

2012 Robert Ross MDA National Personal Achievement Award Recipient

Scott B. Crane

Home and Family

Scott B. Crane, 23, lived in Northbrook, Ill., with his parents Michael and Teena and his sister, Lindsay. He passed away the day he received the letter informing him of this award.

Personal History

At age 4, Crane received a diagnosis of myotubular myopathy, a form of centronuclear myopathy, which causes profound loss of muscle tone and a weakness of skeletal muscles. He began using a wheelchair while in junior high school.

After graduating from Glenbrook High School, he enrolled in community college and volunteered as a mentor and role model at the Rehabilitation Institute of Chicago. He also worked part time at the Corner Bakery Café in Northbrook, where he earned a service award for his hard work.

MDA Leadership

Crane attended MDA summer camp every year, where he enjoyed decorating his cabin, swimming and sports activities. One year he was able to secure the donation of shampoo, soap and hand lotions for the camp sessions through a mutual friend's company.

While a member of the Key Club in high school, Crane organized a fundraising event for MDA. He and his family also have raised money for the MDA Telethon. He was active at a local Harley-Davidson dealership, working their fundraisers during the year, as well as assisting at several MDA Lock-Ups.

Professional and Community Achievements

Crane worked at Open Doors in Chicago, an organization created to provide job placement, educational seminars and diversity programs for

individuals with disabilities. He assisted in the creation of their publication, *Easy Access Chicago*, a guide for accessibility in Chicago.

In the fall of 2009, Crane developed a serious lung condition and spent more than two months in the hospital. Upon his release from the hospital, he started cooking therapy, a food blog and a cookbook while in hospice care. With renowned Chicago chef, Rodelio Aglibot, he started the nonprofit charity, "In Chefs Hands — Food Therapy for the Soul," that teams chefs with individuals with special needs who have a passion for food or cooking. The charity's launch party, attended by more than 600 people, was held June 14 within a week of Scott's passing. His legend will live on forever.

Words to Live By

Crane, known as "Mr. Determinator," kept his positive attitude by providing an inspirational quote every day to his myotubular myopathy/centronuclear myopathy (MTM/CNM) Facebook friends around the world. He always ended his emails with the saying: "Spread smiles to everybody, everywhere, each and every day. Eat well, laugh often, live and love life."

Photo courtesy of Tom Rossiter.

