

RULES FOR ONLINE PEER SUPPORT ACTIVITIES:

FACEBOOK GROUPS AND THE NUOSU DISCORD
SERVER



**Suolisto-
sairaudet ry**

These rules govern the operation of the online peer support groups* administered by Suolistosairaudet ry. By joining a discussion group, members agree to abide by these rules.

Association

Suolistosairaudet ry is a national patient organization that advocates for people living with inflammatory bowel diseases and other gastrointestinal conditions, as well as their loved ones.

The association's online peer support groups provide a space where people in similar life situations can support one another and share their experiences. Suolistosairaudet ry may communicate and share information within the groups when necessary, but the actual content of the discussions is created by the members themselves.

Association Disclaimer

Suolistosairaudet ry's discussion groups on Facebook and Discord are freely available to members for discussions and conversation starters created by both members and the association. Anyone accepted into a group may participate in discussions.

The discussion groups contain a great deal of valuable and accurate information, but Suolistosairaudet ry cannot guarantee the accuracy of all content shared. Although efforts may be made to correct inaccurate information, no one is obligated to do so. Therefore, all information found within the discussion groups is provided without any guarantee of accuracy or suitability for any particular purpose.

Suolistosairaudet ry, its staff, and its volunteers cannot be held responsible for the presence or use of inaccurate or offensive information shared within the groups.

Membership

The online peer support groups maintained by Suolistosairaudet ry are primarily intended for people living with inflammatory bowel diseases or other gastrointestinal conditions.

The groups intended for parents of children with gastrointestinal diseases, parents of children with IBD, and the CCD group are the only groups that also include family members and loved ones. To be accepted into a group, a person must have a diagnosed condition or a strong clinical suspicion confirmed by a physician. In the parents' groups, this means that the member's child must have a diagnosis or a strong suspicion of the condition. In the CCD group, either the member or their loved one must have a diagnosis.

For the group intended for parents of children with IBD, an additional criterion is that the child with IBD must be 20 years old or younger. This age limit exists because care is typically transferred from pediatric to adult healthcare services no later than the age of 20, and care practices may differ significantly between these services.

Membership in the association is generally not required to join the online peer support groups. Only individuals using a genuine personal profile and agreeing to the group rules may be accepted.

Participating in a patient organization's activities, whether on social media or elsewhere, carries the risk that information about a person's health may become known to others. The association works in various ways to ensure that discussions remain as safe as possible. However, it should be recognized that the security measures of social media services and the actions of group members cannot be fully guaranteed. For this reason, every member is personally responsible for deciding how openly they wish to discuss themselves and their medical conditions within the group.

Administration and Moderation

Administration and moderation are carried out by the association's trained volunteer peer supporters and staff members.

Within the online peer support groups, administrators and moderators are identified in the group member list. Volunteer peer supporters participate in discussions as individuals sharing their own peer support experiences.

Administrators and moderators are responsible for approving membership requests, monitoring discussions, and ensuring compliance with the rules. They have the right to remove content that violates the group guidelines or the association's rules and to issue warnings regarding a member's behavior.

If rule violations continue, the member may be removed from the group. In cases of serious misconduct, a member may be removed without prior warning.

Administrators and moderators must not be blocked, as doing so prevents them from participating fully in discussions. If an administrator has been blocked, they have the right to remove the member responsible for the block without warning.

Peer Support Principles

Everyone has an equal right to share their experiences and express their opinions respectfully toward other members and in accordance with general online etiquette.

Discussions should be constructive and supportive.

The primary language of the groups is Finnish, but in the English groups the primary language is English.

The groups are intended for sharing personal experiences. Advice encouraging someone to start or stop medication should be avoided, as decisions regarding medical treatment and its implementation always belong to healthcare professionals.

Confidentiality and Privacy

Discussions that take place within the group, as well as information about group members, must not be shared outside the group.

Members must respect the privacy of others. This means that no confidential or otherwise sensitive information about another person may be disclosed without their permission.

Accordingly, information regarding a partner's, family member's, or friend's illness, symptoms, or medications must not be shared publicly without the consent of the person concerned.

Members should also exercise careful judgment when sharing their own confidential information.

Speaking about identifiable individuals in a negative context is prohibited. As an association, we cannot provide a platform for discussion about a person who is not present and unable to participate in the conversation. Public officials should not be mentioned by name.

Legality

The sale or distribution of any treatment-related products, including prescription medications, over-the-counter medicines, ostomy supplies, and diapers, is prohibited within our groups.

All members are required to comply with Finnish law and copyright regulations.

Marketing

Members may share personal experiences regarding legal goods, products, and services relevant to the group's focus, provided they do not receive personal financial benefit from doing so.

Directly advising others to use medications, vitamins, or dietary supplements while acting as a representative of a particular brand is prohibited.

Repeatedly promoting or recommending specific product categories while representing a seller or manufacturer may be considered hidden advertising.

To avoid misunderstandings, members should not advertise discussion groups that are not affiliated with the association. Fundraising and the promotion of fundraising campaigns are prohibited within the online peer support groups.

*Discord

The rules above also apply to the Nuosu Discord Server.

To participate in peer support discussions on the Nuosu Server, users must first join the server. The *Member* role is granted after accepting the rules, which then unlocks access to the discussion channels.

Suolistosairaudet ry reserves the right to clarify, update, and modify the discussion group rules as necessary.