



“Always be a strong voice for your child”

As parents of a child living with hemophilia, Barbara and Wes have taken on the role of not only parents, but now the advocate, the voice, and the people who might very well save the life of their child.

This story is about parents of a child living with both hemophilia and autism and the challenges of living in a rural area, learning about hemophilia from having no knowledge to begin with, and how to deal with those who may not know how to handle kids who have a bleeding disorder.

David was diagnosed with hemophilia at birth during a routine blood test in the hospital, when the injection site wouldn't stop bleeding. His birth mother was a carrier, but no one else in the family had it. When David was two years old, his aunt, Barbara, and uncle, Wes, adopted him and moved him from California to a rural area in Nevada, and have raised him as their own for the past ten years. The first thing Barbara and Wes did was get connected with the Nevada Chapter of the National Hemophilia Foundation,

which helped teach her and Wes about the bleeding disorder.

David spent much time at a children's hospital in California for spontaneous bleeds for the first two years of his life. From age 2 to 8, Barbara was the one infusing him three days a week through a port in his chest. During this time, he was cooperative and had no problem infusing.

Things changed just before his 10th birthday. David had a fever-induced seizure which caused him extreme anxiety, and caused him to be scared of infusions. Barbara said "he screamed, fought and cried at every infusion. We tried everything over the years, from holding him, talking him through infusions, playing music, candles, breathing techniques, candy, new toys, singing, and so on." He has improved over the last couple of years, but still yells when Barbara puts the needle in. A lot of this anxiety and fear has to do with David's autism.

It was during the hospital visit for the seizure where Barbara had to use her voice to advocate for her son and also caught a glimpse at how a smaller hospital in a rural area might not be as educated about hemophilia as they should be. "The nurse did not understand why I was so concerned with infusing him before she was able to get his antibiotic administered and wanted me to stand out of the way until she was completely done with the intake process, like accessing his vein, and putting a catheter in. I had to nicely but firmly tell her, 'I know what's best for my son with hemophilia and that is to infuse him and I need to infuse him right now.' The nurse later apologized."

Barbara's advice for parents of a child with hemophilia living in a rural areas is "if they have the opportunity to be connected with NHF-NV ... take advantage of that. They will help you with so much and be there for you."

Her advice for parents in general? "Always be a strong voice for your child."

The Nevada Chapter of the National Hemophilia Foundation offers a number of support groups,

including groups for families of newly diagnosed children. For additional information on support groups or any other services and benefits provided by NHF Nevada, please call (702) 564-4368 or email Anne at amcquire@hemophilia.org.