



EDMARC
Hospice For Children

Hope for the Journey.

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Caring for the Children - Why the nation's first children's hospice now needs your help.

It was not a good week for the Pavlat family. On Monday, Jack had surgery for colon cancer. On Friday, his wife, Barbara, learned she had breast cancer. And in between, on Wednesday, their 3-year-old daughter was diagnosed with a deadly form of cancer known as neuroblastoma.

"Our doctor said we were going to need some help," Jack remembers. "That was an understatement."

The Pavlats were able to get the help they needed—and more—from Edmarc.

Jack and Barbara both recovered, but the same wasn't true for their daughter, Suzanne, whose cancer was already in stage four when it was found. Over the next several years as the family spent months at places like Walter Reed Medical Center and St. Jude's Children's Hospital pursuing help for Suzanne, Edmarc was always there when they got home.

"Because of Edmarc," Jack says, "Suzanne was able to be a little girl even when she was in treatment. They would do things like bring the blood to us when she needed transfusions so she could stay home. They made life so much easier for us."

No child has yet survived stage four neuroblastoma, and sadly, Suzanne was not to be the exception. In 2001, she died at age 12. At the end, her father tearfully recalls, "The Edmarc folks contacted the funeral home and arranged for a van instead of a hearse so it wouldn't be so obvious. And they let me carry her to the van. I carried her into our house when she was born, and I was absolutely going to carry her out."

It's hard to imagine, but in southeastern Virginia there are thousands of stories like Jack Pavlat's. That's how many family members Edmarc has been able to help through the overwhelming trauma of a child's death or life-limiting illness since it was founded in 1978.

The Nation's First Children's Hospice still leads the Way. As the nation's first hospice designed specifically for children, Edmarc has become a model program for children's hospice care around the country. Even five years after Edmarc was created, there were still only four children's hospice programs in the U.S., and today we remain the only freestanding children's hospice in Virginia.

Our main mission is to do whatever is necessary to keep the ill child in the loving atmosphere of home, under physician-directed care. Over the years word has spread around South Hampton Roads and the Peninsula about Edmarc, how we can ease the pain and assist with practical needs of families who have nowhere else to turn when a child is seriously ill.

Because, when a child is the hospice patient, every member of the family is affected. Parents are frantic. They need to know they're doing everything possible. Siblings feel lost and sometimes confused. They need special attention and friends who understand.

That's why from the beginning Edmarc has also addressed emotional, social, spiritual, and financial pressures. We offer support groups, programs, and events for every family member. We collaborate with Children's Hospital of The King's Daughters, Make-A-Wish Foundation, and other organizations to bring our families comprehensive support. We work with public schools, community services boards, and Social Security on vital services and the financial ramifications of a catastrophic illness.

And we do indeed make a difference. For example, numerous studies cite a divorce rate of 75 percent in families where a child has died. But we're proud to say that for Edmarc families, the divorce rate is under 20 percent.

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The nature of what we do means our services have to be available 24/7, so it takes a special kind of person to work with these children and families. Not only do our critical-care RNs and crucial support staff have to be the best and brightest, they must have a tremendous spirit of giving that isn't easily depleted. Theirs is not an easy job to do.

How Would You Decide Which Child to Turn Away?

In 2005, Edmarc provided hospice care to about 28 children per day. Today that number has more than doubled, to an average of 70 children per day. We'd like to help more families, but we're already stretched thin. We simply don't have the resources to be there for the growing number of children who need our services.

Unlike in adult hospice programs, many of our families are, understandably, seeking a cure for their child's illness. As a result, some of our patients require hospice care for many years. Then there's the fact that health insurance covers only about 10 percent of our costs. And since we don't turn away a seriously ill child just because the family can't pay, funding is always on our minds.

To that end, we had a fundraising feasibility study done. And we've determined there's only one way Edmarc can help the steadily rising number of families in need: through a \$1.5 million Program and Endowment Campaign.

It's not just the around-the-clock hospice care we need to fund. Events like our spring fling, summer picnic, and fall festival connect our children and families with others struggling with the same burdens. And whenever a young life is cut short, whether or not the child was under our care, our bereavement programs and ongoing support groups help parents, siblings, and schoolmates cope with their grief.

A child with a life-threatening illness changes everything for a family. Think about Thanksgiving with a child in hospice care and two other healthy children. A holiday dinner may be the last thing on mom's mind, which is why every Edmarc family has a Thanksgiving sponsor to supply a turkey dinner with all the trimmings. It might not seem like much. Yet exhausted parents tell us that acts of kindness like this make their situations a bit more bearable.

"Edmarc's level of care has always been outstanding," says Herb Bevan, M.D., a pediatric oncologist. "But what the family remembers most is their level of empathy and emotional support."

Nicole LaBeth will never forget the compassion she felt from Edmarc's staff after son Trevin was born with a condition called trisomy 13. Nicknamed Tiger by his nurses because his cry sounded like a growl, little Trevin had a brief life of only two months. Even so, Edmarc was there.

"When one of Edmarc's social workers came to our house for a visit," Nicole remembers, "she brought Trevin a Tiger Beanie Baby. That night we looked down at him in his bouncer and there he was hugging that little tiger. It fast became his favorite toy. We would always laugh when we would find him sucking on his tiger's nose. There was never a place we went that little tiger didn't go."

As Nicole and our other parents know, there is nothing in this world worse than losing a child. In the midst of such a profound tragedy, Edmarc staff does everything possible to be a source of comfort. After their daughter's death, Jack and Barbara Pavlat became volunteers with us to help other parents. Today, Jack is able to speak warmly about his family's Edmarc experience.

"It's almost 24 years that we've been associated with Edmarc," he says, "and they're good memories. Today I believe that Suzanne's purpose was to connect me with this organization."

Won't you, too, connect with Edmarc, so that we can be there for more suffering children and terrified parents who are facing the greatest loss of their lives? The simple truth is that we need you because they need us. With your generous campaign gift, we can extend their time together and help them find comfort and hope. Sometimes that makes all the difference.

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Funding Priorities-----

Edmarc Endowment & Program Campaign

Funds raised through Edmarc's \$1.5 million Endowment & Program Campaign will be allocated as follows:

Unrestricted Endowment: \$250,000

These unrestricted endowed funds will ensure that Edmarc's exceptional care and services will continue for the growing numbers of children and families who will need us in the future. It will also enable us to provide the services and care that these families need the most, whether that's home health care, pain management, counseling for siblings, bereavement support, or other vital services.

Restricted Endowment: \$700,000

This restricted endowment will be designated for the most crucial care and services required by new Edmarc children and families in the future. This would include additional professional nursing care and assistance from medical social workers provided at home, bereavement support for families, and a special purpose fund to help our families cover unexpected expenses such as transportation to treatments in other areas and funeral expenses when necessary.

Program Fund: \$550,000

In 2005, Edmarc provided care and services to about 28 children per day. Today, that number has more than doubled, we care for an average of 70 children per day. This program fund will enable us to meet the program needs of Edmarc's current children and families, including ongoing support groups, events and activities to help struggling parents, weekend retreats for bereaved families, and our Peace by Piece program for grieving children and teens.

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Pledge Letter-----

I (We) will make a pledge of \$ _____ to be paid over _____ year(s) to Edmarc Hospice for Children campaign.

I am sending an initial payment of \$ _____.

The balance will be paid in ____ Annual, ____ Semi-Annual or ____ Quarterly installments of \$ _____ beginning in ____ (month) of ____ (year).

I would like my contribution to be allocated for:

____ Unrestricted Endowment Fund

____ Restricted Program Endowment Fund

____ Current Program Fund

____ I have included Edmarc Hospice for Children in my estate plans

Name _____

Address _____

City _____ State _____ Zip _____

Phone # _____ E-mail _____

Signature _____ Date _____

Please indicate how name or names should appear on a contributors list.

____ Check Enclosed

____ Please charge my credit card
____ Visa/MC/Discover Card # _____

Exp.Date _____ Billing Zip Code _____ Signature _____

My/my spouse's company will match this gift: Yes ____ No ____

Name of company: _____

Please make checks payable to Edmarc Hospice for Children. Pledges may be sent to:
516 London Street, Portsmouth, Virginia 23704.

Edmarc Hospice for Children is a 501(c)(3) non-profit organization. All gifts are tax deductible as provided by law.
Thank you for your gift.

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Campaign Contributors

Raised to Date 3/13/2013 - \$\$1,038,020.09

\$200,000 and above

Patricia and Douglas Perry Foundation

\$100,000 - \$199,999

TowneBank Foundation

\$50,000 - \$99,999

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Southeast Virginia Community Foundation

\$25,000 - \$49,999

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Greenbrier Self Storage - S. Grey Folkes & W. Lewis Witt

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\$250 & under

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