Hello, my name is Tiffany Vickers. Among many things I am a wife, mother, and student. On March 1, 2003 I gave birth to my youngest daughter Grace. My pregnancy with Grace was problematic, and we were constantly in and out of the doctor’s office. At the midpoint of my pregnancy my doctor told me they suspected she might have Down Syndrome based on anomalies seen during an ultrasound exam. We were offered the opportunity to do amniocentesis, but ultimately decided against amniocentesis. I knew I would love her regardless of what the future might hold.

When I went into labor I was so excited to meet Grace. A few hours after her birth it was clear she didn’t have Down Syndrome, but there were concerns that couldn’t be explained. At that point genetic testing was ordered to determine what might be causing her symptoms. I found out several days after her birth that she has 22q11.2 Deletion Syndrome. As a parent I found that I was scared, believed that I lacked the skill set that would be necessary to care for her, and more than anything I wanted her to be okay. The visit with the genetics department was frightening, and not a lot of help, but at least we had a diagnosis. I was handed a list of 200 potential problems, and provided a telephone number for the early intervention programs offered through the Utah Department of Health.

The day I left the genetics office began the amazing journey of the last 12 years. Grace was placed in an early intervention program we saw numerous specialists for her facial anomalies, hearing difficulties, speech issues, and developmental delay. At the time the specialists seemed to know so little about 22q, and they all seemed to have a different name for what was having such a large impact on Grace’s life. Is it DeGeorge Syndrome, is it Velocardiofacial Syndrome, or is it 22q, no one seemed to know. It was frustrating, and so often I felt alone. I decided to put things on hold; I left a good job, and discontinued my education to make sure that I was taking the best care of Grace. Over the years she’s battled hearing issues, cognitive issues, and cardiac problems, but overall I feel incredibly lucky. For the most part Grace has been quite healthy, and she has enjoyed so many of the wonderful things life has to offer, and for that I will always have a deep sense of gratitude.

When I decided to go back to school last year to complete my master’s degree I knew that I needed to do something that would help children and families affected by 22q. I decided that I wanted to study health promotion and education because it seemed to offer a springboard for bringing awareness to 22q. It has occurred to me over the years that parents and caregivers need social support in the form of other parents, and support groups who understand what it means to have a child with 22q. So often I found myself wishing I could talk to another parent, or someone who understood what I was feeling in the darkest moments. It has also occurred to me that no one has ever really studied how social support services help parents and caregivers in their capacity to care for themselves, and their child. This is an area of health and wellbeing that I find incredibly interesting, and it seems to be a missing
component in our healthcare system. The teen years are fast approaching, and I’m excited to learn from other parents how to best survive.

I am asking parents and caregivers of children with 22q to assist me in my graduate studies by participating in a survey. The goal of the survey will be to further the research that suggests that social supports can have a positive impact on caregivers of children who have been diagnosed with 22q11.2 Deletion Syndrome.

I am looking forward to the opportunity of getting to know all of you, and developing some great friendships along the way.

Thank you,
Tiffany Vickers