

KNOWLEDGE TRANSFER PROGRAMME 2018

SERBIA - SWEDEN

STOCKHOLM-BELGRADE

2018-2020

Swedish Rheumatism Association



Reumatikerförbundet

The Association of Rheumatic Diseases Patients of the Republic of
Serbia



REPORT

Background

Since the establishment of ORS, we had been organising different activities for rheumatic diseases patients and their supporters within our four branches. In 2017 our organisation celebrated its 10th anniversary and we felt that there is a need to expand and improve our activities, learning from an organisation with a long tradition. We wanted to strengthen our position and to start reaching to another level – growing from a small to a medium-sized organisation in the following three years.

The main source of our income were the pharmaceutical companies (94%) until 2017. We wanted to reduce their contribution to our budget by 20% in the following three years.

We have established good cooperation with two medical high schools and we intended to consider cooperation with a medical faculty. We were keen to gain insight into the Patient Expert Programme (PEP) project that Swedish Rheumatism Association had developed and hoped to then begin and steadily develop successful cooperation with target institutions in Serbia in the following year. We wanted to improve the cooperation with medical faculties and become a part educational program. And the PEP was the best way to achieve this aim.

Through previous contacts with Swedish Rheumatism Association it was agreed that the

- Teaching organisation would be:
Swedish Rheumatism Association (SRA), and the
- Learning organisation would be:
The Association of Rheumatic Diseases Patients of the Republic of Serbia (ORS).

It was also agreed that Latvian Rheumatics Association should be involved in the project as learning/observing association, but they withdrew from the project because of a lack of resources.

What do we wanted to achieve – Aims

The aims of our knowledge transfer programme were for us to:

1. Fundraising

- Learn how to gather more voluntary contributions of money and other resources. Following the knowledge transfer visits we would organise a seminar to disseminate information with the representatives of all our branches. After the seminar our activists would have been trained to collect money for different activities. Those activities would attract more members and provide better life for people with RMDs.

2. Patient Expert Program

- Implement the Patient Expert Program. The implementation of this program would strengthen the connections with medical institutions, provide first-hand knowledge for future doctors,

- provide better care for RMDs patients in the future. The PEP would allow the organisation to collaborate closer with the universities, the doctors, researchers, health professionals.

3. Cooperation among sister organisations

Develop strong relationships with the sisters EULAR organisations.

Implementation of the project

The implementation of the project had three phases:

- First phase – Serbian delegation visited SRA in Stockholm,
- Second phase - Swedish delegation to visit ORS in Belgrade, including two instructors who would teach our members,
- Third phase – Instructors to come to Serbia to hold exams.

Implementation of the first phase

Serbian delegation including Mirjana Lapcevic, ORS President, Vera Govedarica, Marija Kosanovic and Nenad Nedic, all active members-volunteers of the association, visited SRA Central Office in Stockholm from 4 - 8 September 2018.

Our Swedish hosts offered an excellent, comprehensive and varied programme (included as Attachment A to this report).



Our hosts showed us the Central Office's premises

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The first day of the visit was reserved for the introductions of both associations looking for the similarities and differences in order to meet the aims of the project in a better way. We also had an opportunity to meet with the SRA CEO, Mr. Leif Salmonsson, as well as the other leading people at the Central Office. Annika Sjöberg delivered a lecture on Communication and Fundraising, while Eva-Maria Dufva talked about Lobbying.

Berryl Svanberg and Carina Thorstensson presented us with something completely new on the second day. Although the members of ORS are mostly affected by osteoarthritis, we do not have specialised programmes for those people. So, we were interested in SRA's schools for osteoarthritis and to learn more about educated persons who disseminate knowledge on this disease. Li Alemo Munters presented SRA's activities in the field of research and how the Swedish organization supports the researchers in rheumatology. We enjoyed the conversation with Ms. Lotta Haakansson, SRA President during the working lunch.



The guests and the hosts from left to right:

Top row: Tidiane Diao, Nenad Nedic, Carina Thorstensson, Marija Kosanovic, Vera Govedarica, Berryl Svanberg, Sitting: Mirjana Lapcevic, and Lotta Haakansson.

On the third day we had an opportunity to get acquainted with the PEP project through lecture and demonstration by Maria Nylander, the PEP instructor.

We also visited the Center of Rheumatology within the famous Karolinska Institute. After visiting the rheumatology facilities, all our questions were answered by Professor Aleksandra Antovic of the Rheumatology Center Stockholm. The added bonus was that Professor Antonovic was Serbian by birth and was able to explain in Serbian how the Swedish health system worked and answer the many questions we have had for her. This conversation helped us to understand the Swedish way of care for rheumatic patients in a better way and to see what we could improve in our country.

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"Thank You" to our hosts at the Rheumatology Center in Stockholm. The visit to this center was a very educational and enriching experience.

On the last day we had an opportunity to see what new technologies are available in Sweden and what mobile phone? applications (apps) are used by the Swedish Health System. The lecture on the Membership Strategy followed, which was also a „new technology“ for us because we do not have a strategy which is focussed only on membership. We have also got more information on the process of decision making within the SRA.



We had a lot of opportunities to ask questions and to discuss different topics with our hosts.

Implementation of the second phase

In this phase, four members of the Swedish organisation including Lotta Haakansson, SRA President, Maria Nylander, Ingrid Cederlund, both PEP Instructors, and Nina Schwerin, SRA Interantional Coordinator, visited Serbia from 13-16 October 2019. During this phase six members of ORS, who are RA sufferers

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themselves, were educated in order to become the Patient Expert's Partners. We also visited some relevant institutions lobbying for the Patient Expert Programme.



The SRA delegation arrived into Belgrade late in the evening on the first day, so we started with the programme on the second day in the morning. Our guests were welcomed by Prof Nemanja Damjanov, MD PhD, Director of the Institute of Rheumatology, Prof Mirjana Sefik-Bukilica, MD PhD, President of Rheumatology Association of Serbia, as well as Mirjana Lapcevic MD, ORS President.

The educational lectures were held at the Institute of Rheumatology. Rheumatologist Dr Ivica Jeremic MD PhD, delivered a lecture on rheumatoid arthritis at the very beginning of the programme.



A meeting at the Ministry of Health was followed by the meeting with the Dean of the Faculty of Medicine, University of Belgrade, Professor Nebojsa Lalic, MD PhD. Ms Lotta Haakansson helped us to present the project from the right angle to Professor Lalic who showed a great interest in the project and was very willing to find a model how to incorporate this programme into the future doctors'

education and training.

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The meeting with the Dean of Belgrade School of Medicine was a start of future cooperation.

The PEP education started in the afternoon of the second day and it was continued during the third day and the first half of the fourth day. The six members of our association, including Sonja Ilic, Sara Ivanovic, Marija Kosanovic, Nenad Nedic, Romana Popovic and Slavica Rakovic attended the course. The participants also received a previously translated film which illustrated what we should know in order to become the PEPs. Our Swedish colleagues sent us a manual to help us in the learning process. Maria and Ingrid answered all our questions very patiently and repeatedly practiced with us, so we were ready to start with learning and preparing ourselves for the exams. A detailed programme of this visit is included as the Attachment B of this report.

We agreed that the instructors would test our knowledge in January 2020.



Our candidates were practicing together for the exams.



Implementation of the third phase

The third and the last phase of the project was implemented from 23-26 January 2020. Two KTP instructors, Maria Nylander and Ingrid Cederlund, came to Serbia in order to hold exams and give us some final advice before we start to work with the students.

All six candidates were ready for the exams as we had been practicing together during November and December. The instructors held the exams during the two days at the Institute of Rheumatology. At the end instructors were satisfied with our knowledge and approved for us to start educating students. The programme of the third phase of the project is included as Attachment C in this report.



At the end of the project all six candidates passed exams in order to become the Patient Experts.

Results of the project

In 2011, when we visited Deutsche Rheuma Liga, the “Patients Partners” project (a project similar to the PEP project in Sweden) was introduced to our delegation. We wanted to start this project then, but timing and circumstances were not right for it. In 2017 when we realised that the circumstances had changed, we applied for the EULAR KTP grant together with our Swedish colleagues in order to learn and later implement this project in Serbia. Once the grant was approved, we started to lobby very actively for the project. We met with approval by the Serbian Ministry of Health. At the same time that the project was starting, the Dean of the Faculty of Medicine in Belgrade was thinking about increasing patient involvement in teaching of students. The Swedish-Serbian delegation introduced the project to the Dean and to the Representative of the Students' Parliament. Both of them were interested in starting with the PEP project at the Belgrade Faculty of Medicine. The President of the Serbian Association of Rheumatologists also attended this meeting and supported the idea of the project. The only thing left to do was to find a proper model for the implementation of the project. After ORS' six activists passed the exam in order to become Patient Experts, the Department of Internal Medicine approved our involvement in education of future students. We will officially deliver our lecture within the 2020/21 school year, during the rheumatology week within the Internal Medicine subject. If this project provides good outcomes, we will be able to expand it to other universities in Serbia. This project will strengthen and deepen our cooperation with rheumatologists, and we also hope to create a fruitful collaboration with the professors at the Belgrade Faculty of Medicine. Through the involvement of patients in the education of medicine students, we are expecting that we will get well educated doctors and that they will make diagnosis more quickly and more successfully.

As we saw in Sweden, there were many programmes for the members with different diagnosis. The PEP project has been involving only the persons with rheumatoid arthritis in Serbia. Our return from Sweden was a starting point to think how to divide our members into several groups according to their diagnosis. We have now formed a few groups: a group for rheumatoid arthritis, a group for ankylosing spondylitis, a group for lupus. We are working on setting up a group for scleroderma and a group for psoriatic arthritis. We will measure quantity and quality of their activities in order to estimate how successful they are.

During our stay in Stockholm we were surprised to see that the Swedish patients could order their medication through an app. In Serbia the procedure for getting the biologics is pretty long and complicated. Through a conversation with our Swedish colleagues we decided to start lobbying for the simpler procedure. We know there is a long way in front of us, but we have started it and we won't give up. In the last two months our delegation had meetings with the representatives of the National Insurance Fund and Ministry of Health in order to ask for the change of procedure for getting the biologic therapy. Our issue is that our patients have to take a one-day sick leave from work every month in order to come to the hospital and get their therapies which they apply themselves at home anyway. In this way we are losing one of the main roles of the biologics - to enable sufferers to lead more productive lives and in the process reduce the number of sick leave days. We hope that, after this procedure is changed, they will be able to get the medications at a pharmacy with the referral by a GP/rheumatologist only once in six months. The officials at the Ministry of Health advised us how to reach this goal at the meeting last week.

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We hope that our actions and representations will be successful and we will be provided with a simpler and cheaper procedure.

One of our main aims for this project was to reduce the contribution of pharmaceutical companies to our budget. In 2017 this contribution was 93%. During the last two years the contribution of pharmaceutical companies was reduced as planned. In 2018 it was 72.33% and in 2019 77.69% which means that it was reduced by more than 15 % for the last two years.

After our return from Sweden, we organised a meeting with the ORS Board members and the presidents of our four branches in order to share knowledge and experience that we had gathered during our visit to SRA. The presidents from the other cities were very interested to start the PEP project at the universities in their towns. They have supported the idea of forming the groups for our members with different diagnosis, organising the ORS members at the local level. We are also planning to share our experience from Sweden as a lecture at the annual national Congress.

We would like to thank the European League Against Rheumatism for supporting us through the Knowledge Transfer Programme and enabling us to visit the Swedish Rheumatism Association. This visit will help us to become pioneers in education of future doctors in our country. We would also like to thank the Swedish Rheumatism Association, the SRA President Ms. Lotta Haakansson, all the staff at the SRA Central Office and our instructors Maria Nylander and Ingrid Cederlund for all the good will, kindness and great efforts they made to teach us, support us and lobby on our behalf. Thanks also goes to Nina Schwerin and Tidiane Diao who have provided administrative support and helped us to make this project so informative, educational, enjoyable and memorable. Last but not least, we express our deep gratitude to the Institute for Rheumatology in Belgrade, and in particular, its Director, Professor Nemanja Damjanov, for the tireless support, understanding and partnership on this project.

Marija Kosanovic

For The Association of Rheumatic Diseases Patients of the Republic of Serbia (ORS)

Exchange program Serbia – Sweden 2018

Visit to Stockholm: 04-08/September 2018

- **4th of September:**
 - Arrival /Hotel
 - Lunch (11.30 – 12.30)
 - Welcome by CEO Leif Salmonsson (13.00 – 13-15)
 - Presentation of ORS (13.15 – 14.00)
 - Presentation of the SRA (14.00 – 15.00)
 - Annika Sjöberg, chief (14.30 – 15.00)
 - Eva-Maria Dufva, chief, (15 – 15.30)
- **5th of September (lecturers Berryl Svanberg & Carina Thorstensson)**
 - Lecture (Patientskolor) fruits and fika/coffee (09.00 – 11.30)
 - Lunch with the CEO and President of the SRA(11.30 – 13.00)
 - Lecture (Patientskolor) fruits and fika/ coffee (13.00 -15.00)
 - Research and PRP: Li Alemo Munters, chief (15.00 – 16.00)
- **6th of September (lecturers Maria Nylander, Helena Bäckafall & Agneta Smith Johansson)**
 - Lecture (Patient Partners Program) fruits and fika/coffee (09.00 – 11.30)
 - Lunch (11.30 – 13.00)
 - Visit to the center of Rheumatology (13.00 – 15.30)
 - Back to hotel for rest
- **7th of September**
 - Erik S: “New technologies for a better health” (9.30 – 10.30)
 - Johan H: “Membership” (10.30 – 11.30)
 - Lunch (11.30 – 13.00)
 - Norah Avielle “The decision process within the SRA” 13.00 – 13.30
- **8th of September**
 - Departure



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Programme of the Reumatiker Forbundet visit to ORS

Belgrade, Serbia

13-16 October 2019

Sunday, 13th October

23.35 Arrival to Serbia

00.30 Arrival to hotel Rex

Monday, 14th October

- 09.00-10.00 Lecture, Ivica Jeremic, MD, PhD, Institute of Rheumatology in Belgrade
- 10.00-10.45 Patient Expert Programme
- 10.45-11.15 Refreshments
- 11.15 Transfer to the Ministry
- 12.00-13.00 Meeting with Dr Vesna Knjeginjić, Assistant to the Minister of Health
- 13.00-14.00 Transfer to the Medicine Faculty
- 14.30-15.30 Meeting with Prof Nebojša Lalić, Dean of the Medical Faculty
- 15.45-16.15 Refreshments
- 16.15-18.15 Patient Expert Programme
- 18.15-19.00 Free time
- 19.30-22.00 Dinner

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Tuesday, 15th October

- 9.00-9.30 Visit to the Institute of Rheumatology
- 09.45-11.15 Patient Expert Programme
- 11.15-11.30 Coffee break
- 11.30-13.00 Patient Expert Programme
- 13.30-14.30 Lunch
- 15.00-16.30 Patient Expert Programme
- 16.30-16.50 Coffee break
- 16.50-18.20 Patient Expert Programme
- 18.30 Free evening
-

Wednesday, 16th October

- 08.30-11.00 Patient Expert Programme
- 12.00 Departure

Attachment C

Schedule of the Exams

Belgrade, Serbia

23-26 January 2020

Thursday, 23th January

Arrival of the instructors

Friday, 24th January

11.00-12.30 Exam Romana Popović

12.30-13.30 Lunch

13.30-15.00 Exam Sonja Ilić

15.00-16.30 Exam Sara Ivanović

Saturday, 25th January

09.30-11.00 Exam Nenad Nedić

11.00-12.30 Exam Slavica Raković

12.30-13.30 Lunch

13.30-15.00 Exam Marija Kosanović

19.00 Dinner

Sunday, 26th January

Departure of the instructors