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Medical Notebook: MB couple forms group to raise awareness of mesothelioma

It was the day after Father's Day last year, when they first heard the term.

The term was mesothelioma -- cancer of the lining of the lung -- and after months of ineffective testing for what was going on with Alan Reinstein's lungs, doctors finally had made the correct diagnosis.

Alan's wife, Linda Reinstein, turned to the Internet to learn more about mesothelioma.

"I sat paralyzed as I pulled up information that was so dark and grim," she said.

Mesothelioma is a deadly but obscure cancer, and it was hard to find much information on the Internet. Was there a standard treatment? How long could patients expect to survive?

The Manhattan Beach couple had already struggled for months to find out what was wrong with Reinstein's health. Of course, when the mystery was solved, it was little consolation, given the bleakness of the outlook.

Reinstein had major surgery shortly afterward to remove his left lung, his diaphragm and the lining around his heart.

The surgery to save his life was so extensive that it nearly killed him, he said. His appetite was gone, and he had to force himself through nausea to eat, lest he be implanted with a gastric feeding tube.

His recovery was difficult. "When I came home, I could barely get upstairs," said Reinstein, 64.

The difficulty wasn't made easier by the feeling of being alone, especially at the outset of the diagnosis. Eventually, Linda Reinstein set out to organize a group, nationwide in scope, to combat that isolation.

Mesothelioma is caused by the inhalation of asbestos fibers, and those who are hit by it often in their past worked with the mineral, which is widely used as an insulation and fireproofing material. About 30 percent of the people who have it either served on a Navy ship or worked in a shipyard. The disease tends to hit about 30 years after exposure, although it can be 10 to 50 years.

Actor Steve McQueen died from it in 1980, and Grammy Award-winning singer-songwriter Warren Zevon died from it in 2003.

Experts figure that many mesothelioma deaths are never diagnosed correctly, with the victim succumbing to pneumonialike symptoms and no autopsy being performed. Maybe more tragically, sometimes when the disease is correctly diagnosed, the patient is told by the doctor that there is nothing that can be done, said Dr. Robert Cameron, a mesothelioma expert and chief of thoracic surgery at UCLA Medical Center.

As she helped her husband, Linda Reinstein learned more about the disease. She started to wonder why it was so little known, especially since she kept running into people whose loved ones also had the same disease.

After Reinstein's surgery and long recovery, he wasn't going to run marathons again, and he wasn't going back to his job as a manager for a computer consulting firm. But the cancer was gone and he was stable.

Linda Reinstein, given her years of work as a volunteer in the community, still felt there was something that could be done. When she heard of controversial

legislation regarding lawsuits over asbestos-related diseases, she decided to take a trip to the capital in March, to meet with senators and their staffs, joining others to speak out against what some say was going to be a windfall for corporations and others responsible for the asbestos in the first place.

It was on the plane flight back home that she realized she could be doing much more.

"How can I take the tragedy in my heart and turn it into something that will save someone else?" she questioned.

It seemed to her that people with asbestos-related diseases and their loved ones weren't connecting. They couldn't find each other to offer support and advice. It seemed like something that was being regarded as a rare disease was actually much more widespread.

There was a need for a grass-roots, nonprofit organization, one that would "give a voice to the victims," Linda Reinstein said.

When she got home, she decided to talk to a contact back east she had made on her trip, Doug Larkin, whose father-in-law was diagnosed with mesothelioma. Turns out he was having roughly the same thoughts about organizing.

So they formed the Asbestos Disease Awareness Organization.

"What we like to think we did is turn anger into action," Linda Reinstein said. "We wanted to unite victims, and launch a national asbestos awareness campaign."

"Being able to have other victims talk to us, and telling them what to expect is extremely valuable and comforting to them and to us," Alan Reinstein said.

In just a month's time, the group is showing results, uniting hundreds of victims and their families, Linda Reinstein said.

And the asbestos bill? It was scrapped in April.

If another asbestos-litigation bill comes along, Linda Reinstein said the ADAO wants to have input, especially to craft legislation that will be fair to the victims, not just a bailout to the companies. For one thing, a commission or task force of economists, medical experts and others should be formed to help determine just what a fair settlement would be for victims of asbestos, she said.

Because asbestos-related diseases can come 50 years after exposure, many victims are alone and aged, and often too frail to have the type of surgery that her husband had, Reinstein said.

That's why it's so important to have an independent, nonprofit group to speak up for them, she said, to advocate for research and work for awareness.

Send comments to lee.peterson@dailybreeze.com or to Medical Notebook, Daily Breeze, 5215 Torrance Blvd., Torrance, CA 90503-4077.

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Asbestos Disease Awareness Organization

"Voice of the Victims"

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