



Love and support for families with childhood cancer

I will never forget March 15, 2019, or the phone call we received that day. Our baby girl, Olivia, had a bump on her head which we recently had biopsied. "Are you sitting down?" she said, and I could hear it in her voice. That was the day we got Olivia's diagnosis and the day that we were admitted to the hospital to begin treatment and a journey that I had never imagined for our littlest one or our family. Olivia "Livie" was diagnosed with Acute Lymphoblastic Leukemia at 15 months old. Her overall treatment protocol would last two years and required us to stay in the hospital for most of the first five and a half months. Besides Livie, we have twins, who were two years old at the time of diagnosis.

To say our world was completely turned upside down immediately feels like an understatement. My husband and I had to divide and conquer. He stayed home with the twins and worked while I stayed in the hospital with Livie. In the beginning, there were weeks when I made it home once, maybe twice, to see our twins, take a good shower, and get some new clothes. If I had extra time, I'd read a bedtime story before heading back to the hospital and Livie. That was a tough time; I was so scared for my little girl and all she was going through.

Being in the hospital that long and having our family fractured was extremely difficult. I felt like I was failing as a parent because I could not be there for all my children. I couldn't protect the twins from the immediate changes that came with Livie's diagnosis, such as mommy and Livie no longer being at home. I also couldn't protect Livie from everything she would endure with treatment. I could help her through it, but I couldn't stop it from happening. It just was what it was, and sometimes it felt like time would stand still. There were days when it was just Livie and me waiting and hoping to get a day or a weekend at home. However, her labs needed to improve enough to have that time at home; watching them remain low or nonexistent during those times left me feeling trapped and helpless.

One particular day when I felt this way, there was a knock on the hospital room door, and it was Cheryl from Why Me. I will never forget meeting her or our conversation; she was so open and supportive. Cheryl brought some things for Livie and me. She also asked about my husband and the twins and if we needed anything. Upon leaving, Cheryl mentioned we would see her the following week. Knowing she would be back and if we needed anything, all we had to do was ask brought comfort that I didn't even know I needed. In the beginning, I didn't know anyone who had a child diagnosed with cancer and didn't know where to turn. Those weekly visits from Why Me became so important to me. Depending on treatment or childcare, sometimes that was the only visit I would have the whole day or week. It was an immense weight off my shoulders to visit with someone and have a non-medical conversation about my family and our needs and hopes for the future.

Why Me invited us to their Easter Egg Hunt event, and we arranged for a grandparent to stay at the hospital with Livie. That afternoon we took the twins to the event at Sherry's House. It was the first time my husband and I could go anywhere with the twins since Livie's diagnosis. Before that, we were much like ships passing in the night, just swapping in and out of the hospital so he could see Livie and I could see her brother and sister.

The reality is that life doesn't stand still once your child is diagnosed with cancer. I've realized that it keeps moving forward; it's just that the path looks different than you imagined, and it is sometimes hard to navigate. Why Me has become an essential part of navigating this new path, the events they put together give families a safe and fun way to participate. Often, our kids might miss out on holidays and birthday parties because of the medical realities of treatment. {Continued on next page}











{Continued from previous page} At the Easter event, initially, I looked like a deer in headlights, but the staff welcomed us with open arms. They brought the kids to the arts and crafts table and settled us right in. It also warmed my heart to watch my little ones hunting for eggs on the playground with these big smiles on their faces. It was like a moment of peace in the storm. Why Me understands the importance for our kids to have typical-kid experiences whenever possible - even when everything is feeling completely upside down.

Why Me has been incredible throughout our family's journey; in the beginning, it was like they were picking me up out of the puddle of devastation and fear, letting me lean on them for support. They were always there and did so much without being asked. The hospital visits with snacks and Livie's favorite things, asking about the holidays and what we needed for the other kids. For me, that was so helpful because when I was in the thick of it all, I felt like I didn't even know which end was up. I was trying to survive the day or the next hard thing, and I was so overwhelmed I sometimes didn't know what support to ask for outside of the medical needs of my daughter, but they did, and they've continued to check in and support us all through treatment and beyond.

Once we were home and made it to the maintenance phase of treatment, I began to attend the parent support group virtually due to covid. Yet again, a wonderful group of people welcomed me. That monthly meeting was so helpful. I finally realized I needed support from other families who knew what it was like to go through this. Danielle does such a fantastic job of running these groups. She keeps up with where we are at with treatment and asks how that particular stage is going. It's so personal and, again, comforting. The staff goes above and beyond to get to know your family and provide support wherever needed. Even now that we are off treatment, I still can't find another place that offers the support that Why Me does.

Furthermore, I didn't initially realize that not all programs or states have a resource as we do with Why Me. Once I started talking with other families of children with cancer from different parts of the country, it became even more apparent what a special place Why Me & Sherry's House is. Often there are many options for support during treatment, but I've found that most stop when treatment ends. Why Me continues forever for the child and their family, inviting them to family events and staying in touch. During the pandemic, they continued to work hard to provide support and a community in whatever way they could and as safely as possible. It is an invaluable resource for these children and their families, like ours.

I am forever grateful for all Why Me has done for us; they took me under their wing in some of my most challenging moments and provided me a safe place to cry, struggle, grow and heal.

We are now almost two years off treatment; Livie is in remission and doing well. We continue to navigate life after treatment, even welcoming a daughter, Adelyn, to our family in August of 2022. With Why Me, I've found a place we can keep returning to where it always feels like friends and family surround us. Though I'm not sure what the future will hold, I know Why Me is always there.

-Tiana, mom of Olivia



After a big snowstorm on Thursday, December 17, 2020, we decided to take our three boys outside for a snowball fight. Our youngest, Sebastian, was so excited, but he only played for ten minutes before wanting to go back inside. That was certainly not normal behavior for our 3-year-old boy. He kept complaining that he was freezing. He was shaking, and his cheeks quickly became bright red. When I took him back inside, I noticed his face and eyes looked different. I tried to warm him up with a blanket and a hot chocolate. A few minutes later, he felt warm and eventually had a fever. It all happened so fast and out of nowhere. Concerned, I called his pediatrician, but they wouldn't see him until the following week. We did not feel we could wait that long, so I took him to the emergency department at UMass Memorial in Worcester. The hospital assumed Sebastian was sick with Covid - so many people were still getting sick from it, and he had a fever. They only did the swab for Covid and sent us home. They told us we would receive a call with the results and bring him back to the emergency department if he got worse.

The fevers continued for days, and his Covid test was negative. At 11:30 pm, we decided to take Sebastian back to the emergency department. It was so hard to be there. Christmas was just a few days away, and we were worried about Sebastian. Again, we explained all his symptoms. His fever would not go down with Tylenol, and his back and legs were hurting him.

> Finally, they listened to me and decided to do bloodwork. I still remember that night so vividly. While Sebastian lay in the hospital bed, sleeping like an angel, we kept looking at each other, wondering what the results might be. The worst day of our lives was Wednesday, December 23, 2020, at 4:33 am. Doctors came into our room with tissues, and I knew it must be serious. A day before Christmas, we discovered our 3-year-old has T-Cell Acute Lymphoblastic Leukemia (ALL). At that moment, everything changed, and Sebastian's diagnosis broke our

hearts. In just one week, we went from having a healthy boy to watching our baby fight for his life. It was all a blur after that. The doctor told us we would stay in the hospital for at least two weeks. Sebastian immediately got a blood transfusion and had surgery to have a port-a-cath placed. After, they started his chemotherapy treatment right away. The nurses continue to be amazed Sebastian doesn't move to have his port accessed. He has been a hero and is the bravest little boy. It has been a journey having a sick child, from high fevers to infections or allergies to medications. It has been challenging, but we have learned much because of him.

Why Me has greatly supported our family; they have helped us with gas and grocery cards. We get food from the pantry at Sherry's House when needed. We attend their monthly support group. They helped us with school supplies, and the boys attended summer camp for a few fun days at Sherry's House. The best part about Why Me is that when we get invited to fun family events, it is not only for Sebastian but also for his two older brothers. We get to do things as a whole family still. Just knowing that we have Why Me as a friend on our side makes us feel so special. We are very grateful.

Sebastian is now five years old and has started school. He has been on treatment for the last two years and has about six more months to go. We are hopeful for his future. Even though he is still in treatment, we try to keep his life like a "normal" child. He enjoys playing at the park, playing with his tablet, and likes to go SixFlags with the family every summer. -Guadalupe, Sebastian's mom

Was caring, funny, and witty, and he could always make you laugh. He was unique. Patrick had a big personality and was a talker. He knew a lot about all kinds of things and would readily share with anyone who would listen. His idea of healthy eating was a chick-fil-a sandwich, a 20-piece box of McDonald's chicken nuggets, a barrel of Dunkin Donuts munchkins, and the meatballs at any family function. Of course, he followed it with Gatorade, his drink of choice. He collected sneakers and proudly displayed them on his "sneaker wall" in his bedroom. Patrick was a great and loyal friend. We were best friends and shared a special mother-and-son bond. Patrick loved his family and was always ready to go on an adventure, whether Cape Cod, New Hampshire, Maine, Rhode Island, or just a family party.

Patrick was your typical teenager - attending high school, hanging out with friends, and enjoying time with our large extended family, but that is where "typical" ended. On November 14, 2018, after persistent headaches, we were referred to UMass for testing. That is when they discovered a mass on Patrick's brain. He would never again be typical. 15-year-old Patrick was diagnosed with stage 4 Glioblastoma, an aggressive brain tumor.

Patrick's diagnosis would forever change our family. Immediately, our family grew to include all the support Patrick needed. It took doctors, nurses, social workers, tutors, and other caregivers to help process and

accept his diagnosis and the lasting impact on our lives. Claudia, the hospital social worker, first introduced us to Why Me as a resource for our family. I reached out to Why Me and began attending the parent support group. There, I felt supported by other parents also in the fight for their child's life.

"Why Me continues to be a part of our family, I attend their monthly bereaved mother's luncheon. This luncheon allows me to talk about missing Patrick and what I go through daily. We understand each other's pain in a way only another bereaved mom can."

-Meg, Patrick's mom

Initially, Patrick was not interested in any of Why Me's events or groups. He started his treatment, consisting of

chemotherapy and radiation. Patrick did not complain and only worried about me. Once he realized that Why Me was my source of support, Patrick began attending the events for me and eventually for himself. He joined their teen group, where he volunteered to help at the annual Holiday Party and did fun outings like going to Frightfest at Six Flags.

Our family was becoming part of the Why Me family, further expanding the caregivers that were now part of our lives. Why Me gave us tickets to events, gift cards, and other fun activities during his grueling treatment; these moments provided us with much-needed family fun. The emotional support I received from staff, other Why Me parents, and those in the support groups was key in helping us allow Patrick to be as "typical" as possible again. The support enabled us to foster Patrick's independence, which was sometimes scary.

Patrick passed away in January 2021 but not before checking off many of his bucket list items - obtaining a driver's license, getting a job, and buying and driving his car. Why Me continues to be a part of our family, I attend their monthly bereaved mother's luncheon. This luncheon allows me to talk about missing Patrick and what I go through daily. We understand each other's pain in a way only another bereaved mom can. Why Me has helped to support and encourage me to move beyond the grief to help others in their difficult journey.



# **Support Services through the Pandemic**

Why Me and Sherry's House strives to facilitate personal connections and support for families with childhood cancer. We found new ways to re-imagine these connections and support throughout the pandemic.

Initially, we maintained relationships with our families through email and phone calls. We offered non-perishable food and essential items from our pantry and would leave them on the porch for contactless pickup. All of our support groups went virtual - because childhood cancer is isolating enough without a quarantined pandemic. We continued to think outside the box for other ways to help make families smile and create a few fun memories.

By June 2020, we found our groove by hosting a virtual trivia night and a drive-in movie with all social distancing protocols in place. We provided bags of "summer fun" to help bring a few extra quarantined smiles to our younger children. We played virtual bingo with our teen group and drove around the area delivering RC cars to our kids.

We "masked up" when necessary and moved forward with our family fun events in new ways, utilizing the driveway and backyard at Sherry's House. We put up spider webs and Halloween decor all around the backyard of Sherry's House and created a Spooky Stroll. We held a drive-thru Holiday party for our families that included presents, a Santa sighting, and crafts to work on at home. For our annual Angel Tree Remembrance evening, we added Christmas lights and ornaments in the backyard and hung snowflakes adorned with the name of a Why

These events helped the families who needed us most to feel supported and safe when the world felt unsteady. We continue to remain committed to their overall health and safety.



















### Family Fun in 2022



### Easter Egg Hunt | April

We welcomed families back inside Sherry's House, with masks, to do crafts. Then sent everyone outside to hunt for eggs and take a photo with the Easter Bunny.







For Mother's Day, we celebrate our Why Me Moms with a social evening out, honoring them and all they do for their family. This year charCUTErie Woo did a private workshop with us at Lock 50.









### Halloween Stroll | October

The Halloween Stroll is one of the few events that has continued in its re-imagined form. This year, families did crafts inside Sherry's House then enjoyed our not-so-spooky walk through with games and over 150 carved pumpkins.



#### Angel Tree | December

Families will hang their gold angel ribbon on our tree for the holiday season. This evening is focused on remembrance and the precious angels, no longer with us.











Holiday Party | December

For the first time in 3 years, our annual Holiday Party will be back in-person. Families will enjoy crafts, dancing, teen activities, a performance by the Shepherd Hill Show Choir, and a visit from Santa and Mrs. Claus. Every child in attendance receives a present.

## **Fundraising in a Pandemic**

In March 2020, everything came to a halt. All of our fundraisers for that year and well into 2021 were canceled. While the money from those canceled events was significant, we were able to pivot some events into a virtual option that far succeeded expectations. In 2022, all fundraisers have come back fully, in-person. Here's a snapshot of the last few years...



### 2021 | Virtual pasta class with Volturno Pizza

Through Facebook live participants could follow owner, Greg Cailfano Jr.'s, steps easily and ask questions along the way. It was a great way for the whole family to participate in a fundraiser, while at home.













#### 2021 | 100 Mile Ruck March

The 100 Mile Ruck March Challenge is a military inspired event. From Sherry's House, athletes ruck (hike) 25 miles a day for 4 days, returning to Sherry's House. They camp on a local brewery's farm each night and continue the following morning. Athletes carry everything needed for the 4 days on their backs, navigate the 100-mile course, cook their meals, set up and break down their camps each night, and tend to their feet and bodies. The inaugural event had 10 of the 15 athletes complete the challenge.

### **2022 Fundraisers**

### The Heart Dance | AC Hotel, April 2022

Photos courtesy Erika Sidor Photography







### Golf Classic | The Haven, June 2022

The Haven golf course is praised as being as much fun to play on the 500th round as it is on the first. Day includes full round of golf, lunch on the course, auction and more.

Save the Date for June 12, 2023





#### 100 Mile Ruck March | July 2022

Photos courtesy Jackie Mushinsky, Spencer Cable Access

This year, 33 athletes attempted the challenge of rucking 100 miles in 4 days. The weather added a relentless heat wave with soaring temperatures, creating new challenges for an already tough endurance event. 18 of the 33 completed the challenge and crossed the finish line.

Save the Date for July 20-23, 2023





### Bruins Alumni Game | November 2022

Photos courtesy Craig Michaud Photography

This year, our Why Me All Star team was given the honor of participating in "Hockey Fights Cancer Night" with the Worcester Railers. Our team played the Bruins Alumni against legends like Frank Simonetti.

Interested in playing in 2023? Contact Rebecca Kuczarski at rkuczarski@whyme.org





# Get Involved

Volunteer

We offer countless opportunities for you to show your support as a member of the Why Me Volunteer Team. Volunteers can offer their time and talents in a number of ways including childcare, meal assistance, fundraising & family events, housekeeping and much more.

Donate Items From Our Wish List

Hundreds of families pass through the doors of Sherry's House each year creating a constant need for food, toiletries, household supplies and family essentials. We have created a wish list, updated monthly, that includes items to assist families residing at Sherry's House, as well as those families who live locally but require additional resources.

Attend a Fundraiser

Fundraising events take place throughout the year and offer a little something for everyone. From motorcycle rides to golf tournaments and car shows, the funds raised from these events are crucial in allowing us to provide services free of charge. Additionally we accept donations of concert tickets, gift certificates, gift baskets, sporting event seats and more to be used in our auctions.

Donate Gift Cards

The increased needs of a child being treated for cancer often result in mounting financial stress. Gift cards help lessen the financial burden on families while away from home and commuting to the hospital at a time when income is reduced and expenses are escalating. Gift cards for gas, grocery stores, pharmacies, fast food, restaurants, and VISA/AMEX are especially helpful during such a difficult time.

Hold a Food Drive

The pantry at Sherry's House is always open for our Why Me families. We are always looking for groups and individuals to host food drives for us throughout the year so that we can continue to offer this amenity to our families. Ask your neighbors, friends, school or office to join together in hosting a drive.



For more information on zettinz involved, visit www.whyme.org/get-involved

