



## The Birmingham News

### A tiny angel flies home

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My nephew watched as the doves flew over his daughter's fresh grave in Elmwood Cemetery.

Brandon and his wife, Patti, had held on to the last of the elegant white birds, not quite ready to let it go. Finally, as the flock circled overhead, waiting, the couple sent the dove heavenward. "We love you Madi," my nephew said.

We buried Madisyn Kemp on a cold, clear and windy day last week. She was 3-and-a-half years old. For much of her life she'd been hooked up to machines. In the last year or so there were five - a ventilator, a feeding pump, a cough-assist machine, a suction device and a pulse/oxygen meter.

Madi - a beautiful, happy child - had seemed healthy her first four months. Then Patti noticed how soft her cry was, and how little she moved her arms and legs. Her pediatrician sent her to Children's Hospital, where neurologist Dr. Tony McGrath made the diagnosis. Madisyn was born with Spinal Muscular Atrophy, or SMA. An inherited disease (the child of two carriers has a one-in-four chance of developing SMA), it destroys the spinal cord nerves that control muscle movement, even breathing and swallowing.

Few in our family had ever heard of SMA, which, though rare, is the No. 1 genetic killer of children under age 2. As you can imagine, Patti and Brandon were devastated and didn't know where to turn. Thankfully, they met other local families dealing with SMA, thanks to the national groups Fight SMA ([www.fightsma.org](http://www.fightsma.org)) and Families of SMA ([www.fsma.org](http://www.fsma.org)), which have Alabama chapters.

Through those groups, Patti and Brandon made lasting friendships and were there to provide comfort and support as children of their new friends died of SMA. One was little Baylee Peterman, who had become Madisyn's best friend. At Madisyn's memorial service, the Kemp and Peterman families rejoiced in knowing their little girls were together again, free from the bonds of Earth and machines.

When Madisyn's time came, those caring families were there for Patti and Brandon, who understand how much they've been blessed. First came the child, an angel really, to bring them love and purpose. Then came the disease, to bring them friends and to mold their character.

Children with SMA lose their ability to cry, to crawl and even to smile. Although their muscles weaken, their intelligence remains intact. Madisyn knew everything that went on. She communicated with her eyes, which could signal both annoyance and joy.

Madisyn showed more of the former when her baby sister, Bryanna, was born last year. Eventually they came to enjoy each other's company.

Among the many families who helped and inspired them were Scott and Amy Stein, who lost their angel, Amanda, to SMA in 2007. The year before, little Baylee passed away. Baylee's mother, Ann, spoke at Madisyn's memorial service.

Madisyn lived longer than most children with SMA. Maybe her death, and those of all the other angel-children, can shine a spotlight on a disease in desperate need of a cure. E-mail Kathy Kemp at [kkemp@bhamnews.com](mailto:kkemp@bhamnews.com).

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