



Faces of AGENT ORANGE

Maine



Sharon Perry

By Jim Belshaw

Even when the letter came in 1984, Sharon Perry and her late husband, Reuben “Bud” Perry III, didn’t make any connection with Agent Orange. No red flags were raised about what was happening in their home, happening to him, happening to their daughters. The oldest, Danielle, would be sick all her life. The youngest, Lisbeth, would be diagnosed with autism — but not until she was 26. Lisbeth would have a son and he, too, would be diagnosed with autism. Bud would die in 2005 after many difficult years of dealing with the aftermath of the Vietnam War.

But in 1984, they stood in the kitchen, reading the letter about a class-action suit brought on behalf of veterans who may be suffering from the lingering effects of Agent Orange. They didn’t think it had anything to do with them.

“I’ll always remember standing in the kitchen and looking at one another and saying to him, ‘you’re not sick,’” she said.

She saved the letter anyway.

“I put it away because you never know,” she said. “After that it was always in the back of my mind.”

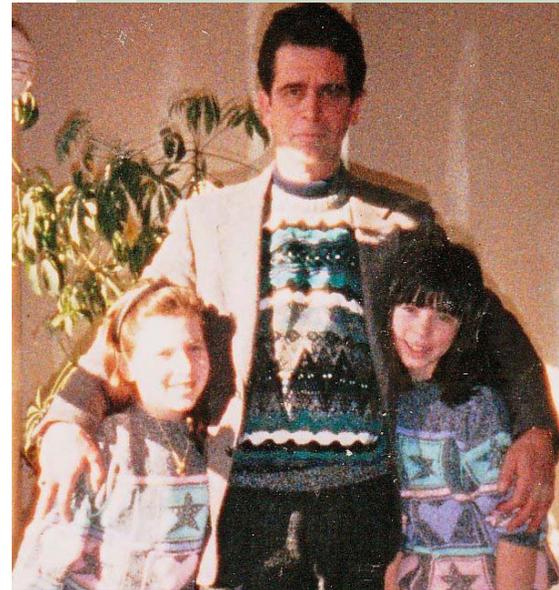
Bud pulled two tours in Vietnam, each with the “brown water” Navy, working

in the war’s rivers. When he came home, new battles arose. He would eventually receive a 70 percent disability for PTSD and 30 percent for his unemployability. He put in a later claim for peripheral neuropathy for the loss of the use of his feet. Lower amounts were awarded for disability in both arms. He turned to alcohol to ease the pain. His sister wrote the VA a letter in support of the PTSD claim in 1999. She said the family did not recognize the young man who came home from Vietnam. Something was wrong. She said his soul seemed to have been ripped from inside him.

Sharon said, “He had a real rough time dealing with his PTSD, and self-medication was how he dealt with it. They wanted to blame his troubles on that.”

Sharon tried to see a VA administrator. When her path was blocked, she chewed out his secretary. She never did get in to see him, but she did get to speak with someone in charge of claims. He set up an appointment with a neurologist. The physician said the peripheral neuropathy likely was caused by Bud’s diabetes, a trail that led back to Agent Orange.

“What the VA doesn’t want to acknowledge is that it’s all caused by Agent Orange because there’s a link





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between Agent Orange and diabetes,” Sharon said. “So they don’t want to give thumbs up to the peripheral neuropathy. I don’t know why. Well, that makes all of us have to deal with the repercussions and emotions of all that. What, are we crazy? That’s how the game is played. If they drive you insane, they’ve won. If they don’t, and you decide to speak out, if enough people do that, maybe they’ll lose.”

Her husband started getting sicker in 1998. In 2004, Sharon urged him to put in a claim for rheumatoid arthritis. She was told that sometimes the VA can find that a veteran has improved and they’ll take away money. So if you’re relatively happy where you are, you should stay there.

Reuben “Bud” Perry III died in 2005.

His oldest daughter, Danielle, had trouble with infant pneumonia and ear infections. She was diagnosed with serious allergies to numerous everyday sources. She suffered with severe sinus problems and reoccurring strep throat. In the second grade, she began having serious neck spasms. There were times when she couldn’t move her neck at all.

“It continued to happen on and off over the years,” Sharon said.

When Danielle was 10 years old, Sharon said she suffered muscle spasms over her entire body. She was unable to walk. They had trouble finding help. Finally, they went to see a neurologist. He said he wanted the parents to tape the next episode with a video camera. They did and brought the tape to him.

“He said, ‘she’s faking,’” Sharon said.

It is hard for her to talk about it even today.

“You don’t fake so your feet turn inward all day long. Nobody — *nobody* — does that,” she said. “This kid could not do that for days at a time. She was in pain and there was no treatment for her pain. I kept thinking, can I go along with these people and believe my daughter is a fake? I couldn’t. I had to make a decision. This was my little girl — *my little girl* — who had nobody else but me to stand up for her. And that’s what I did. And it was hell. I can’t tell you how much hell it was. You can’t imagine how much hell it was.”

At 26, Danielle developed a new set of symptoms. Sharon found a doctor who was actually able to identify her problem, and that was at an emergency room, where Danielle was diagnosed with spondylolithesis and spondylolysis (conditions that affect the vertebrae). The doctor ordered medications that have helped ease the pain.

The list of Danielle’s diagnoses looks like this: asthma, Post-traumatic Stress Disorder (PTSD), anxiety, conversion disorder, spondylolithesis, spondylolysis, comprised immune system, hip dysplasia, cervical dysplasia, ovarian cysts, migraine headaches, fused vertebrae, bulged discs, fibromyalgia, debilitating muscle spasms, major depression, gastritis, arthritis, torticollis, granuloma annulare, and tachycardia.

“She is one of the reasons AO Legacy exists today,” Sharon said. “It kills me to know that she continues to endure a host

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of medical challenges without any real medical intervention and treatment plan. And she is not alone. Everyday I meet another child of a Vietnam veteran who is going through the same thing.”

She saw people writing on Betty Mekdeci's Website (Birth Defect Research for Children, Inc.). Sharon called her. Betty told her one of the persistent problems in the Agent Orange battle was the lack of a lobbying presence in Washington.

Sharon, along with Danielle, set out to make their presence known on the Internet. They created a Web page: <http://www.agentorangelegacy.us>; at another site — <http://www.agentorangelegacy.ning.com> — they created a support community where veterans and their children could tell their stories.

She said her primary goal was to create that lobbying presence on Capitol Hill, and she wants it there for the children of Vietnam veterans.

“I want to say to the children, ‘this is about you,’” she said. “But when they come to me, it's about the veteran. The veteran is sick or the veteran is dying or the veteran has died. When you're in that frame of mind, you can't talk about anything else. You don't care about you, because your entire focus is on your parent. It's taken us two years to get to the point where we can now put the focus on them.”

Significant numbers of Vietnam veterans have children and grandchildren with birth defects related to exposure to Agent Orange. To alert legislators and the media to this ongoing legacy of the war, we are seeking real stories about real people. If you wish to share your family's health struggles that you believe are due to Agent Orange/dioxin, send an email to mporter@vva.org or call 301-585-4000, Ext. 146.