

<http://www.rheumatic.org/jessie.htm>

JESSIE, scleroderma

In 1992, our daughter, Jessie, was twelve years old. She was bright and active, strong physically and mentally. She was in the accelerated program in the sixth grade, and was a dedicated basketball player, track runner and flutist. She had also been playing the piano since age four.

1992

12

6

4

Over a period of a year, Jessie's active life slowed down. She became more and more easily fatigued and her energy level dwindled. I also noticed that the skin on the right side of her face was tightening. Her beautiful face was losing the round symmetry it once had. My husband and I took her to several doctors but they had no concrete diagnosis. Months passed and the facial condition was worsening, so we took Jessie to a head and neck specialist.

가

가

가

He named her condition hemi-facial atrophy and he described it as a rare progressive disease that destroys connective tissue. He then referred us to a neurologist in Reading, PA for further examination. Jessie was tested for possible tumors as well as bone and nerve damage. When all the results came back negative the doctor was puzzled. Despite our relief over the negative results, we were still agonizingly asking ourselves, what was progressively destroying tissue in our daughter's face? We were told that when she fully matures and the atrophy stops, tissue could be replaced surgically, so he referred us to a plastic surgeon at Philadelphia Children's Hospital.

(hemi-facial atrophy)

connective tissue

가 tumor

가

가 ? 가

( 가 )

In the meantime, Jessie was still trying to deal with the loss of energy and constant fatigue while maintaining her studies and extra-curricular activities. I would have to read her history and science to her while she rested on her bed after school. Basketball season was rough. I watched her determination to excel at all endeavors. It made me proud and yet quite worried.

가

가

Then one day she complained that her knees were hurting. The school's trainer said it was probably just growing pains. Spring came and with it track season. She continued with practices but one day after a meet her left knee blew up. A trip to an orthopedist was the next stop. He ordered physical therapy and pain medication.

가

(orthopedist)

After a few weeks her knee wasn't responding and she was now having trouble straightening it. We decided to get a second opinion. Another orthopedic surgeon said she needed surgery immediately. Blood work was done before she went into the hospital and a high ANA titer test made the doctor suspicious that arthritis was involved. We didn't think anything about it until three days after surgery. Jessie woke up in the morning with tremendous pain. The joints in every part of her body were affected. She couldn't lift her arms to play the flute. Her fingers were so swollen and the pain so great she couldn't play the piano. She even had trouble taking the cap off the toothpaste tube.

( )

가

가

가

ANA

가

(arthritis ?)

3

(arthritis ?)

( )

가

가

Her life changed overnight. She spent the next three months on the sofa. By the time she got showered and ready for the day, she had used all of her energy and had to go back to bed. We knew our Jessie was in serious trouble.

3

가

가

I started doing research at the library. I read everything I could on atrophy, connective tissue disease, juvenile rheumatoid arthritis, scleroderma, lupus and lyme disease. I realized she needed to see a rheumatologist.

가

(atrophy ?), connetive tissue

(juvenile rheumatoid arthritis),

(scleroderma),

(lupus)

(lyme

disease)

가

We visited a rheumatologist in Reading and he was very kind to Jessie. He drained fluid from her knee and gave her Naprosyn, an anti-inflammatory medication. The Naprosyn upset her stomach. She didn't have an appetite anymore and started losing weight. The doctor changed her prescription to Tolectin, giving her Tagamet for the stomach upset.

가

Naprosyn-

Naprosyn

가

Tolectin

가

가

Tagamet

Continuing to lose weight - ten pounds in all, she suffered everyday. The smallest tasks were an effort for Jessie. She couldn't sleep through the night because when she would move, the pain would wake her up. Her back hurt. Her hips hurt. Her legs, ankles, even her neck and jaw hurt. Walking was a chore, and when she did walk, you could see she was in pain. We were devastated as we thought we were losing our little girl. We were visiting the rheumatologist weekly now and weren't seeing much improvement. The more I read about this disease, the more discouraged I became because I didn't see any cures, only symptomatic treatments.

가 . - 10 , .  
가 . 가  
가 가  
1  
symtomatic

Because Jessie's condition was severe and she was so young, our rheumatologist felt she needed to see a specialist in juvenile rheumatoid arthritis at Hershey Medical Center. After more tests this doctor believed Jessie had a form of scleroderma because of the involvement with the soft tissue loss in her face. This is the first doctor who felt the two conditions were related.

가 Hershey Medical  
Center 가 가 . 가  
가 가  
... ... 가가 가 가

After being informed the condition was incurable, Jessie was prescribed methotrexate, a cancer medication that could cause serious side effects, but which might slow the progression of the disease. Jessie's blood would have to be monitored regularly because of the damage methotrexate could do to her internal organs. This medication was bad, but the disease was worse.

methotrexate -

methotrexate

I can't describe the horror I felt after that diagnosis and prognosis. My daughter was facing an incredible crisis in her life and though I had to be strong and supportive of her, I was crumbling inside. Despite the frightful possibilities of these very harmful side effects, methotrexate seemed like our only choice.

가  
가 ( 가 ) 가  
Methotrexate

All during this time we would hold each other and cry and pray together for God to help us. We drew closer together as a family and drew closer to God. It had become a precious time because in our pain we drew strength from our Creator who promises He will never leave nor forsake us. I cried out to Jesus with my whole heart for Him to show us what to do.

가 가 가

Then a friend gave me a book from the library called "The Road Back," (see footnote) written by Thomas McPherson Brown, M.D. I read it that same day and into the night. I knew it was our answer. Dr. Brown's words echoed my own suppositions that Jessie's arthritis was caused by an infectious agent.

가 Thomas McPherson Brown 가 "The Road Back"

Brown 가

Immediately we made an appointment at the Arthritis Clinic where Dr. Brown had practiced. The clinic was three hours from our home and we had a morning appointment, so we went the day before and stayed at a hotel. This gave us enough time to get Jessie ready in the morning. The next day my husband carried her into the office. This was at the end of August 1993. After a lengthy office visit and history given, the doctor prescribed one week of intravenous clindamycin and five hundred milligrams of tetracycline every other day.

Brown 가 the Arthritis Clinic

3 가 가

가 1993 8

1 (intravenous clindamycin)

500mg (tetracycline)

Luckily, we found a doctor in Allentown, PA (only an hour from our home) who has experience with this therapy, and he administered the clindamycin intravenously for one week. My wonderful

husband drove Jessie to Allentown each day for her treatment while I started her on some essential vitamins. This was the first week of September 1993.

( 1 )

1

1993 9

We considered home schooling Jessie because of her weak condition, but she chose to go to school. She dragged herself out of bed very early each morning to have enough time to get ready. By Christmas that year, our daughter started coming back. She was walking normally and gaining back the weight she had lost. Her physical therapist saw her muscles strengthening and we were encouraged. It took another year, however, before she could run again, but she did run - and she's still running! She even played varsity soccer last spring and was one of the fastest runners on the team.

가

가

가

가

1

가

The atrophy has been arrested and is much less prominent. Jessie's skin has softened on her face and is less tight. Her physical therapist saw muscle mass return in her legs and arms. It was marvelous.

(atrophy)

Jessie has been on the oral tetracycline for two and a half years and her laboratory figures continue to improve. She will be tested regularly. Jessie has no pain or swelling. There is no question in my mind that antibiotic therapy has corrected my daughter's disease.

2

가

가

Now as September 1996 approaches, Jessie is sixteen and preparing to march in the band as the new drum major. She is back playing the piano and also riding her horse "Little Dee" every chance she gets. Her fingers are even nimble enough for all of the typing involved in her position as a yearbook editor. Jessie is so much stronger, not only physically, but spiritually. She allowed God to teach her many things - patience in pain, hope in struggles, and trust when there seems no way out. I'm thankful to God for Dr. Brown's life, his work and for all that The Road Back Foundation has done to get the message of antibiotic therapy to people in need. I hope our story will help someone else who is battling with this same destructive disease.

1996 9 가 . 16  
Little Dee  
가 yearbook (are  
nimble ?).  
가 .- , ... ..  
. - Brown  
The Road Back ... 가

Bernadette K. Dutton  
Telephone USA (570) 622-2250

(570) 622-2250