EULAR Knowledge Transfer Program

Project Report «Patient Expert»

Cyprus – Sweden

CYPRUS LEAGUE AGAINST RHEUMATISM

Reumatikerförbundet

2016
**Background**

Patient involvement in the education of health professionals is increasing in Cyprus. There is big interest from Universities and other health professionals’ groups to involve patients with RMDs to educate the students of medical schools about RMDs, the obstacles they face as well as the impact on daily life for the people with RMDs.

Also, through this initiative it is envisaged to promote early diagnosis and to enhance the knowledge and skills of future doctors about RMDs.

For people with RMDs, volunteers of Cyplar, to be able to speak and educate the medical students and other health professionals, was a need for them to be educated and to enhance their communication skills as well as be trained on how to best share the messages and talk to people with a medical background.

The Sweden patient organisation run very successfully a patient experts project, since 1995, aiming to educate and speak to medical students and health professionals about RMDs and especially for the diseases RA, AS & OA.

The knowledge-exchange programme consisted of the actions below:

- Representatives of Cyplar visited Sweden in order to be educated and trained on the project patient experts.
- Representatives of the Sweden organization visited Cyprus to support the implementation of the project, and the training workshop of the first patient expert group.

**Project Aim**

The programme aims to engage people with RMDs, with undergraduate medical students and health professionals in learning partnerships.

By implementing in Cyprus, the patient experts project and through this to educate and train people with RMDs in order to be able to speak and educate the medical students and other health professionals about RMDs.

We also aim to develop supportive material for the project.

**The goals of the exchange project is the following**

- By the end of the project (2016), 8 people with RMDs, from different diseases, will be trained and educated to be patient experts.
- By the end of the project (2016) the supportive materials will be translated and printed.
- By the first year (2016-2017), 8 sessions will be organized at the universities for the medical students.
- By the end of the second year (2017), a follow up training will educate 12 more people with RMDs.
- By 2017, 12 sessions will be organized for the medical students and other health professionals.
The CYPLAR’s representatives visiting the Swedish Rheumatism Association

The knowledge transfer started with the visit of the representatives from the Cyprus League Against Rheumatism (Cyplar) to the Swedish Rheumatism Association in Stockholm, from 22nd of May to 26th of May.

The Cyplar’s representatives:

- Marios Kouloumas – President of CYPLAR Board – RA
- Andri Phoka – Secretary of CYPLAR Board – AS
- Dr Joseph Joseph due to health issues was not able to travel with the Cypriot delegation

The Swedish Rheumatism Association representatives:

- Ingrid Cederlund – Patient Instructor – RA
- Maria Nylander – Patient Instructor – RA

First Day Monday 23rd of May

The programme initiates at the offices of the Swedish patient organisation, with the presentation of the Swedish organization and a tour in the office, to be familiarized with the environment and the excellent work that the organization do in Sweden.

The Swedish patient organization is an umbrella organization. All types of RMDs are represented by the organisation with branches nationwide. 60-65 members of staff are in the head office & branches, supported by volunteers with RMD. The organisation counts about 50,000 members. The aims of the organisation is to raise awareness about RMD, to campaign for equal rights & treatment & improve the quality of life for people with RMDs, to promote contacts with fellow patients, to support research by fundraising.

The next presentation was about the **patient expert programme** and the objectives /goals and aims of the programme. The patient expert programme was imported from USA back in 1988 and in the meantime and after many years of implementation and experience the aims and the content of the programme was upgraded to inform the medical students about the burden of the disease and the daily obstacles that the people with RMDs face.

The patient expert programme includes at the training of the medical students the examination of the Wrist and Hand, of the Knee and the Hip. There are about 50 Patient Experts in Sweden today and about half of them they are trained on the three examinations. The education course to become Patient Expert includes lectures, clinical training and self-study. The materials that they are using for the education course are for the Hand-Wrist / Hip/ Knee handbook, a DVD and a Tape Recordings.

The recruitment of the Patient experts is a very important part of the programme. The most important criteria amongst others, for a volunteer to become a Patient Experts is that must be a patient with RMD, must have good self-management of the disease, speaking confidence and experience in treatments.

The funds for the programme initially became from a pharmaceutical company and now is funded by the Universities which are paying the Swedish Association for every education meeting with medical Students.
At the afternoon, the first session was about the Patient Expert – Partner in action. Mrs. Agneta Smith Jonasson, who is one of the most experience Patient Expert in Sweden with RA, has presented how she is making the presentation to the medical students and the examination of the wrist and the hand, following the below steps:

- Self-presentation
- Hand and Wrist examination
- The materials that she is using for the presentation i.e. x-rays, needles, screws that used to be on her body after surgeries
- Presenting the obstacles that a person with RA face at the daily life

At the next session, the representatives from Cyprus with the guidance and the observation by the patient experts from Sweden started to learn and to practice how to exam the wrist and the hand joint.

The last workshop of the day was about the Wrist and hand anatomy. By using the handbook, the Patient Expert Instructors, Ingrid and Maria showed the Hand’s and Wrist’s anatomy on a very detailed and easy way to be easily understand and learned.

**Second Day Tuesday 24th of May**

On the Second day of the education visit Dr Ioannis Parodis a Rheumatology from the Karolinska Institute presented three different topics focusing on the early detection and the importance of the patient experts at the education of the medical students. The lectures about RA, Lupus and OA were very informative. After the lectures, he showed the way that a Rheumatologist must examine a patient with rheumatism. Firstly, the way the doctor should be seated, and the way that a Doctor should approach the patient, verbally and physically to gain the trust of the patient: the way he speaks and asks for more information regarding the patient situation and the way he touches the patient. After that he shows the examination on the wrist and the hand, hip, and the Knee on a patient (Maria Neylander), the dialog that he is using in every day.

It was really a very good presentation – workshop that helps the participants to realize the importance of the approach of a Rheumatologist examination and the importance of the Patient Expert programme to have this kind of examination for all the RMD patients.

During the afternoon, a visit at the Karolinska Institute Rheumatology Hospital was organized. The participants had a tour in the outpatient area, in the day care department, the physiotherapy department and oat the inpatient clinic. Afterwards a Patient Expert’s demonstration was given by Mrs. Agneta Smith Jonasson and by two medical students, in the Hospital education center.
When the presentation was finished, medical students have been asked “how helpful was for them this presentation “and their answer was “We couldn’t imagine only by reading the books how is a patient with RMD, how many deformities may have, and how many obstacles in his/her everyday life has” This is another one evidences of the importance of the Patient Expert programme.

The night finished with a great dinner offered by the Swedish organization in a very nice restaurant.

**Third Day Wednesday 25th of May**

The third day began with a presentation of the CYPLAR program. CYPLAR is a nongovernmental nonprofit organization and is representing the People with RMD’s in the Republic of Cyprus. Has 5 staff members and they operate many projects focusing on the raise awareness of RMD’s with many programs and events. Also, the major activities are patient’s information and education, patient’s rehabilitation, psychosocial support.

As the practice is the best way to become a professional, the programme continues with practice on the hand and wrist examination. Marios and Andri made practice of the examination with Ingrid ‘s and Maria’s guidance and observation. It was very helpful for them to become more familiar with the examination.

On the second part of the day programme, a short draft evaluation of the education was prepared and the highlights of the days were presented.

**But the most important part was the planning of the implementation of the Patient Expert program for CYPLAR in Cyprus.** The participants decided on the details of the implementation of the education programme in Cyprus in order to educate the first 8 people in order to become a Patient Expert. Was decided for a two Days Education Workshop, which will be organized at the dates that the two Sweden experts will visiting Cyprus in order to support the implementation of the workshop. The dates of the workshop decided to be on the 24th to the 27th of October.

Also after the discussions about the details and the content of the programme which will be implemented in Cyprus, was decided to focus at the examination of the hand and wrist and not the Hip and Knee examination, since this examination is the most important and must be made by all Rheumatologists in all patients with any rheumatic disease. The Hip and knee examination will be applied after CYPLAR become, experienced and succeed of the Hand and Wrist Examination-Patient Expert Programme.

**The draft action plan with concrete steps that was decided for the implementation of the programme in Cyprus is the following**

4 Weeks < Develop the outline of the programme and the detail action plan
4 weeks < a collaboration with a rheumatologist
4 weeks < a collaboration with the medical school of the University
8 weeks < to develop the criteria for the patient recruitment
8 weeks < to develop the role description and the contract of the Patient Experts
16 weeks < to recruit the patient experts
16 weeks < to develop the workshop programme
16 weeks < to translate and printing the manual and the booklet
16 weeks < to develop the evaluation form
16 weeks < to organize the workshop

The visit finished with a wonderful city tour of Stockholm and a Dinner.
The patient experts from the Swedish Rheumatism Association visiting CYPLAR 24th – 27th of October

At CYPLAR a big preparation for October workshop started from the beginning of June.

The aim was to educate - trained 8 people to become Patient Experts.

First an action plan was made for the education – training, this was a must to be able to be on the time for all the preparations, and for the implementation of the programme in Cyprus.

A first draft of Patient Expert Program with all the details was developed with the aim, objectives, collaborations, evaluations etc.

There was a meeting between Dr Joseph Joseph who is a Rheumatologist Professor at St Georges Medical School at University of Nicosia, in order to develop the education programme and the first training workshop. They took the decision, of course with the agreement of the medical school, to have the first day of the workshop - education in the St Georges Medical School Nicosia - University establishments in Nicosia. Also, decided that a lector of the Nicosia University will give a presentation about the effective communication, and a production of a Video of the workshop.

To continue with the preparation the following steps was made:

- The three days’ program of the Education – workshop – and the visit of the representatives from the Swedish Rheumatism Association.
- The Recruitment Criteria’s of volunteer to be able to participate in the program. So, after the preparation an announcement on the FB, Tweeter, by emails and by phones have been made, to find the participants.
- At the same time a translation of the Patient Expert manual was made and then the printing for all the participants.
- The execution of the action plan

The first patients who was selected to be educated as a patient experts are the following
Nikos Nikolaou (RA), Maria Avraamidou (RA) Irene Pitsillidou (OA)
Irene Karis (RA) Olga Paschali (OA) Chryso Yiasoumi (Lupus) Andri Charalambous (SpA) Veli Koulouma (OA) Sofia Constantinou (RA)

Workshop first day 25th of October at the St George’s Medical School

The first day began with an Ice breaker, by talking each participant about themselves, about the disease, their experience, the daily obstacles and how they cope with the disease.

The first presentation was made by Ingrid Cederlund, presenting the Swedish Rheumatism Association, informing generally about the Association.
After Maria Neylander presented the Swedish Patient Expert Programme. With this presentation participants, the future CYPLAR’s Patient Experts had the opportunity to understand better the role that they will play for the project of CYPLAR and the very important job that they should do, not only for the future of the Cypriots Patients with Rheumatism, but in general for all the patients with Rheumatism in the World.

Andri Phoka continues by presenting the CYPLAR’s Patient Expert Program. The presentation include the aim, the objectives the goals and the ways that CYPLAR will apply the programme in the organization according to the needs in Cyprus.

Dr Joseph Joseph made a very nice presentation of St School, giving lot of information hosted the education, and explanation about the academic Georges medical school. This understand the future Patients Expert will meet the students (in and how much knowledge of the student will have at the time educate the students.

Dr Joseph Joseph continued with a lecture about RMD’s. With this lecture, Dr. Joseph explains the differences between autoimmune inflammatory diseases and degenerative rheumatism diseases.

A presentation and sharing experience of the Rheumatology Day was made by DR Joseph Joseph and Medical School Students. The Rheumatology day is a very important initiative taking place every year at the medical School of the university with the aim to bring together the students and the patents with rheumatic disease. The Students give the feedback that they have during the Rheumatology day and explained how important was for them to better understood the Rheumatology and the cost for people that they are safer from this disease.

**What is a Rheumatology day?**

Dr Joseph has put in the academic program of ST George’s Medical School in Nicosia the Rheumatology Day. Rheumatology Day is part of the MBBS life structure section of Year 1, where students learn about conditions of the musculoskeletal system and skin: that is, the specialties of rheumatology, orthopedics and dermatology. It is one day every year that students who study at that time Rheumatism, have the chance to see patients with rheumatism, to talk with them and learn from them about their disease and the obstacles they have in everyday life.
Continuing the programme Ingrid Cederland, Maria Neylander, Marios Kouloumas and Andri Phoka showed the Hands on Hands joint examination with the help of Dr Joseph Joseph and some of the Students. At this part a Video Capture has been made by other students of the University.

You can see the Video at YouTube link: https://youtu.be/Sk6rrGUcYBY

After a nice light lunch the programme continued with a Hand Examination that Dr. Joseph made to each one of the participants. The goal of this examination was for the future Patient Experts to have a good knowledge about the signs that rheumatism leave in their hands (deformities etc), so they will be able to teach better the medical students.

The last lecture we had for the day, was about Effective communication by Dr Theano Kalavana Assistant Professor in Clinical Communication Skills. She taught participants generally about the communication skills that a person must have for giving, lectures, presentations and even to communicate in everyday life. She also gave some tips to the participants for giving a good self-presentation and how to gain the audience.

The high light of the day was the Tour at the St George Medical School. It was a great opportunity to see the Universities establishments. The tour included: the reception, the Administration, the Library, the Lecture Rooms, the Faculty offices, the Clinical Skills Labs and a state-of-the-art Gross Anatomy / Neuroanatomy Lab.

Workshop day 2 26th of October at CYPLAR office

The second day of the Education took place at CYPLAR's office in Nicosia.

The education programme continued the second day with the Hands Joint Examinations – Practice with Mario’s, Andri’s, Ingrid’s, Maria’s guidance. It was the time for practice, as practice makes perfect 2 hours were spent for the practice.

Ingrid and Maria continue with the self-presentation. It was important for Patient Experts to know how they will present themselves, what is the limits in their presentation in order not to lose the audience but earn it.
After that the group was divided in sub groups of two and a role playing took place together with a self-presentation and hand and Wrist examination.

The last but not least was the Patient Expert demonstration by Ingrid Cederlund and Maria Nylander. They gave a demonstration of how the actual Patient Expert make the job, with the self-presentation the examination, the details of the everyday life of a patient with rheumatism and the obstacles they have.

The Education Program closed with an Evaluation of the two days’ workshop by the Participants.

In the night, a dinner with the entire participants took place on a nice Greek Tavern, and chat, to end the two days’ education with nice atmosphere and good motions.

Final day 27th of October at CYPLAR office

The morning of the last day of the program intended only to the people in charge of the program. Which means Andri, Marios, Maria, and Ingrid have a meeting at CYPLAR’s office in Nicosia to evaluate the program, decide about the next steps. It was decided that one day workshop will be organized for the people participated at the workshop and they should present what they have learned in order to get a diploma and the authority to teach the medical students.

Finally, the two patient experts Marios and Antri who have been trained in Sweden was examined by the Swedish patient experts and both was approved and became patient experts.

The visit in Cyprus was finished with a Sightseeing Tour.

On behalf of the Cyplar board and members we would like to thank the Swedish Patient organization and the two patient experts for the support of the implementation of the programme in Cyprus and also Eular for funding the project and for gave us this opportunity.