

SUCCESS STORY- RESPITE CARE

Lila* was born with a congenital heart disease known as hypoplastic left heart syndrome. She also has a hypoplastic lung. One of the most rare and complex of all congenital heart diseases, hypoplastic heart disease occurs in newborns when the left side of the heart does not form properly and is unable to adequately pump blood. At that time, her family was told the prognosis for Lila's life expectancy was six months.

At age five, Lila was a miracle. She still had many health challenges and required 24-hour care by her adoptive parents, Beverly and Jim. The couple rejoiced in their daughter, more than prepared to meet her special needs and show her great love and care. As her health needs increased, they contacted a Respite Care program funded by Rappahannock United Way. This program trains volunteers to enter a home and care for someone in need, giving that person's caretaker the opportunity to run errands, for instance, with the relief that their loved one is in good hands.

Many Respite Care volunteers enter homes to care for seniors, so providing volunteer support for Lila would be a unique and special case. Respite Care Volunteer Katie was contacted about her interest and availability for Lila and their relationship has blossomed since the first meeting. Since then, Katie has provided numerous visits to the home, usually twice weekly, which involves a 54 mile round-trip from her home. Katie reads to Lila, helps her with puzzles, creates art projects, watches videos, plays on the computer, sings with her, and plays with dolls. One particular volunteer note from Katie written on July 1, 2010 reads as follows:



*Lila is not pictured

"Lila attended camp in the morning, and I visited in the afternoon. Beverly was able to do yard work while Lila and I played a few games including hide and seek. This is one of my favorite things to do with her because when Lila hides, she doesn't realize two very important things. One: I can follow her oxygen tubing to find her very easily (that's cheating, I know). And two: she often hides under her bed. Well...only a portion of her hides under the bed, while her entire body is sticking out. Lila does not realize I can see her and often giggles while I search and search to no avail..."

During these special one-on-one times with Lila, volunteer support for Lila's mother and father provides a dual role which includes respite to allow them to do housework, cut grass, complete yard work tasks, do laundry, run errands, and have lunch with a friend. Katie has accompanied the family on a visit to Children's Hospital, where Lila receives all of her tests and monitoring of the disease process. During the extended trip to the hospital through northern Virginia traffic, Katie was able to keep Lila comfortable and occupied for the long ride.

Lila is currently six years old, and though she continues to struggle for her health at times, she and her family are hopeful. As we all follow Lila's status, we are given an opportunity to reflect on the precious gift of life, and how even seemingly small gestures convey immeasurable love and support. The physical and emotional burdens of caring for a child with such severe medical issues is especially difficult, but Lila's life journey has been made easier with the support of Respite Care's Volunteer, Katie. Katie has provided time, assistance, friendship, and support in a unique way to help this special family. This program offered hope and a caring support system which has not only provided respite, but has enhanced the quality of life for a child and her mother and father, who are cherishing the gift of life every day.

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