



Jen and Tracy VanHoutan have created the nonprofit Noah's Hope Fund after two of their children were diagnosed with Batten Disease, a degenerative disorder. Laine (far right) and Noah (center) both have the hereditary disease. Emily, shown here in a photo taken last year, is Laine's twin sister.

| SUBMITTED

For the children

Family starts nonprofit to fund research about Batten Disease

BY ANGELA BENDER

For The Sun

The VanHoutan family is faced with the knowledge that two of their three children might not live to see their teens. But knowing that has not stopped them from creating a nonprofit organization to raise money to support research, raise funds and inform the community about the disease that afflicts their children so that others may benefit.

"(Jen and Tracy VanHoutan) realize they probably will not save their children," said Julie Kukla, a friend of the VanHoutans. "Even if a cure was found, the little boy they once had (will not return to the child he was)."

When Noah was three, the VanHoutans of Downers Grove were concerned about his speech delay. He also began having tremors. They took him to a neurologist who said he would grow out of it. A few months later, Noah collapsed and stopped breathing. Doctors said he had a seizure and was diagnosed with childhood epilepsy. Nine months later, an MRI revealed that Noah had atrophy in part of his brain, but doctors could not identify a cause.

Meanwhile, the family noticed Noah was gradually declining. He was having difficul-

ty doing everyday tasks such as brushing his teeth and eating with a fork. He eventually was referred to Duke University, where in March 2009, Noah was diagnosed with late infantile NCL, which is known as Batten Disease. The hereditary childhood disorder has no cure and is extremely rare, occurring in just two to four of every 100,000 births in the United States. Over time children with Batten Disease cannot walk or communicate. They lose their vision and motor skills. They become bedridden, are tube fed and suffer from dementia. Children with Batten Disease generally do not live beyond 12 years old.

"On a good day, they'll get a little smile (from Noah, now 7)," Kukla said. "But that's all at this point."

Because of his diagnosis, Noah's younger twin sisters, Laine and Emily, also were tested. Laine, now five years old, was diagnosed with Batten Disease as well. More than a month ago she, too, lost the ability to walk.

The VanHoutans have established Noah's Hope Fund to fight this disease. But because fewer than 450 children in the United States are diagnosed with Batten Disease, it receives little research attention or funding.

"They want to find a cure

AT A GLANCE

What: Acts of Kindness Cabaret in Life ... Sunny Side Up

When: 7 p.m. June 25

Where: Grace United Methodist Church Fellowship Hall, 300 E. Gartner Road, Naperville

What: Cabaret show to benefit Noah's Hope while increasing awareness, understanding and enjoyment of cabaret. Light refreshments served.

Tickets: \$35 in advance and \$40 at the door

Contact: willcountymotc@yahoo.com or call 708-655-3242

On the web: Visit www.noahshope.com or www.actsofkindnesscabaret.org

so nobody else has to go through this," Kukla said.

To do just that, Kukla, who is co-philanthropic chair for the Will County Mother of Twins group, has arranged an evening of cabaret in Naperville with all proceeds benefiting Noah's Hope. Acts Of Kindness Cabaret, which hosts eight to 10 of these kinds of benefits each year, will put on the show.

AOK Cabaret is a nonprofit organization, using professional performers who volunteer their time and talent as fundraisers for charitable organizations. Each show features three singers and a pianist. AOK, which is based in Wheeling, also provides lighting, sound, technical staff, printed programs, and publicity.

According to founder Hilary Ann Feldman, who began the nonprofit in 2005, by putting on these performances for less than \$300 to the organizations, nonprofits, like Noah's Hope, can host a nice event without worrying they will make money.

"I am a musician, and I don't make a lot of money," Feldman said. "I always want to write checks to organizations I think do good work, but I can't. So this is what I have, and I found others who are interested in contributing in the same way."

Kukla is thankful for this novel approach to fundraising, who noted that the title of the Naperville performance is "Life ... Sunny Side Up," which focuses on how people deal with life's obstacles.

"(The title) speaks volumes for the determination of the VanHoutan family," Kukla said, "who make positives out of all the negatives they have been given."