



Sonia was a trickster almost from birth. Prior to her accident, before she even turned one year old, she would run around the house with a rubber mouse in her mouth. Her humor remains one of her greatest charms.

Below is Sonia and her brother and sister in costume.



## The Story Behind the Story

Princess Sophia's Gifts is a fairy tale based on a real story. It is the story of how my daughter acquired her disability and how we, as a family, learned to live with the changes and challenges that resulted from her disability. I originally wrote the story to read to my daughter's class at the beginning of each school year throughout her elementary years. I wrote it to help her classmates see beyond her disability, to see her gifts – the things that make her uniquely her. Ten years later I pulled the story out of my file and decided it needed to be published so others could benefit from what we had learned.

The need for the story started to simmer while sitting on the sidelines watching our older two children play their ball games. Little children would come up to Sonia, sitting beside us in her wheelchair, and look at her with curiosity. They would ask why she was in the wheelchair. I could feel and see the curious parents and older siblings strain to hear the answer. I started to answer the young children on two levels, one to satisfy the young child asking the question and the other to inform the curious onlookers. After a couple seasons of ball games, the idea to write a children's story seemed the best way to explain our situation and build understanding. So began the fairytale of Princess Sophia's Gifts. As I wrote, with the idea of building understanding for others in mind, I discovered that the writing of the story helped me in my personal journey to understanding. It gave me a way to put our experience, our story, into something tangible. I had often referred

to life, prior to my daughter's disability, as living a fairytale, only I did not realize it at the time. It seemed only natural to begin our story as a fairy tale. As with most fairytales, prior to happily ever after, there is some type of seemingly insurmountable challenge. This was certainly part of our story. Our daughter's choking accident and near death left her extremely physically disabled. Our life irrevocably changed. Most physical abilities are taken for granted; these were lost to our daughter. She cannot talk, walk, eat, sit, or even blow her own nose. The impact of this accident was profound. It changed our perceptions and even our most basic assumptions about life.

As I wrote Princess Sophia's Gifts, I was writing our family journey. After scavenging, as toddlers will do, my youngest daughter choked on an unpopped popcorn kernel. As she ran around and played for an entire day, there was no sign or indication that the kernel was resting at the bottom of

her lung. Much later, when she was lying down in bed sleeping, the kernel was able to move with each breath causing swelling and eventually the little kernel blocked her breathing. When her breathing stopped, so did her heart. She had no vital signs for twenty-five minutes before being brought back to life. When it comes to brain damage this is roughly fifteen minutes past the last possible chance to recover. The first neurologist to meet with us after our daughter's accident had a five minute rule. She did not hold out much hope for one who had no oxygen to the brain for longer than that. She was very blunt in her assessment. She stood at the end of our daughter's hospital bed and told us she would be "little more than a lump." Later she commented that "at least we had other children" as though our daughter was a throw away commodity that no longer served its function. It was encounters such as these, of which there were far too many, that became part of the journey through dark tunnels.

Many people have written about near death experiences sighting images of light and encounters with others. Although I had rarely considered this, I often wondered about that time when my daughter's heart did not beat and she



Sonia loves horses and they love her. This is Sonia with her horse Lilla.

was unable to take a breath. As our daughter ever so slowly recovered to the extent possible, it was clear her spirit was still strong. Although my faith was shaken, I was certain my daughter had already seen the eyes of God. She has a radiant smile and beauty that shines through her. Her laughter is intoxicating. We often do things simply to get her to laugh such as walk into a wall, pretend to trip or do something just plain silly to merely hear her laugh. And she is so patient with all of us (most of the time). Whenever we return home, she squeals with delight and her whole body greets us with joy. These are incredible gifts, ones we savor and ones we seek. These gifts had to be conveyed in the story as these are the true essence of being. The women in Princess Sophia's Gifts are the embodiment of these gifts. The first woman is a reflection of an older version of Sophia and the other women are the gifts they offer.

With tragedy come questions, most especially "why". Why me? Why us? Why, why, why? The search for answers and the

desire to fix, to return to 'normal', is strong. It pushes and compels. Each new milestone, pothole and sleepless night triggers new questions and pangs of loss. Learning to handle these encounters is part of the journey, a journey that seems never-ending. 'Happily ever after' is not part of real life. Nor is it part of the Princess Sophia's Gifts fairytale. Like my daughter, the princess does not miraculously return to being non-disabled. Nor does everyone come to understanding. In this fairytale and real life story, happily ever after is an acceptance of what is, as well as a push for unanticipated possibilities to unfold. It is a dynamic balance.

One of the biggest challenges to our real life story as well as to writing this fairytale is that of expectations and norms. In writing children's literature, the expectation is that the main character, the child in the story, must be the one to encounter the challenge and the one to overcome the challenge or be part of the solution. The main character cannot be passive. Yet, the point of this fairytale and the real life story is that neither Princess Sophia, nor my real life daughter, have the physical abilities to be the heroine in the manner we expect.



Family vacation in the Canadian Rockies.

Both the character in the story and my daughter lose these abilities we take for granted. This does not mean they lose their gifts or their ability to master the challenge. In fact it is their gifts that show us the way through the challenge. For instance, in the story the royal family determines it is time to return home when they realize their daughter's laughter is the real warmth of their home. It is Princess Sophia who reveals the answers to Athena's question through her laughter and a squeeze of the hand. It is through her essence, her beauty, laughter, joy and love that the Princess

teaches understanding and ways to grow. These are treasures so easily overlooked when we encounter people or situations we do not understand. Like this story, the child heroine is the one who plays the vital role in overcoming the challenge. Yet, this is not as easily recognized because it is outside our common understanding that one who is so physically limited can have such a profound effect on others.



Sonia Prom 2007

As with many fairytales, there is often guidance that is offered. The trick is that one needs to recognize and accept this guidance. Athena is the guide in Princess Sophia's Gifts. She is the poetic representation of wisdom and reason. In real life, wisdom is gained through experience and reflection that leads to understanding. Wisdom is not simply granted or found, it requires time and the willingness to travel through complexities and make sense out of the senseless. Wisdom is the embodiment of the many people who have touched our life and helped in small or big ways to live with the challenges of disability. The writing of this story was part of this journey toward wisdom. The writing helped me weave together the pain and hurt of our journey with the love and hope we held for our daughter and our family. May your gifts always shine!

by Diane Hovey, PhD



### Book Readings

Sonia does not like it when people talk about her disability. However, she loves her story and doesn't mind the discussion of her disability in the context of a book reading. Her story gives distance and a respectable way to discuss her disability and her gifts. Both of us dress in costume for

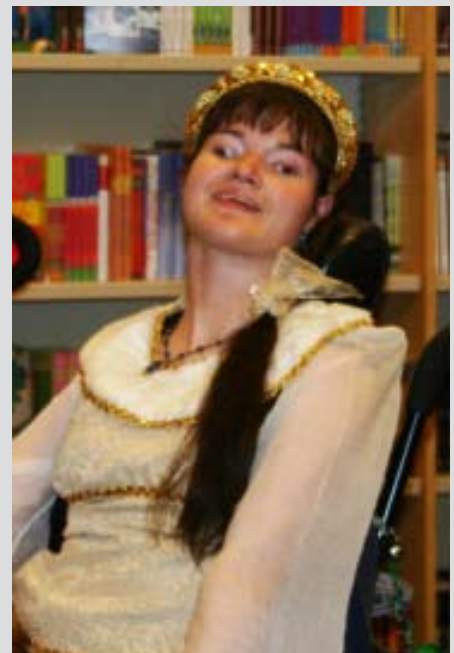
readings because it makes reading and listening to the story more fun and because it gives distance, making it easier to tell the story one step removed.

If interested in a book reading or more information about Princess Sophia's Gifts contact Diane Hovey at:

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Book reading at Barnes and Noble, 2009