

Knowledge Transfer Programme 2015

Poland-Switzerland

report

“*Knowledge Transfer Programme*” is a program realized as part of the European League Against Rheumatism (EULAR). It is aimed to exchange experience between societies of patients with rheumatic diseases in Europe. In March 2014 representatives of the Polish Rheuma Federation “REF” familiarized themselves with examples of good practice at Rheumaliga Schweiz (RLS) in Zurich, Bern and Lucerne as part of this project. Sources of information included reports from people involved in the Swiss League, materials in the Internet and materials printed for the League as well as observation of activities for patients.

What did we learn?

Self-organization, collaboration, volunteer activities provide real benefits and it can be demonstrated by achievements of Rheumaliga Schweiz (RLS) that was funded as a non-governmental organization in 1958 and included in the Standing Committee for Social Leagues of EULAR at that time.

The Swiss League is a network of independent organizations: 20 cantonal and 6 functional ones focused on patients with one disease: rheumatoid arthritis, systemic lupus erythematosus, ankylosing spondylitis, fibromyalgia, osteogenesis imperfecta, scleroderma. It is possible to visit websites of participating organizations from the RLS website.

The Main Board of the League includes 9 people elected for a 4-year period, including 3 physicians. The Board employs 24 office workers and it corresponds to 14 full-time positions.

MANAGEMENT

There have been attempts to find such a model of action that would not generate any losses that might lead to an organization failure in a long-term, but at the same time to be perceived as a user-led organization.

The Board’s rule is to set targets that are not extremely optimistic. In order to receive trust of different stakeholders it is important to realize tasks that have been contracted and projects in an efficient way.

In the period 2012-2017 the Board would like to meet the following targets: 1/ further improvement of products offered, 2/ social communication, 3/ collaboration with participating organizations.

Therefore, projects are gradually professionalized.

It is interesting to see that a management strategy prepared at the central level does not have to be reflected at the local level.

FUNDING

RLS has prepared a development strategy as well as plans and financial forecasts for the next 10 years. Its task is to double income in this period. Sources of income include, apart from donations and money from product sales, donations from governments, insurance societies, pharmaceutical companies, funds for individual projects of the foundation and other non-profit organizations as well as assignments by will.

After information bulletins regarding methods to assign assets by will to the RLS had been introduced, the mean value of assignment by will increased.

IMAGE, SOCIAL COMMUNICATION

The RLS image is aimed to draw common attention to rheumatic diseases. Despite the fact that rheumatic diseases are one of five of governmental priorities public opinion cannot perceive this problem. This target is divided into three tasks: 1/ information regarding rheumatic diseases for laymen 2/ providing information about the League activity to the public knowledge, 3/ presenting one's position in public media

The press division has 2 specialists and is involved in communication with defined target groups and it also assesses the efficacy of League activities based on number of participants, media coverage etc.

PROJECTS AND SERVICES

National courses. For many years the RLS has been involved in the education of coaches, instructors and physical therapists. Training sessions cover skeletal system practice, yoga, back exercises (*active backademy*), osteoporosis gym (*osteogym*), prophylactic sessions in water (*aquawell*) and therapeutic exercises in water (*aquacura*).



Representatives of the REF Federation have familiarized themselves with a range of courses at the initial meeting, and then they observed a group during activities in Biel where aqua exercises are

Aquacura in Biel

conducted as well as in Lucerne where balance exercises are conducted.

Instructors have groups of 8-12 subjects. Adults at the age of 50-60 are predominant. Sessions are usually held in early afternoon hours as it is the best time with regard to venue accessibility and rental prices.

The latest project that is co-funded by the health insurance system regards prevention of falls in the elderly, and will be aimed at 60 physical therapists.

Website. Since 2012 significant financial investments have been made to make a website more professional and to be ranked highly by Google. 2 specialists are employed for tasks related to the website and it corresponds to 1.5 full-time positions. One specialist is responsible for the content and the other for technical issues. Leaders of local organizations submit topics to be placed on the website. Online questionnaires are especially popular, and they included the following: “Do I suffer from osteoporosis?” or “What sport is the best for me?” The health professional section includes materials aimed at: instructors (exercises), social workers, pharmacists, medical assistants, general practitioners and rheumatology specialists. The website is in German, French and Italian.

Publishing series. 2-3 publications belonging to color-coded series are published each year. The blue series is targeted at patients, the green series regards prevention, and the yellow series presents more general content. The book entitled „*Alimentation*” has been published as part of the yellow series and has been translated into Polish. Books are distributed via an online shop, hospitals, specialized medical offices and during social events. Only some books are sold and the price is only to cover the publishing costs, e.g. “*Pain*”. When it was distributed in 2013 a



successful information action was performed on trams, and leaflets with an order form were distributed.

Currently, a decision has to be made whether books should be limited only to e-books.

“Alimentation” in Polish

Journals. “ForumR” is targeted at patients with rheumatic diseases, their family members and health professionals.. Its circulation is 39,500 copies and 56,000 readers. It is read mostly by women (90%); people at the age above 60 years (75%)

and patients with rheumatic diseases (85%). “ForumR” is distributed by organizations belonging to the League and medical offices.

Physicians invited by the publishing house are authors of texts that are further processed by a journalist specializing in health articles. In trilingual Switzerland translation fidelity is a problem.

In Zurich there is also “Info”, a journal for patients with RA published by an organization of such patients, Schweizerische Polyarthritiker-Vereinigung (SPV). Apart from yearly topics and latest news on the organization it also publishes extensive interviews with famous patients with RA, and recently there has been an interview with the Miss Switzerland. Similarly to “ForumR”, “Info” is published 4 times a year in three languages.



The organization for people with ankylosis spondylitis Schweizerische Vereinigung Morbus Bechterev in Zurich also publish an own journal named “Vertical”.

Polish delegation in SPV

Online shop. The strategy of this shop offering supportive equipment is to support changes in patients’ behavior with the help of ergotherapists. A device to protect joints and/or to facilitate force transmission is appropriately selected thanks to instructive sessions performed earlier.

The shop is managed by 4 people: product manager and ergotherapists. Its offer includes 337 articles classified depending on their indications: personal hygiene, clothes, kitchen, meal preparation, cleaning activities, health. The shop has 1,270 orders a month, and the mean order value is € 40. Hospitals, therapists (15% discount) and larger institutes are also ordering parties.

Actions. The Family Saturday and Action Week have approximately 200 participants every year, and these actions are held regularly.

A social campaign entitled “Attention - rheumatic diseases” and conducted with celebrities has wide coverage. In 2013 the topic included hands in rheumatic

diseases. There have been excellent posters of “Hands”; journals, newspapers and TV had information about the campaign. A culminating event was at the Main Station in Zurich and many people were attracted to the League stand. 2014 was the year of feet.

Thanks to staying there for a few days it was possible to understand a dual nature of processes of changes in a non-governmental organization in a well-developed European country.

Based on statements on the League as a non-profit organization it is possible to demonstrate significant effects of market relations. Therefore it is a quasi-company that is managed by professionals, predictable with regard to its economy, a company that invests, analyses its profits and employs employees.

CONCLUSION

This Knowledge Transfer Program was very useful and fruitful for Polish Rheuma Federation “REF” in our efforts to develop a professional umbrella organization. It will benefit all our members and people with rheumatic diseases and their relatives in general.

The book entitled „*Alimentation*” has been translated into Polish and has been published as a book (distributed free of charge during social events) and e-book (www.reuma.idn.org.pl).

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Program of visit 17th March 2014 – 21st March 2014

	Mon 17.3.	Tue 18.3.	Wed 19.3.	Thu 20.3.	Fri 21.3.
9.00-10.00			RLS Informations „publications“ <i>Katrin Bleil</i>	RLS Informations “living aids and webshop” <i>Monika Oberholzer</i> <i>Olivia Hagenbuch</i>	RLS Informations „communication“ <i>Monika Siber</i> <i>Erika Rösch</i>
10.00-11.00		Informations „Internet“ 10.30-12.00 <i>Patrick Frei</i>	RLS Informations „Management“ <i>Valérie Krafft</i>		RLS Last questions & goodbye <i>all</i>
11.00-12.00	11.50 Arrival				
12.00-13.00	Transfer to the hotel Check-in	Lunch with the team			
13.00-14.00					
14.00-15.00		BE Visit Rheumaliga Bern Participation at the course „Aquacura“ in Biel 16.25-16.55 and 17.00-17.30 h	SPV Visit Schweizerische Polyarthritiker Vereinigung	LU Visit Rheumaliga Luzern Participation at the course: 15.30-16.30 Balancegym 16.30-18.30 Osteogym	Transfer to the airport 17.15 h departure
15.00-16.00	Welcome-coffee at the Rheumaliga Schweiz Information about “national courses” <i>Martina Roffler</i>				
16.00-17.00					
17.00-18.00					
18.00-19.00				Networking dinner with Director of RLS Valerie Krafft	
19.00-20.00					



In RLS Office in Zurich

We would like to thank our friends from Suisse Rheumaliga for their support, patience and devoted time.

We thank also EULAR for possibilities to realize our plans.