This report represents Spondylitis Association of America’s responses to Charting Impact, a joint project of BBB Wise Giving Alliance, GuideStar USA Inc, and Independent Sector. Charting Impact uses five simple yet powerful questions to encourage strategic thinking and help organizations share concise information about their plans and progress toward impact.

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<td><a href="http://www.spondylitis.org">http://www.spondylitis.org</a></td>
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**Mission:**
To be a leader in the quest to cure ankylosing spondylitis and related diseases, and to empower those affected to live their lives to the fullest.

The content of this Charting Impact Report is the sole product and responsibility of Spondylitis Association of America. This report does not in any way represent an endorsement from Independent Sector, BBB Wise Giving Alliance, or GuideStar, nor does it represent fulfillment of the BBB Wise Giving Alliance’s *Standards for Charity Accountability*. For more information on Charting Impact, visit [www.guidestar.org/chartingimpact](http://www.guidestar.org/chartingimpact)
1. What are we aiming to accomplish?

The Spondylitis Association of America was founded in 1983 to address the unmet needs of people affected by ankylosing spondylitis, a crippling form of spinal arthritis that strikes young people, by disseminating educational information, advancing medical and scientific research and providing emotional support programs. Prior to SAA's inception, there was no resource for educational materials, no patient support networks, and little to no medical research was being undertaken in the United States. SAA was the first and remains the largest resource in the US for people affected by ankylosing spondylitis and its related conditions. For 30 years, SAA has provided patients and their families with the most up-to-date medical information as well as direct access to the thought leaders in the field of spondyloarthritis. SAA's Strategic Plan supports and drives a vision of a world free from the pain and disability of ankylosing spondylitis and related diseases and encompasses three distinct areas of focus: • Serving the diagnosed by means of education and support • Serving the undiagnosed by championing accelerated diagnosis • Advancing medical research to uncover the causes, develop more effective treatments and ultimately discover a cure

2. What are our strategies for making this happen?

Goal #1: Serving the diagnosed. Long-term strategy: Create and maintain support and educational programs for those affected. Near-term activities: • Development of SAA's Management Tool for Spondylitis -- the world's first cross-platform application / website that will allow people with spondylitis to track their symptoms, medications, and much more. • Treatment guidelines -- SAA, in conjunction with SPARTAN and the ACR, is developing practice guidelines in spondyloarthritis to reduce inappropriate care, minimize geographic variations in practice patterns, and enable effective use of health care resources. • Spondylitis.org and SWIFT - Spondylitis Web Info for Teens -- SAA's primary websites receive more than 300,000 unique visitors per quarter and are our primary avenue of reaching the 2.7 million adults in the US with spondyloarthritis. • Support Groups -- SAA maintains Support Groups in 30 states and provides extensive training to Support Group Leaders so that they are able to educate, inform and support the patients and family members who attend meetings across the country. • Educational Materials -- SAA produces the largest library of print and audio/video educational materials in the field of spondylitis in the US. • Spondylitis Plus -- SAA's flagship, advertising-free news magazine provides news and information to the spondylitis community • Managing Patients in an Emergency Setting -- SAA's Emergency First Responder Education Program provides critical training to EMTs, and other first responders in the proper care and handling of patients with neck and/or spinal fusion. Goal #2: Serving the undiagnosed. Long-term strategy: Reach out to new professional and patient populations to raise awareness of the disease. Near-term activities: • BackPainTest.org -- In July 2011, SAA's Screening Tool for Ankylosing Spondylitis went live on its dedicated website. • Attendance at the American College of Rheumatology's Annual Scientific Meeting -- Each year, SAA joins well over 10,000 clinicians and researchers where advances in disease management and research are shared. Goal #3: Advancing medical research. Long-term strategy: Facilitate research, collaborate with researchers, and providing patients the opportunity to participate in clinical trials. Near-term activities: • Spondylitis Patient Registry. The registry will be a compilation of three existing patient databases that have been used in ankylosing spondylitis research. • TASC Genetic Study -- SAA provided the seed money that led to the creation of the TASC Genetic Study (Triple A Spondylitis Consortium) whose researchers, have identified multiple genes that increase the risk of developing spondylitis.

3. What are our organization's capabilities for doing this?

Prominence in the field. SAA is the only nonprofit patient advocacy organization in the United States dedicating all of its resources to improving the lives of those affected by spondylitis. As the undisputed frontrunner in spondylitis, SAA enjoys a worldwide reputation for excellence and is highly regarded among clinicians, researchers and the constituents we serve. Medical and Scientific Advisory Board (MSAB). SAA's MSAB is composed of many of the most highly regarded spondylitis thought leaders in North America. This panel of volunteer physicians ensures that the medical and scientific information SAA
the TASC genetic study uncovers three variants in the RUNX3, LTBR-TNFRSF1A and IL12B regions of the genome. In 2010, two more genes implicated in AS, ANTXR2 and IL1R2, are discovered by the TASC genetic study. In 2009, SAA completes development and production of the first-ever training video for nationwide recruitment of patients and families for the study. Together with HLA-B27, these genes account for roughly 70 percent of the overall cause. In 2008, TASC Genetic Study identifies two new genes, ERAP1 and IL23R, that play a role in susceptibility to spondylitis. This is the most significant breakthrough in AS research since HLA-B27 was uncovered 34 years ago and SAA played a significant role in making the study possible. SAA oversaw the nationwide recruitment of patients and families for the study. Together with HLA-B27, these genes account for roughly 70 percent of the overall cause. In 2009, SAA completes development and production of the first-ever training video for emergency first responders, titled "Ankylosing Spondylitis: Managing Patients in an Emergency Setting, A Primer for First Responders". The program is accredited by CECBEMS (Continuing Education Coordinating Board for Emergency Medical Services); In 2010, two more genes implicated in AS, ANTXR2 and IL1R2, are discovered by the TASC genetic study. In 2011, the TASC genetic study uncovers three variants in the RUNX3, LTBR-TNFRSF1A and IL12B regions of the genome.

4. How will we know if we're making progress?

Program evaluation to determine future of each program is ongoing and vigorous. Indications include cost vs. benefit, return on investment, whether the program continues to be in line with the mission and whether resources are available to sustain or expand the program. In terms of serving the patient population, both diagnosed and undiagnosed, website statistics, printed material distribution numbers, conversion rates and a host of other indicators are examined to determine the relative merit and potential impact of each program. The number of people attending patient seminars, support group meeting and availing themselves of SAA's free educational resources are also tracked. Data collected from on-site patient satisfaction surveys is rigorously analyzed and used to plan future programs. SAA's successes in the research area are evaluated based upon verifiable achievements in the understanding of causative elements of the disease (number of associated genes identified), the number and reach of scholarly articles accepted to peer reviewed journals and SAA's contribution to extending the knowledge base of spondyloarthritis in the US (such as providing the template used by the CDC to determine SpA prevalence in the National Health and Nutrition Education Study.) The impact of our work in the field of research is also quantified and evaluated by the number of patients/controls recruited to participate in research studies and surveys.

5. What have and haven't we accomplished so far?

In 1985, SAA produces the first comprehensive patient self-management book, Straight Talk on Spondylitis, which receives high praise from medical professionals worldwide. In 1999, SAA and the University of Texas (UT) form the North American Spondylitis Consortium (NASC) - a consortium of 10 university medical centers and SAA. The National Institutes of Health provide a $6.5 million grant and designate SAA as clinical coordinating center for the AS Family Genetic Project. In 2005, SAA begins supporting a second major research project. "The Development of an Online Screening Tool to Identify People at Risk for AS", with Dr. Michael Weisman as Principal Investigator. In 2008, TASC Genetic Study identifies two new genes, ERAP1 and IL23R, that play a role in susceptibility to spondylitis. This is the most significant breakthrough in AS research since HLA-B27 was uncovered 34 years ago and SAA played a significant role in making the study possible. SAA oversaw the nationwide recruitment of patients and families for the study. Together with HLA-B27, these genes account for roughly 70 percent of the overall cause. In 2009, SAA completes development and production of the first-ever training video for emergency first responders, titled "Ankylosing Spondylitis: Managing Patients in an Emergency Setting, A Primer for First Responders". The program is accredited by CECBEMS (Continuing Education Coordinating Board for Emergency Medical Services); In 2010, two more genes implicated in AS, ANTXR2 and IL1R2, are discovered by the TASC genetic study. In 2011, the TASC genetic study uncovers three variants in the RUNX3, LTBR-TNFRSF1A and IL12B regions of the genome.
as well as additional areas that also seem to play a role - PTGER4, TBKBP1, KIF21B and CARD9. Other genetic suspects include CDKALI, TRADD and STAT3. In 2012, the release of the first ever epidemiology study data conducted by the CDC in the US, and supported by the SAA and by SPARTAN. The CDC researchers used the data and statistical methodology from the SAA Screening Tool for Ankylosing Spondylitis as a foundation for the patient questionnaire that was developed by the CDC for the 2009/2010 study. To-date, manuscripts authored by the CDC researchers, Drs Reveille and Weisman have been accepted for publication by JAMA and by Arthritis and Research, the ACR peer review journal. Additional manuscripts are forthcoming. In 2013, SAA completed Phase I of a national patient registry on ankylosing spondylitis. By combining three existing patient databases that have been used in research, the composite database can look at thousands and potentially tens of thousands of patients and be able to track health trends, disease severity over time, age, gender, race and many other factors to improve understanding of the disease.