

REPORT

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

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Ann Rheum Dis 2005;64(Suppl II):ii93–ii100. doi: 10.1136/ard.2004.033225

All the psoriatic arthritis and psoriasis patient advocacy organisations are devoted to promoting public awareness and patient education; supporting access to effective treatments and physicians committed to the welfare of patients; working with physicians and other organisations to facilitate development of new treatments; and supporting research for more effective treatments and a cure for psoriasis and psoriatic arthritis. They have participated in the remaking of health politics in the late twentieth century. This was an era in which small patient support and advocacy groups were transformed into sophisticated national health organisations integral to the formation of national health policy and research, treatment, and education funding by working with physicians, legislators, pharmaceutical companies, third party payors, and the media. As we enter the twenty first century, some of these groups have done critical surveys of patients and physicians to discern needs that are redirecting their programming and reshaping directions in the field. Many national leagues have united to form international organisations. Although differences in their national health-care systems, the age of their organisations, and the diseases they cover are reflected in the focus of their individual activities, much unites them. Whatever their size, as their roles have come to be recognised in the healthcare community, the patient advocacy organisations welcome being invited to the decision making table. This report describes a sampling of these organisations.

Patient advocacy organisations were born of a need to provide support and education for patients who could not find it elsewhere and to generate new resources for patient, public, and professional education, and for research for better treatments and, ultimately, a cure for these rare diseases. However, they then participated in the remaking of health politics in the late twentieth century. This was an era in which small patient support and advocacy groups were transformed into sophisticated national health organisations integral to the formation of national health policy and research, treatment, and education funding by working with physicians, legislators, pharmaceutical companies, third party payors, and the media.

In the early years, the groups struggled not only to make changes in public policy but also to gain recognition from the medical community, a struggle every patient based organisation faced as this remaking of health politics occurred around the world. As their organisations became larger, the volunteer founders hired professionals, but patients continue to constitute the bulk of their volunteer boards. As we enter the twenty first century, some of these groups have conducted surveys of patients and physicians to discern needs that are redirecting their programming and interactions with their constituencies, the results of which are

reshaping directions in the field. As their roles have come to be recognised in the healthcare community, the patient advocacy organisations welcome being invited to the decision making table.

This report on a sampling of national organisations provides a profile of how each of four different such groups operates and focuses its work. The profiles are followed by a discussion of international organisations, which can serve as links for physicians to other national organisations around the world.

NATIONAL PSORIASIS FOUNDATION (USA)

The National Psoriasis Foundation (NPF) was founded in the USA in 1968 by patients and physicians in order to share information, overcome isolation, and fund research to find better treatments and, ultimately, a cure. These ideals remain at the core of the organisation's mission, which is more important than ever in the present century: to improve the quality of life of people who have psoriasis and psoriatic arthritis (PsA) through education and advocacy, and to promote awareness and understanding, ensure access to treatment, and support research that will lead to effective management and, ultimately, a cure.

The first national population survey about psoriasis and PsA, the NPF's Benchmark Survey on psoriasis and PsA, was conducted in 2001. The results revealed that one million US adults, 0.5% of the adult population, have PsA and that 4.5 million US adults (2% of the adult population) have psoriasis.¹ In addition, in the survey 31% of those with psoriasis said they had had persistent joint pain or stiffness for three months or longer but had not been diagnosed as having PsA, suggesting that many of these individuals might have PsA and not be aware of it.¹

Because of the large number of people affected by psoriasis and PsA, there is much demand for information on these chronic, difficult diseases. Each year, the NPF receives nearly half a million contacts for information on these diseases. It strives to meet these needs by providing a comprehensive website, educational booklets, community education meetings, and an annual national conference. Specific examples of distribution of information on PsA include: approximately 14 000 visits each month to PsA related pages on the organisation's website (www.psoriasis.org) from more than 69 000 unique monthly visitors and more than 26 000 educational booklets on PsA distributed each year from a total of 250 000 educational booklets.² Many individuals have made the added effort to learn more in person about psoriasis and PsA. In 2003, more than 750 individuals attended seven community education workshops about psoriasis and PsA

Abbreviations: ADIPSO, Association for the Care of People with Psoriasis; ASIF, Ankylosing Spondylitis International Federation; IFPA, International Federation of Psoriasis Associations; NPF, National Psoriasis Foundation; PsA, psoriatic arthritis; PAA, Psoriatic Arthropathy Alliance; RA, rheumatoid arthritis; SAA, Spondylitis Association of America

throughout the USA.² At the 2004 national conference, more than 300 attended a session focusing on PsA.²

New dermatologist education programmes planned

The NPF also understands the need for education among medical professionals. Because so many patients with psoriasis experience joint pain, the dermatologist may be the first to diagnose PsA. In the 2001 Benchmark Survey, fewer than 20% of respondents said they had seen a rheumatologist compared with almost 60% who had seen a dermatologist.¹ This evidence, and the fact that it is well established that patients usually develop psoriasis before PsA, suggest that the dermatologist may be the first to diagnose PsA. In order to educate dermatologists at an early stage in their careers, the organisation offers an annual chief residents' meeting for senior dermatology residents—the only workshop of its kind for dermatology residents. More than 600 residents have been trained over the past six years in this two day comprehensive educational course on psoriasis and PsA led by members of the NPF Medical Board. The organisation also raises awareness among dermatologists about PsA through its publications, including the medical journal, *Psoriasis Forum*.

Impact on quality of life and treatment satisfaction/dissatisfaction

Research by the NPF into the impact of PsA has revealed important data that support the need for continuing patient and physician education. According to the 2001 Benchmark Survey, PsA has a negative effect on patients' lives, seriously affecting day to day activities, including losing sleep or sleeping poorly (75%) as a result of the disease.¹ Of those working or in school, 69% said it prevented them from performing daily activities.¹ The NPF survey panels, developed as a follow up to the Benchmark Survey, and conducted twice a year, have consistently indicated that PsA has a larger negative overall impact on quality of life than psoriasis alone. A survey panel in 2004 revealed that individuals with PsA consider it a larger problem in everyday life (49%) compared with those with psoriasis (39%).³

However, patients with PsA are consistently more satisfied with treatment than patients with psoriasis. According to a 2004 survey, 34% of PsA patients indicated they were highly satisfied with treatment compared with 15% of psoriasis patients.³

The organisation is committed to its outreach efforts to the PsA patient community, providing information and encouragement to explore available treatment options. In a 2003 NPF survey panel, respondents were asked about their awareness of different treatments. More individuals who were NPF members responded that they had heard of a treatment compared with those who were not members (fig 1).⁴ By testifying at the US Food and Drug Administration (FDA) hearings on new psoriasis therapies, developing educational materials, facilitating basic and clinical research, and implementing a range of advocacy efforts, the organisation supports the development and awareness of new therapies for psoriasis.

The NPF proactively continues to assess the needs of people with psoriasis and/or PsA by conducting surveys twice a year to determine how it can serve these needs. By providing education and support for people with psoriasis and/or PsA, advocating for more access to appropriate treatment, and supporting research that may, ultimately, lead to a cure, the NPF continues its mission into the twenty first century.

SPONDYLITIS ASSOCIATION OF AMERICA (USA)

The Spondylitis Association of America (SAA) was established in 1983 to serve the needs of those with ankylosing

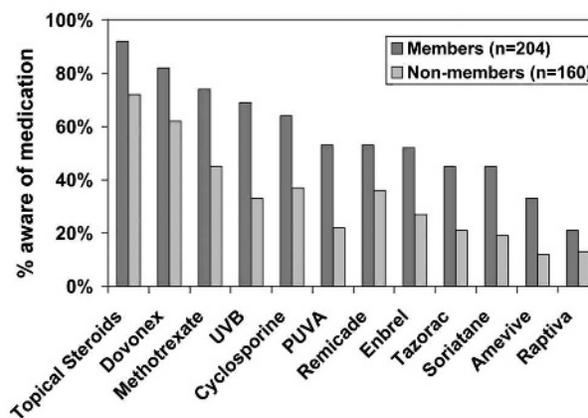


Figure 1 National Psoriasis Foundation members are more educated about treatment options than non-members. Respondents of a 2003 Foundation Survey Panel were asked if they were aware of a list of medications used to treat psoriasis and psoriatic arthritis. Responses by members of the National Psoriasis Foundation and non-members are shown. (Reproduced with permission of the National Psoriasis Foundation, OR, USA, from the 2003 Foundation Survey Panel on patient awareness about treatment options.)

spondylitis, psoriatic arthritis/spondylitis, spondylitis of inflammatory bowel disease, undifferentiated spondyloarthritis, and reactive arthritis. The mission of the SAA is to be a leader in the quest to cure ankylosing spondylitis and related diseases and to empower those affected to live life to the fullest. The SAA supports research, offers patients education about the disease, peer support, and advocacy at a wide variety of levels, including a website (www.spondylitis.org)—which averaged >850 000 hits per month in 2004—and its news magazine, *Spondylitis Plus*, which has a circulation of 40 000.

The SAA has become adept at working at the grassroots level⁵ and beyond⁶ employing the synergy of collaborative, complex relations with federal agencies,⁷ state and local governments, non-governmental organisations,⁸ academia, and industry⁹ 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.¹⁰ According to Dr S Sztejn, chief of the Rheumatoid Diseases Branch of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), the SAA's role in the study has been critical¹¹:

As far as I know, the NIH, or at least NIAMS, has never funded an ongoing study with a patient-advocacy organization acting as the coordinating center. It is the SAA's ability to reach families which is essential for success.

Understanding the genetics of AS may help researchers better classify the various spondyloarthropathies, including PsA. Further, the NIAMS established the North American Spondylitis Consortium to search for genes that determine susceptibility to ankylosing spondylitis. The consortium is formed by researchers from 10 research centres and staff from the SAA, who hope to learn more about genes that play a role in the disease and collect medical information and genetic material from 400 families nationwide. Important knowledge is being generated, and it is hoped that the

research also will yield insights into the spondylitis that affects some PsA patients.¹²

Unity of concerns

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

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

Figure 2 shows data representing responses to a question—“What two SAA activities are most important?”—designed to discern the needs of SAA members in a 2001–02 Annual Membership Survey.¹³ The commonest response was “Research” (36%); the second was “Information through publications and videos” (29%); and the third was “Informing health professionals about diagnosis and treatment” (22%). Other choices, such as legislative advocacy, support groups, seminars/symposia/forums, and expansion of website, received 3–4% each.

Early diagnosis and access to treatment

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 rheumatologists¹⁴; 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.¹⁵ However, recent studies strongly suggest that the new biologicals produce a significant improvement in PsA resulting in an improved health related quality of life. Although there are few or no data relating to the socio-economic consequences of antitumour necrosis factor (anti-TNF) therapy in PsA, some studies in RA strongly suggest the cost effectiveness of biologicals in active disease, supported by research that indicates a greatly reduced rate of indirect costs and work days lost.^{16,17} Since recent studies have

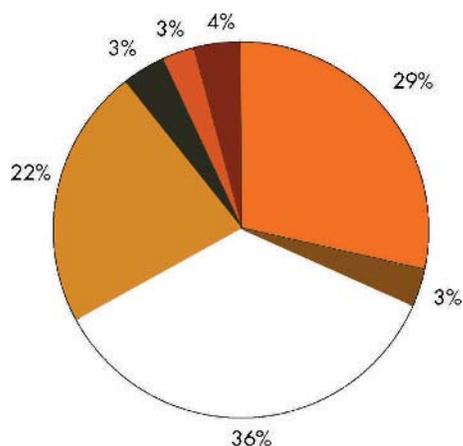


Figure 2 Responses chosen for the question “What two activities of SAA are most important?”: Research (36%); Information through publications and videos (29%); Informing professionals about diagnosis and treatment (22%); Legislative action (4%); Information through seminars/symposia/forums (3%); Expansion of website features (3%); and Support groups (3%). (Reproduced with permission of the Spondylitis Association of America, Sherman Oaks, CA, USA, from the Annual Membership Survey 2001–2002.)

implicated that etanercept, which is approved for PsA, may halt radiographic progression of the disease,¹⁸ 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

The SAA plays a pivotal role by bringing the patients’ perspective into research¹⁹ and ensuring that patients have the continued opportunity to participate in innovative, high quality clinical trials, to increase federal funding for PsA research, and to protect the privacy of patients and their families.

PSORIATIC ARTHROPATHY ALLIANCE (UK)

The role of the Psoriatic Arthropathy Alliance (PAA), established in 1992, is to help patients and support the work of professionals in the UK’s ever-pressurised National Health Service (NHS) by offering support for patients via better education and identification of needs. Patients and patients’ representatives need to be included within health care to provide input on the needs, why patients fail to comply to treatment options, what patients want from the service, and how existing services can be improved. When the PAA was set up, this assertion was anecdotally based on the experiences and desires of those who contacted the organisation. However, support for this view has developed nationally in the UK.

The traditional “top down” approach, where the health service is sometimes run for the convenience of those running it and not for the benefit of those who use it, needs to become a partnership of mutual benefit. Very often, the changes that need to take place are not costly but just ways of looking at sensible approaches. These can be by providing clinics, which will fit within the lifestyle of those who need to attend, or providing follow up support via a named member of staff who is able to offer advice. A report published by the UK Department of Health, *Patient and Public Involvement in Health—The Evidence for Policy Implementation*,²⁰ demonstrates that the views and needs of patients are now being sought, recorded, and included. The report’s executive summary defines the key findings that include “Patients feel involved in their care when they are treated as equal partners”, “High quality information enables both self management and patient involvement”, “Public involvement influences the policies, plans and services of NHS organisations” and “Partnerships enable learning, resources and expertise to be shared across health economies”.²⁰

The history and process that led to more patient empowerment started in 1990 with the introduction of the National Health Service and Community Care Act 1990 by the UK government, which required local authorities to consult with users and carers. In 1991, *The Patient’s Charter* established a clear framework for patient entitlements. With subsequent further studies and discussion with local communities and patient organisations, *Local Voices* (1992), *The New NHS: modern, dependable* (1997), *The Voluntary Compact* (1998), *A First Class Service* (1999), and *The NHS Plan* (2000), which defines a 10 year plan of modernisation of the NHS, with a vision of a service “designed around the patient”,²¹ all have taken the patient centred approach closer to the needs of patients.

Benefits provided

As the first organisation in the world to initially focus on PsA, the PAA has played a vital role in developing better recognition and awareness of PsA. The PAA provides support and information for all those who need it. This is particularly important, as patients do not always want to become a fee

paying member. The PAA register, which is a non-fee paying service, has more than 10 000 names entered; free advice, support, and telephone help are always available. Mail and telephone enquiries are in excess of 10 000 per year. The PAA website (www.psoriasis-uk.org) receives about 300 000 hits per year. The organisation also publishes a journal called *Skin 'n' Bones Connection* twice a year with more than 1000 copies directly sent to subscribers and a further 2000 copies distributed via other patient or professional routes.

The development of the organisation has also been influenced by patient needs; this has led to activities that have moved beyond just PsA to the development of material and activities about psoriasis and other related conditions. The need to provide what patients want has been achieved via the development of a resource folder called Psoriatic Care Fact File; originally produced in 1997, the file was distributed as a hard-backed ring binder to every rheumatologist and dermatologist in the UK (800 copies) and as a CD-ROM (4000 copies) to interested general practitioners. Annual patient conferences have been provided free of charge since 1995 with an average of 200 patients, carers, and professionals attending each meeting. Numerous patient information leaflets have been developed, with free supplies given to professionals to distribute; more than 20 000 leaflets are distributed annually via this route. Patient focus groups are held both within the UK and internationally, under the name InterPSO; so far two international meetings have been held with participants from Germany, France, Belgium, the Netherlands, and UK taking part.

The PAA's role has been that of an organisation that provides simple solutions such as a *Guide to Physiotherapy and Exercise in PsA*, which includes simple exercises to keep and improve mobility. The PAA has also developed contact with other organisations and continues to develop a voice for PsA and psoriasis. Interaction with the NHS and UK governmental departments involved members of PAA providing input into drug appraisals (National Institute of Clinical Evidence) and treatments, such as a recent study on the use of oral methotrexate with the NHS National Patient Safety Agency (www.npsa.nhs.uk).

The patients' perspective

The patients' perspective about psoriasis and PsA continues to centre on effective therapies and available services. The PAA has recorded standard data from application forms and letters of subscribing members for internal use.²² The use of topical creams twice a day, every day, is still the biggest problem for patients with psoriasis. Compliance with topical treatments was surveyed in the PAA's TOPSO Study in May 2003, and a summary was published in the organisation's *Skin 'n' Bones Connection* journal in 2004.²³ The study was a postal questionnaire and received 1281 adult responses from five countries (UK, France, Belgium, Germany, and the Netherlands). The key finding was that only 27% of patients complied and completed the course of treatments prescribed. The reasons given for lack of compliance or failure to work were: inconvenient to use (51%), treatments took too long to rub in (26%), the process was too complicated or difficult (17%), and the treatments were too restricting (8%). Interestingly, in free text answers, 7% responded that they only used their treatments when they felt they needed it. Anecdotal evidence from telephone enquiries gives potential disability, lack of recognition, diagnosis, and effective pain management as issues for those with PsA.

It is the view of the PAA that the role of the patient in the UK will have greater impact on the delivery of health care than previously experienced. The assertions and anecdotal evidence gathered by organisations such as the PAA have

begun to be transferred into health messages and policy²⁴ as set out in the Department of Health's *NHS Plan 2000* policy.

ASSOCIATION FOR THE CARE OF PEOPLE WITH PSORIASIS (ITALY)

Founded in 1989, the Association for the Care of People with Psoriasis (ADIPSO) is the youngest of the organisations reported here and, as might be expected, is focused on the most basic concerns of patients with psoriasis: sensitising public opinion regarding the problems of the disease, promoting initiatives in the interest of patients, and informing them of the latest treatments available. In 2004, the newsletter had a circulation of 200 000, more than 600 000 booklets were distributed, and the website (www.adipso.org) received more than 10 000 visits every week.

ADIPSO has marked a notable achievement: it has worked with the Ministry of Health and Welfare to have psoriasis and PsA officially recognised as social, as well as disabling, diseases, an objective finally realised, which means that patients now receive all their treatments free.²⁵ ADIPSO also contributed to the development of the research programme of the Institute of Rheumatology of the "La Sapienza" University of Rome on methods of evaluating the gravity of the functional deficit of PsA patients, including the Arthritis Impact Measurement Scale (AIMS)²⁶⁻²⁷ and has collaborated with the genetics group at the University of "Tor Vergata" of Rome in several studies, as well as in a study about depressive symptoms in patients with psoriasis.²⁸⁻²⁹

In addition to the enormous physical consequences of the disease, it is important to emphasise the significant psychological impact of psoriasis and PsA. ADIPSO takes great effort to provide support to members dealing with damaged self-esteem and depression due to social isolation and even loss of jobs because some people fear contagion, as well as pain, disfigurement, and disability. Many patients feel that there is no escape—not from the disease nor its treatments. It is these burdens that will be lifted when new treatments are made available.

As it is important for people with psoriasis to have a support network to help them learn to live with the condition and take control of the disease, ADIPSO seeks to provide support for 15 groups in cities around Italy, which meet monthly. In these groups, patients meet with each other and are reassured that there are people who care and are concerned about their condition and who can provide them with the information they need.

INTERNATIONAL PATIENT ADVOCACY ORGANISATIONS

Dozens of patient advocacy organisations, from small patient support groups of perhaps 10 members to large groups with professional staffs and a nationwide network of chapters, have formed around the world. In addition to those specifically serving people with psoriasis and/or PsA, there are those dedicated to helping people with arthritis, such as the Arthritis Foundation in the USA, which provides information on PsA. Despite their diversity, many of the national leagues have seen the value of uniting in international organisations to work towards common goals.

International Federation of Psoriasis Associations

The International Federation of Psoriasis Associations (IFPA), founded in 1971, brings its 23 member associations (table 1) together to exchange ideas on how to improve patient care. It helps find support for international meetings to bring patients, physicians, and researchers together to increase their understanding of these diseases, and it represents the interests of its member associations at

Table 1 Members of the International Federation of Psoriasis Associations (2004)

Country	Organisation/location	E mail	Website
Australia	Psoriasis Association of Victoria Inc Glen Waverley Victoria	pav@virtual.net.au	
Belgium	PSORIASISSTICHTINGvzw Lochristi	info@psoriasis-vl.be	www.psoriasis-vl.be
Canada	Psoriasis Society of Canada Halifax Nova Scotia	judymisner@eastlink.ca	
China	China Psoriasis Foundation Beijing	Hy348829@hy.cgw.cn	
Denmark	Danmarks Psoriasis Forening Hvidovre	LK@psoriasis.dk	www.psoriasis.dk
Estonia	Eesti Psoriaasiliit—EPSOL Tallinn	epsol@venus.nlib.ee	
Finland	Finnish Psoriasis Association Helsinki	ingemo.tornroos@psori.fi	
France	Assoc. Pour La Lutte Contre Le Psoriasis (APLCP) Vannes	michele.corvest@wanadoo.fr	www.aplcp.org
Germany	Deutscher Psoriasis Bund e.V. Hamburg	kunz@psoriasis-bund.de	
Iceland	Samtök psoriasis og Exema (SPOEX) Reykjavik	spoex@psoriasis.is	www.psoriasis.is
Indonesia	Indonesian Psoriasis Foundation (Yayasan Psoriasis Indonesia) (Yapi) Jakarta	yapi@psoriasis.or.id	www.psoriasis.or.id
Israel	Israel Psoriasis Association Holon	psoriasis@bezeqint.net	
Italy	Associazione Nazionale per la tutela del Malato di Psoriasi e Vitiligine (A. S. N. P. V.—onlus) Milano	info@asnrv.it	www.asnrv.it
Kenya	Psoriasis Association of Kenya Nairobi	howaweru@skyweb.co.ke	
Lithuania	Psoriasis Society of Lithuania Kaunas	jbalciuniene@takas.lt	
Norway	Norwegian Psoriasis Association Oslo	gensekr@psoriasis.no	www.psoriasis.no
Singapore	Psoriasis Association of Singapore Singapore	psoriasis_sg@yahoo.com	www.psoriasis.org.sg
South Africa	South African Psoriasis Association (Western Cape Branch) Brackenfell, Cape	cathalex@sybaweb.co.za	
Spain	ACCIÓN PSORIASI Barcelona	psoriasis@pangea.org	www.pangea.org/org/psoriasi
Sweden	Swedish Psoriasis Association (PSO) Johanneshov	birgitta.rehnby@pso.se pso@pso.se	www.pso.se
Switzerland	Schweizerische Psoriasis & Vitiligo Gesellschaft (SPVG) Bern	spvg@bluewin.ch	www.spvg.ch
UK	Psoriatic Arthropathy Alliance St Albans, Herts	info@psoriasis-uk.org	www.psoriasis-uk.org
USA	National Psoriasis Foundation/USA Portland, OR	sdecker@psoriasis.org	www.psoriasis.org

Table 2 Members of the Ankylosing Spondylitis International Federation (2004)

Country	Organisation/location	Email or tel no	Website
Australia	Ankylosing Spondylitis Group of New South Wales New South Wales	denisemckeon@bigpond.com	
	Ankylosing Spondylitis Group of Queensland East Brisbane, Queensland	johnjohn@powerup.com.au	www.arthritis.org.au/asgroup
	Ankylosing Spondylitis Group of Tasmania Claremont, TAS 7011	mlimbric@tassie.net.au	
Austria	Österreichische Vereinigung Morbus Bechterew (ÖVMB) Wien	office@bechterew.at	www.bechterew.at
Belgium	Vlaamse Vereniging voor Bechterew-patiënten v.z.w. (VVB) Knokke-Heist	vvb@come.to	www.vvb.rheumanet.org
Canada	Ankylosing Spondylitis Association of British Columbia (ASABC) Surrey, British Columbia	a-griddick@uniserve.com	
	Manitoba Ankylosing Spondylitis Association Winnipeg, Manitoba	(+1-204) 256-5320	
	Ontario Spondylitis Association (OSA) Toronto, Ontario	info@spondylitis.ca	www.spondylitis.ca
Croatia	Croatian Ankylosing Spondylitis Society Zagreb	(+385-01) 37 87 248	
Czechia	Klub Bechtereviku Praha 2	Klub.bechtereviku@seznam.cz	www.sweb.cz/ klub.bechtereviku
Denmark	Gigtforeningen for Morbus Bechterew København	torben@bechterew.dk	www.bechterew.dk
France	Association Française des Spondylarthritiques (AFS) Rennes	afs@fr.st	www.aplcp.org
Germany	Deutsche Vereinigung Morbus Bechterew e.V. (DVMB) Schweinfurt	dymb@bechterew.de	bechterew.de
Hungary	MEOSz Bechterew section National Federation of Associations of Disabled Persons Budapest	(+36-1) 358 12 74	
Ireland	Ankylosing Spondylitis Association of Ireland (ASAI) Dublin	info@ankylosing-spondylitis.ie	www.ankylosing-spondylitis.ie/
Italy	Associazione Italiana Spondiloartriti (A.I.Sp.A) Firenze	(+39) 0584-49083	
Japan	Japan Ankylosing Spondylitis Club (JASC) Tokyo	(+81-422) 45-7985	
Norway	Norsk Revmatikerforbund (NRF)/BEKHTEREV Oslo	nrf.adm@rheuma.no	www.rheuma.no
Portugal	Associação Nacional da Espondilite Anquilosante (ANEA)	info@anea-sede.rcts.pt	www.anea-sede.rcts.pt
Singapore	Singapore Ankylosing Spondylitis Club (SASC) Singapore	(+65) 6227-9726	www.arthritis.org.sg
Slovenia	Drustvo za ankilozirajoci spondilitis Slovenije (DASS) Ljubljana	dass@siol.net	
Switzerland	Schweizerische Vereinigung Morbus Bechterew (SVMB)		
	Société suisse de la spondylarthrite ankylosante (SSSA)		
	Società svizzera morbo di Bechterew (SSMB) Zürich	mail@bechterew.ch	www.bechterew.ch
Taiwan	Ankylosing Spondylitis Caring Society of ROC Taipei	wei3228@ms3.hinet.net	www.ascare.org.tw
Turkey	Ankilozan Spondilit Hasta Dernegi (ASHAD) Izmir	ashad@ashad.org	www.ashad.8m.com

Table 2 Continued

Country	Organisation/location	Email or tel no	Website
UK	National Ankylosing Spondylitis Society (NASS) Mayfield, East Sussex	nass@nass.co.uk	nass.co.uk
Ukraine/Slovenia	Society of sufferers with Ankylosing Spondylitis (Bechterew's Disease) Solotonosha Ukraine	Fax (+380-475) 2172	
USA	Spondylitis Association of America (SAA) Sherman Oaks, CA	info@spondylitis.org	www.spondylitis.org

international forums and meetings to increase communication between patients, physicians, and industry.

IFPA is currently undertaking a vigorous programme to develop psoriasis associations in countries where none exist by providing expertise and encouragement. Until recently, no associations existed in Africa. IFPA support has led to their formation in Kenya and South Africa; Botswana and Tanzania are soon to follow, and four more African countries have been targeted for 2005. IFPA representatives also have been helping to establish associations in India, Panama, and Argentina.

The 1st World Psoriasis and Psoriatic Arthritis Conference, to be held in Stockholm in June 2006, is another major IFPA initiative. It will bring together physicians, researchers, and members of psoriasis associations to highlight the most recent information about these diseases. It will also help to form a consensus on what research needs to be carried out to further the understanding of psoriasis and PsA and on what psoriasis associations need to do to improve the lives of these patients.

For information about the IFPA or the Conference, contact the Association at 6600 SW 92nd Avenue, Suite 300, Portland, OR 97223, USA; email: getinfo@ifpa-pso.org (website: www.ifpa-pso.org).

Ankylosing Spondylitis International Federation

The Ankylosing Spondylitis International Federation (ASIF), founded in 1983, brings its 27 member associations (table 2) together to help support others form national groups (four in preparation in Australia/Victoria, Bulgaria, India, and Israel) and to increase public awareness of ankylosing spondylitis and related diseases, especially the spondyloarthropathies, of which PsA is one. ASIF also seeks to reach out to healthcare providers in need of up to date information on rheumatology. It seeks to support the aims of its national ankylosing spondylitis organisations, which are well framed, starting with "to contribute to the physical and mental health of patients with ankylosing spondylitis or related diseases" suggesting that someone with PsA and a spondylitic back will fit right into a group that is talking about sharing guidebooks and exchanging exercise videos from one national organisation to another. There is also a considerable amount of sharing of articles for publication in the journals of the member societies. It seems to be a less formal, more grassroots type of organisation.

Nonetheless, the group did well for itself at the European League Against Rheumatism (EULAR) Congress in Lisbon in 2003. E Feldtkeller, a member of the ASIF Executive Committee was asked to present a lecture on "AS in the pharaohs of ancient Egypt" at EULAR, the subject of his recent paper in *Rheumatology International*.³⁰ M Roche, president of the Association Française des Spondylarthritiques, presented a lecture on "Right to Fair

Access to Treatments" within the social leagues programme of the congress. D Vosse mentioned in her lecture the contribution of ASIF in collecting the data. These and other elements demonstrated the good penetration of ASIF and its members into the professional community.

For further information about ASIF, contact the association c/o its president Seoirse Smith, 6 Falcarragh Road, Gaeltacht Park, Whitehall, Dublin 9, Ireland; tel: (+353-1) 83 76 614; email: asai@oceanfree.n (website: www.asif.rheumanet.org).

Other patient advocacy organisations

Physicians can locate patient advocacy associations by contacting the IFPA (getinfo@ifpa-pso.org), the NPF, USA (getinfo@psoriasis.org), or the ASIF (www.asif.rheumanet.org). All these organisations keep current records of the locations of patient associations, both theirs and unaffiliated organisations around the world.

CONCLUSION

Patient advocacy organisations play a vital role in the treatment of psoriasis and PsA. Physicians can rely on these organisations to supply the education and support that make treating these diseases easier. When patients thoroughly understand a treatment, how to use it, and what side effects to watch for, their compliance with treatment is more likely to be thorough. Patient advocacy organisations are also skilled in providing the emotional support that is sometimes needed to make living with psoriasis and PsA easier. These organisations can also assist in helping people find others who are going through similar experiences; talking with others often eases the anxiety of facing the disease alone.

The basic mission of all patient advocacy organisations remains the same and continues to:

- provide psychological and moral support and information for patients
- provide support for physicians dedicated to their care
- apply pressure in the wider arena for better treatments and, ultimately, a cure for the disease.

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