

Working with Alyssa is a unique, personal, and special experience, but then again so is the case with any child.

I began working with Alyssa and her family approximately three and a half years ago. In the beginning months of being with Alyssa I would simply play with her and her sister while her mother was around to take care of Alyssa. Although this may sound simple, this time was critical in my learning about how amazing and unique of a child Alyssa is. I learned about Alyssa's personality; her likes and dislikes and what made her uncomfortable, nervous, or upset. By being with Alyssa on a regular basis, in situations normal to her I was able to learn vital information about her very personal warning signs of having low blood sugars. After years of being with Alyssa I slowly began to develop an instinct of when she should be tested earlier than her schedule to keep her sugars from dropping too low.

During the course of these years with Alyssa I was also able to learn how truly unique her disease is. By training with Alyssa's family and her doctor I learned that there is no degree that could have helped me learn more than the hands on experience I acquired while being with Alyssa on a regular basis. The information I learned was without a doubt something that could not be learned in a text book. This statement should be taken very literally considering Alyssa is the only known case of GSD1a where corn starch isn't tolerated. There is not one day that is exactly like the other, and I am still surprised by her disease after three and a half years of working with her.

However, the most important thing that has happened over this time that I have worked with Alyssa is the trust that I have gained from her. Tube feeding is a very personal experience, especially in Alyssa's case. For 15 minutes every 90 minutes the person feeding Alyssa sits only a foot away from her while pumping food into her stomach. If Alyssa wasn't trusting of the person feeding her then the situation could become dangerous quickly. Alyssa could become upset and refuse to allow the person to feed her and her sugars could drop very quickly, leading to unthinkable consequences.

Every parent should have the right to choose who has this personal of an experience with their child. A child should be able to know, feel comfortable, and trust the person who is responsible for keeping them healthy on a regular basis.

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