

Buffalo Grove boy advocates for disabled older brother

By [Burt Constable](#)

Profoundly disabled teenager Max Randell never has been able to write or utter a single word. But his little brother, Alex, says the 15-year-old communicates with loved ones through blinking, eye rolls, smiles and his infectious laugh.

"It's sometimes a little hard, but it's just how he is," says Alex, who has never known the brotherly tension that often can leave boys less than thrilled with their "little brother" status. The 10-year-old is more than Max's brother. He's his best friend. He's his voice.



Since Max can't ask our nation's medical leaders to fund research into his rare disease, Alex is the one scheduled to make a presentation Tuesday on his brother's behalf.

"He's just so awesome," says Alex, piling onto the couch in the family's Buffalo Grove home to give Max a brotherly hug and coax a smile and laugh from the teen whose disease severely limits the ability to return the hug.

Not meeting the typical developmental milestones of babies who support their heads and react to movement and sound, Max was diagnosed before he turned 5 months old with Canavan disease — a rare neurological disorder in which genes don't produce the protective myelin in the brain, causing the brain's white matter to degenerate into spongy tissue riddled with microscopic fluid-filled spaces. Symptoms start with lack of motor development, feeding difficulties, abnormal muscle tone (weakness or stiffness) and an abnormally large head that is difficult to control. Patients sometimes suffer from paralysis, blindness, seizures or hearing loss. Most children with Canavan die before their 10th birthday.

Parents Ilyce and Mike Randell immediately set out to change that grim prediction for their son. Their research, fundraising and dogged determination led them to establish [Canavan Research Illinois](#), a not-for-profit charity that raises funds for Canavan research. The most promising treatment has been gene therapy, in which healthy genes are injected into the brain with the hope they will make the key enzyme that the mutant genes do not. At 11 months old, Max was the youngest patient in the world to receive an early form of gene therapy to treat his Canavan. He received a more effective version of that treatment through six holes drilled in his head during a hospital stay in 2001.

"Max showed improvement after both gene therapies," says Paola Leone, director of the Cell and Gene Therapy Center at the University of Medicine & Dentistry of New Jersey and a leading researcher into Canavan disease. Leone has been working on a cure since 1994, when she was a research scientist at Yale University.

"It's an absolute mission we have. I work all the time," Leone says. She and her team are working on new treatments they think might be able to stop the disease before it causes severe damage, "but we'll never be able to test it on humans if we don't receive more funding," she says.

While the government has funded some of her work during the last two decades, research by Leone and her team currently is supported by private donations from charities such as Canavan Research Illinois. Alex and Ilyce Randell will spend Memorial Day traveling to Bethesda, Md., where they will tell Max's story and make a plea for government funding before scientists from the National Institute of Neurological Disorders and Stroke and from the National Institutes of Health.

Known as one of the "orphan diseases" because it is so rare (maybe a couple hundred babies are born with the disease in a typical year), Canavan competes for research money against more common diseases. But Leone says a cure for Canavan also might help patients with amyotrophic lateral sclerosis, multiple sclerosis, Alzheimer's disease, Parkinson's disease and brain injuries.

A precocious and bright fifth-grader, Alex says his main duty in life is to "protect" his big brother. Alex has been crusading for his brother and the charity for as long as he can remember.

"I started stuffing envelopes at 2½," says Alex, who always makes a short speech at fundraising events.

"Alex is really proud of Max," their mom says, explaining how Alex started reading from textbook entries about Canavan at an age when most children are content with "Goodnight Moon." Other children sometimes ask difficult questions about Max. The oddest might be "Is he real?" the mom says. Alex can explain details of Canavan disease and the ailments that require his brother to use a wheelchair and eat through a feeding tube, but he becomes much more animated when he explains who his brother is.

"One of the most awesome things about him is just love," says Alex, who still lifts his brother's arm and places it around his neck as they lie on the couch to watch TV. "I used to call him 'Big Ball of Cozy.'"

"He's charming," says Judy Charles, a home health care worker who generally cares for Max for a few hours from the time he gets home from his special education classes until the family is ready to take over the full-time care Max needs.

The boys still share a bedroom because "neither one of them wants to split up," their mom says. "I ask Max, 'Are you happy?' and he always says, 'Yes.'"

A blink means yes and an eye roll means no, the family says. At 64 pounds, Max weighs a pound less than his younger brother, and his weakened body sometimes struggles to make even those small movements. When his mom kisses Max, says she loves him and asks if he loves her, Max blinks extra hard.

"I know he's happy, so there's no real reason to feel sorry for him," Alex says. "I'm sure he'd like to walk and talk, but I know he's happy. He has a great personality, and that's how he wins people over."

A superb wrestler with dozens of trophies decorating his shelves, Alex says he knows what he'll be when he grows up. He dreams about it.

"I am picturing myself looking at things on the computer, looking at neurons. Sometimes I'm wearing a Hazmat suit," Alex says. "When I grow up, I want to be a medical researcher."

Alex joins his parents and their charity in their quest to help Max and others.

"He always tells me, 'If you don't find a cure by the time I grow up, I'll find one,'" his mom says, adding, "I still have a lot of hopes for Max."

For more information about Canavan, visit the canavanresearch.org website, phone Ilyce Randell toll-free at (800) 833-2194 or email her at Ilyce@canavanresearch.org. Tax-deductible donations can be sent to Canavan Research, P.O. Box 5823, Buffalo Grove, IL 60089.

"If I didn't have him, my life wouldn't have the spark Maxie gives me," Alex says. "He's just so lovable."

Max makes a noise, and his mom leans in close.

"Would you tell Alex that he's a good brother?" Ilyce asks Max.

A smiling Max just blinks.