

NEWS

TWENTIETH ANNIVERSARY OF THE CROATIAN LEAGUE AGAINST RHEUMATISM

The Croatian League Against Rheumatism (League) is the most numerous nonprofit association gathering at the national level patients with rheumatic diseases, specialist physicians and other healthcare workers involved in the treatment and rehabilitation of rheumatic patients.

The League was founded on November 14, 1992 in Varaždinske Toplice as a legal successor of the Zagreb Society of Rheumatic Patients that had been active from 1982. The League foundation was initiated by Professor Ivo Jajić (1932-2010), originator of the idea of laymen association of rheumatic patients in our country. Besides Professor Jajić, the Steering Committee consisted of Želimir Vukosav, dipl. eng., Tibor Littvay, MS, and Tonči Buljanović, grad. iur.; subsequently, Professor Božidar Ćurković, Professor Nataša Delimar, Head Doctor Goran Ivanišević, Head Doctor Ladislav Krapac, Head Doctor Ante Luetić, Head Doctor Željko Ostrogović and Head Doctor Ljubo Suton joined the Committee. From these modest beginnings, owing to the enthusiasm of the initiators and all those that joined them with time, the League has grown into a respectable association with about 5500 members in 14 county branches.

Musculoskeletal diseases and conditions are the major cause of long-term pain and disability (according to health burden of the disease). In Europe, 20% to 30% of adults suffer from musculoskeletal pain at the time, two of five individuals with musculoskeletal problems are limited in their activities and musculoskeletal/rheumatic diseases and problems account for up to 60% of the causes of premature retirement. Therefore, the main tasks of the League are socio-educational and promoting activities. Health education of the population, in particular patients with rheu-

matic diseases, about the causes, symptoms, preventive measures, treatment and rehabilitation is aimed at upgrading the quality of life, prolonging their work ability and preventing or at least delaying disability of the population at risk. According to the League statutes, its tasks include providing legal advice, and if possible direct financial and working assistance in adapting the patient's home, organizing rehabilitation, supplying aids and drugs, although it is rarely feasible due to shortage of resources. The League advocates education of health professionals and scientific research through team work with active patient participation.

The League has four committees for economic-promoting, legal, publishing and social-humanitarian activities, and five expert sections for inflammatory rheumatic diseases, degenerative rheumatic diseases, metabolic rheumatic diseases, extra-articular rheumatism and prevention of locomotor system diseases.

Since its foundation, the League's seat is at University Department of Rheumatology, Physical Medicine and Rehabilitation, Sestre milosrdnice University Hospital Center in Zagreb. Professor Ivo Jajić was the first League chairman, followed by Tomislav Nemčić, MD from 2001, and currently Professor Simeon Grazio since 2009. Zvonimir Barišić, grad. eng., is the League co-chairman, long-standing chairman of the Committee for Economic-Promoting Activities, graphic designer of the League printed materials and website. Frane Grubišić, MS, is the League secretary, and Želimir Vukosav, grad. eng., treasurer, long-standing former secretary and the 'good spirit' of the League.

The League is member of the following international associations: European League Against

Rheumatism (EULAR), Ankylosing Spondylitis International Federation (ASIF), and International Osteoporosis Foundation (IOF).

The League has been engaged in various activities aimed at performing its tasks successfully. These include organization of numerous popular lectures and presentations for patients and all those interested in all League branches. The League is one of the initiators of the Bone and Joint Decade National Committee; in the past few years, the activities were especially intensified in the month of October when the Decade activities take place. On the occasion of the World Day of Osteoporosis, ultrasound densitometry measurements were first performed in Zagreb, followed by some county centers (e.g., Split, Rijeka, Osijek, Pula and Slavonski Brod). Those interested in the examination filled in the screening test on osteoporosis and were given advice on additional workup or preventive measures and treatment of osteoporosis. Respective lectures and presentations were also held on the World Day of Arthritis and the World Day of the Spine. In addition, the League has been active through some projects conducted for more than a decade (e.g., Prevention, Early Detection and Treatment of Osteoporosis, and For Better Life of Rheumatics at the Istria County branch), and some other activities such as the presentation at the Day of Slavonia Forests in Našice. Since recently, so-called biologics or biological drugs and their availability to patients with the most severe forms of rheumatoid arthritis, psoriatic arthritis and ankylosing spondylitis have come into the focus of interest. In this respect, the League has taken steps in the scope of the Bone and Joint Decade, resulting in some breakthrough.

The League has established good collaboration with international associations, has taken part in the traditional autumn conference of the People with Arthritis and Rheumatism (PARE), Action Day of the Alliance Against Arthritis (AAA) and activities within the scope of the Bone and Joint Decade (e.g., annual conference of the network of national committees). On the Croatian League incentive, in October 2009, the Committee for Healthcare and Social Welfare of the Croatian Parliament had a special session entitled Bone and Joint Diseases as a Social Issue. At this session, the European Chart on the Work of Patients with Musculoskeletal Diseases was approved

on behalf of the Croatian Parliament. On April 17-18, 2010, the PARE Standing Committee held their meeting in Zagreb, and the Croatian League was their host and organizer of local activities during their stay here. In May 2011, the Working Wonders Exhibition presenting the fate of rheumatic patients and aimed at sensitizing the employers to include them in the working process, organized by the League in collaboration with EULAR and PARE, was held in the Museum of Arts and Crafts in Zagreb. The League was one of the founders of Agora, a network of rheumatic patient societies from Mediterranean countries (La Valletta, Malta, September 23-24, 2011). Frane Grubišić, MS, the League secretary, has been most active in these international activities. The crowning recognition to our League work and engagement in the frame of the international umbrella association of societies of rheumatic patients was the decision made at this year's Autumn Conference of the Societies of Rheumatic Patients held in Zürich on Zagreb as the venue of the next conference to be held in 2014.

In the scope of the Croatian Society of Rheumatology Congress 2011 in Cavtat, Section for Patient Societies was organized for the first time, where the League members took active part presenting the work of the League and their own experience in coping with rheumatic disease. At the 2012 Congress of the Croatian Society of Rheumatology, the League was the main organizer of the section dedicated to patient societies, with the topic of the Psychological-Psychiatric Aspects of Chronic Pain, which was accepted very well. The League has developed the first Croatian national standards for the treatment of patients with osteoarthritis and rheumatoid arthritis.

The county branches of the League are led by renowned professionals, with the exception of the Zagreb County branch that is led by a layman, which should be a preferred practice, while health professionals should take the role of consultants. Chairpersons of the branches are as follows: City of Zagreb – Head Doctor Zoja Gnjidić (former chairpersons were Professor Jadranka Morović-Vergles and Professor Simeon Grazio); Zagreb County – Vlasta Sršek-Cerkvenik, B.B.A.; Krapina-Zagorje County – Branko Markulinčić, MD (former chairman Ivan Šantek, MD); Međimurje County – Olga Novak, MD, MS; Istria County – Head Doctor Vlasta Ur-

ban Tripović; Primorje-Gorski Kotar County – Assist. Prof. Tatjana Kehler (former chairperson Dunja Barak-Smešny, MS); Split-Dalmatia County – Professor Tonko Vlasković; Zadar County – Neven Birkić, MD (former chairperson Ana Šoška Kosor, MD); Osijek-Baranja County – Mira Kadojić, MD, PhD; Karlovac County – Sonja Milanović, MD; Bjelovar-Bilogora County – Jasna Rudec, bacc. physioth. (former chairperson Sandra Ribarić-Bienenfeld, MD); Dubrovnik-Neretva County – Pero Kolić, MD and Šibenik-Knin County – Branka Birkić Plavčić, MD). The activities taken by Mr. Antun Jović, chairman of the Reuma Club from Našice deserve to be noted here.

Publishing the newsletter *Reuma*, formerly named *Reumatičar*, is perhaps the most visible activity of the League. At the beginning, the newsletter Editorial Board was headed by Professor Ivo Jajić, then Editors-in-Chief were Head Doctor Goran Ivanišević (1992) and Professor Božidar Čurković (1993-1997). Since 1998, Professor Simeon Grazio is Editor-in-Chief, and under his leadership the *Reuma* newsletter has been appearing regularly, its quality has been upgraded considerably, enriched by a modern graphic design (graphic design by Zvonimir Barišić, grad. eng.). From 500 copies in the mid-1990s, *Reuma* is now printed in 6000 copies, which are distributed by post free of charge to all League members, while the remaining copies are administered to patients during their treatment and rehabilitation at special hospitals for medical rehabilitation as well as in healthcare institutions where the professionals, League members are working.

The League has published 26 patient handbooks, some of them in several editions. These popular booklets deal with most important rheumatic diseases or topics that are common to all rheumatic patients. The following handbooks have appeared to date (in Croatian): Ivo Jajić: Neck Pain (with Goran Ivanišević as coauthor of the first edition); Ivo Jajić: Back Pain; Ivo Jajić: Rheumatoid Arthritis (with Goran Ivanišević as coauthor of the first edition); Ivo Jajić: Ankylosing Spondylitis (with Goran Ivanišević as coauthor of the first edition); Ivo Jajić and Zrinka Jajić: Psoriatic Arthritis; Ivo Jajić and Zrinka Jajić: Uric Arthritis (with Branka Oklobdžija as coauthor of the first edition); Zrinka Jajić and Ivo Jajić: Osteoporosis; Ivo Jajić and Zrinka Jajić: Osteoarthritis; Ladislav Kra-

pac: Hand Arthrosis; Vlasta Urban Tripović: Painful Shoulder; Jadranka Morović-Vergles and Ksenija Berdnik-Gortan: Systemic Lupus Erythematosus; Jadranka Morović-Vergles and Ksenija Berdnik-Gortan: Reactive Arthritis; Zrinka Jajić: Sjögren's Syndrome; Ivo Jajić: Polymyalgia Rheumatica; Simeon Grazio and Branimir Anić: Drugs Modifying the Course of Rheumatic Diseases; Branimir Anić and Simeon Grazio: Glucocorticoids in the Treatment of Inflammatory Rheumatic Diseases; Simeon Grazio and Tomislav Nemčić: Fibromyalgia; Zrinka Jajić: Algodystrophic Syndrome; Simeon Grazio and Frane Grubišić: Alternative and Complementary Treatment of Rheumatic Patients (with Diana Balen as coauthor of the second edition); Simeon Grazio and Mateja Znika: Guide to Safe Exercise for Patients with Rheumatic Diseases; Simeon Grazio: Carpal Tunnel Syndrome; Simeon Grazio and Branimir Anić: Raynaud's Syndrome; Simeon Grazio and Branimir Anić: Pain and Pain Killers in Rheumatology; Simeon Grazio and Mateja Znika: Physical Therapy in the Treatment of Musculoskeletal Pain; Simeon Grazio and Mateja Znika: How to Prevent and Treat Osteoporosis; and Tomislav Badel and Ladislav Krapac: Functional Disorders of the Masticatory System. The handbooks are distributed to the League members and other interested free of charge, and all are also available on the League website. Ivo Jajić and Zrinka Jajić have written a book entitled *Prevention of Back Pain and Neck Pain*, intended for patients.

Although all work in the League is performed on a voluntary basis, considerable financial resources are needed for its numerous activities, in particular printing the newsletter and handbooks. A minor part of the League income is collected from membership fees, while small resources were allocated on several occasions by the governmental and other institutions, with the exception of Istria County and the towns of Pula, Poreč, Zadar and Našice, where the respective League branches and clubs have been financed by local governments and/or companies. A major part of the resources needed for the League diverse activities is collected from commercials published in *Reuma* newsletter, and from donations and contracts with pharmaceutical companies and special hospitals for medical rehabilitation.

On the initiative of Mrs. Vlasta Sršek-Cerkvenik, the SUPRA support group was until recently active within the League frame. They performed their activities at the local government premises, usually in groups of 5 to 10 members and a number of supporting members. Members of the SUPRA support group used to gather three times a month with the aim to acquire the habit of performing medical gymnastics daily (adjusted to the grade of disease, living conditions and individual properties), healthy eating habits, using mobile phone and personal computer, and joining "social networking". Namely, our patients should become aware that, in spite of their disease, they can themselves influence their quality of life by modifying their lifestyle, adjusting it to the limits posed by the disease. Unfortunately, due to the lack of resources, this praiseworthy incentive had to be discontinued, temporarily we do hope.

What else do we intend to do? The League has been faced with great challenges considering the unfavorable financial situation, i.e. recession. One of the major goals is to increase the number of members and branches across the Croatian counties, whereby the current disproportion in branch memberships should be corrected. The activity of the League members should also be intensified, with special reference to patient engagement. We plan to intensify our educational activities in the form of lectures, presentations, round tables, etc., and to make the League activities more visible in mass media (radio, TV and internet). In addition, we plan to organize and widen practical group activities such as regular physical activities. Although it has already been achieved in some League

branches (e.g., Zadar and Našice), we are aware that it requires additional resources. The number of lectures for patients should be increased, premises for social gathering of patients with rheumatic diseases and other interested should be provided, and public actions to upgrade awareness of the locomotor system role in preserving overall health should be taken (e.g., hand grip measurement or screening for particular rheumatic diseases and impaired function of particular parts of the body). We will continue our activities in international organizations through our engagement in various committees, meetings, etc.

We plan to publish new thematic booklets and reprint some of previous, most sought after booklets. We want to continue issuing the Reuma newsletter if possible by financial resources, hopefully even at a higher frequency. We are very proud of our website (www.reuma.hr), where all information on the League activities, the League statutes, information on the Reuma newsletter and useful links are found, along with the printable League application form. Such a mode of presenting the knowledge of rheumatic diseases certainly contributes to better understanding and accepting the problems associated with these diseases in the society and its institutions. Therefore, the League will continue investing efforts in its activities and promotion of the rights of these patients, to the extent affordable by financial, political and other circumstances in our society.

Simeon Grazio
Chairman, Croatian League
Against Rheumatism