## Scarlett Fritschy | TB Bio and Advocacy Work Prepared By: Carrie Fritschy Prepared On: 11.5.15

## Scarlett's Diagnosis

Our strong and spirited daughter Scarlett spent a year of her life battling tuberculosis in 2013. She was 1 ½ when she started showing symptoms in November 2012. It would be months of sleepless nights where she would spike a 104 fever because the doctors couldn't figure out what was the cause until we received a diagnosis. I can still feel her heat as she would lay on me tossing and turning, her body covered in rashes and sweat as her father and I would take her temperature every 5 minutes to make sure that it never topped 105!

We spent hours upon hours in the pediatrician's office where we would hear that it was an ear infection, a sinus infection or just a cold. Next it was RSV and we were sent home with an oxygen tank because her levels were low. But with each round of antibiotics, the fever would keep coming back. In March 2013 they admitted her to the hospital and tested her for everything they could think of, meningitis, mono, Kowalski's Disease, pneumonia, but never thought of tuberculosis. In the end the x-rays came back showing some abnormalities and diagnosed Pneumonia and sent us home, still with a high fever.

And the fever stayed. We went in for a follow up x-ray one month later, and we were in the pedestrian's office when another doctor in the practice peaked his head in and stated that her X-rays were in. I asked if we could go with her to look at them. As we looked at the X-rays the pediatrician who called us out stated "It looks like chronic lung disease."

My heart dropped, my eyes watered. I knew that couldn't be good. Our pediatrician immediately took us back to the room to try and calm our fears. We started talking about next steps and making appointments with specialist when she said "Let's just test her for TB." Even as they were injecting the Tuberculin test she was saying that there was no way it could be TB, but to just rule it out. I think she was just giving us something to do to get us through the weekend.

And then Scarlett's arm exploded. I immediately started researching and one thing stood out, it's treatable. We returned on Monday and received a positive read and then were sent to Children's Hospital in Denver for three days where we were showed that her X-rays were classic TB. They tried to get a sputum sample but she was just too little. Her first stab at taking the medication, ended with tears and throw up. But after five months, we had a diagnosis.

## Scarlett's Treatment

And then we started treatments. It was another set of sleepless nights when we had to give her four super antibiotics in the hopes that she had just your basic TB and not MDR-TB (Multi-Drug Resistant). We got to hear a not yet 2-year-old tell us her toes tickled, which made her laugh but set anxiety in our minds because we knew it was a side effect to one of the medicines. But luckily the toes that tickled were all she had; she didn't have MDR-TB.

There were a lot of tears, but for the most part she took her medicine at every appointment and progressed quickly. It was just a few more months of her treatment being our routine until we got the final X-rays saying her lungs were cleared and she was done with only 6 months of treatment. And luckily she is done. She is amazing and healthy and gets to live the life she deserves.

But it was a hard time, it was scary and lonely. We didn't share this with anyone as we were encouraged not to and were scared of the reactions we would get. Even from our loved ones that we did tell, we got mixed reactions. People stayed away at first. People accused us of not vaccinating. It was a time where the unknown bred fear and I knew I wanted to fight that stigma and bring awareness and education, so that those who battle this in the future can have a better support system.

## NTCA | TB Ambassador's Project

This year marked my company's 100<sup>th</sup> year anniversary. In celebration, Deluxe Inc. granted 17 employees with 100 hours of PTO to serve a non-profit of their choice. I was lucky enough to be chosen and partner with the National Tuberculosis Controller's Association to build a network of survivors to become Ambassadors with this mission:

To create a team of survivors who will serve as TB Ambassadors willing to raise awareness about Tuberculosis with three fundamental goals:

- 1. Provide an informative and supportive community for patients and survivors.
- 2. Share personal stories to drive change at a local, state and/or national level.
- 3. Provide the media a TB patient perspective to educate and reduce the stigma of TB.

We are looking for more patients and survivors to join us on this mission. We will be holding a survivor training workshop in February 2016 in Denver, CO. If anyone is interested in applying for this training, you can contact me at <u>carrie.fritschy@deluxe.com</u>

We would love to grow this project and create a support network for the TB community.