

OUR SAFETY BLANKET

When Mylo was just 4 months old, he was diagnosed with Progressive Optic Pathway Glioma. Read about his journey with Edmarc inside.

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a note from **EDMARC**



Edmarc prevailed through yet another year of uncertainty. We prevailed because donors, foundations, and granting organizations believe in our mission and support it financially. We prevailed because volunteers continue to help us in countless ways. During the calendar year of 2021, volunteers gave Edmarc 3,035 hours of time which equates to nearly \$95,000! Beyond those impressive numbers, they give us, and our families, their smiles and their hearts. We prevailed because staff worked hard to meet stretch goals. With a staff of 15 covering 2,400 square miles, we keep our administrative costs to less than 10% year after year.

As we move through 2022, we are hopeful. Spring began with a return to some semblance of normalcy. We celebrated our Spring Fling, Easter basket deliveries and annual volunteer recognition events in person once again. You could feel the excitement in the air of gathering with each other as we have in the past. We look forward to a summer picnic and end-of-year pool party for families ... in addition to our 26th Anniversary Charity Golf Classic in August.

We continue to grow and change with the times. We have a sense of resiliency amongst our staff, board and volunteers. If we had become complacent during the pandemic, Edmarc would not have thrived to our current level. We kept pushing forward – even during an uncertain time – and made plans for the exciting next chapter of our organization. Stay tuned for more in the coming months!

Edmarc began nearly 44 years ago as a grass roots effort by a group of determined individuals. That same tenacity has carried us through these seasons of change. Thank you for standing by us and being a friend to Edmarc. Most of all, thank you for helping us provide hope for the journey to those who need it most.

Well wishes to you,

Debbie Stitzer-Brame
Executive Director, Edmarc

EDMARC HAS BEEN OUR SAFETY BLANKET

When Mylo was just 4 months old, he was diagnosed with Progressive Optic Pathway Glioma - a tumor had formed behind Mylo's eyes. A whirlwind of events then ensued as we navigated the best treatment options for our sweet baby boy. Mylo required a biopsy and a central venous line to be placed. During this hospital stay, Mylo began seizing and required a shunt be placed in him as well. He was hospitalized for his first Thanksgiving. Once the biopsy results returned, he began chemotherapy that December. Over the next couple of months his physique began to shrink. A lot was happening, all revolving the health and life of Mylo. He needed us, and we needed help.

Mylo was admitted to Edmarc in March of 2016, and with this entrance into the Edmarc family, a HUGE burden was lifted. We had support 24/7. Nurses brightened our days with home visits, allowing Mylo to stay in a comfortable environment as he received care. Abbey, our social worker, has been a support to Mylo's sisters after other counselors were just not the right fit. She has also helped me through multiple storms in my life. Volunteers came in to help with home projects that were falling behind as we focused on care for Mylo. One time, a Navy chief crew came in and raked leaves, hung blinds, and painted walls. There were kind volunteers who cleaned out my gutters that were overrun with leaves. We weren't able to make time to accomplish these tasks, but Edmarc did.

We always looked forward to the activities and events like the Santa Run Gift Delivery, Spring Fling and the costumes at the Fall Festival. It's like gathering with family during the holidays-our Edmarc family. It was also nice to attend functions where other families were facing similar challenges and understood that even though their child was sick, it didn't mean they needed to stop making memories as a family.

Edmarc had become a safety blanket and a happy place for our family. That's why when Mylo had improved enough to be discharged from the program in November of 2020, it was bittersweet. No parent

wants their child to need pediatric hospice services, but Edmarc had become so much more than a weekly nursing visit. Edmarc had become part of our family and vice versa. But we knew upon discharge, we would not be left completely alone...we still received invites to Edmarc events, and if Mylo ever needed their services again, Edmarc would be there.

In early 2022, Mylo's tumor had begun causing issues again and he was just not himself. Mylo is a good-hearted kid who loves to dance, be tickled, and always has a smile on his face even when he's feeling bad. Much of Mylo's personality had been overcome by his illness. His mood and temper began to change. He preferred lying on the sofa more and no more jumping, no more dancing to songs in movies, no more kitchen dancing with mommy. And like any good family member, Edmarc was there once again to provide support. The nurses restarted their visits to check in and provide treatment. Abbey was once again at our side, checking in on the girls. Our safety blanket was back, and it was comforting to see familiar, caring faces.

Since reentering the program, Mylo has begun a two-year clinical trial treatment protocol. We have seen great improvement, and a recent MRI has shown significant decrease to a portion of his tumor! His delightful personality has returned, and he continues to spread joy, smiles and laughter to anyone he encounters. We are thrilled at the positive outcomes recently, but we know this journey is not over. There are always risks involved. We also know that no matter what Mylo's journey looks like through the ups and downs, Edmarc will be there walking alongside us.



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SUPERHERO SPOTLIGHT

Hi, my name is David, and I am 3 years old. When my mom was 20 weeks pregnant with me, my parents were so excited to have an ultrasound to find out my gender, during which the gynecologist told them they needed to be referred to a maternal-fetal specialist. There was fluid on my left lung, forehead, and back of my neck. I had a slim chance of survival, but miraculously made it to my birth where I was diagnosed with Cornelia de Lange Syndrome. This is a rare genetic mutation disorder that affects multiple systems of the body. My lungs are weak, and I depend on a ventilator. My motor skills are having a hard time developing, but my physical, speech, and occupational therapists are helping me with this. I also have to eat through my peg tube, so I get all of my nutrients through liquids.



I am expected to spend my lifetime being dependent on others, but fortunately, I have so many people in my life that love me. My mom, dad, and siblings are always there for me. I have friends and teachers at school to play with, and my nurses come visit me at home to care for me. I bring so much joy to the people around me and am also cute to boot!



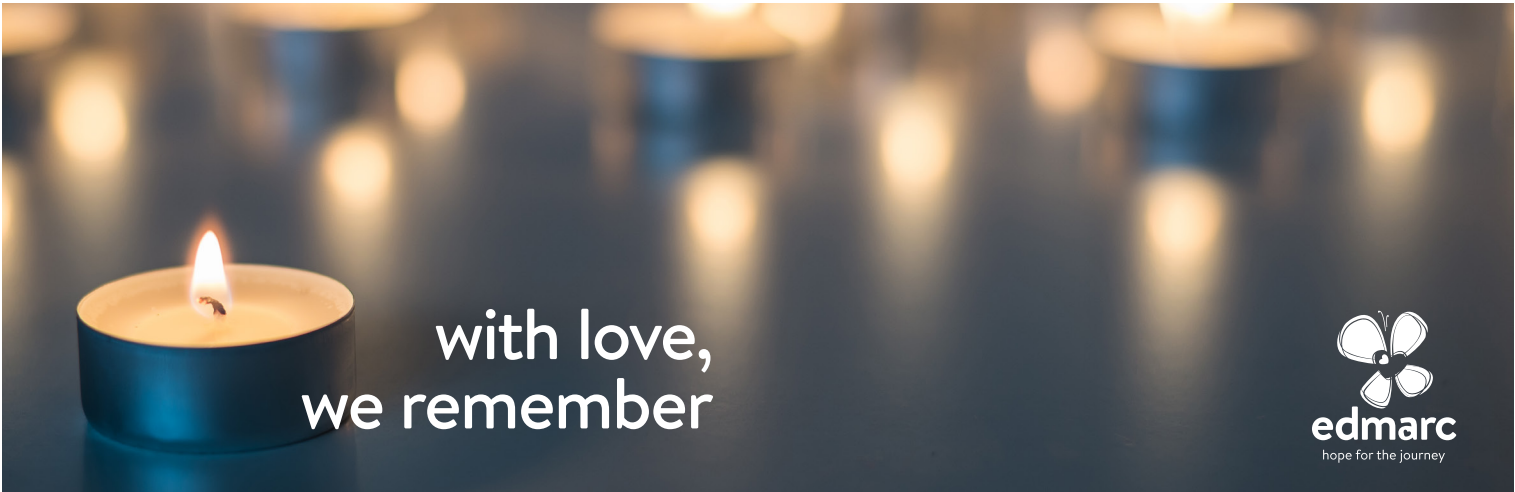
A HOLIDAY TRADITION

We cherish holiday traditions at Edmarc, and we were so happy to be able to bring it back in a COVID-safe way this year. Caring for the families at Edmarc is about more than the necessary medical and social work care. We care for the whole family, and we do it all year long; especially during times when the days are shorter, busier, and harder than ever. It is not easy to be a child, or to have a child who is sick during the holidays. It is especially difficult to be a grieving family at a time that is supposed to be merry and bright. We shoulder the burden and try to lighten the load so our families can just focus on being together and making memories with each other.

Volunteers began lightening the load for Edmarc families in November when they delivered complete Thanksgiving meals to 65 families. In December, 27 sponsors from our supportive community provided gifts and complete holiday meals for 68 Edmarc families. The Edmarc offices were filled with volunteers from the middle of November until mid-December, sorting, organizing, and packing

food donations and wrapping and organizing gift donations into hand-sewn Santa bags. On December 12th, Santas, photographers, and Edmarc staff joined Fire and Police from each city in Hampton Roads to deliver those gifts to our Edmarc families. We were very fortunate to have groups help us with delivery that included Dominion Energy, the Noblemen, Bayside HOG, and the Middle Peninsula Jeep Association. We are so grateful to our community partners who sponsored families, volunteers who sorted, wrapped, and organized, Fire and Police, and our Santas who made the magic happen for our families.





DAPHNE KATE T. (10/15/21-10/15/21)

Daphne was a very sweet baby girl who brightened and touched the lives of all those around her. Though little Daphne’s time here was far too short, she was loved immensely by her family. Left to cherish her sweet memory are her devoted parents, Kelly & David, big sister, Natalie, and numerous other family and friends.

ABIGAIL F. (9/24/06-10/19/21)

Abby was an amazing young lady who inspired so many with her journey, determination, and desire to help others. Abby, both courageous and wise beyond her years, was a fierce lover of her family and friends, and had a great sense of humor. She enjoyed cooking, Harry Potter, Girl Scouts, school, and camp. She impacted so many in her short life. Abby fought hard and long and truly was an inspiration to many. Abby is lovingly remembered by her parents, Patty & Joe, sisters, Maggie & Emily, and numerous other family and friends.

ALEJANDRO V. (10/26/21-10/26/21)

Alejandro was a precious little boy who was so deeply loved even before he was born. His time with his family was short, but the legacy he leaves is great. He will be lovingly remembered and deeply missed by his parents, Jonathan and Citlally; as well as numerous other family and friends across the country.

OLIVIA P. (11/13/03-11/4/21)

Olivia, known to family and friends as “Livi Pie,” was an inspiration of hope and perseverance to all she encountered. Her smiles and giggles could light up any room. Olivia enjoyed car rides, going to the movies, and strolls around the neighborhood on a beautiful day. She also loved watching her favorite shows like Sponge Bob and Peppa Pig. Olivia is lovingly remembered by her parents, Jennifer & Percy, her brother, Peyton, sister, Addie, and numerous family and friends.

ALEXIS Y. (1/13/06-11/15/21)

Alexis, known to family and friends as “Lexi Lou Lou”, was an incredible young lady who was rarely seen without a huge grin on her face. Lexi was strong, sassy, and always true to herself, despite many hardships she faced. Lexi’s favorite color was purple, and she loved to play with fidgets and her cat. She was a fierce protector of those she loved. Left to cherish her precious memory are her mother, Sarah, sisters, Gabriella, Sophia, Caylynne, & Mckenzie, brothers, Yusuf & Christopher, and numerous family and friends.



DEXTER H. (10/20/11-11/21/21)

Dexter could be described so many ways, but above all he was sweet, kind, and goofy. More than anything, he loved spending time with his family, cooking with his mom, being wild with his brother, and adventuring with his dad. He was an active kid who loved skateboarding, hiking, and exploring. The tenderness and care he showed everyone around him made him an absolute joy. He was wise beyond his 10 years, and the impact he leaves behind is immense. He had such a kind and loving spirit, and he left his mark on those that were lucky enough to know him. He was so deeply loved and will be forever cherished by his parents, Salvija and Dan; his brother, Dashiell; and an entire community who will hold him in their hearts.

KATIE S. (8/1/04-11/25/21)

Katie Rae was just that: a ray of sunshine. Her light shone so bright in so many ways, most notably of which was the kindness she showed everyone around her. It seems that everyone who knew Katie has some story of how she showed them kindness and grace. She was bright, witty, and creative, and spent time covering the walls of her room with artwork and spending her time working with her diamond dots. She adored her friends (and her pup!), as well as her band and church families. Her faith, humor, and bravery were truly incredible. She will be remembered always by all who knew her, and will be especially missed by her parents, Tom and Heather; her brother, Jacob; and her sister Daisy.

TOI P. (4/12/13-12/12/21)

For anyone who knew TJ, it is the absolute truth that there was nothing in this world as big and colorful as his personality. He had a way of warming the hearts of everyone around him through laughter and his undeniably impressive sense of style. He brought joy to everyone he met with his beautiful smile that would light up a room. The strength and fight he had was immeasurable. Throughout his journey, he endured challenges that he faced with a level of strength that far surpassed his 8 years. Throughout

his battle, he earned his nickname “Superman” a hundred times over. His zest for life will be missed, and he will never be forgotten. He lived each day to its fullest. He will be forever remembered and loved by his parents, Toi and Adrea; as well as his brother, Legend; and countless friends and family who were lucky enough to know him.

EVA B. (1/26/09- 12/31/21)

Eva was a true Diva, a precious young lady who brought so much joy to all those around her. Eva’s strength and courage were matched by few, and she was an inspiration to all who had the honor to meet her. Eva loved the color yellow, Mickey Mouse Clubhouse, and chocolate. She enjoyed going to school to see her friends and spending time with her family. Eva is lovingly remembered by her parents, Akeia & Devon, big sister, Ariana, and numerous other family and friends.

ARIA B. (7/27/20-2/2/22)

Aria was a fighter in every sense of the word. A precious little girl, she brought so much joy to all those around her. Aria defied medical odds and persevered in the face of a very challenging illness. Aria never stopped smiling or loving life, fully embracing the love of her parents and her family’s faith. Aria taught so many what is truly important in life. Her smile and her laughter were contagious, and she had a flair for fashion with her adorable outfits and hairbows. She loved spending time with her family, especially her mom and dad. Left to cherish her sweet memory are her parents, Sara & David, and numerous family and friends.

DANIYA K. (5/22/16-2/4/22)

There are few words that can describe how amazing Daniya was. Daniya was a very strong and courageous little girl who never complained about a thing. Daniya lived her life so full of love and happiness, embracing each day, and having fun. She brought so much joy to all those around her and taught many of us some very valuable lessons. It was an honor to all who had the privilege to know her and spend time with her. Daniya is lovingly remembered by her parents, Hamid & Mona, and numerous other family and friends.

MARCELINO N. (2/17/22-2/17/22)

Marcelino, "Nino," was a precious, adorable, and immensely loved little boy who was adored by his family even before he was born, and he undoubtedly melted the hearts of everyone who was privileged enough to meet him. The impact he made on the world is vast, and he will be deeply missed and loved by his parents, Lary and Gerardo; his siblings, María José and Sebastián; as well as countless friends and family.

ALMA VICTORIA D. (4/1/22-4/1/22)

Alma was a beautiful baby girl who brightened and touched the lives of all those around her. Though little Alma's time here was far too short, she was loved immensely by her family. Left to cherish her sweet memory are her devoted parents, Epi & Larry, big brother, Larry, and numerous other family and friends.

NOLAN M. (1/15/17-4/12/22)

Nolan was a wonderful little boy that always graced us with a huge grin on his face. He fought a long and difficult battle with cancer, yet he never complained and always found time to laugh and enjoy every moment. Nolan will be greatly missed by all those who had the privilege to know him. He will be lovingly remembered by his parents, Tim & Brianne, sister, Norah, brothers, Kellen & Will, and numerous family and friends.

STONE C. (11/28/21-4/17/22)

Stone was a very sweet little baby boy who brightened the lives of his family and all who had the pleasure to meet him. Though his time here was very short, he was truly a little fighter and an immense blessing. Stone will be lovingly remembered by his mother, Jenica, big brother, Jaxon, and numerous family and friends.

JOSHUA T. (10/19/2010-4/21/2022)

Joshua was a fighter in every sense of the word. A precious little boy, he brought so much joy to all those around him. Joshua fought a long difficult battle with his illness, enduring it with enormous courage and strength. Joshua taught so many what is truly important in life. He loved spending time with his family. Left to cherish his sweet memory are his parents, Janet & Jonathan, brothers, Aiden & Kylan, sister, Ma'Leah, and numerous other family and friends.

JAYDEN C. (5/24/2008-4/24/2022)

Jayden was an amazing young man who brightened the lives of his family and all who had the privilege to know him. Jayden, courageous and strong, fought a long difficult battle with his illness. Jayden had such a kind and loving spirit truly leaving his mark on those that were lucky enough to get to know him. He was truly a blessing and was adored by all those around him. Jayden is lovingly remembered by his parents, Susan & Terry, little sister Yemaya, and numerous family and friends.

MAKHI M. (5/11/22-5/12/22)

Makhi was a very special baby boy who touched so many hearts in his short time here on earth. Makhi was loved immensely by his family and will be missed greatly. Left to cherish his sweet memory are his devoted parents, Zoe & Parker, superhero grandmothers, Susan & Kelle, and numerous other family members and friends.

SPRING MAGIC

The Easter Bunny was busy this year as we welcomed spring with a fun-filled day of crafts, activities, prizes, pictures with the Easter Bunny, a special appearance from Wags, and of course, the famous Edmarc Easter egg hunt! Families came together on a beautiful 60-degree day and watched as their kids decorated Easter eggs, played Pin the Tail on the Bunny, decorated the sidewalk with chalk, and indulged in candy-filled eggs from the not-so-difficult Easter egg hunt.

On the heels of a successful Spring Fling, Easter Bunny helpers stepped into their roles by putting lots of love and attention into Easter baskets for each child involved with Edmarc—not just the Edmarc patient, but their siblings as well. Volunteers paid special attention to specific needs for each child, taking exceptional care not to include candy in baskets for kids who cannot eat candy, and adding special touches like including their favorite TV show character stuffed animal. As one mom said, “our children were so surprised and felt so special on Easter morning... those baskets brought a lot of magic to our house.” We delivered 207 Easter baskets to 83 families!

Special thanks to the Portsmouth Rotary for providing generous financial support for Spring Fling, to the Tidewater Tots Childcare team for being our Craft and Activity Coordinators that day, and to Elf Patrol and all the Easter basket donors for your generous donations.



In HONOR of Edmarc gratefully acknowledges the outpouring of support in honor of family members and friends.
October 1, 2021 – April 30, 2022

**IN HONOR OF
MR. & MRS. KEN**

& ANNE ABLETT
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PATRICIA AMOROSO
LATORIA CHANTAE ARNOLD
LINDA ARRINGTON
MARILYN ARUTA
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SARAH & MILTON BROWN
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Faith Shartzter
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Sharon C. Sutton
Patricia Goldstein
PC&A
Alan and Lori Strickland
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Sara Burton
Sara Burton
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Joan and Allen Hogge
Joan and Allen Hogge

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Paul McRae

Wendy McGrady

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Frank & Sandra Willoughby

Bobbie Tabor

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Arthur and Phyllis Canupp

Sara Burton

Sara Burton

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In MEMORY of Edmarc gratefully acknowledges the outpouring of support in memory of family members and friends.
October 1, 2021 – April 30, 2022

**IN MEMORY OF
KEN ABLETT**

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A.J. BARBARO

MADELINE MARIE BARNES

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CURTIS AND

TREVOR COLEMAN

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BRIANA CRAWFORD

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THANK YOU FOR BEING A FRIEND, EDMARC VOLUNTEERS!

Every year in April, there is a whole week dedicated to appreciating volunteers. At Edmarc, we would like to think that we express our appreciation for our volunteers year-round, but in April, we hold a special event just to show our wonderful volunteers how much they mean to us! This year's event looked a little different than previous (non-COVID) years. We did not have any awards or plaques to give out, just a lot of love and appreciation to spread. As guests arrived at the Woman's Club of Portsmouth, they were greeted by Edmarc staff and offered a hand-made candle, to symbolize the light they shine on Edmarc.

Maggie, Edmarc's longest-serving staff member gave a beautiful testimonial in memory of Ken Ablett, one of Edmarc's special volunteers who passed away last year. Landon's grandparents, John and Patti Sanderl, shared what it was like to interact with Edmarc volunteers while their grandson was in our service. Volunteers are the very foundation upon which Edmarc was built, and we truly have some of the best volunteers there ever were.



Thank you ...

Thank you to the many, many individuals, businesses and organizations who make the work Edmarc does possible and bring joy to our families across Hampton Roads by donating food baskets and gifts for the holidays, items from our Amazon wish list, professional services and more!
October 1, 2021 – April 30, 2022

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Welcome Matt McDermott



My journey to Edmarc has been a long and winding road. I have been a nurse for 25 years, graduating from Rutgers University with my bachelor's degree in 1997 and receiving my master's degree in 2003. I started in home care right out of nursing school and never looked back. I have worked in a variety of settings, including Medicare-certified home care, licensed home care, specialty pharmacy and now hospice. I believe that all people, regardless of age, deserve to be

cared for in the privacy and safety of their own home. I also believe that home care provides the nurse with tremendous autonomy and flexibility, benefiting both the patient and the nurse. I have four beautiful children, two of whom have gone on to become nurses as well. When not at work, I enjoy spending time with my family, including my two brothers and their families, as well as several four-legged creatures who keep us constantly entertained. I am extremely proud and grateful to be a part of the Edmarc family and look forward to many years of leading a team of true professionals as we work together in providing amazing care to our patients and their families.

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