

The Role of the SAA in the 21st Century

The SAA recently was invited to co-author a paper in a supplement of the leading academic journal, *Annals of Rheumatic Diseases*. GRAPPA, the international group of rheumatologists and dermatologists advancing knowledge in psoriasis and psoriatic arthritis was responsible for the development of the supplement which included 31 papers, ranging from pathophysiology through the clinical management of psoriatic arthritis (PsA).

The supplement was published in March 2005, both in hard copy and online and can be accessed, free of charge, in its entirety at http://ard.bmjournals.com/content/vol64/suppl_2/

The SAA co-authored paper, entitled *Psoriatic arthritis and psoriasis: role of patient advocacy organizations in the twenty first century* discussed how the SAA and counterpart organizations have transformed from small patient support and advocacy groups into sophisticated national organizations integral to the formation of national health policy and research, treatment and educational resources.

The paper emphasized the role of the SAA and how we have become adept at working at the grassroots level and beyond, employing the synergy of collaborative, complex relations with federal agencies, state and local governments, non-governmental organizations, academia, and industry to develop effective ways to address specific needs. For example, in 1999, the SAA provided seed money for initiation of the AS Family Genetic Study project, a four year study of the genetic characteristics of families with multiple cases of ankylosing spondylitis, by researchers at the University of Texas Health Science Center at Houston. In year 2, the grant was funded by the National Institutes

of Health (NIH) for US\$5.5 million. Understanding the genetics of AS may help researchers better classify the various spondyloarthropathies, including PsA. Important knowledge is being generated, and it is hoped that the research also will yield insights into the spondylitis that affects some PsA patients.

Unity of concerns

According to SAA annual patient questionnaires and other informal surveys, the PsA population continues to address the same issues as the spondyloarthritis population at large:

- Need for early diagnosis
- access to effective treatments
- need for effective methods to address the chronic fatigue, physical limitations, and chronic pain caused by this disease.

Common areas of interest expressed in the 2002 surveys were "Research" (36%); "Information through publications and videos" (29%); and "Informing health professionals about diagnosis and treatment" (22%). Other choices, such as legislative advocacy, support groups, seminars/symposia/forums, and expansion of websites, received 3–4% each.

Early diagnosis and access to treatment

Although it is unclear whether patients with PsA develop spinal involvement late in the course of their disease or whether PsA with spinal involvement is simply seen late by rheumatologists; this warrants further research and, if the latter, efforts should be made to assure earlier diagnosis and treatment. According to Gladman et al, the impact of PsA on patients appears to be similar to that of rheumatoid arthritis (RA) on patients. However, recent studies strongly suggest that the new biologicals produce a significant improvement in PsA resulting in an improved health related quality of life. Since recent studies have implicated

that etanercept, which is approved for PsA, may halt radiographic progression of the disease, this has potential far-reaching socioeconomic consequences for the individual and society at large given that PsA can be a disease spanning six decades.

Advocacy in research and public policy

In recent years the SAA has played a pivotal role by bringing the patients' perspective into research and ensuring that patients have the continued opportunity to participate in innovative, high-quality clinical trials, and that the privacy of patients and their families continues to be protected.

As our role continues to grow within the healthcare community, SAA welcomes being invited to the decision making table.

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References

Psoriatic arthritis and psoriasis: role of patient advocacy organizations in the twenty first century

Gail M Zimmerman, Laurie M Savage, David C Chandler, and Maria Maccarone Buonfigli

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