

Trevor Schaefer's Testimony
U.S. Senate, EPW Committee
Oversight Hearing on Cancer Clusters
And Children's Health
March 29, 2011

I want to thank Chair Barbara Boxer, Ranking Member James Inhofe, and my senator, Mike Crapo, for taking on the subject of childhood cancer and cancer clusters and what they mean to our public health. I would like to thank *all* of the senators on the Environment and Public Works Committee for the care you give in debating the environmental and health dilemmas a modern world creates and for allowing me to address some of those issues today. And-- I am so *very* proud to be able to state that I am here today as a witness for **both** the Majority and Minority committee members.

Most of you don't know me other than that I am associated with **S.76**, also known as **Trevor's Law**. By the end of my testimony my hope is that you will not only know *me*, but that you will remember me as the voice of every child in this great nation.

(As you have been told) I am a twenty-one-year-old brain cancer survivor. In November of 2002 at the age of thirteen, I was diagnosed with a highly malignant *Medullablastoma*. What a word! I could barely

pronounce it correctly, let alone get my mind around what it meant to my future.

Until that time, you see, I was living and thriving in McCall, a small town located on a lake nestled in the beautiful mountains of Idaho. I was enjoying a fairy tale life in paradise: boating with friends and family in the summer, snowboarding in the winter and playing football for my seventh grade football team. But the carefree days of my childhood changed abruptly and dramatically after my cancer diagnosis. My entire world came crumbling down around me. Cancer was an alien word to me, one that was synonymous with invasion and death. I had to suddenly face the realization that there was a chance I might never see my friends, my family or my home, again.

Like a snap of the fingers I was robbed of my childhood and my innocence. The antiseptic world of hospitals became my life as I went through invasive tests then endured an eight hour surgery to remove a golf ball sized tumor from the base of my brain. While I recuperated I could not even stand. I barely had the strength to open my eyes. How could it be that a mere two months prior to this I was struggling for a touchdown, and now I was struggling to stay alive? Soon after leaving the hospital I entered an even more terrifying life: I began fourteen grueling months of radiation and chemotherapy treatment.

Unfortunately I wasn't the only kid with this pernicious disease in my town. In the same year of my diagnosis there were four other brain

cancers in our tiny resort community with a year-round permanent population of 1,700 residents. Over a ten year period there was an abnormally high number of cancer cases diagnosed there prior to, and after, my diagnosis. My mother was alerted to, and alarmed by, these numbers and took this information to the Cancer Data Registry. She expressed her fears that perhaps our beautiful little town was the wrong kind of paradise. Her fears were responded to in a patronizing fashion, the official telling her that even if her data proved true, our town was too small to warrant a cancer cluster study: We were not *statistically significant*.

Just as she never let me give up my fight for life, she refused to give up the fight for the truth. That encounter at the Tumor Registry started both of us on the course that has led to *this* day in *this* room to consider the overall issue of childhood cancer clusters and how best to respond to those who believe they might be part of one. Some of those issues could be resolved through **S.76** which, among other things, will provide the most effective means of coordinating agencies and ensuring outreach to, and involvement of, community members.

What happened in my community continually repeats itself throughout this *entire* country, year in and year out. It impacts many of your neighborhoods and many of your neighbors. Nationally the statistics for childhood cancer are alarming. According to the CDC, *forty-six children per day (two classrooms-full)* are being diagnosed with cancers *unrelated* to genetics or family history. The National

Cancer Institute states that there are over 12,500 children diagnosed with cancer each year. As **S. 76** states, “cancer is the second leading cause of death among children, exceeded only by accidents.”

According to Dr. Sandra Steingraber, Childhood cancers are “swiftly rising cancers... pediatric leukemia, brain tumors amongst four-year-olds, ovarian cancer amongst adolescent girls, testicular cancer amongst adolescent boys. These cancers are rising rapidly and of course **children don’t smoke, drink or hold stressful jobs**. We therefore can’t really evoke lifestyle explanations. There are no good familial links that we know of. We are beginning to recognize that not only pre-natal life but adolescent life is a time of great vulnerability to cancer causing chemicals, when the connection between health and the environment becomes even more important.” (Steingraber interview by Rita Dixit-Kubiak, *Seacoast Spirit*, Vol. I, No.5).

The emotional and monetary costs of childhood cancer and cancer clusters continue to mount, unraveling the very fabric of our society thread by thread. Many of us young cancer survivors will forever face chronic health challenges resulting from the heroic medical measures used to save our lives. According to Kevin Oeffinger of New York’s Memorial Sloan-Kettering Cancer Center, childhood cancer patients’ “health problems, which include heart disease, lung scarring, strokes and second cancers, can be caused both by their original tumors as well as the harsh treatments used to cure them.” In fact, more than 73% of

patients cured of pediatric cancer will develop chronic illness within thirty years of the diagnosis. (*New England Journal of Medicine*).

Senators, nothing is quite so lonely as being a child with cancer. Lying in a hospital bed and sitting in a chemo chair getting chemotherapy treatments and blood transfusions while other kids are outside playing ball and riding bikes isn't exactly the childhood I, or any of us, had in mind. Out growth and social advancement may be stunted, but in other ways we are forced to become mature beyond our years: learning to be patient and resilient, and becoming courageous warriors fighting our own battles without any armor.

Children who have had cancer often experience confusion and embarrassment as they try to return to a so-called *normal* life and are dealing with the physical side effects related to their diagnosis and treatment. I can attest to that. During my chemotherapy treatments I developed neuropathy, more commonly known as Foot-Drop. I walked with a decided limp and felt as though I could fall over at any moment. During the time of my treatment and this side-effect, I was changing schools. I was cautioned to think twice about going someplace new: *the kids would laugh at you because you walk funny*. Don't think that wasn't always in the back of my mind *every* hour I spent in school while I had this condition.

Although it has been almost nine years since my diagnosis of brain cancer, I am constantly reminded of this bully who tried with a

vicious determination to take my life. Every morning I still wake up with a distinct ringing in my ear which I have with me every second of every day, a residual effect from my brain tumor, only one of many. Before brain cancer I could have appeared before you and delivered this entire testimony from memory. The residual cognitive effects of chemotherapy make it difficult for me to do that.

Several years ago when cancer struck me I fought so hard for my life. I endured the countless needle pricks, blood transfusions, nausea, vomiting and physical therapy so I could live to see the sunrise and the snowfall. I am so grateful to be alive. Still, the aftermath from the cancer treatments that I received have affected me in a way where I may never be able to have children of my own. How ironic that I battled so hard to save my own life, succeeded, yet now I may never be able to give life.

The emotional side effects from cancer can be devastating to a once active and vibrant child. We can feel a range of emotions that include fear, depression, anxiety and symptoms similar to Post Traumatic Stress Disorder. We may also feel lost or isolated because we no longer have stability or a sense of control over our lives. Lack of interest and poor self-esteem can last long after our final treatment is over.

I would also like to stress that childhood cancer doesn't only attack the victim, it greatly impacts every member of the family.

Siblings often experience concern, fear, jealousy, guilt, resentment and feelings of abandonment which can last long-term. Relationships between family members can become tense; there can be stress on a marriage, and frequently a family breaks up.

So many times at my treatment appointments, I would see a parent alone with several children, one of whom was the sick member of the family. My mother and I sometimes talked to these parents. Most of them had heartbreaking stories to tell of families going bankrupt, having to sell their house, or a mother losing her job because she had to stay home with her sick child. One time we learned from a frazzled mother sitting near us that her husband had just left her a few weeks before. She'd lost her job and couldn't afford a babysitter for the rambunctious two-year-old in her arms who was *autistic*. She had no choice but to bring him along to the clinic while her older, six-year-old son lay on the couch next to her shivering under a blanket while awaiting his turn for treatment for advanced bone cancer.

Coping with a life-threatening disease like cancer is an ambiguous and unpredictable process. Although there has been a significant increase in the cure rate of childhood cancer, there needs to be more focus and research on what causes this disease and other catastrophic and chronic illnesses in children. There is an increasingly vast body of evidence showing that some chronic conditions such as birth defects, developmental disorders among children, and cancers are linked to the

ubiquitous toxins that are dumped into the food children eat, the water they drink, and the air that they breath.

In small towns throughout our nation possible cancer clusters exist. 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*. **S. 76** allows people in small communities to have their voices heard and their concerns validated about the environmental impact on their children. It would have been a different story for my mom all those years ago had this legislation been in place. This is true for so many communities throughout the nation.

Take **Clyde, Ohio**, for instance, where twelve-year-old Tanner was diagnosed with Leukemia in 2008. Tanner is one of *thirty-five* kids who have been diagnosed with cancer since 1996. His older sister, Tyler, is a cancer survivor and she is only seventeen. The cancer rate in this cluster is almost *six times the normal rate* for children in this part of Ohio.

And then we have **Sierra Vista, Arizona**, where *eleven* children were diagnosed with Leukemia in a five year period. Linus was a toddler at the time of his diagnosis. Jessica was also two years old-- and the list goes on.

In a community just outside Boise, Taylor was diagnosed with Hodgkin's Lymphoma at age eight, and Gracie was diagnosed with kidney cancer at age two. Zach, at age thirteen, has been fighting Leukemia since he was eleven years old, and Paige was diagnosed with thyroid cancer at the age of fourteen.

And then there's my little friend Bradley who lives near my home. He is seven years old and has battled Neuroblastoma (a rare cancer of the nervous system) since he was three years old. His body is intersected with surgery scars resembling a road map. Bradley has been an amazing fighter and an inspiration to all who meet him. Lately, however, you can see that some of the spunk has gone out of his personality. He's become more aware that his little brother is bigger and taller than he is. And just a few months ago he was diagnosed with an old person's affliction—*cataracts* in both eyes. One day a few weeks back, Bradley's teacher found a note that he had scribbled. She gave it to his grandma. She shared it with us. In it, Bradley asked what it was like in heaven and said that he was afraid to die because he did not want dirt in his eyes.

From these few examples alone you can see why it is that I have been inspired to help develop and propose legislation like **S.76**. Introduced in the spirit of amity *not* enmity by **both** Chair Boxer and Senator Crapo, this truly **bi-partisan bill** is especially encouraging to a neophyte to the political system like me. Despite our charged political

climate, **Trevor's Law** is proof that party affiliation need not prevent senators from putting children's health above politics.

What I especially like about **S.76** is that it could help pinpoint the causes of predatory disease at its earliest stage by bringing together agencies with the relevant expertise needed to investigate and report disease clusters in a timely manner. Through this multi-agency system, the burden could be lifted off the health community which for now shoulders the arduous responsibility as the repository of cancer information. And it will also make the investigative process transparent and inclusive. No longer will those who reside in fear in small communities be told that they have no place at the table, that they don't count because they are *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.

Environmental toxin exposure is insidious in all instances, yet it affects our children in greater proportion than adults. Let me reiterate, children are **more vulnerable** to chemical toxins than adults because they have faster metabolisms and less mature immune systems.

Toxins don't respect geographical boundaries or property lines. Cancer eschews all boundaries, too. This disease spares no ethnic group, no socio-economic group nor any geographical area. In its wake we are left with the burden of enormous personal and social loss.

I made a promise to myself that if I survived I would dedicate my time in this world to helping other children with cancer so they would not have to suffer the way I did. Senators, I was spared. I truly believe I have been given a second chance at life to convey to you the urgency and importance of a need to address the growing dilemma of childhood cancer clusters. On behalf of all the children with cancer who are suffering now and for those who may one day suffer, I strongly encourage your support for **Trevor's Law**.

In closing, I would ask you to consider how much your child or grandchild's life and well-being are worth? And while you're doing that, please close your eyes for a brief moment and picture a world without children.

Thank you.







NDCAL

National Disease Clusters Alliance



Putting Children Above Politics

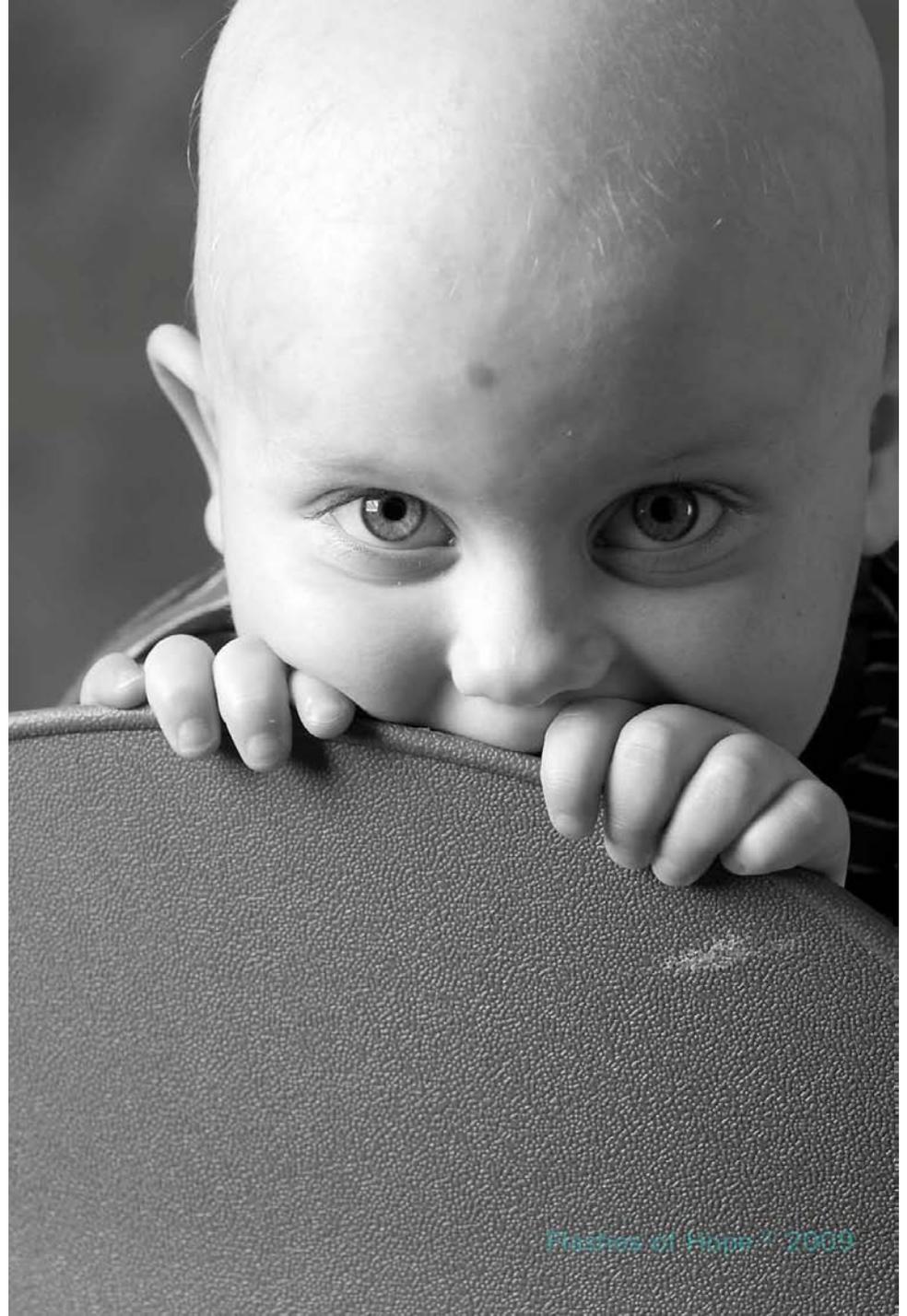
Trevor's Law, U.S. Senate Hearing

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Meet some
of our
children

harmed by
disease
clusters

and chronic
disease



Disease Clusters and Hotspots



In memory

Stephanie

Fallon NV



Rumi





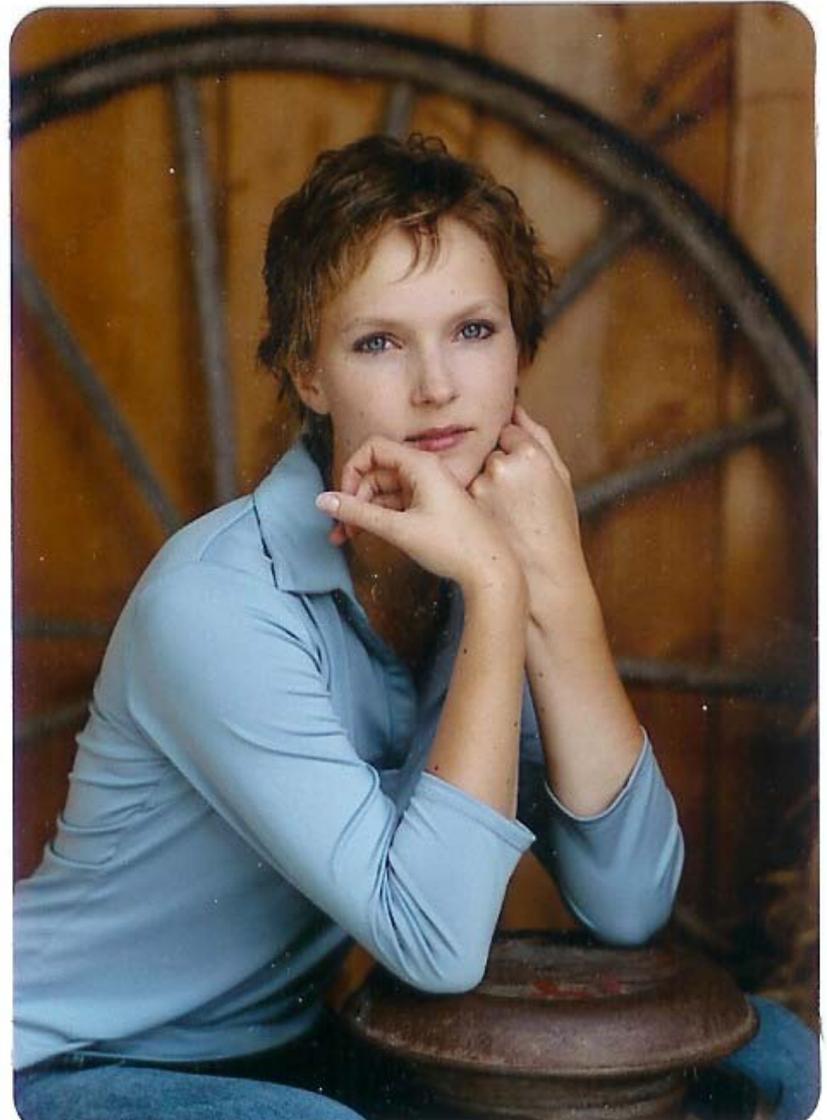
Jacob, 4 years old

His smile is what keeps our family going

In memory

Nikki

18 years old



Morgan



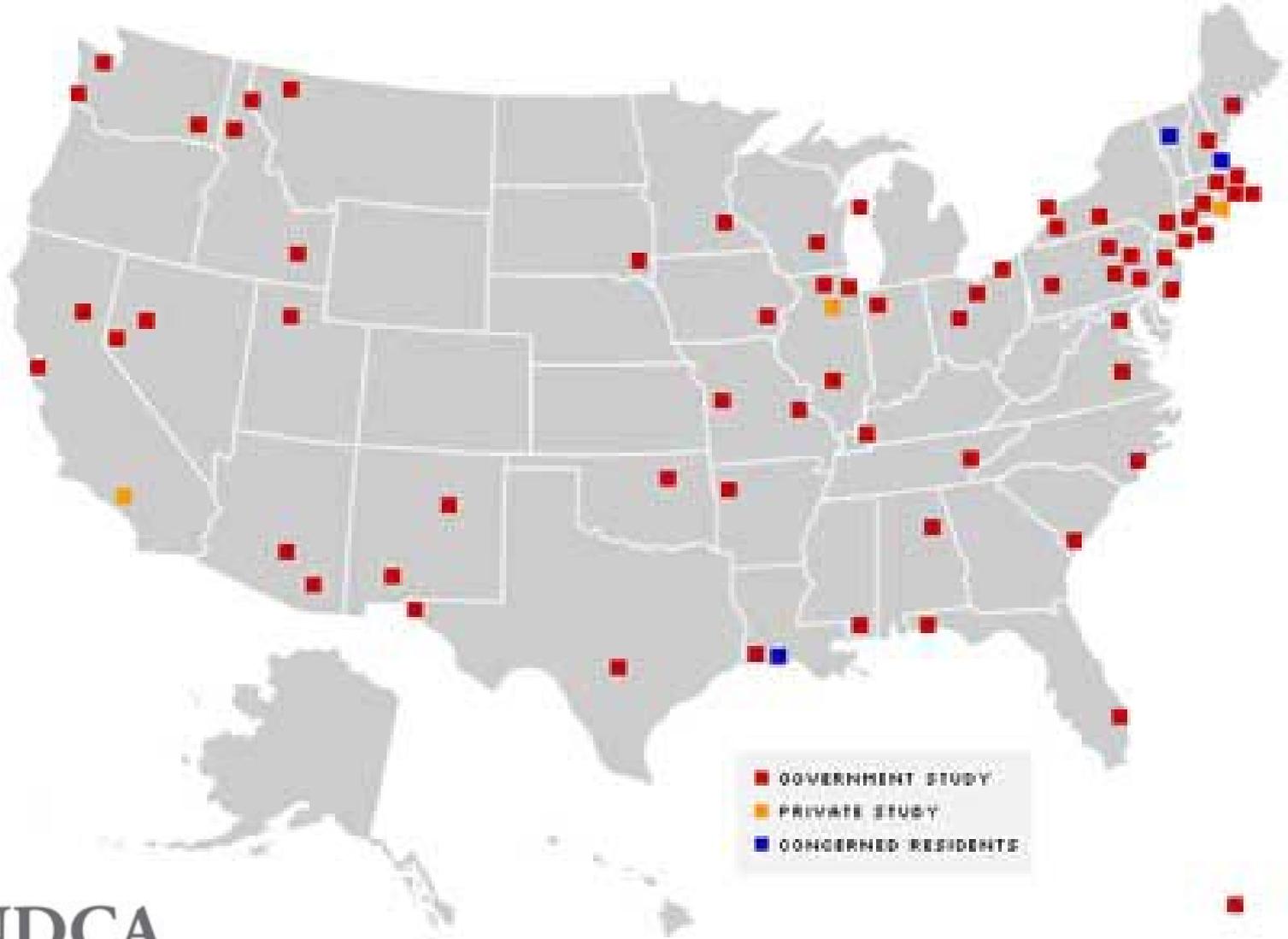


Kids can't fight cancer alone!

Mason



Disease Clusters and Hotspots



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In memory: Julee





Madelyn



Madelyn



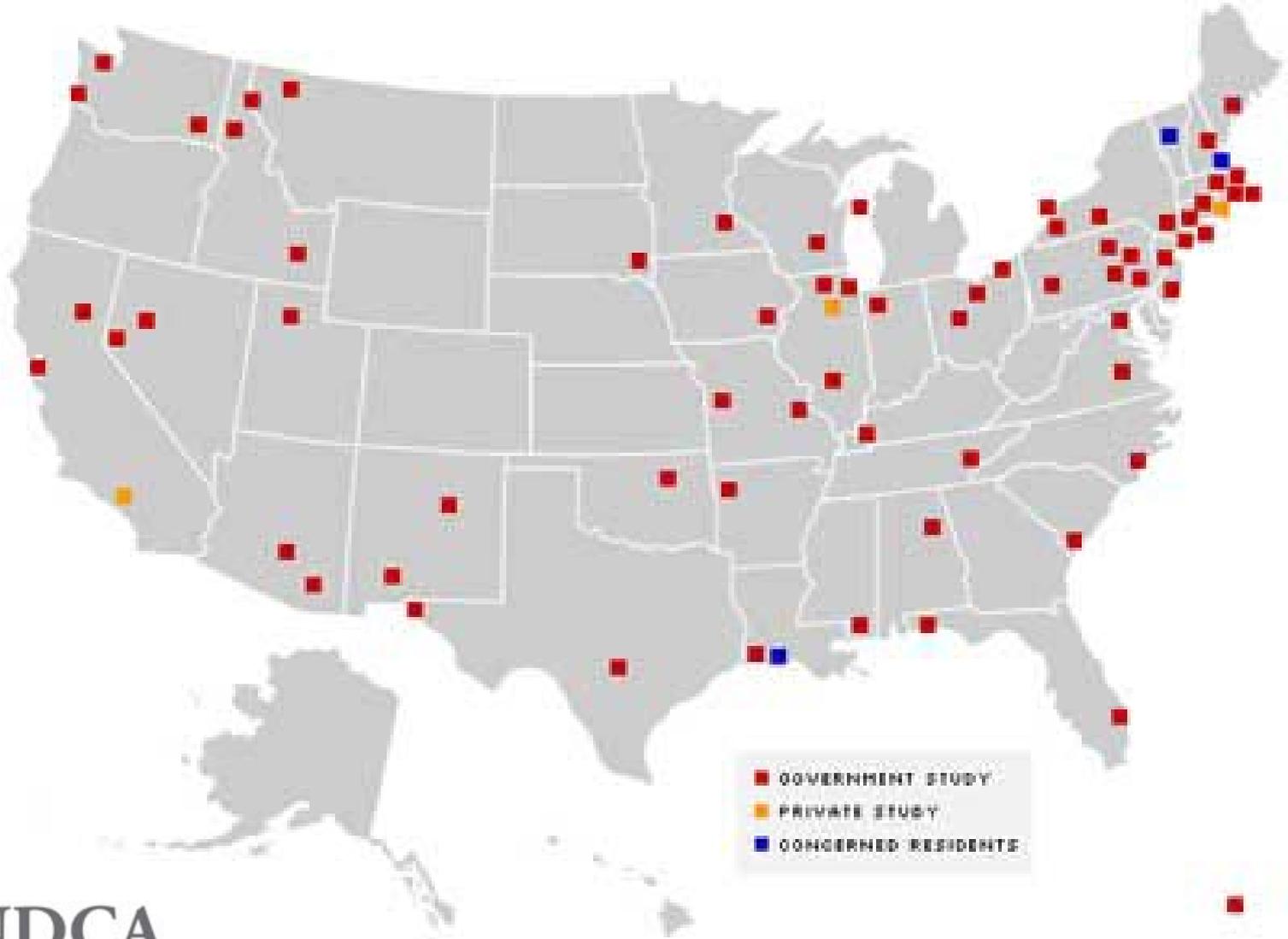
Levi



Joey



Disease Clusters and Hotspots





Linus



Evan wants to be a chemist



Amina, Downs syndrome and leukemia



Disease Clusters and Hotspots



In memory

Adam

Fallon NV

