To develop and agree a common lexicon/terminology to describe the safest end terms used, for example triggers, escalating factors, pre-diagnosis, pre-exposure, celiac autoimmunity, and gluten desensitization.
- To consider global regional aspects that may impact on earliest phases of celiac disease.
- To stimulate interchange of ideas and concepts.
- To interact with other groups especially those that focus on prevention trials/strategies for diseases with similar epidemiology and etiologies as celiac disease e.g. Type 1 diabetes, food allergies.
- To harmonize methodologies, in particular as they address the “omics” and other discovery technologies.
- To offer expert opinion on cutting edge methodologies as well as tools for studies of the earliest phases of celiac disease.
- To consider translational opportunities for diagnosis, prevention and treatment from studies of the earliest phases of celiac disease.
- To liaise with patient advocacy groups and agencies to address the population health affecting individuals prior to diagnosis.
- Interact with other ISSCD Committees.
- Contribute to the dissemination of potentially important finding.

Membership

Members are:

- The Board will appoint the Chair and Co-Chair of the Committee.
- The Committee members would be appointment by the Co-Chairs and the ISSCD Board.
- The Committee will be composed of eight members, including the Co-Chairs, but may be enlarged by agreement with the ISSCD Board.

In attendance shall be:

- Co- Chair and Committee members
- ISSCD Board Members may attend the meeting as required
- Ad hoc appointees
- ISSCD administrators may attend the meeting as required.

Meetings

The Committee will meet at least three times a year. The Committee may meet additionally to discuss specific issues at the request of the Chair. The Committee will report at least annually to the ISSCD Board. Meetings will be held online, except for meetings during the ICDS or other conferences. Notes and actions from meetings will be minuted.

Selection Process:

ISSCD members will be notified of Committee vacancies on the ISSCD website and/or by other electronic means. Expressions of interest for Committee membership will be reviewed by the Chairperson who will provide their recommendations to the ISSCD Board for final approval. The members of the Committee will be selected by the Chair and ISSCD Board based on their proven clinical and scientific experience in the field.

Conduct

Members of the committee will be formally announced on the ISSCD website and are not permitted to publicly promote themselves as members of the committee e.g. on third party websites or social media platforms. Committee members do not have authority to speak on behalf of or represent the ISSCD, unless authorised by the ISSCD Board. All members of the committee must complete a conflicts of interest and confidentiality form and at each committee meeting they must disclose any new conflicts of interest that may have arisen.