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Sarah Heyne

Grace Heyne, Sarah's mother: In early 2007, Sarah began saying that her neck hurt and she didn't feel well. She was nine years old and in the middle of fourth grade. I noticed she had swelling or bumps on the side of her neck and thought maybe it was an infection. Her pediatrician did some blood work and Sarah tested positive for mononucleosis. We figured that was the cause of the swollen glands and they would go away. But they didn't. The doctor had us put heat on the glands and massage them, but nothing helped and Sarah's neck continued to hurt. Because she wasn't getting better, her pediatrician suggested we see an ear, nose, and throat (ENT) specialist.

The ENT doctor said there was fluid in her ears and that her throat looked infected. He recommended putting a tube in her right ear to help it drain and said while he was doing the procedure, he'd examine the area to see if anything else was going on.

That was Friday, May 4, 2007. When Sarah was in the operating room, the doctor called down to the waiting room and said, "I'm taking a piece of the tissue I see in there. I don't want to ruin your weekend, but I don't like what I see." I wasn't thinking cancer, but I thought, "He doesn't like what he sees? What could he be seeing?" He told me that they'd send it to the lab and get back to me on Monday.

When Monday came, I really wasn't worried. But I decided to come home from work for lunch, which is something I never do. There was a phone message from the ENT saying, "Got the results of the pathology report. Call me back." When I called, he got right on the phone and said, "Would you like to come into my office, or do you want me to tell you over the phone?" And that's when I knew something was really wrong. I said, "No, you need to tell me now because I'll never make it to your office." He said, "Sarah has cancer."

The next thing he said was, "Call your pediatrician because she has already contacted Memorial Sloan Kettering. She's waiting for your call." On Friday, when he did the biopsy, although he didn't tell me, he suspected it was cancer and alerted the pediatrician. The pediatrician contacted [Dr. Leonard Wexler](#) at Sloan Kettering over the weekend. Dr. Wexler was willing to see Sarah on Sunday, but the pediatrician opted not to tell us until Monday, in case the lab results showed something different. I brought Sarah over to her office right away. She called Sloan Kettering and we made an appointment to see Dr. Wexler on Wednesday.

Leonard Wexler, MD — Sarah's Pediatric Medical Oncologist: Our philosophy is, if you've got a child with cancer, you shouldn't have to wait a week or two weeks for an appointment. We try to schedule all new visits on an urgent basis; a couple of days or less is standard operating procedure around here.

I wanted to be a doctor before I got sick, and I still want to be a doctor, a doctor for kids.

Sarah Heyne

I think Sarah's workup here (the process of confirming her diagnosis) really highlights what's offered at our cancer center. A CT scan showed that there were lymph nodes in her neck that were quite large, and there was a large mass at the back of her throat (her nasopharynx). It was possible that it was a [rhabdomyosarcoma](#), a tumor we sometimes see in this part of the body in a child of Sarah's age. Here at Sloan Kettering, if there's a question about the precise diagnosis, we often perform special genetic diagnostic testing on the cancer cells to be absolutely sure we know what it is. With this and other tests, we found that Sarah actually had nasopharyngeal carcinoma. These are very sophisticated tests which are not routinely available in other hospitals.

In the world of pediatric oncology we deal with conditions that are very rare to start with. But nasopharyngeal carcinoma in a little girl Sarah's age is extremely uncommon. The good news is that the doctors at Memorial Sloan Kettering have a pretty good idea about how to treat them.

Telling Sarah She Had Cancer

Grace: Now as it happened, this was the week before my second marriage. We received Sarah's diagnosis on Monday, we now had an

appointment with Dr. Wexler on Wednesday, and the wedding was set for Saturday. I didn't know what to do. Sarah was going to be a flower girl. I spoke to her pediatrician, and she said, "Go through with the wedding." They didn't want her to feel bad later on, that because of her diagnosis, the wedding didn't happen. But I didn't want Sarah or her older sister Kelsey to know about the cancer before the wedding. They were both so happy and excited about it. I faxed a note to Dr. Wexler asking him not to tell Sarah that she had cancer when he met with us for the first time on Wednesday. Not yet.

When we met Dr. Wexler on Wednesday, he privately told Sarah's father and me that he doesn't like to withhold information from his patients, but in this case he understood our request. He made it clear, though, that he would talk to her about it at her next appointment the following Monday. So, we had the wedding as planned on Saturday. Sarah threw her rose petals and had a great time. And on Monday, we went to Sloan- Kettering to get Sarah ready to start treatment.

Sarah Heyne, Age 11: That was the day I found out I had cancer. I knew what cancer was because a friend of my mom's had just died from it. When Dr. Wexler said I had it, I got scared.

Grace: Dr. Wexler explained to her that she had nasopharyngeal carcinoma and that it's a form of cancer. She said, "I have CANCER? What a rip-off!"

Sarah: I asked Dr. Wexler if I was going to lose my hair. The first time we went to Sloan Kettering, I wondered why there were kids there with no hair and why some of them were hooked up to pumps [IVs]. My mom said the pumps gave the kids medicine and the medicine made them lose their hair.

Dr. Wexler said yes, I would lose my hair, but that it doesn't hurt; you don't even feel it. A lot of times it falls off while you're in the shower or when you're sleeping.

Coping with Chemotherapy

Grace: Sarah started the chemo on May 16th. They told me that her hair would start falling out in two or three weeks. At that time her hair was past her shoulders. They recommended I cut it so it wouldn't be as much of a shock when it fell out. Sarah said, "How are my friends going to look at me when I have no hair?" I said, "Well, let's get them used to it." So I had a "haircutting party" for her over Memorial Day weekend. Sarah had four or five of her friends over, and I put her hair in a ponytail and cut it so they would get used to her with short hair.

Sarah: But then a couple of days later when I woke up, there were little hairs all over the pillow and I thought, "Here we go." I got very upset.

Grace: Sarah got chemotherapy on a three-week cycle. She got two different chemo drugs, cisplatin and 5-fluorouracil (5-FU) for a week, and then she had two weeks off. During her chemo week, she got a continuous infusion of the drugs from a portable pump that she was able to take home. But it was that second week when she felt the worst.

Sarah: It was not fun. I threw up a lot, especially on the first round. And while I was having chemo, my taste buds didn't work. Everything I ate tasted like metal, and it was gross. I didn't want to eat, and my throat was very sore. I started to lose weight, and I took a lot of naps because I was very tired.

But after two rounds of chemo, I took scans again and Dr. Wexler told me the cancer had gone down 85 to 90 percent! So we said, "Wow, we did this chemo for a reason." It made me really happy!

Dr. Wexler: Sarah had a very dramatic and very prompt response to her chemotherapy. And, unfortunately, she began experiencing the common side effects of the chemo as well.

There's a pretty standard chemotherapy regimen that we use for children with nasopharyngeal carcinoma, even in advanced cases. There are two chemo drugs, which we generally try to give six times. One of them we don't give concurrently with radiation therapy, the other we do. The challenge of using these drugs is their immediate and longer-term complications. We needed to manage Sarah's side effects in the short term and then monitor her to make sure that she didn't develop the potential long-term effects on hearing and kidney function. Thankfully she's been fine, so far.

Grace: She really had a great response to the chemo. So much so that I asked Dr. Wexler if we still needed to do the radiation.

Sarah: And he said yes, because the chemo is very fast, and it can get a lot of big things, but it can't really get the little cancer things. So that's why there's radiation, so they can zap it. It's just like getting an x-ray. It didn't hurt at all and the treatments only took ten or 15 minutes.

Dr. Wexler: By the time she got to the radiation therapy, her tumors had essentially disappeared. But we know that with using just chemotherapy,

Dr. Wexler: By the time she got to the radiation therapy, her tumors had essentially disappeared. But we knew that with using just chemotherapy, without radiation, they would likely recur. By this point, her prognosis was superb.

Radiation Therapy

Grace: Dr. Suzanne Wolden was Sarah's radiation oncologist. She specializes in nasopharyngeal cancer, which is pretty rare. Sarah had 34 rounds of radiation, every day, Monday through Friday. We drove into Manhattan from Long Island every day for seven weeks. Sometimes we would stay over at the Ronald McDonald House a few blocks away from the hospital. But for the most part, we went in, got the radiation, and came back home.

Suzanne Wolden, MD — Sarah's Pediatric Radiation Oncologist: Based on Sarah's great response to the chemotherapy, we were able to lower the amount of radiation she got. She received image-guided radiation therapy (IMRT) with "dose painting," a technique that few hospitals can offer. IMRT allows us to precisely shape the radiation beams to the size and shape of the tumor, delivering highly effective doses of radiation to tumors while minimizing damage to surrounding healthy tissues. Dose painting takes this precision even further. Using sophisticated imaging techniques, we identify areas *within* the tumor that might need a higher "boost" dose of radiation, based on the presence of cells that are resistant to radiation therapy or are especially aggressive.

There are other hospitals that can offer dose painting, but none has the experience using it with children that we do. Pediatric radiation oncologists are pretty rare. I personally treat more children with radiation therapy than any other physician in the country. That experience is critical because radiation therapy in children can cause significant long-term side effects. The growth and development of normal bones and tissue can be disrupted by radiation, which can lead to appearance issues, functional problems (such as swallowing and hearing), and neurological issues within the brain.

Because of our experience and ability to treat Sarah so precisely, she's had no lasting side effects from her treatment. Her salivary glands are fine, as are her hearing and swallowing functions. Because her throat was very sore during her treatments, she wasn't eating and she started to lose weight. We managed this with a temporary feeding tube that was put into her stomach so that she got the nutrition and hydration she needed. This is fairly standard with head and neck cancer patients. Sarah was very matter-of-fact about it. She basically said, "Do what you have to do."

Finishing Treatment

Grace: In September, Sarah really wanted to go to school on the first day to see her teacher and see who was in her class. She was supposed to start her last round of chemo that week but we asked Dr. Wexler and the team if we could postpone it until the following week.

Sarah: And also my birthday was the same week. September 9th.

Grace: So she went in on the first day of school, she met her teacher, met the class, and we had a birthday party. And then on Monday, it was back to Sloan Kettering for the last round of chemo.

Sarah: When I had that last round of chemo, I got a high fever. I had to stay in the hospital for a week. And then I got pneumonia, which was probably because I wasn't walking around as much as I should have, even though my mom told me to. I wouldn't get up, I wouldn't even sit up. So I got pneumonia in my right lung, and I had to stay in the hospital for another two weeks.

One day when I was in the hospital, my mom told me I had mail. It was from my class. I opened every card, and I got very happy. One of my cards was from a girl who I didn't really know and she said, "If you want to be friends with me, sit with me at lunch." That was really nice.

Grace: When she finally got out of the hospital, it was October 3rd. The next day was school pictures, and she really wanted to be in the class photo.

Sarah: I wore pink, a pink bandana on my head, everything pink except my shoes.

A few weeks later we went back to Sloan Kettering to see Dr. Wolden, who said the radiation was a wonderful success!

Grace: Those were her words: "a wonderful success."

Sarah: And then on November 4th we went to see Dr. Wexler, and he told us that the cancer was all gone. And I was like, "Yeah!"

A couple of weeks after my last round of chemo I finally tasted something, and it didn't burn my throat. It was homemade chicken noodle soup. It still tasted a little weird, but I was like, "Whoa, my taste buds are coming back!"

Lessons to Share

Grace: Through our experience at Sloan Kettering, we met a lot of different people. There was one little girl in particular Sarah became friends with.

Sarah: Her name is Alyssa and she's my age. She started chemo a couple weeks after I did. One time when we went to Sloan Kettering, she was there as an inpatient so we went to visit her. I said to Alyssa, "Have you been fighting your mom to get up?" She was in her bed, covered in covers. I said, "Okay, but don't really do that, because that's what I did, and I got pneumonia. And that kept me in the hospital for another two weeks. So even if you just sit up, it will help." I also told her that she had to eat something, doesn't really matter what, and that will help too. I think she was happy that we visited her and I think I helped her. I feel very proud of myself that I did that.

I remember one day during treatment when I got really mad. I kept saying, "Why me? I'm only nine. I'm not even double digits yet!" My mom and I talked about it for a long time, and we came up with a bunch of reasons. Maybe God knew I was strong and I could get through it, so I could write a book to help other kids with cancer (which I am doing). Or maybe I needed to go through this experience because I want to be a doctor. Maybe it will make me a better doctor because I know what it's like to be a patient.

Grace: Other parents of children just diagnosed with cancer may be reading this, and I know how they feel, to get that phone call. Your whole world suddenly stops and you think, "Oh My God, Oh My God." After I got through that I let the doctors help me along. I trusted that they were the experts. Yes, I had a million questions, and the whole team at Sloan Kettering was very open to our questions. But I let them guide me. I remember the first two weeks — I walked around Sloan Kettering like a zombie. I couldn't understand why other parents weren't looking so upset. I know now that after the early shock wears off, you get into a routine, your mind settles, and you begin to believe everything is going to be okay.

Sarah: I wanted to be a doctor before I got sick, and I still want to be a doctor, a doctor for kids. I want to go to the best college. I think about it every time I walk past the medical school across the street from Sloan Kettering.

Grace: Every time we pass Weill Cornell Medical College on the way to Sloan Kettering, she says, "Is that going to be where I go to school?" And I say, "Could be."

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