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Saturday's gala charity ball helps fight Canavan Disease

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For families with children who have Canavan Disease, the recent proclamation by Gov. Rod Blagojevich making October Canavan Awareness Month came at a perfect time.

It's traditionally the month when Canavan Research Illinois holds its annual fund-raiser. This year is no exception. The eighth annual Canavan Charity Ball will be held Saturday at the Renaissance Hotel in Northbrook.

The biggest difference between this year's ball and last year's will be the absence of some of the children who are fighting for their lives. Two have died in the past year.

Peggy Shapiro-Nyeholt, of Des Plaines, grandmother of 9-year-old **Max Randell**, of Buffalo Grove, likens the quest for a cure or gene therapy to being on a train track.

"We were grateful to see **Max** turn 8," she said, "and even more grateful when he recently turned 9.

"But, with each birthday, we also worry we are running out of time." The neuro-degenerative disorder usually claims its young victims before they turn 10.

Shapiro-Nyeholt likened **Max's** fight for his life to being on a train track with an unseen engine advancing upon him.

"His parents, Ilyce and Mike, and all his grandparents are racing to stop the train, determined ... to get there before it hits our **Max**," she said.

Shapiro-Nyeholt said his disease is "on hold" temporarily, but no one knows for how long.

"We are ... trying to get there first, and we will never stop," she said. "With our last breath we will hold that train back, but we need the help of the community to do it.



"Every cent raised is another way to make a difference for these children, battling a little known disease, with very few advocates."

Shapiro-Nyeholt said the research supported by Canavan Research Illinois is freely shared with other scientists.

"It does have the potential to make a difference for all the neuro-degenerative diseases," she said. "The train we stop may be the one that is on its way to hit someone with MS, ALS, or Parkinson's, as well."