'MATTIE IS A GIFT FROM GOD'

His poetry books are on the best-seller list. But young Mattie Stepanek has a rare and fatal disease. In this exclusive, his mom talks about her "miracle" boy...and the pain of losing her three other kids.

Mom, can I have another cookie?" pleads 11-year-old Mattie J. T. Stepanek, as he silently glides into the kitchen of his home in Upper Marlboro, Maryland. Jeni, his mother, insists he wait until after lunch. "Awww," says the disappointed Mattie. Jeni straightens out the orange electrical plug from his wheelchair and lovingly shoos him away, telling him to answer the constantly ringing phone so she can speak to a visitor.

As much of the world knows, Mattie is a child-poet who suffers from a rare, debilitating form of muscular dystrophy. He spent nearly six months last year in the pediatric intensive care unit of Children's National Medical Center, in Washington, D.C., his condition so grave that hospital officials said they would do everything possible to grant his three most cherished wishes. Mattie said he wanted to speak to former President Jimmy Carter about world peace, have Oprah Winfrey spread his peace message on her TV show, and have his poems published in a book. Mattie was granted each wish, and--defying expectations--he stabilized sufficiently to be allowed to go home.

Now the sandy-haired boy with the impish grin and oversize wire-rim glasses is back with his mom, who in 1992--just two years after Mattie's birth--learned she had a more manageable, adult-onset form of the same disease. Like her son, Jeni, 42, uses a motorized wheelchair. And though her illness is progressive, her condition is stable for now.
For his part, Mattie draws as much pleasure as he can from each day, papering his bedroom with pictures from Harry Potter books, adding to his extensive collection of rocks, conducting online chats with admirers, playing with friends, and writing his heartfelt poems.

Last summer, 200 copies of Mattie's poems were printed by a small publisher, VSP Books, in Alexandria, Virginia. By February, his second collection had reached the number one spot on The New York Times best-seller list. This month, a third collection, Hope Through Heartsongs, will be published by VSP Books/Hyperion.

Jeni Stepanek—who was divorced from Mattie's father in 1997—works part-time as a researcher for the University of Maryland and homeschools her son. (Jeni reports that he loves history and literature.) The two live in the cozy basement apartment of a friend's suburban home and manage to go out to dinner occasionally and entertain visitors, who are asked to sign their very thick guest book.

Remarkably stoic, Jeni greets each day with hope—despite the unimaginable pain she has endured: Her three older children all died from the same disease that afflicts Mattie. In her own words:

Too often, I am asked, "Why on earth did you have four children if you knew this was going to happen?" The truth is, I didn't know. Nobody knew.

I was just shy of 25 when I married in 1984. When my daughter, Katie, was born the following year, it was clear something was wrong with her medically, but nobody understood it. Although she had working lungs, it was as if her body didn't know what to do with the oxygen. I was pregnant with my second child when Katie died, suddenly, just before she turned two years old. Losing her was devastating.

Stevie was born one month later. He looked healthy at first, but eventually the doctors told me that whatever had caused Katie's death, Stevie had the same thing. He died when he was only six months old.

When Katie was an infant, I had participated in genetic counseling. I was told that her disease was a "fluke." After Stevie's birth, however, the doctors said it probably was a genetic disorder, but that the probability of it happening again was only one in four. That was their thinking then. No doctor said to me, Have another child, it's safe. But it was said that the odds were in my favor. I was 29, with an empty lap, and I wanted to try one more time for a healthy child.

My third child, Jamie, was born in February 1989. Shortly after his birth, I saw my baby hooked to all the alarming monitors, and I knew it was happening again.

The doctors said they still couldn't explain it, but that there was a significant chance all my children would be born with this disease. At that point, I decided not to have any more biological children and to look into adopting. Jamie, meanwhile, was able to come home from the hospital at three months, and he did all right for a while.

This is one of the hardest parts. I was very careful, but against all possible odds, I found out on Christmas Eve, 1989, that I was pregnant again. I burst into tears when the test came back positive. Shocked and scared, I called our pastor, who told me, "This child is here for a reason. This is a spirit meant to be."
I knew in my heart I had to go through with the pregnancy. It was a personal decision that many people disagreed with. But I felt my only choice was to support this life, no matter how short it might be.

On July 17, 1990, Mattie was born. He was the sickest of my four children, and they told me he probably wouldn't make it through the night. I have no idea how he survived, but eventually I took him home. I decided then that he was a gift from God.

Jamie was still at home, too, and I cared for the boys 24 hours a day, seven days a week. I would have loved to take them to the zoo or picnics or out to play, but they were too sick. Still, whatever role there was for me as a mommy, I embraced it.

During this time, I started getting horribly tired with terrible headaches. I was afraid I had mono or some catastrophic illness. Finally, I had a muscle biopsy, and I found out I had mitochondrial myopathy, also a rare form of muscular dystrophy. The doctors then went back to reevaluate my children's records, and figured out that I had the adult form of their infant-onset disease. Their mutation of the disease is so rare that only a few people in the world have it. There is no screening test and no cure.

Jamie died in November 1992. But he lived long enough and got big enough for doctors to conduct tests on him that gave them valuable information on how to treat Mattie. Jamie was very sick during his last two years of life, but I believe he lived for his brother. He gave Mattie more time.

By the age of three, Mattie was already exhibiting an interest in writing. At first, it was mostly expressions of his grief after the death of his brother. I began jotting down his poems, which are about life and loss, challenges and hope. By the time he was four, he was handwriting some of them himself. Obviously, he's had experiences other children his age never have to face. By the age of five, he already had his philosophy of life, which I was astounded by: "Remember to play after every storm." I knew he had a natural gift.

For a while, he was able to go to elementary school pulling his oxygen tank on a luggage carrier. He even earned a black belt in karate before he became dependent on a wheelchair.

Even though we both try to stay optimistic about life and the future, we get frustrated sometimes. I don't often cry or show that I am upset on the outside. But inside, it takes a lot of strength to hold things together. Each day, we have to make the choice to see the glass as half full. It's not always easy, but it is always our choice.

Mattie was born with optimism and hope. He knows there's a heaven, and he talks about what he wants to do once he gets there. He is an inspiration to many people, especially me.

When his first book was published last year, nobody thought Mattie would live very long. I prayed desperately for a miracle. I don't know how long this miracle will last, but I know now there was a reason for him to keep living. His poems have brought so much joy to people around the world. This one child has had such an impact. Mattie was given a magic lamp, and he created something with it that will last.

Some nights, after I snuggle with him and go back to my room, I wonder how I will go on if he dies. I do get scared. But Mattie has taught me that you have to celebrate life every day. And you have to keep hoping for miracles.
PHOTO (COLOR): The poet with his mom: "a natural gift"

PHOTO (COLOR): At a book signing in Alexandria, Virginia

By Stephanie Mansfield and Jeni Stepanek

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