

Daily Herald

Benefit salutes those working to find cure for rare Canavan disease

By Ruth Gesmer Silverman Daily Herald Correspondent

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Rarely do a dozen kids, some of them charity beneficiaries, attend fundraising balls. But, Canavan Research of Illinois has never let norms stand in its way.



At the group's recent gala, awards were presented to Gov. Rod Blagojevich (who sent a representative), state Comptroller Dan Hynes recognizing the state appropriation of \$10 million toward stem cell research, and to Canavan researcher Dr. Scott McPhee.

Hynes looked on as Mobile Music deejay drew the little ones to the dance floor. They were the children of several attendees, including three who are in a race against time to live.

Among the first on the floor was Max Randell, circling around in his wheelchair with the others, including 3-year-old brother Alex and cousins Markus and Jack Hartman, 5 and 3, from Barrington.

Hynes said when he sees Max he is heartbroken.

"I'm inspired by the courage and the fight Ilyce and Mike Randell and all these families have taken on," he said. "We must find a way to get stem cells to these children and to others who would benefit from such treatment."

The Buffalo Grove 8-year-old can't speak, but he laughs at the music and at the video that shows his journey through the course of the genetic neurological disease which usually claims its victims before the age of 10. On dance floors and at roller rinks, he loves to pull the wheelchair of his friend Celeste Stern of Woodridge.

The daughter of Theresa Delgado and Kevin Stern, Celeste also has Canavan, as does the newest child-guest at the event, 18-month-old Nataliya, daughter of Heather Rosin and Thyme Gausvik of Grayslake.

Max is one of very few in the United States who have had a gene transplant directly into his brain. He can still see, can maneuver his chair, and he loves school.

Max's grandmother, Peggy Shapiro-Nyeholt of Des Plaines, said the family is hopeful the transplant will keep the deterioration at bay long enough for stem cell therapy to be developed.

McPhee, a New Zealand native, looked on with obvious emotion. He is the post-doctoral research fellow — with principal researcher Dr. Paola Leone — at the University of Medicine and Dentistry of New Jersey.

Unlike many researchers, Leone and McPhee elected to get to know some of the kids they are trying to help. At the dinner, McPhee crouched down to tousle Max's curls and placed his own hand on the joystick

on the wheelchair, delighted to be involved with one of the kids he is trying to cure.

He recognizes the emotional pitfalls, but says, "I also greatly value the inspiration that I get from an understanding of the challenges that others face daily," McPhee said.

Ilyce Randell bristles when she recalls another researcher.

"When he told me he never wanted to meet my son, I said good-bye," she recalled.

The event raised \$32,000 from those who were at the Renaissance Chicago North Shore in Northbrook and from many who didn't even attend.

To inspire donations to Canavan Research Illinois, an anonymous donor will match (dollar for dollar) every new or increased donation to the charity until March.

To make a donation, go to www.canavanresearch.org/.