



Nicholas Scott Moore

February 7, 2001 - October 8, 2011

Nicholas Scott Moore: Nicholas finished his long battle on Saturday morning at the University of Minnesota Amplatz Children's Hospital.

Nicholas' family includes his parents, Matthew and Elizabeth Moore of Oskaloosa; his brother, John "Jack" Moore at home in Oskaloosa; grandparents: E.R. and Scottie Moore of Oskaloosa and Nanci Jahnke of Manhattan, KS; great grandmother, Marie Stamos of Oskaloosa; uncles and aunts: Patrick and Ruth Moore of Minneapolis, MN; Shawn Moore and Chuck Cordray of New York, NY; Christa Jahnke of Los Angeles, CA; Dr. William Jahnke of Minneapolis, MN; Loring Jahnke of Minneapolis, MN; Dr. Susan Koch of Portland, OR; and Lynn Nelson of Vienna, VA and several cousins.

Nicholas Scott Moore, son of Matthew Brooks and Elizabeth Vining Elise Jahnke Moore, was born February 7, 2001 at Mercy Medical Center in Des Moines, Iowa. At birth, Nicholas was diagnosed with a terminal skin disease, Recessive Dystrophic Epidermolysis Bullosa (RDEB), an extremely painful and progressively destructive disease. In his early years, prior to the destructive progression of his disease, Nicholas was able to enjoy a limited amount of physical activity, such as playing in the snow and riding his toy motorcycle. Nicholas loved to travel and enjoyed visits to the beach and mountains. Despite his inability to eat quantities of food, Nicholas was a voracious nibbler and loved to "go out to eat". As Nicholas experienced more

limitations from the RDEB, he found pleasure in video and computer games, all kinds of music, driving a golf cart, baking with his mom, and hanging out with his brother and his brother's friends, many of whom went out of their way to include and involve Nicholas in whatever activities they were doing to the extent possible. After his love of his animals, by far, Nicholas' biggest joy in life was attending Oskaloosa Elementary School, through the fourth grade. This joy was made possible and pleasurable by all the fine people at the school who went to extraordinary lengths to provide and maintain an environment conducive for Nicholas. Like all of the RDEB'ers, Nicholas endured a life of pain beyond anything imaginable or describable. He continued to amaze his family and friends with strength and courage. Nicholas spent the last eight months of his life at the University of Minnesota where, despite a successful Bone Marrow Transplant made possible by his brother, Jack, he succumbed to double pneumonia allowed by a suppressed immune system. During his 10 years of life, his will to persevere was amazing and all who knew Nicholas realized that behind all those bandages was a funny, brave and thoughtful little boy.

Nicholas was preceded in death by his grandfather, William Jahnke.

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Tribute Wall



“ *Nicholas Scott Moore*

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