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:
DAVID HALLEGUA, MD & KATHERINE CULPEPPER

As 2007 draws to a close, SAA and the spondylitis community have ample cause for celebration. The recent reports from the TASC Genetic Study confirm the identification of two new genes that contribute to AS. The importance of this development cannot be overstated. The two new genes, combined with HLA-B27, account for roughly 70% of the susceptibility toward AS.

In July 2006, SAA joined TASC, (Triple A Spondylitis Consortium) assuming responsibility for nationwide patient recruitment – one of four recruitment sites in the US. Over the past year our efforts have been focused on promoting enrollment, qualifying patients into the study and obtaining blood samples for DNA. Our requests for involvement were answered by many SAA members, and for all of you who participated and got involved, thank you! In addition to TASC leaders Drs. Reveille and Brown, each and every one of you who responded to SAA’s invitation to enroll deserves credit in this success.

As well as news of this momentous advancement, our annual report highlights developments in SAA’s Screening Tool project, a multi-year study designed to produce a web-based questionnaire to assist in diagnosis of the disease. The past year saw considerable progress on this project which you'll read about in these pages.

While promoting research remains a priority for SAA, we’re also pleased to report that significant expansion of SAA patient educational and support programs occurred during the year. The volunteer network of Spondylitis Educational Support Groups grew by an impressive 48%, and in addition, SAA hosted a two-day training seminar for Group Leaders.

Our support also expanded to the younger members of the spondylitis community. Recognizing the special needs of our teen population, SAA created a teen website, S.W.I.F.T (Spondylitis Web Info for Teens). Response from the teen population has been enthusiastic and the site now receives as many as 14,000 hits per month.

Our year ended on a bright note with news that once again SAA has been awarded Charity Navigator’s coveted Four-Star designation for effectively managing our finances, outperforming the vast majority of nonprofits evaluated in terms of governing our finances -- your donations.

Many thanks to all the SAA supporters who have made this past year’s achievements so noteworthy.

Sincerely,

DAVID HALLEGUA, MD                       KATHERINE CULPEPPER
Board Chair                                                       Executive Director

“...research continues to be a priority for SAA...”
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SAA was the first and remains the largest resource for people affected by spondylitis in the United States.
SAA is succeeding in research by addressing the issues that matter most to you.

The Development and Validation of a Screening Tool for Ankylosing Spondylitis

When you told us that earlier diagnosis was needed, we collaborated with industry and researchers to bring about the development of a Screening Tool to aid in early diagnosis. In 2008, after three years of intense work, the tool will be widely disseminated on the Internet.

By answering specific questions relating to type and frequency of back pain and related symptoms, individuals will determine their likelihood of having the disease. In addition to helping people seek an informed diagnosis, the finished product promises rich opportunities for increasing awareness of AS among the general public.

Future patients will no longer need to suffer the loneliness, sense of isolation and pain of an unacceptable 7-10 year diagnosis period.

Emergency Transportation, Care and Handling

When we heard that you were afraid to go to the emergency room because no one knew what you had or would listen to you when you tried to explain it, we collaborated with the editors of a major emergency medicine text book to bring about change.

As of March 2008, the principal text book, Paramedic Care: Principles and Practices (Third Edition), utilized throughout the field of emergency medicine, will contain a chapter on AS and its specific care.

Major Breakthrough in AS Genetic Research

When you asked us what causes AS, we went to our major donors for support, we went to researchers to seek collaboration, and we went to government agencies to find out how to initiate genetic research.

Today, after nine years of effort, through TASC and its collaborative relationships, researchers, with SAA’s support, have achieved the first major breakthrough in AS genetic research in 34 years. The uncovering of two additional genes implicated in the cause of AS has been announced by the TASC team of researchers. The overall known genetic contribution toward AS now stands at about 70%.
These findings fling open the door to a better life for people with AS. They reveal the real potential of earlier recognition of susceptibility, the real potential of improved treatments, and they pave the way to a better future where AS will no longer control our lives and those of generations to come.

**We couldn’t do any of this without your commitment and support…**

When you told us that you wanted to participate in advancing AS research, we came to you for help. You responded. None of these breakthroughs could have been made possible without your help, your commitment, your resources and your courage.

There is always more to learn. We still need your support. But if we keep doing the right things, which we plan to do, we believe with your continued commitment to research, good things will continue to happen to bring about a brighter future for those with susceptibility toward AS and related diseases.

We are on the way and right on track.

**Research has also taught us…**

- About one-fourth to one-half of people with AS also have arthritis in the joints of the arms and legs.
- Osteoporosis is an important complication of AS which, if untreated, can result in a spinal fracture.
- In about five to ten percent of those with psoriasis, arthritis also appears.
- Reactive arthritis is characterized as a rare disease – fewer than 200,000 sufferers.
- About one-fifth of those with psoriatic arthritis will have involvement of the spine.
- One out of every five HLA-B27 positive individuals who are infected by either one of two specific types of bacteria will develop reactive arthritis.
- Approximately one in five people with inflammatory bowel disease (especially Crohn’s disease) will have arthritis in one of the joints of the arms or legs.
- Sometimes juvenile spondyloarthritis can look like other diseases, and doctors must take care to make a correct diagnosis.
- AS affects about two in every 1,000 Caucasians.
The SAA Community is made up of an expanding and evolving group of patients, family, friends, physicians and researchers. In the early days, this community was predominantly interconnected by a diagnosis of ankylosing spondylitis. While AS is the most common form of spondyloarthritis, there are significant numbers of people facing other forms of SpA who needed a place to turn to for information, education and emotional support.

And so, in 1992 SAA’s community expanded to include those affected by psoriatic arthritis, enteropathic spondylitis, reactive arthritis and undifferentiated spondylitis. Many in our community cope with the challenges of more than one of these diseases, either over the course of their disease progression or concurrently.

Defining the size of the spondylitis community is a challenge we continue to face. Until recently, AS prevalence estimates wavered between .1 and .2%; however, new data -- and early diagnosis efforts -- have revealed that the current prevalence could actually be as high as .5%. And if you include the other forms of spondyloarthritis, the percentage climbs to well over 1%. Which means that SpA is in no way a “rare” or even “uncommon” disease, directly affecting over 3 million Americans.

But SAA’s community is bigger still. Like all chronic diseases, SpA affects many more people than just the patients themselves. Each patient is at the center of his or her own personal community of family, friends, co-workers, employers, and loved ones, each experiencing their own challenges in coping with the effects of living with SpA. SAA keeps their specific needs in mind, focusing content of Spondylitis Plus and other materials to address their issues, increase their knowledge and help them to share their perspectives.

In 1996 our ability to serve our community expanded significantly with the development of SAA’s website. More than one million monthly hits on our website confirm that our community is more vast than we first imagined. Weekly, hundreds of thousands of people seek us out to learn more about the disease, whether it be to aid their search for a diagnosis, learn about the genetic implications, read up on the current breakthroughs in medical research or connect with others who are living similar experiences. Better than any other barometer, this significant level of activity attests to the true extent of the SAA community.
INFORMATIONAL PROGRAMS

Whenever we poll the spondylitis community to find out what they most want and expect from SAA, the answer is the same -- information. We strive to provide it in a number of ways.

www.spondylitis.org

SAA's website is the most comprehensive collection of timely information about every aspect of ankylosing spondylitis, psoriatic arthritis, enteropathic spondylitis, reactive arthritis and undifferentiated spondylitis in the country. With over 600 pages of material ranging from research updates to the latest advances in medications, to tips for better managing your disease, www.spondylitis.org is your portal to everything you need to know about AS and related diseases.

S.W.I.F.T.

While our award-winning website provides the single most comprehensive resource in the US for adults affected by these diseases, spondylitis is also a young person's disease. And so, in early March, we launched a sister website, Spondylitis Web Info For Teens (S.W.I.F.T.). At http://teens.spondylitis.org, teens and young adults have a safe haven to gather information about AS and related diseases.

Toll-Free Information Line

While more and more organizations are turning to automated phone trees and voice-mail services, SAA provides a Toll-Free Information Hotline to ensure that your questions will be answered by a knowledgeable, friendly staff member who has the tools to provide assistance when you need it – now.
Spondylitis Association of America

PROGRAMS

EDUCATIONAL PROGRAMS

SAA’s educational programs and services are all designed to empower people to take control of their disease.

Publications & Materials

Straight Talk on Spondylitis
This groundbreaking, internationally recognized book was originally published in 1985 as the first ever educational text written specifically for the spondylitis patient. SAA, in conjunction with our volunteer medical board, has updated and revised this important work to reflect current medical advances, many of which SAA was instrumental in bringing about. This new edition will be partially funded by the JB & Emily Van Nuys Charities and will be available in early 2008.

Brochures
SAA regularly adds new educational brochures to our publications library. By year’s end, SAA had printed 14,000 educational brochures to be distributed to patients and physicians beginning in 2008. This year’s brochures were sponsored by a grant from Amgen & Wyeth.

Exercise DVD Reformat
SAA’s popular exercise video, Back in Action, is being revised and updated. This 60-minute program has been divided into 22 modules that demonstrate a full range of flexibility, stretching and strengthening exercises. The reformatted DVD will be available in January 2008 with funding provided by Centocor, Inc.

Spondylitis Plus
This quarterly publication is mailed to members in over 40 countries, keeping them abreast of breakthroughs in spondylitis research, new treatment options, coping skills and personal stories from those living with spondylitis.

Patient Educational Seminars

SAA’s nationwide Patient Educational Seminars are designed to give all those affected by spondylitis an opportunity to interact directly with the top researchers and clinicians in the field.

This year Seminars were held in Washington DC, Chicago and Los Angeles, with others scheduled in New York, Seattle and Atlanta. The DC seminar was sponsored by Amgen & Wyeth, Abbott and Centocor; Chicago by Abbott and LA by Amgen & Wyeth. The New York and Atlanta programs will be made possible by a grant from Amgen & Wyeth and Seattle will be funded through SAA’s Corporate Partnership Program.

“The SAA seems to put its members first, rather than the organization itself.”

- Los Angeles, CA Patient Educational Seminar Attendee
Continuing Medical Education

In March, SAA co-sponsored a Continuing Medical Education program in conjunction with Cedars-Sinai Medical Center titled, “Medical and Surgical Approach to Spine Disease and Spine Deformity in Ankylosing Spondylitis”. This accredited program will be available to medical professionals on our website for up to two years.

SUPPORTIVE PROGRAMS

We are committed to supporting the spondylitis community by providing the education and information that is critical to successful disease management.

National Support Group Network

SAA’s renewed commitment to the national Educational Support Group network brought forth stellar growth in the program over the past year. The addition of groups in Dallas, Denver, Little Rock, Boise and Spokane contributed to a 48% increase in the number of groups around the country. SAA's expanded presence on the East Coast was demonstrated by the recruitment of new leaders to facilitate groups in Stamford, CT, Summit, NJ, Richmond, VA, Savannah, GA and on New York’s Long Island.

In May, SAA presented our first Support Group Leader Training Session, a two-day event held in Los Angeles. On the first day, Leaders attended an Educational Seminar and heard the experts speak about the medical management of spondylitis, as well as the emotional impact of living with a chronic disease. On the second day, Leaders attended workshops designed to build their confidence in managing group dynamics and to provide information to help their members become active self-managers. The Support Group Leader Training was funded by a grant from Amgen & Wyeth.

Message Boards

Our interactive message boards boast nearly 10,000 registered participants and approximately 1,500 people from all over the world log on daily to seek support, information and to speak to others who understand what it is like to live with spondylitis.

With nearly 11,000 topics on subjects ranging from medication to exercise to family, our message boards are a wealth of information that offer 24/7 support to all who participate.

Medic Alert

SAA has partnered with MedicAlert to provide a discount for our members, beginning in early 2008, to obtain the ID bracelets and other products and services that can save lives in case of emergency. We've also collaborated with Brady Publishing to include information about the proper handling of spondylitis patients in the textbooks that are used to train emergency personnel around the country.

“Support group meetings allowed me to cope so much better as I was finally face to face with my peers in the battle to live with the effects of spondylitis.”

- Phoenix, AZ Support Group Member
The Corporate Partnership Program provides a way for the Spondylitis Association’s pharmaceutical partners to positively impact the spondylitis community by contributing funds to the organization’s general operating budget. We would like to thank the following partners who played a vital role in helping to fund SAA’s educational programs and services* through their partnerships. Partnership levels range from $20,000 to $80,000.

Premier Corporate Partners

Abbott

AMGEN

Wyeth

Associate Corporate Partner

centocor inc

Supporting Corporate Partner

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*The Spondylitis Association of America is solely responsible for the content of all educational programs and services.

FOUNDATIONS

Support received from foundations helps the Spondylitis Association advance its 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. We are grateful to the following foundations for providing support in 2007.

The Cecile and Fred Bartman Foundation

Blank Charitable Foundation

Chapman & Associates Charitable Foundation

Community Foundation Alliance

Kautz Family Foundation

The Koven Foundation

Peravid Foundation
DEVELOPMENT

Membership and Individual Giving

Advancing medical research and improving the lives of SpA patients everywhere means responsibly raising the funds needed to support scientific study and provide educational and emotional support to the community. At SAA, this is a substantial commitment. The most significant source of financial support comes from membership gifts and contributions from individuals.

This year, individuals’ gifts to SAA reached $472,970 and accounted for 46% of our overall revenue. Leadership gifts of $1,000 or more increased 37% while the average donation rose 10% as SAA’s reputation for responsible fiscal management continues to grow.

Jane Bruckel Research Fund

Named for our Co-Founder and long-time Executive Director, now retired, the Jane Bruckel Research Fund was established in 2006 to provide funding for opportunistic research projects that are in line with SAA’s core mission. To date, over 300 contributions have been received totaling over $78,000. At year’s end, the first grant was made from this fund to support the development of a visual assessment tool that will aid in fostering early diagnosis.

Jane Bruckel Tribute Dinner

In September 2006, SAA hosted the Jane Bruckel Tribute Dinner in honor of Jane’s contributions to the spondylitis community. Masters of Ceremonies and SAA Board Members David Hallegua and Brian MacKenzie presided over an evening of tributes, testimonials and reminiscences in honor of Jane’s body of work. Thanks to the commitment of one woman, supported by thousands of SAA members and friends, many spondylitis patients now live more active, more rewarding lives. The Jane Bruckel Tribute Dinner provided a small opportunity for the spondylitis community to show her our appreciation.

Fourth Annual eBay Auction Reaches New Heights

SAA’s fourth annual online auction proved to be our most successful yet. With over 100 items on the block, SAA members and friends entered into the friendly competition to see who would emerge victorious and walk away as the winning bidder. This next year, we’ll be calling on the entire SAA community to help procure auction items and to get the word out about this growing event.
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 2007, SAA allocated only 5% of our donated revenue to fundraising and only 14% to management and general operating overhead. 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.

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.

Charity Navigator, America’s premier independent charity evaluator, has awarded SAA our THIRD consecutive 4-star rating, for our ability to efficiently allocate and grow our finances. Only 9% of the charities rated have received three consecutive 4-star evaluations, indicating that SAA outperforms the vast majority of charities in America in its efforts to operate in the most fiscally responsible way possible.

This “exceptional” rating from Charity Navigator differentiates SAA from its peers and demonstrates to our members, donors and friends that the organization is worthy of the trust they have shown us.
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, 2006 to June 30, 2007. Due to limited space, we have only 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 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 Diann Peterson, Director of Membership & Communications at 818-981-1616, ext. 226 or by email at diann.peterson@spondylitis.org so that proper recognition may be assured in the future.

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