

Leading Allergy Asthma Patient Advocate Retires After 28 Years of Nonprofit Service

Written by Australian Business

MCLEAN, Va., Sept. 16, 2013 /PRNewswire-USNewswire/ -- Allergy & Asthma Network Mothers of Asthmatics (AANMA) today announced that Nancy Sander, president and founder, has retired after 28 years serving as the nation's premier allergy and asthma patient advocate.

"It's been an incredibly fulfilling and always unexpected journey," says Sander. "I've been blessed more than I can ever express and cherish every moment I've spent with families, medical care providers, sponsors, members of Congress, federal and state agencies, other advocates, staff and our board of directors because ultimately, working together, we've made a world of difference!"

In 1985, Sander founded the nonprofit organization – or rather, she says, "AANMA found me" – at her kitchen table as she typed out what would be the organization's flagship newsletter, *The Mothers of Asthmatics (MA) Report*, to help families break free of the allergy and asthma tailspin.

Sander was a homemaker-mother of four whose 7-year-old daughter Brooke's severe, life-threatening asthma and environmental and food allergies came with countless hospitalizations, emergency department visits, doctor appointments, medical bills, sleepless nights and missed school days -- until they were referred to an investigational research program at Georgetown University Hospital.

"There I met allergist Martha White, MD, who changed my beliefs about what life could look like for Brooke. In addition to receiving the research medication, we got our treatment plan straight. She taught us how to use tools such as a daily symptom/medication diary system and a peak flow meter, and how to be a partner in Brooke's care, not just the administrator of the plan. I learned why she was using some medications daily and why I should give albuterol at the first, not the last, sign of symptoms."

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"It changed our lives. When I wrote about what we learned, it changed other people's lives, too."

Sander and White established the AANMA Board of Directors with a simple mission statement that remains true: **To eliminate suffering and death due to allergies and asthma.**

Sander's gift was making research and medical news as practical and friendly as a kitchen table conversation. A newspaper reporter saw *The MA Report* and wrote a story that garnered national attention. Soon radio and television interviews followed.

The response was overwhelming. Volunteers joined Sander and her children to fold, stamp and bundle newsletters. They alphabetized the index card mailing address system before an Apple dealer donated the first Mac. The early seeds planted grew into an award-winning organization.

Among her many recognitions and awards, Sander's most cherished is the 2012 Distinguished Service Award from the American College of Allergy, Asthma and Immunology – an award that had never before been awarded to a non-physician.

Sander served as the first patient advocate on the coordinating committee of the NHLBI Guidelines for the Diagnosis and Management of Asthma since 1991. In the years that followed, Sander heralded patient-centric values in many ways: FDA guidance calling for dose counters on inhalers; federal and state laws ensuring students have the right to carry and self-administer asthma and anaphylaxis medications at school; exposure of companies illegally mass manufacturing nebulizer medications; research into patient belief systems, including the "Language of Asthma": words frequently used by medical care providers that result in misused medications by patients and parents; and NIAID Guidelines for the Diagnosis and Management of Food Allergy in the U.S.

Sander has written numerous children's books and videos; launched and served as editor in chief of two award-winning magazines: *Allergy & Asthma Health* and *Allergy & Asthma Today*, as well as special editions such as *Anaphylaxis: A Guide for All of Us* ; and produced patient education tools such as The Indoor AIRepair Kit, "The Peak Flow Meter Book," "The Asthma Organizer," and "My Personal Guide to Allergy & Asthma."

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Her first book, "A Parent's Guide to Asthma" (1989), became a cherished guidebook for families across the country, and Sander plans to update it in retirement. "With better medications and understanding of the immune system, it would seem like making good choices should be a cinch," she says. "But it's not. There are still huge misunderstandings about the disease and parents still struggle with many of the same issues we faced 28 years ago."

Sander says there are three others who earned founder status at AANMA. "Dolores Libera, Sandra Fusco-Walker

and

Laurie Ross

are defining cornerstones of the organization. Dolores started as a volunteer 25 years ago and I hired her the same day. She probably performed every function within the organization and as Director of Publications oversaw all of our award-winning newsletters, magazines, pamphlets and more. Sandra also began as a volunteer and directed our Outreach Service Coordinator program -- but she found her true calling as Director of Patient Advocacy. Great fun to go to Capitol Hill with and everyone there loved her!

Laurie Ross

began as a freelance proofreader and has been keeping every word straight since."

Sander will be working with the Board's transition committee and on special projects such as the Family Allergy & Asthma Decision Mapping Project but looks forward to new ventures and more time with her husband, children and three grandsons.

In her never-ending patient advocacy call to action, Sander encourages families to join and continue to support AANMA: "Since 1985, families come first! It is through your interaction that AANMA's leadership and staff know how to carry your voice forward to decision-makers. Membership matters because YOU matter! Be active! Learn more at www.aanma.org or pick up the phone and talk to AANMA's great staff at 800-878-4403!"

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