

Family fight helps son, others

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By MARIE WILSON Contributor

Max Randell, 9, of Buffalo Grove has Canavan disease, but his family believes he is just as normal as any kid his age.



Although he was diagnosed with the degenerative brain disorder at 4 and a half months of age, Max enjoys some of the same activities as his 5-year-old brother Alex: horseback riding, baseball and boating.

"Clearly he's like a regular kid in a wheelchair, basically; just his body can't do what he wants it to do," his mother, Ilyce Randell, said.

Of course, few children have proclamations issued in their honor by two different village governments on the same day.

On Sept. 10, both the villages of Palatine and Buffalo Grove presented Canavan Research Illinois with a proclamation proclaiming the month of October as Canavan Disease Awareness Month in honor of Max's 10th birthday this month. Representatives of this charity accepted the proclamations.

The villages of Deerfield and Northbrook also have created proclamations in Max's honor.

The proclamations mentioned the ninth annual charity ball that is being held Oct. 13 at the Hyatt Deerfield in honor of Max's birthday.

Fighting the disease

Max's body does not perform as he would like it to because Canavan disease progressively decreases the brain's ability to respond to nerve stimuli.



Zero Boundaries Woman Contest winner Ilyce Randell and her mother, Peggy Shapiro-Nyeholt, play with Max Randell 8. — Michelle Lohmann / Staff Photographer

To fight the disease affecting her son, Randell and Max's grandmother, Peggy Shapiro-Nyeholt, founded Canavan Research Illinois immediately after his diagnosis.

Randell said the foundation works to connect and inform families of Canavan children and raise money for research. She strives to achieve those goals by meeting with politicians and posting information on the CRI Web site at www.canavanresearch.org.

"She (Ilyce) is really into research and political issues," Max's father Mike Randell said. "She really puts herself and CRI out there and networks with local politicians to move policy along."

Research completed by CRI has resulted in new gene therapy treatments and medicines, and improved the quality of life of dozens of children with Canavan disease. Max is just one of them.

"He's a medical pioneer," Ilyce said. "He's always been on the forefront, and that's kind of because of what we're doing; I mean we want to save these kids."

Based on the results of Max's MRI, the gene therapy he first received at 11 months old -- and again at 3 years old -- has helped.

"He's not baseline for Canavan disease," Ilyce said. "His mind and social skills and everything like that are that of a normal 10-year-old."

Linnea Edstrom of Arlington Heights, Max's one-on-one aide, has learned to understand Max's method of communication, in which he moves his eyes, face and body in subtle ways to express himself.

"He's cheerful and easy to get along with. He doesn't fuss and he likes a lot of activities," Edstrom said. "He's happy because the people around him are happy."

TV help for home

Edstrom is in her second summer watching Max at his home. This summer, the ranch-style home includes a new addition, courtesy of the "Live with Regis and Kelly" show's Mom's Dream Come True Contest.

The Randells were chosen as one of the winners of a room renovation by HGTV's Monica Pedersen, who hosts the show "Designed to Sell."

The Mom's Dream Come True Contest became the second sweepstakes the Randell family has won after being entered by Shapiro-Nyeholt. Ilyce was also victorious in last year's Diet Rite Zero Boundaries Woman Contest after receiving a nomination from her mother.

"It's helpful to have another space," Ilyce said of the new porch-turned-great room. "Because this is it, we don't have a basement."

With the renovations complete, Max can now access the room and the backyard patio from his wheelchair with the same ease of the rest of his family.

And as Max's family members go about their daily routines, fighting Canavan disease through the funding and networking efforts of CRI, he fights it during therapy sessions for more than four hours a week.

"Alex and Max go horseback riding together," Mike said. "Max does horseback riding therapy and they let siblings come too."

Max also completes speech, occupational and physical therapy and has played buddy baseball through the Buffalo Grove Recreation Association for the past two years.

"He has a motorized wheelchair, and the buddy helps to make sure he went to the right base," Ilyce said. "Because the kids, all of them in chairs, they think it's hilarious to just go all over the field."

Max also enjoys riding on his family's pontoon boat down the Fox River, proving that despite having a disease, he is a normal kid.

"I don't think that would have been possible if we had just let the disease run its course," Ilyce said. "The life expectancy for Canavan disease is seven to 10 years, but he's going to be 10 in October, and he's going to be here for a long, long, long, long time."

Charity ball

The Canavan Charity Ball will be held Oct. 13 at the Regency Ball Room of the Deerfield Hyatt Hotel, 1750 Lake Cook Road. Hors d'oeuvres and the silent auction preview will be at 6 p.m. The Dinner and raffle will be at 7:30 p.m. Dancing will last until midnight. For tickets, call (800) 833-2194.

The featured speaker will be Paola Leone, Ph.D. Leone is an associate professor in the Department of Cell Biology, at University of Medicine and Dentistry of New Jersey School of Osteopathic Medicine in Stratford, N.J. Leone and her team are world leaders in researching Canavan disease as well as many other areas of biomedical research related to diseases of the brain.

Canavan Research Illinois can be reached at P.O. Box 8194, Rolling Meadows IL 60008-8194; (800) 833-2194; info@canavanresearch.org and www.canavanresearch.org and www.savingmax.com.