





# YEAR IN REVIEW

## **Our Mission:**

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.

## a message from

# BOARD CHAIR DAVID HALLEGUA, M.D.

The Spondylitis Association enjoyed a record-breaking year on many fronts. From stepping up the pace of genetic research into the causes and the cure, to bringing together the most prominent spondylitis researchers in the world to exchange ideas, to extending programs and services to more people than ever before — 2006 has been a banner year for advances in research, education and patient advocacy.

As this report shows, it has been an exciting and eventful year. With the energy of our committees, the commitment of our volunteer leadership and the professionalism of our dedicated staff, SAA has raised the bar in terms of meeting the needs of spondylitis patients and their families.

And we've done it all while continuing to keep administrative and fund-raising costs low, once again earning a highly coveted 4-star, or "exceptional," rating from Charity Navigator.

In the following pages, you'll learn more about what makes the Spondylitis Association of America a national organization with no equal. Ankylosing spondylitis (AS) and its related diseases — reactive arthritis, psoriatic arthritis, arthritis associated with inflammatory bowel disease and undifferentiated spondylitis — are chronic inflammatory diseases with onset of symptoms generally occurring before the age of 35. As the only organization in the US devoting all of its resources to improving the lives of those affected by spondylitis, SAA is the first and foremost resource for news, information, educational materials, patient advocacy and research advancement in the nation.

None of this year's laudable achievements would have been possible without the lifeblood of all nonprofit organizations — our members and donors. Their support, combined with the generous financial contributions from our foundation and corporate supporters, has provided the working capital to carry out our mission as we respond to the needs of the spondylitis community — today and in the future.

SAA's Board of Directors is exceedingly proud of the organization's achievements in 2006. On behalf of the Board, I would like to thank everyone whose enthusiasm, professionalism and commitment made those achievements possible. After 23 years under Co-Founder Jane Bruckel's visionary leadership, SAA is securely positioned to meet the challenges of the future. I look forward with confidence to 2007.

Sincerely,



DAVID HALLEGUA, MD Board Chair

There are
at least half
a million
people with
spondylitis
in the US,
making it
more prevalent
than multiple
sclerosis, cystic
fibrosis and
Lou Gehrig's
Disease
combined.

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SAA was
the first and
remains the
largest resource
for people
affected by
spondylitis.

# RESEARCH



or nearly 25 years, SAA has encouraged and facilitated collaboration among prominent researchers as a means of accelerating advances in spondylitis research, diagnosis and treatment.

#### **AS FAMILY GENETIC STUDY**

In 1998, SAA raised the seed money for the AS Family Genetic Study, the first genetic research toward understanding ankylosing spondylitis in the United States. Data generated from NASC (North American Spondylitis Consortium), which evolved from the AS Family Genetic Project, uncovered regions on



chromosomes that advanced researchers' knowledge of susceptibility toward AS. In addition, the data suggested that genes may also play a significant role in severity and outcomes of the disease.

In recent months, the National Institutes of Health (NIH) committed an additional \$5.25 million to spondylitis genetic research by awarding a grant to an international team of researchers headed by Dr. John D. Reveille, University of Texas, Houston. SAA continues to play a critical administrative and recruitment role in this phase of the study, which will conclude in 2011.

The four interrelated projects of the study seek to find the genes that cause AS, to identify the genes that predict severity and outcomes, to identify the spectrum of

related diseases in family members of people with AS, and to determine how the genes interact with each other. The new study — to be known as TASC (Triple A Spondylitis Consortium) — brings real hope for the future.

# "SPONDYLOARTHRITIS 2006: THE UNMET NEEDS CONFERENCE"

"Spondyloarthritis 2006: The Unmet Needs Conference" was chaired by Dr. David Fox, Professor of Internal Medicine, Director, Division of Rheumatology, University of Michigan Health System, and co-chaired by Dr. John Reveille. *Arthritis and Rheumatism*, the official peer-reviewed journal of the American College of Rheumatology, will publish a paper reviewing the conclusions from the conference.

The National
Institutes of
Health (NIH)
called SAA a
'major national
AS patient
advocacy organization with a
proven history of
successful patient
recruitment to
and retention in
clinical studies."

SAA sponsored 15 seats at the conference for new physicians — currently Fellows in Rheumatology — with the goal of attracting young investigators into the specialized field of spondylitis research. By making initial investments now for the next generation, SAA is working to ensure that future research challenges will be met successfully.

#### **SCREENING TOOL FOR AS**

SAA and its research partners are working to create a validated screening tool to help people with back pain determine their likelihood of having AS. The screening process is intended to differentiate between back pain that is inflammatory in nature and back pain that results from other causes. The questionnaire-like screening tool is intended both to expand knowledge and to raise awareness of AS. It will be made widely available on the Internet.

This important tool will help identify new cases, promote early diagnosis and encourage care-seeking among patients who may be experiencing AS symptoms and need to be examined by a rheumatologist.

#### **SPARTAN**

SAA's commitment to furthering partnerships among researchers is clearly demonstrated by our affiliation with SPARTAN, a team of researchers and clinicians dedicated to fostering research and education in spondyloarthritis in the United States. SAA was instrumental in establishing this network of medical professionals in 2003.



Spondylitis Association of America™

For over
23 years,
the Spondylitis
Association of
America has
been behind
every major
milestone
achieved in
spondylitis
education,
research and
treatment.

# Spondylitis Association of America ↑ aintaining excellence in pa

THE ROLE

# PATIENT PROGRAMS

aintaining excellence in patient programs has traditionally been a cornerstone of SAA's mission. This past year, SAA provided programs and services to more people than ever before.

#### **INFORMATIONAL PROGRAMS**

Website Spondylitis.org is the number one ranked site on major search engines and receives more than one million hits per month. Providing more than 600 pages of up-to-the-minute content, the site also offers interactive message boards visited by people the world over, with a supportive community of nearly 5,000 registered posters.

OF EXERCISE IN SPONDYLOARTHRITIS Iritis [Eye Childhood Onset LIVING WITH SPONDYLITIS Inflammation] Spondyloarthritis in Spondyloarthritis Spondyloarthritis SPONDYLITIS A Family of Related Diseases Spondylitis Association sociation of America America Spondylitis Association of America G SPONDYLITIS . ENTEROPATHIC ARTHRIT ■ PSORIATIC ARTHRITIS ■ REACTIVE ARTHRITIS IIC ARTHRITIS RTHRITIS THRITIS UNDIFFERENTIATED SPON TATED SPONDYLOARTHRITIS ■ ANKYLOSING SPONDYLITIS

■ ENTEROPATHIC ARTHRITIS ■ PSORIATIC ARTHRITIS

UNDIFFERENTIATED SPONDYLOARTHRITIS

Community E-Newsletter SAA's Community E-Newsletter helps people stay informed on a variety of topics including special programs and events, the latest news regarding spondylitis, new educational materials, updated website features and more.

Toll-Free Information Line Our toll-free hotline is staffed by knowledgeable personnel who provide callers with assistance and guidance. Whether someone is trying to locate a rheumatologist in his or her area, find validated information about the disease or is seeking to speak to someone who understands — the information line makes it possible. All callers receive an information packet including useful information about spondylitis as well as an extensive resource list.

## **EDUCATIONAL PROGRAMS**

Community Based Patient Symposiums SAA continues to offer the only large-scale patient educational symposiums in the country specifically designed to meet the needs of the spondylitis community and to provide them with

cutting-edge information about advances in research, treatments and coping strategies. Over the years, more than 60 programs have brought patients, families and friends together with the leading

experts in the field of spondylitis. The interactive meetings offer ample time for questions and answers as well as an opportunity to participate in small, informal group sessions for sharing experiences, offering support and exchanging information.

Publications and Materials Twenty-five years ago, there were no resources available for a newly diagnosed spondylitis patient to learn about the disease. Today, SAA produces the most comprehensive informational materials on spondylitis and each year adds to the growing library of publications specifically written for patients and their families. SAA's publications include "Straight Talk

Spondylitis.org, the #1 ranked site on major search engines, receives over 1,000,000 hits per month. on Spondylitis," the first self-help book for spondylitis patients, as well as numerous pamphlets, booklets and videotapes.

#### ■ Brochures

Each year, SAA adds four new brochures to our collection of publications. This year's titles include: "Spondyloarthritis: A Family of Related Diseases;" "Iritis: Eye Inflammation in Spondyloarthritis;" "The Role of Exercise in Spondyloarthritis;" and "Childhood Onset Spondyloarthritis." In 2006, SAA distributed 25,000 educational brochures to patients and physicians — including 4,000 rheumatologists nationwide.

#### **■** Spondylitis Plus

SAA produces the only national magazine, Spondylitis Plus, dedicated to

meeting the unique needs of the spondylitis community. This award-winning news magazine offers cutting-edge information on the science of the disease, advances in research, treatment and medications, as well as personal stories from those living with spondylitis. Spondylitis Plus is read in 40 countries around the world.



National Support Group Network An informed and reliable support network can play a valuable role in the lives of those affected by chronic disease. Spondylitis patients and their families exchange ideas and practical information

with one another through a nationwide system of Educational Support Group meetings. Participants support one another in the daily task of collectively and individually striving for optimum health.

SAA supports this network by providing group leaders with guidance and educational materials to aid them in disseminating the latest news and information about spondylitis. In 2006, SAA began to develop a comprehensive training process and manual for all support group leaders. In addition, a board member was appointed as advisor to the group, and monthly conference calls were instituted to provide opportunities for the sharing of best practices. In 2006, SAA's emphasis was on strengthening and building the support group infrastructure by providing extensive training.

Message Boards This on-line community is visited by people from all around the world. More than 5,000 registered posters frequent the message boards seeking information, advice and support from others in the spondylitis community. Periodically, topics of discussion are raised by SAA moderators for response and discussion within the community.





SAA publishes
the largest
library of
publications
and materials
dedicated to
spondylitis
patients in the
United States.



# CORPORATE PARTNERSHIPS

To further SAA's mission 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, SAA partners with corporations whose objectives are similarly focused. These partnerships allow SAA to more effectively provide programs and services to the spondylitis community as a whole. They help to increase the scope of SAA's influence as a patient advocacy organization and to fund projects that otherwise might not be possible.

Corporate Partnership levels ranging from \$20,000 to \$80,000 provide a means for SAA's pharmaceutical partners to positively impact the spondylitis community by contributing funds to the organization's general operating budget. In 2006, our Corporate Partners also provided significant sponsorship funding for development and distribution of educational materials and community-based patient education symposiums.



#### PREMIER CORPORATE PARTNER

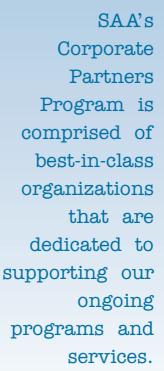
Amgen & Wyeth Pharmaceuticals funded four patient educational brochures, which were widely distributed among the spondylitis community as well as to more than 4,000 rheumatologists. In addition, the company provided \$35,000 of funding for Spondyloarthritis 2006: The Unmet Needs Conference.





## **ASSOCIATE CORPORATE PARTNERS**

In addition to partnership funding, Centocor, Inc. provided \$35,000 for Spondyloarthritis 2006: The Unmet Needs Conference and the Screening Tool for AS.







#### **SUPPORTING PARTNERS**

In addition to its partnership funding, Abbott **Laboratories** provided \$35,000 for *Spondyloarthritis* 2006: The Unmet Needs Conference.



#### OTHER CORPORATE SUPPORT

**Pfizer Pharmaceuticals** provided \$35,000 in support of Spondyloarthritis 2006: The Unmet Needs Conference.

# **DEVELOPMENT**

#### **FOUNDATION PARTNERS**

SAA enjoys the support of several family foundations that dedicate themselves to the organization's mission. In many instances, these foundations assist in the continual strengthening of the organization's vital infrastructure in order to support growth of services. These funding partners ensure that the organization can maintain or increase program service levels, even as scarce resources are allocated to other essential needs. In 2006, a critical year of transition for the organization, SAA received nearly \$200,000 in financial support from the following Foundation Partners:

The Cecile and Fred Bartman Foundation

**The Harold Simmons Foundation** 

The J.B. and Emily Van Nuys Charities

The Jean and E. Floyd Kvamme Foundation

**Larry Hillblom Foundation** 

#### MEMBERSHIPS AND INDIVIDUAL GIVING

Membership dues and individual giving provide a significant portion of SAA's operating funds each year. In 2006, we achieved increases in individual giving at all gift levels and realized a total increase in this funding category of 25% over the previous year. Leadership's gifts of \$1,000 or more increased by 43%, while average donation per member increased by 14%, as more and more members expanded their support beyond minimum requirements.

Loyal and continued support from SAA's membership and donors enables the organization to address operating needs and provide critical program services

such as the Toll-Free Information Hotline, as well as operation of SAA's website and production and distribution of the *Spondylitis Plus* news magazine.

Jane Bruckel Research Fund SAA Co-Founder Jane Bruckel has been a driving force in championing research to uncover the cure for spondylitis. In June of 2006, in honor of Jane's lifetime of work, the SAA Board of Directors established The Jane Bruckel Research Fund. The fund will be utilized to maintain ongoing research projects as well as to support new research opportunities in the search for a cure for AS and related diseases. This year, as a result of generous contributions to research in past years, SAA was able to continue funding patient recruitment for the AS Family Genetic Study until the second round of funding from the National Institutes of Health (NIH) was approved.

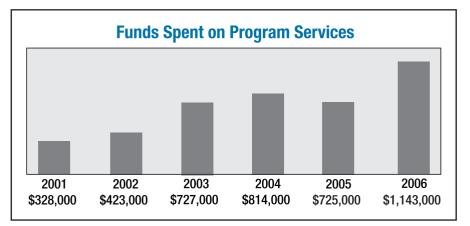


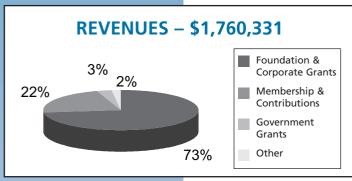


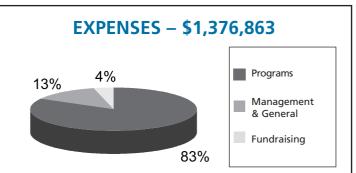
SAA is the only US organization dedicating all of its resources to serving the needs of people affected by spondylitis.



# **FINANCIALS**







All accounts of the Spondylitis Association of America are maintained in accordance with generally accepted accounting principles for not-for-profit organizations as established by the Financial Accounting Standards Board.

Copies of audited financial statements are available upon request.

#### **FOUR-STAR RATING FOR SAA**



Charity Navigator, America's premier independent charity evaluator, has awarded SAA our second consecutive 4-star rating for our ability to allocate and grow our finances efficiently. Fewer than 12% of the charities rated have received two consecutive 4-star evaluations, indicating that SAA outperforms most charities in America in its efforts to operate in the most fiscally responsible way possible.

Sound fiscal management has always been an important part of SAA's commitment to our constituents. This "exceptional" rating from Charity Navigator differentiates SAA from its peers and proves that the organization is worthy of the trust our members and donors have shown us.

In 2006, SAA outperformed most charities in America in the area of fiscal responsibility.

SAA is committed to responsibly generating the income needed to operate efficiently and to provide the programs and services on which our constituents depend. In fiscal 2006, SAA allocated only 4% of our donated revenue to fundraising while demonstrating a 57.6% increase in the number of dollars spent on programs and services. Both of these indices far exceed industry standards and stand as testament to SAA's pledge to make every donation count in the quest to improve the lives of everyone impacted by AS and related diseases.

# THANK YOU FOR SUPPORTING SAA'S MISSION

It gives us great pleasure to acknowledge our donors who have made contributions during the period of July 1, 2005 to June 30, 2006. Our most sincere thanks and appreciation to all our donors who have generously contributed to SAA, but due to limited space we have listed gifts of \$50 or more. It is through the generous support of individuals, foundations and our corporate partners that SAA is able to continue to affect positive changes and make significant advancements in medical research and treatments for those living with AS and related diseases.

Every effort has been made to ensure that this list is accurate and complete, but in the event of an error or omission we extend our apologies and encourage you to contact Susan Jones, Director of Development at 818-981-1616, ext. 231 or by e-mail at susan.jones@spondylitis.org so that proper recognition may be assured in the future.

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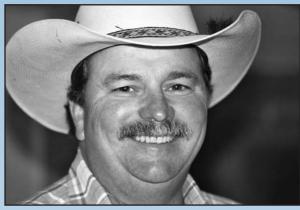
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