

Reflections

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Providing support a second time

After experiencing the Gilchrist Kids team's loving support, provided during their daughter Holly's last months, the Linthicum family called Gilchrist when the unthinkable happened a second time – their baby daughter Alexa was diagnosed with the same, previously undiagnosed fatal genetic condition.

There were never any answers for Holly Linthicum – no diagnosis for her frequent seizures, or her floppy body, or her extreme developmental delays. The day she died, with her parents and her Gilchrist Kids nurse by her side, the cause of the 2-year-old's long list of medical issues remained a mystery.

It wasn't until nearly two years later, after her baby sister Alexa began showing the same symptoms, that genetic testing finally provided Ashleigh and Dave Linthicum with an answer – both girls suffered from a rare and fatal inherited mutation.

Within weeks, the Linthicums made a decision: They would call in Gilchrist Kids again, so they would already have the support they needed in place when Alexa began to decline. The guidance the team had offered not just for Ashleigh and Dave, but also their oldest daughter Hailey, during Holly's last months, had been invaluable. They knew they had to have Gilchrist Kids by their side once more.



Erin Batton, Gilchrist Kids nurse, holds patient Alexa as mom, Ashleigh, and big sister Hailey provide entertainment during a recent visit.

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“Having Gilchrist Kids here for our family is so important. I know that they are there for us whenever we need them.”

Ashleigh Linthicum



Alexa loved getting her picture taken

For Ashleigh and Dave, Gilchrist Kids’ presence during Holly’s decline offered crucial physical, emotional and educational support after more than a year spent cycling in and out of the hospital. While her doctors were attentive, they were baffled by Holly’s condition and could only tell Ashleigh and Dave, “We’ll have to wait and see what it means.”

Their Gilchrist Kids nurse not only provided them with the equipment and medications they needed to keep Holly home, but also acted as a guide – explaining what each and every change in Holly might mean as the end approached.

“She prepared me for what was next. I wanted someone who could be honest with me, who could provide both the best case and worst case scenarios,” Ashleigh said.

The experience with Holly was so helpful that the Linthicums knew they wanted to call Gilchrist Kids earlier this time, while Alexa, who suffers from seizures that are hard to control, poor muscle tone and severe developmental delays, is doing reasonably well. They were even able to request the same volunteer who supported them during their journey with Holly.

Because the girls’ genetic mutation is so rare, they don’t know how long they’ll have with Alexa. For now, she’s stable, and while Holly only lived to be 2 years and 4 months old, Alexa, at 17 months, is a smiling and happy child who appears to be more interactive and aware than her sister ever was.

“She may not need as much from us now, but that’s the beauty of calling us in early,” said Alexa’s nurse, Erin Batton. “Her care can change as it needs to. It can be more or less as she needs it, and we can be on top of every symptom. We know Alexa’s baseline.”

“After much careful consideration, we have decided to bring hospice care in while Alexa is healthy. The amount of support they can give us makes it worthwhile. We met her nurse the other day and absolutely love her! She has already been helpful and is helping take some of the load off me.”

Ashleigh Linthicum on Alexa’s CaringBridge site, April 3, 2014

Gilchrist & Joseph Richey join forces in October

Gilchrist Hospice Care and Joseph Richey Hospice, one of the state’s oldest hospice organizations, are pleased to announce that the two non-profit organizations will be joining forces effective October 1, 2014.

Joseph Richey, which provides care both in patient homes and at a hospice center on Eutaw Street in Baltimore City, will join the Gilchrist umbrella of services, which are designed to provide care that is coordinated, comprehensive and compassionate through the end of life.

The move is designed to enhance services to all terminally-ill individuals, especially those residing in the city, where Joseph Richey operates the only free-standing inpatient hospice facility. That facility will be renamed **Gilchrist Center Baltimore – Joseph Richey House** and will continue its long-standing mission of serving the underserved through both acute and residential hospice care. Joseph Richey’s existing home care program will be merged into Gilchrist’s current program, and all home care will be provided by Gilchrist staff.

Joseph Richey Hospice also includes Dr. Bob’s Place, a facility designed to provide palliative and hospice care exclusively for children. Although Dr. Bob’s has suspended operations, the two hospices hope

to work together on reviewing and enhancing how pediatric services are delivered in the region.

“We are truly honored that Joseph Richey’s Board of Trustees chose to join forces with Gilchrist. This new partnership will allow us to benefit from the histories, strengths and missions of both organizations,” said Catherine Y. Hamel, Gilchrist Executive Director. “Joseph Richey and Gilchrist share a vision of care that is compassionate and dignified, and both remain committed to serving all those in need of hospice care and services, regardless of insurance limitations or ability to pay.”

“This new relationship with Gilchrist will enable us to continue providing care tailored to the individual needs of patients and families,” said Dr. Michael L. Levin, Board Chair of Joseph Richey. “We are delighted to partner with an organization that shares our vision and values.”

New! Recurring Gift Program at Gilchrist

We now have an even easier way for you to give each month.

Through our recurring giving program, your donation will automatically and securely be deducted from a bank account or credit card of your choice each month. You choose the date of the withdrawal and you can decide to stop payments at anytime. You can also choose to designate your gift to one of our programs or inpatient units. No matter how big or small, your gift will make a difference in the lives of hospice patients and their families.

Visit Gilchristhospice.org/recurring to sign up today!

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Upcoming Travels to Tanzania

Gilchrist Hospice Care and its partner hospice in Tanzania, Nkoaranga Lutheran Hospital's Hospice and Palliative Care program were the dual recipients of this year's FHSSA Global Partnership Award.

Presented this spring by Global Partners in Care, the sponsoring organization for the transatlantic partnership and dozens of others like it, the award recognized Gilchrist's "exceptional effort and commitment" to Nkoaranga, both in fundraising and outreach.

Formed in 2009, the partnership took on added significance two years later when a loss of funding threatened the Tanzanian hospice's existence. Gilchrist stepped up, pledging to underwrite Nkoaranga's bare bones day-to-day operating budget indefinitely through fundraising.

More recently, Gilchrist has raised funds to help enhance the program; in September, a new four-wheel drive vehicle that will serve as an ambulance to transport patients across the rough terrain, is scheduled to arrive. The ambulance was funded through the generosity of the Cole Foundation, with additional support from three area Rotary Clubs (Hunt Valley, Towson and Towsontown) and other fundraising efforts.

In addition, donations from GBMC nurse manager Nancy Amann-Santos have supplied playground equipment for Nkoaranga's Kids Club, which supports children with HIV, and seed money for a building campaign to create a palliative care building for the program.

Amann-Santos is part of a four-person team of Gilchrist and GBMC employees and volunteers scheduled to visit Nkoaranga next year. A visit originally planned for this September was postponed.

For more information, please visit gilchristhospice.org/tanzania