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Barbara Barnes

Barbara's Story

The burning went away, but then about a month later I had a severe pain in my right side. I went to the emergency room, and the doctors said it was gas and sent me home. About two weeks later, I went to a different hospital with this same pain, and they told me the same thing. They didn't do any scans or any tests. I said, "It's not gas. I know what gas feels like." So then they told me that it was a muscle strain.

Finally, in November, I went to my neighborhood internist and told him about the pain in my side. He did a blood test, which showed that something was wrong with my liver. Then he sent me for a sonogram of my liver, which also indicated a problem.

By this time it was January of 2001. He admitted me to a hospital in Brooklyn for more exams. They did a whole battery of tests, a liver biopsy, and CT scans, and then he told me it was lymphoma.

Choosing a Hospital

My internist wanted me to be treated at the hospital where he was on staff. But a friend of mine said, "You need to get to Sloan Kettering." I didn't know what to do to get an appointment, so I went to mskcc.org and got the information about who to call. I didn't have any information about my condition like what stage my disease was, or any details. They suggested that I just fax them my test results and reports, and they would figure out who I should see. They called back and suggested I see Dr. Ariela Noy.

Ariela Noy, MD — Barbara's Medical Oncologist: When Barbara came to see me in early 2001, she had already been diagnosed with diffuse large B cell lymphoma. This is a pretty aggressive but very common type of lymphoma.

Lymphoma is not one disease; it's actually about 50 different diseases. They're broken up into large categories of more aggressive but curable diseases, and the less aggressive but chronic diseases. What Barbara had — diffuse large B cell lymphoma — is the most common type of aggressive, curable lymphoma. There are about 30,000 to 40,000 cases reported each year of this kind of lymphoma.

Barbara: My first appointment with Dr. Noy was on Valentine's Day 2001. When I met her, I began to feel much less afraid. She was very nice and very frank. She said there was no magic pill and that I needed chemotherapy. She explained the process. I appreciated her directness, her honesty, because I'm the kind of person who needs to know exactly what's going to happen.

Dr. Noy was very reassuring. She didn't make any promises about curing me. But she was really upbeat and said, "We're going to try this, and if it doesn't work, we'll try something else. And we'll keep going until we get the right cocktail. We'll get it right." She made me feel like she would do whatever she had to in order to make me well.

Dr. Noy: I reviewed the CT scan Barbara had when she was first diagnosed, and it showed a lot of cancer in her body. It was in the lymph nodes near her heart, in her liver and her spleen. At her first appointment with me, three weeks after her initial diagnosis, she had another scan that showed that the cancer had already spread to her lungs. Amazingly, despite the fact that she had so much cancer, she looked so healthy and beautiful. She didn't even feel that bad, just a vague aching pain in her right upper abdomen.

One of the advantages to being treated at Sloan Kettering is the expert input that goes into planning each patient's treatment. I am part of the Lymphoma Disease Management Team, which is made up of medical and radiation oncologists, pathologists, radiologists, and other specialists. We work closely together to care for more than 1,000 new lymphoma patients and many more ongoing patients each year. Every treatment plan developed for a new patient is presented to the team for review. That's something that's unique to a cancer center. Patients don't just get a plan based on the opinion of one doctor, they get a plan that reflects the opinions of every member of our disease management team.

Treatment

Barbara: I started chemo two weeks after my first visit with Dr. Noy. It was February 28, 2001.

I had no idea what it would be like to get chemo. I thought I would be in a hospital bed. But no, I sat in a chair and they put an IV in my arm. When the medicine went in, I didn't feel it at all. They gave me two types. One was a four-hour drip, and then the other one was really quick. I thought, "Okay. I'm fine. I can do this."

I went home on the subway, and I was tired but fine. That was a Wednesday. On Thursday, I felt so well I went to Atlantic City, but Friday was a really bad day. That's when it actually kicked in. I was nauseous, and really weak and tired. By Saturday, I felt a little better and I kept feeling better, but then I had to gear myself up for the next round of chemo.

I remember being on my knees praying, "God, I will fight as hard as I can if you just let me get through this chemo stuff." When I went in, Dr. Noy said, "I have something that's going to help. I'm going to give you Procrit after you get your chemo." Once I got the Procrit, I never felt again like I

said, "I have something that's going to help. I'm going to give you a haircut after you get your chemo. Once I got the haircut, I never felt again like I had after that first chemo treatment. I got tired and I didn't feel 100 percent, but I was really okay."

Dr. Noy told me I would lose my hair. I couldn't imagine it. I didn't lose it until the third round of chemo. It was about the sixth week when it started to fall out. Two days later I just shaved the rest of it off. Two days after that I decided I wasn't going to be a hermit and stay in the house ... so I got a wig.

My cancer became very real to me once I lost my hair. But by then the mystery, the uncertainty, was sort of gone. Not gone, but it just wasn't at the forefront. There were things that I started looking forward to doing, like going out and not just staying in the house. By then, the weather had started getting really nice, and I decided I needed to get out. I would go for a long walk or take the subway into the city and look in the store windows. It's funny, people I didn't know would chat with me on the bus, on the train. We would talk about anything. That made me feel a lot better.

I didn't share what was going on with many people, just my immediate family and closest friends. When people called me on the phone, I'd just tell them I was really busy. I didn't want people to know I had cancer because I just didn't want the pity, the sad faces, the stories about their aunts who didn't make it. I went to church every Sunday, which helped me feel a lot better. I didn't even tell my friends at church. They just thought I was doing something really funky with the wig. But every night I went home, took the wig off, took the scarves off, and looked in the mirror, and there was no denying it. It was there. It was real.

I received chemotherapy from late February until early May — six rounds. After the last chemo, I had a CAT scan and a PET scan. When Dr. Noy told me my PET scan was negative, she was genuinely happy. She said to me, "You are like my poster child for lymphoma. I cannot believe how well you did, considering how much cancer you had in your system."

After I finished my treatment, I went back to Dr. Noy every few months for a CAT scan. I never really celebrated finishing chemo because I was always so nervous that the cancer would come back. But soon I only had to go every three months, then every six months, and then once a year.

Six weeks to the day after my last chemo treatment, my hair started growing back. I was very, very blessed and lucky with my treatment. It was only three months, and I wasn't even that sick, aside from the first day. It wasn't what I feared it would be. It was three months out of my life, which is a small thing, in retrospect.

Dr. Noy: The doctor who initially diagnosed Barbara recommended that she have the standard treatment at that time, which was CHOP chemotherapy. C-H-O-P is an acronym for the drugs that we use. C is for cyclophosphamide, H is doxorubicin (the chemical name is hydroxydaunorubicin), O is vincristine which was originally marketed as Oncovin, and P is prednisone.

However, Barbara's lymphoma was very advanced. At that time (2001), CHOP chemotherapy only had about a 40 percent cure rate for someone in Barbara's situation. So after we confirmed the diagnosis, we talked about different treatment options.

There was a new drug available called rituximab. When I first saw Barbara, I had recently returned from an international medical conference where we saw preliminary data from a new study. The data showed that rituximab improved outcomes in patients with large cell lymphoma. We decided to add rituximab to her CHOP chemotherapy and gave her a higher dose of cyclophosphamide, based on new data that pointed to improved effectiveness. We also decided to give Barbara treatment every 14 days instead of every 21 days, the traditional way of giving the chemotherapy. One of the great things about being at Sloan Kettering is that we are constantly on that leading edge. Whatever's out there and new, we know about it.

[Dr. Noy] made me feel like she would do whatever she had to in order to make me well.

Barbara Barnes

Barbara had six treatments over 12 weeks. She did beautifully. She didn't have a single major complication. She was never hospitalized, never had a fever. Best of all, she's been fine ever since. It's very, very rare for patients like Barbara to relapse so many years after her treatment is over. Her risk of getting this cancer again is just about the same as somebody who never had it before.

Today, rituximab has revolutionized lymphoma treatment. The outcomes are so much better, both in the short term and long term. Depending on the type of lymphoma, it can be given alone or with combination chemotherapy. Because of rituximab, most of the people diagnosed with diffuse large B-cell lymphoma today are cured.

Lessons to Share

Barbara: Last year, I was on 34th Street in Manhattan, and I passed a young woman with a bald head who was absolutely beautiful. I stopped her in front of a store and told her so. She said, "Well, I don't feel beautiful. I have breast cancer."

At first, I could feel myself feeling sorry for her. But then I realized that's not what she needed. So I said, "Okay, so what are they doing? What type of treatment are you taking?" She was a little stunned, but told me she was on chemotherapy. So I asked her, "So how do you feel? Are you sick? Are you nauseous?" She just looked at me. I said, "I've been through it. I understand." That was the first time I actually shared it with somebody other than family.

I said, "Look at me, this was years ago, six or seven years ago. I'm okay."

She started crying and said, "I came out today for the first time without a wig. I felt like everybody was laughing and staring at me."

I said, "No, they're probably staring because you're so beautiful."

She was only about 30 years old. Then she said, "I don't know that I'm going to be all right."

I told her, "Try not to think like that. Try to believe you're going to be okay."

She showed me her driver's license picture. "I had long, beautiful hair, and now it's gone."

"But it will grow back," I said. "It's fine. Let it go. Let the hair go." I told her, "Go buy some beautiful scarves and some earrings, and you'll be fine." I didn't know how advanced her cancer was, and she didn't want to talk about it, but I told her, "I have been through chemotherapy. Your hair grows back. You live life."

She said, "You must be my angel."

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