

**Spondylitis
Association
of America™**

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.

For over 20 years, the Spondylitis Association of America has been behind every major milestone achieved in spondylitis education, research and treatment.



Hundreds of supporters gathered in California for the Fifth Annual "Walk in the Park: On Your Feet to Defeat AS."

YEAR IN REVIEW



a message from
THE BOARD CHAIR AND THE EXECUTIVE DIRECTOR

As a leader in the quest to cure AS and related diseases, the Spondylitis Association of America (SAA) has been at the forefront of every major advancement in education and research for these diseases. Today, SAA continues to be the respected voice of the spondylitis community as we support collaborations among prominent researchers and clinicians as a means of accelerating research and fostering a better life for people with AS and related diseases.

There is no doubt that this has been an extraordinary year of progress. SAA and research partners working on the AS Family Genetic Project announced the discovery of seven regions on chromosomes that contribute to the cause of AS. This breakthrough discovery paves the way for identifying the exact genes that influence the cause and severity of AS.

We also spent the year working behind the scenes to prepare for a new research endeavor; that is, the development of a screening tool to identify people at risk for AS. The goal of the project is to develop a questionnaire that will differentiate between AS and other causes of back pain to facilitate earlier diagnosis.

SAA's collaboration among researchers is exemplified by our partnership with SPARTAN, a network of medical professionals in North America who are dedicated to research, awareness and treatment of spondylitis. SPARTAN's work is important to the future of research in this country, because they are educating the next generation of rheumatologists and helping to foster an interest in our group of diseases. We are proud to have organized the first SPARTAN meeting several years ago and to work side by side with these preeminent researchers.

2005 also saw an increase in media attention for AS and related diseases. Selected findings from the AS Life Impact Study were published in a major medical journal and received far-reaching press coverage including the BBC in Great Britain.

Perhaps most important are our continuing efforts on a daily basis to provide information, networking opportunities and resources to individuals affected by these diseases in order to empower patients to take charge of their lives and effectively manage their disease.

These and all of SAA's groundbreaking achievements would not have been possible without the generous financial support of our donors. Thank you for believing in the importance of our mission and for partnering with us to lead the quest to make the world a better place for all those living with spondylitis.

Sincerely,



DAVID HALLEGUA, MD
Board Chair



JANE BRUCKEL, BSN, RN
Co-Founder and Executive Director

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

SAA has an expert team of advisors, the Medical and Scientific Advisory Board (MAB,) to assist in providing credible and cutting-edge medical and scientific information so that patients and their doctors can decide on the best course of action in treating the disease. The expertise of our MAB members, under the leadership of Dr. Walter Maksymowych, is far reaching. Many members are both researchers and clinicians in the field of AS and related diseases, and many serve on the editorial boards of prestigious medical journals as well as national and international professional medical societies.

Both as individuals and as a group, our medical board members serve SAA's constituency in a variety of roles. This year, MAB members created a "Rapid Response Team" to assist in answering patient questions and to provide important position statements regarding the changing landscape of spondylitis medications and treatments. Members have consulted with SAA staff to develop important educational brochures which were distributed to patients and rheumatologists. They volunteered their time to speak at Patient Educational Seminars and Support Group meetings. Most importantly, they are instrumental in leading the research studies to find the cure for spondylitis. Several members of the MAB have taken leadership roles in the development stages of two important projects – a co-sponsored international meeting with the National Institutes of Health, which will focus on uncovering the unmet needs in spondyloarthritis research, and a research project to develop a screening tool for AS.

We owe a debt of gratitude to the SAA Medical and Scientific Advisory Board for all of their efforts and generosity of spirit on behalf of our constituency.

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SAA is
developing a
screening tool
to identify
people at
risk for AS.

SAA BOARD OF DIRECTORS

SAA's Board of Directors, led by Dr. David Hallegua, is comprised of a talented group of volunteer leaders dedicated to SAA's mission to be a leader in the quest to cure AS and related diseases and to empower those affected to live life to the fullest.

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Mimi Kennedy *Actress, Activist and Author, Los Angeles, CA*



SAA Board of Directors- Front row: Jane Bruckel, Co-Founder and Executive Director; David Hallegua, Chair; Ellen Carroll, Secretary; and Brian MacKenzie, Vice Chair. Back row: Leslie Kautz; Bob Ulrich; Mike Supancich; Jeff Horn, Treasurer; and Kim Cooper. Not pictured: Earl Broidy; David Eldridge; Ann Howat; John Pennington; and Tom West.



SAA conducted the AS Life Impact Study, the only extensive survey of AS patients in the country.

For over 20 years, SAA has encouraged and facilitated collaborations among prominent researchers as a means of accelerating advances in spondylitis research, diagnosis and treatment. 2005 was a breakthrough year.

AS FAMILY GENETIC STUDY – This year, we are closer to our goal of finding a cure than ever before as we celebrate a major breakthrough in AS research. For the first time, researchers have identified the regions on seven chromosomes that contribute to the cause of AS.



Six years ago, SAA provided the seed money to launch the first major genetic study of AS in North America. The National Institutes of Health (NIH) followed with a multi-million dollar grant to expand the project, enabling collaboration among ten university medical centers and SAA, working to identify the genetic causes of AS. SAA spearheaded the collection of data from 400 families with sibling pairs who have AS. With this important collection of data, researchers, under the guidance of Dr. John D. Reveille, Principal Investigator, were able to proceed with the research, which led to this

remarkable discovery. Now that the regions are known, SAA is preparing to fund and recruit for the next phase of research – to find the exact genes that determine the cause and severity of AS.

NATIONAL AS LIFE IMPACT STUDY – This year the results from the National AS Life Impact Study were analyzed by a team of researchers led by Dr. Millicent Stone at the University of Toronto. The findings, which highlighted a need for increased awareness and earlier treatment of the disease, were published in the June 15, 2005 issue of the highly respected peer review journal, *Arthritis Care and Research*.

This study, the first of its kind, was commissioned by SAA in 2002. Over 2,000 adults with AS participated in the survey. By surveying individuals with AS, the findings revealed that many people visit multiple doctors before receiving a correct diagnosis and that adults with childhood onset disease experience much greater impairment during later life. Dr. Robert Warren, one of the publication authors and Chief of Rheumatology Services at Texas Children's Hospital, summed it up best when he stated, "Many children can have arthritis of the spine for years, but it can go overlooked and untreated. We need to diagnose their illness early and provide appropriate medications and other therapy." With new and effective medical options available for AS, early diagnosis and proper medical care can have a significant impact on managing the disease.

SCREENING TOOL FOR ANKYLOSING SPONDYLITIS – This year, SAA began working with researchers under the direction of Dr. Michael Weisman, Principal Investigator, to design the study protocol for a screening tool that will identify people at risk for AS. This important tool will help identify new cases, greatly improve early diagnosis, encourage care-seeking among patients who learn that they are at risk for AS and help raise awareness about the disease. The screening tool is expected to be launched in 2007.

SAA sponsored
the first major
genetic study
of AS in North
America.

PROGRAMS AND SERVICES

Maintaining excellence in patient education traditionally has been a cornerstone of SAA's mission. Through our efforts we strive to empower those affected by spondylitis to successfully manage the disease and to achieve optimal health.

PUBLIC AND PATIENT EDUCATION – SAA provides information through publications, videotapes, an interactive website and a toll-free information line. SAA's award-winning website continues to offer patients more than 400 pages of content offering in-depth coverage of advancements in research, diagnosis and treatment of AS and related diseases. The message boards remain a popular and highly frequented meeting place. SAA's website receives over one million hits per month and remains the number one portal for those seeking information about AS and related diseases. Over 50,000 educational publications were distributed which included SAA's flagship bi-monthly magazine, *Spondylitis Plus*, the ever-respected *Family of Related Diseases* brochure, the updated *Your Guide to Living with Spondylitis* booklet and *The Rheumatology Directory* containing more than 650 patient recommended rheumatologists.

COMMUNITY BASED PATIENT PROGRAMS – SAA continues to provide the only large-scale educational seminars in the U.S. for patients to learn more about living with AS and related diseases as well as hear about promising therapies and receive updates on cutting-edge research. During the 2005 fiscal year, four regionally based patient educational seminars were held in Chicago, Los Angeles, Portland and San Antonio. These seminars brought patients, families and friends together with leading experts in the field of spondylitis. Drs. John D. Reveille, Elaine Adams, Muhammad Asim Khan, Perry Nicassio and Atul Deodhar, hailing from prestigious medical centers nationwide, engaged attendees during the half-day seminars. The seminars concluded with interactive sessions, which included a "question and answer" period and an opportunity for attendees to mingle and share experiences with each other and the experts. SAA also offered education and networking opportunities through 22 patient support groups in seventeen states.

CONTINUING MEDICAL EDUCATION – Through an education grant in partnership with the Albert Einstein College of Medicine, SAA was able to provide 500 physicians with Continuing Medical Education on the *Diagnosis and Management of AS*. Continuing Medical Education programs included a series of twelve live educational teleconferences, as well as medical education courses available on the SAA website. In addition, SAA provided information and publications on spondylitis from its exhibit at the Annual Scientific Conference of the American College of Rheumatology.



Guests applaud speakers at a Patient Educational Seminar.

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

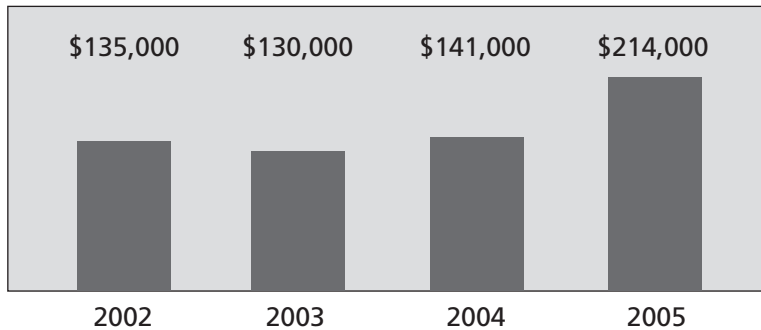
★ ★ ★ ★ **FOUR STAR RATING FOR SAA** ★ ★ ★ ★

The Spondylitis Association of America is committed to responsibly generating the income needed to operate efficiently and to provide the programs and services upon which our members depend. This year that commitment was recognized with a Four-Star rating from Charity Navigator, America's premier evaluator of nonprofit organizations. The rating is Charity Navigator's highest and most prestigious, signifying that SAA outperforms most other charities in America in its efforts to efficiently manage its finances. Fewer than one-fourth of the charities they evaluate are afforded this level of distinction.

YEAR OF THE INDIVIDUAL GIVER

Because of the generous support of our donors, the Spondylitis Association of America is able to accelerate advances in education, research and treatment for AS and related diseases.

INDIVIDUAL GIVING



Through the generosity of our individual, foundation and corporate donors, over \$1 million was raised this year to advance the quest for a cure and to provide services to empower those living with spondylitis to live life to the fullest. We are deeply grateful for the generous support we receive from all our donors. The biggest growth this year came from individual donors who are the lifeblood of our organization. Contributions from individuals rose 52%, making the year's fundraising efforts a tremendous success. This was truly the "Year of the Individual Giver" and we dedicate 2005 to you.

SAA receives
Charity
Navigator's
highest
and most
prestigious
rating.

Other fundraising efforts which generated revenue included:

• **A WALK TO REMEMBER**

In May, hundreds of people gathered at scenic Lake Balboa in Southern California to take part in SAA's Fifth Annual "A Walk in the Park: On Your Feet to Defeat AS." This year's event was attended by celebrity host Mimi Kennedy and included presentations by LA City Councilman Jack Weiss, SAA Board Chair Dr. David Hallegua, and SAA Medical and Scientific Board Member Dr. Michael Weisman on topics such as how AS impacts the family, advances in AS medications and treatments and the ongoing genetic research that will lead to a cure.

• **GOING, GOING, GONE!**

2005 marked the rollout of SAA's first online e-Bay auction. Over the course of one week, members and non-members alike fought to outbid each other for the

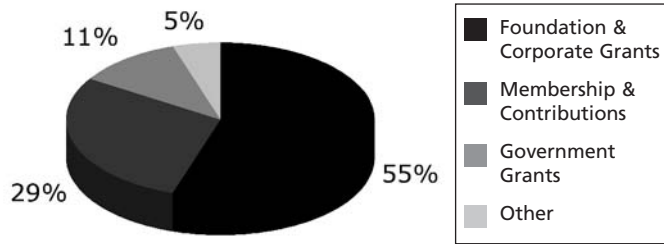
chance to walk away with autographed memorabilia from sports legends, musical greats, stars of stage and screen as well as exotic international vacation packages.

• **STAND TALL – STOP AS**

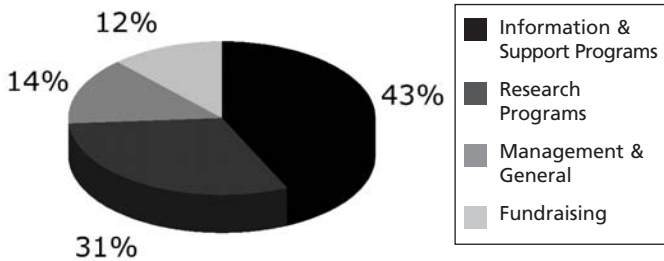
Also in 2005, SAA began marketing our Stand Tall to Stop AS silicone bracelets. Our first batch was sold out before we even had them in stock and they continue to be a best seller. Today, almost 2,500 bracelets are being worn by patients, their families and friends, raising awareness and helping to educate people about spondylitis.

And so, despite a difficult economic climate for nonprofits nationwide, SAA has enjoyed a year of tremendous growth. We are deeply grateful to our committed supporters who have made that and all our successes possible.

REVENUES – \$1,110,010



EXPENSES – \$979,183



THE GREG FIELD AWARD

In April 2005, SAA presented the first Greg Field Award to Dr. Muhammad Asim Khan. The award is named in honor of AS patient and Buick aficionado Gregory Fallowfield (Greg Field to his friends) whose refusal to allow AS to limit or control his destiny has been an inspiration to countless AS patients and their families. Dr. Khan exemplifies everything Greg Field stood for and is uniquely deserving of the honor.



Dr. Muhammad Asim Khan

As a world-renowned researcher and respected clinician, Dr. Khan has worked tirelessly to advance the medical and scientific community’s understanding of AS and related diseases for more than 30 years. As an AS patient, Dr. Khan has weathered the challenges of living with a chronic disease for more than 45 years.

Greg Field once said, “that two things were important to achieve everlasting meaning in one’s life. The first was to discern early in life the things that make you happy, the things that you enjoy doing, and then just do them. The second was to do something for others -- something of a lasting nature that would make their lives happier so that they, in turn, could find meaning in their own lives.”



Dr. Khan is a living testament to the philosophies of Greg Field and we at SAA are proud to honor him as the first recipient of the Greg Field Award.

SAA is the only U.S. organization dedicating all of its resources to serving the needs of people with spondylitis.

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, 2004 to June 30, 2005. 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.

\$50,000

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The Larry Hillblom Foundation

\$20,000

GOLD CIRCLE

The Cecile & Fred Bartman Foundation

\$5,000 - \$10,000

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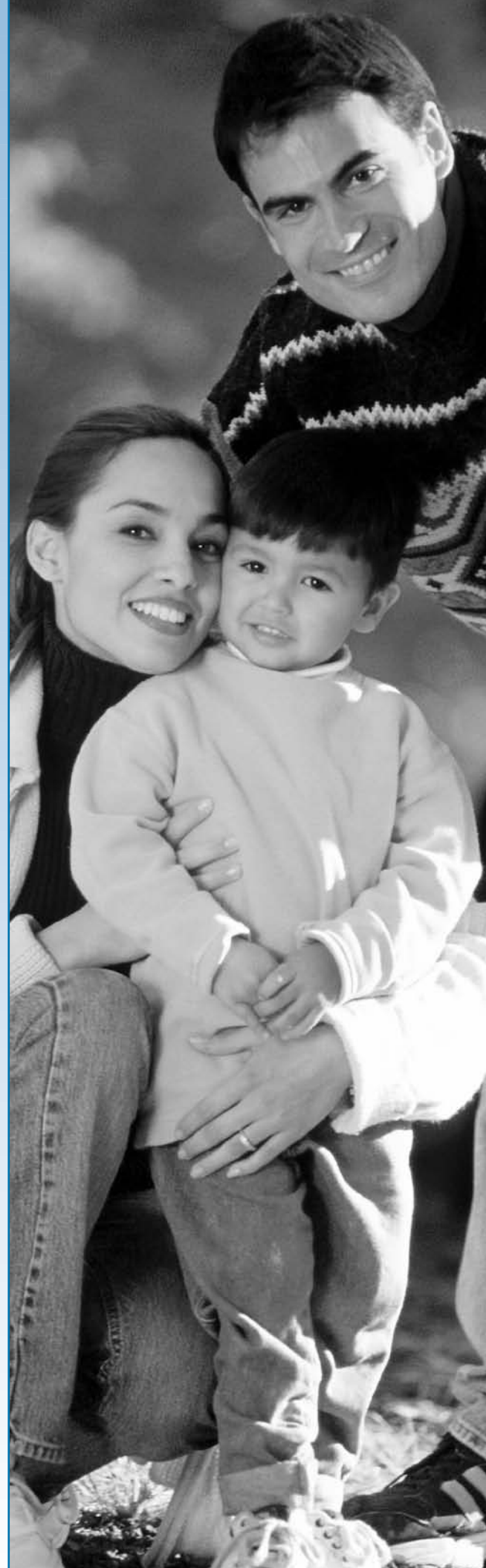
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