



edmarc
hope for the journey

Progress Report







Our Past, Our Present, Our Future

Milestones are a natural point to think back and look ahead, and Edmarc's 40th anniversary is definitely an exciting milestone for our organization. Started as a grassroots effort in 1978, when Edward Page, the minister at Suffolk Presbyterian, and a little boy in his congregation, Marcus Hogge, were both dying from terminal illnesses. Rather than let this defeat them, their two families worked together to create something positive. Edmarc—named in memory of Ed and Marcus—was the result. Our services aim to relieve suffering, improve quality of life, facilitate informed decision-making, and assist in care coordination between clinicians and across sites of care.

Today, through our home health and hospice programs, we touch the lives of over 1,000 individuals annually. We help families navigate through the diagnosis, treatment and grieving processes of a child bearing the burden of a life-threatening illness. As one program participant recently shared with us: "Edmarc is so much more than what meets the eye ... it is the flicker of light that was all but lost when hope seemed just outside our grasp."

If Edmarc were another type of organization, we could look at the number of families we serve annually—and say, "Good enough!" But "good enough" is never good enough for us, particularly when there is so much more to do in three key areas:

- Making sure children get the care they need.
- Eliminating distance and money as barriers to care.
- Keeping families and children together, in sickness and in health.

As we look ahead, we are humbled by the prospect of giving more of ourselves to more people across the Commonwealth.

In this spirit, we have an opportunity and an obligation to do better for our children. As we look forward, we are focused on expanding our geographic reach to allow us to provide care for more children in desperate need of our help. There will be more light in a family's darkest time—a chance for something normal in a time of chaos and pain. A child who wants to be cared for at home deserves to be at home. They will have the life they want, for however long they have left. We give families hope for their journey ahead.

Finally, and most importantly, please know how grateful we are to you for your support as we move forward with a strong team, the continued dedication of our Board of Directors, volunteers, and supporters. Thanks to all of you, we have set the foundation for what is certain to be an incredible 2019.

With gratitude,

David

David Pritchett
President, Board of Directors

Debbie

Debbie Stitzer-Brame
Executive Director



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Edmarc Staff

- **Deborah L. Stitzer-Brame** – Executive Director

BIOGRAPHICAL SKETCH

Born and raised in Uniontown, Pennsylvania, Ms. Stitzer-Brame is a Registered Nurse and graduate of Salem College School of Nursing in Salem, West Virginia. Prior to joining Edmarc in 1999, Ms. Stitzer-Brame was a healthcare professional at major medical centers/organizations throughout Hampton Roads, including LifeNet Health, Sentara Norfolk General Hospital, and Riverside Regional Medical Center. Her extensive professional and community involvement includes leadership in organizations such as the United Way of South Hampton Roads, Children’s Hospital of the King’s Daughters, Kiwanis Club of Norfolk, Virginia Association of Hospices and Palliative Care and National Hospice and Palliative Care Organization.

- **Laurie Barbaro** – Director of Clinical Services
- **Teresa Black** – Patient Care Coordinator
- **Kathryn “Rosie” Brooks** – Assistant Director
- **Adelaide Cooke** – Community Resource Coordinator
- **Rob Ericson** – Patient Care Coordinator
- **Abigail Gellene-Beaudoin** – Medical Social Worker
- **Madalyn George-Thiemann** – Patient Care Coordinator
- **Shannon Henry** – Patient Care Coordinator
- **Mary Helen Hilton** – Director of Development
- **Dawn Jennings** – Patient Care Coordinator
- **Kristen L. Jones** – Development Associate
- **Jasna Krispinsky** – Patient Care Coordinator
- **Maggie Lewis** – Medical Records Clerk/Receptionist
- **Brittney C. Twisdale** – Medical Social Worker
- **Sara Zandford** – Bereavement Program Director

STAFF DESCRIPTION

Edmarc employs 16 staff members: 12 full-time employees including the Executive Director, an assistant director, a receptionist/medical records clerk, a development director, a development associate, a director of clinical services who is also a registered nurse, two patient care coordinators who are registered nurses, two medical social workers, a bereavement program director and a community resource coordinator. Edmarc also has four registered nurses who work when needed. Additionally, Edmarc has approximately 150 volunteers. All registered nurses and social workers have extensive training in hospice/palliative care and caring for children.

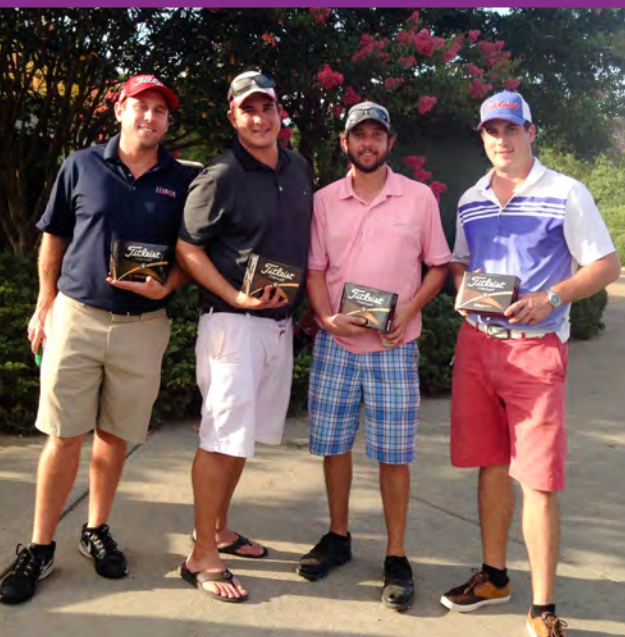


Our Mission

Edmarc's Mission is to ease the trauma of a child's illness or death, and to reduce the disabling effects of pediatric illness, loss, and bereavement on families.

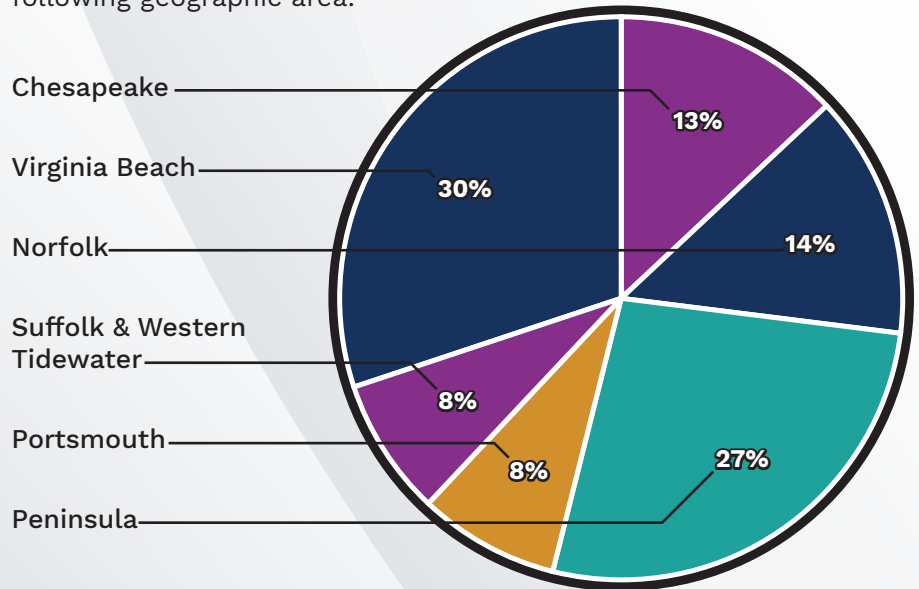
Our Vision

Edmarc sees a community in which no child or family is denied pediatric hospice services and a society that wholeheartedly accepts and supports pediatric hospice care.



Edmarc: Highlights at A Glance

Over Edmarc's 40-year history, our families served come from the following geographic area:



Edmarc's average monthly clinical census (or patients actively receiving treatment) is 72 families or roughly 250 people. Bereavement support serves 197 families on average or about 690 people. The total number of family members served by all Edmarc programs – home health, hospice, perinatal and bereavement – on average is over 1,000 individuals.

COMMITMENT OF STAFF IN ONE YEAR ACHIEVED THE FOLLOWING ACCOMPLISHMENTS:

- 315 families were served through the home health and hospice program.
- Provided 5,778 hours of skilled nursing care.
- Provided 3,221 hours of supportive services through our social work department.
- Provided support services to 102 siblings.
- Cared for 164 families through our Hospice Bereavement Program and- 35 families in our Community Bereavement Program.
- Held 10 socialization events and family outings.

COMMITMENT OF VOLUNTEERS IN ONE YEAR ACHIEVED THE FOLLOWING ACCOMPLISHMENTS:

- Volunteers donated nearly 5,000 hours.
- Over 1,000 individuals assisted with special events, transportation needs, providing emotional support and so much more. With the help of these volunteers, Edmarc can offer dozens of services we otherwise could not.
- Volunteers sponsored and participated in holiday parties, theme park outings, and provided food baskets at Thanksgiving and Christmas time.
- Brought Christmas to each Edmarc family complete with a team of carolers, gifts and Santa Claus.
- Sponsored sporting events and the annual Edmarc picnic and provided hours of support at Camp M.A.G.I.C.



Isaac

Family Testimonial from Laura Hershberger

On my third wedding anniversary I shared with my husband the happy news that we were pregnant with our first child. At the time we were a Navy family living in Virginia and our parents were cross country in California. Sadly, our 19-week gender scan did not bring news worth celebrating. We found out our baby had a likely fatal condition, and we had about five weeks to make difficult decisions. The OBGYN Social Worker referred us to Edmarc.

Two months later, we had our prenatal hospice orientation with Edmarc's social worker, Brittney. As my pregnancy went on, Brittney was there to listen and offer support. The staff gifted me with wonderful resources including a legacy kit to make my baby's footprints in clay and a recommendation of one of their charitable supporters, a photographer named Bob Harper. We received a dream maternity photo shoot on the beach and in studio, thinking this might be the only pictures we'd have of our baby journey.

On August 14, 2013, my 31st birthday, Isaac Bruce was born with no complications. He was perfect in every way, with the exception of an apricot size encephalocele in the middle of the back of his head. The doctors were astonished that there was not nearly as much damage to the brain as they thought there would have been and planned removal surgery and repair for the following day. We called Edmarc to share the happy news, and I could hear the relief in their voices of congratulations, as well as the all-too-familiar ache of knowing we still had a battle ahead.

During this first month as new parents, it was crucial for the Edmarc nursing staff come visit us. Madalyn would come weekly and it wasn't long before we were affectionately referring to her as Mimi, the name her own grandkids had for her. She would come and talk me through everything from Isaac's first cold to advice for sleeping. Britney would come at least once a month, and I practically knew the entire organization on a first-name basis. Everyone from Debbie, the Executive Director, to any of the clinical team would always take time to see us or answer our calls at whatever hour we needed them.

When the holiday season arrived, Edmarc showed up with deliveries at Thanksgiving and brought an entire caravan of Santa's workshop with them to bring a trunkful of presents to our family. We like to think this is where Isaac's love of tractors first started, as there was a John Deere theme to many of his gifts. Isaac continued to grow stronger and pass more milestones in the new year, and we welcomed his baby sister Siena Hope on March 24, 2015.

We made the difficult decision to finish my husband's Navy career at the original six-year commitment so that we could move our family home to be closer to grandparents. It was an impossible goodbye trying to express our sincerest gratitude for everyone at Edmarc on our farewell night of at the 2015 Halloween bash.

That Christmas Isaac gave us an early gift as he took his first continuous walking steps in our backyard. By his two-and-a-half birthday in February, he was a full time, unsupported walker. Fast forward to present day, Isaac just graduated from two years of special education preschool. He talks in sentences of 9 and ten words and loves to impress people with describing his surroundings and how beautiful, adorable, fantastic things are. He knows every song on a four-disc "Raffi" CD. He loves sports and has learned to drop kick a ball as he continues to work on his hand/foot and eye coordination. But the biggest thing that has never changed is his beautiful smile, his fully belly laughs, and the endless hugs he gives.

We continue our care with a team of specialists in San Francisco but miss the support of our Edmarc and our Navy medical family every day. We are thankful for the moments when we can come full circle and share our story with those who supported us from the very beginning. We look forward to the day our family makes the trip back to Virginia so Isaac can walk the steps of Edmarc and remind everyone that miracles do exist!



Maddie

Family Testimonial from Wendy Mezzenga

What do you do when you are not more than a baby yourself and all of a sudden you are given the responsibility of caring for a medically fragile child? Who could ever understand the terror and the joy you feel every time you look into the biggest pair of baby blues you have ever had the privilege to love?

I knew Maddie had complications, but to hear the doctor say she would never grow up, mentally or physically, and that I shouldn't expect any happiness out of the perfect-looking little girl I had just given birth to was just too much for me to accept. So I rocked her and I cried for 6 straight months. At that point my Nanny told me I had a choice. I could either enjoy the time we were given and make happy memories, or I could keep rocking and crying and waste the precious gift of time. That was it. I knew that Maddie had a greater purpose and I resolved to find it.

We began making the most amazing memories, but not all of the time was happy. She spent so much time in the hospital her first few years. I was lucky enough on one of those many nights at Children's Hospital to find another mom pacing the floor. As mother's do, we shared our fears. Her fear was that she would soon say goodbye to her child. Even as she said it wouldn't be long, she had a calm about her I envied. Before she left, she gave me an Edmarc brochure, but I didn't think about it right away. Let's be honest...who wants to think about a child dying?

Making that call was the best thing I could have done. Edmarc stepped into our lives and all of a sudden I had incredible support. I had nurses to talk to the doctors. I had social workers that seemed to know my needs before I mentioned them. They were like fairy Godmothers. I felt empowered and went on to live a life that wasn't perfect for everyone, but it was our life and perfect for us. We fit in. Maddie had a fan club and loved them all!

Edmarc was there every step of the way. We made those memories my Nanny described every time we went to an Edmarc function. Those memories are what get me by today. If you have been blessed enough to look into the eyes of your child and not have to worry about tomorrow, then count your blessings this Thanksgiving. Edmarc gave us a chance to experience the joys of life even while being faced with the uncertainty of death. I am thankful for being Maddie's mom for 17 years ... it was the most amazing dance of my life!

Thank You Donors!

We deeply appreciate each and every gift because collectively all gifts impact our mission and ability to make a difference to the children and families who need it most. Below we give special thanks to supporters making gifts of \$250 and above between the dates of July 1, 2016 and June 30, 2017.

\$15,000 +

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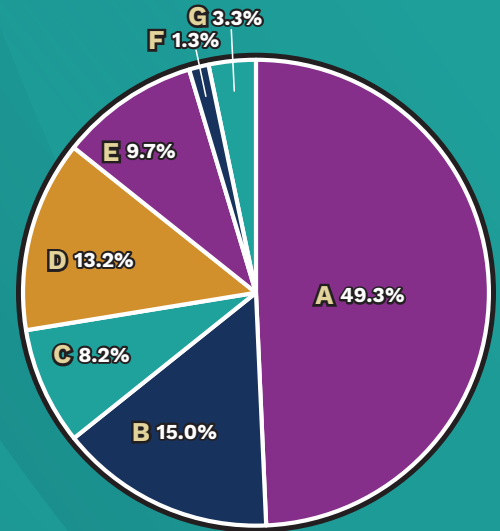
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Financials

EDMARC CONSOLIDATED STATEMENT AS OF JUNE 30, 2017

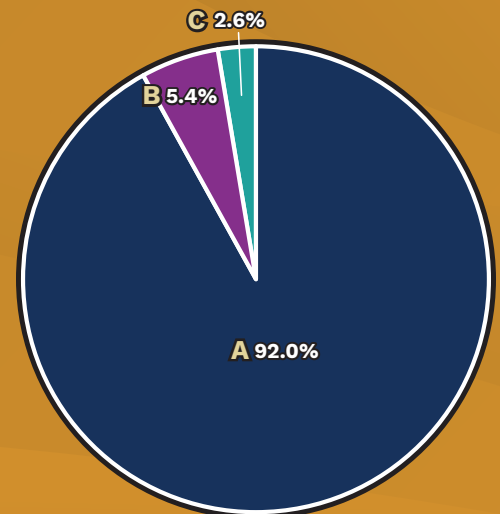
Revenue & Support:



| | |
|--|-----------|
| A Contributions..... | \$644,127 |
| B United Way..... | \$195,920 |
| C Program service revenue..... | \$106,735 |
| D Fundraising, net of expenses... | \$172,784 |
| E In-kind donations..... | \$126,380 |
| F Interest income | \$17,222 |
| G Unrealized gain/loss on investments..... | \$42,967 |
| Net assets released from restrictions | |

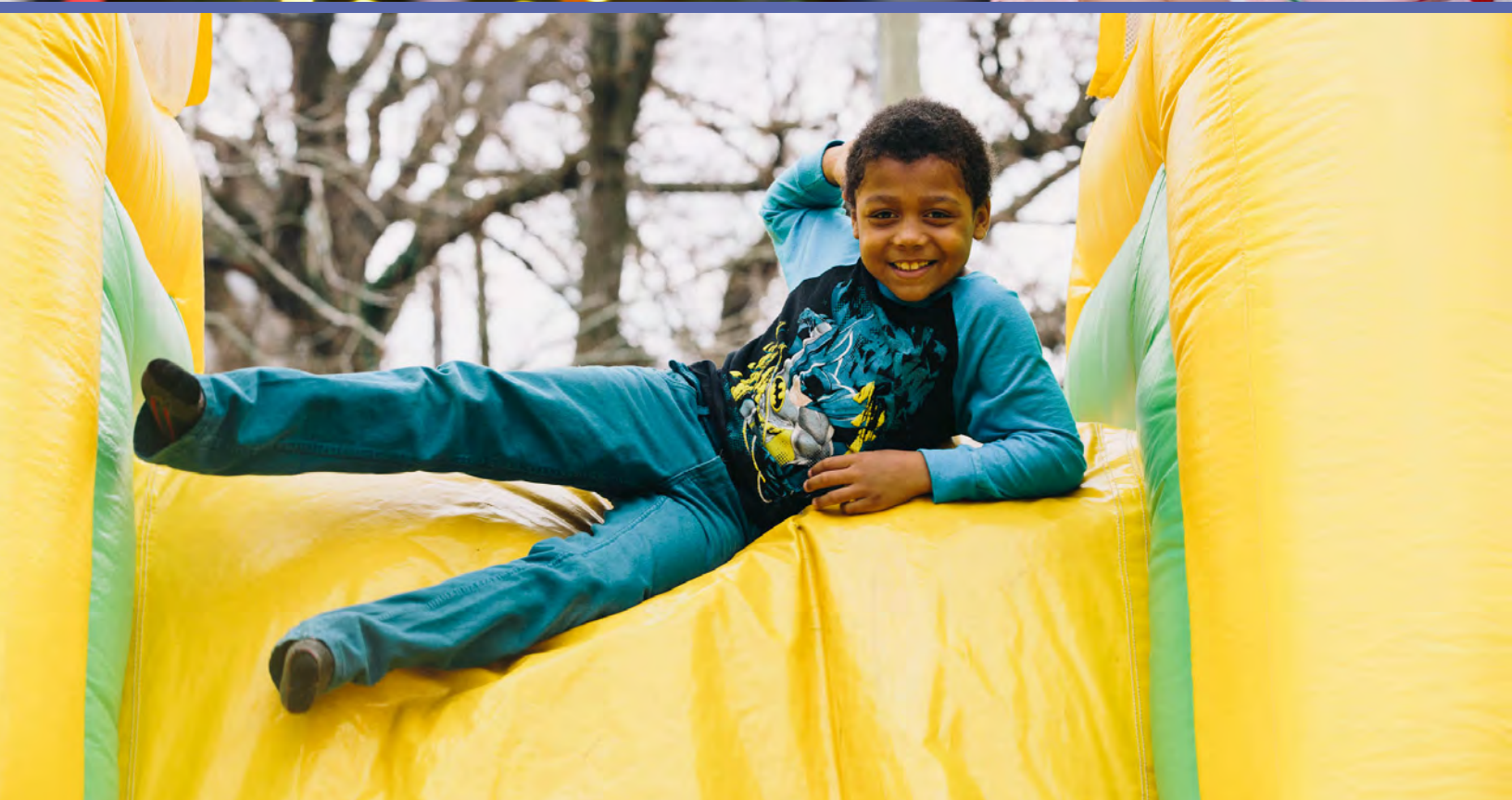
TOTAL REVENUE AND SUPPORT
\$1,306,135

Expenses:



| | |
|--------------------------------------|-------------|
| A Program services | \$1,128,084 |
| B Management and general..... | \$65,955 |
| C Fundraising | \$31,823 |

TOTAL EXPENSES
\$1,225,862



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