

EFCCA Academy and Beyond: Empowering Finland's Youth in IBD Advocacy

The Youth Group

Hi! I'm Aleksi and I want to tell you about our youth group and its operations here in Finland. We are a part of Finland's association called IBD ja muut suolistosairaudet (IBD and other intestinal diseases). Our association and youth group were previously IBD only, but have since expanded to cover all intestinal diseases. IBD has gained such notoriety here that we no longer need to focus solely on bringing awareness about it and can help inform about other intestinal diseases, and help those affected by them as well.

Our association acknowledges that young people need their own representation and supports our operations fully. The youth group has worked for around 20 years by now. There have been times when the youth group has been less active, but lately we have focused on establishing new ideas and renewing old ones. The association considers anyone aged 18-35 to be eligible to join our group and activities.

I joined the youth group a couple of years ago and during that time there have been a lot of changes and new ideas. Our group used to consist of 4 youth members and an association staff member who oversees our activity and helps set up our plans, but last year we decided to increase the youth group's size to 5 youth members to accommodate for the increase in manpower needed. There are many other young volunteers in the association as well, but they do other things like peer support or social media posts about their lives with intestinal diseases.



The Finnish IBD youth group

What We Do

We have a yearly weekend get together that is planned by our youth group. The weekend is usually held at an activity center or some place similar that can offer housing, food, and things to do. The weekends consist of peer support, creative and physical activity, information and conversation about requested topics and, after the scheduled events, relaxed hanging around. We also have a sauna reserved because it is a common place for finns to relax and get to know each other.

Another thing we launched a year ago is our youth Discord server. It makes it easier for young people to find peer support, ask questions and to connect with each other. It also helps us inform them about upcoming events and makes it possible to communicate easier

with our target audience. The server currently has around 100 members, and new ones are constantly joining.

Updating our name was the most recent change. We changed our group's name to better reflect our goal of including everyone. Before our activity was named CroCo (Crohn and Colitis), with our logo being a crocodile. For the new name, we held a contest where people could suggest a name and the one we selected to best fit our cause would be awarded. We selected Nuosu as the new name, which roughly translates to “youngsters with intestinal diseases”.

What We Plan For the Future

Our association also hosts bigger events each spring and fall for all our members. Last fall we had a cruise to Åland and this spring our association will be celebrating its 40th anniversary. Even though the events are for everyone, we wanted to do something for just the youngsters. These activities we plan to host would be a kind of pub crawl where people complete tasks to earn points and the winner gets a prize in the end. You can also participate alcohol free of course and the main point is to bring young people together and make it easier for them to get to know each other. We want to give youngsters something interesting and a good reason to come to these bigger events. This idea comes from retired youth group members who hosted a similar thing.

We also plan to make use of the discord server to start hosting youth targeted activities online and to recruit volunteers to moderate the server and help with other things they want to be a part of. There is a lot of potential in keeping up with the online scene to help us connect with others better. That is why we are also constantly on the look for new platforms and opportunities.

With IBD being more prevalent here than ever, and peoples' need for support and information increasing, our association is continually expanding and so is the youth groups vision on what we can do for other young people. We envision a bright future for our operations and for it to be someday possible to host even more youth targeted events.

Advice for engaging new youths

Last time we held our youth weekend we had more applications than ever before, with many of them being from new people. I'd say the most important thing for engaging new youth is finding the right tools for bringing awareness about the activity. Of course advertising it is a no brainer, but for youth to actually find all the information might be hard. For example, we advertised the youth weekend on our webpage, association magazine, social media and discord server. Yet talking with one of our discord members about our youth activity they were surprised and said that they didn't know we had all of it. So to actually get the information out there might be harder than you think, and that is also why it is important to stay up to date with all the ways of spreading information and using them.

A great youth group is the cornerstone for youth activity. Young people usually know best how to engage their peers. But a youth group can't work efficiently without the association's backing. Having our association's support and trust in what we do is really important for our success. Having an assigned youth group overseer from our association's staff also makes

our work a lot easier. Help with budgeting, booking places, setting up meetings etc. really goes a long way to make it easier for us to focus solely on planning and providing things for the youth.

Finding young volunteers is also a key factor in engaging the youth. The more people there are, the easier it is to plan out and realize activities. We have approached some youth activity participants ourselves, when we thought they would make a fine addition to our volunteers. We also try to make volunteering as easy as possible and to allow people to help in any way they can. For example, they can spread information through social media posts, work as a moderator for our discord server or if they just want to host one event and nothing more that is fine also. Volunteering shouldn't feel like a burden. Being flexible is really important to make it fun and interesting for everyone.

What has EFCCA and its academy taught?

Before establishing the EFCCA youth group we had to complete the EFCCA academy. It was an online training platform that taught us about EFCCA's history, how an association like EFCCA runs and how to successfully run our own group. We also had to complete different assignments, of which this paper is the final one.

Learning about EFCCA's history was really interesting. It is fascinating to realize how much the association has grown from its humble beginnings. It was also interesting to learn about establishing an association and how such a large project can be managed. A favorite part of mine was learning about the laws and governance of EFCCA. No association can run without a working structure of rules and laws, so having us learn about them as one of the first things gave a really good start to the academy.

The academy also taught us many important skills in managing a successful group and how to realize our ideas. We went over the plans of EFCCA's founders and previous youth groups and learned from their experiences. We also learned about strategy, planning and executing our own ideas. I'd say one of the most important aspects of bringing ideas to life is good communication between all the participants of that plan and everyone bringing their own expertise to the group and working towards including everyone's input.

There are still challenges to overcome for us to establish the youth group into action. We need the knowledge on how to lay a good foundation for our cause. Luckily the academy gave us good tools in doing that and, with the help of EFCCA's staff, board and members, I feel like the youth group can become a new important part of EFCCA and its operations.

EFCCA has taught about the importance of dreaming big and holding onto a vision even though it might be against the odds. It is important to work to support those in need and to provide something good. With EFCCA's youth group my hope is for us to be able to offer something to young people all over our shared borders and to share our ideas together to advance our unifying cause.