

## An Extraordinary Year

According to Jody Conner, 2014 was “both the most devastating and most miraculous year ever.” She’s referring to the roller coaster ride she and her family have been on since their youngest son, Bryce, was diagnosed with Leigh’s Disease, a rare, inherited neurometabolic disorder that affects the central nervous



Bryce's progress allows him to enjoy more of his favorite outdoor activities.

### What is Leigh's Disease

According to the National Institutes of Health, Leigh's Disease is a progressive, genetic disorder usually diagnosed in “infants between the ages of three months and two years. Rarely, it occurs in teenagers and adults. Leigh's Disease can be caused by mutations in mitochondrial DNA or by deficiencies of an enzyme called pyruvate dehydrogenase. Symptoms of Leigh's disease usually progress rapidly...The most common treatment for Leigh's Disease is thiamine or Vitamin B1...The prognosis for individuals with Leigh's Disease is poor. Individuals who lack mitochondrial complex IV activity and those with pyruvate dehydrogenase deficiency tend to have the worst prognosis and die within a few years. Those with partial deficiencies have a better prognosis, and may live to be 6 or 7 years of age.”

For more information, please visit

<http://www.ninds.nih.gov/disorders/leighsdisease/leighsdisease.htm>.

system. Now 5 years old, Bryce was completely normal until age 4 when he began having trouble gripping objects, and one of his ankles turned inward. Soon after came the personality changes, excessive fatigue, and a dragging leg. Tests indicated brain damage, and the family sought out a neurologist. An MRI and genetic testing confirmed the Leigh's Disease diagnosis, for which there is no cure or medication, only vitamin



Bryce's hard work at Richmond Hope Therapy enabled him to take his first steps in late December.

supplementation. By this point, Bryce could no longer walk, talk, lift his head or move at all. “He had regressed back to the condition of a 6-month-old,” said father Brian. “The doctors said there was absolutely nothing they could do. It was the worst day of our lives.”

The “Mama Bear” in Jody, however, knew there had to be something they could try, so she set out to understand not only everything about the disease itself, but also how the entire nervous system worked. She literally spent thousands of hours researching online sites and medical journals to learn everything she could. A specialist in Richmond told the family about a clinical trial for which Bryce qualified, but Jody did not want to take the chance on him receiving a placebo, so she struck out on her own to find out what was healing these children in the clinical trial. After reading through hundreds of pages of medical jargon in the trial studies, she discovered that the “drug” that was used in the clinical trial was a modified version of a tocotrienol, a member of the vitamin E family. After further research she came up with her own



The Conner Family – Colton, Jody, Brian and Bryce – enjoy some family time at the beach.

“cocktail” of tocotrienols, antioxidants, and vitamins. Since beginning this two-times-daily vitamin regimen treatment last summer, the difference in Bryce has been nothing short of astounding.

“His cognition is back,” said Jody. “He can move again, crawl and scoot across the room. He’s back to being a 5-year-old.”

The Conner family, which also includes older son Colton (18), learned about Noah’s Children through a physical therapist at the Children’s Hospital of Richmond. “Noah’s Children is an extraordinary group of caregivers,” Jody said. “The whole team showed up soon after we called and got things rolling. They connected us with resources, answered questions, taught us helpful massage techniques, and have been there for us every step of the way. And they referred us to Richmond Hope Therapy, where, because of the intensive physical therapy, Bryce was able to take a few steps on his own in late December. The support of Noah’s Children has literally been almost as life-changing as the turnaround in Bryce’s progress. They are amazing.”

And so is Bryce. His parents say he doesn’t feel or know he’s different, and the family works hard to make his life as normal as possible. Like other kids his age, he loves his pets, dinosaurs, X-box games, and riding a special therapeutic bike that helps with mobility. “He tears around the house on that thing now,” laughed Brian. And soon, Bryce will begin the Noah’s Children Music Therapy program.

“Noah’s Children has helped lighten our load and made our ‘new normal’ even better,” Jody concluded. “We don’t know where things will end up, but we feel less alone now because of the network of people we’ve met and the support we’ve received from Noah’s Children. We believe Bryce will walk again. He’s come so far.” Indeed he has. Godspeed.



## Cooking for a Cause

During the month of March, Noah’s Children is seeking volunteers willing to prepare home-cooked, freezer-friendly meals. Receiving a home-cooked meal is a simple, yet significant, way to show support and encouragement for our families and takes away the worry and hassle of food preparation so they can focus on their child.

Thanks to Franklin Federal Savings Bank’s donation that allowed us to purchase a freezer, the meals you prepare will be stored and available for our staff to deliver to families in need.

## Our Goal: 40 Meals for a Family of 4

Need ideas or inspiration?  
Visit these links to find  
60+ Healthy Freezer  
meal recipes:



- <http://thrivinghomeblog.com/healthy-recipes-index/healthy-freezer-meals-recipes/>
- <http://www.takethemameal.com/recipes/>

Once completed, meals can be delivered to Noah’s Children at:

**5855 Bremono Road • Suite 409 • Richmond, VA 23226**

For questions regarding the meal program or to schedule a delivery, contact Lee Ailstock, Volunteer Coordinator, at [Carolyn\\_Ailstock@bshsi.org](mailto:Carolyn_Ailstock@bshsi.org) or (804) 287-7686.

Thanks in advance for your assistance!

## More New Staff

As Noah's Children continues to grow, additional staff continue to be added. We are delighted to welcome our two newest team members.



### Tammy Ratliff, RN, IBCLC, CEIM, HUG Baby Certification

Tammy Ratliff joined Noah's Children in October 2014. Compassionate and approachable, Tammy brings extensive experience in perinatal care, infant massage, and lactation consulting.

Tammy's 17-year career includes experience as a neonatal nurse at Johnston-Willis Hospital. She is a 1996 graduate of John Tyler Community College, a board-certified lactation consultant, and certified in infant massage.

"I am drawn to children," Tammy said. "I love the kind spirit they possess. I feel that each child regardless of how long they live – minutes, hours or years – has a purpose and should be honored and respected."



### Diane Pelkey, RN, MSW, MSN

Diane joined Noah's Children in November 2014. A graduate of Syracuse University with a degree in nursing, Diane joined Bon Secours 22 years ago and has worked the majority of that time caring for adult hospice patients. Previously, she worked at Sloan Kettering, Children's Hospital of Pittsburgh, and as Director of Social Services in Charlottesville.

"People have often asked how I can work in such a sad field for so many years," said Diane. "I understand I cannot change the fact that a child or adult is dying, but I believe that wonderful victories can be achieved even until the very end."

## Shop at Rite Aid

Noah's Children has partnered with Rite Aid and is now an official KidCents charity! KidCents is a program created by The Rite Aid Foundation that allows Rite Aid customers to round up their purchases to the nearest dollar and donate their change to help support kid-focused charities.



It's easy and free to join. Just take these few simple steps:

- Visit [www.kidcents.com](http://www.kidcents.com) and follow the steps online to become a Rite Aid wellness+ member and enroll in the KidCents program (<https://kidcents.riteaid.com/howitworks>).
- Then login at [www.kidcents.com](http://www.kidcents.com) and click "Select a Charity" on the website menu.
- Search for Noah's Children in the list of official KidCents charities, then click on the "Select this Charity" button.

Now the next time you shop at Rite Aid, your change will be rounded up to support Noah's Children programs. We encourage you to invite your friends and family to participate as well. Imagine the difference your change can make!



## 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

Laura Grace Pickral

8/23/13 – 11/25/14

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



## 2014 Round-Up

*Noah's Children is humbled by your kindness, generosity and continued support. We couldn't exist without our friends in the community.*

*Because you give so freely of your time and/or financial contributions, we were able to make great strides in serving our patients and their families during 2014. Here is a recap of a few of these achievements.*

- 1,741.5 total hours of service provided by volunteers
- 95 Easter baskets made and delivered
- 566 hours of Music Therapy provided to patients and their siblings
- 27 families received Thanksgiving meals which served a total of 200 people
- 62 Back-to-School Backpacks created and delivered
- 76 children from 27 families received Christmas presents



Visit Our New Website  
[www.noahschildren.org](http://www.noahschildren.org)  
(804) 287-7686



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