Dear Friends:

It was a little over 35 years ago that a group of volunteers recognized a need for people impacted by spondyloarthritis that was not being met. Imagine what this small group of caring and compassionate individuals envisioned when they embarked on creating a community where people impacted by a “disease with a funny name” receive support, information, education, and be represented within a very long list of social causes facing the American public. It’s daunting and humbling.

Yet, here we are today, 35 years later. The Spondylitis Association of America continues to stand as proof that a group of caring individuals can turn their hopes, dreams, and vision into something amazing and life-changing.

PAST. PRESENT. FUTURE.

Our story is filled with heartfelt memories of the many people we’ve accompanied on their journey with this challenging disease. We’ve grown so much over the years and will continue to grow in the foreseeable future. However, we will always be rooted in our core values: we listen; we care; we support; we encourage.

Thank you so much for your continued support throughout the years and for allowing us to be your trusted resource and community.

L to R: Current SAA CEO Cassie Shafer; Former SAA Executive Directors Jane Bruckel & Laurie M. Savage

OUR 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.

We listen.

We care.

We support.

We encourage.

OUR SHARED VOICES
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Jane Bruckel, BSN, RN
Co-Founder of SAA, first President of the Board of Directors and the first Executive Director

Harry Bruckel, CPA
Volunteer accounting consultant from SAA’s inception through 2005

Our Board
The Spondylitis Association’s volunteer Board of Directors is made up of recognized leaders across many areas of expertise. They represent the broad diversity of our membership and contribute significant amounts of time, talent, and energy to further the mission of the organization.

THE SAA TEAM

Cassie Shafer
Chief Executive Officer

Richard Howard, MBA
Chief Mission Advancement Officer

Diann Peterson, CFRE
Chief Philanthropy Officer

Elin Aslanyan
Director of Programs, Editor in Chief

Jason Blackwell, MBA
Director, Brand Experience & Public Affairs

Sean Ewert
Director of Philanthropy

Kristine Callender, MPH, CHES
Programs Manager

Ryan Miyamoto
Web Developer & Content Manager

Manny Caro
Development & Annual Giving Manager

John Highberger
Operations Manager

Cynthia Rodriguez, MPA
Programs Coordinator

Helene Hart
Membership Associate

Our Team
The Spondylitis Association’s staff members are passionate professionals with a wide range of knowledge and skills and come from a multitude of lived experiences and backgrounds. We are held together by our common goals of living out SAA’s mission to create and deliver lasting change for all people within our community whose lives have been impacted by spondyloarthritis.
SAA continues to identify and support ground-breaking research projects through its SAA/Bruckel Early Career Investigator Award in AxSpA (ECI) and additional grants for exploratory research. The ECI award, which began in 2011, is instrumental in recognizing researchers for their outstanding contributions to the care and understanding of patients living with spondyloarthritis.

To date, SAA has invested nearly $1 million to support promising and innovative spondyloarthritis research and remains committed to supporting additional research projects for the foreseeable future including exploratory and stop-gap research grants. Recipients of such funding include Dr. Lianne Gensler, Dr. Joel Taurog, and Drs. Mark Asquith and James Rosenbaum. These research projects include: evaluating children at increased risk of developing spondyloarthritis based upon a family history of AS and positive HLA-B27 marker; examining the various alleles of HLA-B27 to potentially provide new information that could help explain why some HLA-B27 is associated with AS while some HLA-B27 is not; and exploring the potential role for fungus or yeast in the pathogenesis of spondyloarthritis.

Dr. Maureen Dubreuil and Dr. Kristine Kuhn, PhD were also both named as ECI recipients in Spring 2018 and awarded a $20,000 grant each to continue their research efforts. Dr. Dubreuil’s research examines the complications of spondyloarthritis and the side effects of treatment. Dr. Kuhn’s clinical and research interests are related to spondyloarthritis with a special emphasis for those with overlapping Inflammatory Bowel Diseases (IBD).

SAA continues to advance the belief that supporting research will lead to an eventual cure. In the short-term, insights gained from these studies should also empower and engage clinicians and others in the medical community with opportunities to critically evaluate information such as patient interviews, physical exams and laboratory tests to formulate a diagnosis and devise more treatment options.
SPONDYLOARTHRITIS AWARENESS MONTH

During the month of April, SAA initiated a series of activities to drive awareness of spondyloarthritis by engaging both the general public and medical community. The 2018 multi-channel campaign included a toolkit for constituents to request official Proclamations of April as SpA Awareness Month by their Mayor and a pledge to distribute key messages through social media.

Key messaging for this year were geared toward educating the front-line medical community on recognizing the symptoms and knowing when to refer to rheumatology; emphasizing that the disease is not restricted to only certain ethnicities or genders; the importance of funding research; and empowerment for those who are living with the disease. Spondylitis Awareness Month was first championed in 2009 by Michael Smith, an SAA lifetime member, tireless patient advocate, and creator of the beloved Spondyville website. Mr. Smith was hugely instrumental in spondylitis having its own month. Sadly, Mr. Smith passed away on December 6, 2016 at the age of 65, but his voice and advocacy efforts are still reflected and echoed within the annual awareness campaigns observed every year.

WORLD AS DAY

Each year, SAA and advocates from around the world collectively promote awareness of ankylosing spondylitis and mobilize supporters to take action. Our theme for 2018 was #GoBlue4AS. We encouraged supporters to wear blue, take a selfie, and post the #GoBlue4AS hashtag on their social media accounts.
PATIENT SUPPORT & EDUCATION

SAA currently sponsors and provides guidance to 39 active support groups

SpA Patient Educational Seminar – Denver, CO (April 28, 2018)
The program featured Rheumatologist Liron Caplan, MD, PhD and Clinical Health Psychologist Jana Bolduan Lomax, PsyD. This program was streamed live online and recorded for archival.

SAA attended and exhibited at several medical conferences
- The SPARTAN Annual Conference (Spondyloarthritis Research and Treatment Network) in Boston, MA
- PriMed Southwest 2018 Regional Conference in Houston, TX
- PriMed West 2018 Regional Conference in Anaheim, CA
- The European League Against Rheumatism (EULAR) Annual Conference in Amsterdam, NL
- The Rheumatology Nurses Conference – Fort Worth, TX

This AS Life Live! (New episodes and two bonus episodes were released in 2018.)
This educational video series is hosted by Dan Reynolds, lead singer of the Imagine Dragons rock band. The program is a collaboration between the Spondylitis Association of America, Novartis Pharmaceuticals Corporation, and Dan Reynolds.

SAA updated several educational brochures.
We were a grassroots organization and run by all volunteers for the first four years. Initially, there were differing opinions on what we should do first: fund research, educate patients and medical professionals, or remain a support group.

Since no information had been available from any source, most of us were desperate for information about our disease. We started compiling copies of articles on the disease for our "library." These reprints and copies of articles were sent by our doctors and members. Our biggest source of articles was a member who had access to the medical library at UC Davis. We indexed the articles and made the list available for members to order copies. I was kept busy filling these orders. I'd have to go back and forth to have copies made at a business down the street and then back home to fulfill the order from our office, which was in my home. In fact, our first corporate contribution was a copy machine for the home office so that I wouldn't have to spend time going back and forth.

When we first got together and shared our experiences, we all expressed anger at the medical profession for the years of misdiagnoses. Each of us had been told various things like: “You don’t have arthritis because you’re too young,” or “It’s all in your head,” or “Your symptoms are like ankylosing spondylitis, but you can’t have it because you’re a woman,” etc. So, we set out to educate doctors on the signs and symptoms of early disease.

And I think we did a pretty good job of, at least, creating awareness amongst rheumatologists. Our first symposium was attended by 100 rheumatologists eager for information. A couple of years later, we sent a free copy of our comprehensive patient book, “Straight Talk on Spondylitis,” to every rheumatologist in the country.

I remember the first couple of times we had a booth at the annual meeting of the American College of Rheumatology. Many doctors who came by our booth made encouraging comments such as saying that it was about time that an organization formed for ankylosing spondylitis. But some doctors, loyal to another organization, said that we weren’t needed.

Through the years, we expanded to programs aimed at doctors and medical professionals from other fields. But even with all those years of effort, I am still saddened every time that I hear that someone has a delay in diagnosis. "I understood the needs of the patient population we served. The programs, projects, goals and direction of the organization, all mirrored our personal experiences."

JANE BRUCKEL
SAA CO-FOUNDER
And there are still women being told today that it is “a man’s” disease. I continue to believe in the importance of a two-pronged approach for bringing about early diagnosis. One is through education/awareness of doctors, PTs, etc. and the other is through research to identify a diagnostic tool.

At the beginning, we recognized that research was badly needed, but we didn’t have a clear vision on how to fund it. It wasn’t until years later when our organization had more clout with the National Institutes of Health. I met with the Director of the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS) and declared, “You don’t know us now, but you will. We’re going to jump-start research in this country and be a leader in the quest to cure AS and related diseases.”

Being the first was not an easy path. I had a lot of challenging adventures along the way, but I always believed in asking people for advice and using their expertise. We needed to blaze a trail where no one else had. To do that, we had to push forward with confidence and courage.
There are many people who have played a significant role in SAA’s journey. Michael is one of them. As a teenager, he experienced ankylosing spondylitis symptoms for over six years before receiving a proper diagnosis. He had been told by a doctor that the chronic pain and symptoms that he was experiencing were all in his head. It would take several years, a blood draw that tested positive for the HLA-B27 marker, and a visit to another Internist to finally put the pieces together. The diagnosis was devastating, but Michael knew he wanted to find and help other people impacted by the disease.

“There was nothing out there,” says Michael as he reflects on life before SAA. “I’m not surprised that SAA is still having to educate the frontline medical community on the disease,” he adds. Prior to SAA’s founding in 1983, there was no support network, no educational materials geared to the patient, not even a single pamphlet for people affected by spondylitis, whether they were newly diagnosed or had lived with the condition for decades.

SAA’s founder, Jane Bruckel, was in the room the night of the first support group meeting. “Thank God for Jane,” he says. He remembers that she really had the heart, courage, and passion to take the ball and run with it. But he also remembers that there were many other people in the room that night who were severely impacted by the disease. Admittedly, he was terrified by the prospect of what his future might hold. It’s important to have support from others, but he thought that raising funds to support the organization might be a better path for him. Now more than 35 years later, he continues to support SAA and recognizes the importance of funding research to find a cure.

“SAA is an incredible organization, and I feel incredibly proud about what it has accomplished. It has everything that someone living with this disease might need whether it’s information, a support group, or education. But more than that, SAA offers hope.”
Susan Stehn has a comforting smile and an unmistakable warmth. It’s been more than 35 years since attending the first support group that began her journey with SAA, but she still remembers the excitement radiating through the group.

At the onset, she and others recognized the need to educate the medical community and to get involved in research. “I knew research was crucial to helping people living with the disease,” she explains.

Stehn first started experiencing AS symptoms at the age of 14. When she was 17, her symptoms were believed to be some form of arthritis, but she still did not have a proper diagnosis. By the time she was 22, she started to experience fusion in her hips. She sought out an orthopedic surgeon who recommended surgery. In the years following, she endured five hip surgeries that were paid for out of pocket by her parents to cover the expenses. Unlike some others living with the disease, Susan was always able to work and to do most activities that she wanted. But the lack of information about her condition was frustrating and isolating. Her uncle finding the article was truly a blessing and a life changing opportunity to meet others living with the disease. “The first meeting was hopeful, encouraging, and uplifting.”

Throughout the years, she worked alongside Jane Bruckel and other volunteers to help change the landscape for people living with the disease. She recalls how exciting it was when the first connection between the HLA-B27 gene and the disease was discovered. “It was a realization for me, a relief of sorts, that the effects of this disease upon my body were not my fault. I no longer had to carry the responsibility for the pain it brought upon me. I felt emotionally cleansed,” says Stehn.

Her advice to others who are newly diagnosed and even those who have been living with the disease for any period of time is to be grateful for things you can still do and appreciate that there are more options available today than ever before.

Susan acknowledges the many contributions that she and others played in helping to move the organization forward. “It takes a group of dedicated people to accomplish great things, but Jane really is a remarkable person with incredible leadership skills. I will always be grateful to her.”
2018 EXPENSES & REVENUE

FY 2018 REVENUE

<table>
<thead>
<tr>
<th>Source</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Corporate &amp; Foundation</td>
<td>577,010</td>
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<tr>
<td>Individual &amp; other</td>
<td>539,730</td>
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<tr>
<td>Investment Income</td>
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<td>Bequest</td>
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<td>Interest income</td>
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<td>Program revenue</td>
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<tr>
<td>Unrealized gain on investments</td>
<td>($8,267)</td>
</tr>
<tr>
<td><strong>Total unrestricted revenue</strong></td>
<td><strong>$2,300,504</strong></td>
</tr>
</tbody>
</table>

Net assets released from restrictions/Satisfaction of programs $412,460

Total unrestricted revenue and other support $2,712,964

Functional Expenses

**Program Services**

- Patient conferences, education & support $597,108
- Awareness & support groups $252,529
- Physician education (MRI, Rheumatology) $160,566
- Other (Research, Guidelines, Life Impact) $479,369

Total Program Services $1,489,572

- Management and general $307,047
- Fundraising expenses $83,888

Total expenses $1,880,507

Increase in unrestricted net assets $832,457

Net assets, beginning of year $2,672,006

Net assets, end of year $3,504,463

Year Ended June 30, 2018
## STATEMENT OF FINANCIAL POSITION

### Assets
- Cash & cash equivalents $201,473
- Investments, at market value $3,176,245
- Grants receivable $65,971
- Prepaid expenses & other current assets $12,571
- Property & equipment net $97,575
- Deposits $5,441

**Total Assets** $3,559,276

### Liabilities & Net Assets
- Accounts payable $16,452
- Accrued vacation $38,361

**Total Liabilities** $54,813

### Net Assets
- Unrestricted net assets $2,564,650
- Board designated fund $234,622
- Temporarily restricted net assets $705,191

**Total Net Assets** $3,504,463

**Total Liabilities and Net Assets** $3,559,276

With your generous support, we can turn heartbreak into hope.
Through Corporate Sponsorships, SAA's pharmaceutical members can positively impact the lives of the 2.7 million people living with spondylitis in the United States. The following pharmaceutical companies are current corporate members.

**Platinum Sponsors**
- abbvie
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- UCB
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Susan Foreman
Beatrice Frask
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Jean Garrick
Herwin Gill
Craig Gimbel, DDS
Bill Giser
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Brett Siegel
Spondyloarthitis Research & Treatment Network (SPARTAN)
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Crystal & Gabe Sumner
Theodore Theophilos
Daniele Thomas
Fenton & Genevieve Tom
Javier & Pamela Torres
Alison Toth, MD
Laura Wagner
Hanan Watson
Tom & Barbie West
Keenan & Orna Wolens
The Quest Legacy Society recognizes those individuals who have taken the special step to include SAA in their estate plans through charitable bequests, trusts, insurance or other forms of deferred giving. Information about the Quest Legacy Society can be found at spondylitis.org/quest.

SAA is honored to recognize these Quest Legacy Society members:

MEMBERSHIP & INDIVIDUAL DONORS

SAA does not receive funding from the government. Through generous donations from our members and individuals, like you, we are able to live out our mission and continue our efforts. We have made every effort possible to ensure that this list is accurate and complete. In the event of an error or omission, we extend our apologies and encourage you to contact Diann Peterson, Chief Philanthropy Officer at 800-777-8189, ext. 226 or by email at diann.peterson@spondylitis.org so that proper recognition may be ensured in the future.

$500 - $999
Brian Aldrich
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Douglas Good
Doug Granat
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Jeff & Nathana Horn
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Brice Wu
Young Foundation

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Michael Willis
Darren B. Wolpert
Mary Ann Wray
Brice Wu
Young Foundation
SAA’s volunteer fundraising events raised more than $45,000 during FY18! Our dedicated volunteers hosted outdoor concerts, live drawings, held special shopping days to benefit SAA, encouraged their communities to take action online with a donation, and created rock albums for sale.

The common thread through all the fundraisers was a compelling story. Each of our wonderful volunteers inspired others to give to SAA by telling their personal stories of living with ankylosing spondylitis and related diseases. SAA is proud and honored to have benefited from the many events that were held on our behalf.

- Kristen Bradshaw
- Kristin & Casey Cornelius
- Fox Fine Jewelry
- Jennifer Frey
- Eric & Christina Koval
- Susan & Ross Lorenzana
- Brenda Moreland
- Jessica Moreland
- Larry Seltzer & Naomi Langer-Seltzer
We started something remarkable and unprecedented 35 years ago. We will always honor our past. As we go forward and look to our future, we may need to change some ways in which we think in order to solve problems and develop solutions to better meet the needs of our community. But we will never change how we feel or care for the people we serve.