

EULAR
KNOWLEDGE TRANSFER PROGRAMME



ROMANIA - CYPRUS

**ROMANIAN LEAGUE AGAINST RHEUMATISM (LRR) - CYPRUS LEAGUE AGAINST
RHEUMATISM (CYPLAR)**

R E P O R T

July / October 2012

Knowledge Transfer Programme is an annual programme developed by EULAR Standing Committee of PARE (European League Against Rheumatism) which provides a defined grant to the educational visits programme. The programme is designed for patient organisations who wish to develop their skills and improve their knowledge by learning from the experience of other organisations in the EULAR network.

The steps followed by the Romanian league when applying for Knowledge Transfer Programme:

- Romanian League Against Rheumatism tracked down one major lack in its organizational process which is **the lack of a volunteerism programme**.
- The next step was to identify a teaching organization with a strong experience in having ongoing successful volunteer programmes. Having in mind a great presentation on Volunteerism held in 2009 on the occasion of a EULAR Congress, we consulted the Appendix of the Guidelines Knowledge Transfer Programme "The List of Skills and Needs in organisations" and we identified Cyprus League as a potential teaching organisation.
- We received a positive answer to our learning request and together with their response letter we sent the Application Form and the forecasted Budget Form (filled in according to the Knowledge Transfer Programme Guidelines) to EULAR secretariat (to Mr. Florian Klett). We found the form, the Guidelines and all other necessary information and documents on EULAR's website:

http://www.eular.org/index.cfm?framePage=/pare_educational_visits.cfm

The project was approved and **according to the application:**

- The teaching organisation was CYPRUS LEAGUE AGAINST RHEUMATISM (CYPLAR)
- The learning organisation was ROMANIAN LEAGUE AGAINST RHEUMATISM (LRR)
- The project was divided into 2 phases: the 3 days visit of the Romanian league's task force at Cyplar's headquarters in July 2012 and the 3 days visit of the Cyplar's delegates at LRR's headquarters in October 2012.
- An amount of 70% of the total project's costs was sent to the Romanian League in order to start launching and developing the project;
- The report (containing a detailed presentation of the activities rolled-on during the project and a next-step strategy) and the financial documents were to be sent to EULAR secretariat after the close-up of the project in order to be refunded with the 30% of the funds.

The general/specific objective of this educational exchange visit was to gain the appropriate knowledge from the Cyprus League against Rheumatism regarding the ability to organize ourselves in a more efficient way and hold an efficacious volunteering database by applying the volunteering strategy of Cyprus League (recruitment policy, motivation a.s.o.).

- I. **Within the first phase** of the project, the educational visit of the Romanian task force took place in **Nicosia, Cyprus from 9 - 12 July 2012**.

Romanian delegation included Codruta Zabalan - Romanian League's Vice President and Corina Stefan - member of the Romanian League. The presentation and the on-going interactive discussions were led by Mr. Marios Kouloumas, the president of Cyplar and Miss Persefoni Markidou, Psychosocial Support Officer. They participated to all the discussions during the whole 3 days and supported us, answering to all our questions and giving all the necessary details and explanations in order to have the best understanding of the presentations.

The first day focused on analyzing the organizational structure of the Cyprus league in terms of administrative, membership, executive board, public relations, social aspects, fundraising, campaigns, the relations with third parties.

We learned about "*Who is Cyplar*", their aims and objectives, their members and memberships, their board, directorate and leading management,



we learned about their programmes which are structured on five domains:

A. *Psychosocial Support* (structured on: 1-Personal and Group Support, 2-Support, Information, Education and Creative Occupation Center, 3-Encouragement and Support of the Young People with Rheumatism for the Creation of the Family Program, 4-Financial Help Program)

B. *Volunteer's Body*

C. *Information, Prevention Program and Educating Program*

- we were very much impressed with the Annual Week for Rheumatism because everybody connects now that week in May with fighting against rheumatism;
- the idea of handing out pamphlets is a very creative one and can attract many people;
- also regarding media as the 4th state power is a wise thing to do because this is the best way of raising awareness of rheumatic diseases.

D. *Rehabilitation Services*, classified in 4 programs: Physiotherapy Education Program, Occupational Therapy Education Program, Physiotherapy /Home Care Program, Occupational Therapy / Adjustment of the Work and Living space Program

Another innovative idea is having paraffin treatments in the exact location where their headquarter is and the offer is well appreciated among patients.

- E. *Fundraising*, focused on organizing different events, on sponsors and on member subscription (organizing events with entrance tickets and lottery tickets and theatrical shows premiers are other 2 ideas which can lead to a viable way of raising money, of catching media attention and of strengthening the relations between the League and its members)



After lunch, the second part of the day focused on the presentation of Ms. Roulla Pitsillidou, the vice-president of Cyplar, who is the mentor of **the Creation and Support Day Centre**, a centre that gives patients the opportunity through a diversity of techniques to find the courage to come out of their homes and meet new people, to socialize, to share experiences and to overcome numerous fears that arise due to the difficulties that they experience from suffering from this disease. The variety of activities offered by the Centre (medical, nutritional, physiotherapy; ergo-therapy, artistic and creative workshops of drawing, hagiography, silk drawing, cooking and make-up, movies, theatres, excursions, music concerts, board games etc.) are supported by self-supported teams classified on 6 groups: Children & Parents, Lupus, Scleroderma, Spondylitis, Youth and Fibromyalgia.

In the evening Cyplar organized 2 events meant to strengthen the relations between Cyplar league and Romanian League (focused on knowing the natives premises of Cyplar and the people who make everything possible, the members of the Cyplar league): a sightseeing tour of the Nicosia Centre and a welcome dinner at a Traditional Tavern with national dishes and songs. A very welcoming atmosphere that made ourselves at home.



The second day and the third day focused entirely on **the Volunteers Programme** of Cyplar. Mr. Michael Lakatamitis, the coordinator of volunteers in Cyplar organization made a comprehensive presentation of their program for volunteers. Also **The Cyprus Coordination Council of Volunteerism**, which is a governmental body and is founded by the Government, presented us their **“Educational scheme for volunteers”**.

We learned about the aims and objectives of such a programme, motivation, recruiting and managing volunteers, training volunteers, placing, monitoring, supporting, motivating and evaluating volunteers.

The second part of the day was used to discuss **the next steps**. We asked for the helping materials (the presentations, the Guidelines and the Volunteer Code of Cyplar) in order to translate them and tailor them to our legislation and needs and we started to chart **the first draft of the Action Plan of implementing the volunteer project in Romania**.

II. Within the second phase of the project, the educational visit of the Cyprus task force took place in **Bucharest, Romania, 25 - 27 October 2012**.

Cyprus delegation included Marios Kouloumas - Cyprus League's President and Michael Lakatamitis - volunteers' head coordinator in Cyprus League.

The specific objectives of this visit were to support Romanian League against Rheumatism in raising awareness on the great benefits resulting from working with volunteers and to also support our first attempt of raising volunteers and developing a volunteering strategy.

Being here on the occasion of Romanian National Congress of Rheumatology made a huge difference and helped our voice to be heard within the Romanian HPs community and also the Romanian Society of Rheumatologists.

The first day the programme started with **introducing Romanian League against Rheumatism** to our guests (presenting our headquarters, our administrative structure and our current activities) and **“a grand tour” of Rheumatic Diseases Centre “Dr. Ion Stoia”** (that hosts our headquarters). The centre's **history** was presented first by Ms. Vasilica Greceanu (a member of our secretariat), then Ms. Dana Dombi (head of management department) continued with the presentation of the **road a patient needs to take in order to access treatment** and took us on tour of **inpatient and outpatient hospitalization department, radiology, blood tests laboratory, immunology desk, physiotherapy department and kineto-therapy department**.



The next step was to assist to our league's first meeting with an official representative of "**Volum Federation**" - an association working closely with National Body of Volunteers.

At the end of the day we took part to the **Grand Opening of the XIX-th Romanian Congress in Rheumatology, which took place at the Romanian National Art Museum.** The Congress was preceded by the first South-East European postgraduate course in Rheumatology for Adult and Child.

The next day was dedicated entirely to the National Congress, where besides the Scientific Programme, the Posters' session and the symposia, there were parallel sessions with the patients (mediated by Romanian League Against Rheumatism) and Romanian Society of Medical Partners in Rheumatology (the Society was established this year and integrates nurses from all over the country; its first major action was to become a member of EULAR and to hold their first meeting during the congress). The common sessions for patients and nurses offered topics like:

- **"Assistance in Rheumatology: Rheumatology Nurse - a communication bridge with patients and patient leagues"**
- **"Rheumatic Treatment care for patients - specific tailored needs"**

President **Marios Kouloumas** held the presentation on ULOs - **"User Led Organizations - existence recommendations and practices"** in order to present the great need of becoming a user-led organization and the benefits of being one in the future, among which I shall mention the patient empowerment, higher influence on decision-making process, increased professionalism, credibility and accountability and greater control on the patients' rights being respected and on patients' needs being achieved. After the congress people addresses the league in order to find out more on this subject.

Ms. Codruta Zabalan (on behalf of Romanian League) held 2 presentations **on the topic of better communication and collaboration with nurses and health professionals.** The presentation **"Partners in Treatment - Companion Guide for the management of Rheumatoid Arthritis"** was extremely well received and I was already offered support by one nurse and 2 kineo-therapists who wanted to get involved in future LRR activities. Their enthusiasm was raised by Mr. Michael Lakatamitis who, on behalf of Cyprus League, presented **"Volunteerism in patient leagues - a complementary activity in the health care of rheumatic patients".**

The day ended with a symposium on biologic treatment and dinner at Bragadiru Palace, an 1894 historic building.



The day of 27 October was dedicated to strengthening bonds between the two leagues, by organizing a social-touristic visit at Sinaia Mountain Resort in Prahova County, where members of both leagues visited **Sinaia Monastery** (named after the great Sinai Monastery on Mount Sinai; the monastery gave its name to the nearby town of Sinaia) and **Peles Castle** (considered by many one of the most beautiful castles in all Europe)

The day ended with a lunch celebration of our guests and birthday of one of Romanian League's member.



As a conclusion of the Educational visit Romanian League against Rheumatism became aware of the great benefits a volunteer programme implementation within our league could have. We became aware of the fact that Volunteers are one of the most important aspects of a Non-Governmental Organization and they could fill in the gaps of the needs that NGOs have by providing services and helping in a professional way.

In order to work effectively with volunteers we need to have a successful Action Plan on volunteerism first. Please see below the next steps:

Action Plan of implementing the volunteer project in Romania

- Organising the task-force to deal with implementing Volunteer Programme in Romania
- Discuss the outcomes of the Edu Visit Programme
- Start our National Programme for Volunteers by drafting the aims and objectives of such a programme
- Translating in Romanian language the materials/documents given by Cyprus League (“Volunteers Corps Program – operational guidelines”, “Volunteer Code”, “Leaflet for recruiting volunteers - motivating people to become volunteers”)
- Drafting “Romanian Guidelines in working with volunteers”
- Starting the collaboration process with the National Volunteer Body in Romania “Pro Vobis” and Association “Federatia Volum”
- Organising training sessions
- Drafting our own documents to work with (adapted on national needs and cultural issues): Application Form, Information Pack for recruiting volunteers, Volunteer Code, Volunteer Agreement, Diplomas, Certificates, Thank-you letters, Reference letter, Evaluation Form of the Program/Project/Volunteer Corps
- Create a data-base for volunteers – “Volunteer Register”
- Organising Volunteers in Groups and appointing a Volunteer Corps Coordinator
- Initiate short-term strategic projects and long-term strategy involving volunteers
- Monitor and evaluate programme and projects