

Julie Gundlach

ADAO 2011 Alan Reinstein Award Honoree

Young woman battles rare mesothelioma, promotes complete ban on asbestos use

Julie Gundlach was only 35 and a mother of a three-year-old daughter in 2006 when doctors handed her a diagnosis of mesothelioma – a rare and often-fatal disease people commonly associate with older men who have worked in an occupational setting that brings them in close contact with asbestos.



Gundlach, now 39, had just come through surgery to remove a tumor the size of a small cantaloupe from her pelvic area and a complete hysterectomy – procedures performed following what was thought to be ovarian cancer – when doctors told her she had something quite different: mesothelioma. They told her to focus on recovering from the surgery, but to get in touch with an oncologist.

The oncologist intended to start chemotherapy, though he promised Gundlach no hope that it would be successful.

“It was made clear that the treatment was to prolong my prognosis – not to cure me,”

Gundlach said. “I was told to see a lawyer and to get my affairs ‘in order.’”

“There is nothing so devastating as to be told to put your affairs in order. While my doctors didn’t say, ‘You will die,’ the implication was clear.”

Gundlach said she went home in a fog, trying to cope with the reality that what she had was deadly and something completely foreign to her.

“I didn’t know what mesothelioma meant. I thought this could not even be possible,” she said. “It was unbelievably hard to function at this time – I would look at my daughter and just be overwhelmed with grief for the times of her life I would surely miss.”

Turning to the Internet to search for information on mesothelioma didn’t help to alleviate her confusion or abate her fears. She said she found the word ‘mesothelioma’ popping up on legal firm sites that provided only basic information. And data she read about the prognosis was chilling: six to 12 months survival; “virtually always fatal” and “painful decline inevitably ending in death.”



“That was enough information to strike terror in my heart,” she said.

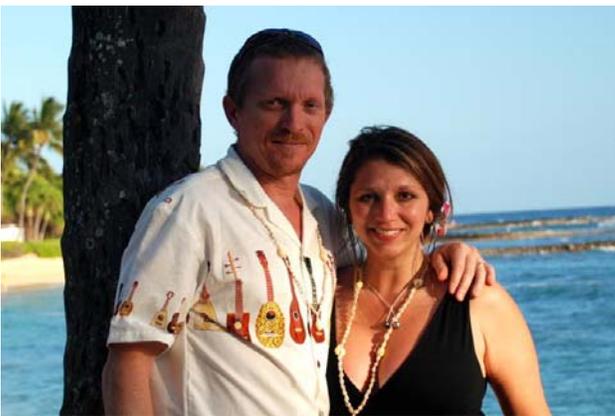
In the face of such a grim reality, Gundlach began praying to God, asking Him to show her what to do. And the very next web site she came upon was the Mesothelioma Applied Research Foundation – a site that became, as she calls it, ‘my lifeboat in stormy seas.’

A doctor on the site wrote: “If you are reading five-year survival statistics, their data is five years old. There is hope.” It was what Gundlach needed to read to feel a faint glimmer of hope in her situation. She also learned that the foundation had their annual conference coming up that fall in Chicago.

It was with trepidation and a thirst for knowledge about her disease that Gundlach attended the conference.

“I was terrified. I didn’t even want to go to Chicago,” she said. “I was crawling out of my skin and in a state of shock.”

While at the conference, Gundlach met doctors who specialized in treating mesothelioma; people from other organizations that give voice to victims of asbestos exposure; and mesothelioma patients who were currently living healthy lives.



“That seemed unreachable to me,” she said. “While I was there that weekend, I met the people who would become a huge part of my support group, as well as my soon-to-be medical team: Dr. Robert Taub, director of Columbia’s Mesothelioma Center, and Dr. John Chabot, chief of GI/Endocrine surgery at New York-Presbyterian Hospital; and Mary Hesdorffer, CNP, medical liaison of the Mesothelioma Applied Research Foundation.” Gundlach added that the encouragement she received from other patients at the conference buoyed her significantly.

“I came home knowing I wanted to go to New York for treatment, but not knowing how I would even begin to manage it.”

Despite what seemed a herculean task, Gundlach began booking flights to New York; contacting friends who could escort her to treatments; reaching out to family and her husband Dan to care for her daughter, Madeline; and dealing with her insurance company, which was fighting her every step of the way because she was going out of network for her care.

Gundlach says it was during that time that she learned to ask for help – not an easy task, she admits.

“It was all too overwhelming to comprehend. It just became so necessary to ask for and accept help,” she said. “When people asked me what they could do, I would have to tell them. You can only do what you can do. You can’t be everything to everybody all of the time.”

Gundlach’s mesothelioma treatment, which began in January 2007, consisted of two surgeries with a heated chemotherapy wash performed at New York-Presbyterian Hospital in Manhattan. After the surgeries, she traveled from her home in St. Louis to New York three times a month for three months for 12 interperitoneal chemotherapy treatments of adriamycin and cisplatin through ports in her abdomen. She then received four interferon treatments.

“I traveled mostly with friends for my treatment at this time,” she said. “They were short, overnight trips, and it was important to us that my husband Dan remain home with our three year old. It was so difficult being a mother at that time.”

Those friends also brought over food, cleaned the house and watched Madeline when family members weren’t available. Not only that, friends threw her a huge benefit to help offset medical and travel expenses.

“We could not have managed without all of the angels in our lives,” she said.

Today, Gundlach continues to battle her mesothelioma though her scans recently came back showing her condition is stable. When asked how she was exposed to asbestos, Gundlach hesitates to give a definitive answer, for she has none.

“Everyone wants to limit it to one thing,” she said. “My father worked as a commercial electrician. He may have had asbestos fibers on his clothing. He also changed his own car brakes in the garage and I helped him.

“My parents built their own home. Asbestos was in the walls, in the floors and in the insulation. There’s no way to trace *the* fiber that caused my mesothelioma. I was a kid in the early 1970s. It was everywhere.”

She says that she continues to deal with overwhelming fear on a daily basis, but truly believes that courage is defined by the willingness to take action in the face of fear.



One way she is transforming fear into courage is by getting the word out about the dangers of asbestos exposure and that it can affect anyone. At a recent Earth Day event in her hometown, she gathered 1,000 signatures from attendees to present to Washington politicians to demand that they force manufacturing companies to stop using asbestos in their products.

She will also take part in the Seventh Annual International Asbestos Awareness Conference April 1-3, 2011, at the Marriott Buckhead Hotel & Conference Center in Atlanta, where she will receive the Alan Reinstein Award. The award applauds those who, despite a diagnosis of mesothelioma or other asbestos-related disease, have reached out to the community to promote greater public awareness of asbestos

exposure and to push for its complete global ban.

The conference is presented by the Asbestos Disease Awareness Organization and sponsored by the Barbara Ann Karmanos Cancer Institute in Detroit. While there, Gundlach will also be part of a conference on April 2 on Public Health.

As Gundlach takes each day at a time to fight her cancer, she said she has three wishes. Her first wish is to save her own life so that she can be there for Madeline and Dan. The second is to come up with a cure to save everyone from the horrific disease of mesothelioma, and the third is for a complete ban on asbestos.

“More than anything, I want to live,” she said. “And even though some days it feels impossible to live, laugh and love as fully as I am able to, I will never give up hoping for a cure.

“That is what I would share with anyone with a serious chronic disease – never give up hope and remember that your life is yours, not the diseases.”

For more information about the Seventh Annual International Asbestos Awareness Conference, visit www.AsbestosDiseaseAwareness.org or www.karmanos.org/view_news.asp?id=801.

Advice from Julie Gundlach to those who have been diagnosed with mesothelioma or other asbestos-related disease, and to the community:

- Use the help that people offer you – have lots of helping hands to help you cope with your disease.
- Find doctors who are specialized in treating mesothelioma, if that is your diagnosis. It’s not enough to have a really good oncologist and a really good surgeon. If they can’t tell you the kind of experience they have, it means nothing, Gundlach says.
- Attend the Seventh Annual International Asbestos Awareness Conference for useful information on the latest treatments and research. Visit www.AsbestosDiseaseAwareness.org.
- Visit the Mesothelioma Applied Research Foundation (MARF) Web site at: http://www.curemeso.org/site/c.kkLUJ7MPKtH/b.3076109/k.FF9C/Mesothelioma_Applied_Research_Foundation.htm. Gundlach says MARF’s site is the best and most trusted source for mesothelioma information.
- To those who believe they may have been exposed to asbestos but have no symptoms, Gundlach advises them to tell their physician and watch for the symptoms – but not to dwell on it. There isn’t anything one can do after exposure to lessen the risk.
- Turn anxiety into action and contact your legislators and ask them why they are still allowing the manufacture of goods containing asbestos.
- If, like Gundlach, you’re angry that asbestos is still being used on a global scale, speak up! If you don’t know what to say, or where to start, there is no where better than the Asbestos Disease Awareness Conference, Gundlach says. The amount of information is staggering, she added, and finds it refreshing to see so many people working so hard for the same goal of eradicating the use of asbestos.

About Asbestos Disease Awareness Organization (ADAO)

Asbestos Disease Awareness Organization (ADAO) was founded by asbestos victims and their families in 2004. ADAO seeks to give asbestos victims and concerned citizens a united voice to raise public awareness about the dangers of asbestos exposure. ADAO is an independent global organization dedicated to preventing asbestos-related diseases through education, advocacy and community. ADAO’s mission includes supporting global advocacy and advancing asbestos awareness, prevention, early detection, treatment, and resources for asbestos-related disease. For more information visit www.asbestosdiseaseawareness.org.

About the Barbara Ann Karmanos Cancer Institute

Located in mid-town Detroit, Michigan, the Barbara Ann Karmanos Cancer Institute is one of 40 National Cancer Institute-designated comprehensive cancer centers in the United States. Caring for nearly 6,000 new patients annually on a budget of \$216 million, conducting more than 700 cancer-specific scientific investigation programs and clinical trials, Karmanos is among the nation’s best cancer centers. Through the commitment of 1,000 staff, including nearly 300 physicians and researchers on faculty at the Wayne State University School of Medicine, and supported by thousands of volunteer and financial donors, Karmanos strives to prevent, detect and eradicate all forms of cancer. Its long-term partnership with the WSU School of Medicine enhances the collaboration of critical research and academics related to cancer care. Karmanos is southeastern Michigan’s most preferred hospital for cancer care according to annual surveys conducted by the National Research Corporation. Gerold Bepler, M.D., Ph.D., is the Institute’s president and chief executive officer. For more information call 1-800-KARMANOS or go to www.karmanos.org.

Asbestos Disease Awareness Organization is a registered 501(c) (3) nonprofit organization
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