

Between volunteer and professional activities – a Swiss example of practice for health promotion in rheumatic diseases

Introduction

Knowledge Transfer Programme is a programme carried out as part of the European League Against Rheumatism (EULAR). It is aimed at exchanging experience between societies of patients with rheumatic diseases in Europe. As part of this project, in March 2014 representatives of the Polish Rheuma Federation “REF” [1] familiarized themselves with examples of good practice at Rheumaliga Schweiz (RLS) in Zurich, Bern and Lucerne (photo 1). Sources of information for this paper included reports from people involved in the Swiss League, materials on the Internet [2] and materials printed for the League as well as observation of activities for patients.

The welfare of Swiss citizens when calculated per adult is the highest worldwide. The health expenditure is approximately 11% of GDP and is similar to that observed in Germany or France (in Poland it is 6.9%) [3]. The life expectancy for Swiss men is 80.5 years, for Swiss women 85.0 years (in Poland the values are 72.4 years and 80.9 years, respectively) [4].

As many as 34% of the Swiss are socially active (volunteer activity). In Poland material welfare increase is not associated with an increase of the social capital defined as: activities for the local community, participation in election, optional meetings, positive attitude to democracy, membership in organizations and functions [5]. Self-organization, collaboration, and volunteer activities provide real benefits, and this can be demonstrated by the achievements of Rheumaliga Schweiz (RLS), which was funded as a non-governmental organization in 1958 and included in the Standing Committee for Social Leagues of EULAR at that time.

Methods of work

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 organization failure in the long term, but at the same time to be perceived as a user-led organization, and this is emphasized by the League slogan “Our action – your mobility”. The Board’s rule is to set targets that are not extremely optimistic. In order to obtain the trust of different stakeholders, it is important to efficiently fulfil contracted tasks and projects.

In the period 2012–2017 the Board aims to meet the following targets: 1) fur-



Photo 1. In RLS Office in Zurich – Polish representatives together with Swiss team.

ther improvement of products offered, 2) social communication, 3) collaboration with participating organizations. Therefore, projects are gradually professionalized.

Funding

Rheumaliga Schweiz has prepared a development strategy as well as plans and financial forecasts for the next 10 years. Its task is to double its income in this period. Sources of income include, apart from 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 at drawing common attention to rheumatic diseases. Despite the fact that rheumatic diseases are one of five 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's activity to the public knowledge, 3) presenting one's position in public media.

The League benefits from a possibility to place free advertisements in promotion spots that have not been sold, as non-profit organizations are allowed to do that.

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

Projects and services, namely products

The Office Director, Valérie Krafft, claims that the RLS has very good products that can be offered to recipients without hesitation.

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*) (Photo 2).

Representatives of the REF Federation 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 conducted as well as in Lucerne where balance exercises are conducted.

Instructors have groups of 8–12 subjects. Adults aged 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 concerns 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 the website more professional and to be ranked highly by Google. Two 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 pop-



Photo 2. Aquagym in Biel.

ular, and they included the following: “Do I suffer from osteoporosis?” and “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. Two to three publications belonging to colour-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. A 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.

Online shop. The strategy of this shop offering supportive equipment is to support changes in patients' behaviour. 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: a product manager and ergotherapists. Its offer includes 337 articles classified depending on their indications: personal hygiene, clothes, kitchen, meal preparation, cleaning activities, health. In 2014 the shop had 1,270 orders a month, and the mean order value was €40. Hospitals, therapists (15% discount) and larger institutes are also ordering parties.

Journals. *ForumR* is targeted at patients with rheumatic diseases, their family members and health professionals. Its circulation is 39,500 copies, with 56,000 readers. It is read mostly by women (90%), people aged over 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 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 Bechterew in Zurich also publish their own journal, named *Vertical*.

Actions. The Family Saturday and Action Week have nearly 2000 participants every year, and these actions are held regularly.

A yearly campaign is conducted with celebrities and has wide media coverage. In 2013 the main focus was on hand problems in rheumatic diseases. Excellent strong visuals were created and widely used in journals and newsletters. Also TV received information about the campaign and reported about it. 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.

Summary

As a result of staying there for a few days, the authors could acquire knowledge about the dual nature of processes of changes in a non-governmental organization in a well-developed European country.

For 10 years the RLS has been introducing changes consistent with the full bureaucratic background [6]. As a result the RLS was professionalized. Thanks to a higher reputation and specialization, it is possible to obtain excellent market results.

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.

The Swiss League incorporates apparent contradictions, such as structural dualism – field and functional organizations, dependency dualism – a set hierarchy only partially subordinates lower levels to higher management levels, dualism of the main objective – a non-governmental organization and a professional organization at the same time, a company that brings profits and a non-profit organization at the same time, dualism of its social role – a commercial company or *user-led* organization, multilingualism and sensation of local autonomy. Old habits smoothly change into new habits, old expression measures and actions change into new methods of communication with society, creating new demands, and new management methods prevail.

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