

Every child is precious

and every moment with them matters.

Your Forever Gift™ Will Make a Meaningful
Impact for the Children Receiving Our
Hospice Care and Other Support Services

Capital Caring
Kids



“Tap, tap, tap, tap!” Presenting a set of luminescent wings with brilliant blue feathers, a bluebird arrived on the transom window to welcome Justice Hope Coleman home on a very cold March day.

Justice Hope Coleman entered hospice care in her very own room at her home on March 17, 2017 — and passed eight days later, at the age of twelve and a half. Her mother, father, and siblings were surrounded by the same kindness and comfort as the Capital Caring Kids team prepared them for life without Justice. The day came for Justice to go, but the hospice care devoted to her family remained, which gave them the strength to go on.

[Read more about Justice's Journey with a Feathered Friend](#)



Since opening our doors in 1977, the care of infants, children and adolescents has been a significant part of our mission. Capital Caring Health has grown to one of the three largest not-for-profit advanced-illness and end-of-life care organizations in the country with one of the most advanced children's programs.

Every child is precious, and every moment with them matters. At Capital Caring Kids, we serve children from infants to age 21 who are facing chronic, life-limiting medical conditions or who are struggling with the loss of a family member. We recognize that children require a specially tailored approach with compassionate, nurturing support.

We are fulfilling the critical needs of children in our community.

Q&A with Dr. David Steinhorn, Medical Director for Children's Hospice and Palliative Care Services

In 2018, Capital Caring Health launched a Virtual Pediatric Consultative Rounds Program led by Dr. David Steinhorn, Capital Caring Kids Pediatric Hospice and Palliative Care Physician.



These bi-weekly rounds allow us to collaboratively coordinate the pediatric patients' care with children's specialists from Children's National Medical Center, INOVA and other pediatric providers across the country. This complex care coordination improves communication among providers and provides expert consultation based on best practice for specific pediatric needs. Since initiating these virtual rounds, our pediatric hospice patients have experienced improved pain and symptom management, enhanced communication between providers, and a decreased number of hospital admissions.

In addition to participating with a number of national level palliative and hospice membership organizations, Capital Caring Kids is a member of Alliance Kids, a group of non-profit pediatric hospice organizations in the Mid-Atlantic region who work together to serve children in our community facing serious illness and end of life. We continue to invest our resources in educating and developing expertise among our pediatric staff according to national best practice standards. Our innovative approach to pediatric hospice and palliative care has been nationally recognized through several published projects.

How Do Children Become Connected to Capital Caring Kids?

"My pediatrician just told me my child has a serious medical problem." For most children, childhood is full of discovery, and hope, and joy...but, some children are faced with challenges that threaten a long life.

With the family at the center of our care, we listen carefully to the families' needs and wishes while respecting their unique cultural and belief systems.



Sometimes, parents are the ones to start the conversation when they seek answers from their pediatrician on how to support the child's needs and wishes. Pediatricians familiar with our services initiate the difficult discussions with parents about the child's decline and when palliative or hospice care is advised.

Hospice can be a frightening word to parents as it may be perceived that medical providers are "giving up hope for a cure for their child." With the adoption of the 'concurrent care' legislation in 2010, parents are no longer required to forego curative or life prolonging treatments for their children to be eligible for hospice benefits. Now state Medicaid programs followed by most other commercial insurers must provide access to curative treatments and the full scope of hospice benefits.

Because of concurrent care, nearly 20% of children in our palliative and hospice program experience stabilization of their disease progression and are able to live longer with the added layer of support provided by the hospice team.

Without access to curative treatment, some of these children would succumb to their illness within six months. One of the saddest problems is that many children are admitted to hospice late in their disease journey and the family misses out on the added layer of support hospice provides. Capital Caring Kids reframes what hope means to help slow progressive decline and help children enjoy a high quality of life for as long as possible.

Where Does the Hospice Care for Children Take Place?

Most families prefer to have their child at home during this delicate phase of their lives and Capital Caring Kids makes it possible. When a child returns home from the hospital to begin hospice services, everything is delivered to create a safe and calm environment, even when it means setting up "a miniature ICU" with high-tech ventilation and feeding equipment in the home.

Capital Caring Kids is dedicated to walking alongside the children and families we serve no matter how long or how arduous that journey becomes. The only way we can continue to do this important work is with support from thoughtful donors who want to become a part of this meaningful journey with us.



Capital Caring Kids provides holistic symptom-directed care encompassing the social, emotional, psychological, and spiritual needs of children facing serious illness. Our philosophy is to care for the entire family as long-term illness has a profound impact on everyone who loves the child. Capital Caring Kids coordinates all care with the child's own pediatric primary and specialist doctors with the family as the center of care.

When the child's needs go beyond what can be managed at home, we provide intensive inpatient symptom management at our four specialized facilities which have accommodations for overnight stays for family members.

Play is the universal language of childhood and especially important to children who are confined by their illness. We take play seriously by offering interactive play opportunities through our Child and Family Clinical Services Specialist and integrative therapy staff. Children are encouraged to express their wishes and process their emotions through art, music, movement and imagination to alleviate pain and anxiety.

Our social workers help the child and family cope with emotional and practical issues of dealing with a terminal illness, including keeping them connected to their school community for education and socialization. Spirituality is an important part of every child's life and our chaplains help children find meaning and purpose in the midst of illness and end of life.

Pet Therapy can play an important role in healing. By providing certified therapy pet visits, children are empowered to express emotions they are unable to verbalize and experience the unconditional love and support that only a special animal can provide.

Capital Caring Kids also embraces children and teens struggling with the loss of a parent, sibling, or close loved one at no cost. Our children's bereavement programs encourage children as they learn to express and cope with the tragic loss of a loved one. Grief support is offered to any child in the community through our community partners, regardless of whether we served their family member through hospice services.

We serve all families within our diverse community and no one is turned away due to their inability to pay. Our Pediatric Charity Care Fund ensures that every child and their family has access to our compassionate hospice care. We rely on our community to fund children's bereavement as it is the one service required that is not reimbursed by insurance.

How Can I Help?

Partner With Us To Comfort Our Kids.

Many families with ill children are very young and don't have the same financial resources as those better established in life. Our charity care alleviates the sleepless nights of worry and the heavy burden of paying for services when they've spent whatever they have fighting a child's long-term illness.

Please consider becoming a part of the path to nurture children who will not live their dream of a long life and those grieving the loss of a loved one, as well as the families who love them. Consider making your Forever Gift™ to support Capital Caring Kids.

Would you help us fund the following needs for our children and families?

Capital Caring Kids Hospice Service Forever	\$5,000,000
Chair of Pediatrics	\$3,000,000
Capital Caring Kids Hospice Services for a Year	\$500,000
Pediatric Equipment & Supplies	\$100,000
Pediatric Inpatient Suite	\$100,000
Children's Bereavement Programming	\$50,000
Specialized Therapy – Pet, Art, Play, Music Therapy	\$25,000 <i>per therapy category</i>

These children are leaving behind memories of laughter, courage and little moments shared with their families. You can leave a legacy full of compassion and support for these children and those who will need our hands to hold for years to come by making a Forever Gift™.

Our hearts call us to this important work and we need you to keep them beating strong by supporting the expansion of children's services across our region.

Become a part of the story of hope that Capital Caring Kids shares with children and families facing the unimaginable.



Tara Hoit, Director of Children's Programs for Capital Caring Kids welcomes your call or email to discuss your donation interests and provide more details for you.

Call 540.295.7223 or email thoit@capitalcaring.org

Justice's Journey with a Feathered Friend

About the little bluebird....

The bluebird tapped on Justice's window each day, sometimes disturbing her sleep. As Justice began to experience more agitation and distress, the bluebird became more frantic as if he wanted to fly into her room to soothe her. It was as if the bird knew Justice was uncomfortable but was fighting with her strong spirit to stay here — no matter how much her little body hurt. Wednesday came and the hospice team moved Justice to the living room AND the bird followed! Thursday, with the help of a calming medicine, Justice seemed more comfortable and the bluebird sat peacefully. Bob Marley's song "One Love" played and twinkling lights surrounded her amidst soothing peppermint scents. Justice died Saturday night.

On Sunday morning, the bluebird came one final time to the window as the mother, father, and siblings sat at the kitchen table absorbed in their grief. The bluebird did not fly to Justice's window; instead, he came to them. Then, he flew away. Not everyone will find a feathered friend, but every child will have the love and compassion from our experienced children's team. Whether or not you believe in spirit animals, we can all agree on Hope. Hope. Justice's middle name says it all. You are not walking this path alone.



[RETURN TO PAGE 2](#)

Should you or a loved one need hospice or palliative care, please call our
24 Hour Care Line
800.869.2136



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