

# A POWERFUL PATIENT

Once disabled by rheumatoid arthritis, AMYE LEONG left her wheelchair – and became an advocate on the world stage.

As a little girl in Bakersfield, Calif., Amye Leong used to stick olives on her tiny fingertips, climb a favorite tree and nibble away for hours. “I wanted to stay up there, gazing out, on top of the world,” she says.

And for years to come Amye felt on top of the world, excelling at school and sports, becoming homecoming and prom queens. But then came the curious chest pains during her senior year in high school.

Rest didn’t provide relief; a cortisone injection seemed to do more harm than good. Blood tests later helped confirm a diagnosis of rheumatoid arthritis (RA) – which was attacking the joints in her chest.



Amye Leong at home in Santa Barbara, Calif.

It was the early 1980s. Her first medication: 26 aspirin a day.

They didn’t help much, she says. Neither did several disease-modifying drugs she tried. RA took a heavy toll on her body during college and graduate school. On bad days she was in a

wheelchair – or worse, in the hospital – with pain so severe it hurt to have a sheet covering her.

Amye was depressed and at times despairing – but deep down, that determined little tree climber was looking for a way back to the top.

## GROWING SUPPORT

By 1987, Amye was living with her parents and on disability. Her needs were taken care of, but what she wanted was someone to talk to about this disease.

“Mom and dad were always there to care for me. But we never talked about what was happening to me,” Amye says.

She had so many unanswered questions and assumed that others like her did, too: questions about sex, assistive devices, how to get in and out of a car gracefully. “I couldn’t be the only person in my 20s trying to figure this out. I needed people like me to help me problem solve,” Amye says.

With the help of her local Arthritis Foundation office and her hospital, Amye started a support group specifically for young adults – a place where people could share and learn from others like herself.

There were five people, including Amye and the program director, at the first meeting. “We sat there talking for, like, three and a half hours. We could not leave,” Amye recalls. At the next meeting, “Thirty people showed up, and then a month later 60 people showed up, and then the significant others started to come. One group became six, then 10, then 40 groups around the country.”

That success was the first of many for Amye. “I interrupted joint replacement

surgeries with speaking engagements at national conferences, meetings with legislators, government officials and national researchers,” she says. “Momentum was building that changed people’s views about arthritis. Decision makers heard our real life challenges of being young with arthritis.”

## PROOF OF PROGRESS

Ask a rheumatologist about the biggest change in arthritis care over the past 25 years, and biologics will probably be the answer. But Amye will tell you there’s an even bigger story.

“To me, what’s really changed is the perspective of and about patients. We have a voice now. We can say, ‘Hey, I’m not happy being in a wheelchair or in constant pain. We can look for and get support and resources,’” Amye says. “It’s this thing called self-help, which wasn’t even a category in bookstores 25 years ago.”

And she says the concept has evolved and branched out. First it was people connecting with others like themselves in small groups to find answers. Then patients became partners in their medical care – learning what to ask and what to provide their doctors. Today’s offshoot, she says, is researchers engaging patient advocates as “team members.” Amye represents the voice of the patient in medical research meetings

for OMERACT (Outcome Measures in Rheumatology), and was spokesperson for the Bone and Joint Decade, a global United Nations initiative promoting musculoskeletal health.

During her unexpected career as a motivational speaker and advocate, she served as chair of U.S. Surgeon General C. Everett Koop’s National Council on Self-Help and Public Health. In the 1996 Olympics, she carried the Olympic Torch as a Community Hero – from a scooter. Her biggest surprise was receiving the nation’s highest honor for community service, the 2002 President’s Service Award, at the White House from President G.W. Bush.

Amye has also been an advisor to the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS), and currently serves as an advisor for the National Institutes of Health.

After so many health challenges, how did Amye rediscover the determination of her younger, tree climbing self?

“The picture I had of myself was never in a wheelchair. I was determined to get the right experts to help me make the right decisions about my health care. It not only got me out of a wheelchair, but placed me firmly on the world stage to help millions of others like me,” she says. “Every time I look at olives, I chuckle with pure gratitude for being where I am today.”

–HOPE CRISTOL

The young tree climber



Homecoming and prom queen

Amye’s parents bring healing laughter to the hospital.



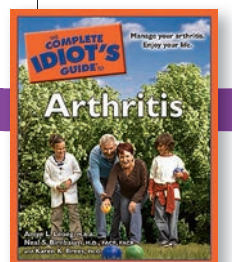
After one of 16 surgeries



Carrying the Olympic torch as a Community Hero



One of several books Amye authored



Speaking for the Bone and Joint Decade

