

July 19, 2011

Dear Sally,

First, please allow me to extend my heartfelt condolences in the loss of your son, Kevin. It breaks my heart to think of your loss. I am also writing to thank you for your article in the DBA Newsletter about Kevin's life and passing. Of course, I read it and was in tears by the end of Kevin's story because I could easily see myself in your shoes a few years from now. There were times when I could see my daughter's life ending prematurely due to iron-overload and it tore me up.

Our daughter was diagnosed with DBA at birth and was lucky enough to respond to prednisone. She is small in stature, but not dramatically so, and her doctor never suggested we put her on transfusions to give her a growth break from the prednisone. So she never had any transfusions until she was 22 years old (after the one she had at 7 weeks). At age 21 we found that she also has the gene for hemochromatosis and her test results showed that she was severely iron-overloaded.

It took about a year to convince her to do something about it. My husband and I tried everything - begging, crying, tough love... everything. She finally agreed to try it. Like you, we would find her unused chelation equipment in a box in her room. Our frustration was immense! She is a smart, lovely, educated, capable young woman who was refusing to deal with the issue. Then, she was hospitalized for intense chelation on her doctor's recommendation. She had decided to restart her home chelation when she read Kevin's story. It finally hit home and what a difference it made! It confirmed her decision to take responsibility for the iron overload. She called me and asked if I had read Kevin's story (instead of me hounding her to read it). She had also read the other 15 pages of the DBA newsletter concentrating on iron overload!

Today, she is still chelating 12 hours a day. She occasionally takes a day off if the headaches get too bad, but she is doing it! This is an answered prayer for us! I cannot tell you how relieved we are and how thankful we are that you wrote down Kevin's heart-breaking story. I want you to know that you have probably saved my daughter's life and I will be forever grateful to you for your courage to share Kevin's story with everyone. I think of you often and the pain you are in. I will keep you and your family in my prayers. I hope that your healing will be helped in some small way by this note. Thank you again. We are eternally grateful.

My best wishes to you and your family.

Lori