



“A Blessing Wrapped Inside of a Challenge”

by Amy Bekier

To describe what it is to live with muscle wasting Facioscapulohumeral Muscular Dystrophy is illusive because of its ever changing nature. Just as you come to grips with your weakened body the disease progresses relentlessly. There is a constant grieving for the loss of physical capabilities and independence. But before you think that this is a maudlin piece I want to point out that blessings always come wrapped inside of challenges.

This disease not only affects the person diagnosed but forever changes the lives and dynamics of the entire family. It becomes OUR disease. I was diagnosed in my teens but have lived with it from the day I was born because my Dad was severely affected with FSH. My slight built Mother was his caretaker with us kids pitching in. Our home was filled with accommodations. Our entire existence revolved around the disease. We lost count of the number of times he lost his balance and crashed dead weight onto the floor unable to get up. I'll never know how he didn't break a bone, damage an eye or get a concussion. He had difficulty simply raising his hands to feed himself or comb his hair. Where is the blessing? It is that he taught us to never give up. He was determined to live a full life. He married, raised two children and owned a home. Finally in his 40's he stopped driving and unable to lift his arms any longer, went on disability. He died at 54 from what is now called deep vein thrombosis, a hazard of inactively sitting in a wheel chair. Today it might have been preventable.

Imagine my horror as a 17 year old active teenager when I awoke one morning to find my right shoulder dislocated. The muscles had atrophied and no longer held my arm in its socket. The pain was excruciating. I knew, I knew in my heart of hearts what was happening to me. The fear that I faced was whether I would be as severely affected as my Father. I began living life as if I was running out of breath. This was hell for those around me adding to the difficult dynamics of the family.

Today at age 58 my disease has progressed and I am on disability. If I have learned anything from life's lessons it is to never give up, to live life with zest, curiosity and humor. I write this piece not only for myself but for all of my FSH friends. I pray for the day that they don't need airway machines to assist weakened chest muscles. I pray that we can all stand from our chairs with the strength to raise our arms high above our heads. To be able to do the everyday inconsequential things that are so important to quality of life. I pray for the severely disabled children. For those that are hearing disabled from FSH and for those who have lost the ability for their mouths to form the words they wish to so eloquently say. The ability to smile would be a precious gift. The blessings in this challenge are the wondrous people who have risen above their limitations. Only a treatment or cure could answer those challenges. Someday...please let it be in my lifetime.