

Taking the best care of Luke

When Luke was a few months old, his mother Kelly Bowker-Pottle felt something was wrong. He was not reaching developmental milestones. "With Luke, everything was delayed," she shared. "Walking, talking, all of it."

By 2020, the severity of Luke's condition had increased. He was having 200 seizures a day and falling constantly. The COVID-19 pandemic was raging and scheduling an appointment with a specialist was nearly impossible.

Luke was eventually examined by a specialist, diagnosed with epilepsy and prescribed multiple medications. None lessened Luke's seizures. After genetic testing, Luke was properly diagnosed with GRIN2D gene mutation and seizure disorder, a mutation which causes seizures that hinder brain development.

Kelly was in shock at the diagnosis. Only one in 22 kids in the world has the diagnosis, and the doctors acknowledged they didn't know how to treat it.

Because there is no cure for GRIN2D, the family faced many uncertainties, frustrations and feelings of hopelessness. Managing Luke's seizures involved numerous trials, negative reactions and a frightening incident occurred when he took new medication and woke up from a nap unable to stand or move. His mother described him as "a limp spaghetti noodle." The denial of a prescribed and necessary wheelchair was the breaking point for Kelly. Although Luke was 6 years old, developmentally, he was like an 18-month to two-year-old toddler wearing diapers. A request for advice from her neurologist resulted in a referral to Noah's Children, which was precisely what the family needed.

Since connecting with Noah's Children less than a year ago, Kelly expresses gratitude for the daily support provided by the medical staff, the monthly visits, help with completing social security and Medicaid paperwork, and for being able to obtain the wheelchair and receive additional therapy for her son.

Noah's Children therapists come to her home to work with Luke and even built a safe play area for him. Kelly spoke candidly about the impact of Luke's condition on their family life. She is thankful Noah's Children is mindful of the siblings because they

“I need someone to teach me and guide me on how to take care of Luke and that's what they've done. Every step of the way, I feel that Noah's Children are the ones that I go to. They help me figure out what to do next...it's a huge comfort. They are 24/7. If I contact them about anything, they immediately answer and help me figure out what to do with any situation.”

— Kelly Bowker-Pottle

2024 IMPACT REPORT

Your contributions at work



"have definitely suffered as he has gotten older." Luke constantly screams, which makes it challenging to go out in public since people don't understand and tend to stare.

Noah's Children provides family outings where the Bowkers socialize in community with other families with special needs children. At the Noah's Children carnival, everyone felt completely comfortable.

"We can go and [not] feel judged...all the other kids received King's Dominion passes and got to go out somewhere fun that we don't normally get to go to because Luke can't tolerate it."

Caring for special needs children affects the family as a whole and each family member individually. Kelly shared that Noah's Children helps to balance things — not only with advocacy for services but also with normalizing life for her other nine children.

Although Luke's prognosis is uncertain, his seizures have decreased from more than 200 per day to about 127 per day and he has not fallen since he began a new medication.

A request for advice that resulted in a referral to Noah's Children has offered the family essential guidance and support.

"We're still learning so much because every day is different with Luke, but we are taking things day by day and remain grateful for the ongoing assistance from Noah's Children."

Commitment to excellence

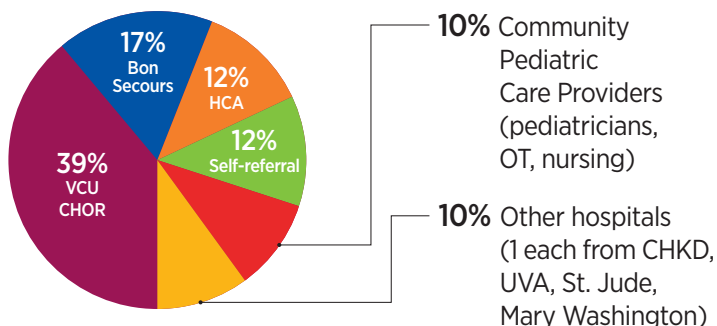
With the support of our generous donors, Noah's Children was able to accomplish the following in 2024:

- A Program Supervisor and Program Manager were hired to assist the team in enhancing, developing and expanding the services and support offered to families.
- Sibling and bereavement support services were expanded.
- Two Nurse Practitioners were enrolled in the Pediatric Palliative Care Certificate Program at the University of Maryland (ongoing).
- Staff members participated in the Virginia Nurses Association Conference, the Good Grief Conference and the Palliative Care Symposium to gain knowledge and skills in best practices for assisting patients with life-limiting illnesses, addressing grief-related crises, managing chronic or life changing situations and navigating end-of-life bereavement challenges.

78 patients served.

Average daily census: 58 patients, up from 54 patients in 2023.

2024 referral sources



 1501 Maple Ave., Suite 105 | Richmond, VA 23226

 noahschildren.org

 804-287-7686

 **Donations can be mailed to:**
Bon Secours Richmond Health Care Foundation
920 Libbie Ave., Suite 100 | Richmond, VA 23226

Donate online: givebsmh.org/Richmond
Select "Noah's Children."

Questions? Call 804-287-7700



By the numbers | 2024



68,000

miles driven for home visits
and family support services



\$63,520

supported social events
and programs for
Noah's Children families
which includes \$15,520 for
sibling events, Sibshops and
summer camps



234

individuals received
Thanksgiving meals



802

music therapy hours



\$8,800

provided for clothing
and school supplies to
70 school-aged patients
and siblings



13,000

in counseling support
serving 36 individuals
for 600 hours



\$10,000

supported inpatient
(hospital boxes),
crisis/emergency, perinatal
and hospice support



\$72,000

provided families
with financial assistance
to help with bills and
other expenses



228

individuals received
holiday gifts serving
57 families through our
holiday adoption program



\$39,675

in bereavement support
serving 52 families
(196 individuals) with funeral
services, meal support and
family assistance



2,130

volunteer hours
(includes 375 hours for the
Kids Helping Kids program)



\$43,000

provided in meal support
for 40 families
(178 individuals monthly)
(1,896 individuals yearly)