

Pediatric cancer: One girl's tale  
By Mary E. Hart

Today, Lexi is an 8-year old girl living in Merrimack, NH and happily attending a friend's birthday party. But, just a year ago, Lexi's life was quite different – she was battling a type of bone cancer called Ewing sarcoma, which is found in the pelvis or legs.

In January of 2008, Lexi's mom, Brenda, brought Lexi to her pediatrician to have her swollen right thigh checked out. At first, the pediatrician thought that Lexi might have Lyme disease, but after that was ruled out, an MRI showed a mass on Lexi's right femur, which is the long bone in the thigh.

Lexi's pediatrician referred her to the oncology department at Children's Hospital, where further testing showed that the Ewing sarcoma had spread (metastasized) to Lexi's lungs. Due to the aggressive nature of the cancer, the oncology team led by Holcombe Grier, MD, decided on a three-pronged treatment plan for Lexi of chemotherapy, surgery and radiation.

During the chemotherapy treatments, Lexi stayed with her parents, Brenda and Larry, at the Ronald McDonald House, which offers accommodations for families of pediatric oncology patients. The biggest challenge for Brenda through this was "having to watch Lexi go through each cycle of chemotherapy," says Brenda. "Lexi had fourteen total cycles of chemo, and it was heart-wrenching to watch Lexi be fine, and then go through the chemo; be sick; have her blood levels go down; and then get back to normal, only to have to go through the cycle again. That was the absolute worst part of it for me."

Throughout this tough time, Lexi and her family found comfort and strength in their Christian faith, and received much support from their church and community. They had an appreciation celebration on April 24, 2009 to thank everyone who supported them through Lexi's treatments. Their church helped them with donations, meals and prayers. The family also benefited from an outpouring of help from their community, who all went above and beyond. Lexi's dad works for a real estate office that had bowl-a-thons; a local school had a girls' field hockey team versus the boy's soccer team fundraiser; another school in the area had a Monte Carlo night; and their pediatrician had a Pampered Chef party to raise funds to help out Lexi's family.

"We also had bracelets made up with Lexi's name on them," says Brenda, "and our church and RE/MAX worked together to sell the bracelets. They were great for fund-raising and the bracelets reminded people to pray for Lexi during her treatment. We received so many prayers from people all over the United States – from Florida to Maine and even Alaska."

In May of 2008, a third of the way through chemotherapy treatments, Lexi had surgery to remove the tumor from her femur. The surgeon removed the part of the femur bone that had the mass, and replaced it with an allograft, which is an actual donated bone that is placed between vertebrae to develop fusion. "The surgery was a success and thankfully, the affected part of the femur was a place that didn't affect growth," says Brenda.

After the surgery, Lexi was in a spica cast for three months to make sure the allograft had time to fuse properly. A spica cast is a large cast that starts at the chest, goes down to cover almost the whole leg that needs to be immobilized, and also covers half of the other leg. There are holes in the spica cast at the stomach for breathing and another hole for toileting. Being in the spica cast was difficult for Lexi, but she soldiered through it, showing the same spirit she had throughout. "Even when Lexi was in the spica cast and was constantly in a semi-sitting position for three months," says Brenda, "she would say 'This isn't that bad.' She was amazing through her entire treatment."

The one part that was grating on Lexi was the thought of not being able to go back home after her surgery. "She didn't want to stay at the Ronald McDonald house any longer after her surgery," says Brenda, "because of the stairs and because she just wanted to be home. That meant that we had to commute back and forth from Merrimack into Boston for her appointments and treatments, but that was what was best for Lexi, so we did it, and it meant the world to her." With the help of the spica cast, the bone and the allograft fused together quite nicely.

Brenda can't say enough about how much Children's Hospital helped them. "Annette Werger, the nurse practitioner, was the person we mostly saw at Children's for Lexi's treatments," says Brenda. "When we were going through something difficult, all we had to do was see her face and that calmed us down instantly. The whole team at Children's Hospital was wonderful. They helped us with whatever we needed, and the Jimmy Fund and Children's works so well together."

When asked what advice she has for other parents who have children with cancer, Brenda advises them to "trust in the Lord. Just knowing that he's in control and will work things out is what you need to know. It's out of our hands and in his hands because he's sovereign and in control. That's truly what got us through all of this."

November 7, 2008 was Lexi's last radiation treatment. She still goes to physical therapy for work on her right leg; and gets checked every three months to ensure that the cancer hasn't come back. As Lexi's Make-a-Wish, she and her family will be going to the Atlantis Resort in the Bahamas.

#### SIDEBAR 1 Pediatric Cancer on the Rise

If you've seen "A Civil Action", starring John Travolta, about water contamination in Woburn in the 1980s, or you've heard talk about the Nyanza dye factory in Ashland, and increased levels of arsenic in the water, you know that there have been documented incidents of environmental contamination in Massachusetts. And you've probably also heard about the increasing levels of childhood cancer rates in Massachusetts, which researchers believe are due to environmental (non-genetic) factors. Should you be concerned?

The Massachusetts Cancer Registry (MCR), which is affiliated with the Massachusetts Department of Public Health, studies childhood cancer

rates (among other cancer studies) in Massachusetts over a nine-year time frame. The last published report covers 1990-1999, and the next one will be out in 2010 covering 2000-2009. In the time frame of 1990-1999, there were 2,688 cases of invasive childhood (ages 0-14 years) cancer diagnosed in Massachusetts, at a rate of approximately 270 cases per year. 53% of these cases were diagnosed in childhood males, and 47% were diagnosed in childhood females. There were 16.7 cases diagnosed per 100,000 children, which was slightly higher than the national rate of 16.1 cases per 100,000 children. The three most common cancers indicated in the Childhood Cancer 1990-1999 report were leukemia, central nervous system cancers and lymphomas.

John Jacob, Spokesperson for the Boston Health Commission, stated, "While it's seen from the report that there's a prevalence of cancer, it doesn't tell you what is specifically causing that prevalence. The Massachusetts Department of Public Health is actively involved in tracking cancer rates to see if they're able to determine the causes through epidemiology and disease tracking, including the Massachusetts Cancer Registry."

The Silent Spring Institute in Newton, MA, has found that researchers estimate that 5 to 90% of childhood cancers are due to environmental factors, depending on the specific type of cancer. They have developed a free online tool that can be utilized by researchers, public officials, and concerned parents and community members to map and compile cancer data, including childhood cancer data, for all sections of Massachusetts. This tool is called MassHEIS, which stands for the Massachusetts Health and Environment Information System. Through MassHEIS, it was determined that from 1993 to 2002, the top Massachusetts towns for high cancer rates in this area include Acton, Amesbury, Arlington, Everett, Melrose, Weston, Wilmington, Winthrop and Woburn.

Even though it wasn't included on the MassHEIS graph, Ashland is known as a site for increased cancer rates due to the Nyanza dye factory, which dumped toxic waste into the waters in the 1960s and 1970s. This toxic waste caused high levels of arsenic in the water, which was proven by a study in 2006 to have caused increased cancer rates.

Methuen has also been the study of a childhood cancer health consultation by the Massachusetts Department of Public Health and the U.S. Department of Health and Human Services in July of 2008. There were two adjacent sites (4 Gleason Street and 254 Broadway), which were thought to be contaminated by releases of oil and hazardous waste in 1991, 2004 and 2005; and one site (54 Osgood Street), which was thought to be contaminated by a fire in 1994. Childhood cancer rates were studied in these areas and others in Methuen from 1982 to 2008 and the cancer rates were average for the city and state overall. The possibly contaminated soil, sediment and surface water at all three sites were removed and the sites were remediated in 2005 and 2006, so any increase in cancer rates from these contaminations are unlikely, according to the study.

It is believed that children are more likely to be exposed to any environmental contaminants in their area because they play outdoors

quite often, and are closer to the ground to breathe in any contaminated dust, soil and vapors. Even if adults are exposed to these same contaminants in the same amount of time, children, by virtue of being smaller than adults, receive higher doses of those contaminants per their body weight.

#### SIDEBAR 2 – How to Stay Healthy

So, what can you do to help prevent childhood cancer in your children if you live in an area that has an increased rate? Your most important defense for your children is for them to have overall healthy lifestyles, lots of physical activity and to maintain healthy weights, says Dee Sandquist, MS, RD, American Dietetic Association Spokesperson. “It’s all about the total diet and how everything in your diet works in synergy together,” says Sandquist. “As part of a total balanced diet, all of the nutrients interact together, because no one food contains everything you need.”

Some of the top cancer-preventing foods that Sandquist recommends include berries and fruits, which contain cancer-fighting antioxidants; beans and legumes; whole grains; leafy greens; and 100% fruit juice, like grape, pomegranate and orange. However, Sandquist advises that you eat fruit over juice. “When you choose fruit over juice,” says Sandquist, “you get the added benefit of fiber, which is good for preventing colon cancer, whatever your age. Vegetables and fruit also have a complex composition of vitamins, minerals, fiber and phytonutrients, which appear to protect against various cancers. And, they’re low in fat.”

For further nutritional information for a healthy lifestyle, check out the American Dietetic Association ([www.eatright.org](http://www.eatright.org)) and the MyPyramid ([www.mypyramid.gov](http://www.mypyramid.gov)), which replaced the standard Food Pyramid back in 1992. The American Dietetic Association states

#### SIDEBAR 3:

##### Where to Stay during Your Child’s Treatments

If your child is receiving cancer treatments, that’s going to be a top (if not the top) focus of your life. What if your child requires several days of hospitalization for treatments, and you live far enough away from Boston to not make it feasible to go in and out of Boston every day nor stay at a hotel each night financially? Here are the places that Children’s Hospital Boston recommends for family accommodations:

- Devon Nicole House: Provides accommodations for up to 13 Children’s Hospital families at \$50.00 for first night and \$25.00 each additional night. [www.childrenshospital.org/dnh](http://www.childrenshospital.org/dnh)
- The Family Inn: Provides accommodations for up to 10 families of transplant patients at \$20.00 for a single person and \$5.00 for each additional person weekly. [www.thefamilyinn.org](http://www.thefamilyinn.org)
- Hospitality Homes: Accommodation in host homes throughout Boston at no charge. [www.hosp.org](http://www.hosp.org)
- The Boston Ronald McDonald House: Accommodations for families of

pediatric oncology patients at \$10.00 per night or \$200.00 per month.  
<http://www.ronaldmcdonaldhouseboston.org/index.htm>