

"National Tragedy"

"The untold story of childhood cancer clusters in America and our government's indifferent, ineffectual and inconclusive-by-design treatment of towns with more than their fair share of rare disease"

My name is Lesley Pacey and I am the mother of Sarah Pacey, a leukemia survivor who was part of a recent childhood cancer cluster on the Eastern Shore of Mobile Bay, Alabama. This is our story.

It is the story of a town with too much cancer and neurological diseases and it is the same narrative that is unfolding in communities throughout the U.S. It is the untold story of childhood cancer clusters in America and our government's response to them.

It is a cautionary tale that I have come to believe begs to be told in a documentary.

This national tragedy - of which most Americans are oblivious - centers on the plight of parents like me who grapple to understand why disease clusters exist in their communities but who have discovered nothing more in their exhaustive quest than the heartbreaking truth that government agencies tapped to protect our health and our children's health are indifferent to our concerns.

Time and again, public health agencies in America fail to properly track and respond to cancer cluster concerns, failing our families - often with life and death consequences.

Imagine the horror of discovering your child has cancer. Suddenly, you are engaged in a battle for your child's survival. Now imagine you discover a higher than expected number of children and adults in your community have rare cancers, too. You contact state and federal public health agencies designed to investigate your suspected disease cluster, expecting help. They do little or nothing.

You are totally alone in your quest for answers.

That is where I found myself after my daughter Sarah was diagnosed with leukemia at 2004 at age 4 - totally alone. And my story repeats itself every day in America, where children in suspected disease cluster communities launch campaigns for answers - only to find indifference and incompetence from public health officials. This is not the exception but the rule in communities throughout America where pockets of once rare diseases are becoming commonplace, popping up at increasingly alarming rates.

Injustice in Alabama

State public health agencies around the U.S. receive about 1,000 requests each year for cancer cluster investigations, according to the National Disease Clusters Alliance. But those agencies are largely ill equipped to handle such investigations, according to a 2007 Johns Hopkins study and the National Disease Cluster Alliance.

Alabama is no exception.

My daughter, Sarah, was part of a "confirmed childhood cancer cluster" centered in and around the idyllic south Alabama town of Fairhope. The cluster occurred between 2000 and 2005 and included six children, two of whom died.

The Centers for Disease Control (CDC) defines a cancer cluster as a greater-than-expected number of cancer cases that occurs within a group of people in a geographic area over a period of time. Long before the state health agency's admission in 2008, I knew Fairhope met those qualifications.

Initially, the Alabama Department of Public Health's own website fueled our fears. It showed new leukemia cases in Baldwin County, where Fairhope is located, jumped from seven in 2001 to 17 in 2002. Non-Hodgkin's lymphoma rose from 13 new cases in 2001 to 31 new cases in 2002. And Baldwin County saw eight new cases of brain and other nervous system cancers in 2001, compared to 13 new cases of brain and nervous system cancers in 2002. All this occurred on the heels of neighboring Mobile County - with several Superfund sites on the opposite side of Mobile Bay - being ranked in 2000 as the 8th most polluted county in the U.S.

Upon my request, the state health agency began two rare cancer studies. Admitting their concern over the spikes in blood related and neurological cancers in my county, they would make history - launching the first public health assessment ever performed by the state public health agency.

The first study, launched in 2005, ended abruptly a few months later with no explanation. Not surprisingly, those "new incidence rates" suddenly disappeared from the state health agency's own website.

The other state health study began in 2007. After admitting elevated levels of certain cancers in Baldwin County, and interviewing more than 50 people with rare cancers on a list of more than 90 people, that study ended for lack of money, lack of staff, lack of protocols, questionnaires that were "too open ended," and because most cancer elevations in our area by this time appeared within normal ranges, according to state public health officials.

State public health director Charles Wornle in 2008 admitted that a childhood cancer cluster had occurred in our area. The astounding thing was that he also was telling us that his office could not and would not investigate it any further - mostly because of deficiencies within his department.

"We recognize that any time you have a cancer cluster, it's logical that folks get worried about it, especially when it involves young children," Dr. Charles Woernle, assistant state health director, told the Mobile (Ala.) Press-Register in a Dec. 13, 2008 article. "Now, thank goodness, we have determined that the initial cluster has dissipated and we haven't had a recurrence."

Except for some soil and water testing at a local preschool, no other environmental testing was ever conducted. But with rare cancers still popping up on my radar at an alarming rate, I continued my quest for answers, logging the names of the chronically ill on my own and pushing for partnerships with university researchers for environmental testing.

In 2008, four years after Sarah was diagnosed with leukemia, a Fairhope city councilwoman helped me form a nonprofit agency aimed at researching the scope and possible environmental causes of a spate of rare cancers - in children and adults - as well as neurological diseases on the Eastern Shore.

A nonprofit seemed and currently remains the only chance our community had to find answers that we never got from our governmental health agencies.

While I have a passion to protect my children and champion for my community, taking on what our government should have amounted to a tremendous personal sacrifice for me and so many other parents and grandparents around the country who already have lost so much. We know what it is like to have cancer strip all normalcies from our lives and tear our families apart. We live day in out, hoping, praying our child will defeat death. Other activists have endured the horror of burying their babies.

Still, these community champions push on. Fueled by a passion for the truth and a tenacity born of pain and loss, so many parents in cancer cluster communities throughout the U.S. have initiated, funded and organized their own studies because public health agencies simply aren't protecting our children or holding polluters accountable.

When the state public health department stopped investigating our cluster in 2008, I remember feeling wounded by their lack of concern for Sarah and the other children and adults in my community who suffered and died. But I was not surprised. Everything I had read - everyone I had networked with from disease cluster communities around the U.S. - prepared me for this moment. History was simply repeating itself in a cruel way.
Inconclusive By Design

I have become well aware that pinpointing the cause of a cancer cluster rarely - if ever - happens. Public health investigations - if they commence at all - begin half-heartedly and with the self-fulfilling prophecy that they will be unsuccessful.

Often, when studies are conducted, they are deliberately fail to link a contamination source to localized disease clusters, according to the 1992 report, "Inconclusive By Design, Waste, Fraud and Abuse in Federal Environmental Health Research."

"Instead of systematically applying precautionary public health principles consistent with their legal and ethical duties, the federal agencies have engaged in politically-driven whitewashes," said the report created by the Environmental Health Network National Toxics Campaign Fund. "They have become virtual propaganda tools of polluting industries

- making public reassurances instead of public protection their foremost focus. One result has been an increase in public complacency and government inaction at many sites where further precautions to reduce toxic exposures are merited."

The report continues: "The methods of distortion in the agencies investigative techniques have varied from site to site, but underlying most of their activities is a single theme. The studies in which they are engaged often may appear to be formal and scientific, but behind this veneer are 'Inconclusive by design.' Quite predictably, no finding of an association between disease and exposure is drawn in studies and assessments which (20 years ago) cost over \$30 million per year in tax monies."

"The inconclusive results of studies are used by polluters and governments to quell public concern and justify cutting corners on remedial expenditures needed to end public exposure to toxics. Thus, in addition to wasting millions of dollars of taxpayer's money, they are jeopardizing public health. More rigorous public health evaluations have indicated that many of these communities should be subject to precautionary measures to reduce public exposures to chemical wastes," the report states.

Idaho brain cancer survivor Trevor Schaefer knows this harsh truth. S. 76, Strengthening Protections for Children and Communities From Disease Clusters Act, introduced in January 2011 by Sen. Barbara Boxer, D-California and supported by Erin Brockovich, was named Trevor's Law in honor of this young survivor. Schaefer was one of five people diagnosed in 2002 with brain cancer in his small town. He has devoted his life to advocating for children in disease cluster communities.

If passed by Congress, Trevor's Law would vastly improve the government's ability to track and respond to disease clusters. The law would appoint the Environmental Protection Agency as the central agency for disease cluster tracking and response; provide support to state and local health departments for disease cluster investigations; create response teams with expertise from a variety of fields, including community outreach; advance research to improve methods, guidelines, and tools used in disease cluster response; and increase community involvement in disease cluster response. The bipartisan-sponsored legislation remains stalled in the Senate.

"In small towns throughout our nation possible cancer clusters exist," Schaefer said in his testimony before the U.S. Senate, EPW Committee Oversight Committee on Cancer Clusters and Children's Health on March 29, 2011. "Parents are trying to get authorities to investigate these clusters and to discern what caused the disease patterns. Scientist and health activists say the government's current response to disease clusters ranges from piecemeal to non-existent. Some people are told that their small populations render them statistically insignificant. There is nothing insignificant about even one child becoming part of a cancer cluster then dying of that cancer without ever knowing why. Trevor's Law seeks to rectify that by allowing people in small communities to have their voices heard and their concerns validated about the environmental impact on their children's health."

For too long, those concerns have fallen on deaf ears.

In the 1960s and 1970s, the U.S. Centers for Disease Control and Prevention investigated 108 cancer clusters around the United States, most of them childhood leukemia. They found no definite causes for any of them.

Currently, there are 42 documented disease clusters in 13 U.S. states, showing incidence of numerous types of cancer, birth defects and other chronic illnesses, the Natural Resources Defense Council reported in 2011. Only one of the 42 clusters -- in Libby, Montana -- showed a specific source for chemical contamination: asbestos. In the other clusters, NRDC saw signs that documented exposure to toxic chemicals hurt the people who lived nearby.

In 1990, the CDC turned cancer cluster studies over to the states while still offering some oversight. Things didn't improve. Each year across the U.S., over 1,000 citizens ask public health agencies to investigate suspected disease clusters, but state agencies are usually unable to offer a substantive response to such requests.

A 2007 Johns Hopkins study revealed that state health agencies in general lack the protocols, funding and staff to conduct successful chronic disease investigations. Only 12 states have cluster response teams and most states lack experts in chronic disease epidemiology or biostatistics. Some lack access to medical libraries. No state reported having pre-approved research protocols that would allow timely and scientifically valid cluster investigations.

No answers for Fallon

Hundreds of state and federal experts spent millions investigating the leukemia that sickened 17 children and killed three between 1997 and 2004 in Fallon, Nevada. But somehow, the nation's most intensive investigation ever of its most well documented cancer cluster remains inconclusive.

In 2001, my dear friend Floyd Sands, lost his daughter Stephanie, 21, to leukemia in that cluster. After losing Stephanie, Floyd became frustrated with the slow pace of state and federal health agencies' investigations into the Fallon cluster. He became convinced that the state and federal investigations in Fallon were "inconclusive by design," meant to protect powerful economic and military interests rather than to identify the roots of the cluster.

The odds of the leukemia cluster being due to chance alone were calculated to be 1 in 232 million by state and University of California epidemiologists. But Floyd told me that his hometown's cluster marked the CDC's 109th consecutive failure to link cancer to the environment. Nevertheless, he fought for answers in Fallon and championed for children's health nationwide. He helped form the National Disease Cluster Alliance (NDCA) in 2005 so communities with emerging disease clusters might gather the tools to conduct their own investigations.

"It is my dream and my personal vision that no community ever endures what Fallon, Nevada and our children endured, and lost," Floyd said in 2008 statement. Tragically, the activist, who uncovered evidence that the Fallon childhood leukemia cluster was accompanied by an adult brain cancer cluster, succumbed to brain cancer in 2009 at age 56.

NDCA grew out of the urgent need to identify and respond to emerging disease clusters. It includes scientists, public health professionals, and community activists joined together to help communities facing disease clusters. Through that network, I found and later convinced two University of Arizona researchers to come to Fairhope.

"Currently, there are no government agencies that either track or respond sufficiently to disease clusters in communities," states the NDCA website.

The real question: What is more precious than our children?

We need to ask lawmakers why this public health crisis continues - why caregivers who lack resources and expertise have become homespun epidemiologists and environmental researchers.

We need to ask why politicians penalize those who pinpoint disease hotspots, as was the case in 2010 when the Florida Pediatric Tumor Registry Program provided data to a Florida pediatric oncologist and a University of West Florida researcher to identify pediatric cancer clusters in the Sunshine State. The Florida Department of Public Health did not praise the report for ferreting out the state's problem areas. Instead its leadership scrambled to discredit the report and its authors and politicians who had funded the independent childhood cancer database for 30 years cut all state allocations to the program.

We need to ask why politicians will talk about a cure for cancer all day, but no one wants to look into environmental causation of cancer. We need to ask why cancer clusters are allowed to go unchecked especially when cancer is on the rise everywhere in America. Cancer is the second leading cause of death among children, exceeded only by accidents. According to the CDC, 46 children per day - or two classrooms full - are being diagnosed with cancers unrelated to genetics, family history or unhealthy lifestyle choices.

It is time that local, state and federal governments finally acknowledge that when so many of our children are being diagnosed with cancer, that many of them live in the same neighborhoods, that toxins in their environment may have played a part in causing the illnesses. Our innocent children deserve to have their government entities care enough to seek out the causes in as transparent a fashion as possible, states a petition supporting Trevor's Law.

I am blessed that my Sarah survived her battle. But I am painfully aware of how close we came to losing that amazing kid. When I remember the Hell she endured and the devastation of watching her being wheeled away more than two dozen times for spinal taps, surgeries and too many chemo infusions to count, I feel the anger for how she was disregarded by our

government well up inside of me. I refuse to accept that her cancer and the large number of rare diseases in my community are statistical anomalies and I refuse to believe that having so many sick and deceased neighbors is normal or acceptable.

We should demand an overhaul of our public health agencies established to protect our health and a strengthening of environmental laws that affect our health. Every American deserves answers and the assurance that the air we breathe and the water we drink are safe. I believe a documentary would connect the dots of the plight of cancer clusters in America and illustrate in a very poignant way the heartbreaking tale of the toxic assault on our precious children.

Unless we touch America with our stories and our children's stories, the families living in suspected cancer cluster communities will remain random voices crying in the wilderness with no power or unity. It is my hope that a documentary would unify those voices and shaming our lawmakers into supporting legislation that would improve disease cluster tracking and response, as well as enacting stricter laws regarding polluters.

This documentary would show rising pediatric cancer rates, highlighting some of the communities where cancer clusters exist, telling the stories of victims, scientists and even government officials who have been impacted by this issue. But mainly, "National Tragedy" would examine our government's response to these clusters and ask, "Who is protecting our children from toxic trespass?" and "What could be more precious than human life? Money? Industry? Politics?"