

# Natalie's Wish

■ By Susan Hillgren

"If you could snap your fingers and know that you couldn't fail, what would you do?" Sharon Corzine and Betty Thompson, leaders of the St. Andrew's Discovery Experience workshop, posed that question to our covenant group in February 2003.

Without hesitation, Nancy Stack responded that she would fund doctors researching cures for "orphan" diseases. Because "orphan" diseases affect less than 200,000 people, research money for them is scarce.

Nancy's 13-year-old daughter, Natalie, has Cystinosis, a rare genetic disorder that causes the amino acid, cystine, to accumulate in the body's cells. As cystine is trapped in the cell, it forms crystals that slowly destroy the organs in the body.

Right now, there is no cure for Cystinosis. The medicine given to prolong the life of Cystinosis patients like Natalie is so potent, doctors used to give it to lab rats to cause stomach ulcers. The medicine is foul-tasting and must be taken every six hours around the clock. Natalie has been ingesting this drug and enduring the strong side-effects of abdominal pain and headaches since she was an infant.

Our covenant group had held Natalie and Nancy in our hearts and prayers through the years filled with a blur of doctor appointments and

medical tests. But Natalie's life is not one of sorrow or defeat. On the contrary, she embraces life with pure joy and unstoppable courage.

While our covenant group was progressing through the Discovery Experience, Natalie had her 12<sup>th</sup> birthday. Her mother took her to Ruby's for lunch and asked what her birthday wish was. Natalie grabbed the pull-out napkin and scribbled on it with a purple crayon, "To have my disease go away forever." Too reserved to speak her wish, she handed the napkin to her mother.

Nancy came to our next covenant group with this napkin in hand. She knew her God-given passion was to fulfill Natalie's wish through the Discovery Experience. She had identified her spiritual gifts of mercy, administration, faith and giving. With this knowledge, she set into motion a campaign to fund research for finding a cure for Cystinosis.

Nancy explained, "The spiritual gifts journey with Sharon and Betty helped me to focus on how to share Natalie in a positive way. Prior to it, I had an inner voice saying 'It's too hard to talk about her disease all the time. I don't think you should publicly expose Natalie because it might be hard on her.' But it's time now. I can't live my life as her mother and not do this. I am going to share her birthday wish."

Within three months, Nancy and her husband, Jeff, organized a fundraiser for the Cystinosis Research Foundation. It is now an annual event called "Natalie's Wish."

To date, they have raised more than a million dollars.

Nancy admitted, "I can't say I love to fund-raise. It's hard to talk about Natalie's disease all the time. But, I have learned joy doesn't have to be something fun or easy to do. Joy for me is seeing the money we've raised used for 'orphan' disease research."

Nancy smiles when she thinks back on the first session of the Discovery Experience when our covenant group was discussing passion assessment. "I remember thinking to myself, that

there is no way I am going to fit in this workshop."

But, a napkin with a birthday wish scribbled on it changed all that. Now, Nancy is faithfully using her spiritual gifts to help make Natalie's wish move closer to a reality.

For further information regarding "Natalie's Wish," contact Nancy Stack at 949-760-5375 or [heystack4@aol.com](mailto:heystack4@aol.com)



Natalie and Nancy Stack