

THE BUTTERFLY PROGRAM

Denver, Colorado

When a child is losing the battle with life-threatening illness, it's particularly hard for parents — and doctors — to stop treatment and accept hospice. Usually, that reluctance means the symptom control and emotional support that palliative care can offer is not available to that family.

The Butterfly Program in Denver has bridged that gap by offering supportive and palliative care to children and their families when the child has a terminal condition, regardless of whether treatment for the illness is continuing. A collaboration between The Children's Hospital of Denver and Porter Hospice, part of Centura Health at Home in Denver, the program allows for curative and palliative care to complement one another in a comprehensive approach to end-of-life care.

"This model was developed because parents have a difficult time letting go," says pediatrician Brian Greffe, MD, medical director of the program. "If families want to take advantage of supportive care while still exploring aggressive interventions they should be allowed to do that."

Because of the partnership between the hospital and hospice, the program can reach out to children both in the hospital and at home, providing seamless continuity of care. Outpatient and inpatient coordinators ensure that eligible children are identified early in their illnesses. Once referred, a Butterfly team member meets with the family, and interdisciplinary meetings are held every two weeks to discuss care of each child enrolled in the program. Members of the team include Greffe, a pediatric registered nurse, a social worker, a chaplain, inpatient and outpatient



coordinators, and a bereavement counselor. The team also works closely with the child's primary care physician.

Beyond that, The Butterfly Program has extended its reach into rural communities in Colorado and surrounding states that don't have the resources to provide hospice care tailored for the special needs of children and their families.

In one case, Greffe flew to a rural area outside of Billings, Montana for emergency consultation with the family of a young cancer patient. The hospital in the small town had never cared for a child with a life-threatening illness, and the closest hospice was in Billings. The Butterfly team spent a few hours teaching the local caregivers about palliative care, then visited with the family and the child's primary doctor. "She passed away three days later very comfortable and surrounded by her family," Greffe recalls.

The team, while small, has instituted innovations for hospitalized children as well. It developed the *cocoon*, a portable armoire that can be moved into any patient room to transform it into a home-like atmosphere. Painted with butterflies, the *cocoon* contains blankets, butterfly

pillows, stuffed animals, a coffee pot, television, VCR, books, movies, and toys for siblings, to provide comfort.

The Butterfly Program is close to Medicaid approval for reimbursement specifically for children's palliative care. This would provide payment for both curative and palliative care. Once Medicaid begins paying for palliative care for children in Colorado, the hope is that it will set a precedent for commercial insurers.

Although reimbursement issues are important to The Butterfly Program, the program offers palliative care services to *any* child with a progressive terminal illness, regardless of the family's ability to pay.

Greffe believes the Butterfly model is unique but can be replicated in other hospitals, particularly if they find good home care and hospice partners.

The relationship between Children's Hospital and Centura's Porter Hospice works well because The Butterfly Program fulfills both their missions, explains Erin Denholm, CEO of Centura Health at Home. "When decisions need to be made, you really need to have the mission and vision be your framework," she advises other organizations seeking a similar collaboration. "To have created this together has made for remarkable synergy."



INNOVATION HIGHLIGHTS

CREATIVE COLLABORATION — HOSPICE, HOSPITAL, HOME CARE PROVIDER

OUTREACH TO FRONTIER HOSPICES

SEAMLESS TRANSITION FROM INPATIENT TO OUTPATIENT CARE