

EULAR KNOWLEDGE EXCHANGE PROGRAMME BETWEEN BOPRD AND CYPLAR



BOPRD – Bulgarian organization for people with rheumatic diseases



CYPLAR – Cyprus league against rheumatism

REPORT

March/October 2014

INTRODUCTION

Every year, EULAR provides a defined grant to its knowledge transfer programme. The programme is designed for patient organizations who wish to improve their skills by learning from the experience of other organizations in the EULAR network. This is mainly done through visiting an organization in another country.

GENERAL

BOPRD is a young organization and it is extremely valuable to learn and gain knowledge from very well developed and professional organizations. Considering the achievements and activities of CYPLAR, presented during the PARE Conferences and EULAR congress, we, the representatives of BOPRD decided that it would be good if CYPLAR shared their experience with us.

During The Autumn Pare conference in Zurich, representatives of the Bulgarian organization for people with RMDs and Marios Kouloumas, the president of CYPRUS LEAGUE AGAINST RHEUMATISM (CYPLAR) discussed the opportunity to apply for the knowledge exchange program, funded annually by EULAR.

The general specific aims of the educational exchange visit between BOPRD and CYPLAR was to gain the appropriate knowledge from the experience of the Cyprus League in:

- Fundraising and working with sponsors
- How to run a professional organization

The project was approved and according to the application:

- The teaching organization was CYPRUS LEAGUE AGAINST RHEUMATISM (CYPLAR)
- The learning organization was BULGARIAN ORGANIZATION FOR PEOPLE WITH RHEUMATIC DISEASES (BOPRD)

The educational programme consisted of 3 main phases:

1) Visit of BOPRD representatives in Cyprus and discussing the following topics:

Fundraising

- How to organise fundraising events
- How to communicate with sponsors - not only with pharmaceutical companies

Developing a successful organisation

- How to make the organisation professional
- How to recruit new members

Summary of the discussed topics and action plan preparation

- making a short summary of what the representatives from BOPRD have learned
- development of a smart action plan

II) Follow up

- Implementation of the gained knowledge

III) Visit of the representatives of the Cyprus league against Rheumatism in Bulgaria

I. FIRST PHASE - VISIT OF BOPRD REPRESENTATIVES IN CYPRUS

The first step of the program took place on 25-28 March, 2014 in Nicosia, Cyprus. The representatives of BOPRD who visited CYPLAR were Boryana Boteva, vice president of BOPRD, Snezhana Bozhinova, coordinator of BOPRD and Zorka Bozhanina member of BOPRD. Representatives of CYPLAR who were the training team were Marios Kouloumas – president of the League, Persefoni Markidou – Psychologist, Kypriana Pangalou and Veli Koulouma

First day:

Sightseeing and Welcome Dinner.

Our hosts from CYPLAR welcomed us during the afternoon of the day of our arrival with a very exciting sightseeing tour and a pleasant welcome dinner with several members of CYPLAR.

Second Day:

The day was busy with a very inspiring program with presentations, talks and discussions at the CYPLAR office.

Overview and discussion of the programme

After the overview of the program we were asked to write down our expectations from the visit in the frame of the exchange program. Every one of the BOPRD's delegates wrote their expectations. They can be summarized as follows:

1. To learn the basics for good and productive communication with institutions, doctors, pharmaceutical companies, etc.
2. How to convince people with rheumatic diseases to become members of the organization where they can be supported.
3. To learn how to raise funds for developing our organization for instance to pay staff which will improve the management of activities.

CYPLAR – Structure, work and activities

Persefoni Markidou held presentations focused on: Information about CYPLAR, their aims and objectives, members and membership, memberships in other organizations, the structure of the league, executive board, their programs.

CYPLAR is a national organization established in 1984 by a small group of rheumatic patients for the provision of suitable medical treatment and support to Cypriot patients, so as to ensure in every way, their right for a good standard of living with

quality, dignity and respect from everyone. Today CYPLAR has 4300 members out of which 3400 are rheumatic patients. They have 3 offices in Nicosia, Larnaca and Limassol one in each city respectively with five paid staff members and 154 volunteers.

Members of the League are all adults suffering from rheumatic diseases and parents of underage sufferers. There are members who are not sufferers but who show strong support for the fulfillment of the goals of the League.

The board consists of 18 members and all are people who suffer from a rheumatic disease. They are elected every 2 years and work voluntarily.

The executive committee consists of the President, Vice President, General Secretary, General Treasurer, assistant general treasurer and General organizer.

Our hosts from CYPLAR shared in detail their main programs about:

A. Psychosocial Support - personal and group support; support, information, education and creative occupation center; encouragement and support of young people with rheumatism for the creation of the family program; financial help program

B. Volunteer's Body – recruiting volunteers, educating and motivating them

C. Information, Prevention Program and Educating Program – lectures, seminars, workshops, events (World arthritis day, Awareness week, etc.), self-management program, informative booklets, website, press conferences, etc.

D. Rehabilitation Services - Physiotherapy Education Program; Occupational Therapy Education Program; Physiotherapy /Home Care Program; Occupational Therapy / Adjustment of the Work and Living space Program; Treatment with Paraffin; Hydrotherapy Programme

E. Youth project

F. RMDs and work

G. Fundraising - Events (Christmas Tea, Theatrical Show); Sponsors; Member Subscriptions

All the information that was presented initiated a fruitful discussion where it was emphasized that the creation of every programme is initiated by the needs and problems of the patients such as the need for information or support. We were given a very good example for an awareness campaign – the Annual awareness week. Inspired by that, we decided that this great idea could be implemented in Bulgaria as well. Discussing CYPLAR's fundraising program that they shared with us we also decided to implement some of the ideas in our country.

Build a Professional Organisation

Another important topic that has been discussed was “how to build a professional organization“. The presentation by Marios Kouloumas gave us detailed information on the basics on how to establish a professional organization. The fundamental uses that have been discussed were strategic plan, business plan, organogram, structure and management of the organization.

In order to achieve the aims of the organization we have to develop a strategy plan. It is of great importance to have a vision and mission for the organization.

We learned that the vision statement should be broad enough to include all perspectives for an ideal world for people with RMDs. It should be understood and shared by the members and inspiring for the people involved.

The mission statements are similar to the vision statements - inspiring everybody to act. It should be a short statement – preferable in one sentence with what the organization is working to achieve.

We should define the objectives of the strategy plan, which should be **specifically** focused on achieving the mission and **smart** objectives – how much of what and by when it should be done. The objectives should be measurable, achievable, and relevant to the mission as well as properly timed.

A strategy on how we are going to achieve the objectives should be developed. Using our strategy with relevant actions we will meet our objectives. This is our action plan:

- What actions or changes will occur
- Who will carry out these changes
- By when they will take place, and for how long
- What resources (i.e., money, staff) are needed to carry out these changes
- Communication (who should know what?)

For good management of the organization an organizational chart has to be created. This is a diagram that shows the structure of the organization; relations between the staff; relation of one branch to another; relations between people within the organization. A job description should be developed and provide information about key management staff and their expertise.

Development of communication strategy is also of great importance for the professional organization. The communication strategy should

- outline the objective/goals of the communication,
- identify stakeholders,
- define key messages,
- identify potential communication methods
- obtain feedback on the strategy / evaluation procedures

Recruit members

After lunch we discussed the membership strategy and ways to recruit members and volunteers. In order to achieve this it would be important to have printed leaflets that present the role of the members of the organization as well as the volunteers. The procedure of becoming a member should be easy and simple. Every new member should receive a welcome letter and pack with information for the organization, newsletter, membership card, etc. A good idea for recruiting members is offering different kinds of incentives for members, such as reduced prices in various shops and services.

Presenting their database, CYPLAR has given us very important tips on how to manage our database with all members easily and effectively.

The membership strategy should include effective communication with members by different means – by meetings, letters, phone messages, etc. Engagement of the members is also of great importance. We should encourage them to help us to

achieve our overall organizational objectives. It is necessary to be sure that people understand what we do and to demonstrate the success of our work.

We should develop different programs and activities for our members to provide information, support, education, etc. and supply different services to them.

Third Day

The third day of our visit was focused on fundraising and communicating with partners and stakeholders. In the morning Kypriana Pagkalou presented different fundraising campaigns and activities of CYPLAR. In the afternoon Marios Kouloumas had a presentation on communication with partners.

Fundraising programme

Kypriana Pagkalou presented the Fundraising programme of CYPLAR. The aim of their program is to raise money for supporting the programmes and services of CYPLAR. She explained in detail the different sources of financial contribution.

We learned a lot of important tips and realized that fundraising is also branding the organization and marketing.

She shared with us their experience and present activities and events for fundraising. The idea for recycling plastic caps was really inspiring so we decided to organize the same campaign in Bulgaria.

The brilliant tradition of CYPLAR to organize the Annual awareness week impressed us. We intend to start organizing such an event where we are going to apply the multi sponsors funding.

There are different events that we can do in order to find new sponsors as well as to continue working with the existing ones. It is important to develop informative file portfolios of our activities; sending "Thank you" letters to the sponsors; meeting once a year (or more) with our sponsors in order to keep strong relation.

Communicate with Partners

After lunch we discussed the communication strategy. Marios Kouloumas led the presentation - discussion explaining to us some tools and techniques of communicating with partners, how to communicate and when to communicate.

In communication with partners there are many challenges like - being heard; being clear, being convincing and being effective.

Communication is important at any stage and field of our work – in managing projects or programs, in contacting and involving new partners, keeping those who are already involved, in raising awareness, etc.

When communication is by means of face-to-face meetings we should be well prepared which may include presentation of the organization with our objectives, activities, etc. In addition during the face-to-face meeting we should be able to listen actively and react creatively.

In written communication we should construct effective paragraphs to write clear sentences and use reader-friendly layout and designs.

When communicating with partners we should try to keep regular communication and keep them informed. In order to build a sustainable partnership we should be

transparent and have mutual respect. It is important to illustrate the mutual benefits of the partnership and to show the outcomes and the results of the partnership. And of course acknowledgement is of great importance.

Summary of the visit

At the end of the second day we summarized what we learned from our hosts from CYPLAR and developed our first action plan.

They asked us to read again our expectations, which were written at the beginning of our work meeting. We were happy as well as our hosts that this first phase of the program was fruitful and inspiring and our expectations were satisfied.



II. SECOND PROJECT PHASE

In the frame of the second project phase we started implementing the gained knowledge. We developed our first action plan and made the first steps to implement it. One of the main points in our action plan was raising public awareness about RMDs. In June, BOPRD and the Association for people with RA organised an awareness event, named “Hug me with your heart”. The aim of this event was to inform the public and the stakeholders about RMD’s and their impact on peoples’ daily life and activities, but also to show that people who suffer from RMD’s are talented and equal to the other members of the society. The event was quite successful and there were a lot of people who took part in it.

After the awareness-raising event, representatives of BOPRD and the Association for people with RA had a formal meeting with the director of the National Health Insurance fund. The discussed topics were connected with access to biological treatment and making the process of applying for biologics easier.

We started developing a project about the first awareness week for RMDs in Bulgaria.

We made the first steps in organising a fundraising campaign by recycling plastic caps. We prepared a poster and organised meetings with potential partners.

III. **THIRD PHASE** - visit of representatives from CYPLAR to Bulgaria.

The work meeting took place in Sofia, Bulgaria, 21-23 October 2014. CYPLAR's delegates were Marios Kouloumas and Veli Koulouma. Representatives of BOPRD were Boryana Boteva, Snezhana Bozhinova, Bozhidar Ivkov and Todor Petrov.

First day

Overview and discuss of the programme.

The programme of the work meeting was discussed and accepted.

Report of the educational visit in Cyprus

The basic draft of the first phase of the exchange programme – the visit in Cyprus was presented by Snezhana Bozhinova followed by a discussion of what should be included more, how it should be structured, etc.

Action plan: what has been implemented.

In this section we talked about what has been implemented after BOPRD's visit in Cyprus.

We briefly presented the draft project for the first awareness week about RMDs, which we named "**Let's talk about RMDs**".

We also mentioned the fundraising campaign for recycling plastic caps, which we named "**Small things are of great importance**".

BOPRD - Structure, work and activities

A presentation about BOPRD's structure and our activities was presented. After the presentation we had a discussion on particular issues, which will improve our present activities in the direction of becoming a professional organization. We were advised about our weaknesses and supported in our good initiatives by Marios Kouloumas.

Fundraising campaigns

In the frame of this section we discussed in detail the draft projects of the first awareness week "**Let's talk about RMDs**" and the campaign for recycling plastic caps "**Small things are of great importance**".

The first awareness week about RMDs is planned to take place every year in May. In 2015 it will be held during the week 11-17 May. We presented all the events planned for the week. With different events we are going to achieve our objectives for raising awareness, recruiting members, etc. One of the important things we intend to do during the first awareness week is to have an awareness booth in a public place.

We amended our draft to a comparatively final project with program, action plan and budget and it was presented at the meeting with sponsors on the next day.

Boryana Boteva presented the project for recycling of plastic caps “**Small things are of great importance**”. First steps for implementation of the project are already done. A poster was developed and printed already. The pilot phase of the project will take place in Plovdiv, where our partners will be two hospitals. We intend to issue a brochure which will provide information about assistive devices for people, who suffer from RMDs and about our campaign for recycling plastic caps. With the incomes from the campaign we intend to buy such devices for the members of BOPRD. There is lack of information about assistive devices in Bulgaria that is why we consider that such a brochure will be very helpful at one hand and on the other hand this is an easy way to make the project more popular.

In the evening we visited a traditional Bulgarian restaurant and had a lot of fun together.

Second day

Discussion on the development of the Strategy plan

We had a discussion for the period of the strategy plan and we agreed for it to be next year in 2015 as then there will be the election for a new board. This also makes the strategy plan more simple and easy for the beginning. We started to develop our strategy plan guided by our experienced colleague Marios Kouloumas. We defined our vision and mission as well as our objectives. Then according to our objectives we will start thinking for actions, which will be in accordance with our resources. The strategy plan which will be completed by the board of BOPRD will be printed as leaflets to be given to our members.

Meeting with sponsors

During the visit of our colleagues from CYPLAR a very important meeting with sponsors took place and we had the chance to present the project for the first awareness week about RMDs in Bulgaria. Representatives of three pharmaceutical companies attended the meeting, which was extremely successful and we agreed to follow up and to meet again in order to discuss details about sponsoring.

Membership strategy

We discussed the membership strategy with finding ways for effective communication with members by different means according to our possibilities at the beginning. We discussed the engagement of the members which is of great importance and

establishing easy way for membership as the present one has some weaknesses. We should encourage them to help us to achieve our overall organisational objectives.

We should develop different programs and activities for our members to provide information, support, education, etc. and supply different services to them.

How to recruit members

This topic was discussed at our visit in Cyprus and we summarized the important items. We spoke in particular about the possibility to recruit members during the forthcoming events in 2015. A great opportunity for that will be the stand we are planning to have in a public place during the First awareness week in May 2015. We are planning to issue and disseminate leaflets for recruiting members. These leaflets will contain information about BOPRD and its activities and the other one will contain information about the incentives that the organization provides to all members

Communication strategy

When communicating with partners we should try to keep regular communication and keeping them informed in order to build a sustainable partnership. We should be transparent and have mutual respect. It is important to illustrate the mutual benefits of the partnership and show the outcomes and the results of the partnership. And of course acknowledgement is of great importance.

Third day

Discussion on the preparation of the final report

We summarized what we learned and started to implement and talked about preparation of the final report and the financial report to EULAR. We developed the **Action plan after the visit**

- Finalize the report and also the financial report for the knowledge exchange program
- Develop an action plan for the first Awareness week for RMDs
- Develop an informational leaflet about the first awareness week and all activities during this week
- Further development of the fundraising campaign by recycling plastic caps
- Developing an informative leaflet about the recycling campaign
- Developing a leaflet with the strategy plan
- Develop membership and communication plan
- Develop a leaflet about BOPRD and our activities
- Develop a leaflet for the rights of people with RMDs in Bulgaria



CONCLUSION

This knowledge exchange program was very fruitful and useful for the members of the BOPRD in our striving to develop a professional organization. This will benefit all our members and people with rheumatic diseases in general.

BOPRD wants to thank our friends from CYPLAR for their support and devotion. After this program we are very inspired to continue our work.

BOPRD would also like to thank EULAR for providing the financial support and possibility for all this to happen.

Report has been prepared by:
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