

## PRESS RELEASE

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### **Pediatric Hospice Family to Share Stories of Love and Resilience During 22nd Butterfly Luncheon**

HOUSTON (Feb. 16, 2023) – Jake Hampton’s first year of life was fraught with dozens of pediatrician visits and concerned family members when he received a diagnosis of Hunter syndrome at the age of 13 months. As Jake’s health continued to regress, the Houston Hospice Butterfly Program cared for the Hampton family through their end-of-life journey. Now, four years after Jake’s passing, the Hampton Family will share their memories and the impact of hospice care on their family, during the Houston Hospice 22nd Butterfly Luncheon, held at The Junior League of Houston, Friday, March 24, 2023, at 11:00 am.

#### **The Journey of Jake**

When Jake Hampton was 13 months old, he was diagnosed with a rare genetic disease called MPS II (Mucopolysaccharidosis type II) or Hunter syndrome. Although his illness progressed, his short life was filled with the love of family and laughter with friends. Towards the end of his 17-year life, his parents, Wallis and Monica, and twin sisters, Natalie, and Nicole Hampton, sought the care of Houston Hospice’s Butterfly Program for Pediatric Hospice Patients, specializing in advocating for the unique needs of children at the end-of-life and their families.

“The doctors told us that Jake would probably pass away between the ages of 8 and 13,” said Wallis and Monica. “While Jake lived well into his teen years, he eventually neared the end. That was a heartbreaking time for us,” they continued.

For Jake, Hunter syndrome meant that his body did not have enough of the enzyme iduronate 2-sulfatase needed to break down certain complex molecules causing a buildup in harmful amounts. This caused permanent, progressive damage affecting appearance, cognitive development, organ function and physical abilities. When Jake was a young boy, he could walk, talk, and play, but as his disease progressed, he became nonambulatory and nonverbal.

Through thick and thin, Wallis and Monica made sure that their children felt loved and supported. Natalie and Nicole were busy with school and community-focused activities, while Jake attended school and benefited from aquatic therapy. However, with increasing respiratory distress, the Hampton family contacted the Houston Hospice Butterfly Program for pediatric hospice patients and their families.





Throughout Jake’s end-of-life journey, the Butterfly Team created a holistic approach to care that helped him feel comfortable. This interdisciplinary team included a pediatric hospice physician, patient care manager, hospice aide, social worker, chaplain, bereavement counselor, and volunteer. Together, with Jake’s family, they arranged for necessary medical equipment, supplies, and medications. The Butterfly Team assessed Jake’s needs 150 times and at all hours of the day and night. When the family needed support, Houston Hospice created a custom, patient-centric plan of care focused on Jake and his family living their best quality of life.

“As Jake got older and his condition worsened, Houston Hospice cared for him at home, so we could spend more time together,” said Natalie and Nicole. “Knowing he was always cared for helped our family savor our time together and still enjoy our time apart without constant worry,” they continued.

At the age of 17, Jake passed away, peacefully in his home, in his bed, surrounded by his loving parents, sisters, and a Houston Hospice nurse.

“Houston Hospice calmed our fears and made his remaining time precious. The hospice team kept Jake smiling and allowed us to be attentive parents to Jake as well as his sisters,” said Wallis and Monica.

After a patient’s passing, 13 months of individualized bereavement support is offered to every Houston Hospice family to help them begin to normalize grief and loss. Included in this free counseling is written information, support groups, and one-on-one counseling.

### **The Journey of Grief**

Isolated by the COVID-19 pandemic, Natalie and Nicole felt the need to connect with the rest of the world, especially with siblings of people with disabilities. In the summer of 2021, these special siblings created [SpecialSiblingsConnect.org](https://SpecialSiblingsConnect.org), a safe space for all special siblings to share their personal experiences.

Recognizing the importance of creating a resource for special siblings of those with a chronic disability, the collection of advice and stories was made into a book called *By Siblings, For Siblings* by Natalie and Nicole Hampton with illustrations by Nicole Hampton and published in May 2022 by [BookBaby](https://BookBaby.com).

**ABOUT:** Since 1980, Houston Hospice has provided uncompromising, compassionate, end-of-life care to patients and families across all socio-economic backgrounds, ethnicities, and beliefs, regardless of their ability to pay. We are the oldest, largest, independent, nonprofit hospice in Southeast Texas and a member of the Texas Medical Center. For more information, please visit [www.HoustonHospice.org](https://www.HoustonHospice.org).