

Introduction - short description of the need

The basic idea was to create a new youth camp by following the concept of Nordic Rheumatic Youth Camp, which we established in 2017. The idea of the Nordic Rheumatic Youth Camp is to empower young people and offer peer support across country borders. The camp is planned and organized by a group of Nordic volunteers who have their own personal experience of living with rheumatic diagnoses as well as the empowering effects of peer support.

Besides arranging contemporary, sought-after, and interesting events, international cooperation between our nordic associations is also a way to attract and encourage more young members to our associations.

Nordic Rheumatic Youth Camp 2019 was a second edition of our youth camp and we received a total number of 47 applications including participants from all the Nordic countries. Due to cancellations the total number of participants was 34 + 4 planning team members.

The camp was held at Kiskallio sport center in Lohja, Finland on 4th-7th April 2019. The Camp program contained a mixture of lectures, social events, and physical activities.

Learning - referencing project aims and objectives, what has been achieved and how

The aim of Nordic Rheumatic Youth Camp was to empower young people with rheumatic diseases to bond across borders and aid them in the understanding that they are not alone with this lifelong disease. The aim of the camp was to make it possible for people to learn about themselves, get new knowledge about their own diagnosis and realize that there are other youths out there with the same diseases. The Camp offered young people a chance to experience peer support and get to know others with the same diagnosis and share their stories and experiences. This made it possible to exchange tips and tricks from one another about everyday life with chronic illness. The aim was also to offer a chance for making long-lasting friendships between youths with rheumatic diseases across the Nordic countries. The camp also offered people new knowledge about other Nordic regions and make great memories and experiences, which they in turn can share with friends, family, and acquaintances from their rheumatic youth organizations.

From the beginning, the project intended to empower young people by encouraging peer support between youths with rheumatic diseases throughout the Nordic countries. The Camp's aims are therefore to empower the strengths that each participant has, help him/her make friendships, and learn more about the Nordic regions.

The Camps have resulted in the making of lasting friendships, as the young people attending have grown as persons. These friendships were forged between the participants, as they all have something in common - the rheumatic disease - and can therefore support each other in a

way that “healthy” friends often cannot. Furthermore, it gives the participants an opportunity to share their life stories, give each other advice about living with a rheumatic diagnose, as well as sharing the struggles that this can pose in their daily lives.

Youths have made friendships that have last through the years and others have rekindled their friendship from the first camp to the 2019 camp. The campers from 2017 have informed planners how their lives have changed to the better and the camp helped them get their lives back and stop looking negatively at their rheumatic disease, and instead start to work on with their disease and the health both mentally and physically.

The camp has given the rheumatic organizations new youth board members in Finland and volunteers in Denmark, so the camp has broadened the youth horizon and knowledge about their own country’s organization.

Evaluation - what should be measured, and how. How do we use it for the future planning

Measuring the outcome of the camp was done with mentor group sessions and a questionnaire to find out how the camp was experienced, what could be different and what the planners could do better.

We as planners measured how the sign up went and what the participants were hoping for. We used the feedback from last camp to make up this year’s camp program. The theme for this year’s camp was empowerment for young people with rheumatic disease. What measured was the happiness, joy, empowerment and the new friendships that have been made during our camps.

We have a facebook like page where we can see the statistics behind the visitation just round the time we posted the application form. We had around 2000 clicks on our Facebook like page when we put out the date for application. We have been using social media to get the word out there to the generation Z and the millennials as ourselves. We have used our strengths to plan our meetings and the entire camp, all of us have a unique set of skills which we tap into during planning.

We use the information from all feedback received to improve us as planners and to develop the planning and execution of the camp in hole. We want to give the participants a chance to express themselves and give them a chance to be a part of the planning with their ideas and points on what to do better, eg what should be left out, what to include more off and what new things should be included.

Added value of the cooperation with the partner organization

The planning process of Nordic Rheumatic Youth Camp 2019 has strengthened the cooperation between the Nordic National associations for young rheumatics. In the planning group we have learned a lot from the challenges we faced when planning the Camp in 2017 and focused on improving our team working skills and methods in communication.

In the beginning of the project 2017, the planning team consisted of seven volunteers and a couple of employees from the Swedish and Finnish organizations, and the tasks and roles of different people and associations were unclear. There were also changes in contact persons in different associations which made the communication even harder.

After the camp in 2017 our team has been firmly established, and the size of the team has settled to 4 volunteers plus one employee from the Finnish organization. Currently there is one youth delegate per country from Finland, Denmark, Sweden and Iceland. Unfortunately, due to personal reasons, the delegate from Norway dropped out and we were not able to find a new volunteer despite our efforts. Three of the current delegates have been involved in the project from the very beginning and everyone is motivated to continue and keep on improving our work.

Having an established planning committee has helped us a lot in the process of planning the camp in 2019. As we have gotten to know each other we are more aware and used to each other's working methods and we know each other's strengths and how to use them. We work as a team sharing responsibilities and delegating our tasks and this is now done in a more structured way than in the beginning of the project. As everyone is now more aware of what is expected from them, we are also more motivated and committed to the work we do.

The planning committee is mostly working through online platforms and Skype-meeting, but on top of that we have found it to be very crucial to have planning meetings twice a year when we can gather together and work in productive ways. These planning meetings and face to face communication is highly appreciated and above all we feel very important when setting up the goals, visions, ideas and building up the concrete plan for our next year's camp. Our planning committee forms from people with different nationalities and we are not working in our mother tongue, so we do believe that face to face meetings twice a year lower the chance of misunderstandings. The planning group meetings also have an empowering meaning to the planning group members and working together is also one way for us to experience peer support. As the camp concept is running by volunteers, face to face planning meetings also have a big motivational meaning and makes volunteers more committed to this project. These meetings have helped us to become more united and to get a more united vision.

Working together with other associations across country borders has been very fruitful and eye-opening. As the camp aims to empower young people it has also been very empowering from the organizers' perspective too. The planning group is keeping regularly contact to each other and sharing the newest updates from their events, activities or campaigns and sharing ideas they receive from each other with their local associations as well.

Cooperation beyond the Nordic countries

Thanks to EULAR knowledge transfer program on every camp we have also invited a visitor from a partner association outside the Nordic countries. In 2017 we included a participant from Latvia and this year 2019 we had participant coming from Versus Arthritis Scotland, Jay O'Reilly

During the camp Jay presented and shared with us about the amazing work they are doing in the UK and the creative working methods they are using with children and young people with arthritis. After the camp Jay shared her feedback with the whole group and was happy to notice how well we had included physical activities to our programme and how much healthier our diet was. To those aspects Jay mentioned she will want to focus more in their activities in Scotland as well.

“I have been sharing my experiences with my colleagues and they are all super keen to learn more about and have been really inspired by your approach. Klaire and I's manager has already started to explore funding options so we can invite you over to Scotland to one of our weekends. It would be fantastic if this could be the start of us all being able to work together more closely to support young people with arthritis!” Jay says.

Here is a link to Youtube to Jay's interview published on the Facebook page of Nordic Rheumatic Youth Camp: <https://youtu.be/N4XqYzF14j8>

As an attachment Jay's bullet point report about her main areas of learning.

Evaluation

One of the goals for international cooperation and creating a youth camp concept across country borders has been to make all our associations more interesting towards the youth and get more members involved. And that is one of the things we can prove to be achieved!

Participating to the Nordic Rheumatic Youth Camp has activated youth to become members and volunteers of their National Association. As an example, two of the participants from NRYC 2017 are now board members of the Finnish National Association for Young Rheumatics (Suomen Reumanuoret). Several people from Norway have also expressed their interest in becoming volunteer planners for next year. One of the Swedish participants also said that after the aqua gymnastic session had at the camp she will start to attend to her local aqua gymnastics as well.

After the first Nordic Rheumatic Youth Camp 2017 we have received a lot of interest and attention outside the Nordic countries as well. In February 2018, Aino-Maria got to attend the EULAR Pare conference 2018 in Brussels and present Nordic Rheumatic Youth Camp in the best practice Fair. People were very excited to hear about the camp concept for young people that was planned and implemented by the young people themselves. We also got an invitation to present our camp concept in 25th European Pediatric Rheumatology Congress in Lisbon September 2018. Unfortunately, due to financial reasons we were not able to attend.

Pare conference was also an important chance for us to grow our network and get introduced with other association working with the same target group. We are now more aware of all the other association and their work around Europe and vice versa. As a result of the contacts created in the Pare conference 2018 we found also a partner to Nordic Rheumatic Youth Camp 2019 from Versus Arthritis Scotland Jay O'Reilly and that was a start of a new cooperation.

On December 2018 Nordic Rheumatic Youth Camp was presented in the International Volunteer Forum 2018, Moscow Russia, "Best international volunteering practices in the field of medicine". The International Volunteer Forum was a huge event and gathered together all in all 15 000 participants! International attention has gotten us more followers on social media and more applicants to participate for the camp.

Next steps and implementation.

Nordic Rheumatic Youth Camp 2020 Denmark

We are currently working for making the third edition of Nordic Rheumatic Youth Camp happen in Denmark in Spring 2020. We are currently applying for new funding. All members of the planning group are highly motivated to continue working with organizing the next camp.

Volunteer recruitment from Norway

We are currently looking for one new member from Norway to join our planning committee and we have few interested candidates for the position from the NRYC 2019.

Cooperation with Versus Arthritis

We are open for new ideas and ways for cooperation with the Versus Arthritis in the future. The planning committee will have a Skype meeting with the representatives of Versus Arthritis before the next planning meeting takes place in September 2019. We are also looking for funding opportunities that would allow us to visit Versus Arthritis in Scotland and learn more from their activities in practice. We are planning to implement the ideas we got from Jay to the NRYC 2020 and add more creative methods and art to our program. Versus Arthritis is planning to step up their levels of physical activities at their workshops.

Setting up own website

We are looking for different possibilities to open our own web page with information about our camps and pictures from the last camps. The webpage would also have updated information for the next camp and possible a payment portal to process sign-ups.

Future vision

We believe in the camp concept we have created, and we believe it will live for decades and grow stronger and bigger. We want to gather people together and create the best possible atmosphere to experience the empowering and inspirational effects of peer support. We think our project is still quite young and we want to make sure that it will stabilize its position as an annual event and well-known brand among the Nordic youth with rheumatic diagnosis's. In a long run our dream is to grow bigger and beyond the Nordic borders. In every camp we have invited a participant outside the Nordic countries and this is a tradition that we want to continue too. For the moment we want to keep the idea and brand of a Nordic camp and organize it in the Nordic countries but as next steps we are planning to grow the number of participants coming outside the Nordic countries. In the future we would want to see the camp grow more open for other participants coming from the Eular Pare countries.

AN EMPOWERING CAMP FOR YOUNG PEOPLE

Join us in Kisakallio, Finland
4-7 April, 2019

Nordic Rheumatic Youth
Camp 2019
Finland

Registration will open in January.
Follow us on Facebook
@nordicrheumaticyouthcamp
and Instagram @nordicyouthcamp

Nordic Council
of Ministers



Here is more picture form the camp :

<https://reumaliitto.kuvat.fi/kuvat/Viestinnän+kansio/Sonjan+kuvia/Nordic+Camp/Toimistolle/>

Attachement 1.

Bullet point Report – Nordic Rheumatic Youth Camp

By Jay O'Reilly

Volunteer Development Officer, Joint Potential Development Officer & Artistic Lead for YPFS Scotland

Main areas of learning...

-Exercise, there was a lot built in throughout the day. Including in lectures and group work. On top of that the young people, on the whole, are far more active and all participate in sports/exercise in their own time. It is used as one of their tools to self-management. Within our own practice we talk the talk but do not walk the talk! We advocate healthy eating and exercise whilst creating an environment where bad choices around meals and lack of exercise are enabled. (i.e, sweets cakes, not very healthy food and a programme where we sit for most of the time.)

-Diet – so much healthier, the majority of the food was plant based accompanied by fish or chicken and potatoes/pasta. 4 meals a day – 8am, 11.30am, 4pm and 8pm. On the whole there seemed to be far better mental health, far less catastrophizing compared to our young people.

-More free time which really allowed the participants from the 5 Nordic countries to get to know one another and left plenty of opportunities for real peer to peer support.

-A lot of excitement around the art side of our work. They are looking to engage with younger children and think this could be the way to enable it. I would love to work with them to help develop a similar practice in their respective countries and to continue to share more about what we do.

-It would be great to enable an exchange, for me personally seeing what other young people are capable of, the fact many were employed or are still studying I think would make them great role models for our young people here in Scotland. We have been trying to show our participants the importance of having a positive attitude, to instil in them a belief that they are capable young people and that in spite of their condition there is a whole world out there for them to explore. This would be a major step to help them build their confidence, resilience and make bonds with other young people just like themselves. Since coming back from Finland, I have already been cascading my learning to the whole team in Scotland who are extremely interested in the project and the charity across the Nordic regions.

-We are already looking into funding options so we can invite the planning team over to Scotland so we can continue to learn from one another and to strengthen the bonds

between us all.

-For me it truly was the most amazing experience that I will never forget, and I am so grateful to have had the opportunity.

-The organizing team were all brilliant, so friendly, warm, kind and relatable. It is easy to see why they have the large number of young people attending the camp. Witnessing first-hand the positive impact it had on their lives was a real privilege.