

(This article appeared in *The Eagle Tribune*, a North Andover newspaper reaching 60,000 + subscribers in 26 communities in Massachusetts' Merrimack Valley and Southern New Hampshire. Reproduced with permission.)

Saturday, September 20, 2003

Dad vows to keep promise to his late son

By Jason B. Grosky

Staff Writer

SALEM, N.H. -- Benjamin Amiss was a little more cranky than usual on the night family and friends filled the house to celebrate his father's 32nd birthday. Jason M. Amiss gently bounced his slouching 8 1/2-month-old baby boy on his knee and blew out the candles as the camera flashed.

The next morning, Jason's birthday, followed the regular family routine. At 6 a.m., 4-year-old Rachel climbed into bed with her dad and mom. Jason brought Benjamin to bed and the family foursome cuddled beneath the blankets. Jason had a mid-morning flight to Chicago, so he and wife Kathleen took advantage of the longer-than-usual morning family time together.

Just before he left the house, stopped in to say goodbye to Benjamin, who four months earlier was diagnosed with a genetic disease that left his body so weak that he could not lift his head. With a kiss and a smile, Jason Amiss told his baby boy: "I love you buddy. You always need to remember that."

"That was the last time I saw him alive," said Jason, 32, a computer industry manager and native of Methuen. "You never want to bury your kid. You want your kid to bury you. But my wish came true. I prayed to God that if you can't heal him, then to take him, and God answered my prayer. The best birthday gift I got was that he didn't suffer."

Benjamin died Sept. 8 on his father's birthday, four months after being diagnosed with spinal muscular atrophy. The disease attacks cells in the spinal cord and affects the muscles closest to the trunk of a body, weakening a child's arm and legs.

Unlike a healthy child, Benjamin was never able to hold up his head or support his own weight. If an adult picked him up, his body would sag forward and hang limp like a "10-pound rag doll," Jason Amiss said.

Benjamin suffered the most severe form of the disease. While his parents knew he was likely to die before turning 2, "we thought we had months or at least another year to spend with him," Kathleen Amiss said.

Jason said he is bringing the family's story forward to fulfill a promise he made to his baby: That in Benjamin's name, he would do whatever he could to call attention to the disease in hopes of finding a cure.

In the 12 days since Benjamin's death, his father contacted the New Hampshire attorney general's office and is seeking tax-exempt status to create The Benjamin Fund.

Jason Amiss said his efforts are paying off already. Having worked a network of family and friends, he said he raised \$6,000 for a walk to raise funds to fight the disease. The walk is happening today in Chelmsford.

He wants to use the foundation and its to-be-constructed Web site to spread awareness about the disease -- which he refers to as "The Thief" -- and raise money for the Families of SMA (FSMA), a global nonprofit organization seeking a cure. The Spinal Muscular Atrophy Foundation calls the disease the "No. 1 genetic killer of infants and toddlers."

One in 40 people carry the gene that causes SMA, which is regularly confused with the better known Lou Gehrig's disease (amyotrophic lateral sclerosis).

In the Amiss family's case, the parents learned they were both SMA carriers after Benjamin was diagnosed. The odds of two adult carriers having a child born with SMA is one in four, according to the foundation. Rachel, their 4-year-old, does not have the disease.

When Benjamin was born Dec. 16, he appeared to be a normal newborn, Kathleen Amiss said.

"We came home with a healthy baby boy and for us, it was a Norman Rockwell picture. We had our girl and our baby boy," Jason Amiss said.

But by two months, Benjamin's development seemed slow, she said. They went to the doctors several times, and Benjamin was diagnosed May 5.

The doctor notified Kathleen of the diagnosis over the phone. Jason Amiss said he had done extensive Internet research about the disease, but had not fully told his wife how serious it was.

"We just crumbled to the floor for the day," she said.

Knowing their time with Benjamin was limited, Jason Amiss said the family tried to cram in as many occasions as they could so he could live a full, if abbreviated life. They went camping, went to Santa's Village and visited often with family and friends.

In addition, the illness gave Jason Amiss a new sense of faith. The Catholic family prayed every morning and night. They took Benjamin to healing masses.

"In 8 1/2 months he showed the kind of strength to fight the nastiest disease and he's taught me so much about life," Jason Amiss said.

In his final weeks, the disease weakened Benjamin's throat muscles to the point he had trouble eating, Kathleen Amiss said. In addition, his breathing was labored on hot days. In the months preceding his death, Benjamin fought off two colds without contracting pneumonia.

The Amisses said they did whatever they could to care for Benjamin without "intrusive" measures. They opted not to put him on a ventilation machine or have him undergo a procedure where food would be pumped directly from a tube through an incision into his body. Benjamin was also treated by a chiropractor three times a week to alleviate pressure and help improve his spine.

On the day he died, Benjamin went to the chiropractor and then the grocery store with his mother and sister. True to form, he fell asleep in the shopping carriage.

When Kathleen Amiss loaded the groceries and her children into her truck, Benjamin appeared to be sleeping. His body was limp as it normally was. Twice on the ride home, Kathleen asked Rachel to "fix your brother" -- which meant to prop up his head when he sagged forward.

When they got home, Kathleen noticed Benjamin's lips were turning blue. She looked at his fingernails. She knew what their white color meant. She raced in the house and called 911. Jason Amiss got word before reaching the airport and raced home. The family met at Caritas Holy Family Hospital in Methuen and Kathleen told the doctor it was time to "let him go."

Jason said the doctors pronounced his son dead about 11:10 a.m. He held his son's body for about three hours. Rachel patted his head and said good-bye.

"I was blessed to have had Ben for those 8 1/2 months," Jason Amiss said. "You always have that moment where you see a picture of Ben or think of him and it brings back that heartache and floors you. I feel guilty that we're moving on as best we can, but I made my promise to him to try to find a cure in his name."

More information about Spinal Muscular Atrophy and attempts to find a cure may be found at www.fsma.org or www.smafoundation.org. People may contact the Amiss family at 2 Primrose Way, Salem, or by phone at (603) 890-6300.