JOE INGINO
By Jim Belshaw

“I never put two and two together,” Joe Ingino said.

It took a long time before he could do the math, and even after the metaphorical numbers in his Agent Orange equation added up, he still had difficulty talking about it. He does to this day.

“Talking about it now, you just get choked up,” he said. “Sometimes you want to punch something, you know? You just keep blaming yourself. I went to two Agent Orange town hall meetings and listened to other fathers talking about their children, and it just gets very emotional. It’s very difficult to listen to them and then to speak about your own children. It’s very hard.”

Joe served with the First Infantry Division in 1969-70. In 1971, he met the woman who was to be his wife. In 1972, they married. His wife would suffer through several miscarriages, but eventually they had six children, one of whom lived for only a brief time.

“My wife carried our daughter for seven months, and something happened that caused the baby to break away from her,” he said. “She lived for a day and a half, maybe two days. Then she died.”

One year later, another daughter, Katie, was born. At birth, she was diagnosed with an “imperforate anus” and scoliosis. A specialist performed emergency surgery that saved her life; several months later a second surgery came. The physicians wanted to move her to another hospital for the initial surgery, the same hospital in which Joe’s daughter had died the year before. He couldn’t bring himself to take another infant through those hospital doors. A different hospital was chosen.

In the course of Katie’s hospitalizations, a physician showed Joe pictures of his daughter’s spine.

“It looked like a bag of bones,” he said. “It was just a whole thing of bones, and none of them were together or connected.”

Katie would not be the only Ingino child with longstanding health problems. All of his children have asthma; all of them showed learning disabilities in their school years. In later years, Katie would give the Inginos a grandson, but he, too, would be diagnosed with health issues — hearing difficulties and autism.

None of the birth defects or illnesses had shown up anywhere in Joe Ingino’s family medical history or his wife’s.

Joe had been going to the VA for many years. On one visit, after routine blood
Joe Ingino’s Story Continued...

work was done, his PSA numbers came back alarmingly high. He went to see a urologist. He was diagnosed with prostate cancer. It was the beginning of a long decline.

“I had prostate surgery,” he said. “Then everything escalated — diabetes, coronary problems, hypertension, a pacemaker.”

The residual issues often related to prostate surgery forced him to give up his job as a truck driver for a local municipality, but he was still active in VVA. He served as president of Chapter 82, Nassau County, Long Island. He attended conferences and town halls, listening to other veterans speak of Agent Orange-related issues for them and their families. He began to see his own health problems and his children’s in a different way.

“I thought I was just another regular Vietnam vet with some PTSD problems and stuff,” he said. “Then everything started weighing on me more with my children.”

An insidious side effect – guilt – came with the knowledge of Agent Orange-related health issues. He blamed himself for his children’s health problems.

“We blame ourselves,” he said. “It bothered me immensely. It really bothered me. Just the idea of it.”

A veterans’ counselor told him of “false guilt,” assuring him that he had done nothing wrong. His family supported him unequivocally, a unified stand for which he is appreciative. But he still speaks of guilt with difficulty.

“Everyone said, ‘You didn’t do anything wrong,’ but it’s still this guilt you have and you’re blaming yourself,” he said. “It might be ‘false guilt,’ but it doesn’t feel like it. We all feel like we brought this stuff to our families. I don’t have to tell you how much it pisses us off.”

He continues to be active in VVA, encouraging veterans to learn everything they can about Agent Orange and its effects. He said that in his time as president of Chapter 82 he frequently received calls from veterans’ wives with questions about their husband’s health after they read Agent Orange stories in The VVA Veteran.

He visits congressional offices whenever he can, often finding young aides who want to be helpful but who know little or nothing about Agent Orange. They’ve heard of it, but often just hearing of it is the extent of their knowledge.

“I just want Vietnam vets to please get checked out,” he said. “Learn everything you can about Agent Orange. Go to the VA or find a service officer and ask questions. There’s lots of information at VA hospitals. There are a lot of things the VVA has about Agent Orange. Vets need to get their stories out about children, and let the country know what they’re going through, and what their children are going through.”

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Karl Hansen’s son, Adam, had been dead five years before questions about Agent Orange arose. Until then, Karl had not given the herbicide a thought in all the years that followed his Vietnam tour of duty. But after Adam’s death, he found himself reconsidering not only the tragedy that befell his son, but health problems faced by other of his children as well.

Burkitt’s lymphoma, a form of cancer so rare that only 300 cases a year are reported in the United States, led to Adam’s death. He was 25 years old. The exceptionally aggressive disease killed him so quickly that Karl had little time to investigate the rare cancer’s mystery. After Adam died, Karl needed answers and began researching Burkitt’s. It was in the course of that search that Agent Orange unexpectedly entered the discussion.

Karl served with the Army in Vietnam in 1968-69. He remembered the spraying, but thought little of it, even when he was in Vietnam.

“I didn’t have a clue,” he said. “I knew there was spraying going on, but I didn’t know if it was for mosquitoes or what it was for. I didn’t think about it at all when I was there. What caught my attention was the stuff I saw on the Internet and after I joined VVA and saw some of the articles on Agent Orange being written.”

Karl and his wife had six children — four daughters, then Adam, then another daughter, a birth order that was something of a family joke, because it was exactly the opposite of Karl’s parents. His father, a Navy veteran, also had six children. But first came four boys, then a girl, then a boy.

Karl said Adam was a “wonderful kid.” Neither a smoker or drinker, he steered clear of the trouble a boy might find growing up. He was a good student and built a reputation as a hard worker in every job he took on. At 25, he was a newlywed with a good job in Provo, Utah, managing the care of model homes for one of Utah’s largest home builders. He was in his last semester at Brigham Young University and due to graduate. Karl was so proud of his son, who would be the first in the family to graduate from college.

Around Mother’s Day 2005, Karl heard that Adam had been sick. He went to a doctor who diagnosed some kind of parasite.

But the problem persisted. Adam’s stomach became distended, and on a visit to one of his sisters, she was shocked at the sight.

“When she saw him, she told him something was very wrong,” Karl said. “She said, ‘You’ve got something growing in you.’”

He went to a doctor again, and this time
he was hospitalized immediately. A colonoscopy showed cancer in his colon. The physician identified it as Burkitt’s.

“I had never heard of it until I found out about Adam,” Karl said.

Treatment was difficult. In the first round of chemo, Adam had a pulmonary embolism. The hospital “crash cart” kept him alive, and after a week in the ICU, he showed signs of recovery. Then came the second round of chemotherapy. It would be even worse. Severe neurological problems prevented him from performing the simplest movements. His eyes began to move in different directions, and the neurologist didn’t know what was wrong. After two weeks, a nurse from a different department asked if anyone had tested for toxins in his blood. A test showed an ammonia level several hundred times higher than normal.

“There was nothing they could do for him,” Karl said. “We had to let him go.”

After Adam’s death, Karl began the search for answers. In that search, he came across Agent Orange for the first time.

“I ran across something about someone’s son who had died of Burkitt’s, and a doctor told him several first-born sons of Vietnam veterans had died of it,” Karl said. “The doctor wouldn’t document it. So I don’t know if it was someone shooting off his mouth, or if there was something to it. But it made me start thinking more about Agent Orange. I remembered at the base camps and firebases I spent time at that there was no foliage in the immediate area. There was a lot of dirt, but no foliage.”

In The VVA Veteran, he read about the daughter of a Vietnam veteran who suffered from Raynaud’s disease, which causes discoloration of the fingers and toes, primarily. It is believed the disease decreases the blood supply to the affected areas.

Two of Karl Hansen’s daughters suffer from Raynaud’s. One has had it for several years; the second was diagnosed only months ago.

“She was at her daughter’s soccer game, and it was rainy and cold,” he said. “She took off her glove, and her fingers were white, almost to the knuckle.”

Karl has been concerned about tremors in his hands. He worries that the coming years will make them only worse. He has another worry as well: One of his daughters has suffered from similar tremors for several years.

No one in his family or in his wife’s family has any history of any of the diseases that have afflicted Karl and his children.

“What makes me sick is when I think about Agent Orange possibly having something to do with this and what it did to my kids,” he said. “It just tears you up. I don’t know if any of this will be passed on to my grandchildren. I have 12 grandchildren. I think there’s a very good chance that all of this is connected to Agent Orange.”

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Dan Griffin's daughters provide a clear demarcation line for him.

He has two daughters – Kim, born while he was in Vietnam, and Shannon, born after his return. Kim is healthy. Shannon is not. She has been diagnosed well into adulthood with numerous blood-borne diseases and dysfunctions of her autoimmune system. One of these diseases has so disfigured her face, she cannot bring herself to leave her home. Her nose has virtually disappeared.

“She’s a prisoner of war,” Dan said. “She's a POW of the Vietnam War.”

She adamantly refused to have her picture included in this story until persuaded to do so by her father.

“She was a beautiful young woman,” he said. “To me, she’s still beautiful, and I love her. But I hope she never sees this story or these pictures.”

He said Agent Orange came to mind immediately when Shannon began having health problems.

“I made the Agent Orange connection pretty much as soon as she started having problems,” he said. “One born while I was in Vietnam, and she’s fine; the second, born after Vietnam, and she’s not fine. It wasn’t too hard for me to come up with a connection there.”

He has his own Agent Orange connection in a melanoma removed from his back. He served in Vietnam from 1968-69 as an infantryman with the 1st Cav. He has no memory of being sprayed directly, but there is no doubt he spent a year in an area that saw spraying.

“In the early years, you had to prove you were sprayed, but you no longer have to do that,” he said. “You have to prove only that you were in Vietnam. They sent me a map with the locations where my unit operated. They had an overlay that showed where Agent Orange was sprayed. Three of them were right where we were.”
He received a check from the Agent Orange settlement.

“I got my $600 check,” he said. “Did you know you get the same amount if you die?”

His battle now is on behalf of Shannon. She is 38 years old. Her quality of life is poor. She is always tired, always beset with fevers. Her father said she’s been diagnosed with Hansen’s (leprosy); Sjogren’s syndrome (an autoimmune disease); Mitral valve prolapse (when the valve between the heart’s left upper chamber and the left lower chamber doesn’t close properly); Raynaud’s disease (discoloration of the extremities caused by blood vessel spasms, resulting in cold and lack of sensation in the fingers and toes); and “saddle nose.”

“She’s gone to just about every specialist there is, and most of them say, ‘Well, we’re just not sure,’” he said. “One disease is disintegrating the cartilage in the hip, ankle, heart, and nose. The nose is gone. Basically, she doesn’t have a nose. And not just because I’m her father, but she was a very attractive woman, and now she won’t leave her home.”

They cannot get insurance coverage for the damage to the nose, because insurance companies say the surgery is “cosmetic.”

He has had no discussion with the VA about his daughter, even though he is more than familiar with the theory that says he should put in a claim and wait to see if it is granted.

“You look at the diseases they’re compensating veterans for, and it’s a long list,” he said. “It’s common now to see guys making claims connected to Agent Orange. I’ve been to a lot of funerals, too. A lot of guys I know died with an Agent Orange-related disease.”

But they don’t grant compensation to the children of male veterans. He has been involved in veterans’ affairs for many years and is the executive director of VVA Chapter 49 in Westchester. His experience in veterans’ affairs leaves him doubtful about any forthcoming help from the VA for the children of Vietnam veterans.

Like so many other veterans with children suffering from exotic diseases with no family history to connect them with such diseases, Dan Griffin says the VA must conduct studies on the diseases and Agent Orange. He does not expect that to happen until the VA culture is changed.

He says what is needed is some kind of collection point, a telephone number or e-mail address, where veterans could call to report birth-defect problems. He points to the importance of knowing the numbers of children and grandchildren in the veterans community who suffer from diseases and birth defects likely connected to Agent Orange.

“The whole mentality at the VA is Save Money,” he said. “They’re slowly taking care of us veterans, but they’re not doing anything for children with birth defects, except for spina bifida. I thought maybe after they did that it would open the door, but there has been nothing added for children. And it’s been years now.”
Sheila Clement looks at things like any other nurse would, and she would like to see medical science focus on what it can do for the children and grandchildren of Vietnam veterans.

She was married for about two years to Jerry Fox, whom she called “JD.” He was in the U.S. Army and served in Vietnam 1968-69, at the same time as his brother, Rick, now 62, who was a Marine.

JD died in 1994 at the age of 41.

“JD’s brother is dying, as we speak,” she said.

Sheila and JD married after his tour of duty.

“I knew them a long time. JD and Rick were happy, normal teenagers. They’d go fishing together and things were fine. But they came back very different,” she said. “My ex-husband quickly disintegrated after he came back from Vietnam. He was bloated-looking. From the chest down, he was huge. He looked 20 years older.”

Her belief is that an herbicide like Agent Orange affected his internal organs.

“He was only a teenager when he went over. It gradually ate away at him,” she said. “When he died, they figured his heart just exploded.”

After a domestic violence episode, JD and Sheila divorced, but she is not buying the assumption that Post-traumatic Stress Disorder is the only cause of antisocial behavior in some Vietnam veterans.

“I knew JD and his brother from teenagers. They weren’t like that back then. Plus, Vietnam veterans were not all on the front line, but that didn’t mean they were not exposed to Agent Orange,” she said. “They could have been working in the motor pool and not on the DMZ. Some have no horror stories, but so many of them came back acting the same as those that did, looking older than they are.”

JD’s brother performed a supply job in the Marine Corps, and now he is only middle-aged, but he is deathly ill.

Sheila has a friend upstate from her Michigan home who surrounds himself with Vietnam paraphernalia and speaks in phrases he learned in-country. He neglects his health and keeps to himself.

“I’m from a tiny lakeshore town, and I personally know at least five people who are messed up or who died from this chemical. I would like to know what’s going on inside of these people.”

It was at her friend’s home that she picked up a copy of The VVA Veteran.
magazine and read about Agent Orange and saw the number of obituaries of Vietnam veterans in their 60s.

Suddenly her list of five names seemed to grow exponentially.

“Looking at this magazine, all the emotions came back. I was sitting there thinking, here I go again. You think you put it away, and then something happens that keeps it coming back. Was I meant to read this?” she said.

Sheila (who retired from nursing because of fibromyalgia) and JD had one child, a son who is now 38 years old. He has two daughters, who are 11 and 14. Her son has had bouts with Bell’s palsy, and he has increasing pain in his joints and muscles.

Sheila is proud of his children, her A-student granddaughters. But her eldest granddaughter was born with “lazy eye” and had to wear special eyeglasses. She took seizure medication for a time and has been referred to a lung specialist for intermittent fluctuations in her oxygen level. She was subjected to multiple EEGs and underwent sleep studies.

Sheila’s younger granddaughter was born with galactosemia, a rare genetic metabolic disorder severely affecting the body’s ability to break down enzymes. If left untreated, galactosemia can cause brain damage, an enlarged liver, or kidney failure and the child can die. It is likely to be passed on to her children. Her younger granddaughter also has severe allergies.

“Are they doing genetic testing? Are they doing blood tests? When did that gene kick in and mutate? My son’s blood work showed that he passed it on,” she said.

Sheila thinks that miraculous things can happen now because of gene therapy, and she would like to see a massive registry of blood and tissue samples and the results put into a research databank.

“Collect it and log it until something pops up in the research,” she said. “Figure out these connections. It’s not far-fetched. It’s also not about compensation; it’s about relief. Just do the testing and the studies. It’s possible now to alter the course, to manipulate a gene, to fix it or stop something from happening. There has been enough heartache already. We need to stop this now. We can’t afford to have it affect our future generations. With the medical advances of today, we can deal with it. The time has come to stand up and admit what has happened. We can no longer brush this under the rug.”

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Shelia Snyder asks a straightforward, troubling question: “Why do I have to worry about my grandkids because their grandfather served our country? There is nothing to justify that.”

Her husband, Henry, served in Vietnam with the Army in 1968-69. He is diabetic and the recipient of a VA-approved claim related to Agent Orange. One of her grandchildren, born with multiple and devastating birth defects, died a few months after her first birthday. When the founder of the Agent Orange Quilt of Tears, Jennie LeFevre, died in 2004, Shelia and Henry took over, travelling with the Quilt, and sharing information about the horrific effects of Agent Orange.

It wasn’t until the late 1990s that Shelia became aware of the Agent Orange issues veterans and their families had been dealing with for many years. Her husband, Henry, had met a Vietnam veteran, Jack Griffin, in an online chat room and over time forged a close friendship. Because the chat line was voice, not typed, Shelia often picked up bits of the conversation while at home with Henry.

Both men came from Michigan, and there was much talk about hunting and fishing and other things they had in common. One day one of those commonalities caught Shelia’s ear.

“Jack told Henry about Agent Orange,” she said. “At that time Henry had become diabetic. He used to drive a truck for a living, but once he became diabetic, he had to stop. Jack told him he needed to make a claim with the VA. He was just on him and on him and on him about having that checked out. Finally, Henry got tired of hearing Jack push, and he went to the VA.”

Henry put in a claim for diabetes. Shelia called it a “lifesaver,” because it allowed both of them to educate themselves about Agent Orange. Jack advised him on what to do and how to handle the VA. When Henry’s claim finally was approved, though, the celebration was bittersweet.

Jack Griffin had serious health issues of his own — non-Hodgkin’s lymphoma.

“Jack died of Agent Orange-related cancer almost to the day that Henry got the letter from the VA saying that his claim had been approved,” Shelia said. “Henry went into a terrible slump when Jack died. It was like Jack was part of our family. His voice was in our house every day. It was very strange for me. Henry and I had lost parents together, and I never saw the kind of reaction I was getting after Jack passed away.”

About the same time, two people came into Shelia Snyder’s life that would have great influence over the years to come. One was Fred Wilcox, who had written a book, Waiting for an Army to Die: the Tragedy of Agent Orange. The book tells the stories of veterans and their families and the legacy of Agent Orange that
Shelia and Henry Snyder’s Story Continued...

afflicted them.

The second person was Jennie LeFevre, the widow of a Vietnam veteran and the creator of the Agent Orange Quilt of Tears. (On the Web it is at www.agentorangequiltoftears.com)

After the death of Jack Griffin, Shelia read about the Quilt of Tears traveling to a town not far from the Snyder’s Florida home. She thought she might get ideas for making a quilt in remembrance of Jack. It took some doing on her part to talk Henry into going, but he finally acquiesced.

Shelia took the Wilcox book with her. When she finally got a chance to speak with Jennie LeFevre, Jennie was busy with other people. Shelia and Henry waited on the periphery. Then Jennie noticed the book in Shelia’s hands.

“She looked at my book and said, ‘Oh, my God, you have that book! I have the same book!’” Shelia said.

It was not the only coincidence.

“It was really weird, because she thumbed through it, and she had started to tell me how she had highlighted certain areas of the book,” Shelia said. “I opened my copy of it, and I had done exactly the same thing. It was strange.”

The beginnings of their friendship “broke the ice” with Henry, and he started coming out of the depression that had come with the death of Jack Griffin. Shelia found herself working with Jennie on the Quilt project, an effort she found to have great importance.

“Now I feel like the Quilt is Henry’s PTSD therapy,” she said.

In 2004, their granddaughter, Hope Nicole, was born. Before the birth, the family faced a grim prognosis. Tests showed that the infant had no brain, only a brain stem. Babies such as this are expected to die at or shortly after birth. Hope Nicole would live more than a year.

While speaking with a hospital counselor, Shelia mentioned Agent Orange. In an online retelling of the story, Shelia wrote: “I brought up the subject of dioxin/Agent Orange … but she honestly didn’t seem to have a clue about dioxin. After I explained some about Agent Orange, the counselor dismissed the subject quite quickly, which I didn’t really like, but I was becoming too overwhelmed with the options and decisions that were being explained to my son and pregnant daughter-in-law.”

The possible Agent Orange connections to birth defects in the children and grandchildren of Vietnam veterans is something Shelia Snyder does not want to see so easily dismissed.

“I want to prevent these things from happening in the future,” she said. “I don’t want to see this happening to generation after generation. The VA needs to pay attention to birth defects. There’s research and information others have done. Legitimate scientists a whole lot smarter than I am have done a lot of work on these questions. The VA needs to pay attention to these people. All of this information has been there for years, and they just keep shoving it under the carpet. They pay no attention to it.”

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The Morrices
By Jim Belshaw

Bobbie Morris sells cars in Pennsylvania, car sales being something that runs in the family. Her Vietnam veteran husband, Philip, worked in the car business for 37 years. When Bobbie first sits down with a customer, she likes to “break down the walls,” make the customer comfortable, and create an atmosphere in which conversation is open and easy-going. It helps her to sell a car. It helps some customers in ways she hadn’t dreamed.

“You have no idea what happens when I talk to some of the men,” she said. They talk to her about things they don’t discuss with men who sell cars. When the sales associate is a man, it’s all business. Everyone in the cubicle is there to discuss buying a car—interest rates, down payments, monthly payments. It’s all business.

When the sales associate is Bobbie, other matters come up. “There was one guy, he came in to buy a utility vehicle,” she said. “So we got to talking, and all of a sudden, he’s telling me about problems he’s having with his legs and with his diabetes.”

When the conversations turn this way, there is a question she always asks: “Were you in Vietnam?”

The man with diabetes said yes, he had been in Vietnam. She steered the talk to Agent Orange and told the customer where he could find more information on it and how he could get tested to see if he qualified for VA benefits.

He called the next day and said he was coming in to talk about the payment schedule on the vehicle. His wife came with him. She pulled Bobbie aside.

Bobbie recalls what the man’s wife said: “She said, ‘Do you know why he came back? It wasn’t about the payment. It was because you talked to him about Vietnam.’ ”

He wound up joining VVA Chapter 862, to which Bobbie’s husband belongs.

Bobbie said the “light bulb” on Agent Orange came on a year ago at the AVVA Leadership Conference in Louisville, Kentucky, where speakers at a town hall meeting spoke about Agent Orange and its effects, not only on veterans, but on their children and grandchildren. Veterans spoke, too, telling of health problems suffered by their children.

Bobbie could not help but think of her daughter, Dara Rae, who has been deaf from birth, 37 years ago. She now has three leaks in her heart. Doctors worry that she may not be up to the surgery because of other health problems.
Thinking about her daughter inevitably brought tears. Her AVVA regional director saw her crying and asked if she was all right.

“I told her about Dara, and she said, ‘You’re not alone,’ ” Bobbie said. “I always thought I was.”

Before the town hall meeting switched on the Agent Orange “light bulb,” Philip and Bobbie hadn’t given herbicide a thought. Over the years, he had received two letters urging him to be tested, but he threw them away. The letters spoke to “in-country” Vietnam veterans. Philip served with the Air Force in Thailand.

After the convention, Bobbie struck out on a search to gather as much information as she could. She found that Agent Orange, thousands of barrels of it, were stored at Korat Air Base, where Philip was stationed.

Her brother, 100 percent disabled and a Vietnam veteran, told her that when he first arrived in Vietnam, he thought it was raining. He was soaking wet. He was the newbie, and he asked if it was the monsoon.

The Air Force was spraying.

“A year ago, all of this came together for me,” Bobbie said. “We need to get information out to as many people as we can. I see myself working on this for a long time. This is something I’m going to continue with. First and foremost is Beaver County, because I live here.”

To that end, she and others held a second annual Veterans Day balloon release to generate publicity in the local media and draw attention to the Agent Orange issue. While working on an AVVA project, she called widows in her chapter whose husbands had died from Agent Orange-related diseases.

“I wanted to know if they could tell me one thing they wished they’d had,” she said. “They all said they didn’t have enough information on Agent Orange. So I guess what drives me now is to get the information out. That’s what they need.”

Bobbie said her boss, Keith Edwards, at Morrow Ford Lincoln & Mercury, is very supportive of her Agent Orange outreach efforts. He contributes the orange balloons for the Veterans Day balloon release.

“My boss says people tell me everything,” she said. “He doesn’t know what it is, but they sit at my desk, and they tell me everything. Well, I think people are called to do different things. I am honored when veterans open up to me and talk to me about Vietnam. I have tremendous respect for all they have gone through—their physical, spiritual, and mental suffering, and if I can help just one person, I’ve done some good.”

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Pete Petrosky and his wife had planned on having a large family. They talked about it before getting married. At least five kids, they agreed, a house full of kids. They stopped after two daughters.

“I was not going to bring anyone else into this world,” Pete said. “We wanted to have a large family. But after those two kids came, I said something’s wrong. There’s either something wrong with me or something wrong with you [his wife], because we have no history of anything like this in either of our families.”

Those “two kids” who came were his daughters, Lisa and Kimberly. Lisa was born with some kind of “soft tissue” growth covering the roof of her mouth. He remembers trying to get more information from doctors, but it never went beyond “a soft tissue growth.” Whatever it was, it did not belong there.

Kimberly, his second daughter, was born with a cleft lip that would evolve into even more serious health issues and a long history of surgeries. At one point in her young life, she nearly died and would have done so had not the Petroskys rushed her to an emergency room.

Pete believes he knows what caused the birth defects—Agent Orange, and it has shadowed him since his time in Vietnam.

“I want some kind of explanation or a better understanding from the VA that it accepts that veterans have a connection to something like my daughter’s cleft lip,” he said. “They’ll recognize women Vietnam veterans as having problems with these kinds of things, but not men, not me. It makes no sense to me. This Agent Orange thing has stuck in my craw for a long time.”

He served at Bien Hoa in 67/68 during the TET Offensive in the Air Force. He worked in the motor pool, servicing all of the vehicles on the base and working with the Army as well.

“We had a service that went out on the perimeter at night to bail out the 101st and 173rd when they got stuck,” he said, laughing at the memory of pulling the Army out of the mud. “I went out on the perimeter with a wrecker. Real quiet vehicle, right? We worked on all the equipment they used.”

He remembers the base being sprayed with Agent Orange. He remembers the aircraft overhead dumping their loads of vegetation killer.

Back home, he no longer gave any thought to Agent Orange. He and his wife began what they thought would be that large family. The first was Lisa.

“We didn’t know anything about Agent Orange with the first one,” he said.

They went for a regular check-up on the new baby one day, and the doctors found the odd “soft tissue” covering the roof of her mouth. They took her to a specialist to have the tissue surgically removed.
In 1973, Kimberly was born with a cleft lip. “The doctor brought her out to me, and she was wrapped up in a blanket,” he said. “It was quite upsetting. The doctor said, ‘Don’t get too excited. She’s a very healthy baby.’ Well, it was back to the specialists again.”

At the time, he was having trouble holding on to jobs, too. The economy was sour. The nearby Pittsburgh steel mills were anything but solid economically. Meanwhile, surgery to correct the cleft lip beckoned for Kimberly, who was then six months old.

At nine months, she nearly died. Pete’s wife called him at work. She couldn’t get Kimberly to wake up. Pete rushed home. He couldn’t wake her, either. They put her in the family car and rushed her to the emergency room.

“She was breathing, but very little,” he said. “The doctors didn’t know what was going on. After all was said and done, it turned out to be a bowel obstruction and gangrene had set in. If we hadn’t gotten her in when we did, she probably would have died.”

But Kimberly was far from being out of the woods.

“Later on down the road, it got infected and she needed surgery again,” he said.

More surgeries for Kimberly came. The cleft lip had flattened her nose and her nostrils needed to be rounded. Years later, as she began attending school, it was discovered that she had a “still eye.”

His oldest daughter, Lisa, has never been married. She is 40. His younger daughter, Kimberly, 36, is married and has two healthy children.

“If you don’t think we went through pure hell when those two kids [his grandchildren] were born …” he said, his voice trailing off. “I was scared to death. I had to sit down with my daughter when she got married and explain to her and her husband that they might have consequences down the road.”

At a recent Agent Orange meeting, he began talking to a Marine who served at Khe Sanh. The Marine told him one of his sons was having a serious problem with anxiety. Pete told him he had noticed a change in his youngest daughter since the birth of her children. She seemed to be anxious frequently.

“It was my wife who said it had to be the Agent Orange,” he said. “I’ve watched documentaries on TV about how many Vietnamese children have cleft lip/palate. My thing with the VA is it won’t even recognize male veterans as being carriers of anything. I haven’t talked to the VA about it. I’ve gone in for PTSD, and I mentioned that the kids might be connected somehow to my PTSD problems.”

The VA has awarded him a disability due to PTSD.

“I sit in on meetings with veterans from all over Pennsylvania, and what are we doing? Nothing,” he said. “They say there’s nothing we can do. I say, ‘Bullshit.’ We’ve hit a stumbling block, and it needs to be opened up and recognized nationally as far as I’m concerned. I’ve been on a vendetta about this for some time now.”

He spoke of a chapter member whose daughter was born with severe birth defects. She is 36 years old and has never been able to walk or talk.

“She’s never driven a car, she’s deaf, she crawls around on the floor, and those two parents have never abandoned her,” he said. “To never hear your child speak, to never hear your child say ‘I love you’ or anything like that—it has to be a very tough row to hoe. My wife and I have managed to raise a family, and we have a home and two grandchildren, but this Agent Orange thing bugs me. It really bugs me.”

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 importer@vva.org or call 301-585-4000, Ext. 146.
Jim “Butch” Whitworth

By Jim Belshaw

When Jim “Butch” Whitworth went home to Missouri from the recent Vietnam Veterans of America Leadership Conference in Orlando, he needed to buy an extra suitcase to take back all of the Agent Orange materials pressed upon him by those at the conference who had been involved with the issue for many years.

Butch, too, stresses the importance of communication when it comes to such matters. It is critical that Vietnam veterans know they may be due substantial assistance from the Department of Veterans Affairs (VA) concerning diseases related to Agent Orange exposure.

“When they gave me that material, I copied and copied and copied, until I finally had to buy a $60 suitcase to bring all the stuff back for my fellow veterans in St. Peters VVA Chapter 458,” he said.

He had a special, compelling interest in the Agent Orange material, the most striking being that after years of battling disease himself and having gone through the heartbreak of serious medical difficulties with his daughter, he had been unaware of the VA help available to him. He hadn’t even considered contacting the VA about it.

He was, in fact, exactly the kind of veteran to which he now finds himself so dedicated.

“People in VVA gave me the information,” he said. “And I read articles in The VVA Veteran. I’ve got a couple of guys in my chapter with problems or their kids or grandchildren have problems. I’m reading all this stuff, and I know something’s not right. And people from VVA are telling me I needed to make a claim with the VA. Well, I hadn’t done any of that.”

Over the years, he had spent $10,000 of his own money on insurance, and $5,300 for medicines.

“The people at VVA were flabbergasted,” he said. “I didn’t figure the government owed me anything, and boy, they jumped all over my butt.”

He served in Vietnam in 1968 as a radio operator with the 1st Air Cav. In addition to the workaday exposure to Agent Orange, he remembers reading in later years about chemicals involved with the diesel fuel used to burn human waste.

“I remember wearing gloves but no mask,” he said. “I remember that black smoke curling up all over the place. We all had to take a turn at it. It was a detail like KP or guard duty.”
About eight years ago, his heart problems began. Today, he’s on his second pacemaker. A third back operation in 2002 ended his career in construction. Then in December 2007, he had a terrible pain in his groin area. He couldn’t shake it for weeks and finally went to see a doctor.

Blood tests were ordered and a CT scan done on his stomach area. There was no hernia. But there was leukemia.

Admitted immediately to a hospital in St. Louis, chemotherapy began. Then a bone marrow transplant when it was found that his sister was a perfect match. He lost 33 pounds.

“It was quite an ordeal for me and my sister,” he said. “I got the transplant and spent three weeks and three days in the hospital. I’ve survived two years this past July.”

Long before his own health deteriorated, he and his wife faced a long, difficult battle with a brain tumor diagnosed in their toddler daughter, Emily, in 1978. She was 2 ½ years old. A neurosurgeon told them Emily would not live to see her tenth birthday.

Today, she is 32, married and a marine biologist at the Mayport Naval Base in Jacksonville, Fla. But she must deal with severe handicaps as a result of the brain tumor and the efforts to control it.

“We fought it for 18 years,” Butch said. “They’d bore holes in her head and run tests. They put in a shunt that became infected, and finally they went after it with a Gamma Knife. They took out all of the tumor, except for one little piece. She’s handicapped now. She has a terrible limp, her right foot is turned inside, her hip gives out, and she lost the use of her right arm.”

Butch’s father gives insight to his granddaughter.

“My dad said, ‘That daughter of yours has the most incredible drive and determination. She’ll work four hours to do a job that would take you or me two minutes.’ ”

Butch has three claims pending with the VA. In addition to his VVA friends, his own doctor insisted on him making the claims when she found out he was a Vietnam veteran. He’s on YouTube, too, doing everything he can to spread the word.

“If nothing else, I’m hoping that sharing my story will help,” he said. “I just tell people this is what I had, and I had it bad.”

He comes from an extended family with many children. He is unique among them.

“I’m the only one who has these cancers,” he said. “I’m the only one who has a pacemaker. And I’m the only one who served in Vietnam.”

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Dayna Dupuis Theriot writes a letter filled with questions, not the least of which is to whom she should send it for answers. She scours the Internet looking for such answers and finds only tantalizing clues, or more to the point, one clue, one connector between her son and the various abnormalities that have been visited upon him. The clue repeatedly shows itself, but never to the degree that she can say it is the answer with any certainty.

“My father was in an area that was heavily sprayed with Agent Orange,” she said. “He’s been through a lot. I don’t know how he would handle it if we found out this kind of thing was transferred from his body to us. It would have a powerful emotional effect on him. I would hate for him to blame himself. What I’m doing now is just looking for answers. You don’t know who else is out there with the same problems.”

Dip in anywhere in her letter and “powerful emotional effect” becomes understatement.

“My son, Keeyan, was born August 2, 2000, weighting only 4 lbs., 14 oz.,” she writes. “He has problems before coming home with his sugar levels and body temperature. We stayed in NICU (Newborn Intensive Care Unit) for five days before allowing us to go home. He then came home to vomiting, choking, and almost losing him in our home.

“He was checked by his pediatrician to discover his esophagus was strictured. It was narrowed so severely that it only allowed a few drops in at a time and not
Dayna Dupuis Theriot’s Story Continued...

even his own mucus could be digested. It is similar to Esophageal Atresia. He was admitted, and the surgeon dilated the esophagus. It lasted two weeks before collapsing again. So in September 2000, only 4 weeks old, a thoracotomy was done. They would cut out the narrowed part and resection the damaged esophagus.”

As her letter continues, it takes on a peculiar phenomenon of language, one in which mothers become conversant in a medical language usually reserved only for specialists, men and women who have spent the greater part of their lives studying such things. It falls to mothers to understand medical terms and procedures that would leave most people scratching their heads.

This is not the case with the mothers of children like Keeyan Theriot. They understand the complications, because the complications become the stuff of daily life.

“After the procedure was done, he assured us that Keeyan would be fine,” she writes. “He then began vomiting, choking, and the esophagus was so irritated that it began to bleed. We began PH probe studies to find out what was going on. The studies showed reflux and it was really bad. So they put him on a drug given to patients with esophageal cancer to be able to tolerate feedings. It didn’t help …

“We went to see a Pediatric Surgeon for Rare Anomalies. He gave us a few options … He mentioned doing a fundoplication/nissen so he would not be able to vomit. The procedure was done at age 4 1/2 … only to be discouraged by vomiting and bleeding ….”

Some of the questions Dayna asks are the same questions asked by the wives of other Vietnam veterans exposed to Agent Orange:
+If the children of women veterans are determined to suffer from such "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."
Tommy Thornton

By Jim Belshaw

“I remember being sprayed several times. We didn’t have any idea what it was they were spraying. When we were out on the road between Pleiku and Dak To, we were recovering a couple of tanks and a bulldozer, and they sprayed us. A bunch of planes, C-130s, I think, came over. They were spraying along the road.”

— Tommy Thornton

Tommy Thornton had four children, all daughters — Tracy, Hope, Angela, and Chelsey.

Tracy was born in 1970. She had numerous problems from birth. She stayed sick for about the first six months of her life. Thornton says he never really got an answer as to why. Eventually, Tracy also was found to suffer from severe dyslexia. But by then, she had been labeled.

“Retarded,” he said. “But she wasn’t.”

She died in 2002.

“She had surgery on her back,” he said. “They say she committed suicide, but I don’t believe it. She woke up in pain, took some medication, went back to sleep. Woke up in pain again, took more medication, went back to sleep and didn’t wake up. I think she overtook her pain medication. It’s easy to do, especially when they give drugs that are dangerous. She was 33 or 34. My memory’s crap, man. When I need to remember something, I can’t.”

Hope was born a year after Tracy. She, too, suffered from numerous problems. He provided a list:

Migraines, seizures, chemical imbalance causing syncopal episodes, Barrett’s Esophagus in first stage, gerd (gastroesophageal reflux disease), acid reflux, irritable bowel syndrome, polyps, colitis, mitral valve prolapse, asthma, bronchial spasms, chronic bronchitis, chronic pneumonia, interstitial cystitis, diabetes, neuropathy in legs, cervical cancer, cancerous tumor removed from abdominal wall, cancerous tumor removed from left breast, losing hair and teeth.

“This is the short list so far,” he said. “There may be more to come.”

Angela, born two years after Hope, is a cancer survivor and unable to have children of her own.

“She’s doing OK, but I’ve kind of lost contact with her,” he said.

The youngest, Chelsey, is 15 years old.

“She’s losing her hair, clumps of it come out,” he said. “And she has bad pain in her legs that hasn’t been diagnosed.”
He served in Vietnam in 1967-68. He said he worked on recovery teams and spent a lot of time out on Vietnam’s roads, bringing back helicopters, tanks, trucks, APCs, and even men killed in action.

“I traveled on every road you can name in Vietnam for one reason or another,” he said.

When he returned to the states, and after his release from the Army, he had digestive problems for about two years. He suffered from acne as well. He continues to suffer from chronic fungus infections, athlete’s foot, and other related problems.

“I’m on the Agent Orange Registry with the VA, but I didn’t get nothing out of it,” he said. “I had skin problems all the time.”

He’s 61 years old and lives alone, about fourteen miles outside of Woodville, Texas.

“I didn’t connect any of it to Agent Orange until way later, because nobody ever said anything about it,” he said. “I didn’t talk much about Vietnam.

“You have to understand that for a lot of years I didn’t talk to people much,” he said. “That was a lot of my problem getting my VA benefits. I didn’t talk a lot about what I did, and I didn’t talk a lot about what I went through. It was eating me from the inside out. And when I did try to tell someone about what was bothering me, they’d say things like that didn’t happen. They’d say I was lying. Those people don’t understand. They didn’t care. So I was diagnosed as being paranoid schizophrenic and all kinds of weird stuff. But I was just suffering.”

He said he’s talked to the VA about his children but that nothing comes of it. He is haunted by the guilt he feels for having “caused” the problems for his children, and he now worries about grandchildren and the possible health problems they may face as they grow older.

“I stay pretty much to myself,” he said. “I haven’t worked since 1986. I’ve had back problems since I got back from Vietnam, and they tell me the pain in my legs is peripheral neuropathy, and it’s directly related to Agent Orange, but I don’t know and I don’t care. But when it starts showing up in my kids … man, it sucks. I don’t get it. But I guess it’s how our government works — denial, denial, denial.”

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When an Agent Orange diagnosis first confronted Sherri Wise’s father in 2002, he denied the fact of it.

“He said this is our country, that our government would not do this,” she said.

He went into the hospital two days before 9/11. On that fateful day, Sherri and her mother rode a hospital tram to visit him. They found themselves surrounded by veterans.

“We saw these men who were disfigured, emotionally distraught, physically incapable of fighting,” she said. “But the minute that first plane hit, you could see the wheels turning in their heads. When the second plane hit, we were surrounded by men who said they would protect us. We were never in danger, but it was the most touching thing. The whole time we were there, everywhere we walked, there was a man trying to reassure us that everything would be OK.”

Soon the fact of her father’s condition became too much for him to deny—heart attack, stroke, diabetes, eyesight failing, kidneys failing...

“It was one thing after another,” she said. “The VA doctors said they could relate everything he had to Agent Orange. His main reaction was to worry about the family. His first question was: ‘Could I pass any of this on to my kids?’ We were all born after his exposure.”

He served in Vietnam with the 82nd Airborne in 1966-67.

“He had such faith that our country’s government would make it right,” she said. “I’m angry. We’re all angry. But he kept saying: ‘They’ll make it right. I did what I had to do in Vietnam. I’d do it all over again.’ That amazes me.”

Sherri has undergone 13 back surgeries. Diagnosed with degenerative back discs at 20 years old, her doctors expressed disbelief that it could happen to someone so young.

“I have fibromyalgia, neuropathy, Type 2 Diabetes, arthritis, and depression,” she said. “I’m 35 years old. The doctors said there is no reason for me to have degenerative discs at this age. I was born with a leg out of socket, as well.”

Her older brother has been diagnosed with degenerative discs and severe depression; her younger sister suffers from depression.

Sherri’s youngest child was born with a congenital heart defect; her oldest is...
bipolar. There is no family history of such things.

“I look at them, and I wonder if I passed this on,” she said. “Deep down, I know I did, and it just breaks my heart. Any time any little thing comes up with them, I’m really hit by the fact that I did this to them. I know logically I didn’t, but it makes no difference. The VA won’t do anything. They either don’t know how or don’t care.”

She praises one doctor the family has met throughout the years, the first doctor to diagnose her father. She said he was an older man who was straightforward about Agent Orange and the fact that so little research has been done to determine its effects on the children and grandchildren of Vietnam veterans.

“That man sat with us and talked to us about it, and I think he was the most honest man we met.”

In May 2008, her father entered the VA hospital for the last time. She said he died as a result of an allergic reaction to a drug and that his last 11 days were spent in confusion, unable to respond to those around him, unable to eat.

“It was very difficult,” she said. “But he never stopped saying, ‘They’ll take care of it. They’ll make it right.’ Until the day he died, he believed that our government would take care of it.”

She said she was consumed with anger when he died and that her anger did not find a release until she became involved with Agent Orange Legacy, an Internet support program for the families of Vietnam veterans. She began meeting and talking with other family members whose experience tracked with hers.

“It was strange talking to other people who had gone through it, and I started realizing all the things that correlated,” she said. “These people were going through the exact same things and experiencing the exact same things with their loved ones.”

She stresses the importance now of spreading information about Agent Orange. Like so many others, she is adamant that the VA must research the question of links between the veterans’ Agent Orange diseases and health issues arising in their children.

“It needs to be talked about,” she said. “Somebody has to talk about it. The biggest thing to tell the government is: You did this. Now help us. Honor these veterans.”

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Gary Jones’s Story

By Jim Belshaw

Gary Jones’s story is brought to you by the California Veterans Benefit Fund.

For Gary Jones, the puzzle that is Agent Orange can be explained, or more to the point, not explained, by two words — “circumstantial” and “coincidence.” The words are at once the core and the conundrum of his Agent Orange experience.

“The problem with all this Agent Orange discussion is that everything is circumstantial,” Jones said. “We can’t prove anything. But after awhile, the word ‘coincidence’ just doesn’t work anymore. Something is causing all these different problems.”

He pulled two tours of duty in Vietnam, one blue, the other brown. The first for the young Naval officer came in the deep water off the Vietnam coastline; the second came inland, in the brown water of the Cam Lo River, near the DMZ, where he worked delivering supplies with Marines and an ARVN unit.

“My job was kind of like being on the old Red Ball Express, but on water,” he said.

Before Jones returned to Vietnam with Vietnam Veterans of America in recent years, the dominate memory of the country for him always came with a reddish hue, not the deep, rich green that stretches across Vietnam as far as the eye can see.

“Everything was reddish,” he said. “Red mud, red water. Everything in my mind was red because we’d killed off the vegetation.”

The area in which he operated was heavily saturated with Agent Orange, the chemical defoliant being delivered by air, from the backs of trucks, and by hand. At the time, he said, no one knew much about the defoliant.

“We didn’t have a clue,” he said. “You could smell the stuff. I thought it was mosquito spray or something. No one told us anything.”

Because he was stationed near a large base, certain amenities were enjoyed. The locals washed the Americans’ clothes — in barrels that once held Agent Orange. The Americans, if they could get their hands on one of these barrels, often cut it lengthwise and used it as a barbecue.

For many years, Jones congratulated himself for escaping the lingering effects of the chemical that had brought so much misery to the lives of others. Then several years ago, he noticed a rash near his ankles. It would come and go, and come and go, never rising above the level of irritant.

“Then I had a pretty substantial breakout up and down my legs, and they did a biopsy on it and came back as ‘psoriasis-like,’” he said. “It’s basically an immune-deficiency disease. In the most critical cases, it can become nephrotic. A year or two ago, I started getting pretty sick, and it turned out I was dealing with a nephrotic syndrome that attacked my kidneys. So now I have
two problems, and both are immune-
deficiency related.”

At his own local VVA chapter, he spoke
with a former Army warrant officer. The
Army friend struggled with exactly the
same health problem.

“Then he says, ‘I’ve got five other
guys with the same thing,’” Jones said.

“Now the word ‘coincidence’ has gone
completely out of the conversation, and
I’m thinking, ‘OK, you’re being hounded
by immune-deficiency problems, and the
group includes only those guys who were
in-country in Vietnam. What does that
mean?’”

He can prove nothing, continually finding
himself circling back to “circumstantial.”

Then his oldest son developed the same
 rash, but on his chest, not on his legs. His
youngest son battled a serious attention
deficit disorder that still plagues him.
Neither Jones nor his wife knows of anyone
in their immediate or extended families
with either of the medical diagnoses given
their sons.

“I don’t expect to go to the VA and have
a conversation about any of this,” Jones
said. “I’m already being compensated for
PTSD and a hearing loss. At one point
I had decided to go in and talk about it,
but I decided I needed to get a lot more
evidence and a lot more of the story before
I submit anything. But I plan to put it on
my record.”

He said he has no complaints about the
VA and, in fact, calls himself “a kind of
advocate for the VA.” He’s heard all the
horror stories about VA health care and says
he believes them, but he also believes that,
in the larger picture, the VA provides good
health care for veterans. Still, he sees room
for improvement and changes.

He said statistics show that 80 percent of
veterans don’t use the VA system at all. He
would like to see the VA work closer with
civilian doctors so the general practitioners
will be more likely to make inquiries of
veterans.

“In all the intake interviews I’ve done with
new civilian doctors, I have never been
asked: Are you a veteran? Where did you
serve? What were you exposed to?” he
said.

Jones wants the VA, and the government in
general, to recognize that men and women
in the armed forces are routinely exposed to
toxic situations rarely faced by civilians.

“There should be a general health program
where these people are monitored
throughout their lives so that problems
that are not only proven to be connected to
their service, but are probably connected,
are watched,” he said. “We need to stay
on top of these health situations so when
something connected to military service
arises, they can respond to it quickly.”

Jones doesn’t think the VA can do this by
itself. He sees a need for civilian health
professionals to be part of the system.

“If what I’m suggesting is too much for
the VA to do, and I’m inclined to think that
it is, then the civilian medical community
should be supported to take care of veterans
who are not in the VA system,” he said.

“These Agent Orange guys are dying
30 and 40 years after the fact with no
treatment. That should never happen. We
owe our veterans the support they need.”

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Herb Worthington’s e-mail, meant to provide background on his own Agent Orange-connected diseases and the diseases now afflicting his children, is not yet two sentences long before the words leap off the page.

“It rips me apart with self-hatred every time I tell it,” he writes. “I get so sad, the tears flow like a stream, and it makes it that much more difficult, because the keyboard is totally blurred.” Asked about it later, he says, “I hate myself. Why? For bringing all this pain and suffering to my children. They don’t deserve it.” He has not spoken to his children about it. “I don’t have the courage,” he said.

His daughter, Karen, 35, suffers from multiple sclerosis (MS). His son, Michael, 33, has suffered from bronchitis and allergies since infancy. Michael’s own children also have been diagnosed with chronic bronchitis, and Herb says the grandchildren also display uncontrolled and inexplicable fits of anger. Herb, himself, is 100 percent disabled, diagnosed with Agent Orange-caused Type II Diabetes. He suffers from “terrible” Peripheral Neuropathy, which the VA recognizes as a service-connected condition.

“It starts out as a tingling, like pins and needles,” he said. “Hands and feet get cold. You think they’re cold, but they could be warm to the touch. As it progresses, they go numb and have stabbing knife-like pains. They say it’s a circulation problem, a secondary condition usually to diabetes. Now the VA in Newark is trying to deny guys because of self-medication because the disease is also symptomatic to alcoholism.”

Married for 41 years to Angela Sorrentino (“She supports me 10 million percent”), he is President of the New Jersey State Council. They met in high school. Both went to college, Herb working a full-time factory job to stay in school at the New York Phoenix School of Design in Manhattan. They married in 1968, the summer before their senior year. Five days after he graduated in 1969, he was drafted. After completing AIT, he received orders to Vietnam as
The Worthington’s Story Continued...

a Light Weapons Infantryman. He was assigned to the 2/60 Recon Battalion, 3rd Brigade, 9th ID. He found himself in “charmingly named hell holes” such as the Parrot’s Beak, Tan Tru, the Plain of Reeds, and then with the 25th ID in Cu Chi. “What is significant of such places is the amount of Agent Orange dumped on the Plain of Reeds and the barren dust bowl camp known as Cu Chi,” he said.

Three years after he came home, he and Angela started a family, the firstborn being Karen, who would grow into such an attractive woman that strangers stopped her on the sidewalks of New York to ask if she were a model or an actress. “She was talented, played two instruments, was an athlete (all state softball catcher), and an A student,” he said. “Everything went well until her senior year of high school, when she started getting migraine headaches.”

Several MRI’s and doctors later, she was diagnosed with MS. She married, then divorced, and swears she will never have children for fear of passing the disease to them. “She still works, but she uses a cane, and the right side of her face is numb,” Herb said. “Now she’s beginning to fall down. She goes to the MS center in New York. She’s seen so many specialists and tried different treatments, but I think most of it is a bunch of crap. It’s so sad to see her like this.”

He sees signs of disease in his grandchildren, too. His son, Michael, has two children, one 3 years old and the other soon to be 5. “Both suffer from bronchitis,” he said. “And they can turn to anger in a second. I can see the physical change in them when they do it. I can see it coming, because I watch them like a mother hen. I’m looking for anything, you know?”

He has worked as a veterans service officer and has visited the VA to discuss his diseases and the illness of his children. He comes away angry. “I went to doctors I knew in the VA,” he said. “I went to the regional office and spoke with people I knew, and I asked if there was anything, and there was nothing. You talk to these doctors, and you mention the possibility of Agent Orange, and they ‘yes’ me to death and say, ‘Oh, that’s interesting.’” He doesn’t know what the future will bring. In the present, he carries a great anger toward the VA and the government and the Vietnam War. “I had a map set out for me (his life), and the war ruined almost everything,” he said. “It ruined whatever chance I had to do in life; it ruined my health; it ruined my children’s health. The VA hates me. They will tell you that I have an acid tongue. This thing has consumed my life like no one can imagine.”

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Betty Mekdeci

By Jim Belshaw

If there is a moment that represents the long battle Betty Mekdeci fought to shine a light on the origins of birth defects, it might be when a court’s representative wrote to her about an Agent Orange project she proposed. She was told it was far beyond her ability. It was simply too big. “Awesome,” the letter said. She could not possibly do it.

“That made me so angry,” she said. “You just didn’t tell me that I couldn’t do something. It made me really mad.”

She had been engaged in the fight for birth defect information for some years. She was the co-founder and executive director of Birth Defect Research for Children, Inc. She had been in courtrooms, going up against high-powered opposing attorneys and, in some cases, even her own attorneys. She didn’t do well in those court cases. Then someone told her she wouldn’t do well on her own, either.

“I had been thinking a lot about birth defect research globally, why we couldn’t learn anything, why typical studies didn’t work, and how the major causes of birth defects had been discovered. They had all been discovered by cluster identification or what we call an Alert Practitioner, who is someone who starts seeing a number of unusual birth defects. Then they look into the background of these cases and find a common factor.”

She set out to create her own Alert Practitioner, one involving thousands of people, people who were desperate to learn about birth defects.

Birth Defect Research for Children is a non-profit organization providing parents with information about birth defects and support services for children. The BDRC sponsors the National Birth Defect Registry, a research project that studies the links between birth defects and a number of causes, among them exposure to Agent Orange, an issue of particular note to Vietnam veterans.

Her interest in birth defects began in 1975, when her son was born with birth defects. Eventually, she would link those defects to a drug she had been prescribed (along with many other women) – Bendectin. Her efforts would lead to the removal of Bendectin from the world market. The initial search for information began with Betty and her mother.

In 1982, she and her husband, Mike, founded the Association of Birth Defect Children, now called Birth Defect Research for Children.

“We decided to start the organization because there was nothing for families with children who had birth defects, and it was very difficult for families to get information,” she said. “I don’t even remember how in the world I had the audacity to even suggest it. People are
so hungry for someone to be concerned when their child has a problem.”

Since 1986, when the first Agent Orange Class Assistance Programs were funded, BDRC has worked with Vietnam veterans and their families. It was during this time that work was begun on the National Birth Defect Registry, a unique form of data collection on families with birth defects.

Working with the New Jersey Agent Orange Commission to develop the Vietnam veterans’ exposure section of the registry questionnaire, the BDRC collected information from thousands of families. It found a consistent pattern of disabilities in their children.

In 1992, the association presented a report to the House Committee on Veterans Affairs and the National Academy of Science Committee on Agent Orange.

“With the Vietnam veterans’ children, we found immune-endocrine problems,” she said. “We’ve found learning and attention problems, thyroid problems, and childhood cancers.”

She said studies of Gulf War veterans found a “structural, observable, and non-arguable birth defect, a cranial-facial birth defect.”

Today, she is working on a new approach with Vietnam veterans that will allow the veterans and families to come to a central location for extensive evaluation.

“The problem is there are so many people affected,” she said. “I’ve thought about this for a long time, because I’ve worked with veterans for so many years. What we want is centers that are funded and staffed with people who have expertise on the effects of chemicals and in this new research. Families would be given vouchers so they have a place to stay and can be evaluated. There’s a lot going on but veterans don’t have access to it.”

Much more detailed information on Birth Defect Research for Children may be found on the organization’s Web site – www.birthdefects.org. E-mail should be sent to: staff@birthdefects.org. The mailing address: BDRC, 800 Celebration Avenue, Suite 225, Celebration, FL 34747. Telephone: 407-566-8304.

When she began her search for birth defects information, she never imagined she would find herself with an organization the size and scope of BDRC. She never imagined that one day the federal government would be coming to her for information. She never imagined she would be in contact with thousands of people.

“It’s a big dream, but when we started this, people said you can’t get Bendectin off the market, but we darn well did,” she said. “They said you can’t start a birth defects registry, but we darn well did.”

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Sonja Holybee says of her oldest child, Stephanie, 35: “She will not give in to it.”

She says the same thing of her other two children, Melisa, 33, and Dan, 30. But Stephanie is the oldest, the first to be diagnosed with illnesses never before found in either her immediate family or the extended families of her parents.

Her mother can find only a single connector: “I feel that the only way Stephanie could have gotten any of these things is from Agent Orange,” Sonja says. “There’s nothing in me or my family or in Ken’s family that shows this stuff showing up. The lone factor is Agent Orange.”

Sonja’s husband, Ken, former VVA California State Council President and an Army veteran, served in I Corps. He swam in Vietnam’s rivers; he was sprayed frequently with Agent Orange by the lumbering aircraft charged with the mission of killing vegetation in Vietnam. Ken reports they were told that they were killing Mosquitoes.

He has not been diagnosed with any Agent Orange-connected disease by the VA.

But disease has been visited upon his children. Stephanie was the first, diagnosed with rheumatoid arthritis, scleroderma, and Raynaud’s Phenomenon.

A brief visit to MedicineNet.com is required to draw an elemental picture of what the young woman faces in her life.

Rheumatoid arthritis is an autoimmune disease that causes chronic inflammation of the joints. It can also cause inflammation of the tissue around the joints and in other organs in the body. Those with autoimmune diseases have antibodies in their blood that target their own body tissues. Rheumatoid arthritis typically is a progressive illness that can cause joint destruction and disability.

Scleroderma is a chronic connective tissue disease classified as an autoimmune disease. Hardening of the skin is one of the most visible symptoms. It is not contagious or infectious, cancerous or malignant.

Raynaud’s Phenomenon is a condition resulting from a series of discolorations of the fingers and toes after exposure to changes in temperature. At first, the digits turn white, then blue. Then the blood vessels reopen, turning the digits red. Raynaud’s most frequently affects women.
The Holybees’s Story Continued...

Stephanie Holybee, first diagnosed at 17, suffers from all three. She was in special education classes until her junior year in high school, when, her mother said, she was moved into “bottom classes” to finish her high school education.

Sonja Holybee said her daughter has never surrendered to any of the afflictions.

“All of a sudden it just hit,” she said. “They diagnosed her with one thing after another, all one on top of the other. But this girl forces herself to lead a very active life. She works two jobs. She’s a grocery clerk at Safeway and works in a daycare facility, too. She bowls on Thursdays, because she just won’t give in to it. She says, ‘It’s not going to kill me.’ When she was first diagnosed, the life span was 10 years. She just won’t give in.”

Sonja’s second daughter, Melisa, was born with an extra ankle. She can turn her foot “in really weird positions.” The extra bone that made this happen has been removed. Nine years ago, at age 24, she underwent surgery for supraventricular tachycardia (a rapid heart rhythm). Melisa’s thumbs are short and stubby; when she first started text messaging, she found she could do it better than most. A friend noted that her unusual thumbs worked quicker on the keys because of their size.

“Melisa works with disabled children in group homes,” Sonja said. “She’s been doing that ever since she got out of high school. She enjoys it.”

Her youngest child, Dan, 30, a sheet metal worker, is sterile.

None of the children are married.

“No one in the extended family has ever been diagnosed with any of these diseases,” Sonja said. She said her husband, Ken, is “one of those people who keeps everything inside, but he feels he gave all these problems to his kids. He doesn’t think they would have them if he hadn’t been exposed to Agent Orange.”

Sonja Holybee believes the government needs to acknowledge that the children of male Vietnam veterans suffer from rare disorders.

“They should, at the very least, be treated for the same conditions as the children of female Vietnam veterans,” she said. “If you’re the child of a male veteran, there’s no chance that you’ll be taken care of. More than just acknowledgment, kids like Stephanie should get some kind of treatment. Stephanie would love it because her meds cost a fortune every month.”

The Holybees live in Forestville, a small town in northern California’s wine country not far from San Francisco. Long ago, Sonja said, her husband went to the VA and discussed their situation with a doctor.

“Kenny asked that VA doctor about Stephanie, and that doctor said there’s no way that Agent Orange had anything to do with Stephanie’s condition. No way.”

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It is hard to know when a group of disparate elements will coalesce in the mind to bring focus to a hazy, if not inexplicable, subject. “Connect the dots” might be the plausible cliché to describe the phenomenon, but “connect the dots” carries too little weight to describe the moment when clarity came to Bob Cummings.

“I probably started making connections between these things and Agent Orange when my grandson died in 1991, six days after he was born,” he said. “Then I started putting things together. I found out more about Agent Orange exposure and finally I thought: ‘It is me.’ ”

And so he began the struggle that so many Vietnam veterans face, the idea of their exposure to Agent Orange during the war explaining, not only exotic diseases visited upon themselves, but diseases, sometimes fatal, visited upon their sons and daughters and even their grandchildren.

“It’s hard to come to grips with,” he said. “They say these things are a one-in-a-million chance, and I’m asking, ‘What’s going on here? Was this me? Was this because of something I did?’ I have no history of it in my family; my wife has no history of it in her family. So you question it. You wonder and wonder.”

He has been married twice. From his first marriage, came Robbie, born with spina bifida; and a daughter diagnosed with Bell’s palsy. From his second marriage came Cole, born with a congenital heart defect. He has three other children, all healthy.

He said Cole’s heart defect has been more than just a physical detriment to his son. “Cole is scared to death to get married,” he said. “It terrifies him no end to have a child with a birth defect, especially after what happened with my grandson who died. Cole said to me, ‘Dad, I’m so afraid to get married and have children. It really scares me.’ ”

Cummings said he is grateful his son spoke with him about it. “I’m glad he said something,” Cummings said. “You know, there has to be a lot of kids out there thinking the same thing and too afraid to say anything about it.”

Cummings was born and grew up on the Pine Ridge Indian Reservation. He lives now in Michigan, about four hours north of Detroit. “God’s country,” he calls it. In 1971-72, he served with the 101st Airborne and 1st Cav. He remembers clearly the aircraft overhead, spraying the defoliant, soaking the jungle and the troops below. He knew it was “weed killer,” but had no clue to its toxic effect on human beings.

So when Robbie was born with spina bifida, he never thought to connect it with Agent Orange.

“Robbie has no use of his limbs,” he said. “I’m still good friends with his mom (they’re divorced), and she pretty much takes care of everything he needs. Vietnam Veterans of America service representative George Claxton got a VA claim for him.”

His first marriage didn’t survive the stress of Robbie nor that of the war itself. He said he drank heavily upon returning from Vietnam, and his marriage fell apart, largely due to his alcoholism.
“You go through a stage because of the guilt,” he said. “You go through a suicidal stage. You go through a stage where you say, ‘God, I don’t ever want to go through something like this again. I don’t ever want to have more kids.’ There are so many feelings you go through. Parents of children with birth defects understand these emotions.”

He remarried — an “angel,” he said. Then Cole was born with a heart defect. Now 25, Cole has difficulty finding work. Because of insurance issues, employers are reluctant to take him on. Cole has a pacemaker and doesn’t have the stamina of others his age. Bob Cummings once spoke with an insurance agent about health insurance for Cole. The agent said his company could pick up Cole. It would cost $500 a month. Says Cummings, “Cole is my hero.”

It was when he and others began a VVA chapter, and he started having conversations with other veterans, that the heretofore disconnected events of his life began to take on a more solid form. He started making the connections that led him to Agent Orange and its long-lasting effects, not only on veterans, but on their families as well.

It all came together at a state council convention in Marquette, Michigan, right after his grandson died. He started asking other veterans what they could do to focus attention on the Agent Orange issue.

“So a bunch of us in my chapter came up with the idea of the Agent Orange flag,” he said. “We had done so much on the POW/MIA issue that we thought it was time to bring attention to the Agent Orange issue. I designed the flag, but it wasn’t just me who made it. It was all the guys in the chapter, and the state council, too. The support I had for the project was mind-boggling.”

Another surprise came with the flag project — telephone calls from the widows of men who had died from Agent Orange-connected diseases or whose children had died from strange diseases.

“They didn’t know where or who to go to for help,” he said. “I always told them to contact their veterans service representatives in their areas. But surprisingly, a lot of service reps in small communities, like the one I grew up in on the reservation, have no clue what’s going on. That in itself is horrific. How do we reach out to these small communities? Towns of a 1,000 people, places like that. They have no clue. We have an obligation to make sure they know.”

Cummings threw himself into the Agent Orange issue until the day when one of his children surprised him with a question.

“One of the kids asked me when I was going to start spending some time with them,” he said. He said it was “like running into a wall.” He curtailed his Agent Orange activities, telling himself the time had come for others to carry on.

Now, with his children grown, he says he is ready to increase his involvement in Vietnam Veterans of America.

“My motto has always been, what can we do for the children who are the innocent victims of this war? We, as Vietnam veterans, have an obligation to do whatever we can to get help for our children. So I call on my brothers and sisters to stand up and get involved and help out. Call your chapters and different veterans organizations. We have not won the war that our children are fighting. We need to win the battle for these brave children who have stood with us through thick and thin. They are calling on us for help.”

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Mike Demske
By Jim Belshaw

Mike Demske remembers well the difference in Vietnam’s riverbanks before Agent Orange and after the herbicide was sprayed. The riverbanks provided excellent cover for the guns trained on the Navy Swift Boats.

“We were just getting annihilated,” he said.

Then Adm. Elmo Zumwalt ordered the river banks sprayed.

“I’ll never forget the first time we went down a river where the bank had been sprayed,” Mike said. “It was like looking at the moon. There was nothing.”

He also remembers no attention was paid to the effects of Agent Orange on the health of the boat crews. That Vietnam’s rains might wash the chemical into the river was of no consequence to the Swift Boat crews.

“A lot of times we’d tie our clothes to a rope and run them in the prop wash to do our laundry, not thinking that the river was filled with the stuff and it was soaking into our clothes,” he said. “We were all 19 and 20 years old. We didn’t know any better.”

After his tour of duty, he wouldn’t give Agent Orange another thought until about 15 years ago, when he came home from a softball practice and couldn’t get enough water to slake his thirst. He went to his doctor. He was diagnosed with Type 2 diabetes.

That same year, he attended a VVA National Leadership Conference. Of the 30 veterans meeting to discuss Agent Orange, five had received the same diagnosis of Type 2 diabetes.

“Everyone was telling me to file a claim with the VA,” he said. “It wasn’t listed as a presumptive disease then, but once it was, I received some compensation.”

But his health problems were just beginning. On the same day he was diagnosed with diabetes, he also was found to have psoriasis. Then in January 2009, he was found to have Fournier’s gangrene. An infection spread to his groin area, and he eventually had surgery that removed his scrotum.

Health complications would not be limited to him.

His son, Scott, born in 1973, began having seizures while serving in the Air Force and was medically retired. He is a school teacher today and still suffers from the seizures. Doctors told him
that an abnormality in his frontal lobes disrupted electrical signals in the brain, causing the seizures.

A second son, David, born in 1978, was diagnosed with juvenile diabetes at the age of ten. Diligent with his medical care, David was able to participate in his high school and college tennis teams. Scheduled to graduate from college in May 2001, he died of myocarditis (an inflammation of the heart muscle) in January of that year.

“For a long time, I made no connection between Agent Orange and Scott and David’s problems,” he said. “I probably started thinking about it after David died. It was really a tragedy. He was a senior in college, going to graduate in May.”

At a VVA meeting in Silver Spring, he was able to question the then-Secretary of Veterans Affairs.

“I asked him if he was aware of any studies that would link our exposure to dioxins to problems with our children and grandchildren, and he looked at me like a deer in the headlights. He couldn’t respond. He had no idea.”

“The VA secretary had an aide there,” Mike said. “He was writing everything down and basically told us, ‘We’ll get back to you.’ Which of course is bullshit. That’s why we’re trying to get enough evidence to prove there’s a problem out there and to do something about it.”

Because the VA refuses to conduct studies on the questions, the evidence gathered is anecdotal. But Mike Demske finds the anecdotes compelling.

“Money is one reason they won’t consider guys in the blue water Navy,” he said. “So many of those guys served on crews that worked on jets that flew through that stuff and brought it back to the aircraft carriers. We have one guy in our chapter who was on a crew. Those crews normally were made up of five guys. Well, four of the five guys on this crew have diabetes—and the VA won’t even look at them.”

At the very least, like so many other Vietnam veterans who have had to face similar health problems, he says the VA should fund studies to see if a link exists.

“I would want them to do decent studies of what the effects are on the children and grandchildren,” he said. “I’m sure there’s some kind of effect. My oldest son, Scott, has ADD, and his son has it, too. I never thought Agent Orange would be part of it, either, but everyone at that meeting was talking about problems their children and grandchildren have.”

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Linda May’s Story

By Jim Belshaw

Linda May’s story is brought to you by the Vietnam Veterans of America Buckeye State Council.

Nine days before the Christmas of 1982, Linda May looked upon her newborn son, Steven Burdette Shaffer, and mourned the losses to come.

“He suffered horribly,” she said. “I think I grieved for him from the moment I first saw him, because I knew I wouldn’t have him long.”

She would never see him walk or hear him talk. There would be no high school graduation, no college diploma. He would not marry. She would have no grandchildren.

“I was grieving all those losses even though I still had him,” she said.

Today, on the CdLS-USA Foundation Web page, characteristics of the Cornelia de Lange syndrome may be found, some of them being: low birth weight, slow growth, small stature, small head size, microcephaly, thin eyebrows that frequently meet at midline, long eyelashes, downturned lips, excessive body hair, small hands, gastroesophageal reflux, seizures, heart defects, and others.

Doctors told her he would not live through the night; then they said the week; then the month.

“After about a year of them saying not to expect a long life span, I finally gave up and said I’m not going to listen to this any more,” she said. “In my own thoughts, my own instinct, I didn’t expect him to die in the hospital. I expected to have him for years longer.”

Steven died on Jan. 15, 1998, a few weeks after his 15th birthday.

“Our pediatrician knew what kind of syndrome he had,” she said. “It was very unusual. Many doctors were not familiar with the syndrome, at least at the time. But the pediatrician was very well read. He is a wonderful man.”

Her then-husband, Larry Shaffer, was not a pediatrician. He was a former Air Force mechanic stationed in Thailand during the Vietnam War. He told her of a chemical that sometimes dripped on him from aircraft he walked beneath, on his way to fixing instruments on the F-105 Thunderchiefs.

“The first words out of his mouth when he saw Steven were ‘Agent Orange,’” she said.

They found a doctor who had been with the Army’s Special Forces in Vietnam. In addition to his medical degree, he held a doctorate in genetics, and he suffered from diabetes connected to Agent Orange.
“He was a friend of our pediatrician, and when our pediatrician had no more answers about whatever was going on, we would see him,” she said. He’s now dead from the diabetes.”

A friend who was a Vietnam veteran with a son who had Down syndrome went to see the pediatrician, too.

“The doctor said that, anecdotally, he had learned to ask the dads of such children if they were Vietnam veterans,” she said. “He had a cluster of them. He said, ‘I just really have to believe there’s something to this. We have all of these odd things going on with children, and they just happen to be the children of Vietnam veterans.’”

Five years after Steven was born, the marriage between his parents ended. Linda said her former husband had undergone a severe personality change, though he was physically healthy when they split up. But he had begun to drink heavily, and his temper became explosive. She believes he then was diagnosed with PTSD and awarded 100 percent disability by the VA. About a year after he left her, his physical health rapidly went downhill.

Around 1988, he was diagnosed with lung cancer. He said during a Friend of the Court hearing that he developed high blood pressure, sleep apnea, and other conditions. He died in 2007 of an apparent heart attack while undergoing chemotherapy for thyroid cancer.

Linda has had no interaction with the VA, though she remains convinced that her former husband’s exposure to Agent Orange during the war played a role in her son’s physical disabilities.

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She believes the VA should commission a study to see if there is a link between Agent Orange and the children of Vietnam veterans.

“When I first met my current husband, I went to a Vietnam Veterans of America chapter picnic, and I asked: Where are the boys?” she said. “There were so few boys compared to the number of girls. It’s probably anecdotal stuff, but that was the first thing I noticed. Vietnam vets have an amazing number of girls, but they seemed hardly to ever have boys. And the boys at this picnic, well, some had disabilities. I believe there are all kinds of things they need to pay attention to, and they’re trying to avoid it.”

She wishes now that over the years she had written down the events of her life, kept some kind of running journal, so she would have at her fingertips all of the details.

But some details don’t need to be written down. Some are not easily forgotten.

“I miss my baby very much,” she said.

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Joshua Kaderlik came home one day from his fourth grade classes in Minnesota and said to his father, Maynard, “Dad, I’m really dumb.”

It was not said jokingly. It came from the little boy’s heart. He meant every word of it. And every word of it stunned Maynard Kaderlik. The words carried a sadness that defied description or definition.

“That one really hit home,” Kaderlik said. “All his life, he has been degraded by other children who did not realize his learning disability.”

It would hit home again when Kaderlik read the book, My Father, My Son, by Admiral Elmo Zumwalt. It was then that Kaderlik began making connections between the difficult lives led by his children and his exposure to Agent Orange in Vietnam.

Adm. Elmo Zumwalt had ordered the Agent Orange defoliation to protect riverine sailors and others from attacks along the heavily vegetated riverbanks of Vietnam. Zumwalt’s son was one of those men. After Vietnam, his son developed two kinds of terminal cancer, and his own son was born with a severe learning disability.

When Maynard Kaderlik, president of the Minnesota State Council, read the book, he took note that each boy was the same age and that each father had served in the same area of Vietnam. Kaderlik served for two years off the coast of Vietnam and another year in the Mekong Delta on riverine duty with the Navy and the 9th Infantry Division of the Army.

“Zumwalt felt the spraying took his son’s life,” Kaderlik said. “When I was there, it was pretty obvious what had been sprayed. Something that had been green was all gray and dead. We drank the water on the rivers and bathed in it.”

Kaderlik’s health had been good until 2010, when he was diagnosed with prostate cancer, a disease connected to Agent Orange exposure. He believes his children paid for that exposure long before that.
Josh had always had a rough time in school. He is 32 today, and the road has not gotten any smoother.

“Today, he still struggles in the workforce, which can be very cruel,” he said.

In addition to being born with a dislocated hip requiring him to wear a metal brace to put the hip back in place, Josh was born with a severe learning disability. After the day he came home to announce that he was “really dumb,” Josh’s parents decided to transfer him to a Catholic school, though the expense was difficult to bear.

The Catholic school tailored Josh’s classes to his abilities, and within a year his father saw changes.

“It helped a great deal with his self-esteem,” Maynard said. “After one year, it really soared.”

His daughter, Melissa, did better in school than Josh, but had her own problems, too. She is the mother of Jayda, Maynard Kaderlik’s granddaughter. Jayda has been diagnosed with autism. Kaderlik pays for the insurance that keeps his granddaughter in a program offering therapy eight hours day, five days a week.

“It’s a challenge for her mother and her grandpa,” he said. “But she’s getting better. I pay for the insurance so she can be in the program, and I would spend my last nickel to keep her in it. She is such a loving and thoughtful child. For her, learning has been a huge challenge. The cost of the program is very high, but I’d do anything to help her.”

As it is with so many other Vietnam veterans whose children and grandchildren have struggled with exotic diseases, learning disabilities, and other health problems, Kaderlik finds it difficult to face the prospect that it was his exposure to Agent Orange that afflicts them.

“It makes you feel bad that her disability was caused by my service in Vietnam and what my country sprayed on us when we were there,” he said. “She’s [Jayda] going to be a wonderful person in this world.”

He has no doubt about the U.S. government’s responsibility, not only to its veterans, but to their children and grandchildren.

“We went off to serve our country, and now our government that ordered the spraying should take care of the children and grandchildren of the veterans, because it’s affected us in one way or another,” he said. “The veterans are in the fourth quarter of their lives, but the children have their lives ahead of them. They should be compensated monetarily and receive the special care and education they need so they can survive in the world.”

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These are some of the things Sharity Keith-Reichard wrote on an Agent Orange Web page:

- I was 2 when they diagnosed me with Alopecia Universalis (loss of scalp and body hair).
- I was 11 the first time someone tried to pull off my wig.
- I was almost 16 when they told me I would never have children and that I would have to undergo either a “procedure” for many months or surgery to have a “normal” sex life. I had never even had a date.
- I was 21 before I could even talk to a therapist about the embarrassing thing that was wrong with me.
- I was 34 when I found out my condition actually had a name — Mullerian Aplasia.
- I am 39 and I am still sad sometimes that I will never have a child.

There is no history on either side of her family that accounts for any of this. The only known potential environmental factor was her father’s exposure to Agent Orange in Vietnam. He died in March 2009 of Agent Orange-related cancer.

She was 25 years old before she met him for the first time.

She speaks with a strong voice, the sound vibrant and energetic. It is much like her laugh and her sense of humor.

Her father was a Marine in Vietnam. He and her mother never lived together. She did not meet her father until after her mother died of cancer.

“There was a lot of secrecy,” she said. “My mom didn’t like to talk about my dad. I had seen one picture of him in profile. I went through a period in my teens when I was intensely curious about my dad, but my mom wouldn’t answer any questions.”

Shortly after her mother died, Sharity’s father contacted her. A relative had called telling him about her mother’s death. They exchanged letters for a few months. They tape recorded a few conversations. When she thought she was ready, she called him.

“I had typed out a list of 40-something questions that ranged from what color are your eyes to what’s your favorite food,” she said. “I couldn’t say what we talked about. We talked about everything. We talked for eight or nine hours. Where I had been, where he had been. When I actually went to meet him a few months...
later, I found out that I walk like him, I talk like him, I’m a little version of my dad, from my coloring, to my facial structure, to everything. It was amazing. I went to his house to meet him, and when I sat down, the first thing my stepmother said she noticed was that my father and I arranged ourselves exactly the same way.”

They talked about her surgery and, in her words, “You can’t miss the bald thing.” They didn’t talk much about Vietnam. He didn’t like talking about it. He told her to look forward, not backward. He suffered from PTSD, and once became so angry with her that the two of them wound up speaking to a VA counselor.

They talked about her physical difficulties and the long journey it has been for her. She tried speaking with the VA about Agent Orange and the possibility that it played a role in her health problems, but she said she never received a response from the VA.

She has been married for two years. She and her husband have been together since 2001.

“My life has been full of highs and lows,” she said. “I can’t say I’ve always handled it beautifully. I set goals in life. I have a master’s degree in Special Ed. I don’t see the things that have happened to me as reasons to stop trying to have a life. I’ve gone down black holes. I’ve had to rebuild my life a couple of times. I’ve been largely blessed with good friends and people who love me. I guess, though, that it’s mostly been a one-woman show. Yes, I have a husband … a stepchild … a stepmother … cousins — nonetheless, I feel a little alone and a little scared.”

She will be 40 this year. Regardless of what the VA does about Agent Orange research, she sees no help coming in time to make significant changes in her life. Nonetheless, she recognizes that others might benefit from such research, and she hopes the VA will at least study the Agent Orange questions.

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“I’m hoping one day that they will research it,” she said. “I’m about 40. I’m not going to make my hair grow, and I’m certainly not going to go back and grow a uterus so I can give birth. But there are a lot of people out there who will have children and grandchildren who will be affected by this stuff. I worry that the same things that happened to Vietnam veterans will happen to veterans of other wars. These things need to be addressed and a policy put in place. They need to take responsibility for those they’re responsible for.”

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James May

By Jim Belshaw

The May’s story is brought to you by the Vietnam Veterans of Michigan.

Jim May sends four photographs of his infant grandson, Isaiah. The baby is blessed with large brown eyes and a face given to smiles — until the fourth photo appears, and one of those beautiful brown eyes disappears. In its place is an emptiness, a discolored pinkish tissue where the eye once was. In the other three photos, it is impossible to tell that the right eye is a prosthetic. The baby’s real eye is gone.

“At nine months of age, he was diagnosed with retinoblastoma, cancer of the eye,” Jim said. “I happen to know that there are several people in this area (Buffalo, N.Y.) who are Vietnam vets whose grandchildren have had similar problems. He had the eye removed and now he has a prosthetic. He constantly has to be checked, every four months, to make sure it hasn’t spread to the other eye. He also has asthma, which requires him to take medicine every day. We have no family history of anything like this before Isaiah. I haven’t talked to the VA at all about him because they haven’t done anything.”

He said he was going to try to get his grandson’s doctor to post a note in his office saying anyone who is a Vietnam veteran with grandchildren suffering from problems similar to Isaiah’s should contact Vietnam Veterans of America.

He has had other conversations with the VA, all of them concerning Agent Orange, which he is positive lies at the heart of Isaiah’s cancer.

But before trying to get the VA to consider Isaiah, he had to get the VA to consider himself.

He served in the Navy and was classed as “blue water,” serving on a hospital ship off the coast of Danang. He says a good deal of his time was spent off the ship and either on the ground in Danang or in its harbor, which he says is polluted with dioxin even more heavily than the nearby shore.

“We were constantly up in Danang harbor and the Danang military zone where they were doing a lot of heavy spraying of Agent Orange,” he said. “They were even doing it in the harbor area. You’d be up on deck, and you could feel the stuff coming down. Helicopters would fly over and, all of a sudden, we’d get orders for a wash down. Nobody ever explained what it was.”

In 1969, shortly after he returned to civilian life, he experienced a rash breaking out on both legs. His legs became swollen and he had difficulty walking. He was driving a truck at the time and said that the difficulty he had with swollen legs caused him to use his
James May’s Story Continued...

hands to move a leg from the accelerator to the truck’s brake. He went to a civilian hospital to have his legs checked.

“I was in the hospital for like three months,” he said. “They didn’t really know what it was. They were doing all kinds of blood tests on me, but no one said anything about Agent Orange, and even I didn’t make the connection at the time. But I’ve made the Agent Orange connection now because I proved that I was onshore. So they’ve sent the paperwork for Agent Orange testing, plus they asked for evidence of my having a rash within two years of being discharged.”

Prior to this recent change in his situation, the VA wouldn’t consider any connection to Agent Orange at all because he was classified as a “blue water” sailor and was not eligible for Agent Orange consideration. But he managed to find all of his medical and other Navy records from his time in Vietnam, and it was enough to persuade the VA to re-evaluate his case.

“I was a ‘bosun’s mate’ too,” he said. “I proved that I took the captain to and from the shore. The bosun’s mate maintains and runs the shuttle craft to and from shore. When I was there, I’d help load supplies from a truck to the boat. For all intents and purposes, I was on the ground in Danang.”

He said that, because he also has submitted a PTSD claim to the VA, the Agent Orange claim may take up to 18 months to resolve. He’s 63 years old.

He believes the rash on his legs is only the beginning of his Agent Orange problems. In addition to his grandson’s cancer of the eye, each of his two daughters have had problems with what doctors called “suspicious cells” in their uterus.

“They just say ‘suspicious’ cells. This has been going on with both of my daughters. The same exact thing.”

At the Louisville VVA convention, he addressed the gathering and made his argument about the distinction between “blue water” and other types of Naval service. (“I’ve never stood up and talked to 10 people, let alone almost 800, he said.”)

As far as distinctions go, he sees none.

“If I had the chance, I’d tell the VA that blue water, brown water, blue air — it’s all a crock. Anyone who was over there should be included in this Agent Orange fight, because it’s carried by air, carried by water, and basically all of that stuff rolls downhill. All that contamination during the monsoon season would get washed right down to the harbors. We polluted the oceans over there. We polluted the harbors, the rivers, and the shore by spraying all that stuff. It’s not just an in-country thing. They poisoned everybody.”

He doesn’t think he won the day with his argument, but he did return home with one particularly vivid memory. A VVA member running for office called to apologize because he wouldn’t be able to attend the convention.

“He couldn’t attend the convention because he was attending his grandson’s surgery for retinoblastoma,” Jim May said.

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Dennis Whalen’s memory of the Vietnam water is vivid, as vivid as the water’s color — “bright green.” He served two tours with the Marines, the first with the 1st Battalion, 9th Marines, up near the DMZ — “Con Thien, Khe Sanh, we did the whole bit.” They took the highest casualty rate in the history of the Marine Corps.

On his second tour, Dennis worked with the Popular Forces in Combined Action Groups, sometimes in compounds and, after Tet, in roving units, setting up for a few days in one area, then moving on to another.

He never heard of Agent Orange when he was in Vietnam. He didn’t have a clue about it. He was good with the Vietnamese language, though. He picked it up easily. For reasons he can’t explain, he had an interest in it. He’d been a “half-assed interpreter” and had attended Vietnamese language school in Coronado, but he was “dumped because I was a high school dropout, and I couldn’t understand why I was back in school.”

He said he hadn’t joined the Marines to go to school, anyway. He joined the Marines to be a Marine.

“We’d be working in the mountains up near North Vietnam, and there’d be water in the bomb craters, and it would be bright green,” he said. “We never heard of Agent Orange. None of us knew what it was. Of course we drank the water out there. We drank water from the streams at the bottom of all those mountains. Hell, I drank water out of a dead NVA’s canteen. You drank water where you could get it.”

After he left the Marines in the early 1970s, he received a letter from a doctor connected somehow to Agent Orange. Whalen was intrigued by how the doctor knew what outfit he served with and where the outfit worked in Vietnam, but the letter said nothing about any kind of monetary compensation, and he never followed up on it.

“I didn’t know nothin’ from nothin’,” he said. “I just wanted to catch up on some partying. I should have followed up on it, but like a dope, I had other things on my mind.”

After he married and had children, Agent Orange became a subject of more interest.

He had three sons. Two of them were diagnosed with pyloric stenosis and would have to undergo surgery to correct the condition, though neither is completely recovered from the effects of it today.

Pyloric stenosis affects the gastrointestinal tract during infancy. It can cause the infant to vomit forcefully and often.
“The food hits a certain point in the esophagus, and the baby can shoot it out ten feet,” he said.

It can also cause dehydration. It is a narrowing of the pylorus, the lower part of the stomach through which food passes to enter the small intestine. The muscles in the pylorus can become enlarged to the point where food cannot empty out of the stomach.

“My middle son, Sean, was the first one,” Whalen said. “Then my last son was born with the same condition, and it was my wife who picked up on it. She said she couldn’t believe it was happening to us again. And sure enough, Keith had the same condition Sean did. The same doctor performed the surgery, and he said he had never seen two brothers have the same thing like this.”

When Whalen found out that the VA recognizes pyloric stenosis as an Agent Orange-related birth defect in the children of female Vietnam veterans but not of male Vietnam veterans, he laughed dismissively.

“Unless it was an NVA, I didn’t see any women up on the DMZ,” he said. “That’s like a slap in the face to me. We rolled in that stuff [Agent Orange]. We lived like animals in that stuff. And they say only women Vietnam veterans can pass along these diseases? I think it’s a way for the government not to pay the dues on it. It’s an insult to me and other guys, too.”

The VA has rated him as 100 percent service-connected disabled with PTSD, but it has found no connection between Agent Orange and other health problems he deals with. He is now recovering from his fifth melanoma surgery and underwent an Agent Orange screening with the VA, but was given no benefits.

“I don’t understand the VA on this, and I do understand the VA on this,” he said. “It’s the money. I’m not looking at me for the future. I’ve got this melanoma. My days are numbered as far as the future is concerned. I know that. I’m hoping that some day down the road the government will compensate my wife and sons for having these surgeries when they were babies. They’ve got bum stomachs to this day.”

More than anything, he wants one thing in particular from the VA.

“I want honesty from them,” he said. “I want them to man up and say, ‘Gee, you were in that area. You came into contact with that stuff. We know you drank the water, you laid on the ground.’ I would want the VA to say maybe we can compensate the family some way. They should at least put the effort in. This isn’t a fairy tale. It’s not a made-up story. I joined the Marine Corps. I went to Vietnam. I went twice. And I’d probably do it again if I was in the same situation. I put my ass on the line, and now it’s time for the government to come up with something for my family.”

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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.

“She saved the letter anyway.

“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.
Sharon Perry’s Story Continued...

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 AOLegacy exists today,” Sharon said. “It kills me to know that she continues to endure a host
Sharon Perry’s Story Continued...

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.”

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Amy King-Applewhite
By Linda May

Amy King-Applewhite’s younger daughter once had to leave her classroom in the middle of a teacher’s instructions, but it wasn’t because she didn’t want to hear what her teacher was saying. Because of a problem with her eardrum, it sounded to her like the teacher was screaming.

Her eardrum vibrations speed up and slow down abnormally, so that, without warning of the oncoming change, she either hears things at a painfully loud level, or at a level so low that she cannot hear the sound.

It’s only one small part of the story of the child’s problems, her older sister’s problems, and their mother’s problems.

Amy, 35, was born with an undeveloped digestive system.

“I went through many years of testing to find out why my stomach and abdomen hurt,” she said. “Being 12-years-old and having multiple colonoscopies and throat scopes were painful and a violation to my body.”

In spite of the invasive procedures in the 1980s, that were even more uncomfortable than they are today, doctors never came up with a diagnosis.

Amy’s rashes, particularly on her hands and feet, made her skin red, itchy, painful, and peeling. Other children’s reactions can range from tactless to cruel.

“I remember being asked once if I was part snake,” she said.

Her teenage and early adult years were plagued with painful, irregular menstrual cycles (and misdiagnoses for the cause), endometriosis, bilateral fibroid tumor breast disease, and ovarian cysts. Doctors tried numerous medications, laparoscopies, and other surgeries.

“I have painfully gone through many biopsies to make sure that the cysts were not cancerous. My stomach and abdomen problems continued, and my cycle got worse. I was rushed into surgery after they found a large mass growing on the side of my stomach. The biopsy from that also came back ‘unknown tumor, noncancerous,’ ” she said.

In spite of Amy’s medical conditions, she proudly became the mother of two girls. She wanted more children, but she ended up with a hysterectomy. The ovaries that had been left intact, produced cysts that ruptured.

“The emotional pain of being 22-years-old and not being able to have any more children was devastating personally for me. I have remarried, and I am not able to share a child with my husband,” she said.
Amy’s eldest daughter is 15. She has Osgood-Schlatter disease that causes the bones and ligaments to not grow at the same rate. She also has arthritis in her knee, along with chondromalacia patella, a painful cartilage problem. She was born with a stomach condition called mesenteric adenitis. She could not tolerate breast milk, and she cannot tolerate dairy products.

Mom and daughter share the same hand and foot rashes, and allergies to hand sanitizer, aerosol sprays, and fragrances.

The condition that results in the most doctor appointments currently is her reflex sympathetic dystrophy, a neurological disease that disconnects the nerves in her brain to her limbs.

“It started in her leg with extreme pain, swelling, discoloration of her limb, and different temperatures throughout her leg,” Amy said. “She went from walking, to being on crutches, to being bedridden, to being in a wheelchair, unable to walk on that leg at all. Extensive physical therapy, medication, emotional issues, and hospitalizations were how my daughter has spent the last year of her life.

“Then as things were looking up in her recovery, it spread to her arm. Being 15 years old and not being able to go to school, go shopping, go out with her friends, only sitting in the house knowing that she will have this disease for the rest of her life, just hoping and praying she will stay in remission is the only thing we hold on to. If she has another relapse, she may never walk down the aisle, she may never be able to take care of her children some day. That’s our reality,” Amy said.

Amy’s younger daughter is now 14. When she was an infant, they tested her for Down syndrome and Fragile X syndrome. As a baby, she was once rushed to a hospital with an enlarged, failing liver. A blood infection, a dangerously high fever, and a stay in an isolation unit also marked her babyhood. Her immune system was severely compromised until the age of 6. At age 4, they discovered the hearing difficulties that affected her speech. She learned sign language and lip-reading, and doctors suggested shock therapy to the eardrum. The education system is helping her catch up to her chronological peers.

Both children have been put on medications formulated for adults, and some of the drug reactions compound problems they are meant to solve.

“As a woman, and as a mother, searching for answers about my health and my children’s health has always been difficult,” Amy said. “Both sides of my family, especially the women, are very healthy. There are no known stomach problems, female problems, or cancer. My great-grandmother is 104 years old and is predominately healthy. Physically I have been through a lot of pain. Emotionally it has taken a toll on me.”

The children’s medical issues and her own difficulties have kept her from going back to her job as a social worker for which she was educated and trained. There is a laundry list of specialists and therapists the family has to see.
Amy King-Applewhite’s Story Continued...

“This is my story of being a child of a Vietnam veteran, and also the story of grandchildren of a Vietnam veteran,” she said.

Her dad is Keith King, who served in the U.S. Army from August 1969 to August 1971 as a military policeman. For most of 1970 he was a convoy escort gunner with the 218th MP and 630th MP companies.

He has a hearing loss from his service and said he filed a claim “for Agent Orange-related medical issues.”

Amy has brought up her dad’s presumed dioxin exposure with doctors, but they admit they do not have knowledge about the issue. In fact, with her younger daughter, Amy was grilled about drug or alcohol use during her pregnancy. But she’s not looking for blame; she’s looking for answers.

“What I would love to see happen is for the government to have a group of family members and do research to find out what is going on with their health,” Amy said.

“I’m not a person to say ‘send me a check every month.’ Our insurance covers my medical bills, and my daughter is covered through her biological father, but we’ve still got medical bills. I would like to see these children covered under government medical insurance.”


“It would also be a relief to finally have some support and validation and answers,” she said. “You live a good, drug-free life. You work and do all of the things you are supposed to do, and then something hits your children. When you are a mother, and you go through things like this, you just don’t know whether this could be coincidence or this could be because of Agent Orange,” Amy said. “That’s unacceptable for me. I want to know. I just want to know.

“A government’s job is all about protecting you. It’s past time to get back to what our government is supposed to be doing. It’s pretty scary when the government only cares about protecting itself,” she said.

She wonders aloud about her own grandchildren: “How many generations is this going to go on?”

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LeRoy Foster never set foot in Vietnam. He didn’t serve in the blue water Navy off the coast of Vietnam, either. In fact, he didn’t come within about 2,400 miles of Vietnam. But the chances are good that he spent as much time in the company of Agent Orange as those who came into contact with it in Vietnam. He was the scrawny little guy with a “wand” in hand, working his way along a pipeline or security fence on Andersen Air Force Base in Guam. When he showed up, someone would see him from afar and say, “Here comes that little bastard spraying again.”

He spent 10 years on Guam. He first got there in 1968, a fuel specialist working with the B-52s of Arc Light. But the Air Force found other work for him, too. In the stifling heat and humidity of Guam, he wore rubber boots that came up to his knees, rubber gloves that came up to his elbows, and a rubber apron that ran from his neck down to his feet.

“After awhile, you’d start shedding that stuff, because it got too hot,” he said. “I had a face shield, but it only covered the front of my face. It didn’t cover the sides.”

He hand-sprayed Agent Orange from a 750-gallon tank on a trailer. The Air Force wanted security fences and pipelines kept clear of vegetation. The trailer had a 50-foot hose with a wand on the end to spray Agent Orange. The guys who saw the “little bastard” coming to spray felt sorry for him.

“A sergeant named Ralph Stanton remembered me,” the retired master sergeant said. “He remembers me spraying that stuff. He remembers me wearing the rubber boots and gloves and sweating to death in all that heat. He said he felt sorry for me.”

Foster started spraying Agent Orange in September 1968. In October, the outbreaks of chloracne began. Marked by eruptions of blackheads, cysts, and pustules, chloracne has been linked to dioxins, including those connected with Agent Orange. Nobody told him much about Agent Orange. Nobody told him there was anything to worry about.

“I’ve got a re-enlistment photo from March 1971 at Guam, and you could see the chloracne down the sides of my face,” he said. “I was covered with the acne. It was all over my body – my chest, my buttocks, the upper part of my thighs, my back. It started in October 1968. I didn’t know it at the time, but it wasn’t a coincidence. There I was breaking
LeRoy Foster's Story Continued...

out all over my body, and I didn’t know what it was. I thought it was the heat or something.”

He hand-sprayed the pipeline for six years. He married an Air Force dependent living on Guam and repeatedly went back for tours there, spending a total of 10 years.

“Nobody told me anything,” he said. “Nobody told me I was going to be damaged the rest of my life by this stuff.”

He retired in late 1987. He made claims to the VA. He was denied. Other illnesses came.

“The whole time, I’m fighting the VA,” he said. “It was a terrible thing for me to discover that all my illnesses are connected to Agent Orange. Nobody said a word.”

In 1987, he took a test for employment with the Postal Service. He did well and was ordered to take a physical. He didn’t get the job. He would never get the job. The Postal Service told him the physical found evidence of severe spinal stenosis and anklylosing spondyliosis, a chronic, inflammatory arthritis and autoimmune disease.

Eighteen years ago, he and his third wife had a daughter, Alicia Jean Foster. She was born with asthma and has suffered weight problems and emotional difficulties all of her life.

“There may be things wrong with us that we don’t even know,” he said. “She’s always had this rash on her body, and the skin on her feet is always cracking.”

His persistence with the VA eventually led to a 100 percent disability rating in 2005. But the anger remains.

“They said I had no proof I was exposed to Agent Orange,” he said. “And you know what? It’s right there in my Airman Performance Report. It’s called Vegetation Control. But they don’t put in any details, because it was such a menial task, and then they say I don’t have any proof. How many guys are going to document every little thing they did when they were in the service?”

Early in 2010, his daughter gave birth to her own daughter, Amelia Ann. The baby suffers from multiple birth defects. He firmly believes all the illnesses — his, his daughter’s, and his granddaughter’s — are linked to Agent Orange.

“If they look at all the illnesses I had when I was on active duty, if they look at those records and the VA records, they have a road map of a man, a veteran, who was exposed to Agent Orange, and it’s progressed through my life. It’s a road map! They can see it. I’d like to have somebody come up to my face and tell me I’m lying. I really would.”

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Arthur Dekoff

By Linda May

Arthur Dekoff says he is far from the only one in his family who is affected by the Vietnam War.

“My daughter wasn’t in that war,” he said. “But there’s no doubt in my mind that she’s paying the price because I was in it.”

Jessica Dekoff seemed healthy until she started kindergarten and a teacher said Jessica was dozing off in school. That’s when the seizures began.

“We took her to a children’s hospital. The diagnosis was epilepsy, and they treated her for that, but the seizures kept going,” Arthur said. “Then she had a stroke, and she lost the use of her right side, and it also left her mentally handicapped.

“The doctors kept questioning me about if I had ever been out of the country, and I told them I was in Vietnam. That was the end of the questioning. They didn’t need to talk about it any longer,” Arthur said.

The CT scan confirmed that it was Moyamoya disease, a rare condition first identified by the Japanese. It is more common in Asians but can affect anyone. Girls get it more often than boys. The walls of the internal carotid arteries of a person with Moyamoya, which supply blood to important areas of the brain, become thickened. Blood clots can form which may cause strokes and transient ischemic attacks.

Moyamoya can strike at any age, but the average age of diagnosis is around seven years, right about Jessica’s age at the time. About seven percent of the time, the disease runs in families, and those cases are due to a particular genetic defect.

“They told me my daughter had a year to live,” Arthur said.

A trip to another hospital in Ann Arbor, Michigan, resulted in medication that controlled the seizures. Jessica lived, but at 34, she has the mental capacity of a 9-year-old. She can say words but not complete sentences and does not always understand what is being said to her.

The stress was too much on the marriage between Arthur and Jessica’s mother.

Arthur’s present wife lives with Jessica and Arthur in a small mid-Michigan town.

“She knew me before I went to Vietnam. She understands me,” he said.

With sores all over his body while in Vietnam, Arthur served as a supply convoy driver during his in-country tour from 1970 to 1971.
When I got back, they asked me about getting sprayed. I wasn’t looking at our planes. I wasn’t worrying about them. I was watching for the enemy,” he said.

He worked for General Motors until problems started—including neuropathy, kidney cancer, and Post-traumatic Stress Disorder—and he took a medical retirement. Now 60 years old, he has also had quadruple bypass surgery.

“I worked until’83 and then I couldn’t deal with work any more,” Arthur said.

What he calls his “world” is six wooded acres, with distance between him and his neighbors. He says of his fellow Vietnam veterans who, like him, left the metropolitan Detroit area for the quieter rural life, “there are a lot of us up here.”

“I leave the house to check the mail, but I don’t get together with other Vietnam vets. I don’t like being around anybody really,” he said.

He feels strongly that the VA medical system has failed him, especially with detecting and treating what Agent Orange might have done to him and his family.

Arthur has another daughter with a different woman.

That child has learning disabilities. Her siblings—who had a different father—do not have any apparent problems.

“My health was great before I was drafted into the army,” he said. “I lifted weights in school. My first problem was those sores that started over there, and I didn’t know what they were.”

Places on his body where there are no sores, have scars from past sores.

“I figure we bathed in it (dioxin), drank it, and whatever else. There should be compensation for our kids,” he said.

Jessica benefits educationally from a workshop that runs five days a week, but her family can only afford to send her two or three days per week.

At the sheltered workshop, she learns and enjoys the company of children or other adults with her level of function, and she participates in the Special Olympics as a swimmer.

“She loves school, and all I can afford is a couple days for her. If I had some extra money to give her a better life, that would be great,” he said.

Considering what the family has given to the nation, it can’t be asking too much.

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“The worst thing is not having an answer,” says former California State Council President and longtime VVA activist Zack Earp. “I know there are lists of birth defects and stories about how Agent Orange affects veterans and their children, but still, I don’t have any definitive answers.”

Like other Vietnam veterans, Earp is deeply concerned about the effects of his exposure to Agent Orange while patrolling the DMZ from Dong Ha to Con Thien for 8 months in 1967-1968, where nearly 180 thousand gallons of toxic herbicides were sprayed. Earp has battled prostate cancer, and he wrestles with Parkinson’s disease, but what weighs on him is how his three sons and his grandchildren have been affected.

“I’ve reviewed many of the AO stories,” says Earp. “All of these kids have very serious health issues, and my kids’ health issues aren’t as obvious or as serious, but I still wonder, was it me?”

Earp’s oldest son, Clayton, was born in 1972 with a heart murmur. He has fought a lifelong battle with hives. “He has these large welts all over his body, head to toe,” said Earp. As an adolescent, Clayton experienced uncontrollable neurological tics.

Seth, born in 1977, exhibited more profound health issues. At 16, he began experiencing grand mal seizures, which precipitated numerous trips to the hospital. Efforts to identify the causes of his seizures were inconclusive. “When Seth was young, his arms would go rigid for no reason. Tests by pediatric neurologists at Cedars-Sinai Hospital, affiliated with the UCLA Medical Center, provided no answers,” said Earp.

Despite his neurological problems, Seth was a bright, intellectually curious student with advanced language skills who hoped to become an English teacher. He wrote short stories and poetry. He played the piano. “Seth’s seizures continued…. There was no warning, no pattern, no regularity…. Over the years, test after test produced no answers.” On Christmas Eve 2009, at the age of 32, Seth died at home after a violent seizure.

“Seth had wanted to have brain surgery to remove the part of the brain that was causing his seizures,” said Earp. “The Chief of Neurology at UCLA wasn’t eager to do the surgery, because it would have involved Seth’s frontal lobe, which was far riskier than temporal lobe surgery. Seth never had a chance to be a regular kid.”
Earp’s third son, Joshua, was born in 1978, and although his was a normal birth, “I could feel something was wrong,” he said. By the time Joshua was 15 months old, he was in respiratory distress and had to be hospitalized at March Air Force Base near the family home in Riverside, California. “He couldn’t keep any food down. He weighed about 12 pounds, less than half the normal weight of a baby his age. He was put into an oxygen tent with pneumonia.”

After consultations with a succession of specialists, it was determined that Joshua had an obstruction in his throat as well as a hole in the upper chamber of his heart—atrial septal defect. “If that wasn’t enough, the poor kid’s main coronary artery was going to the wrong side of his heart,” said Earp. “Three boys in six years, each with birth defects, what was I supposed to think?”

At 2 years 3 months of age, Josh underwent surgery to correct his heart defect, but the damage had been done. His growth was stunted, and he never matched his contemporaries in size. He was able to resume typical “kid activities” but did not have the stamina to keep up. “Josh had to stop for a break all the time,” Earp said. “I think his limitations contributed to his anger issues later in his life. I don’t think he was ever able to relate to his peer group.”

“We need answers. I think we are far beyond the blame game at this point, but it’s not too late to stand in the public square and wave signs and raise our voices. If we can engage the public in our mission, we can be successful,” said Earp. “If we know our exposure to Agent Orange caused these problems, it makes the search for solutions easier. It puts treatment and care within reach. Is that too much to ask?”

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Two years ago, Mark David Finley rolled his mobility scooter into my office. He had come to talk about his tour of duty in Vietnam and to share how his service had wreaked havoc on his health.

Finley had served with the Third Battalion, Third Marine Division, with much of his time along the DMZ in places like Dong Ha. He recalled lying in weeds soaked in a liquid of some sort, “We just didn’t even think about it. We didn’t know what it was.”

In 1971, Finley was back in Illinois and ready to put the war behind him. Fortune was with him on the day he met Alesia, a good Catholic girl who was working at the local drive in. He fell hard. It was the quintessential hometown romance, and soon they were married. In time, they had three sons, Adam, Aaron, and Isaac.

Life was good for many years.

Then, in 1998, Finley’s health started to decline. At the time of our meeting, he had had four strokes and five heart attacks and was waiting for a heart transplant. He grinned, proudly noting, “I was only going to have two years, but I’ve gone longer than that.”

Life for the family became a series of challenges. Finley struggled with the VA’s claims process; he received less than adequate care at the VA; he fought to get bills paid; and he received denial after denial on a claim to make his home handicap-accessible.

Still, the Finleys were fighting the good fight. With news of his father’s health deteriorating at an alarming rate, Adam quit his job in Mississippi to move back to Centralia. “That’s when I went from being just his son to being his friend,” he said.

A gifted musician, Adam recorded several of his father’s favorite songs. Thereafter, Finley took pleasure in sharing these with his friends at the VA hospital. “That’s my son playing! He made this just for me, isn’t that just great?”

Adam recalls, with pride, how at the local VA, his dad would reach out to other veterans in need, offering them friendship and advice. And he would inspire these veterans to do the same for others. “As sick as he was, he always made the best of everything,” said Adam.
Finley continued to touch the lives of those around him until October 18, 2010, when he lost his fight with his Agent Orange-related illnesses, passing away at the age of 60. The members of VVA Centralia Chapter 176 stood by the family; they prepared a funeral dinner after learning that other veterans’ organizations had turned them down.

“I had such a short time with my dad, even though he raised me. I wouldn’t be so mad if I hadn’t watched him suffer. It’s like I watched him die for ten years,” said Adam.

When Adam began researching the long-term effects of Agent Orange, it dawned on him that his own health challenges could very well be related to his father’s tour of duty in Vietnam. For years, Adam has displayed symptoms of attention deficit hyperactivity disorder (ADHD); he has trouble staying on task and struggled with jobs that required him to sit at a desk for extended periods of time. He experiences bouts of forgetfulness.

He recalled the time he set out for a local hardware store, only to find himself in another town. “I had to have driven over two hours, but I had no recollection of the drive or how I got there,” he said.

Adam noted that his personality has “Dr. Jekyll and Mr. Hyde” qualities. He often considers that he may be bipolar. There are times when his skin will burn and break out with hard, red bumps for no apparent reason.

Adam worries about his children. One son faces challenges with his speech and metabolism. In the face of his father’s death and his own health issues, Adam wonders if he, too, will pass away at age 60, unable to see his grandchildren grow up. He admits, “This isn’t just a closed chapter for me.”

Adam remembers his dad’s words: “You got to fight, fight, fight…. You went home from Vietnam fighting, and you’re going to fight again… You’re in a different war. It’s the war called life.”

Said Adam, “When I played ‘Army’ with my friends, every single time I had to be my Dad. He was my hero then, and he always will be. And I will fight the good fight for my children and the generations to come.”

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The intense itching that afflicted Amber Mayhew Workman began in 2004. It led to sores that covered her from head to foot. It took four years before she finally found an answer — Hodgkin’s disease, a cancer that begins in the cells of the immune system. Her father, Roland Mayhew, a former Marine who served in Vietnam in 1966-67, does not doubt that his exposure to Agent Orange is connected to his first-born child’s battle with cancer.

The first doctor to see Amber told her she had scabies, an itchy skin condition caused by a tiny burrowing mite — Sarcoptes scabiei. She was treated for scabies twice. The terrible itching didn’t stop; the constant scratching created more sores.

She next went to see a dermatologist and was told she had eczema. Then she saw a podiatrist. The itching had spread to the bottoms of her feet. She used a fork to scratch her feet in an attempt to gain relief. She said the doctor told her it was all in her head, that she didn’t really itch.

She was so covered in sores that even in the middle of the hot Kansas summer she wore long-sleeved shirts and long pants to hide the sores while she played softball.

Her gynecologist said she had a bacterial infection.

In February 2008, she noticed a large lump that appeared on her neck. She went to a doctor as soon as she could. A surgical biopsy was done. She finally had an answer — Hodgkin’s disease.

Chemotherapy began. After the first treatment, she said the itching stopped. Following the chemotherapy and radiation treatments, Amber was cancer-free, though she still worries about the disease returning.

Her father, a life member of VVA Chapter 604 (Topeka), was a 19-year-old radio operator working alongside a forward observer with a Marine artillery unit. He spent a lot of time in the Vietnam “bush.” He has no memory of any conversation with fellow Marines about Agent Orange.

“I stayed pretty busy,” he said. “I was just trying to keep my head down. I was pretty young. I didn’t know anything about us being sprayed.”
Roland Mayhew’s Story Continued...

In the bush for weeks at a time during Vietnam’s monsoon season, he caught pneumonia. It took two or three days to get his temperature down. Weeks at a time in the bush in the monsoon meant being wet always.

“We lived in ponchos and stuff like that,” he said. “Charlie Company was pretty well shot up when I joined it. Half of them were back stateside.”

He doesn’t care to talk about his own health issues, saying he feels fortunate that at 65 years old he is still alive.

“I don’t want to talk about my own health situation,” he said. “That’s kind of personal to me. I went through quite a bit, and I’d just like to leave it at that. It took me about forty years to step forward on these things, and I just want to leave it there. I do feel fortunate being 65 and all. A lot of guys affected by Agent Orange didn’t make it past 50 years old. The VA takes good care of me.”

He takes good care of the VA and its veterans as well. He has volunteered at the VA for 16 years and has been involved with raising funds for the Wounded Warrior project in San Antonio. The initial success he and others had in obtaining needed items for veterans while meeting customers at a Walmart caused him to share the experience and knowledge with other Kansas VVA chapters.

“We collected almost $6,000 worth of stuff the first time we did it,” he said. “We stay focused at the VA. We get some grants from Indian casinos, too, so we can spend funds on things veterans need at the VA. In San Antonio, we collected something like $34,000 for the Wounded Warriors. It was awesome. Marines always give back for their own.”

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In 1975, when John Miner’s son, Tad, was born, there was no reason for Agent Orange to enter into any discussion about his son’s health problems. John was healthy himself, concerned only with raising a family. He went into the Army right out of high school in the summer of 1966, served two tours in Vietnam, one in Saigon and a second with an advisory team in the Delta. Then he came home for good.

It wouldn’t be until the 1990s that he would become involved in veterans affairs and begin a long campaign to secure benefits for veterans and their families. In that same time frame, his health began to deteriorate — his heart, diabetes, and other ailments that would render him 100 percent disabled. By then, Agent Orange had very much become a part of the discussion for not only John, but for Tad as well.

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“About 12 in my chapter have died in the last seven years,” he said. “That’s a lot for one little area like ours. About 90 percent of them had diseases recognized by the VA as related to Agent Orange. Most of those I see now have developed some type of cancer, and it’s showing up in great numbers. I look at The VVA Veteran every time it comes out and it’s startling to see the number of obituaries in there. You see the numbers, and you realize that what’s happening is what everyone is talking about. We’re dying at a very fast rate.”

John’s concern does not stop with the veterans themselves, but extends to their children and grandchildren, one of the most striking examples being very close to home, his 36-year-old son, Tad.

Born in 1975, Tad spent most of his youth visiting doctors and trying to get well. Shortly after birth, he began contracting what doctors called “pneumonias.” By the time he reached 18 months old, John and his wife, Joyce, grew weary of the vague diagnosis and drove from their Bennington, Vermont, home to Boston, where Tad was evaluated at Children’s Hospital. They stayed for a week.

“The doctors found out Tad had a gamma globulin deficiency,” John said.
John Miner’s Story Continued...

“He was missing something, and it was making him susceptible to disease.”

For the next 18 months, John and Joyce drove the four-hour trip to Boston every three weeks so that Tad could receive needed injections. John had to take off from work, borrow a car (they didn’t own one), and make the long drive. Eventually, they found a location closer to their Vermont home where Tad could receive the injections.

“In Boston, the shots were free,” he said. “In Vermont, they would have cost us an arm and a leg.”

After getting the gamma globulin deficiency under control, other problems arose to take its place — epilepsy, then asthma. Tad started having seizures, suffering a grand mal when he was 7 years old.

“There was damage to his motor control area, which affects mood and temperament,” John said. “At about 12, he developed asthma.”

Around 1994, when John began to encounter health problems, Agent Orange entered the picture. He began researching the chemical’s connection to Vietnam veterans’ health problems. Joyce looked into the connections heavily. They had an additional reason as well — their daughter, Tammy, had been diagnosed with asthma.

“The biggest story with Agent Orange now is showing the government that children are having Agent Orange-related problems,” he said.

John emphasizes the importance of veterans keeping these issues in front of the VA. He has held town hall meetings to discuss Agent Orange and its effects on veterans and their families. Every three months, he participates in “mini-MAC” (Management Advisory Council) meetings with VA officials. VA hospital directors and their staffs meet with veterans, opportunities Miner sees as critically important for veterans to make officials aware of problems and solutions.

He said the VA stopped the meetings last year, arguing that the problems had been solved. Miner saw something other than problems being solved.

“They were getting complacent,” he said. “We’ve been dealing with the VA for 20 years on these issues, and it’s very important for veterans to go to these meetings. They are important links between the veterans and the VA. These issues would just fade away if we didn’t fight. The government won’t do anything unless they’re pushed. And VVA has stepped forward and advocated for all veterans and has taken the lead on these issues. We’re a small organization, but we have produced good results. We’ve had an impact. We just have to keep working at it.”

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