

# Bone and Joint Diseases Around the World. France: Rheumatoid Polyarthritis, Chronic Juvenile Idiopathic Arthritis, and Ankylosing Spondylitis. A Public Health Priority

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**ABSTRACT.** Since its creation, the Association française des Polyarthrites is doing everything possible to come to the aid of people with polyarthritic diseases and to help medical research make advances against this illness. Each year, with the help of sponsors, we organize a national information campaign with first-hand accounts and presentations by sufferers on radio and television stations, so that polyarthritis should be better understood by the general public. Last year, together with other associations, we asked the Minister of Health about the barriers to receiving innovative treatment for polyarthritis because of the cost. Because of this action, the Minister has made additional funds available so that more sufferers can benefit from new treatment. Recently, several associations dealing with chronic and serious inflammatory rheumatic illnesses who came together as an action group presented a text to the Minister of Health about the urgent need to make these illnesses a public health priority. Working sessions between the Minister, patient associations, and rheumatologists to consider how to implement a public health plan are in progress. (*J Rheumatol* 2003;30 Suppl 67:45–46)

*Key Indexing Terms:*

RHEUMATOID POLYARTHRITIS

ANKYLOSING SPONDYLITIS

CHRONIC JUVENILE IDIOPATHIC ARTHRITIS

Rheumatoid polyarthritis (RA), chronic juvenile idiopathic arthritis (JIA), and ankylosing spondylitis (AS) are chronic and serious inflammatory rheumatic illnesses (CSIRI) that are similar in a number of ways: clinical and immunogenetic characteristics, their difficult diagnosis and prognosis, level of pain, the heavy individual and group burden they cause, and their common therapeutic perspectives. They are unknown to the general public, who confuse them with degenerative rheumatism and musculoskeletal complaints linked to aging.

RA and chronic JIA are serious rheumatic illnesses that affect the entire body system; several hundreds of thousands of people in France are affected (from 200,000 to 600,000), particularly women. Onset of these illnesses can occur at any age, including early childhood. Positive AS affects more than 300,000 men and women in France, from a young age into adult life. Chronic juvenile arthritis touches around 5000 children, and can burden their future adult life.

AS can be both deforming and destructive, damaging the motor system and leading to articular attacks that can make simple everyday tasks difficult and sometimes impossible.

CSIRI are characterized by a long disease progression marked by sudden high temperatures, acute disease flares,

periods of quiescence and relapses with after-effects, due to the progressive nature of the disease. The social cost of these illnesses is heightened since people affected must usually leave the workforce less than 10 years after diagnosis. This is even more profound for children, some of whom will be looked after by society for the rest of their lives.

CSIRI leave the intellectual faculties unharmed, but can lead to psychological problems linked to the pain, withdrawal, and a lack of understanding from the family circle.

Corticoids and nonsteroidal antiinflammatory drugs constitute the best evaluated symptomatic treatment for these conditions, but can cause unwanted and potentially serious side effects. Regularly taking strong analgesics affects the quality of life and the lifestyle of the sufferer. Similarly, basic treatments to slow the progress of illness can cause unwanted side effects.

Sufferers have frequently resorted to preventive surgery aimed to correct or re-establish a particular functional capacity.

Current research on RA and the other CSIRI does not benefit from sufficient financial support.

## RECOMMENDATIONS

The degree of difficulty that CSIRI present is not appreciated by the general public or the mass media; clichés persist and CSIRI are confused with other rheumatic illnesses linked to aging. Consequently, people suffering from CSIRI find themselves in a critical health and social situation that requires the following special measures.

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### **Inform People Affected**

- Set up a major information campaign aimed at familiarizing people affected and the general public about suitable treatments and the particularities of pathology, the varying handicaps, sometimes invisible, many-sided, making movement impossible or limited, and which can be related to pain.
- Educate people affected as quickly as possible about the preventive measures: articular economy, access to occupational therapy, organization of the environment, readjustment, hygiene.
- Place the doctor/sufferer dialogue at the information center concerning the range of treatments, their availability, and their risk-benefit relationship.
- Recognize the role of the associations for people affected and concerned with the CSIRI in information and training of the sufferer and those close to them.
- Involve the health professionals.
- Organize consensus conferences and establish good frames of reference that enable general practitioners and rheumatologists to rapidly set up a relevant diagnosis regarding suitable treatment and approaches.
- Set up strict surveillance of risks caused by certain treatments, and more generally, to avoid disease flares or irreversible lesions.
- Take the handicaps and treatments associated with the illness into consideration: necessary bridgeheads between general practitioners and/or rheumatologists and other specialists: ophthalmologists, stomatologists, dermatologists, gastroenterologists, but also chiropractors, physiotherapists, occupational therapists, dieticians, etc., to create global care for the sufferer.
- Develop rapid-access multidisciplinary consultations by placing the person affected at the center of the operation and by telling them about possible alternatives and their drawbacks.

### **Organize treatment**

- Create an observatory for the management of the CSIRI at hospitals and in the community.
- Provide equal access to treatment, whatever the place of residence.
- Coordinate services between various health professionals that persons with CSIRI consult.
- Facilitate more systematic referral to occupational therapy, an essential discipline for prevention, education, and maintaining a normal lifestyle.
- Reinforce links between general practitioners and rheumatologists about decisions that need to be taken quickly. The complexity of the progressive nature of CSIRI demands this symbiosis between generalist and specialist.
- Incorporate in the above services a unit trained in managing chronic pain, and proposing different options: relaxation therapy, medicinal and nonmedicinal treatments, etc.
- Increased understanding of the health professionals, patient associations, and lifestyle of those with CSIRI.

### **Control Pain**

- Recognize the deeply painful nature of the CSIRI (chronic daily and acute periods) linked to erosion, ankylosis, articular destruction, physical deformity and its repercussions, to the effects of treatments and to the concept of “disease flare.”
- Recognize the idea of fatigue, also chronic, linked to immune dysfunction, pain, and the nature of the treatments.
- Recognize the need for initial and continued training for rheumatologists and those involved in treatment of pain in the patients’ daily life. Provide means to warn about it (post-operative, at the time of the synoviortheses, periods of physiotherapy, etc.) and to treat pain both in the short and long term (using analgesics).
- Take grief and depressive tendencies into account, through liaison work between the medical corps, patient associations, and psychotherapists.

### **Develop Research**

#### **Basic**

- Obtain substantial credits from the state to accelerate research in the fields of epidemiology, immunology (inflammatory process), and prosthetic materials concerning the pathologies.
- Research a predictive test for severity.
- Create DNA data banks for serious rheumatic conditions with support from the state.

#### **Clinical**

- Develop protocols for therapeutical trials, together with patient associations and with systematic disclosure of results.
- Keep a close watch on treatments with heavy side effects and on “innovative” medicines.

### **Improve Control over Social Life and Career**

- Encourage those with CSIRI who can and would like to continue a career, through adjustments to job organization, working hours, and through improvements in accessibility and reimbursement for required technical help.
- Facilitate dialogue, in the context of work reorganization, between employer, the person with CSIRI, and the attending doctor (or rheumatologist) for relevant guidance.
- Facilitate dialogue, in the context of academic reorganization, between the director of the school, the school doctor, and the parents of the affected child, for possible orientation.
- Create residential after-school care units, either temporary or permanent, adapted to the specific handicap of those affected by CSIRI.

### **CONCLUSION**

The Association française des Polyarthrites is doing everything in its power for the well being of sufferers, which, even if only indirectly reducing destruction of bone and joints, is generally contributing to progress against polyarthritic diseases.