

Safer Chemicals, Healthy Families Teleconference Talk

My name is Christine Brouwer, and I'm part of this conversation today because my daughter Mira, a beautiful, funny, and smart little girl, was diagnosed with a brain tumor, one week before her second birthday. From the moment my husband and I heard this awful news, we have wanted to know "Why did this happen? What could have caused this?" Today, five years since that initial diagnosis, these questions still haunt us, especially because Mira is no longer with us. Sadly, my daughter is just one of the thousands of children diagnosed with cancer each year, and there are thousands of parents around the country who are struggling with the same question.

Although there are few definitive answers to the question of why children get cancer, I know that many of us have a strong intuitive feeling that something in our environments is causing our kids to get sick. I will most likely never know what caused my daughter's cancer, but researchers are finding more and more links between the hazardous substances in our homes and workplaces and cancer and other diseases.

Mira was 23 months old when she began to complain of headache. A week later, she began to throw up once or twice a day. A week later she began to sit on the couch for longer periods of time. Yet another week later, she was refusing to walk. After 4 weeks of symptoms and tests with no clear answers, her doctor sent her for a CT scan. Five minutes later a technician was saying to us, "the radiologist would like to speak with you." Moments later, we were looking at a CT image on a monitor that the radiologist was explaining showed hydrocephalus (a build up of fluid and pressure on the brain). He said Mira would need surgery immediately to relieve the pressure in her head. The hydrocephalus was caused by a blockage between the brain and the spinal cord. The blockage was a brain tumor.

We were about to embark on a journey that I had never imagined. A parents' worst nightmare is for their child to be diagnosed with a life threatening illness. I was about to watch my 1 year old, and the rest of my family, go through hell.

Mira had 10 hours of surgery the next day during which the surgeon removed only 65% of her tumor. She was on a ventilator in the pediatric ICU for a week when it was determined that she needed a tracheotomy. On January 27, her second birthday, she had two surgeries to insert a trach and a G/J (gastric jejeunal) feeding tube. One week later she had surgeries to implant a Hickman catheter (central IV line) into her chest for chemo administration, and a VP Shunt (tubing) to drain the excess fluid from her brain to her abdomen. You're now only beginning to get the picture.

I am just brushing the surface of her illness. The daily existence of helping Mira to live with her medical disabilities and steering carefully through cancer treatment was incredibly complicated, stressful, and painful. Mira's treatment included 10 more surgeries, 5 cycles of chemotherapy, and 2 types of radiation. After 15 months of

treatment and side effects, Mira had beaten her cancer. The following week she had her trach removed, then also her central IV line. We celebrated every step towards recovery and normalcy. She began pre-K the following Fall and loved school and her friends. On her 4th birthday, January 27, 2008, she woke up complaining of dizziness. She fell down that morning and we guessed that her cancer was back. An MRI the next day confirmed our worst fears—her tumor had returned. The recurrence of an aggressive tumor, after all the treatment she'd been subjected to, did not provide an optimistic picture. She had another successful surgery, and in March began another treatment regimen. A few weeks later, while on vacation in Florida, the treatment made her unexpectedly ill. Mira became very sick, very quickly. We took her to the hospital in Tampa, where she was admitted. She was moved to the PICU two days later, where, her body unable to fight any longer, she died 4 days later.

I share this part of Mira's story because it is not enough to say "My daughter had cancer." It is not enough to say, "She was incredibly ill and it was a horrible experience." You have to get a sense of all she and her family who loved her so dearly, endured. To properly understand why each of us needs to care so much about eradicating the causes of this disease, I believe that you have to envision a child that you love going through this hell. No child should have these challenges and hardships in their life. Our children are not statistics. We need to commit to this issue and act to prevent the harm being needlessly inflicted upon them.

There is growing evidence linking toxic chemicals and carcinogens in our environment with childhood cancer. Over the past twenty years, the rate of childhood cancer has increased. However, there is reluctance on the part of some of our elected representatives to take strong action based on these findings. Many states are now enacting stronger regulations around the disclosure and use of chemicals in household products. Shouldn't we ask businesses to create and sell products that won't harm our children and families? Shouldn't our health be our highest priority?

In my personal quest for an answer, I have run through many possibilities: Was it the new bed we bought at the start of my pregnancy with Mira? Was the wooden frame treated with polybrominated diphenyl ether (PBDE) to make it fire resistant? Did that PBDE make its way into my bloodstream and to my developing baby? Was it dioxins from cleaning chemicals used in our household? Was my minimal use of bleach for laundry and cleaning enough to expose myself and my baby to harmful levels of dioxins? Was it from the fumes of the volatile organic compounds (VOCs) released when we painted in our house? Clearly, part of my dismay is that there are so many possibilities. How can we even begin to decipher what is happening when there are so many possible carcinogens? And then we hear that several children's bath products have ingredients that can combine to create formaldehyde. Could exposures from multiple sources (bedding, clothing, baby bath, paint fumes) be cumulative and add up to cancer?

It seems clear to me that the safe and appropriate response is to begin to reduce the

use of chemicals that are known to be harmful. While it is being determined in more detail what chemicals cause what effects, as a country we should at least take the approach of “first, do no harm.” In Europe, they have recently adopted stronger measures. If companies want to sell certain products, they need to demonstrate they are safe for the intended consumer. The burden of proof lies with the company that stands to make the profit, rather than the government. Why is this not our approach? Why is our country’s priority the freedom to make a profit rather than freedom from disease?

Noted researcher Sandra Steingraber, herself a pediatric cancer survivor, conducted early research into the links between synthetic chemicals and human cancer. She then published a groundbreaking book, *Living Downstream*, in 1997 about the connection between newly available toxics-release data and cancer registry information. My conversations with Sandra, and discussions of her substantial body of work, has reinforced in me the belief that Mira’s brain cancer was caused by some toxic chemical exposure.

One simple fact is that children, especially young children, are the most vulnerable to these exposures. Pound for pound, children eat more, drink more, and breathe more than adults. A bottle-fed infant drinks the equivalent of 7 liters of water per day. If their water is contaminated by chemicals, they will be heavily exposed. Additionally, the organs in the body that remove waste are less developed, leaving contaminants in the body longer. Infants crawl on floors. If carpets contain formaldehyde, toluene, benzene, styrene, and other VOCs, babies and children will touch and inhale them in much larger quantities than adults in the same household. If floors have been cleaned with ammonia, or bleach, they will inhale the fumes and absorb it through their skin.

Children are more exposed to many chemicals during pregnancy and through the high level of chemical contaminants in breast milk. Among the chemicals that are often found in breast milk are several members of the organochlorine class. The list includes: chlordane; DDT; dieldrin, aldrin and endrin; hexachlorobenzene; hexachlorocyclohexane (lindane) heptachlor; mirex; toxaphene; dioxins and furans; PBDEs; and PCBs. Lindane is a chemical used to treat lice. Parents put it on their children’s heads. Do they know that it’s been linked to childhood cancer? It frightens me, and angers me, to know that the “liquid gold” many mothers choose for their children, which, even given this reality, is still their best option for optimal neurological development and immunological benefit, could be the very source of a life-threatening illness. Other substances often found in breast milk include nitro musks and musk xylenes; lead, mercury, cadmium, and other metals; and solvents. Solvents have been linked to childhood brain cancer.

In the summer of 2010, President Obama’s Cancer Panel Report was released, and it talked about the idea that our environment is probably much more to blame for the incidence of cancer than we had previously acknowledged. Interestingly, the American Cancer Society made a statement in response in which they said that Americans needed

to worry less about the environment and make better lifestyle choices for themselves. Clearly, they don't speak for children with cancer. My daughter at age 1, and most children up to age 19 (included in the pediatric cancer category) have made few lifestyle choices for themselves. Instead, they are victims of their and their parent's environment.

Our government can be slow to make changes in policy, not wanting to dampen business freedoms and profits without "proof." I've heard researchers say that they remember the same being said about cigarette production and sales. It took many years for stronger statements to be made about the potential harm of tobacco. And now, tobacco awareness and attempts to prevent lung cancer are a given. But most would admit, it was about 30 years too late. In the past ten years, 7 new pediatric brain tumor histologies (types of cancer cells) have been identified. Why would new types of tumors emerge? Only because of new causes in our environment, such as synthetic chemicals.

What has also become clear to me over these years is that many parents believe that our government regulates harmful chemicals and protects our children and families from known hazards. When they discover that lead has been found in jewelry being sold for children, they're shocked. When they find out that children's mattresses and bedding have potentially carcinogenic chemicals in them, they're dumbfounded. The Toxic Chemicals Control Act needs to be passed, for the sake of our children, and all that love them.

REFERENCES:

More on Sandra Steingraber: <http://steingraber.com/>

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