Jonnie

By Frankie Liang

(Autobiographical Narrative)

Do you know someone who lives with daily pain, gets chemotherapy, and has lost all his or her hair from treatment? I know a brave little girl named Jonnie. She is my 10 year old sister, Jonnie.

My sister Jonnie was seven when we went to Lake Tahoe, Nevada for some fun in the snow in March of 2005. Along with the whole family and cousins, we caravanned to an area near NorthStar Ski Resort. We all shared a big house with a nice backyard. We built a snowman and went sledding. At NorthStar, my little sister Jonnie went down the slopes like a professional downhill skier. She had the time of her life.

When we arrived home, Jonnie started to feel ill. She had both joint pains and low-grade fevers. The fevers went away after taking Tylenol and they returned in the evenings. My parents thought that the pains came from skiing. We all experienced soreness from skiing. After about four weeks of low-grade fevers and joint pains, my parents finally took her to the hospital.

My mom took Jonnie to Emergency where they determined she needed to be admitted to the hospital. Her pediatrician, Dr. Evans ordered a series of blood tests that determined she had Lupus. Her symptoms met the classic definition of Systemic Lupus Erythematosus.

What is Lupus? For those who do not know, Lupus is an autoimmune disease that can affect skin, joints, blood, and major organs. The body's immune system cannot tell the difference between foreign substances and its own cells and tissues. The immune system then makes antibodies directed against it or in other words attacks itself, causing inflammation, pain and damage to various parts of the body, as well as major organs.

My mom stayed with Jonnie while she was in the hospital. Jonnies' doctors proceeded to treat her with Prednisone (steroids) and anti-malarial medicines. Steroids and anti-malarials (used to treat malaria in the old days) help with reducing inflammation in her system by knocking down the immune system. Jonnies' Lupus stayed active and she continued to experience unbearable joint pains, Mylar rash (wolf-like rash in the face cheeks and nose), and inside mouth sores.

In 2006, we went to Hawaii. We went snorkeling, swimming and sightseeing. However, something was wrong with Jonnie. She complained that she couldn't breathe. She started to have low-grade fevers about halfway into our trip, and by the time we left, her fever crawled to 104. As soon as we got back from the airport, my mom took her to emergency. They ran a series of blood tests, which determined that her Lupus was highly active. This time, it had attacked the area around her heart and lungs. They brought her into surgery to drain the fluid around her heart and lungs. The procedure is called a Pericardial Effusion, which requires sticking a needle in her chest and like a straw to drain the fluids. Well, it was no wonder she had such a hard time breathing. They took out 450 milliliters of fluid from the area. She was trying to snorkel in Hawaii with all that fluid. They kept Jonnie in the hospital for another week to give her high doses of steroids (Solumedrol--a more powerful Prednisone) and monitor Lupus activity,

as well as any infections.

You see, as they give her all this medication to take down her immune system, which calms the Lupus down, she is now more prone to infection and other diseases. They monitored her heart, lung, kidney, breathing and brain functions to make sure the Lupus has not started or damaged these organs. Jonnie has a doctor for each of her major organs. Each of her doctors is at the top of their field. Her case is so rare that she has been referred to University of California San Francisco, Pediatric Rheumatology.

Not more than three weeks after her surgery, her immune system continued to attack the heart and lung area again as if there was something there to attack. Doctors performed a second surgery on Jonnie to drain another 300 milliliters of fluid. In total, that is about half of a two litter plastic bottle of soda. By this time, she had been in the hospital for two months. After this surgery, her team of doctors decided that chemotherapy is what Jonnie will need to have. Cancer patients receive this same chemo drug. They gave her high doses of chemotherapy (Cytoxan) and since then, her Lupus has stopped attacking her major organs.

She has been on chemotherapy for almost 3 years now. She gets treatment once a month. She has experienced loosing all her hair, and having to go to school with a wig or just a hat. At school, Jonnie was picked on for having fat cheeks from the Prednisone and for wearing hats and wigs. She felt bad, but she learned to handle her classmates until they understood and stopped picking on her.

She sees many specialists at Kaiser and UCSF, but her main doctors are, Dr. Kim, Dr. Orloff and Dr. Evans. They have helped Jonnie so much.

Jonnie still has pains once in a while, but not like before. Sometimes, various new forms of Lupus appear, like when we returned from the Virgin Islands. In August 2007, she experienced a new symptom of Lupus called Raynaud's Phenomenon. This is when nerve endings in the fingers and toes constrict to an unbearable pain. Jonnie says it feels like small knives slicing her fingers and toes. Several times, she had to go to the hospital so that they can give her morphine just to stop the pain. The Raynaud's stopped when they experimented with the right medicine and found that a blood pressure medication works with her. Her fingers and toes still turn a blueberry color when she is cold, but she no longer has the pain.

Jonnie's Lupus made me realize how important family is and puts things into perspective. Through this experience, my family has become so much closer and stronger than before. It hurts to see Jonnie in pain and that I don't have any power to stop the disease. I can only pray to God to make her better, help her as much as I can and be there for her. Jonnie is so strong and such a trooper. She remains positive, happy, funny and is source of strength for everyone who knows her. Her doctors and nurses just love her. Just recently, the *Make A Wish Foundation* approved her wish to swim with the dolphins and sent us all to Hawaii. It was the best vacation we ever had. Jonnie finally enjoyed a family vacation and wasn't in any pain.

Jonnie aged 7 before she was diagnosed with Lupus (SLE) in July 2005.

She is active, happy and mischievous.

Here, swimming for USA Swimming, Vallejo Aquatics. She received many ribbons and maintained an “A Time”.

The Northstar ski trip (March 2005) with the family and first cousins. Doctors believe it was this ski trip that triggered a sleeping Lupus.

Lupus can be triggered by exposure to the sun and ultra violet rays. Jonnie skied with very little sunscreen protection. We skied from early morning to late at night

One of the many Lupus flare-ups requiring her to go to the hospital for weeks and sometimes months.

Here with sisters, Frankie and Ricki.

Total body pain, unable to walk, swollen face, inside mouth sores, bleeding finger tips.

Only strong doses of steroids and chemotherapy have been able to manage Lupus symptoms.

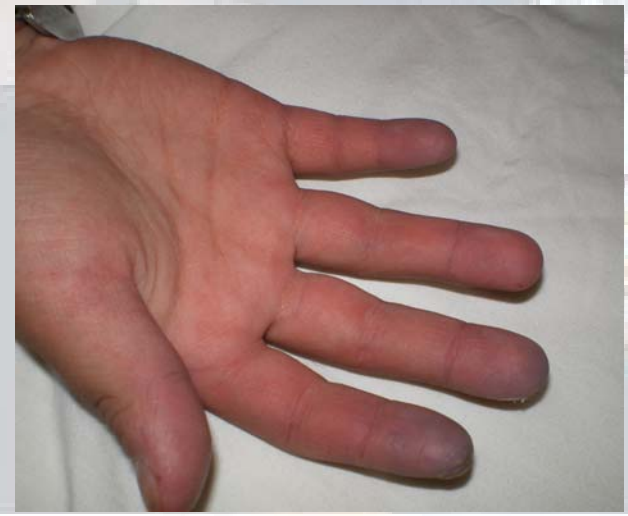
At Kaiser Oakland Pediatric Intensive Care Unit. Jonnie receiving chemotherapy (Cytoxan) through IV, the same drug given to cancer patients.

And there's her Chihuahua, Suerte. He is a healer. He knows her pain and tries to take it away from her. A close-up will reveal his worry lines.

A manifestation of Lupus called Raynaud's Phenomenon.

Jonnie's fingers and toes turn a blueberry color and is very painful. Jonnie describes it like little knives slicing her fingers.

She received doses of morphine for the pain until doctors prescribed Nifedipine, a blood pressure medication that helps with the Raynaud's.



On the road to getting better….

Here, Jonnie and I with our sister, Ricki (middle), at our road trip to Oregon, Washington and Victoria, British Columbia, she didn't get sick at all.

My little sister, Jonnie

She has taught us all so many things, mainly to be strong.

As my mom goes through breast cancer treatment, my mom thinks twice before complaining about chemotherapy IVs, feeling "uncomfortable" for 4-days after chemotherapy, mouth sores, hair loss, everything tasting like metal, loosing feeling in the fingertips and feeling like there are forever crumbs at the bottoms of her feet.

My mom realized that if Jonnie at age 7 can go through it, she can certainly go through it. No, she only focuses on how the treatment will make her better. This is what Jonnie taught my mom.