

Bone and Joint Disease Around the World. The Japan Rheumatism Friendship Association

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ABSTRACT. The Japan Rheumatism Friendship Association (JRFA) was founded in 1960 and today has a membership of about 23,000, with 47 chapters across the country. We periodically conduct a survey of our membership for the Rheumatism White Paper, which we have been publishing since the JRFA was formed. The entire membership is surveyed every 5 years; surveys give an accurate picture of the current state of the disease and reflect the fundamental activities of the JRFA; they shed light on progress in developing effective measures against arthritis, and give people a better understanding of rheumatism. The survey is also a unique resource, for it canvasses a wide cross section of people with arthritis. In Japan, the Rheumatism White Paper is widely regarded as an authoritative source. The aims of the JRFA are to promote the accurate knowledge of RA to improve mutual friendship, and to work for the establishment and development of policies against RA disease. In this way, the JRFA seeks to advance the welfare of RA patients. In this article the activities of the JRFA are described. (J Rheumatol 2003;30 Suppl 67:48–49)

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JAPAN RHEUMATISM FRIENDSHIP ASSOCIATION

RHEUMATISM WHITE PAPER

JAPAN

The Japan Rheumatism Friendship Association (JRFA) was founded in 1960. Today it enjoys a membership of roughly 23,000, spanning a wide range of age groups from teenagers to people in their 80s; there are 47 chapters across the country.

The JRFA has conducted and published a periodic survey of its membership, the Rheumatism White Paper, since its founding more than 4 decades ago. These surveys, conducted every 5 years among our entire membership, are designed to provide an accurate picture of the current state of the disease. The survey reflects the fundamental activities of the JRFA; it facilitates the development of effective measures against rheumatoid arthritis (RA), and gives people a better understanding of the illness. The survey is also a unique resource, as it canvasses a broad cross section of afflicted individuals. In Japan, the Rheumatism White Paper is widely regarded as an authoritative source and is extensively used and cited by people in the medical community as well as in the government.

The aims of the JRFA are to promote correct knowledge of RA by deepening ties of friendship and cooperation, and to work for the establishment and development of counter-measures against RA disease. In this way, the JRFA seeks to advance the welfare of RA patients. To accomplish its goals, the JRFA:

1. Publishes a bulletin, entitled “Nagare,” 5 or 6 times a year
2. Holds annual general and general assembly meetings

3. Provides consultation services for recuperation and rehabilitation
4. Tests, introduces, and distributes self-help devices
5. Conducts an ongoing public relations campaign to enhance awareness of the symptoms of and facts on RA
6. Introduces and distributes books by specialists on RA
7. Undertakes miscellaneous projects

Among our recent activities, beginning last year a new Patient Partners Program was launched in Japan. Five of our JRFA members are now working as pioneer instructors in the program. The JRFA plans to fully cooperate as the program continues to expand. Also, a new health care network project has recently been started. A large number of groups and organizations with an active interest in health care issues work together by sharing issues, information, and solutions over the network.

Unfortunately, Japan lags far behind other countries in the approval of new drugs targeting rheumatism. Wonderful drugs such as cyclooxygenase-2 inhibitors and biological disease modifying antirheumatic drugs that have already been available for years in other countries are not yet permitted in Japan. Methotrexate was approved by the US Food and Drug Administration back in the mid-1980s, and was only finally approved for use in Japan 2 years ago by the Ministry of Health, Labour and Welfare, a lag of 11 years. Pain is the number one enemy of arthritis sufferers, but we still cannot use celecoxib, which was approved elsewhere some time ago as effective against pain and which has minimal gastrointestinal side effects. Meanwhile, we are stuck with traditional nonsteroidal antirheumatic drugs, although some 60% of our members complain that this class of drug causes severe gastrointestinal problems. The same

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story applies for new tumor necrosis factor-inhibiting drugs. The JRFA publishes information about clinical trials in our magazine "Nagare" to help recruit patients for enrollment. One of our prime objectives is for Japan to catch up with other countries in terms of which drugs are authorized, so that some of these promising new drugs can be made available to arthritis sufferers in Japan.

When asked what kind of developments they would most like to see in the area of rheumatology, the great majority of our members — some 85% — expressed the desire to see "the cause of rheumatism clarified, and a clear course of therapy established." Indeed, if this could be achieved, it would not be an exaggeration to say that we would have reached our end goal. Two years ago, after years of campaigning and lobbying by the JRFA and many other related groups, the long-awaited National Rheumatism-Allergy Center was established. This development was especially remarkable in light of the current strain on public finances accompanying the aging of Japanese society and the expanded role of the national health insurance organization. The Center plans to conduct epidemiological surveys via a nationwide network, develop new therapeutic methods, and support clinical trials of new drugs.

These efforts are sure to contribute to a better understanding of the causes of rheumatism, and to facilitate the establishment of clear-cut therapies and treatments. Getting the Center up and running has been one of the JRFA's key goals for many years, and the significance of the Ministry of Health, Labour and Welfare's decision to establish it should prove enormous.

I would like to add the following as our future issues.

1. To study the latest training and treatment methods and information related to patients on a global scale, and actively encourage the Japanese government to provide support in bringing both treatments and education in Japan up to international levels.
2. To create an open international communication network with other patient groups worldwide via the Internet and other media.
3. To take advantage of this International Conference as an opportunity to begin studying and examining methods of raising funds for administrative operations and other activities, and also as an opportunity to develop more effective ways to promote awareness of the JRFA's activities.