

Deak's Run for Hope 2013

May 4, 2013

Snow Horse Elementary School Kaysville, Utah

Dear Friends,

We are at it again; the third annual "Deak's Run for Hope" will be held Saturday, May 4th at 8:00 AM in West Kaysville, Utah. Last year's run was an amazing morning, and substantial success, thanks to the support of many people volunteering, walking, running, donating, and sponsoring the event. We were able to donate \$6,000.00 to the Chromosome 18 Registry and Research Society, along with the ability for our family to attend the annual Chromosome 18 Conference, which was held at the research headquarters in San Antonio, TX. Our "bucket of hope" was filled, and I'll include an excerpt from a journal entry I wrote after spending the week with our extended Chromosome 18 Family:

"There is a popular developmental theory in Psychology based on a hierarchy of human needs. We need the basics; food, shelter and water. We need to feel safe. Coming in a close third, is the need to belong. This need must be fulfilled before one can achieve it's full actualized potential.

I believe this is true.

We need to belong.

We need to fit in, find our nit-ch and feel validated.

It's almost as important as breathing.

This is where I fit.

Within this circle, there is no judgement or second glances when your kid throws a tantrum, in effect tossing his toys and ipad across the room.



(Our Ring 18 Family that was able to make the conference)

Much has been written and voiced over time about the special needs' parents' feelings of isolation.

It is so isolating.

Physically, and emotionally.

Regardless of the number of willing friends and family members, we just cannot shift the burden that we as special needs' parents carry. I can't give away the hours I've lost, flooded with worry, about the life Deakon may need to lead as an adult. I cannot retrieve the lost dreams of retirement and vacations spent alone with my husband. I cannot gently pass along to another, the underlying and constant fear that although I worry most often about Deak's future aloud, I desperately pray that he will live to grow old alongside me..."

This Run for Hope, in honor of my son, benefits an organization that has not only provided life-saving and quality of life research to my son...it has saved my sanity. I have connections with people who understand. Through them, I feel less alone. There is truly no greater gift. Please consider sponsoring or donating to our event, in honor of our son. He is a gift, and his influence in your life will be permanent.

I've included a form, with various sponsorship levels. Please return the form to the address listed by April 4th, for inclusion on our Run T-Shirts. We are so appreciative of your time and consideration.

With love,

Blair, Jenny and Deakon Howe

