

A Family's Faith

When entering the Donahue home in rural Cumberland, Virginia, prepare to be hugged, jumped on and even tackled. Headed by parents, Stephen and Joanna, the family includes five children: Graham, 14; Samuel, 9; Abram, 7; Timothy, 4; and Mary, 2; all of whom greet visitors with great enthusiasm and energy. You may not think that a home with five active children could be peaceful, but this family is fueled by tremendous love, laughter, faith, strength and even serenity.

That sense of calm was essential when, while pregnant with their sixth child in November 2009, Joanna learned that the baby boy had anencephaly, a rare birth defect resulting in the absence of a major portion of the brain, skull, and scalp. Devastated and in shock, Stephen and Joanna were encouraged by their midwife to reach out to Noah's Children for support.

"We had never been through anything like this before," said Joanna, "so we were completely unprepared. Noah's Children came in and educated us about the disease, the statistics, the prognosis and what to expect."

What is Anencephaly?

Anencephaly is one of the most common neural tube defects – a birth defect that affects the tissue that becomes the spinal cord and brain. It occurs early in the development of an unborn baby and results when the upper part of the neural tube fails to close. Why this happens is not known. The majority of babies with this condition do not survive birth. Anencephaly occurs in about 1 out of 10,000 births, although the exact number is unknown because many of these pregnancies result in miscarriage.



The Donahue family – (clockwise), parents Joanna and Stephen, Graham, Samuel, Abram, Mary and Timothy – is surrounded by love, laughter and faith.

Because most babies with this condition do not survive birth, the Donahues didn't know how to prepare themselves or their family for what was to come. Noah's Children worked with them to create a birth plan that would determine the kind of intervention they would pursue if their son were to be born alive. "Not knowing what would happen was incredibly difficult," said Stephen. "But having the birth plan gave us a road map so we would know what to do."

The sensitivity and understanding with which Noah's cared for the entire family were also appreciated. "They were very good about supporting our positions as parents," Stephen said. "From the beginning they wanted to know about our beliefs and feelings about life and spirituality, so that when they spent time with our children, they could also reinforce our family's beliefs and goals."

One of Stephen and Joanna's biggest concerns was how to prepare their five children to accept the sad news. Noah's staff provided emotional support, reading materials and talking points. "But most of all," said Joanna, "They gave their time to listen, talk, pray with us, or just play with the kids. Day or night, we could always count on them. They relieved the emotional stress by taking care of all the details."

Baby boy, Jonathan Elijah Donahue, arrived stillborn on February 3, 2010. "Our children and grandchildren came through

Role of the Nurse

NOTE FROM DR. BOB ARCHULETA: This issue continues our profile series of members of the Noah's Children integrated team. We hope you enjoy learning more about these compassionate employees and their critical functions.



An important part of the integrated team at Noah's Children, the role of the nurse can best be described as part medical provider, part spiritual adviser, part social worker and part volunteer helper all at the same time, depending on the needs of the family. That's a lot of



Patty Hertel

hats to wear, but these four extraordinary women, Patty Hertel, Cathy Poythress, Jennifer Hayes and Beverly Rinde-Thorsen, make it look effortless even as they work around the clock taking care of Noah's patients and families. While they perform all of the "normal" nursing tasks like checking vital signs and administering medications, "that's only a small part of what we do," said team leader, Patty Hertel.

An even bigger part is education. "I have provided more education in this job than ever before in my life," Patty said. "And it's not all medical education. It's also education about support services and how to look for signs that a child is doing poorly or well. We teach families how to pick up and play with their baby even though they may be afraid that one of the tubes may come out."



Cathy Poythress

Added nurse Cathy Poythress, "Instead of looking at death, we teach families how to enjoy life and how to have fun with their child for the time they have remaining."

As gatekeepers of information, the nurses coordinate a patient's care among a variety of doctors, specialists and hospitals, keeping the lines of communication open and all parties updated. By conducting much of the behind-the-scenes work that is often overlooked, the nurses alleviate a great deal of a family's stress. For example, among other things, these nurses make 3:00 a.m. house calls to deliver medical equipment, work with insurance companies to obtain coverage for medications, ensure patients' prescriptions are ready when the family arrives at the pharmacy, and arrange for books and videos to entertain a family's other children during hospital stays. "We just do whatever needs to be done," added Patty.

"Instead of looking at death, we teach families how to enjoy life and how to have fun with their child for the time they have remaining."



Beverly Rinde-Thorsen

The nurses may also find themselves serving as family mediators when disagreements arise over a patient's care options. "We step in and try to negotiate what's best for the families and the patients," said nurse Beverly Rinde-Thorsen. "We become a sounding board, so that families can feel comfortable opening up and talking to us about any number of concerns."

"Families in crisis need someone objective they can call to ask questions, offer advice or just listen, added nurse Jennifer Hayes. "And we provide an unbiased ear that will support whatever decisions the family makes – without judgment."



Jennifer Hayes

The nurses know theirs is an awesome responsibility, and they take it seriously. But they also admire the strength and perseverance of the families they serve. "I am in complete awe of these families and how they handle their situations," added Cathy.

And we are in awe of our nurses.

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this situation very well," said Stephen's father, Joe Donahue, "and I think that's in part due to Noah's Children." Added Joanna's mother, Gail Brandt, "Noah's Children really ministered to the family, going above and beyond the call of duty many times."

Today the family continues to cope with their loss, and credits the support of their church, family, friends and Noah's Children for sustaining them through it all. "The pain never goes away," said Stephen, "and we continue to grieve, but as a family, this will and already has helped us grow in the knowledge of God's grace and mercy in our life."

The love, laughter and faith continue to live on.

Forty One Fun!

More than 300 guests attended this year's Forty One Gala held Oct. 16 at the Hilton Richmond Hotel & Spa in Short Pump. The lively event featured heavy hors d'oeuvres, wine pairings, live music, and silent and live auctions. Auction items included a Golf Getaway at Hilton Head, 41 Bottles of Wine, a handmade Noah's Ark chest, and prints of the original artwork from the Noah's Children 2011 Commemorative Calendar, which was created by art students from 14 Richmond-area schools. This year's event raised \$160,200 for Noah's Children, and we thank everyone who supported this annual fundraiser!



Kids Helping Kids – In Action!

A crowd of 150 students, teachers, principals and friends of Noah's Children gathered on September 23 at the Children's Museum at Short Pump to celebrate the official launch of the 2011 Noah's Children Commemorative Art Calendar. Food and



Student Katelin Kasemersky reaches out to help Noah's Children patients with a card and donation.

fun were the objectives of the event, but it also served as a way for founder Dr. Bob Archuleta to publicly thank the student artists from the 14 participating schools. The event also included a brief video and a testimonial from Christi Hancock, mother of Ella Hancock, a Noah's Children patient who passed away in September 2008.

A few days after the calendar launch event, Noah's Children received the

following card and note from Katelin Kasemersky, a nine-year-old Bon Air Elementary School student. "Dear Noah's Children, I was at the ceremony last night for Noah's Children. The video touched my heart so I wanted to make a picture. Love, Katelin." The letter also contained an \$11 donation from Katelin's own piggy bank.

"It is letters like this one," said Dr. Archuleta, "that demonstrate the capacity of young people to help their peers in need. It's an honor to work alongside such displays of love and generosity."

A Time for Reflection



On Sunday, November 7, Noah's Annual Service of Remembrance was held in the historic St. Mary's Chapel to celebrate the lives of children who have passed away and honor those who loved them. This annual gathering allows families to share their pain, as well as coping mechanisms that have helped them move through that pain to find their new "normal." This year's service was enhanced by the participation of children from the American Youth Harp Ensemble.

As always, it is when the names of the children are read and a candle in memory of each child is lit that the reality of the loss becomes palpable. Said Chaplain Sallye Hardy, "There is something about hearing your child's name called and knowing that, at least while you're in this setting, others understand your pain and loss."

These families uniquely share a piece of each other's stories – and for an afternoon, they are not alone in this journey. For more information on bereavement services offered by Noah's Children, please contact Sallye Hardy at sallye_hardy@bshsi.org or (804) 287-7686.

New at Noah's



Chasity Craft

Welcome to Chasity Craft, who joined Noah's Children in September as Volunteer Coordinator after the retirement of Fran Givens. Chasity comes to Noah's Children with experience in sales, marketing and web content management. She also spent four years as Director of Corporate Relations with Children's Miracle Network. Chasity is excited about

her new role at Noah's Children and is working hard to recruit new volunteers to help with everything from administrative tasks to working directly with families and siblings of Noah's Children patients.

To learn more about volunteer opportunities, please contact Chasity at Chasity_Craft@bshsi.org or by phone at (804) 287-7686.

Great Holiday Gift Idea

Be sure to pick up the 2011 Noah's Children calendars for a beautiful and thoughtful holiday gift for family and friends. Proceeds from calendar sales will be used to continue the Noah's Children mission to provide services to children with life-threatening illness and their families, in concert with all area health care systems and regardless of a family's ability to pay.



**Calendars cost \$12 each (or 5 calendars for \$50)
and can be purchased at the following locations:**

- ◆ Noah's Children Offices (St. Mary's Medical Office Building North, Suite 409)
- ◆ Online at www.noahschildren.com
- ◆ Children's Museum of Richmond (both locations)
- ◆ The Shops at 5807 (5807 Patterson Ave)
- ◆ Bon Secours Hospital Gift Shops (St. Mary's, St. Francis and Memorial Regional)
- ◆ Bon Secours Family Centers (St. Mary's, St. Francis and Memorial Regional)

IN MEMORIAM

Claire Abigail Tanner

12.02.06 - 10.21.10

*We celebrate the life
of this child
and honor all those
who love her.*

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