

# SPONDYLITIS PLUS

march/april 2006

FROM A  
HUMBLE BEGINNING:  
A.S. RESEARCH  
PAVES THE WAY

THE JANE BRUCKEL  
RESEARCH FUND

THE EMOTIONAL  
IMPACT OF  
CHRONIC DISEASE

 Spondylitis  
Association  
of America™



**SPONDYLITIS ASSOCIATION  
OF AMERICA**

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**SAA 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.*

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With all our progress, there is still a long road ahead, but SAA enjoys a time of opportunity and momentum.

Twenty-three years ago, when I co-founded this organization, there was no information available about AS – not a single pamphlet and, incredibly, only very few doctors who were interested in the disease. So our goals in those days were modest: to overcome our sense of isolation, to find out what worked best and what didn't work, to cope with frustrating challenges, and to celebrate our shared successes as we learned how to live with this disease.

We had no thoughts then of White House visits or glittering international conferences, no plans for exciting multi-million dollar research programs and a unique partnership with the National Institutes of Health, no dreams of ground-breaking genetic studies to solve the mystery which, it turned out, had plagued mankind since the days of the Pharaohs. (We also had no one to tell us we were charting a near-impossible course.)

I look back – and it seems not that long ago – to our first meeting – the very first meeting of AS patients in this country. We found camaraderie in the shared experiences of misdiagnoses and lack of information. Our anger quickly turned into action, and my home became the grand central station of volunteer activity. As we sat around my dining room table, we charted the course for accomplishing a series of “firsts” in this country. We planned and published the first comprehensive book on AS written for patients, along with, eventually, hundreds of pieces of other literature. We held the first of what would become annual educational symposiums for patients and doctors. Later, we issued audio and video exercise tapes. We organized patient support groups throughout the country. We gathered publicity and celebrities to our cause.

I look back as well to so many heart-warming letters you have written (please see the letters page in this regard). In one, a man who turned his life around said, “I want to thank SAA for being a significant contributor to me and my family's success.” In another, a woman who had not met me generously credits me for improving the lives of thousands through SAA's patient support groups. I remember my great pleasure in meeting many of you all across the country. In my files, I also find reports of projects, from inception to completion, which recall the many dedicated people who have worked with me over the years. And I take great pride in the solid accomplishments that SAA has achieved to make life better for all of us.

For me, after 23 years at the helm of this organization, the time has come to retire. It's always hard to say goodbye, but I am confident that I am leaving SAA in the capable hands of a wonderful volunteer board of directors and staff who together will never cease working to pursue our mission.

With all our progress, there is still a long road ahead, but SAA enjoys a time of opportunity and momentum. I will retire in June, but I am not really saying goodbye to you. My dedication remains as strong as ever, and I know you will join me in continuing your support into the future. Together, we can end the tragedy of this disease forever.

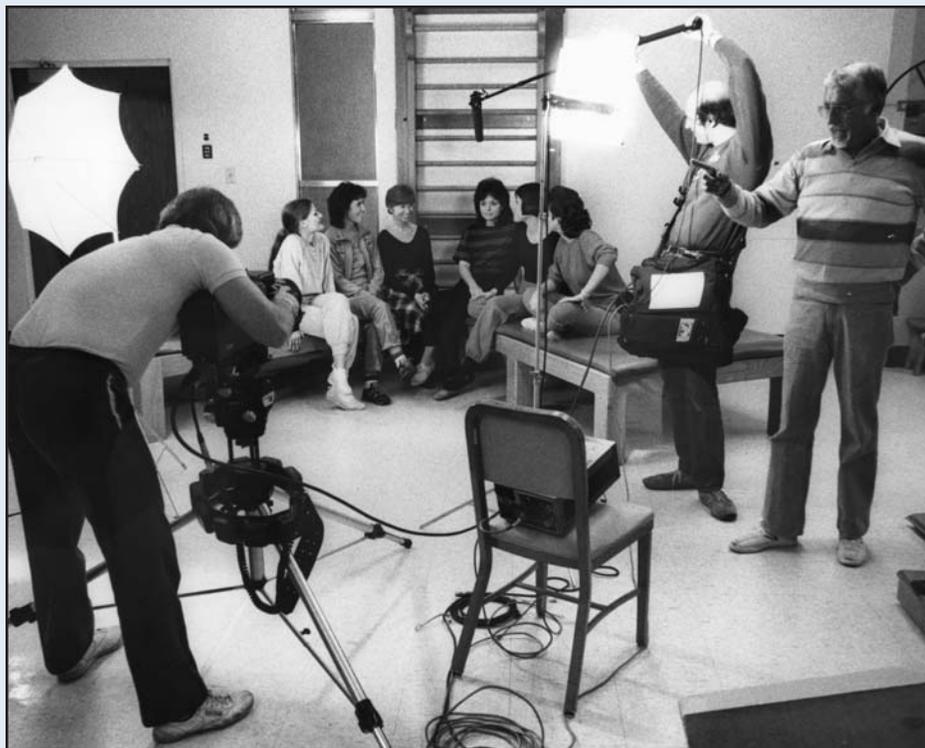


JANE BRUCKEL

Co-founder & Executive Director

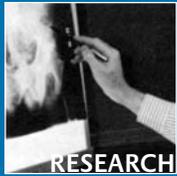
*“I will retire in June, but I am not really saying goodbye to you.”*

## COVER PHOTO



In 1984, just one year after its inception, the Spondylitis Association of America, then still called the Ankylosing Spondylitis Association, participated in an Arthritis Foundation telethon.

Jane Bruckel, Melba Morris, Marie-Ann Sears and Susan Stehn used this opportunity to raise awareness about ankylosing spondylitis (AS) and specifically about AS in women, which to this day is still believed, in some circles, to be a disease of men.



RESEARCH

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### Dear Jane,

Your letter announcing your retirement took me back to a time sixteen years ago when, after years of suffering, I was finally diagnosed. That night as I held my 18-month-old son in my arms I wondered what the future would hold for him and me...would we ever play ball together? I had so many questions running through my mind and no information until I found you and your organization. Suddenly there was hope. There were other people out there fighting this disease and looking for answers. I can never explain to you what a difference that made in my life, but I will try.

I am 44 now. I taught both my sons to play baseball and my oldest son is an Eagle Scout. I have been a scout leader, a baseball coach, a soccer coach and am the co-president of my own company. I am healthy and productive. You and the organization you founded helped to give me the strength and courage I needed to handle my disease one

day at a time. Knowing there are people out there fighting for a cure has given me the hope I need to persevere.

Jane, that is the point of this letter. Your vision to start this organization has given me and thousands like me the life-changing gift of hope. For that you will always hold a special place in my heart and in my prayers. Thank you so much.

Kindest personal regards,  
Bert W. Baker  
Ridgeland, MS

### Dear Jane,

Undoubtedly by now, you have heard from friends, colleagues and persons in reaction to receiving the news that you are retiring from the active leadership of SAA. But, I would be remiss if I did not add my words to those already expressed to thank you for all you have done on behalf of AS patients and their families.

For our family, and especially my son Drew, when the diagnosis of his spondylitis caught us in a strong current, SAA was the rock and firm foothold for us to grasp and find a smoother pathway to journey with you in the quest for a cure.

Sincerely,  
Mary Tuttle  
Iselin, NJ

### Dear Jane,

You have done so much for the Association over the last 23 years, and I wish you the best in the future.

When I found I had AS in 1964, I was shocked and there was no one to go to. I worked in the military hospital and I ran to the medical library---it was devoid of any major article on the subject---just a man laying in a fetal position and about 2 paragraphs. I am so pleased that you have brought us so far, and I appreciate what you have done.

Sincerely,  
Dana R. Spencer, Ph.D.  
Captain, USAF, (Ret)

### Dear Jane,

As a member of SAA for most of the 23 years you have been the executive director, I can really appreciate the fabulous job you have done in building the organization to the dynamic one it is today. Yes, there were many people who supported you on this "remarkable journey", but it was your leadership and creativity that made it happen. Judy and I give you our very best wishes for your retirement.

Very Sincerely,  
Don Bunin  
"AS Veteran"  
San Diego, CA

## LETTERS TO THE EDITOR

*Dear Readers:* We want to hear from you, whether it be informative, uplifting, or a gripe you need to express. Include your full name, address and daytime phone number.

We reserve the right to edit for space and clarity.

Please send letters to:  
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# The JANE BRUCKEL RESEARCH FUND

The next phase in SAA's quest to  
advance research for AS and related diseases

*“By supporting  
this Fund, SAA’s  
members and friends  
will enhance the  
organization’s ability  
to respond to new  
research needs.”*

Building on our exciting successes with the *AS Family Genetic Study*, the SAA has now established the *Jane Bruckel Research Fund*, which will be solely dedicated to advancing research for AS and related diseases. The Fund will honor the dedication of SAA's retiring co-founder and Executive Director to research that will have a direct effect on the lives of spondylitis patients everywhere.



*SAA Co-Founder Jane Bruckel with young researchers at the National Institutes of Health.*

David Hallegua, M.D., SAA Board Chair, says, “By supporting this Fund, SAA's members and friends will enhance the organization's ability to respond to new research needs as they arise, as well as continue the important projects currently underway.”

When SAA entered the research field in 1996, to raise seed money for the AS Family Genetic Study, our efforts motivated other funding sources to take a closer look at the unmet needs of spondylitis research. The seed funds raised by SAA, combined with the early success of the genetic project, served to leverage funding from the National Institutes of Health (NIH), which described the project as “meritorious.”

As a result of this important partnership with the NIH, researchers have identified regions on seven chromosomes that contribute to the susceptibility of AS. SAA's initiation of this important research project was key to its success, and building on that momentum will be the key to future successes as we begin the research to discover the specific genes that can someday lead to a cure.

Another vital research project currently underway includes the validation of a screening tool to help eliminate the frequent agonizing delays in diagnosis. But the goal of The

Jane Bruckel Research Fund is to meet new challenges as well. These include attracting and encouraging the next generation of researchers and clinicians in the field to advance the research that will lead to the cure for spondylitis.

Today, SAA has an excellent international reputation for its research efforts on behalf of spondylitis patients. If not for the dedication of Jane Bruckel, and the numerous members and supporters who have stood by her side, we would find ourselves still facing the beginning of the journey rather than building on the tremendous successes already behind us.

The Jane Bruckel Research Fund will enable the SAA to continue its commitment to advances in research as well as take it to new levels. A letter and brochure outlining the particulars of the fund will be sent to you shortly. Please read them carefully and consider making your own contribution to the future of spondylitis research.

As the Jane Bruckel Research Fund grows into an ongoing source of research financing, its supporters will know that they have been instrumental in supporting special research projects that will benefit spondylitis patients until the fight against this disease has been won.

# From a humble beginning: AS Genetic Research paves the way

As SAA's executive director and co-founder Jane Bruckel approaches retirement, even with all the recognized successes that the association has achieved in so many areas, she notes, "We still need to make more of an impact in disease awareness; we need to get people diagnosed earlier, earlier, and earlier – giving everyone a level playing field as far as recognizing it in both men and women, and we need to continue to be a driving force in the quest for the cure."

## The "Can-Do" Organization

While Jane may have that one regret, she has many unprecedented accomplishments of which to be proud, according to the many researchers and clinicians who have worked with her through the organization.



1996



2006

*Then and Now: Jane with Dr. Steven Katz, M.D., Ph.D.:*

It was the SAA, after all, under her watch that focused attention on AS education and research projects, giving the fight against the disease a major shot in the arm. The "Can-Do" Organization, as Jane calls it, made a commitment in 1996 to speed up research, and she now points out that "for a small foundation, the SAA has made a huge impact."

"We made a commitment in 1996 to research to find the cause, cure and prevention of AS and related diseases; that was the vision of the organization and the board of directors. At that time, I set up an appointment with the director of NIAMS, the arthritis branch at the National Institutes of Health. I said, 'You may not know of our organization, but you will, because we're here to speed up AS research in this country.' I then proceeded to share our vision," Jane recalls.

It was Stephen Katz, M.D., Ph.D., and Director of NIAMS, who first met with Jane at NIH, where she shared SAA's vision to get going in finding the genes that cause AS, which would facilitate getting the disease under control.

Jane looks back: "After Dr. Katz and I sat down for hours with the Director of arthritis research. She shared information with me as to how to speed up research. I advocated them to partner on a conference with us, telling them the disease should not be ignored. I identified where we're at today with research and where we'll go next. We did a major fund-raising campaign, 'Quest for the Cure,' for start-up money."

## Top Researcher Joins the Team

Dr. John Reveille, director of the Division of Rheumatology at the University of Texas Health Science Center in Houston picks up the story here, telling *Spondylitis Plus* that it was Jane who convinced him, due to his reputation, to shift his genetic research focus to include -- if not feature -- the genetics of spondylitis and how it applies to the disease process, his field of specialty.

Dr. Reveille, who is the principal investigator on the AS Family Genetic Study, explains: "I was shifting my focus toward lupus and scleroderma and around that time, Jane approached me and asked if I would be interested in working with SAA and the genetics of spondylitis. She kept at it, and through her dogged persistence and inspiration, she convinced me that working with SAA would be a good idea.

“Subsequently, it led to the SAA, with the help of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), to set up the project along with the generous help of the people who had donated the seed money to see this happen,” Dr. Reveille points out. “Through this, and because of this, with the money being raised with the membership of SAA, the Family Genetic Project kicked off in 1998. Jane then later successfully lobbied the NIAMS to increase funding for AS. She used the family genetics project as a lever to say that we were already doing this research, but that now we needed more money to bring this in the right direction.”

The National Institutes of Health were so impressed with the foundation that they later funded the entire project; Dr. Reveille received a \$5.5 million grant in 1999. SAA, in an unprecedented role in the research arena, was designated as the Clinical Coordinating Center.

Under Jane, SAA was the coordinating center for the 1998 North American Spondylitis Consortium (NASC), which consisted of the University of Texas-Houston and 10 major university medical centers from the United States and Canada, and was created to expand the genetic project. All working to identify the genetic causes of AS. SAA spearheaded the collection of data from some 400 generous families with sibling pairs who have AS. SAA registered these families, coordinated the blood collections, and still maintains a working database for the NASC.

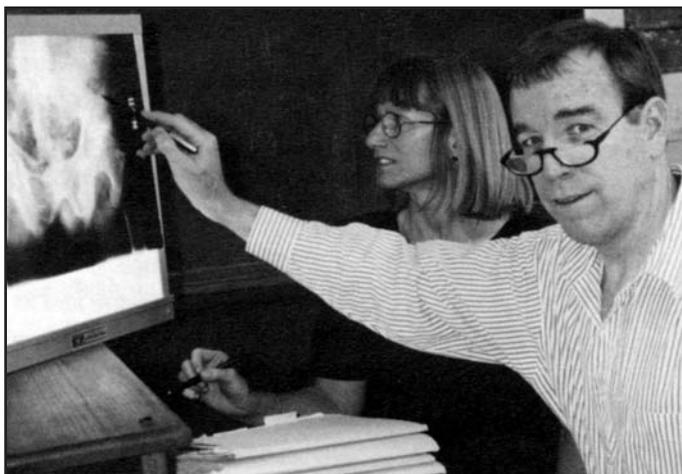
The AS Family Genetic Project has led to the remarkable discovery of regions on seven chromosomes that contribute to the susceptibility and pathogenesis of AS while also banking an impressive collection of data and DNA for future studies. The study also contributed to identifying a chromosome involved in uveitis, an inflammatory condition of the eye in some AS populations.

Allowing no grass to grow under their collaborative feet, the SAA has been providing interim funding while a group of investigators awaits a second NIH grant to fund four additional projects under Dr. Reveille’s guidance.

“It’s safe to say at this stage of the game, that AS genetics are my primary focus,” says Dr. Reveille, who also sees patients, runs a rheumatology division and has administrative duties, but still declares that at least one-third of his time is devoted to AS research. “Jane was so successful in shifting my primary focus to AS, and the partnership has accomplished a great deal.”

### New Meds; New Hope

In 2001, the SAA, along with an international group of researchers, produced the first draft of an “Ankylosing Spondylitis Guidance Document for Industry” on behalf of the U.S. Food and Drug Administration (FDA). This document provides standardized methods to assess the results of a device or therapy being tested for a specific disease. The central purpose is to provide information about the types of label claims that can be considered for a new compound.



*Research Coordinator with Dr. John Reveille*

### The AS Life Impact Study

Always focused on educating physicians and researchers, SAA commissioned a study in 2002 that involved more than 2,000 AS patients. The questionnaire for participants was a self-reporting, self-assessment tool. The study garnered a great deal of information on the impact of AS on the patient’s life. Questions had to do with work-related disabilities, functional impairment, quality of life, and spinal involvement, and the development of a new tool in the form of a line drawing that makes it possible for people with AS to describe on paper the degree to which their posture has been affected by AS.

“The AS Life Impact Study really began years before with Jane pushing us to focus on the question of how much of a difference AS makes in people’s lives; with the study, we’ve got that quantified,” says Dr. Robert Warren, who authored the paper with Jane, Dr. Robert Inman, and Dr. Millicent Stone. Dr. Warren is Chief of Rheumatology at Texas Children’s Hospital and associate professor of pediatrics at Baylor College of Medicine. “Jane’s persistence and determination to succeed, in the context of her personal struggles with AS as well her professional leadership of the SAA, have been a beacon for us all, and certainly for me both as a rheumatologist and as a spondyloarthritis patient myself.”

Another important area of information that came from the AS Life Impact Study was that juvenile onset was a critical predictor of risk for greater disability in adult life. “This was a very significant finding,” states Dr. Warren. “It emphasizes the importance of early diagnosis and therapy, and also suggests an important area of research - the possibility that there are differences in the genesis of juvenile and adult onset ankylosing spondylitis.”

Dr. Warren predicts that “...another AS Life Impact Study in ten years will show us how critically important Jane’s guiding light has been; we’ll see earlier diagnosis and therapy, and find that AS is no longer so disabling.” He also predicts that “Jane will be missed greatly by everyone in the field of AS, as she passes the torch; her challenge to us all is to stay inspired, insightful and determined as we take her light forward.”

# Under Jane's Watch: Education and Support fo

The Spondylitis Association of America's pioneer days consisted of a group of disenchanted ankylosing spondylitis patients sitting around Jane Bruckel's living room trying to figure out how they could get more information on their disease. Little did they know that their early efforts in the areas of education, disease awareness and research would grow to be recognized with worldwide respect and honors.

"It was very exciting because none of us had met anyone with the disease before," remembers Susan Stehn, one of the founding members and the first treasurer of SAA, who had been diagnosed with AS some 20 years before she met Jane. "It was exciting to know that this group was forming to provide education for patients. I had been an employee at the Arthritis Foundation for a while, and they had no printed information for people with AS."

Ms. Stehn now says: "The organization was so tiny; the budget was infinitesimal and they asked me to serve as treasurer of the group. At the beginning, it was a patient support group and even at that, it was more of a local Los Angeles group. We had big goals; all of us had very firm ideas that we were dissatisfied with the available knowledge since we had gone so many years with being misdiagnosed or not diagnosed. We wanted to have an impact on the medical community so that other young people coming behind us would not experience what we had experienced. We had big dreams, all right, but I don't think we had any concept that the organization could go as far as Jane has brought it."

*"Straight Talk on Spondylitis put us on the map."*

— JANE BRUCKEL

## SAA, THE GOLD STANDARD

In that pivotal first year, 1983, the group began to offer a quarterly newsletter that has since become the #1 resource for cutting edge information on spondyloarthritis. A distinguished medical and scientific advisory board was established that volunteered time and talent in producing patient educational materials, which included video tapes and pamphlets.

The next year, 1984, the organization went on to co-sponsor the first U.S. symposium on AS. More than 100 physicians attended the first day of the program, titled "BACK PAIN: The Unsuspected Cause: Ankylosing Spondylitis, Early Diagnosis and Management." The second day, there were 100 eager AS patients lined up to attend a program titled "AS: A Cause of Back Pain. What it is, what it is not, and how to cope with it."

By 1985, the seminal book, "Straight Talk on Spondylitis", was published. The book quickly became the invaluable and sole resource for helping newly diagnosed AS patients and their families reassemble their disrupted lives with solid information while empowering them to fight off encroaching symptoms with structured and well-illustrated exercises. It was written by doctors and patients, and edited by Dr. Robert Sweezey. "You didn't know what to expect from the disease; there was no basis for comparison," says Jane Bruckel, who was herself diagnosed in 1978.

"We produced the first comprehensive and thoroughly researched self-help book for patients packed with vital information. We had a focus group of our core people and we asked everyone, 'What is it we all want to know about this disease?'" recalls Jane.

Jane explains: "Once it was completed, we submitted it to the prestigious American College of Rheumatology's publication, The Journal of Rheumatology and also to the Journal of American Physical Therapy Association for reviews. They were extremely positive. We later sent the book to every rheumatologist in the country! "Straight Talk on Spondylitis" has received rave reviews from doctors and patients in America and overseas and continues to be an indispensable resource for anyone dealing with AS; plans are now underway to update the important publication.

Support programs and seminars were also created each year for AS patients and their families that gave them an opportunity to get together, hear experts speak and meet with one another. "That was incredible," says Jane, "in that it was the first time many people met anyone else with the disease and they no longer felt alone; to this day, you still hear that."

The organization, ever on the front lines in its quest for knowledge, participated in a four-day international research and educational conference in 1991 with the University of Texas, Dallas. SAA was charged with organizing the educational component for arthritis health professionals, such as physical therapists and nurses, as well as the patient education seminars. "I wish I would have learned all of this in physical therapy school," one attendee would lament.

## ALWAYS AHEAD OF THE CURVE

Always ahead of the curve, SAA's interactive website today is one of the leading sources of support and information on the disease in the world, receiving more than one million hits a month. The popular website also provides physicians with CMEs (continuing medical education courses) that explain in great detail how to recognize and treat AS and related spondyloarthropathies.

A primary area where Jane has excelled, according to those interviewed for this article, is her ability to skillfully collaborate with other institutions. SAA has worked with federal agencies, other professional

# r Patients and Clinicians

organizations, academia and industry in their research, education and patient advocacy programs. Dr. Susana Serrate-Sztejn, Chief, Rheumatic Diseases Branch, National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), NIH, said that SAA's integral role, for instance, in one genetic study project was unprecedented in research. "As far as I know, the NIH, or at least NIAMS, has never funded an on-going study with a patient-advocacy organization acting as the coordinating center."

## SEAMLESS TRANSITION

And now, Jane will leave SAA in June with all the pieces in place for continued success and growth of the organization. Her husband, Harry Bruckel, has been by his wife's side all these years as the #1 volunteer and sounding board for the past 23 years. For his generous volunteer work, SAA's board of directors awarded him the first Harry Bruckel Award in 1986, which recognizes outstanding achievements and behind-the-scenes service to the organization. Looking back, he touts his proudest moment was when Jane was invited to the White House for a news conference with President Clinton, due to SAA's strong advocacy efforts for legislation to protect certain populations against genetic discrimination.

A seamless transition is expected that will keep SAA focused on its ultimate goal of finding a cure for the disease while empowering those affected to live life to the fullest, but Jane has certainly left her indelible mark with the foundation's legions of volunteers, her staff, AS patients, physicians and researchers.

## RAISING THE BAR

"Nobody else would have been able to do what she did," says Ms. Stehn. "The longer I knew her, the more impressed I was with her diligence and her knowledge and her unique ability to work with people to accomplish these incredible goals. It's been a long road and it's been a gradual process, but now the FDA seeks information from our group, and the NIH includes us when they want to put on a seminar -- and our stellar research -- these are monumental accomplishments for a group that essentially started out with a few patients that were dissatisfied with the medical community."

Andi Berman, long-time SAA volunteer, says she, too, is truly amazed at what the organization has accomplished in the more than 20 years she has been around. "It's just phenomenal," she says looking back, "I think that the way the organization has matured from a few people sitting around the table to being involved with NIH and worldwide, well, I'm sure it exceeds anyone's expectations. I don't think anyone could have foreseen this growth. People literally had an idea and they made it happen."

Ms. Berman adds, "When you talk about living a life to make a difference, Jane has done that. It's really true. Her life has made a difference."



*Rico's RBI challenge raises funds for AS research*



*The SAA's first board of directors*



*Jane was invited to the White House for a news conference with President Clinton.*

# CONFERENCE INSPIRES A BRIGHT YOUNG MIND

**“The true heroes, for us, are the spondyloarthritis researchers,” says Janette Morgan.**

Mrs. Morgan and her daughter, Rachel, who both have been diagnosed with psoriatic spondylitis (see page 11 for her story), were invited by SAA to attend the recent Spondyloarthritis 2006 “The Unmet Needs” conference held at the National Institutes of Health on March 30 and 31 co-sponsored by the SAA and National Institutes of Arthritis, Musculoskeletal and Skin Diseases, and the event brought leading scientists and researchers together from around the world.



*Jannette and Rachel Morgan enjoy dinner at Mount Vernon after a long day of lectures at the National Institutes of Health.*

We originally learned about Rachel from the Indiana support group leader, Ken Prather, when she was still in high school. Ken had told us about this wonderful young woman who was a motivating force for the adults in his support groups; at SAA, we were all so very impressed with the ongoing news of young Rachel.

More recently, when we learned that Rachel was indeed already following her dream to apply herself to SpA research, it seemed like such a good fit to invite her and her mother to attend the NIH conference. And since the SAA had already committed to sponsoring new M.D.s – currently Fellows in Rheumatology – with the goal of encouraging young researchers into the specialized field of SpA, it was not a stretch at all to extend an invitation to Rachel Morgan to fill one of those sponsored spots.

The conference was chaired by Dr David Fox, Professor of Internal Medicine, Director, Division of Rheumatology University of Michigan Health System, and co-chaired by Dr John Reveille, George S. Bruce Jr. Professor of Arthritis, Director Division Rheumatology, University Texas Health Science Center. Additional committee members included Drs Robert Colbert and Michael Ward, and from the SAA, Mike Supancich, M.D., board member and Laurie Savage, Associate Executive Director.

“These scientists are the true heroes; they’re knights in shining armor to Rachel and me,” Mrs. Morgan tells *Spondylitis Plus*. “All the distinguished researchers who presented at the conference gave me hope for a brighter tomorrow for all of us with spondyloarthritis.”

Her daughter, Rachel, is also hoping to make a brighter tomorrow. She is currently attending Indiana University-Purdue University Indianapolis. She is on-track to earn her Ph.D. in genetics, and her primary research interest is spondylitis.

## Support from the Experts

At Lister Hill Center at NIH, Rachel sat in the front row taking notes and not missing a beat as she listened to lectures with titles such as “Longitudinal and horizontal events of experimental spondylitis,” “Spondyloarthritis and the gut,” and her favorite lecture, “Insights from psoriatic arthritis.”

The latter turned out to be Rachel’s favorite because when she arrived back at her Indiana home late Friday night, she had an e-mail waiting for her from one of the presenters, Christopher T. Ritchlin, M.D., Associate Professor of Medicine, University of Rochester Medical Center, Rochester, New York. Dr. Ritchlin’s research team has made numerous inroads into the pathogenesis of the very disease that Rachel and at least four other generations of her family have had in the area of a molecule known as RANKL. It’s the over-abundance of RANKL in the joints that starts a cascade of molecular events that lead to the erosion or breaking down of bone.

## The Future Looks Bright

Rachel tells us the story: “Dr. Ritchlin isn’t specifically in the field of genetics, but just to have experience in the lab with someone who is working with the disease will help me to get a better understanding for the type of work that is done in the labs, even outside of genetics and what other areas they’re looking at for finding a cure. I’ll be learning the different techniques specific to the disease, the organisms they’re working with; I’ve been working with yeast, and I haven’t had experience with humans. Dr. Ritchlin is working with clinical studies. He said I can work in the lab and also learn what he is doing clinically and eventually, I hope to do the same thing. Clinical work leads up to the development of new drugs and new treatments and so that’s where I want to end up.”

Rachel, in fact, received enough offers from the Spondyloarthritis 2006: “Unmet Needs” conference presenters to get her all the way through grad school and her post-doctoral work and that much closer to reaching her goal of finding a cure for the disease.

We shall all be pulling for her every step of the way.

*We would like to thank our corporate partners for supporting the Spondyloarthritis 2006: “The Unmet Needs” conference:*

- Abbott
- Amgen Wyeth
- Centocor Inc.
- Pfizer

# THE EMOTIONAL IMPACT OF CHRONIC DISEASE

five personal stories

The powerful emotional impact of coping with a chronic condition, such as ankylosing spondylitis, often revolves around the theme of adjustment, especially after receiving a definitive diagnosis after perhaps years of not knowing. Your entire life may change, and everyone in the newly diagnosed person's life is touched.

One thing the people interviewed for this *Spondylitis Plus* article had in common was a willingness to share their private thoughts. Their candid interviews acknowledged their feelings of anger, but also that they have come to terms with the disease and encourage others to do the same.

## 1. Young Scientist on Front Lines of AS Research



Rachel Morgan, now 20, was diagnosed with spondylitis around the time of her 17th birthday. A disease of this magnitude could understandably have caused another student to give up on school altogether, but not this intrepid young woman.

Although the pretty valedictorian of Indiana's Greenwood Community High

School's class of 2004 nearly didn't make it to the podium on graduation day, she has since taken sure steps toward her goal of unraveling the secrets of her painful and debilitating disease.

"When I was in my worst flair in my junior year, I didn't really have a life," recalls Rachel to *Spondylitis Plus*. "I had to drop out of marching band that year. I ended up in a wheelchair and I could barely move, and although I went to school, I then went home, did my homework, and slept the rest of the time. I wasn't living; I was surviving."

The diagnosis came as no surprise to Rachel. As far as she knows, she's the fifth generation in her family to have the genetically related disease and believes it could go back even further than that. Rachel explains: "My mom had it. My grandfather had it and I watched him become fully disabled – so I knew what to expect. I didn't know how fast it would go, but I knew if something didn't happen, I would end up like them."

And now a college sophomore at Indiana University-Purdue University Indianapolis, whose AS is fairly well under control with medication, she

has double majors in biology and chemistry. "My life goal is to find a cure for spondyloarthritis," Rachel says with the poise of a seasoned researcher. After all, her research began years earlier while in high school where she was getting different genetic patterns between her control group and her experimental group; in fact, she proudly says they were "radically different." "If we can find the base reason for the disease, that is our best chance at stopping it; that's why my field of interest is genetics – that's where the answer lies. And now, a Ph.D. in immunogenetics is the closest thing I can find to a major that will expedite that goal."

Rachel says she deals with the emotional impact of having her disease by tying up her hopes for the future in her quest to solve the pathogenic enigma of AS: "When I'm in the worst pain, the most depressed, in a flare – it's what keeps me going. I am going to figure this out. I won't quit until I do. It makes me more and more determined – the disease does."

Rachel, along with her scientific mentor and partner, Dr. Anna Malkova, whose research is focused on the mechanisms of DNA repair and recombination, is working on a grant application. Like a thoroughbred at the gate, Rachel says it cannot come too soon. She is most anxious, she excitedly states, to get on with the genetic research project that has already reaped her some rich results in the area of identifying banding patterns of relevant genes to spondyloarthropathies.

"I'm trying to repeat a former experiment, confirm the results and get these different banding patterns I noticed the first time and go back and figure out which band from the original gel matches to which gene and then see which one of the genes links to the differences," Rachel recounts of her work. It is with a little laugh that she tells where she obtained the blood samples for her experimental group. "Why, I used my family and the Indiana SAA support group with the help of Ken Prather!"

Unlike a lot of college students, Rachel has a steadfast and serious direction set for her life. She sums it up this way: “I keep remembering something my mom told me. She told me I am the answer to generations of prayers in our family – and we’re very motivated, too.”

## 2. Putting AS in focus



Tim Tomkins, 47, an Emmy-winning television and movie writer, producer and director who lives in Southern California, remembers the day that he was first clobbered with the symptoms of the disease that would baffle a gaggle of doctors for nearly two dozen years.

“My disease was turned on in a matter of just 20 minutes; I got it when I was about 23 and under a lot of stress,” he recalls to *Spondylitis Plus*. “I was directing a movie and I felt a sharp pain in my hip. I had to go to the hospital. My knees swelled up to the size of volleyballs and one foot was totally swollen and my toe was bent back.”

At the hospital, the Northern San Diego County physician suggested to Tompkins that he had acquired a sexually transmitted disease. “It was a little humiliating when the doctor gave me a raised eyebrow when he asked me about venereal disease, they were looking at syphilis and/or gonorrhea, and I had to tell him that I didn’t HAVE a high-risk lifestyle, that I was married – and the tests were negative, of course,” he says now with just a hint of bitterness as he remembers the years of despair setting in, along with the feeling of being defeated by the ongoing ordeal, the frustration, but most of all, the pain. “I had 23 years of misery. Absolute misery. I had iritis and also reactive arthritis – blisters on my feet. And then, when you’re having an inflammatory attack, your skeletal structure is being reformed as you fuse. The destruction that is going on to make that happen, well, you want to put a gun to your head. It’s painful; it’s very painful.”

So after 23 years of various doctors eliminating the possibility that he suffered from a myriad of rheumatic and other diseases, Tompkins says he was finally convinced by his physician brother-in-law’s unerring

medical instincts that he indeed had ankylosing spondylitis. “He just asked me 20 questions and bam, bam, bam. There it was.”

And now, armed with a definitive diagnosis, a positive HLA-B27 – and even X-rays that showed fusion, Tompkins thought he was well on his way to feeling better, but the personal carnage was not over. The largest battle was yet to be fought. There would be a yearlong protracted and excruciating battle with his treating rheumatologist over the use of anti-TNF-a drugs. “It took me a year to convince her that I needed the treatment. I was angry about that. She was young and new and I guess she was following protocol. At one point, I brought in a stack of research papers from the New England Journal of Medicine and The Lancet and this infuriated her,” Tompkins says, and then adds with a thoughtful wisdom garnered through the years of travails, “The anger is pretty much gone now because this disease feeds on stress.”

Tompkins says that with the help of his anti-TNFa medication and his diet, he is able to function at a high level again. He makes himself available to personally counsel others diagnosed with AS through an AS support group. “The good thing that came out of this is that I have counseled many, many people with AS and I’ve gotten them into anti-TNF-a treatments,” says Tompkins. “I’ve taught them to be advocates for themselves when it comes to this disease.”

With the disease conundrum behind him, Tompkins looks back and urges other patients to make their doctor visits count: “If you want a higher quality of life, you need to be proactive; otherwise, it’s the luck of the draw which doctor you get. Have your doctor be your partner – and if he won’t, move on to the next one.”

## 3. Reaching for joy

A shocking and senseless beating by a group of bat-yielding thugs on a rampage one cold night in 1998 nearly cost him his life, a sad life already fractured by alcohol, two divorces and 25 years of ankylosing spondylitis, but SAA Indiana and Ohio support group leader Ken Prather says he found himself some old-time religion when he awakened from his 32-day coma.

*“How far you go in life depends on your being tender with the young, compassionate with the aged, sympathetic with the striving and tolerant of those who are weaker than you – because someday, you will be all of these.”*

— GEORGE WASHINGTON CARVER

*“He who angers you conquers you.”* –ELIZABETH KENNY

“The night of the beating, I had a feeling that I had to change,” Ken, now 56, tells *Spondylitis Plus*. “I had put myself in the hospital two times to quit my physical addiction to alcohol, but this was my Creator saying, ‘Look, if you can’t do it, I’m going to help you out.’” Ken, half joking, says that if the goons with bats had removed their jackets, “they could have had wings underneath.”

While the beating he took doesn’t sound like there was any ethereal influence, he recalls the injuries – on top of his full-blown AS – almost as if they belonged to someone else in another time. “I hit the first guy coming toward me,” Ken recalls, “I remember falling in this guy’s front yard and then a policeman talking to me – and the next thing, it is 32 days later.”

Although Ken’s injuries were life threatening, he swears his spirit was miraculously rewoven by the horrifically demoralizing event.

Ken says of his epiphany: “When I was on life support, I had a near-death experience where I envisioned that I needed to take everything that was negative in my life and use it to help other people, it’s about learning from your mistakes and life’s lessons and with this awakening, all my anger just disappeared. It’s been about forgiveness, not only for others, but the main thing, I forgave myself. The beating was my destiny and it is probably the greatest thing that ever happened to me because it turned my life around.” And he hasn’t taken a drink since the pivotal night – Oct. 12 – seven and one-half years ago.

He’s now out of his wheelchair – a miracle in itself, according to his treating physicians, although he walks with a cane and his spine, as a result of his AS and the beating, is totally fused. But he has not let his physical limitations get in the way of his destiny. If the AS causes a flare and he becomes bedridden for a time, others in his group pinch hit for him. “They understand my limitations,” Ken notes.

Since his recovery, Ken has made good on his vow to help other people in need. His volunteer oeuvre has been prodigious. Besides running the two SAA support groups, he moderates a message board, takes small-sized zoo animals to hospitals for visits with sick children, and he has founded an outreach hospice program called “Reaching for Joy.” The name hails from his daughter’s adult daycare center called “Joy’s House.”

“I’d like to think I have a great impact on the people I work with,” Ken says. “I think it’s important to use what we have to inspire others. In having a disease – a very chronic and painful disease, we should not look at this as a hindrance; we should look at it as a tool and a gift to help others.” Ken says that when he started the AS support group, his primary vision was to get everyone together and put them in a more positive light.

He denies feeling any rancor or anger for the alleged gang members who nearly killed him. Nor is he angry about his disease. “I never get

angry. I have nothing to get angry about. I stay active and I exercise every day of my life.” Ken says his wise father used to tell him that he had “never heard of anyone dying from pain.”

Ken says, “People have to understand that this is a life-long disorder and you may as well get used to it and go on from there. I’m not mad at anyone. I’m really happy.”

## 4. Humor: a gift

New York playwright and Spondyville website host Michael Smith says he was forced to grow up when he was finally diagnosed with spondylitis after having shown symptoms of illness for five years.

“This disease is what got me thinking like an adult, not that I was irresponsible, but I looked at things from a young person’s point of view,” Smith tells *Spondylitis Plus*, adding that he probably wasn’t taking the weight of adulthood too seriously. “I was in theater and in middle management at NBC at the time I was diagnosed in 1985 and I was only 34 years old. I used humor to deflect a lot of things and then I had to deal with something that had gravity, I had to be serious. I had to do what I was supposed to do and it just really made me grow up.”

Between the time the symptoms showed up and the definitive diagnosis, Smith saw two doctors: The first one suggested that his lower back pain and neck stiffness were psychosomatic. The second physician he saw before his AS diagnosis put him in a corset, a move Smith now knows worsened his condition, causing him to lose ground on the long-term disease battlefield.

Smith says: “I lost five years where I could have done something in the way of treatment. I lost the opportunity to catch it at the earliest and to work on slowing down the progression. Letting those five years get away from me is my greatest regret. I got stubborn, even though I knew something was wrong.”

But it was that very frustration, he believes, that got him going in the right direction. “I started Spondyville in 1995 in order to talk to a lot of people so I didn’t feel like I was alone,” Smith recalls. “When I came online and found some other people with the disease, it hit me that I could show others that you can keep your life. You don’t just become the disease; you can still be creative and have interests other than just talking about your disease all the time.”

*“For every minute you are angry, you lose sixty seconds of happiness.”*

–AUTHOR UNKNOWN

You could say that Smith still uses his good humor as a coping mechanism, but a darker side of Smith, like emotional shrapnel stuck in his heart, emerges as the discussion with Spondylitis Plus continues.

Smith has recently declared that he is giving up on relationships. “Basically, I have shut that part of my life down because I found it very trying; having to face rejection is difficult, especially when you have to devote so much of your time coping with your disease and going to doctors.

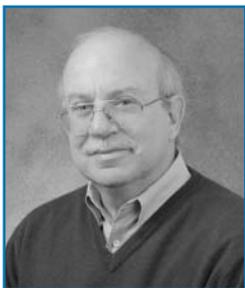
“I’ve been through the gamut of what you can go through. I totally fused within four years of being diagnosed. I’ve been through all the states where things diminish and when you are fighting to deny having the disease and fighting not to ask people for help; there are all these stages you go through and you get to each level of coping – and then you go down to another level and start over again and cope at that level.”

Smith says that AS can be a “spirit crusher” for him, but only if he allows the sadness to creep into his everyday existence. “This disease can crush your spirit if you let it. It’s what it does to your self-image and your emotions and how you interact with people. It can demoralize you as to who you are and what you can do. It can force you into complete and utter despair because you see that you’re not who you used to be. You’re no longer that person, and all the positive thinking in the world will not get you past that.”

But at the end of the day, Smith gets himself up, dusts himself off . . . and gets online with his community of 480 others with his disease and, together, they rescue one another from the demons of their disease with caring -- and also with Smith’s trademark humor.

He says, “That’s a real gift for me.”

## 5. Fighting mad



Perry Nicassio, PhD

Jane Bruckel says without a hint of irony that the Spondylitis Association of America was founded on anger and frustration. She and the other dozen or so members of the founding group were angry that their diagnoses had taken years too long; frustrated about the lack of information on their disease, and apprehensive about the uncertainty of the future.

We can’t all start a foundation. However, it’s easy to understand how a chronic condition could eventually give way to anger and rage. But what can we do to cope with our anger at the disease? We didn’t choose this any

more than we chose our genetics. Facing life with a chronic illness will often bring about visceral feelings that get stuck on the rising anger cycle. And then how do we get out of it? Who do we blame?

“Feeling angry about having a painful medical condition is not so unusual,” says Dr. Perry, a professor in the department of psychiatry at UCLA and whose clinical practice sees many patients with chronic illness. “It’s just that sometimes, there’s no one to blame for this; in order to let go of the anger, you have to be able to say, ‘I’m angry and frustrated; I have to get to a point where I use that frustration to channel productive effort rather than searching for someone to blame for the circumstances I’m in.’”

Dr. Nicassio readily acknowledges that people with AS have every right to feel the way they feel, however: “People have trouble responding to loss; you can’t do what you used to do. You feel tired or you feel physically unable to perform things other people can do that you were able to do previously. The reaction to this tremendous loss is to get angry.”

Ideally, he explains, the patient would learn how to meditate and relax. “Focus on goals that you want to achieve in order to solidify relationships with loved ones. Take stock of what’s important in your life in order to set these goals,” Dr. Nicassio suggests. “Goal setting is a healthy way to deal with the anger, but only after one accepts it and understands it.”

But sometimes we take our anger out on those closest to us. “Anger is often projected inappropriately,” says Dr. Nicassio. “It’s projected onto someone else who is not the cause of the anger – we all do that; it happens to everyone, but if you’ve had a poignant loss, it’s more of a problem and it’s much more of an obstacle. A lot of people with AS are not old and they’ve gone through a lot of trouble; you feel for them.”

Dr. Nicassio says that sometimes if you have overwhelming feelings of anger, perhaps they should be worked through with professional help. “If you feel anger because you have AS, then that becomes a clinical issue in itself and you have to work through it; and sometimes people need to be worked through that with outside help so that they can get to the point where they accept the circumstances,” notes Dr. Nicassio, who also believes that most patients with chronic illness do not seek professional help, nor is it offered to them. “They don’t often get the help they need because of the way the system works.”

Dr. Nicassio suggests that people who are having trouble with pain or who are not responding to their medication can ask to be referred to a behavioral medicine specialist, usually a psychologist who deals with quality of life issues.

*“Anger is one letter short of danger.”*

—AUTHOR UNKNOWN

## Online Auction

John Scanlon says that having AS motivates him to “try to raise money and increase awareness” of the disease and that the SAA online auction is a perfect vehicle for him to do volunteer work for a cause in which he strongly believes.

John, a civil engineer for Northrop Grumman who resides in Northern Virginia, told *Spondylitis Plus* that he thought the online auction would be a good opportunity to help the organization, adding that bidders online know what the disease is – it is a great idea to raise money for the organization. May 7 was John’s third online auction to be held on eBay to benefit the SAA.

The May 7th auction featured such excitingly eclectic items as Peet’s coffee for a year; a signed book by popular author Dean Koontz, whose writing was described by *The New York Times* as “psychologically complex, masterful and satisfying”; fancy hotel and resort stays in fun-getaway locales from Las Vegas to Puerto Vallarta to Ireland – and for those who live in the Chicago area, four ‘VIP’ tickets to a Jerry Springer Show taping, plus a CD and bumper sticker. Now how could anyone resist that one? Thanks to John and to all the wonderful donors and bidders who make the SAA third auction a success.



## Support Meeting Facilitators

The people listed below are a vital part of our support system. They have volunteered to lead support groups across the US because they want to help. If you’d like to find out more about support groups and online meetings, pick up the phone or send an e-mail to:

Glendale, AZ	John Kornfeind	(623) 937-1484	jmmkorn@cox.net
Long Beach, CA	Barbara Crofut	(562) 421-9698	crofutgr@netzero.net
Long Beach, CA	Frances Tomich	(562) 429-9685	
Los Angeles, CA	Janelle Haider	(310) 279.0504	saa_la_ca@yahoo.com
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Houston, TX	Richard Powell	(409) 883-7822	rwpowell@gt.rr.com
Washington DC	Roger Stead	(703) 455-6005	rogerstead@aol.com
Seattle, WA	Paul Stevenson	(206) 524-2186	pastev@Safeco.com

Support online from NY, NY with Michael T. Smith spenser23@aol.com

## Online Poll

You can find this new Instant Poll on our web site at [www.spondylitis.org](http://www.spondylitis.org).

### NEW POLL

Where have you felt the most pain during the past month?

- |   |                                       |
|---|---------------------------------------|
| <input type="checkbox"/> The neck                 | <input type="checkbox"/> The mid-back |
| <input type="checkbox"/> The lower back           | <input type="checkbox"/> Buttocks     |
| <input type="checkbox"/> Hands, feet, knees       | <input type="checkbox"/> Hips         |
| <input type="checkbox"/> Combination of the above | <input type="checkbox"/> Other        |

### OLD POLL RESULTS

Which physical and emotional aspect of spondylitis presents the biggest challenge to you?

More than one of these	49%
Fatigue	17%
Pain	13%
Movement limitations	6%
Peripheral joint involvement	5%
Muscle stiffness	4%
Mood	3%
Other	2%
Side-effects of medication	1%

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# We want to hear from you!

Join us online at [www.spondylitis.org](http://www.spondylitis.org) and tell us your story!

Help inspire and inform other members about your own experiences with ankylosing spondylitis and related diseases.



You can post your story on our message boards, or you can email your story to Chris Miller at:

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To ensure that you do not miss any issues of Spondylitis Plus or other SAA correspondence, please let us know when you move or replace your email address.

Contact Linda Powell by telephone (818) 981-1616 or email [info@spondylitiis.org](mailto:info@spondylitiis.org) so that we can stay in touch

## ARE YOU WILLING TO HELP RESEARCHERS FIND THE GENES THAT DETERMINE THE SEVERITY OF ANKYLOSING SPONDYLITIS?

If so, you may be interested in participating in our study. To participate you need to be at least 18 years of age or older and have been diagnosed with Ankylosing Spondylitis.

### Who is conducting the study?

The study is sponsored by the National Institutes of Health (NIH). The doctors conducting this study are Dr. Michael Weisman at Cedars-Sinai Medical Center in Los Angeles, Dr. John Davis at the University of California, San Francisco, Dr. John Reveille at the University of Texas at Houston, and Dr. Michael Ward at the National Institutes of Health in Bethesda, MD.

### How can I find out more?

Please contact one of the following Study Coordinators for more information:

- **Southern California:** Felice Lin, (310) 423-2422, [linf@cshs.org](mailto:linf@cshs.org)
- **Northern California:** Stephanie Morgan, (415) 502.1698, [smorgan@medicine.ucsf.edu](mailto:smorgan@medicine.ucsf.edu)
- **Houston Area:** Laura Diekman, (713) 500.6852, [laura.diekman@uth.tmc.edu](mailto:laura.diekman@uth.tmc.edu)
- **Washington DC Area:** Lori Guthrie, (301) 435.8434, [guthriel@mail.nih.gov](mailto:guthriel@mail.nih.gov)

## Position Statement from SAA's Medical and Scientific Advisory Board on the COX-2 Inhibitors 9/10/2005

Celebrex, Arcoxia, and Vioxx are examples of a class of drug known as the COXIBS. It appears that all anti-inflammatory agents, COXIB and non-COXIB, may have the potential to increase the risk of heart attacks, heart failure, and strokes. Patients with past and/or current heart disease, and those at serious risk of heart disease (e.g., diabetics), should check with their physicians before continuing to take any of these medications.

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