The Role of User Representation and Arthritis and Rheumatism International

ROBERT JOHNSTONE

ABSTRACT. Arthritis and Rheumatism International (ARi), founded in 1988, is an association of national lay organizations comprising mainly people whose lives are affected by arthritis and rheumatism. ARi's charter defines the organization's aims, including to raise awareness of the needs of people with arthritis/rheumatism, to improve the quality of their lives through education and self-management programs, and to support research into causes, management, prevention, and cure of arthritis. With the aid of a grant from the Pfizer Foundation in 2002, ARi has been able to further develop into a strong organization throughout the world, with a membership of 22 countries. Successful intitiatives include the People with Arthritis and Rheumatism in Europe Manifesto, which has served as a very effective focus for developing action plans, opening dialogues, building partnerships with other organizations, lobbying governments, and gaining media attention throughout Europe. The manifesto (website: www.PAREmanifesto.org) was developed by ARi working in conjunction with The International Organisation of Youth with Rheumatism and the EULAR Social League. These are examples of initiatives that ARi aims to promote on a global scale in the next few years. (J Rheumatol 2003;30 Suppl 67:59–61)

Key Indexing Terms:
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USER REPRESENTATION

As current President of Arthritis and Rheumatism International (ARi), I have a wide and varied background in health and educational concerns in the UK. This includes being a Trustee of the Long Term Medical Conditions Alliance, Vice Chair of the Disabled Living Centres Council, Vice Chair of the UK Public Health Association North West Branch, Member of the Department of Health Herbal Medicine Regulatory Working Group and the Department of Health Transition Advisory Board, Council Member of the Maharishi European Sidhaland Association, a 2001 Best Practice Award winner from the British Urban Regeneration Association.

What Is ARi?

ARi is an association of national lay organizations, whose members are principally people whose lives are affected by arthritis or rheumatism, and whose activities are volunteer-based. Membership of ARi is open to any organization accepted by the Council as being national, lay, and volunteer-based.

Officers of the association include Robert Johnstone as President, Kaarina Laine-Haiko of the Finnish Rheumatism Association as Vice President, and Armin U. Kuder of the Arthritis Foundation, USA, as Treasurer. Secretary General is Don L. Riggin, of the Arthritis Foundation, USA.

ARi has been in existence since 1988, when the organization was founded with 41 delegates from 28 national organizations who were attending the 40th anniversary meeting of the US Arthritis Foundation in Atlanta.

In subsequent years further international meetings were held with increasing numbers of delegates, and in 1996 a charter was signed at the first general assembly of ARi in Helsinki, Finland. The charter — the constitution of the organization — defined the aims and objectives of ARi:

- raising awareness
- improving life
- supporting research

As stated in our charter, ARi provides a forum for a worldwide exchange of knowledge and experiences between organizations concerned with arthritis and rheumatism. It aims to raise awareness of the needs of people with arthritis or rheumatism, improve the quality of those people's lives through education and self-management programs, and support research into the causes, management, prevention and cure of arthritis.

In addition, ARi aims to consult with, complement, and support where appropriate the work of related organizations such as the World Health Organization and the International League of Associations for Rheumatology. It will also assist developing countries in establishing patient-based organizations eligible for membership of the association, and raise funds to support activities and meet objectives of selected organizations.

From the International Organisation of Youth With Rheumatism and the EULAR Social League.

From Arthritis and Rheumatism International (ARi), UK.

R. Johnstone, President.

Address reprint requests to R. Johnstone, Arthritis and Rheumatism International, 14 Hazel Lane, Woodley Park, Skelmersdale, Lancashire WN8 6UN, UK. E-mail: robertjohnstone@onetel.net.uk

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Highlights of more recent activities include the Second General Assembly and 4th ARi Conference in 1998, where Per Aage Bjoerke was selected as President until 2001. As President, Mr. Bjoerke met with many organizations in developing the European Manifesto. By 2001, ARi enjoyed a membership of 22 countries, and began initial developments of an ARi website.

With the aid of a grant from the Pfizer Foundation in 2002, the ARi Council was able to further strengthen the organization throughout the world. This global growth offers many opportunities for ARi to pursue the goals of its charter in every country. An example of initiatives that may be successfully applied on a wider scale has been the experience in Europe.

Case Study: the PARE Manifesto, Europe

One hundred and three million Europeans are affected by arthritis. Yet despite it being the most common chronic disease of our time — and predicted to increase over the next 10 years — it is not positioned on the political health agenda of national governments or the European Commission. In a bid to change this, ARi joined with The International Organisation of Youth with Rheumatism and the European League Against Rheumatism Social Leagues to launch a manifesto that included a declaration of intent, outlining the aims of the organization, and 10 specific calls for action:

- Raise public awareness of arthritis
- Empower people with arthritis/rheumatism by funding user-led programs
- Involve people with arthritis/rheumatism in policy development
- Develop and recognize national and international organizations of people with arthritis/rheumatism
- Provide prompt and good quality health and community services
- Ensure doctor and health professional awareness of arthritis/rheumatism
- Involve people with arthritis/rheumatism in helping to determine relevant medical research priorities and budgets
- Expand research into the societal impacts of arthritis/rheumatism
- Strengthen laws and regulations
- Provide fully accessible education and training programs.

The People with Arthritis and Rheumatism in Europe Manifesto (PARE; website: http//www.PAREmanifesto.org), developed by a steering committee chaired by Richard Gutch of the London-based voluntary organization, Arthritis Care, was launched at the EULAR 2000 congress in Nice, with an exhibition and press conference attended by 50 European journalists.

The Manifesto provides a focus for developing action plans, opening dialogues, building partnerships with other organizations, lobbying governments and other groups, and gaining media attention.

Successes so far have included television interviews, a Manifesto exhibit at the European Parliament in Brussels, and a reception hosted by Madame Francoise Grosset (French member of the European Parliament/Chair, Intergroup on Pain) for members of the European Parliament, health attaches, and European Commission personnel. Thirty-seven of those attending signed to endorse the manifesto, with a further 31 requests for further information.

Members of the European Parliament have been invited to support the Manifesto by providing a written quote of support, by inviting Manifesto representatives to speak before appropriate intergroups, and by providing links to appropriate policy contacts at a national level.

The Steering Group's activities at the European level include lobbying at the European Parliament/Commission, and issuing a regular Manifesto newsletter. At the national level in Europe there have been many successes, with Manifesto activities driven in each country by representatives of PARE.

These representatives coordinate all Manifesto activities and liase with the Manifesto secretariat in Germany. They are able to prioritize Manifesto activities as appropriate for national needs, and seek partners and build alliances within their countries to support Manifesto activities.

Already a huge number of countries are involved in this Europe-wide initiative — Austria, Belgium, the Czech Republic, Denmark, Estonia, Finland, France, Germany, Great Britain, Greece, Hungary, Iceland, Ireland, Italy, Latvia, Lithuania, The Netherlands, Norway, Poland, Portugal, Russia, Slovenia, Spain, Sweden, Switzerland, Turkey, and Yugoslavia.

The Manifesto is now available in 16 languages, including French, English, Dutch, Hungarian, Portuguese, German, Polish, Slovenian, and Spanish. Translations for other languages are in progress.

Successes of European activities: In October 2001, the Austrian Rheumatism League presented the PARE Manifesto to Parliamentary President Dr. Heinz Fischer, at the Austrian Parliament in Vienna, with media present and with advance newspaper and television coverage.

The Latvian Rheumatism Association presented a Latvian translation of the Manifesto on International Arthritis Day, and invited association members to attend a presentation of the Manifesto, with medical aspects, patients' views, and information on foods and exercise.

Rheumatism leagues in Germany, Austria, and Switzerland joined forces to produce the Manifesto in German, with a single-page document and booklet.

The Hungarian League of Patients with Rheumatic Diseases is translating the Manifesto into Hungarian and German and will distribute it via their newsletter to their

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members, together with information about the League. This is seen as the first step towards the organization having its own patient magazine.

In Spain, the Manifesto has been translated into the 4 official languages, and in 2001 a successful media tour was conducted in the 4 provincial capital cities. A video has been produced, and articles on different aspects of the Manifesto have appeared in 4 issues of the Liga Reumatológica Española (LIRE) newsletter. LIRE's website has received many hits, notably from South America.

European Website

On 21 March, 2002 the website (http://www.PAREmanifesto.org) was launched at a press conference in Portugal. All PARE National Representatives were sent press kits for local adaptation and translation to gain media coverage for the website. This is an opportunity for a wide audience to gain access to the Manifesto, and to endorse it online.

Extending Global Activities

The European experience outlined above provides examples of the type of successful activities that ARi as a whole can extend throughout the world in the next few years, both in the countries where the organization is already established, and by helping to establish and support national organizations throughout the Third World.

Doctors, health professionals, and government officials should recognize the growing power of informed patients around the world and the increasing relevance of their contribution to the production of efficient and successful health care. People with arthritis have much to contribute to society nationally and globally and as an international alliance, ARi is in a prime position to hear the needs and direct the message of between 500 and 600 million people.

With your help and support we will do this.

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