Plan Ahead...

“I wouldn’t wish this on my worst enemy.” Having a genetic component, it is unfortunately more likely that spondyloarthritis will affect a descendent. The sentiment of not wishing this on anyone is shared by many people living with spondyloarthritis. Shared wishes and prayers help and inspire. They build community and community values. They provide comfort and healing. They also lead to action. Action can lead to further action.

There is a story of a person traveling along a road who sees a very old man planting an olive tree. The person asks “how long will it take for that tree to bear fruit?” To which the old man stops his work, straightens up his back, pauses and replies “I think around forty years if the summers are good and the rain comes.” The person questions him further, “and are you so fit and strong that you expect to live that long and eat its fruits?” The old man answered, “I found a fruitful world because my forefathers planted for me, so I will do the same for my children.”

If spondyloarthritis plans to affect our descendents, then we need a plan to fight it. Planned gifts guarantee research, advocacy, education and support for our descendents. We show our gratitude and honor to those who have come before and worked to make our lives better by providing for people who would share our pain in the future.

Planned gifts can be the simplest and financially easiest type of gift. What could be easier than naming the Spondylitis Association of America (SAA) as one of the beneficiaries on an IRA? It literally takes 30 seconds and costs nothing. Plans intimidate people and when they hear the word, they run. It sounds complicated and involved. But, remember the statement by your middle school teacher “not having a plan is planning to fail”? Our assets will be divided and distributed when we die. The question is who is making the decision that expresses your values? If we don’t make a decision, then we are leaving it for the government to make the decision. This year more people have told us that they have made a planned gift to the SAA then ever. They are ensuring that the SAA continues the support and quest for a cure. We recognize and honor their intention through our Quest Legacy Society. Quest Legacy Society members made a special commitment and we therefore hold a special endearment for them. Quest Legacy Society members are recognized on our website www.StopAS.org/quest and annual reports in perpetuity. Perhaps their action will inspire you to join. Our Quest Legacy Members are as diverse as people that have SpA, women, men, all ages and education levels. People of all income and assets levels make planned gifts.

There are tax advantages to making a gift to SAA. There are many types of planned gifts from the naming SAA as a beneficiary on a life insurance policy to annuities that provide income to you for life. Call (800) 777-8189 with questions that you may have regarding planned gifts. If you already intend to make a planned gift, please call or use the enclosed envelope to let us know.

Like any gift, planned gifts should be made after ensuring financial security for you and your loved ones. Professional advisors and attorneys have expertise in gift giving and should be consulted.
Making the decision to remember the Spondylitis Association of America in my estate planning was a natural extension of the ongoing resources I have devoted to the SAA since I was first diagnosed with Ankylosing Spondylitis (AS) in 2002. A natural extension yes, but it is so much more than that. Making a legacy gift ensures that the SAA’s good work will continue long after I am gone, benefiting the next generation of people who have this mystifying and often demoralizing disease.

My story with AS starts in 2002, when I was diagnosed after nine months of endless doctors and tests, during which time I had to take medical leave from work. My diagnosis came from a very smart rheumatologist who had a flyer on the wall of her exam rooms for the Houston SAA Support Group.

Whatever the challenge, I tend to jump in with both feet, so I starting by attending the Houston Support Group meetings. I volunteered to help the group leader with any number of activities, from setting up a mailing list to finding speakers.

And I was fortunate because the Houston support group has one of the leading researchers in AS in its neighborhood – Dr. John Reveille. As a result, I was recruited to participate in the TASC genetic study and was proud to donate my blood toward the better understanding of this disease.

That initial participation led me to join the Board of Directors in 2006. I have chaired the Communications Committee, been a member of the Fund Development Committee, and have served as Board Secretary and currently Board Vice-Chair. It has been such a privilege to serve this organization for the past six years. I have seen it grow and flourish, despite some challenging economic times.

Why wouldn’t I want to support an organization that I know is one of the most efficient, well-run nonprofit organizations in the U.S.? My professional career was spent in Public Affairs for one of the most well managed corporations in America. I worked with non-governmental organizations (NGOs). I reviewed grant proposals. And I managed some major United Way campaigns. So I know a well-run nonprofit organization when I see one. And the SAA is a well-run organization. If you don’t believe me, take a look at pages 14 and 15 of this issue!

My other, more personal reason for remembering SAA in my estate planning is that I would like to see a greater focus on women with this disease. Don’t get me wrong, more attention is being paid to women these days. But understanding how the disease affects women is still in its infancy. And because I am an HLA-B27 negative female with AS, I have a genuine interest in this area.

In order to find these and other answers it will take time and money — resources to conduct research. So part of my reason for doing this is a little selfish, but hopefully it will benefit other women, and men, with AS in the future.