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International League of Associations for Rheumatology.

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Globalization of Rheumatology: Activities of ILAR. Think Global — Act Local



In 1997 a distinguished EULAR rheumatologist involved in the development of biologics asked somewhat ironically, “What is ILAR [International League of Associations for Rheumatology] doing?” Now, 3 years later, we are in a position to review ILAR’s activities in recent years and its plans for the future. The current ILAR Executive in its global mission statement outlined 5 areas of special interest: (1) confirming the importance of rheumatology as a specialty; (2) stimulating better education; (3) initiating and updating World Wide Web information on rheumatology; (4) continuing stimulation and support of transregional projects; and (5) tightening the links with WHO and other international health organizations. We will focus on these 5 mission issues.

1. CONFIRMING THE IMPORTANCE OF RHEUMATOLOGY AS A SPECIALTY

We have been privileged to witness the globalization of rheumatology. Regional congresses in Singapore 1997 (ILAR), Montreal, Canada 1998 (PANLAR), Glasgow, UK 1999 (EULAR), Cape Town, South Africa 1999 (AFLAR), Beijing, China 2000 (APLAR), and Nice, France 2000 (EULAR) have all been attended by rheumatologists from many parts of the world, and have followed the same formula, covering the latest developments in basic and clinical science.

Everywhere, although the pace of change varies, rheumatology is evolving from a specialty treating ill defined, supposedly incurable rheumatic syndromes to a diagnostic specialty akin to internal medicine, a specialty characterized by a diagnostic and multidisciplinary approach to musculoskeletal diseases. Although this phenomenon is global, there are still major local differences. In some countries in each regional league, rheumatology, orthopedics, and rehabilitation are not always clearly defined, causing confusion for both the medical community and the public. Some regions lack adequately trained rheumatologists or sufficient numbers to deal with the burden of rheumatic diseases. The migration of a proportion of the population from rural areas to overpopulated urban centers and the resulting “megacities” pose further enormous challenges to healthcare delivery in Africa, Asia, and South America.

Our heritage of a multidisciplinary, holistic, team approach to chronic rheumatic diseases is endangered everywhere in the world. Socioeconomic factors have been responsible for a radical transformation, which will be far more profound and will spread more quickly than any previous change. Not only has inpatient care largely moved to the outpatient setting, but the relation between primary and secondary care is changing. In the US and also in Europe managed care has become predominant. When it rains in Washington, drops fall in Paris and London.

We must anticipate that medicine will evolve from a profession into an industry. This creates a conflict between managers whose first consideration is value for money and doctors whose priority is optimal healthcare, irrespective of cost. Changes create challenges and opportunities for rheumatologists. Rheumatologists are not expensive and may save society a lot of money. They are unique in that they deal with diseases that are often misdiagnosed, poorly understood, and require treatments that often are complicated and of long duration. Most rheumatologists can, after taking a short history and conducting a physical examination, establish a diagnosis in patients who have often consulted multiple other health care providers at great expense.

Globalization may appear to be rather a mixed blessing, a threat no less than an opportunity. Therefore “act locally” is an important message. Rheumatology varies in each region and there are major differences in epidemiology of rheumatic disease. For example, acute rheumatic fever is still a problem in Eastern Europe, Russia, and developing countries, while HIV and tuberculosis related musculoskeletal problems and reactive arthritis are of major concern in Africa and parts of Asia.

The global good news is that we have effective new drugs for chronic rheumatic diseases such as rheumatoid arthritis (RA), osteoporosis, and osteoarthritis (OA). However, these drugs may widen the gap between rich and poor, between hope and despair, because they are expensive and not universally available. Even in developed countries strategies must be developed by rheumatologists to ensure that those in greatest need or who may benefit most are selected for treatment and not only those who can afford these treatments.

2. STIMULATING BETTER EDUCATION OF RHEUMATOLOGY — ILAR/UMER-2000 PROJECT

Throughout the world it is in medical schools where the process of improving rheumatological care can begin. Modern teaching methods can be used to foster enthusiasm among medical and other health professional students for dealing with musculoskeletal disorders.

The ILAR message that the high prevalence and major impact of rheumatic diseases are not reflected in the medical curriculum¹ has been “broadcast” globally at many regional and national congresses and workshops and also at the WHO level². This has produced results.

An obvious global phenomenon currently is that skills in history taking and examination in general and in the musculoskeletal examination in particular suffer from an over-reliance on tests. Medical school graduates have not been trained to solve problems and think critically.

Whether in urban or rural areas, in Asia, in Africa, in North or South America, or in Europe, rheumatologists are presented with many patients who have reached an irreversible stage of decline due to their gout, RA, infectious or noninfectious spondylitis, osteoporosis, or OA and so on. Many patients have never had a proper diagnosis or appropriate therapy and may only have been given corticosteroids. Many of these people could have had better quality of life and less disability, and this at a lower financial cost to society. General practitioners and health professionals working in the community, with even a minimum of skills and knowledge of musculoskeletal diseases, could have recognized diseases and referred patients earlier, thus avoiding disability and even death. Musculoskeletal symptoms are common in general practice and medical wards, but are often at best inadequately assessed or at worst, ignored. The omission of the skill of musculoskeletal system examination, in contrast to the almost universal inclusion of other “system” examinations, demands correction.

The message from ILAR to the rheumatology community is that early investment must be made in better education and increased research in medical faculties and health professional schools, which should lead to earlier referral to the specialist, more appropriate therapy and as a consequence better outcome for the patient, his family, and society. The dynamics of chronic musculoskeletal conditions in the aging population will generate an avalanche of costs, disability, and suffering³.

Many deans and other educators in medical and health professional schools are aware of changes in epidemiology due to aging and to the control of infectious diseases; they are aware of the enormous increase in knowledge as well as changes in medical practice, and feel obliged to change the curriculum. The rheumatological community has to appreciate this transition and take the present opportunity seriously. Rheumatology may help medical and health professional faculties provide better clinical education for

physicians and other health professionals in training because of our special place in medicine. We work in fields that overlap with other disciplines dealing with acute and chronic diseases. Also, our clinical diagnostic approach and knowledge of pathophysiological mechanisms involves immunology, genetics, inflammation, and metabolic bone disorders, as well as teamwork with other health professionals.

The promotion of UMER 2000 Undergraduate Medical Education in Rheumatology has already resulted in several achievements worldwide. Teaching the Teachers sessions have been organized at national and regional levels⁴, in some countries the teaching of rheumatology has been reexamined at the level of faculty deans, and core curricula for rheumatology teaching have been established. The American College of Rheumatology (ACR) has started a clinical educators program and a High Impact Rheumatology teaching program (HIR), and recently interactive education material was installed on the ILAR website⁵.

In Europe, USA, India, China, Thailand, Argentina, and many other countries, the UMER 2000 Project stimulated initiatives that should have an effect on rheumatology globally and locally.

3. INITIATING AND UPDATING WORLD WIDE WEB INFORMATION ON RHEUMATOLOGY

We believe that the creation and development of the ILAR website, with the expert assistance of our webmaster Ray Armstrong, has been one of the most successful and enduring achievements of ILAR during the current presidency⁶.

The spectrum of contacts between countries and cultures is growing rapidly. Population growth and advances in technology — in information technology, in telecommunication, and in air transport, to name only a few — are bringing the regions of the world ever closer together. Countries, regions, and entire continents are becoming interdependent and interactive. This is illustrated by the need to exchange the planned dates for international congresses through the Internet. A global market is emerging. Will this replace the local meetings of the past? Again, think global, act local. Although occurring perhaps less frequently than in the past, local meetings will continue to serve as a training school for communication of first reports by local young rheumatologists and scientists.

Through the Internet, knowledge is increasingly accessible at any place and at any time. Knowledge can now be applied and generated in countries in which there is no long tradition of an education system and where there are only a few rheumatologists. At the same time, the development of a rheumatology global network is intensifying the international competition among researchers and talented young people.

The collision of different cultures even in rheumatology is today a part of everyday life. The great variety of cultures

(in the practice of rheumatology and outlook of the subject) is not a burden; it should be a stimulus and enrichment. This worldwide network is our true substance and strength. The Internet will change our working habits and speed up communication. The Internet can reduce the knowledge and technology gap between remote areas and between developing and developed countries. Finally, the Internet will encourage more intelligent use of expensive resources by means of telemedicine, network rheumatology (rare cases), COPCORD studies (Community Oriented Program for Control of Rheumatic Diseases), and so on.

<http://www.ilar.org> is a source of information for rheumatologists, allied health professionals, medical students, and the general public. One of the virtues of the ILAR website is complete freedom from commercial support. As judged by the frequency with which it is already accessed, the ILAR website has become an important stopping off point for many "surfers." Within less than a year of being established, the site was receiving page hits at a rate of 1000 per day and the numbers are steadily increasing. A review article by Marilyn Larkin⁷ confirmed the importance and future prospects of the ILAR website.

We anticipate that in the future the global approach of ILAR, both through the website and by organizing worldwide conferences, will play a leading role. Successful worldwide educational videoconferences have been produced with ILAR collaboration in Washington (Rockpoint Broadcasting) and in London (ETM Broadcast).

4. CONTINUING STIMULATION AND SUPPORT OF TRANSREGIONAL PROJECTS

The ILAR task force "Outcome Measures for Arthritis Clinical Trials" (OMERACT) has been most active and productive, with a regional group created under the aegis of the ILAR Standing Committee for Clinical Studies and Epidemiology. This group brought together clinicians, epidemiologists, and representatives of the pharmaceutical industry and governmental registration organizations from all over the world to reach agreement using their specific OMERACT protocols. These international consensus conferences on outcome measures in rheumatology are prepared in advance, using the Internet for communication. Results of the outcome discussions are published in a timely fashion so that they can be submitted for ratification by ILAR to the WHO. The Cancun meeting in Mexico (1998) discussed outcome measures for SLE, ankylosing spondylitis, and OA, and the Toulouse meeting in France (2000) dealt with minimal clinically important differences in radiological outcomes and imaging as well as economics and safety of drugs.

A very good interaction was achieved on the drug safety model with regulatory authorities such as WHO, the US Food and Drug Administration, and the European equivalents. A health economic standard was agreed upon.

COPCORD studies initiated by ILAR and WHO and now under the umbrella of the Standing Committee on Epidemiology are active in many countries (India, Indonesia, Thailand, Vietnam, Bangladesh, China, Brazil, Chile, Mexico, Philippines). These COPCORD studies have already shown that in Asia musculoskeletal problems are as frequent in developing countries as in the developed world. These studies are of paramount importance for the collection of data to be delivered for the WHO Burden of Disease record. Despite the considerable impact of musculoskeletal diseases on the prevalence of disability and consumption of medical resources, rheumatic diseases are not even mentioned in the WHO Burden of Disease list. This trend of looking only at killing diseases is changing, but we have to provide the data on musculoskeletal diseases worldwide. Because of the aging of the population in Asia, India, China, and many developing countries, musculoskeletal diseases are becoming a major burden of disease.

The ILAR task force on reactive arthritis is a further example of thinking global and acting local in the Magreb countries of Northern Africa. Synovial fluid samples and synovial biopsies of reactive arthritis cases, which are common in these countries, are prospectively collected according to a protocol and forwarded to French, German, and US laboratories for examination, looking for bacterial markers using molecular techniques such as polymerase chain reaction. The studies are now well advanced and will be reported at the ILAR congress in Edmonton, Canada, in August 2001.

ILAR fellowships in clinical epidemiology of the rheumatic diseases for young rheumatologists include up to \$15,000 US matching funds (from the regional league, host country, host university, or other funds). Currently, students from Bulgaria, Tunis, and Kenya are studying in centers in America and the UK.

The ILAR Minimum Standards of Training in Rheumatologic Arthroscopy were ratified during the ILAR Executive Committee in Beijing, China. These had been prepared by an ILAR working group. The document is now available on www.ilar.org and will increase the quality of arthroscopy. Interest in arthroscopy is increasing as a relatively simple method of improving diagnosis and assessing response on treatment. Studies on synovial tissue obtained by arthroscopy in early disease are improving our understanding of the pathogenesis of inflammatory rheumatic diseases.

ILAR's global presence is further emphasized in its relationship with the pharmaceutical industry, in particular the Novartis/ILAR Rheumatology Prize (formerly the Ciba Geigy/ILAR Rheumatology Prize). This has been in existence since 1969 and is an award of distinction. Worldwide the Novartis/ILAR Rheumatology Prize is considered to be of immense prestige and scientific value to the world of medicine and to rheumatology in particular.

5. TIGHTENING THE LINKS WITH INTERNATIONAL ORGANIZATIONS — WHO, ARTHRITIS AND RHEUMATISM INTERNATIONAL, THE BONE AND JOINT DECADE

There have been many joint activities with WHO during the last 3 years. ILAR was involved in the production of a booklet on low back pain, and in the task force on a global strategy for osteoporosis, these being 2 major disorders of the musculoskeletal system with an important socioeconomic impact⁸.

January 16, 2000, was a day of historical importance. On this day the sixth WHO/ILAR task force meeting on rheumatic diseases was held in Geneva. This meeting reviewed a number of outcome measures for rheumatic diseases that had been developed over several years under the aegis of OMERACT (see above). The WHO/ILAR meeting formally endorsed these outcome measures and acknowledged them as the gold standard in these conditions. At the same meeting, a series of criteria for classification of rheumatic diseases were reviewed. These criteria had been established through discussions by a number of different organizations including ILAR, the ACR, and other groups. The meeting ratified these well recognized criteria as WHO/ILAR classification criteria and recommended their use in clinical and epidemiological studies.

It should be noted that classification criteria should be used not as diagnostic criteria, but for the purpose of classifying patients in studies. With the ratification of the preliminary criteria for the classification of juvenile idiopathic arthritis (JIA), a long semantic quarrel across the Atlantic Ocean will now be ended. All these new WHO/ILAR criteria will be submitted for publication in a rheumatology journal and also published at the ILAR website.

In collaboration with the Human Resources for Health (HRH) division of WHO, an editorial, "Changing medical education and medical practice," was published in the WHO Newsletter June 1998, on "effectively addressing common health concerns — the case of rheumatic diseases"². The newsletter has a large circulation (3000 copies) through their medical education network around the world.

The Bone and Joint Decade, another global initiative with actions locally with which ILAR has been associated from the start, was officially launched on January 13 in Geneva, in the presence of Dr. Gro Harlem Brundtland, Director-General of WHO. UN Secretary-General Kofi A. Annan endorsed this initiative with a declaration of support. The goals of the Decade are to improve the health related quality of life for people with musculoskeletal disorders throughout the world. The objective will be achieved by (1) raising awareness of the growing burden of musculoskeletal disorders on society; (2) empowering patients to make decisions about their care; (3) promoting cost-effective prevention and treatment; and (4) better understanding of the

causes of musculoskeletal disorders through research to improve prevention, diagnosis, treatment, and rehabilitation. To keep up the momentum, it is of the utmost importance that in each country rheumatologists endorse a Bone and Joint Decade national program and work together with orthopedic surgeons, back pain specialists, traumatologists, pediatricians, rehabilitation specialists, patients, and many others to make this program a success.

ILAR's policy of embracing all global initiatives relating to rheumatic diseases results in an opportunity for Arthritis and Rheumatism International (ARI), which represents the arthritis foundations and patient organizations. This organization is now working in collaboration with ILAR and its chairman is at present the chair of ILAR's Standing Committee on Social Agencies. ARI will organize its meeting together with ILAR at the Edmonton congress in 2001. Other organizations are negotiating collaboration with ILAR for the future.

WORLD ARTHRITIS DAY

Together everyone achieves more. From 2000 onwards, ILAR together with ARI has declared October 12 the Worldwide Arthritis Day. The leadership by ILAR at the global level (a position that is envied by some international professional organizations competing with each other) is ensured only because ILAR stands on the shoulders of the regional leagues (APLAR, AFLAR, EULAR, PANLAR). Their support guarantees that global thinking is implemented locally and that ideas from the grass roots can stream through up to the top in a noncompetitive way. The only thing that matters is that the burden of chronic rheumatic disease and its resulting disability will be reduced, and this can only be achieved by better education and more research in basic and applied science, so that the patient will have appropriate medical and holistic therapy before disability sets in. There are many positive new developments and rheumatology is flourishing both scientifically and therapeutically. We have a lot to offer to medical faculties and medical and health professional schools to make sure that the patient who needs and may profit from costly care will receive it. The medical marketplace is changing from inpatient to outpatient, managed care versus holistic care. Challenges create opportunities. Are we rheumatologists prepared for it?

All these global aspects are part of ILAR's International Congress in Edmonton, Canada, in August 2001. You are invited to bring along your views, your research, and your achievements in epidemiology and in the interdisciplinary approach by initiatives in the Bone and Joint Decade. Poster sessions with your local work will be well attended, and leading regional speakers will give state of the art lectures.

The faster the pace of aging of the world population, of technological development, and of discovery of life-saving biological therapies, the more crucial it is to ensure the

development of future generations of doctors acquainted with the diagnosis of bone and joint diseases. That is why we are concerned about the lack of interest shown by today's faculties of medicine in rheumatic diseases. There is at present a clear shortage of young people, clinicians, health professionals, and researchers.

Working together across all borders is essential. Global players are networked worldwide and here lies an enormous opportunity. Even if all technical requisites are met for a functional global rheumatology network, it can succeed only if people are willing to make it work. The diversity of countries and regions is a fact of life. Overcoming language and cultural and mental barriers is nothing new. This heritage is an advantage when it comes to working together across the borders of cultures and continents.

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