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Shannon Kenitz:
*A Powerhouse of Strength
and Endurance*

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Extraordinary Profiles

Shannon Kenitz: A Powerhouse of Strength and Endurance

By Monica Davis

When Shannon gave birth to Grace on March 6, 1999, she was one of the happiest parents on earth. But her happiness began to fade as she noticed a change in her child. Grace wasn't eating well and her eyes began to roll frequently. These symptoms were later diagnosed as seizures. By age five months, Grace was diagnosed as failure to thrive. This was the beginning of a long journey for Shannon and a test of her faith. It was a road she was determined to travel



regardless of the obstacles thrown in her path. At age one, Grace was blind, being fed through a tube, weighed only eight pounds, and had received several blood transfusions, platelet transfusions, and albumin transfusions. She was completely non-verbal and unable to sit or crawl.

The exact cause of Grace's illness was not determined until she was about one and a half years old. She was diagnosed with Mitochondrial Disease in the rarest form. Grace spent three years in the hospital and was tube-fed until she was five years old.

Mitochondria are small organelles found in the cells of the body that function as powerhouses for the cells. Depending on which cells are affected, symptoms may include: retarded growth, loss of muscle coordination, muscle weakness, visual and/or hearing problems, developmental delays, learning disabilities, neurological problems, seizures and a host of other symptoms. In some patients, only one organ is affected, while in others all of the organs are involved. Mitochondrial disorder can range in severity from mild to fatal. To add to Grace's Mitochondrial condition, Grace was then diagnosed with autism at age five and a half.

With God's help, Shannon's faith, tireless efforts and hard work brought Grace from a child who many believed was destined to die to a child who is experiencing a miraculous recovery.

Shannon paid for many of Grace's medical expenses prior to a diagnosis of her condition. Once a diagnosis was made, her lifetime benefits were depleted. Grace was then placed on disability. The stigma of being on disability and being labeled did not sit well with Shannon but through the encouragement of others, she was convinced that placing Grace on disability would be beneficial.

Grace's medical bills were well into the millions by the time she was three years old. Shannon says, "I still get bills and I just put them in a bin, because there's nothing I can do." It has been a constant struggle for her to raise money for Grace's care.



Grace's illness has required that Shannon travel to different medical facilities across the country. Shannon only received state aid and some medical expenses were not covered. Due to the fact that she was a single parent and had no additional funds, many medical centers were willing to write off costs.

Believing that Grace could be saved, despite opposition from family, friends and the bleak diagnosis, Shannon was inspired to consider alternative medicine for Grace.

Grace's therapies are currently over \$15,000 a month. Shannon's saving grace comes from companies that are willing to help pay for some of the expenses. Before Hyperbaric Oxygen Therapy, Grace's care was costing almost \$200,000 per month. Hyperbaric Therapy is considered an alternative therapy treatment for autism. Grace has not been hospitalized since taking this therapy. It is the second highest rated therapy treatment for autism, the first being a diet change. Since being placed on a gluten and soy free diet, Grace's condition has improved tremendously.

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As Shannon states, “some people believe that autism is only behavioral and not treatable, while others believe it is the result of vaccines or toxins in the environment. Shannon believes that “it doesn’t matter how they get it, but that they deserve every chance and right to get better.”

Grace’s diet has helped in curtailing many of the symptoms – the hands banging against the head, the hand slapping and the twirling of the fingers. She receives a blood transfusion every 21 days.

Oftentimes Shannon’s parents and friends didn’t understand her dedication to helping Grace, no matter the costs, which often meant spending countless hours in the hospital and less time with her husband and her daughter Lilian. They viewed it as neglecting her family for something she had no control over.

At one point, things were so bad that Shannon told her family and friends that she never wanted to hear from them again any discouraging words about Grace because they felt that she should consider terminating Grace’s life. “I got about fifty people in the room and I told them, it’s not going to happen, and you’ll not be welcomed in Grace’s room and you won’t be welcomed in my life.”

As they began to see miraculous changes in Grace, Shannon’s parents, family and friends have been very supportive of her efforts to give Grace the best life possible. Many things that Grace could not previously do, such as communicate with her sister and mom, she is now able to do and she continues to improve. Unfortunately, Shannon’s husband and in-laws never supported her, which eventually led to their



divorce. Studies have shown that about 85% of marriages involving special needs children end in divorce.

Shannon’s daughter, Lilian has been incredible during

Grace’s struggle. She has learned to accept other people and their disabilities.

Shannon’s efforts in fighting for Grace have not only been a stabilizing force for her daughter, but have become an inspiration to other parents with children who have autism and mitochondrial disease. The trials and tribulations that Shannon has endured have been very difficult. Her experiences not only gave her immeasurable strength in the face of adversity but she used them to show other parents who are experiencing similar situations that there will be tough times ahead.

Shannon says, “Everyone will not be supportive of you and many of them won’t know how to support you.”



In the beginning it was just a mom trying to save her daughter, but now Shannon’s dedication and commitment to finding alternative medicines and therapies is the saving grace for other parents. Shannon’s and Grace’s fight for life has given them hope. It is the thank you cards and face-to-face appreciation from other parents that drives Shannon to continue her fight for families across America.

Shannon’s advice to parents of children with a genetic-neuro or degenerative diseases is that physicians can

only do so much. “They look at the science behind something. But there is something inside of us called hope. If you don’t have hope, then you don’t have anything. I tell parents that anything is possible. Don’t give up on your child. I don’t know if tomorrow will be my last day with Grace. Just having an extra day with her has made all the difference in the world for me. Never give up hope. No one has the ability to take that away from you unless you allow them to.”

Shannon often had dreams of having everything that Grace needed in one location. Shannon’s dream came true, as she was instrumental in establishing the very first Place of Grace Center.

Through research she located investors who supported her desire to have everything in one location, including occupational therapy, hyperbaric therapy, marriage counseling, speech therapy, cooking classes, nutritional guidance and many other support services. About three years ago the first center was opened in Madison, Wisconsin. In April of 2007, the second center was opened in Irvine, California.



Shannon has become a spokesperson for other parents whose children suffer from autism. She often travels across the country, giving interviews, meeting with politicians and law-makers to bring awareness of the disease and help find ways to raise funds for research.

Shannon’s fight for her daughter and her determination to help find new treatments and funding for autism has been recognized on many news and talk shows such as the CBS Morning Show and the Montel Williams Show. ♦