

The Gift of Noah's Children

Up until age four Brittany Knapp

developed normally – she walked, talked and was potty trained – until her parents, Andrea and Cornelius, began



Brittany is an enthusiastic 7th grader at Carver Middle School.

to notice different speech patterns and sensed that their daughter was not progressing normally. Thinking the cause might be an ear infection, Andrea took Brittany to the pediatrician, who discovered other troubling symptoms and recommended a geneticist, who eventually diagnosed Brittany with Sanfilippo Syndrome (also known as MPS), a metabolic disease.

Soon, severe hearing loss set in, followed by multiple hospital stays for breathing difficulties, among other problems. Today, at the age of 12, Brittany is completely wheelchair bound and unable to communicate verbally. Despite these limitations, Brittany enjoys attending school at Carver Middle School where she is a 7th grader.

Because there is no specific treatment for Brittany's condition, her family relies heavily on the services provided by Noah's Children. The family first learned of Noah's during Brittany's hospital stay in 2007. Since then, Andrea says, "Noah's has been a Godsend. They've done everything for us. Whether I need a simple question answered or if I just need to rant and rave, they're always there for me."

Support from Noah's is especially important to the Knapp family because, in addition to Brittany, Andrea and Cornelius are the parents of two other children, Chelsie, age 11, and Chloe, nearly 2. Andrea also works part-time and attends night school.

Because she is on the go around the clock, Andrea

says that she couldn't have survived this long without Noah's Children. "The staff and volunteers do so much for us. I can call the nurses or social worker anytime to ask them questions. But for us, the best thing about Noah's Children is that they work with the whole family, not just the special needs of the child."

Andrea is also grateful for the Noah's volunteers who have provided them with food, holiday gifts, haircuts, massages, house work, craft activities, and in particular the volunteer who serves as a mentor to Brittany's sister Chelsie.

In many ways, Brittany is like any other child – she loves riding the school bus, watching SpongeBob on television and lounging around in her bean bag chair. A benefit she has that others do not, said her mother, is "the gift of Noah's Children."

For more information on how you can volunteer to help families like the Knapps, please contact Fran Givens at (804) 287-7686.



"In many ways, Brittany is like any other child," says her mother, Andrea.

What is Sanfilippo Syndrome?

Occurring in approximately 1 in 70,000 births, Sanfilippo Syndrome is an inherited lysosomal storage disorder that does not allow the body to properly break down long chains of sugar molecules called glycosaminoglycans. This multisystem disorder is characterized by central nervous system involvement and typically begins to occur between ages 2 and 6. Symptoms include delayed development, deteriorating mental status, below-average height, behavioral problems, coarse facial features, full lips, heavy eyebrows that meet in the middle of the face above the nose, sleep difficulties, stiff joints that may not extend fully, and walking problems. For more information, please visit the National MPS Society at www.mpssociety.org.



Perinatal Palliative Care

**From the Medical Director:
Bob Archuleta, MD, FAAP, FAAHPM**

Congenital anomalies such as anencephaly, trisomy 13, trisomy 18, severe cardiac deformities, severe brain anomalies and renal agenesis are the leading cause of death in the first year of life. When such a diagnosis has been established, parents generally are confronted with two options: termination of the pregnancy or expectant management. Perinatal palliative care, an emerging concept in the field, has resulted in a decrease in the number of parents choosing to end the pregnancy. By integrating hospice and palliative care principles into the process, newborns, families and NICU staff benefit from comprehensive, interdisciplinary palliative care provisions that attend to the medical, emotional, spiritual and practical needs, which result in a greater likelihood of an optimized quality of life for both the newborn and the family.

This type of perinatal care begins at the time that a lethal anomaly is diagnosed in a fetus and affects the obstetric approach for caring for the pregnant woman around the time of delivery. Significant planning is necessary so that palliative care can be provided regardless of whether the infant lives hours, days, weeks or months.

With a prenatal diagnosis, much of the advance care planning can be addressed prior to delivery. These plans include discussing issues and arriving at decisions regarding limited initial resuscitation or the withholding of resuscitative efforts.

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If the decision is to allow a natural death, the palliative care team is prepared to offer anticipatory guidance, which includes preparing parents for how a child in this situation might die. Other plans include insuring the availability of a supportive environment with the presence of family, friends and spiritual advisers as desired by the parents. The supportive presence of the palliative care interdisciplinary team and the desire by staff to be present are as important as the site of care or of symptom management. The environment supports attention to maximizing comfort, minimizing pain and other discomforts (such as bright lights, loud noises and sleep interruptions) and facilitating family involvement.

Palliative care for an infant with a lethal anomaly can be comforting, meaningful, and as ethically and legally acceptable as the provision of life-extending endeavors. For more information on this and other Noah’s Children services, please call (804) 287-7686.

A Generous Gift

On October 8, the Huguenot Show Hunters 4-H Club of Chesterfield County, a group of 13 young ladies who love horses, donated \$1,200 to Noah’s Children in honor of Bowen and Helen Turner, year-old twins born with Wolf-Hirschhorn syndrome, a genetic chromosomal disorder. The twins’ mother, Fiona Turner, is a riding instructor at Level Green Riding School, in Powhatan, where many of the girls ride horses. The money, raised through concession sales, will help Noah’s Children provide support for other families like the Turners, and we thank these thoughtful young people for their generous support!

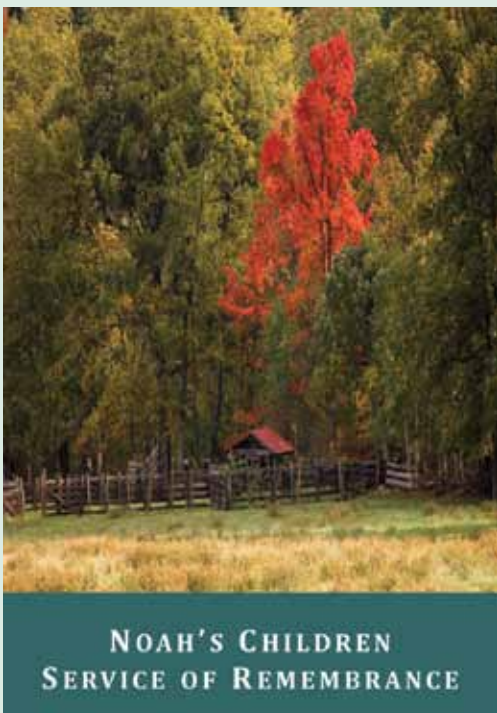


The Huguenot Show Hunters 4-H Club raised money for Noah’s Children in honor of their riding instructor’s twins.

Remembering

On November 22, Noah's Children hosted its annual Service of Remembrance honoring those families whose lives have been forever changed by the loss of a child. With a theme of "To everything there is a season," the event at the chapel at St. Mary's Hospital brought together families who shared stories of their loved ones and consoled each other in their grief. This year's service was developed with a team of parents and volunteers, and included photos, candle-lighting, prayers and comments from families who spoke of their difficulties and inner strength in dealing with the death of their children.

"There is great meaning in having your loss recognized by others," said Rev. Sallye Hardy, Chaplain, "and for an afternoon being able to leave the isolation these families normally live within. This is intended to be a healing event. And while the subject is incredibly difficult, the families who attend find comfort and solace in sharing their grief with others who are familiar with that pain." For more information on Bereavement Services offered by Noah's Children, please contact Sallye Hardy at (804) 287-7686 or at sallye_hardy@bshsi.org.



Volunteer Spotlight: Estelle Call



Estelle Call

We recently sat down with volunteer Estelle Call to ask her a few questions about her experience working with Noah's Children.

How did you come to volunteer at Noah's Children?

After I read a newspaper article about Dr. Archuleta's idea for a children's hospice, I called and said I was interested in being a part of it. I had volunteered with an adult hospice program for six years, and I knew there was a great need for one that served children. Even though I had previously vowed not to become involved in children's hospice, I decided that I could learn to be strong and to give in this way. I realized that it is the families who give to me more than I give to them. To come into a family and be a part of their lives and share their anguish and their joy is very powerful.

Tell us about your experience as a Noah's Children volunteer.

There are times when I weep for the children and families and times when I weep with them. I come home and my life goes on, but theirs continues each day in struggle. I return the next week hoping to see some change... not knowing what to expect in a week's time.

I've had so many special moments as a Noah's volunteer. I've shared fears, hopes, and, yes, joys. I've spent much time with the siblings of ill children, taking them out and allowing them to have some fun in the midst of their confusion and darkness. Occasionally I've brought some of these children to our place in the country just so they can play, run and be free. A particularly special moment occurred when one of those siblings whom I had brought to my home, wanted to bury their loved one at my house overlooking the river! There simply are no words to express the powerful, healing love that takes place when sharing these journeys with the families.

What three words would you use to describe Noah's Children?

Noah's Children is Exceptional, Dedicated and Committed.

Why is Noah's Children special?

Noah's is special because of their role as a hospice specifically for children. They are "in the know" as it relates to the concerns and needs of ill children, as well as of the siblings, family and extended family. Noah's becomes a "family of help" in every aspect.

What would you say to families deciding whether or not to enroll in Noah's Children?

A family in the Richmond area with an ill child will receive the very best and most comprehensive care through Noah's Children. Their team-care approach extends beyond the medical needs. For each family, the Noah's team is there 24/7 with genuine love and experienced help.

Forty One Success!

More than 300 guests ate, bid and danced their way through the evening of October 23, as Noah's Children held its annual fundraiser, Forty One, at the Country Club of Virginia. Along with heavy hors d'oeuvres, wine pairings and music, live and



Dr. Bob Archuleta, Master of Ceremony Andrew Freiden, and the young artists from St. Michael's School unveil the 2009 Noah's Children artwork.

silent auctions brought in a total of \$151,800 to help support Noah's annual operating expenses. "This event," said Dr. Bob Archuleta, medical director for Noah's Children, "as well as additional contributions from the community throughout the year, allows us to continue providing hospice and palliative care services free of charge to the region's most vulnerable children and their families."

A highlight of the evening included the unveiling of a new Noah's Children art piece designed by 2008-2009 kindergartners at St. Michael's School. As you may remember, the original idea for Noah's Children began after Dr. Archuleta purchased a Noah's Ark collage created by another kindergarten class in 1997. Today that tradition continues as a new group of six-year-olds, under the direction of teacher Sue Drudge, created their own interpretation of this year's theme of "Friends." Prints of the artwork may be purchased for \$10 at the Noah's Children offices at 5855 Bremono Road (Medical Office Building – NORTH), Suite 409. For more information please call (804) 287-7686.



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