The Review

March 2022 Issue #13

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Sarah House is a part of a coalition for all pediatric respite and hospice homes

We need Volunteers!

Sign-up on our website to help out at our next fundraising event!



Letter from the Chairman

~ by John Francis

As of the close of calendar year 2021 comes to an end, we have transitioned from FY '21 into FY '22, and with that transition a few significant things have occurred or are in the process of occurring.

First, the Board refreshed its Strategic Goals which include: Fundraising to hire an Executive Director and to buy or build property and small home; pursuing Grants as opportunities arise; strengthening our Board with additional members who bring needed skill sets; and sending an Appeal Letter to 100 people.

Secondly, we have refreshed our Feasibility Study by updating the statistics which clearly show the need for services in the greater Cincinnati area like those Sarah House wants to provide.

Thirdly, we have adopted a Case Statement which clearly outlines the needed services and the proposed solution to meet those service needs. For example, the number of children in our country with complicated, chronic and/or life-limiting illnesses is very large, estimated at around 2 million, and these children's needs place heavy demands on family members. We believe part of the solution is to provide live-in and respite services to these children and their families, thereby providing much-needed end of life care.

Finally, we are in the process of planning our next Special Event to be held later this year.

Your financial support would be GREATLY appreciated, and it's easy for you to simply get onto our website and "Donate" today!

Thank you.

John Francis, Board Chair

Michael's Story

~ by Alicia Quintero

Michael Quintero was born in March 2007. He was a regular cute kid with two naive brand-new parents. When he was 18 months old, we noticed irregular eye movement, balance issues, and some things that just weren't right. Labor Day weekend of 2008, he was diagnosed with brain cancer, Juvenile Pilocytic Astrocytoma. When Michael was first diagnosed, we lived in Utah. We struggled through that first year of treatment but had family and church friends to help us.





In 2010 we moved to Cincinnati for my husband to attend Miami University. We had no idea the excellent level of care we would receive at Cincinnati Children's and the wonderful people we would meet. Life happened; Mark graduated and got a teaching job. Our family grew, adding three more children. Alex, Anthony, and Myra. We continued to live in Cincinnati and continued to fight Michael's cancer.

Michael was relatively stable throughout this time but always on chemotherapy. Always taking medication. His tumor caused him to

lose most of his vision and caused a stroke shortly after diagnosis. He used a wheelchair and a walker. He continued to need a lot of care, way past the age our other children did. He relied on us to help him with everything. In November 2018, complications from his cancer landed him in the hospital for an extended period of time. He wasn't able to come home until April 2019.

Why does Cincinnati need Sarah's House?

For all of Michael's life, he was what I would consider medically fragile. He had a feeding tube for the first year after diagnosis. He was always on chemotherapy. As one drug would stop working, we would try something else. Later in his life, he was on anti-seizure meds, and even with medication, his seizures were not 100 percent controlled. He was a fall risk. We couldn't leave him with a regular babysitter, and we moved 2,000 miles away from all of our family. He was at school or with us, that's it. I love my son but taking care of him was exhausting some days. I wish there would have been a safe place for Michael to go hang out with some friends. A place where staff is trained on his needs, and I could drop him



off and know he would be looked after. Currently, there is no such place for these kids, but Sarah's House could be that.

One week after Michael came home from the hospital, his shunt stopped working, and we made the decision to enter hospice care. There were no more treatments available. Our family had just spent 140 days in the hospital, and we had to make a choice to have hospice come into our home or take him back to Cincinnati Children's for his end-of-life care. My other three children were 10, 5, and 3 at the time. We decided to take him back to Children's. He loved Children's hospital, and he was comfortable there. I wish there would have been a third option. I wish there had been a Sarah's House for us because I would have chosen that. There is a hospice center for adults. Why is there not one for kids? I know talking about terminally ill, and medically fragile children is uncomfortable and hard. But not talking about it and not acknowledging it doesn't make the problem go away. It makes the families going through it have to go it alone. And that is not acceptable.

We need Volunteers!

~ by Ariel Schmid

Sarah House is working on planning our next fundraising event! We are in need of volunteers who are excited to help create a spectacular event. We're hoping to be in person towards the end of summer at a lovely venue for a fun little bash. Be a part of our history and help us start this annual tradition!





We're a part of the "Like House" Coalition!

~ by Kim Marcum-Mercier

Sarah House is an active member of the "Like House Coalition" which is a coalition of existing and emerging Children's Respite & Hospice Home programs ("Like Houses"), predominantly 501(c)(3) non-profit organizations from across the United States that are bound together through a shared passion that families in our communities critically NEED us.

We believe that by supporting a National "Center of Excellence" Leadership initiative, we can leverage strategic and operational best practices, shape a conceptual framework, facilitate consensus, craft guidance for messaging, and champion evidence-based research that will inform federal and state advocacy priorities to amplify a shared voice and seat at the table for decision making.

