Jodi Morgan and her daughter Sophie

Helping Sophie Heal

The Painful Bump on My Daughter's Head Turned out to be a Cancer-Like Disease

Written by Jodi Morgan
Select Photography by Suzi Issa

Sophie was a happy, healthy 8-year-old until a small bump on her head turned out to be Histiocytosis X.

I've always known that my daughter Sophie is one in a million, a unique 8-year-old with a big heart. In November 2010, we first noticed a bump on her head we nicknamed "Ouchie." One evening when Sophie was getting ready for cheerleading practice, she said she didn't want to go because Ouchie was hurting so bad. It was then I knew something was very wrong. Months later, my heart dropped to the bottom of my stomach when we heard the words, "Your daughter likely has Histiocytosis X."

Searching for a Diagnosis

When Sophie had first mentioned the pain, I took her to a dermatologist who prescribed her dandruff medication and then antibiotics, along with taking a culture of the area. After two visits and no results, Sophie's bump had grown larger. At this point, I had a very bad feeling – the kind of gut feeling you get when you know that things just aren't right. During our third visit, the dermatologist took a biopsy of the bump.

When it came back as a lipoma – a benign fatty tumor – we were very relieved. I still had a bad feeling, but was beginning to be hopeful that my butterflies were just me being overprotective and worrying too much – I'm a mom, so it comes with the territory.

When I took Sophie to the same head and neck surgeon my son had been to for ear tube surgery, I thought it was going to be a piece of cake. I knew she had an impeccable reputation. The surgeon, who was also an ENT, looked at Sophie's tumor and said she wasn't convinced it was a lipoma. I asked her if she thought it was cancer, but she said that skin cancer usually doesn't hurt. I began thinking it might just be a cyst or an inflamed hair follicle, but then she insisted on a biopsy.


While Histiocytosis X is a serious disorder, doctors told the Morgans that the cure rate is good, and today, Sophie is on the path to recovery

An Unexpected Biopsy

With multiple stuffed animals in tow, Sophie and I headed to the hospital for the biopsy on Jan. 28. I got a terrible feeling in the pit of my stomach, because the doctor had said it was a very straight forward procedure that should only take about 20 minutes, but the surgery had been over an hour.

The doctor finally came out and said the biopsy hadn't even scratched the surface of the existing tumor. After removing the existing tumor and sending it off for biopsy, she noticed there was a very abnormal inflammatory area beneath it in the lining of the skull. The doctor said she had also sent that area off for biopsy, and the results would be back either Friday or Monday.

By Saturday, we still had no results and Sophie had become very ill. Her face was flushed, and she had developed a rash and low-grade fever. Following the on-call doctor's advice, I gave her Benadryl and Motrin, which seemed to help a bit. Then on Sunday her symptoms were much worse; the fever was back, the rash was red again, and she just felt very tired and slept a lot. She never naps during the day, so I knew something was very wrong.

Don't Google It

I took her to the emergency room, where doctors gave her antibiotics, fluids, and steroids. When she was discharged hours later, she was still tired, but in much better shape. When she woke up Monday, she felt rotten again, so I called her doctor to try and get an appointment that day. We were told to come in to go over the results of the biopsy. It was then the doctor told us that Sophie had Histiocytosis X.

I can't even describe how it felt. When the doctor says, "Don't Google it – it'll scare you to death," it's only natural to get worried. She explained that the disorder is serious, but that the cure rate is good now. She had already called Sophie's pediatrician and the oncologist at Texas Children's Hospital with a referral for us. Even though Histiocytosis X is not cancer, it's treated in the hospital's cancer center.

Treated Like Cancer

Not cancer, but treated like cancer? That meant chemotherapy and radiation, and that my kiddo was really sick. I cried a lot that night and talked to my mom about what we had been told, trying to act like everything was business as usual. The next morning, Sophie was complaining of being short of breath, her rash was worse, and she had a temperature, so we went to the emergency room at Texas Children's.

The doctors examined Sophie and finally had a skeletal survey done. The visit didn't yield much information, but we did get moved to the front lines to see a new doctor. I was so ready for Sophie to stop hurting, itching, and having horrible symptoms that I jumped at the chance. Finally, we got the final biopsy report, and it wasn't good. The words "diffusely and strongly positive" were used. I just wept and wept when I read the results. I had to look at the top of the paper just to make sure they had the right patient.


Sophie with mom and Aiden, who suffers from cerebral palsy

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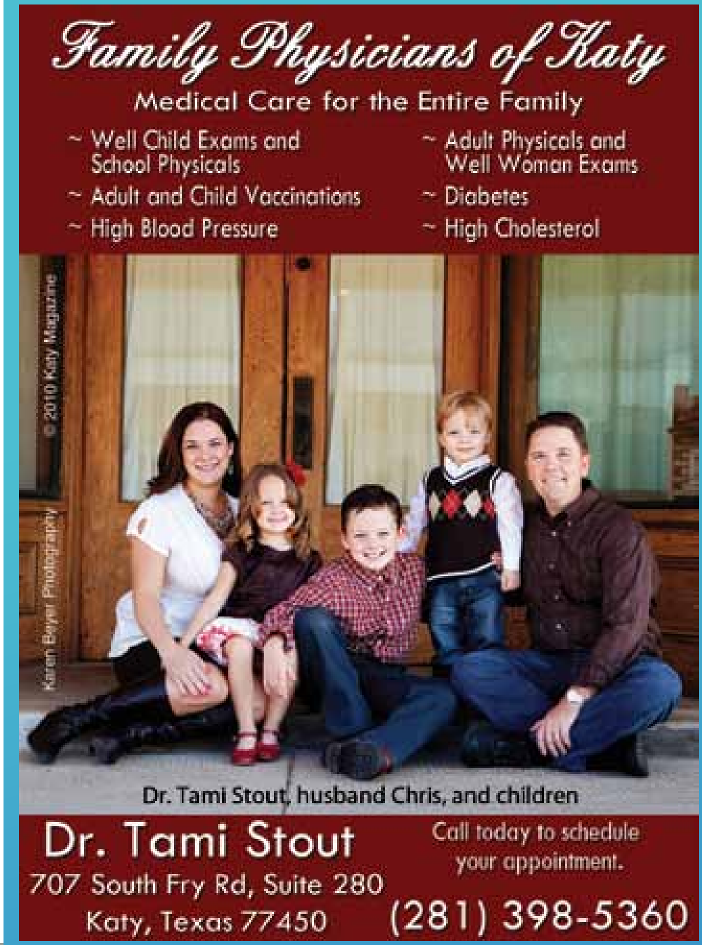
>
> *– Sophie's mom, Jodi Morgan*

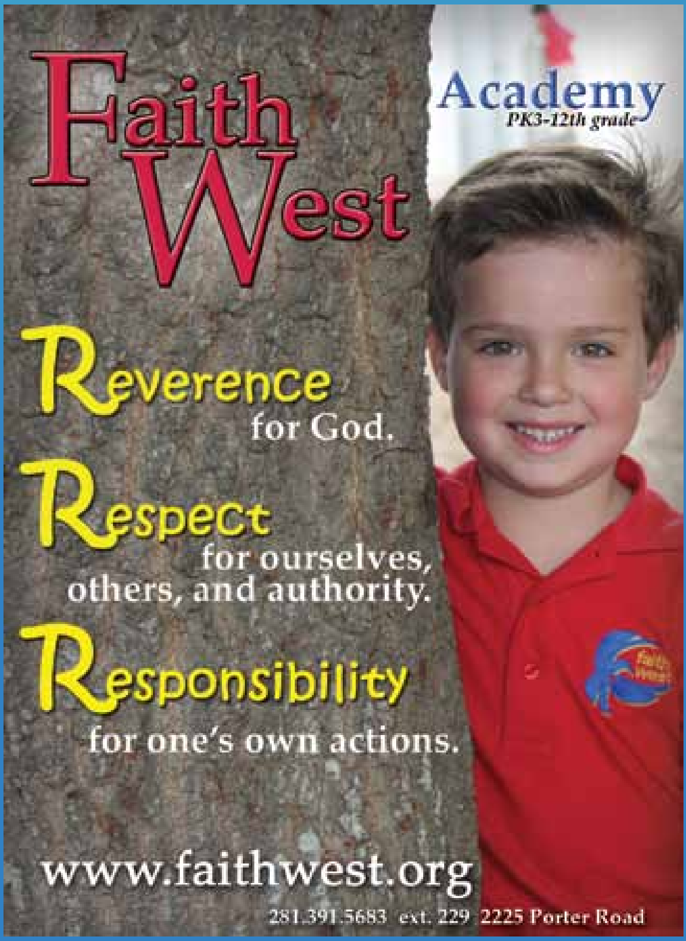
Staying Positive & Strong

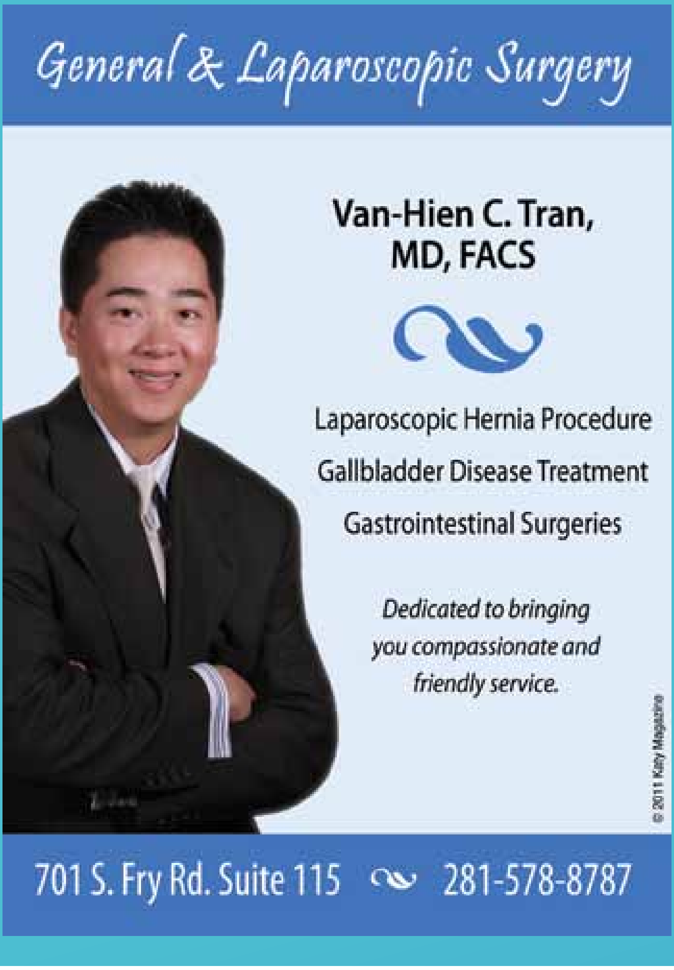
The silver lining in all of this is that Sophie is still in good spirits. We know the prognosis in Sophie's case is good, but not so for many other people afflicted with this disease in its many forms. If we can save some lives by raising public awareness, it will be a worthy cause. Many people go under-diagnosed or misdiagnosed due to lack of information in the medical community. **KM**

EDITOR'S NOTE: We would like to thank Jodi Morgan and her daughter Sophie for sharing their story of hope, courage, and faith. If you have an inspirational My Story you'd like to share, please email editor@katymagazine.com.

Sophie underwent many tests before she was diagnosed with Histiocytosis X







About Histiocytosis

- A rare blood disease caused by an excess of white blood cells called histiocytes.
- Histiocytes cluster together and can attack the body's organs, bones, and nervous system.
- There is no known cause and no known cure for the disease.
- Often treated like cancer, with chemotherapy and steroids.
- Children under 10 make up the majority of those diagnosed with the disease.
- Affects 1 in 200,000 children born each year in the U.S.

Visit histio.org for more info. (Histiocytosis Association of America)

Histiocytosis X is most often seen in children ages 1 to 15. The rate peaks among children ages 5 to 10, according to the National Institute of Health..

Photo by Melissa Brewer of Snapped With Love Photography