

THE POWER *of* Hope

Rheumatoid arthritis almost stole her life. Now she's in control, fighting back as an advocate and author.

STANDING A STATUESQUE 6 FEET TALL WITH A MANE OF BLONDE HAIR, KAREN AGER, 46, HAS MODEL LOOKS. The native Australian, who now lives in New York City, has traveled the world, worked as a nanny to a rock star's children and had brief flirtations with two prominent actors before becoming a teacher at the United Nations International School and marrying her adoring British husband.

Examined from this perspective, her life sounds glamorous, the kind most of us can only dream of. But read her recently published autobiography, *Enemy Within* (New Holland Publishers, 2010), and you realize that nothing could be further from the truth.

Karen has been fighting an aggressive form of rheumatoid arthritis (RA) since her diagnosis at age 17 – though she had symptoms for some time before. She was wheelchair-bound for two years and at death's door from pneumonia. At age 28, her right

[CONTINUED ON PAGE 16]

[CONTINUED FROM PAGE 11]

hip was replaced. She tried to tough out an abusive relationship; she felt no other man would want her because of her RA. And for years, she hid her disease from everyone except family and close friends.

"At times I felt hopeless. I lived in fear every single day that I wouldn't be able to work, that I would never marry and that someone would discover my secret," she says. "I'd lost control of my body. I was a twisted, angry skeleton."

That was then. This is now.

Despite challenges that would floor even the strongest person, Karen has flourished, becoming a tireless advocate for people with RA.

FINDING HER VOICE

Karen's decision to openly share her RA story was triggered by one pivotal event: In July 2001, with the supply of RA medications she brought with her from Australia nearly depleted, she saw a rheumatologist in New York City. She was prescribed a biologic drug that eased her symptoms within 24 hours – and an arthritis advocate was born.

"It was a virtual cure," Karen says of the medicine. "I had a quality of life I'd never had before." And she was stunned and angered to learn that, at the time, her fellow Aussies didn't have access to biologics. "I had been robbed of my adolescence, my 20s and half of my 30s," she recalls. "But suddenly the rest of my life seemed OK. For the first time I had hope, and I wanted to give that hope to others."

When she went to Australia for vacation the following summer, she vowed to tell her story and "start a [public] conversation about biologics." She called various media outlets until an editor at *Time Australia Magazine* agreed to interview her.

"At the time, arthritis got no publicity, so a two-page spread in a national

magazine was pretty big," she says. She also penned letters to the prime minister and other government officials, urging them to make biologics available.

It seems her efforts made a difference. Karen received an e-mail from the Arthritis Foundation of Australia thanking her for generating publicity about the

Joseph and his parents joined Karen and her husband on that year's walk. "I could see her fingers and tell there was something different," says Joseph, now 15 and in 10th grade. "I began to walk to support her, and as I got more involved, it became more important to me."

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drugs. Some two years later, biologics became available Down Under.

After finding her voice as an advocate, Karen never looked back.

She registered for the Arthritis Foundation's (AF) Advocacy Summit in Washington, D.C., in March 2003 and met members of the Foundation's New York office, who invited her to speak at their fundraising walk that year. Since then, she has joined its Board of Governors and speaks at local events and fundraisers. She also consults for the Arthritis Foundation's Women of Distinction Committee in New York (recently renamed "Women on the Move"), and managed to procure a Picasso lithograph for its fundraising auction last March.

INSPIRING OTHERS

She has also quietly opened the eyes of students at the U.N. International School. Seven years ago, one of Karen's second-graders, Joseph Lebowitz, noticed her crooked fingers and the flier she'd put on the bulletin board about the local Arthritis Walk. "Joseph put two and two together," says Karen, who now helps students with special learning needs.

He still walks for AF and encourages others to do so. And thanks to Joseph, "If you came into our school and asked any child what arthritis is, they would be able to tell you," says Karen.

In addition to her formal advocacy work, Karen runs an educational website about RA (www.karenandarthritis.com) and oversees an informal group she founded for women with RA and/or osteoarthritis to chat about the "practical side of living with arthritis," she says.

Now on her third biologic, as well as prednisone and a nonsteroidal anti-inflammatory drug, Karen has good days and bad. "When I'm tired, multi-tasking too much or anxious, I will have a flare," she says. But though her fingers are crooked, her right shoulder is pushed forward, she can't straighten her left arm, her ankles and knees act up and she walks with a slight limp, she says, "I am doing pretty good."

And she is optimistic. "New medications are coming out all the time," she says. "I spent a lot of time angry about my illness, but you reach a point where you have to channel that energy in a positive way. I really would not change the path my life has taken. Accepting and dealing with RA has allowed me to blossom and become the person I was meant to be." —CATHERINE WINTERS