

Eye Gaze computer helps Enna speak

Gift of \$18,000 machine welcome surprise to two-year-old with spinal muscular atrophy

By Cam Tait, edmontonjournal.com January 30, 2011

On her way to a memorial service, Lisa Lohin received a telephone call that brought bittersweet joy to her family. It's an incredible story of loss spun into endless possibilities for two-year-old Enna Lohin.

Enna has spinal muscular atrophy, a disease that affects the spine. She is unable to sit up or speak and is on a ventilator. But her mind is sharp - - sharp as a tack.

Enna was presented with an Intelligaze Eye Gaze, a computer which reads her retina. Simply by looking at an icon on the computer screen, Enna can now express herself.

But the Eye Gaze was originally intended for another girl with the same disease. Kaitlyn Pas died recently at age eight before she was able to use the communication machine.

"I was on my way to Kaitlyn's memorial service Monday when my spouse phoned to say Kaitlyn's family wanted Enna to have the machine," Lohin said. "I just thought of Kaitlyn's mom and dad and what they were going through - and how they still could think of helping others."

The two families share a close bond because of their children.

"Kaitlyn has been an advocate for herself, and now for us," Lohin said. "Now Enna can learn and get an education."

Kaitlyn's mother, Hali Harapchuk sat in the front row as Enna received the Eye Gaze last week. "We wanted to be here and represent Kaitlyn," Harapchuk said. "And I wanted to let people know how special she was."

Harapchuk found out about the Eye Gaze a few years ago. The first trial machine didn't work very well, but when another one arrived, it gave Kaitlyn new independence and an ability to ask for routine things, such as wanting to watch TV.

Kaitlyn lost her battle due to complications caused from her disease.

"I'm so happy the computer went to a family we know, someone who has the same condition as Kaitlyn and someone local," Harapchuk said.

"I'm so happy the computer went to a family we know, someone who has the same condition as Kaitlyn and someone local," Harapchuk said.

The computer cost \$18,000 but doesn't fall under government programs such as Aids to Daily Living. The Variety Club of Northern Alberta and the Children's Ability Fund bought it. "We always like to be there for kids who fall between the cracks," said Don Clarke of the Variety Club.

Enna will be learning the new technology through the GRIT Program under the watchful eye of Amber Michaud.

For a video demonstration of the Eye Gaze, please visit my blog. It will be posted by noon today.

Blog Bytes: The heart and Stroke Foundation needs office volunteers. Read for a final total in last week's ringette fundraiser for the Cross Cancer Institute and Tait's Tender Tales.

Ctait@edmontonjournal.com [Twitter.com/camtait](https://twitter.com/camtait)