

Learn to Live Then Live to Learn  
By Meredith Martin  
Presented at the DSAF Literacy Conference 11/03/2007

It was an extremely windy day in May in my small Nebraska community. I was 9 years old and I wanted to ride bikes to the park with Mom that evening. Mom had agreed to the evening ride, that way she could attend a preschool graduation ceremony there and we could get a little exercise in, too. As we were leaving the park, that good old Nebraska wind was to my back and blowing my shoulder length hair into my face. I was becoming frustrated to the point of almost crying. Mom wasn't doing much better than I was in the frustration department. She responded to my complaining with, "I can't do anything about your hair or the wind right now. You deal with your problem. If you don't like your hair blowing in your face, you may have to think about getting it cut. You will have to decide." Obviously she was tired! Knowing she still had a lot to accomplish at home, on we went.

We were within two blocks from home when a car approached a stop sign. I knew I was supposed to stop at each corner, but the timing was just wrong and I was going a bit too fast to stop immediately, so I rode on through the intersection. Of course when we did get home, I was instructed to park my bike and not to count on riding it the next day.

We went on in and I headed for the bathtub. Mom had to help me wash my hair as I could not get any water in my ears at that time. She ended up getting 4 phone calls and an SOS from the neighbor for something. When Mom finally returned to comb out my hair I said to her, "I'm sorry, Mom. I'm sorry about my hair on the bike ride. I'm sorry you're tired. Next time I'll wear a headband. That'll be better. Is that good

thinking, Mom? Tomorrow I won't ride my bike. I need to learn to stop." Mom knew I was sorry and that I would try harder, I always do. So we did our little hug and then I added, "You know Mom, I am still learning!"

It is so exciting being here today to meet all of you and share just a little bit about my experiences of growing up with Down syndrome. It is exciting to be a part of your "educational conference". Education and my school experiences were, and still are, a very important part of my life. I feel very lucky to have been born during a time when the Nebraska Department of Education felt that Early Childhood Intervention services were important. I sometimes wonder what my life would have been like if I would have lived in a larger community where there may have been some opportunities offered that we do not have in our small town. All in all, though, I think things have worked out this far just the way they were meant to be. Life is good!

As I mentioned, my education began with early intervention in my home. I also received physical therapy and speech therapist. When I turned three, I attended a center base preschool program for children with disabilities and then also attended a private preschool with my non-disabled peers. My parents made sure that not a church event, library program, scouting opportunity, dance, baton, sports, or civic event that I did not attend. Of course it may have meant that they had to be a leader or a

The first day of Kindergarten arrived. Although there had been children with Down syndrome in and around our community, no one with Down syndrome had attended our school. My parents tell me that the transition went smoothly and there were really no questions about where I would attend school. Although I am sure the path was well under construction through early intervention, I had a fantastic elementary resource

teacher who taught me not only to read, but to really enjoy reading. When I found out that I was to speak today, I went to visit her and asked her a little bit about her teaching strategy. She shared that she taught whole word recognition with some phonics. We read A LOT, and there was a lot of repetition in our work. She tied writing and spelling into our vocabulary practice from our reading lessons. With all of that practicing at school and the persistent reading practices I did at home in the evenings, I guess I have become a fairly good reader in spite of my extra chromosome.

I have often heard the saying, “You learn something new each day.” I want to say that is true not only for those of you with regular chromosomes, but also for us who have that extra 21<sup>st</sup> chromosome. Although much of our learning comes from books and school, I think my family and I have learned some of our best lessons just by living our day-to-day experiences

My parents tell me that I was being read to even before I was born. My brother and I were read to every night before we went to sleep. Sometimes, we even got more than one book if we were not very sleepy. In the summer we had our own summer reading time and spent at least an hour reading before we started our afternoon play. Our city library hosted Library Hour for preschool students and summer reading programs. I think my parents were the first ones in line to get my name on those lists.

All of my school years were a blend of inclusion and resource room instruction. Although my parents knew that total inclusion was the trend and that I would not have been a “problem student” in World History or Algebra class, they felt that a more individualized program would better fit my interest, level of understanding and needs for independent living in the future.

When I reached junior high level, I found that many of the girls that were my friends in elementary were moving on and developing their own interests. I began to feel a little left out. I did not like that feeling. As a way of filling in my time, developing a stronger sense of self worth and also improving my future employability skills, I began doing volunteer work at our local nursing home and hospital. That move proved to be an important step in my “education” away from the classroom. By volunteering, I was able to break down some important barriers for myself and for others with disabilities as well. I was able to satisfy an interest of mine, fill in a need, improve my self-esteem, gain new confidence and make a huge difference in my life and the lives of others. One of several things we did learn was that volunteer time at a specific site needed to be limited to a certain length of time. About 3 months after I stopped volunteering at the hospital, they called to offer the job as a paid position.

Graduation time came all too quickly and I wanted to move on just like my classmates. After all, being a graduate of the class of 2000 was a big deal! We looked in to junior college possibilities, but my parents were just not satisfied with the safety issues in a college setting. We were reminded that Nebraska school districts were responsible for education from 18-21, but they would not consider providing support on a college campus. Under the guidance of an advocate, we were able to set up an independent living program with the local school district. My parents and I found an apartment and I moved out of their home just as my friends were moving to their college dorms. The school provided a non-certified job coach/independent living instructor for about three hours a day. Talk about learning through experience! The first week in my apartment was a little tough...my cable TV was not hooked up yet! Otherwise, I quickly settled in

to a routine, which included having my parents over one night a week for supper. I was enjoying my life and my independence, but, there was still one huge void. I wanted a driver's license and a car. So, being the self-determined person that I have become, I began studying the driver's manual, got some resource material on how to study for the test, hired my personal driving instructor and I am now a licensed driver.

I continue to have dreams for my future and they do require the need to keep reading and learning new things. My ultimate dream is to become a pediatric nurse. I think I know that the math and chemistry involved will probably keep me from fully realizing that dream. Also, I am not sure I could stick a needle in a little baby. I am continuing to investigate college options and right now am looking at classes in early childhood training.

A little over a year ago I was elected by my peers to serve as a self-advocate on the National Down Syndrome Congress Board. This wonderful group has sustained my family and me through the years with their publications, resources and convention opportunities. We self-advocates have an absolute blast at the conventions each year. I would invite you to share any suggestions or concerns about issues that affect you or your child. If there is any way someone from the NDSC can assist you, I know they will. If you were not able to attend the convention in Kansas City in August, I hope you can begin planning now to attend the July convention in Boston next summer. You will learn so much and come home energized.

Life is all about learning. My parents say they started out parenting thinking they knew just how to do it. They soon found out that in raising both my brother and me, they had a lot to learn. My brother and I know we still have a lot to learn. Teachers,

employers and the general community need to continue to learn. As all of you probably do, I wish for a lot of things. One wish is for some profound statement that I could create on my own to express my hopes and dreams for my future as a person with Down syndrome and the futures of your children and your families. Unfortunately, that has not happened yet. So, in closing today, I would like to share a quote from Martin Luther King, Jr. Dr. King was indeed a powerful man, who dreamed of equality for all. I believe that he meant for that equality to include not only people of other races, but people with disabilities as well. With that in mind please consider this quote:

Strangely enough, I can never be  
what I ought to be until you  
are what you ought to be.  
And you can never be  
what you ought to be  
until I am  
what I ought to be.

We are traveling this journey of learning day by day , TOGETHER .