

Case for Support: Valley Home Care's Butterflies Program

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Valley Home Care's *Butterflies* Program

Valley Home Care

Since 1987, Valley Home Care (VHC) has delivered high-quality healthcare services, genuine caring and dedication to our patients, right where they need it – at home. Valley Home Care is part of Valley Health System, whose mission is to serve northern New Jersey communities with exceptional, world-class healthcare in a regional healthcare setting. Valley is committed to keeping the community healthy, whether through inpatient care, community-based medical practices and wellness programs, or home care services.

Valley Home Care is one of New Jersey's premier home care agencies. VHC recently achieved 4 stars from the Centers for Medicare and Medicaid for patient satisfaction. The star rating is based on patients' perception of care as reported on their Press Ganey patient satisfaction surveys.

In 2023, VHC's compassionate team of nurses, social workers, and other specialists continued to serve our patients, including those with COVID, while also keeping our employees safe. VHC conducted 281,010 home care visits throughout Bergen and Passaic counties. VHC's skilled nurses and staff provide trustworthy, kindhearted, high-quality care that keeps patients well-managed and educated with less risk for hospital readmission. The VHC team offers a full spectrum of services to meet a variety of healthcare needs including but not limited to the following:

- Hospital to home coordination
- Case management
- Rapid medication reconciliation
- Rehabilitation therapy
- IV therapy
- Maternal and child health
- Medical social work
- Nutritional counseling
- Advance care planning
- Facilitation of community resources
- Telehealth/Telemanagement
- Palliative/Hospice Care

We installed 598 telemonitoring units, focusing on reducing rehospitalizations with congestive heart failure. In addition, VHC offers a wide range of innovative programs designed to address

patients' complex needs, from infancy through adolescence and into adulthood. The programs offered within VHC are personalized, as our specialty staff identifies the patient and family's most pressing needs and tailors a plan accordingly.

The *Butterflies* Program

For infants and children who have been diagnosed with life-limiting or life-threatening illnesses, VHC's *Butterflies* Program provides comprehensive home care services that focus on palliative care, comfort and relief of suffering for the child, and support for their parents, siblings and extended family members. It is the only comprehensive pediatric in-home program in northern New Jersey that can serve any child or adolescent with a progressive, life-threatening illness and provide hospice care.

Valley's *Butterflies* patients suffer from physical pain and the psychosocial and emotional distress resulting from living with a serious illness or condition. Palliative care focuses on relieving the patient's suffering that impacts every aspect of their life and the lives of their entire family. Unfortunately, insurance companies often deem this service as "not medically necessary" and, therefore, not reimbursable.

For more than two decades, *Butterflies* has treated children diagnosed with cancer, including brain, bone, ovarian, soft tissue tumors, and leukemia. With about the same frequency as cancer diagnoses, care has also been provided to children with progressive neurological diseases, such as muscular dystrophy and leukodystrophy. Children with chromosomal disorders, cardiac disease (including heart failure), and renal failure have also been served by our *Butterflies* Program.

Primary goals of the *Butterflies* Program:

- Enhance the quality of life for the child throughout his or her illness
- Establish a collaborative link between all persons providing care to the child
- Facilitate pain control and symptom management
- Provide home-based care
- Evaluate services and implement measures, as needed, to maximize program effectiveness
- Raise awareness about this critical, one-of-a-kind service

VHC is raising awareness about the unique *Butterflies* program throughout Valley Health System, and well beyond. Within Valley, staff is involved with discharge planning and facilitation, attending and presenting at physician meetings, visiting the Neonatal Intensive Care Unit (NICU), and engaging the appropriate departments within Valley Health System regarding VHC's services. Outside the system, staff is continually reaching out to the public and professionals in the pediatric palliative care and end-of-life services communities, and establishing communication channels that connect them to the patients and families that need these services.

Young patients are referred to *Butterflies* from:

- Within Valley Health System
- Mount Sinai (New York, NY)
- New York-Presbyterian Healthcare System (New York, NY)
- St. Joseph's Hospital (Paterson, NJ)
- Englewood Hospital (Englewood, NJ)
- Tomorrow's Children (Hackensack, NJ)
- Beth Israel Hospital (Newark, NJ)
- Children's Hospital of Philadelphia (Philadelphia, PA)
- Morristown Memorial Hospital
- Doctors throughout Bergen and Passaic counties, New Jersey
- Managed care insurance companies
- Physicians affiliated with Memorial Sloan Kettering Cancer Center

Valley Home Care is also dedicated to educating the health care community about the complex needs of these children and their families, both in New Jersey and throughout the country. Since its inception, staff has shared the *Butterflies* Program's goals and services with other hospitals, such as New York-Presbyterian and Mount Sinai, at national conferences, and with specialty clinics, home care agencies, and hospice agencies.

The *Butterflies* Program has been recognized with the New Jersey League for Nursing Award for "...dedication and commitment to the Highest Quality Care given to children and their families."

How the *Butterflies* Program Works

The *Butterflies* Program resembles a traditional hospice model and is a program of the Maternal Child Health Team at VHC. Rose Marie Ranuro, RN, MSN, CPNP, is the Director of Clinical Services, Maternal Child Health and the *Butterflies* Program. A clinical social worker co-manages the care of all the patients on the team, including in-home visits, in addition to coordinating the bereavement program for parents.

An interdisciplinary team of specially trained healthcare professionals meets regularly to discuss patients' needs and the plan of care for their families. The team includes registered nurses, social workers, an art therapist, a chaplain, and a medical director. Other specialists available to the *Butterflies* team include nutritionists, specialized wound care and cardiac nursing clinicians, rehabilitation therapists, home health aides, a music therapist, and volunteers, along with end-of-life doulas.

Children who are terminally ill and are undergoing treatment for disease management may be admitted to the *Butterflies* Program. Once hospice care becomes appropriate, the transition is made as smoothly as possible without changing the team of staff caring for the patient and family.

Each Team member provides care to the child as well as invaluable support to the family. The registered nurse acts as a case manager and has a variety of functions:

- Arranges necessary visits of support services
- Regularly visits the child and family
- Assesses the child and family's home care needs
- Answers questions about treatment, medications, and quality of life issues
- Works to empower parents to do as much as they can in providing their own child's care and comfort

Social workers can visit families and provide ongoing psychological and emotional support and link families to community services.

If the need is appropriate, the home health aide, supervised by the nurse, assists with the child's physical care and can provide comfort and guidance, as needed, for both the patient and their family.

VHC provides bereavement counseling to all grieving parents following the death of their child. If the family wishes, a social worker or nurse may visit. There are various special programs that provide care for particular situations: *Wings of Compassion*, *Stepping Stones*, *Journeys*, and *Music Therapy*.

- *Wings of Compassion* provides support and compassion to grieving parents suffering from perinatal loss, including miscarriage, stillbirth, or death of a newborn. Since one in every five pregnancies ends in perinatal loss, the need is great. Many parents are already benefitting from this imperative service, which is the only one of its kind in the state of New Jersey.
- *Stepping Stones* is an ongoing support group for parents who have lost a child. It is designed to provide a safe setting where parents can get support, come to terms with their loss, and begin to work towards healing. By understanding the unique nature of grieving over the loss of a child and sharing their experiences with others in similar situations, parents can rediscover a sense of purpose and meaning. A licensed clinical social worker facilitates these sessions.
- Valley Hospice's pediatric art therapy program, *Journeys*, specifically works with children and adolescents ages 3 to 17 who are affected by the serious illness or death of a loved one. It gives children a safe place to express their grief, anger, and fear while developing important coping skills. Counseling is provided by board-certified art therapists, who use art and other creative means to help children express their feelings. In 2023, there were 319 children who attended art therapy sessions.
- Valley's *Music Therapy* Program was established in 2018 and provides a unique service effective in addressing patients' and caregivers' physical, emotional, cognitive, and social needs. Music can have potent effects on a person because it engages the brain in a complex way. Studies have shown that music therapy can improve quality of life, inspire feelings of peace, spirituality, hope, and reduce pain. Currently, most insurance companies and government-funded health programs do not cover music therapy.

The *Butterflies* Program continues to provide care for approximately 28 patients annually. Due to life-extending medical care, many *Butterflies* patients are remaining in the program for more than a year. Since January 1999, 377 children have been cared for in this exceptional program.

Releasing Butterflies Ceremony

Our *Butterflies* team hosted our second Butterflies Release Event. We invited the families who lost an infant or child while receiving care from our *Butterflies* team. On June 1st, our *Butterflies* team and many volunteers memorialized our deceased *Butterflies* patients along with their families.

- This event allowed families to meet other families. Whether it has been 20 years or two months since their child passed, families shared special moments talking about their child.
- We displayed photos of each child.
- There were special projects led by our art therapist for the children attending the event.
- The *Butterflies* theme was sprinkled throughout the event with signs, balloons, centerpieces, dessert cookies, a butterflies back drop, pet therapy, a harpist, and butterflies ground decorations.
- The chaplain began the ceremony with a beautiful reading.
- Before we released the butterflies, each child's name was read by the *Butterflies* team.
- Families who started a foundation distributed their literature.
- Two parents shared their book about their children who died.
- Teddy Bears were distributed to the attending children.

When we opened the butterflies box, the butterflies flew freely, some even landed on our guests. This experience became interactive and made it even more special. Siblings had time to talk to their butterflies to send messages up to their brother or sister.

We had a beautiful butterfly pin, which was donated, raffled to a special mom.

A total of 28 families attended. It was therapeutic for the families and also for the *Butterflies* team members who were there to speak to the families and share memories. One grandmother shared, "please continue to release the butterflies. It is his birthday month and this is like his celebration."

Another mom said we should create a video to show other families how valuable the *Butterflies* Team has been to them. We followed up with her idea and we have released 3 videos. The links are here :

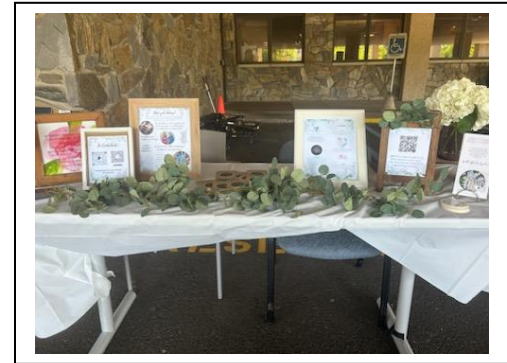
<https://youtu.be/sBQ30w9eltE>

<https://youtu.be/1qn3N45q7VQ>

<https://youtu.be/RhRAHPaD5BY>

One *Butterflies* family even received a visit from members of the Giants Team. See link : <https://youtu.be/tgNyT6PbQVU>

The following are just a few pictures from this event :



The Annual Teddy Bear Party – September 21, 2024

- This annual event focuses on the siblings of children on our service and is always a huge success.

Proposal

For a patient involved in the *Butterflies* Program, the cost per child is approximately \$15,000, much of which is not fully reimbursed. It takes a dedicated team to work with these terminally ill children and their families through the poignant, sensitive, and complex issues involved in their care. Almost all art therapy, music therapy, and chaplain visits are not reimbursed, and nursing and social worker visits are reimbursed about 80 percent of the time. Since Medicaid funding and private insurance do not fully cover the *Butterflies* Program's operating costs, it is necessary for VHC to seek ongoing philanthropic support to maintain and expand the program.

Thanks to the generous philanthropic support of our community, our *Butterflies* Program has been able to reach families who could otherwise not afford this program. Unfortunately, there are many more still in need of these vital services.

The Valley Hospital Foundation is seeking additional funding to support Valley's *Butterflies* Program so that we might reach more families with this service and allow them to benefit from this much-needed program. We respectfully ask you to consider a gift to The Valley Hospital Foundation, which will go towards offsetting the cost of these essential services to our most vulnerable patients and their families.