

## EULAR Knowledge Transfer Programme – final report

### Applying organization

Name	The Finnish Rheumatism Association on behalf of the Nordiskt Reumaråd, NRR
Country	Finland, Sweden, Denmark, Norway and Iceland
Secretariat address	Suomen Reumaliitto, Iso Roobertinkatu 20-22a 5 krs, 00120 Helsinki, Finland
Telephone	+358407079114
Main contact person	Maria Ekroth
E-mail	maria.ekroth@reumaliitto.fi

### Partner organization

Name	The Finnish Rheumatism Association, Swedish Rheumatism Association, The Danish Rheumatism Association, Norwegian League Against Rheumatism and Icelandic League against Rheumatism
Country	Finland, Sweden, Denmark, Norway and Iceland
Secretariat address	NRR, Tidiane Dione, Reumatikerförbundet, BOX 128 51 Alströmergatan 39, 11298 Stockholm
Telephone	
Main contact person	Tidiane
E-mail	

<b>Title of your project</b>
Youth Camp 2017
<b>Describe in max. 400 words your project.</b>
<p>The basic idea was to create a new youth camp concept which would help to get new young members to our associations. Nowadays youth are very international and Nordic Camp seemed to be much more interesting than activities in participants home countries. This was the first camp of a new annual event rotating between the Nordic countries.</p> <p>Our aims were:</p> <ul style="list-style-type: none"> <li>- To learn the needs and wishes of young adults with rheumatism and improve our support for that group in our associations.</li> </ul>

- We needed a wider perspective than just Finnish, because the youth live in an international world. We need to learn from each other, therefore we made an interesting and international concept. Then we can create something that all European Rheumatism Associations can use or do together in the future.
- The aim for Youth Camp concept is to create a yearly event where youth get information about their diseases from professionals; they get peer support, can network widely and stay in touch through social media after that. Eular is a European League and we believe that we should open European co-operation for our members as well to offer international peer support. It makes all of our associations more interesting for youth and we get more members and after that we can offer more peer support and knowledge of their diseases for them.
- The target is to make a full concept containing program, the logo, visual elements and targets
- One of the aims is to make youth's understand that they are not alone with this lifelong disease.

The camp was held in Bosön, Stockholm, 4-7 October, 2017

The camp offered participants different kinds of physical activities, lectures, group discussions and get-togethers. It was organised for young people between the ages 18-30. Five (5) young persons was recruited in early 2017. They planned this camp with this Eular Pare knowledge transfer money. We had two planning meetings with five youth one in Stockholm and the other in Helsinki. They also made a feedback questionnaire and upon received feedback made a report.

The total program is attached to the e-mail.

## Evaluation

### **What have you achieved? (Qualitative indicators of your success)**

*How does the situation in your organization look like? What have you changed? What are the future benefits for people with RMDs?*

- peer support now and in the future
- empowering and understanding atmosphere
- bonding and making friends from other countries
- sharing of experiences
- learning about medication, physical activities and nutrition in self-medication context

A closed Facebook group was formed, Nordic Rheumatic Youth Camp, which is still active. All the RMD's professionals lecturers are shared there for later use.

Young people with RMD's will get better support from our associations because we understand their needs and wants, by using this information we learned during this process. Example we are creating better support web pages for youth in Finland. We also organized a Christmas party weekend for 51 youth who haven't been in touch with our association before.

**Added value of the cooperation with the partner organization**

*(What were the biggest benefits of the cooperation for your organization? What is the most important thing you learned?)*

We learned a lot from needs and wants of young people with rheumatic diseases. We know now, for sure, that they need peer support as much as other age groups, even if they haven't been too interested in to joining our local associations. While youth have bad days with their diseases it helps a lot when they remember that they are not alone, they have friends in the same situations friends which understands. Many participants said that they have made lifetime friends there.

We believe that we can use the information we got during this process and can innovate new support models for youth in our countries.

One of the most important things we learned was to understand how important this planning process was to the youth who were in the planning group. Here are some young people's views:

"First time I have been proud of having this disease because I have change to help others and my family is so proud of me to do this kind of voluntary work". "

"It is hard to find words for the things we experienced during those four days, and together we created an amazing atmosphere of trust and acceptance. We found inspiration in one another, and by supporting each other we can also find the strength in ourselves, although it is hard to see at times. And for that, we will stay grateful. We believe the moments we shared and the warm memories we hold will help us through the upcoming winter!"

**Evaluate your achievement, please. Write down the quantitative indicators of your success.**

**What have you planned and what have you achieved so far?**

**Specific** Members of the planning group and all participants were very satisfied and said that it's easier to continue their life with rheumatic disease after this experience.

**Measurable** Five youth and two mentors (Maria Ekroth, Finland and Tidiane from Sweden) were in the planning group and 31 Nordic youth participants in the camp. The results of the feedback are attached to the e-mail.

**Accurate** We got 7500eur funding from Eular Pare, 27 000eur funding from Nordbok, 3000 eur from NRR and 2000eur from The Finnish Rheumatism Association. This was an excellent result for the new concept and we are very proud of this success.

**Realistic** Our aim was to learn the needs and wishes of young adults with rheumatism and improve our support for that group in our associations. These results were met.

**Timely** Now is the time for planning and applying new funding for this year camp.

*(Please give indicators of your success – dates/months and years, numbers, percentage, grow rates, etc.*

*e.g. in 1 years' time 3 types of members have been registered through new registry database; through new funding abilities 10% more funding has been generated in last 12 months)*

## Next steps

### **What are your next steps?**

*How are you going to apply the gained knowledge in the organisation and/or the branches of the organisation? Please write a short plan of action.*

The concept of the camp will be developed through the received feedback. It was distributed to all Youth Associations in the Nordic countries and it's free to use upon request. In addition, the feedback will be used in future similar national projects regardless of age, target group and disease diagnosis. We have applied funding from Eular Pare in order to plan a new camp and we are going to apply money to the camp itself from Nordbok for year 2018. We hope to finalize the concept this year and make this as an annual project, which would be open for other Eular Pare countries in the future.

We believe that this concept will live decades and will come stronger and better during the time. Youth Camp 2018, 30 participants from Nordic countries, 2019, 50 participants from Nordic + some European countries, 2020 ,50 participants from European countries. European wide internet-page with information and peer support for youth with RMD's.

**Financial report (add budget lines if needed – be as specific as possible)**

**– Please fill the amounts in EURO**

Costs	Costs budgeted	Total costs spent	EULAR grant	Other sources
<b>1. Travel cost</b>				
<i>1.1. Abroad - airfare, medical insurance, transfer</i>	3000	4267	4267	
Applicant				
Partner organization				
<i>1.2. Local transport (taxi etc.)</i>	300			
Applicant				
Teaching organization				
<b>Subtotal Travel costs</b>		<b>17 000</b>		<b>17 000</b>
<b>2. Accommodation</b>		1442	1442	
Applicant	2000			
Partner organization				
<b>Subtotal Accommodation Costs</b>		<b>10 000</b>		<b>10 000</b>
<b>3. Out-of-pocket expenses (meals ...)</b>	500	671	671	
<b>Subtotal Out-of-pocket expenses</b>				
<b>4. Other costs (communication- phone, fax; office supplies, photocopying etc.)</b>	700			
<b>Subtotal Other Costs</b>		<b>3000</b>		<b>3000</b>
<b>5. External services (translation, editing, printing, advertisement etc.)</b>	500	620	620	
<b>Subtotal External services</b>		<b>2000</b>		<b>2000</b>
<b>6. Total Direct Costs (1+2+3+4+5)</b>				
<b>7. Unexpected costs (max 5% of Total Direct Costs)</b>				
<b>8. Allowance to partner organization (500 euros)*</b>	500	500	500	
<b>9. TOTAL GRANT spent (6+7+ 8)</b>	<b>7500</b>	<b>39 500</b>	<b>7500</b>	<b>32 000</b>

\* We acknowledge that the partner organisation is giving valuable time to the applying organisation. For this reason, it is appropriate to include in the budget an allowance payable to the partner organisation for the time it is donating to the project. This allowance will be 500€.

I confirm that the information I have given is accurate to the best of my knowledge.

Place, date:  
Helsinki 15.January 2018

Signed applying organisation:



Maria Ekroth