CARING FOR A SANDHOFF GRANDCHILD

by Sharon Ashford

I'm entering a world I've never attempted before, writing something that others (hopefully) will be interested in reading. But then, this entire past year has been a whole new world for me. On February 12th, 2001, I thought my world had completely fell apart. My Grandson Holden Reamy was diagnosed with Sandhoff. He was 15 months old.

This was a disease that was totally foreign to me and as I soon found out much to my surprise, most of the medical personnel we were in contact with as well. At that time my daughter Kelli was a single Mom, so we did a lot of crying, yelling and leaning on each other. This was something you read about or saw on TV, but it sure didn't happen to you or anyone you knew. When I heard the eye doctor say "blind", I was devastated. Kelli had already been studying the possibilities. She didn't say a word, but my first real hurt had started, I saw the pain in her eyes. As parents, you know how it feels to see your child hurt and not be able to stop it. On the way home I read the literature the doctor had given us, I was totally numb, but could not stop the tears. The first of many that would be shed.

To find out anything about Sandhoff, I had to go to orphan diseases, which led me to NTSAD and Sandhoff. There wasn't anything I liked about what I read. The first stage was denial, then anger– I've never been so angry in all my life, and I wasn't even sure what I was angry about. The only thing I knew for sure, I had to do something to protect my child from the hurt she was going through, not knowing at the time that was not at all possible.

I contacted every one I could contact, parents, grandparents, medical schools and NTSAD. Thankfully the responses from everyone except the medical schools was immediate & very informing. Little did I know how much I would depend on all of you. The news I received from other grandparents was comforting, but not what I wanted to hear. There had to be more I could do than just be there for her.

As was God's plan, she lived very close to me. We learned about seizures together first, and then we started learning all of the other things that go along with this dreadful disease. The real turning point was the NTSAD Conference in Tampa. I had "chatted" with a lot of you via the internet, but now you were real, not just written words. Words cannot explain what that conference meant to all of our family. Finally we were not alone.

Since Kelli was a single mother, I was very involved with Holden's care. She made the final decision on everything and I followed instructions, but I was there. I will never forget the fear in my entire being the first time I kept Holden overnight by myself. I couldn't have slept no matter what. I heard every breath he took, every move he made and I had to fight to keep from picking him up and holding him all night long. It took Kelli a long time before she would even go to another room and leave me with him in the same house, so the overnight thing didn't happen right away, but thankfully it finally did.

I was quite surprised at the conference when talking to other grandparents to find they had never kept their grandchildren for more than a few hours at a time, if at all. Most of the reasons were that their children didn't want to put them through the stress. It would have been far more stressful for me if Kelli had not let me care for Holden. I now know the pressure points to stop the seizures, I know how to give his meds, how to hold him, what noises cause the startles, but most importantly, I know him. You don't get to know anyone unless you spend time with them. I had the privilege of keeping him for nearly a week at one time. It was the hardest, most wonderful week I have ever spent. Not only did I have full responsibility for Holden, Kelli trusted me enough to let me do it. They now live 3 hours away, that is a lot more stressful to me than having them a short phone call away.

Some grandparents may not want the responsibility, but give them an opportunity. Talk to them openly and honestly. If your children aren't spending time with their grandparents, you're not using one of your greatest assets. Not only that, but Holden has been such a wonderful blessing, and not everyone is given the opportunity to hold, care for, and love a real live angel.

Keep in mind we raised some wonderful children of our own, children that grew into wonderful, responsible parents themselves. YOU.

GRANDPARENT GROUP

Grandparents are concerned not only for their grandchild, but also share in the pain of the parents. The NTSAD Grandparent Group was founded in 1996 by Robert Margolis, father–in–law of past President Meredith Margolis. Members receive a directory of grandparents and a copy of the newsletter *Lifeline*. The Grandparent and Extended Family Meeting during the conference is a great opportunity to share experiences and concerns. For more information about the Grandparent Group, contact the national office.