

The Faithful Way

Military families are the epitome of strength and courage, and their sacrifices often go unnoticed. As strong and prepared as they are to serve our country, however, Shannon and Hasahnn Reynolds were not prepared for the outcome of a regular prenatal visit last September. At nine weeks pregnant and because she was over the age of 35, Shannon's doctor ordered standard genetic tests. The preliminary results led to additional testing, including an amniocentesis, which finally revealed their unborn child had Trisomy 18, a rare and life-threatening chromosomal abnormality.

The joy of being pregnant was quickly replaced with the shock of a devastating diagnosis. Most Trisomy babies are stillborn. Those who do survive generally don't live long, perhaps a week or a few months. But there are exceptions, and that's the hope the Reynolds family, which also includes 11-year-old son, Sanji, embraced.

"There was, of course," said Hasahnn, "a tremendous amount of uncertainty. We just didn't know what to expect. We encountered many naysayers who said it would be easier to end the pregnancy. That weighed heavily on our hearts."

"That would have been the easy way out," added Shannon. "But the hard way – the faithful way – meant accepting this child as a gift from God in whatever condition He chose to give her to us. So we prayed. A



Parents Shannon and Hasahnn cradle Nyala, their special gift from God.

lot. And we found Noah's Children through a discussion with our perinatologist. Noah's Children helped us understand the diagnosis, as well as the prognosis, and provided us with everything we needed to prepare for an unknown outcome. A huge part of their assistance came in helping us communicate our feelings and concerns safely, openly and with pure honesty."

The Reynolds family welcomed their baby girl, Nyala, on Good Friday, April 3, 2015. She wasn't breathing on her own and initially had to be intubated. As small as their daughter was, however, the Reynoldses quickly learned Nyala was also a fighter and determined to survive. Her breathing tube was removed after only seven hours.

The next 36 hours brought heart-wrenching scares when Nyala stopped breathing and her heart rate dropped drastically. "We thought we lost her several times," said Hasahnn.

"We made a pact early on," added Shannon, "not to put her through any unnecessary pain because we were selfish and wanted her here with us. We hoped and prayed that we would at least be able to bring her home. Whatever happened then would happen at home. We simply asked God to give us as much time with her as He needed for us to have. Our son, Sanji, announced he wanted to have at least 100 days with his new sister. That was quite an emotional conversation."

What is Trisomy 18?

According to the Trisomy 18 Foundation (www.trisomy18.org), "Trisomy 18 is a condition which is caused by an error in cell division, known as meiotic disjunction an extra chromosome 18 results in the developing baby and disrupts the normal pattern of development in significant ways that can be life-threatening, even before birth. A Trisomy 18 error occurs in about 1 out of every 2,500 pregnancies in the United States, and about 1 in 6,000 live births...Unlike Down syndrome, which also is caused by an extra chromosome, the developmental issues caused by Trisomy 18 are associated with more medical complications that are more potentially life-threatening in the early months and years of life. Studies have shown that only 50% of babies who are carried to term will be born alive, and baby girls will have higher rates of live birth than baby boys."

For more information, visit: www.trisomy18.org

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Nyala was baptized in the chapel at St. Francis Hospital on Easter Sunday, and went home with her family the next day.

The Reynoldses know that prayer and faith bring about change. They saw this in action when Nyala went off her oxygen and feeding tubes about a month after coming home. They saw it when Shannon's family and friends in Illinois convened a special prayer line that continues to meet via phone every morning at 5:00 a.m. to lift up Nyala in prayer. All of these things "remind us of God's miracles and our faith in believing what's unseen," said Shannon.

"Beyond any shadow of a doubt," said Hasahnn, "Nyala is the biggest bundle of joy I've ever seen. She touches everyone around her. Her endurance, perseverance, spirit, and her physical and mental toughness are a sight to behold."

Today, Nyala is happy and content to be surrounded by a family who adores her. The family is also grateful to Noah's Children. Said Shannon, "They've supported us every step of the way. Their attention and calm demeanor have allowed us to love and enjoy the moments with Nyala that many take for granted. It's brought us peace and goodness in a situation



The family credits not only their own prayers, but also those of their friends, Bon Secours and Noah's staff for Nyala's progress.

that seems awful. That's the hope they give."

"As faithful parents, we know this is a test," added Shannon, "and we don't know what the end result is going to be, but we know that God always prepares us. It's always in His hands. What can we do but love on her, and that's easy."

Glorious Gala!

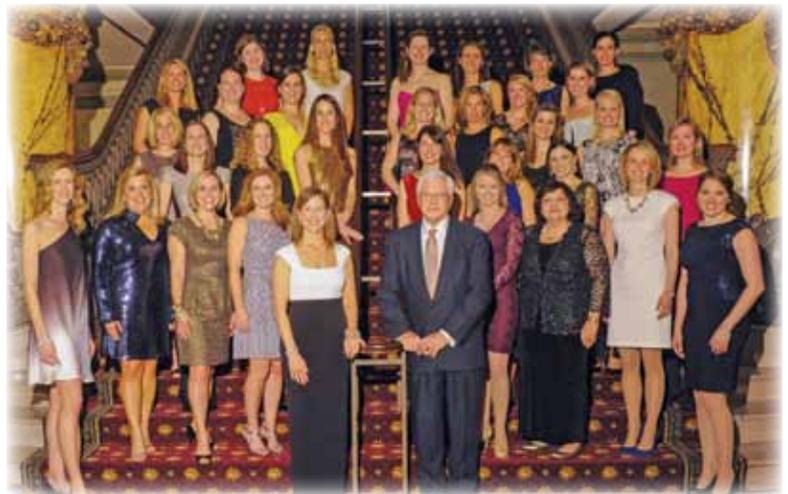
On February 21, The Jefferson Hotel was the place to be as nearly 400 people gathered for the annual fundraising gala, **forty one**. This year's event raised more than \$300,000 to benefit both Noah's Children and Richmond Hope Therapy. Guests enjoyed great food and wine, a silent auction conducted via mobile bidding, and a rowdy live auction with some cutthroat bidding. It was a glorious night, and we thank you for your generous support!



Mobile bidding was a new feature at the silent auction this year.



A rowdy live auction helped to raise over \$300,000 to benefit Noah's and Richmond Hope Therapy.



The Gala **forty one** committee with Richmond Hope Therapy founder, Cindy Richards, and Noah's Children founder, Dr. Bob Archuleta.



Perinatal Palliative Care for an Infant with a Potentially Lethal Anomaly

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



The two key leading causes of neonatal deaths are disorders related to short gestation and low birth weight (23%) and congenital anomalies (21%). When an unborn child is diagnosed with a congenital anomaly (e.g., anencephaly, acrania, trisomy 13, trisomy 18, severe cardiac deformities, severe brain anomalies, renal agenesis with pulmonary hypoplasia), parents may wish to consider palliative care as an alternative to ending the pregnancy or seeking aggressive treatment in the neonatal intensive care unit.

Like hospice, palliative care promotes physical, emotional, social, spiritual and practical support to treat and prevent suffering, and can be provided concurrently with life-saving or curative efforts. An important component of the palliative care experience is Advance Care Planning, a process that supports families in making a contingency plan of care for their child that is consistent with their goals and wishes and is in the best interest of the child.

Advance Care Planning can and should begin as soon as possible after diagnosis and prior to delivery. Significant planning is necessary so that palliative care can be provided regardless of the length of survival of an infant.

Noah's Children is proud to offer this kind of comforting, meaningful care that is also as ethically and legally acceptable as the provision of life-extending endeavors. With our interdisciplinary team of doctors, nurses, social workers, bereavement counselors and chaplains, our staff:

- Educates parents on the probable/possible outcomes
- Empowers parents, fosters hope, relieves fear, and addresses guilt
- Explains possibilities and options
- Develops a realistic birth plan and works to ensure that the parents' wishes are honored during labor and delivery
- Provides anticipatory grief support
- Assists with memory making, such as arranging photographs, handprints, and other mementos
- Accompanies parents to doctors' appointments to support them and help reinforce their wishes to the doctors

Each year, 900,000 U.S. families are affected by birth tragedy



- **849,000 miscarriages** (less than 20 weeks) per year
- **33,000 stillbirths** (20-40 weeks) per year
- **18,000 neonatal deaths** (1 per 212 neonates – less than 28 days)

- Develops plans for bringing the baby home after birth with support from the hospice and palliative care interdisciplinary team
- Serves as the liaison between the parent and the hospital's labor and delivery staff
- Available to attend the birth to support the parents and hospital staff
- Helps collaborate to provide spiritual rituals, such as Baptism
- Provides bereavement support for up to three years after the death of the infant

Above all, we listen to what parents want and support their decisions. To find out how we can help your family, please contact us at (804) 287-7686 or visit us online at www.noahschildren.org.

Volunteer Coordinator Extraordinaire: Lee Ailstock

Volunteers are the lifeblood of any non-profit organization, and Noah's Children is especially grateful to our dedicated and enthusiastic volunteers. We are also grateful



Lee Ailstock,
Volunteer Coordinator
Noah's Children

for the skills, expertise and passion of our Volunteer Coordinator, Lee Ailstock, although her title doesn't nearly describe the many hats she wears. Lee's main responsibilities include the management, recruitment, training, compliance, retention and appreciation of Noah's 178 volunteers – no small task!

Lee guides volunteers through a screening process, training program and orientation, which covers the history, staff roles, and services of Noah's Children, as well as numerous aspects of hospice and palliative care. Those volunteers who have direct patient contact undergo additional training that addresses child development and family dynamics, and the emotional, physical and spiritual dimensions of death and grief.

This thorough training program also helps Lee place volunteers – based on their interests – into one of the following types of volunteer opportunities:

1. **Done in a Day** – These volunteers provide support for short-term projects that can be completed in one day or less. They may help make meals, perform yard work, house cleaning, gift wrapping, etc.

2. **General Services** – These volunteers assist with operations of the office, programs, fundraising and promotion projects.

3. **Patient-Family** – The primary responsibility of these volunteers is to provide companionship, support, and assistance to our patients and their families.

Lee, who joined Noah's Children in October 2013, also mentors volunteers who can use what they learn to help other community organizations. She believes that real hands-on experience and coaching are critical for helping volunteers obtain

a new skill set or improve an existing one. For example, a new volunteer may assist Lee plan an event, which requires a detailed plan, goals, budgeting, vendor contracts and site visits. At the next event, this volunteer will take responsibility for all these details. "It helps me with my workload, and it helps the volunteer learn and grow," Lee said. "I love watching our volunteers become leaders. They make our program so much better."

In addition to her volunteer coordinator responsibilities, Lee also helps manage Noah's music therapy, pet therapy and meals programs, conducts community outreach activities, and plans events, including the Family Fun Days, Volunteer Appreciation Brunch, and the back-to-school and holiday activities. But her heart is with the volunteer component of her job.

"Whether they help once a year or 1,000 times a year," said Lee, "our volunteers are the best. We simply couldn't do it without them." We feel the same way about you, Lee!

Want to join this great group of volunteers? Please visit www.noahschildren.org/how-to-apply to learn more and complete the application form.



Noah's volunteers, the lifeblood of the organization, are placed in volunteer opportunities based on their interests.



These volunteers showed their support for Noah's families by making sure that everyone received an Easter basket.



Noah's holiday helpers take the stress off family members whose children are living with catastrophic illness.

Everyone's Best Friend

For many families, pets bring much joy and laughter, and sometimes even healing. That is the goal of Caring Canines, a local Richmond dog therapy group that currently has 160 specially trained dog teams serving the Richmond area. Trained to provide comfort and affection to those in hospitals, nursing homes, retirement homes, and schools, these dogs also help children who have learning difficulties and developmental disorders.



Annie demonstrates her agility tricks.

Studies have shown the benefits of having physical contact with a pet. It can lower high blood pressure; assist in physical rehabilitation by walking or throwing objects for the dog to retrieve; increase fine motor skills by petting, grooming, or feeding; improve cognitive and communication skills; and even help release endorphins, natural chemicals in the body that help suppress pain.

Caring Canines volunteer Joyce Stargardt couldn't agree more. "The satisfaction and smiles we see in patients and their families is the reason we do this work. It truly does make a difference."

For these reasons, Noah's Children is delighted to announce pet therapy services for our children and families. The process begins with an initial visit by a volunteer like Joyce who assesses the situation, discusses what to expect next, and provides general education about pet ownership and responsibilities.

Recently, a Noah's patient, who suffers from severe anxiety as a result of his life-threatening condition, enjoyed his first visit with Joyce, and her 11-year-old Standard Poodle, Annie. The child was able to play with, walk and groom Annie, who showed her appreciation with agility demonstrations and tricks. By session's end, the child had opened up to both Joyce and Annie, and his anxiety levels noticeably decreased. Obviously, he is looking forward to Annie's future visits!

For more information about Noah's pet therapy services, please contact Lee Ailstock at (804) 287-7686 or Carolyn_Ailstock@bshsi.org.



Joyce Stargardt of Caring Canines with Annie, her pet therapy canine. Annie provides comfort to those dealing with difficult situations.

Noah's Family Outings

Unlike families with healthy children, Noah's Children parents struggle daily to take care of their sick child's myriad needs, while also caring for their other children, as well as work and household responsibilities. It's a daunting challenge,



and quality time together often suffers.

Thanks to the generosity of wonderful donors, however, Noah's Children offers a summertime Family Outings Program that emphasizes activities in which the whole family can participate. Outings can include a visit to an amusement park, play center, museum, summer camp, and more. These activities allow kids to be kids, and families to let go of the sick child's illness while making

positive memories together. Said Lee Ailstock, volunteer coordinator, "The time they spend together is a most precious gift for our families."

For more information and to support this program, please contact Lee at (804) 287-7686 or Carolyn_Ailstock@bshsi.org.



THANK YOU
DONORS AND VOLUNTEERS

*Noah's Children has accomplished
so much over the years
because of friends like you.*

*Whether it's making a donation
or volunteering your time,
your support helps us provide
quality care and services to families.*

*On behalf of the staff
and families we serve,
thank you!*



IN MEMORIAM

Riley Elizabeth Davis
2/11/15 - 2/28/15

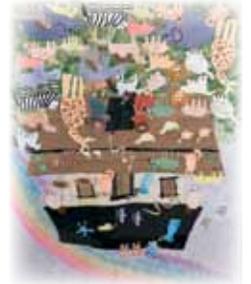
Mahlon Skyler Booth
12/29/01 - 3/21/15

TeAri Shanaye Parker
2/22/15 - 4/4/15

Destiny Nicole Estes
1/5/04 - 4/24/15

*We celebrate the lives of these children
and honor all those who love them.*

Visit Our New Website
www.noahschildren.org
(804) 287-7686



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