

REDFORD OBSERVER

Mia's Makes a Wish

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Make-A-Wish brings joy to Redford girl

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On July 17, a dream came true for Redford's Mia Zerial, a blue-eyed, blonde-haired 9-year-old unable to walk or speak due to Rett syndrome, a neuro-developmental condition she's had since birth.

At a “Wish Fulfillment” party, Make-A-Wish Michigan presented Mia with “EagleEyes,” a device that allows her to operate a computer by moving only her eyes, enabling learning and communication.

“Her smile is full of joy,” said her mother, Michelle Zerial. “EagleEyes is giving Mia an opportunity to explore what is going on around her and show us for the first time that she understands. Mia has never held a book and read it. Mastering something on her own is a new experience for her. That’s where the magic comes in. Watching her blossom and realize her own abilities is truly heartwarming.”

Ron Williams, a special guest at the party, flew in from Salt Lake City, Utah. Williams is director of training and education for the Opportunity Foundation of America, the nonprofit sole supplier of EagleEyes. He taught Mia’s parents Mark and Michelle; sisters Madeline, 11, and Megan, 8; Make-A-Wish staffers; relatives; and friends how to use the system. Mia was ahead of the curve because she uses EagleEyes at Cooke, the school she attends in Northville.

EagleEyes works by eliminating the computer mouse. “Every time we move our eyes, we create positive and negative charges,” Williams said. “EagleEyes uses electrodes taped around the eyes to track the movements of our eyes and amplify the charges. The system captures that movement and translates it to movement of the cursor on the screen.”

Mia's eyes direct cursor

Shae Snyder, communications coordinator for Make-A-Wish, watched Mia demonstrate her skills at the party. In short order, Mia hit a target with her eyes – showing that she understands cause and effect.

“When she placed the cursor on the puppy, the puppy played a song. To witness Mia using the EagleEyes system to communicate with her family for the first time in a simple way was absolutely amazing to see,” Snyder said. “Mia is a huge fan of Ron’s. Whenever she hit a target, she would look to him as if to say, ‘I did it!’”

Make-A-Wish Michigan grants the wishes of children with life-threatening medical conditions. It has fulfilled more than 7,000 wishes since 1984, averaging more than one per day.

“Mia is a beautiful little girl, adorable,” Snyder said. “Her sisters and parents are very special. They’re a great family, humble and grateful for what Make-A-Wish did for them.”

Invented and developed by Boston College professor Jim Gips in the 1990s, EagleEyes is used in 10 states, Canada and Ireland. Of the 80 EagleEyes units in existence, 18 are in Michigan.

Mia is blessed with exceptional teachers, Snyder said: “A lot of them came to the party. You could tell there is this bond between her teachers and her. They really, really care about Mia. It’s something special to witness.”

The Zerials have come a long way. “During a time of desperation when I had a feeling of not being able to give Mia anything more to help her, a time of feeling powerless and not being able to help

my daughter any more than I was, I submitted a letter indicating that my daughter has a life-threatening illness and would benefit from the gift of a ‘wish,’” Michelle said.

Better than Disney

“Mia’s application was accepted and Make-A-Wish invited us to meet with our Wish volunteers, Ken Kavanaugh and Lynn Vela. What a wonderful group of people! There were a few ideas that our family had and we spent many months deciding what Mia would want most,” she said. “Mia had used the EagleEyes system at school successfully and was making quite a bit of progress, so ultimately our family decided that her very own EagleEyes system would be the biggest benefit. In a matter of only a few weeks, the wish was granted and Mia had EagleEyes in her home to use and learn from.”

“Wish granter” Kavanaugh of West Bloomfield said: “I’m happy that this wish is something that’s going to last a lifetime. During the party, I was telling Mia’s dad Mark that we could have sent his family to Disney. But that’s only for a week. At the end of the week, they’d have memories, but that would be it. It gave me a really good feeling to know Mia is now going to be able to communicate more effectively.”

Fellow “wish granter” Vela of Troy, who with Kavanaugh handled lots of the paperwork, said she greatly admires Michelle, who works full time, and Mark, who gave up his teaching job in Detroit to care for his daughters. Vela predicts Mia will learn to spell before long. “Nothing could be more exciting,” she said. Vela enjoys volunteering for Make-A-Wish and meeting youngsters like Mia. “I’m retired and I hate bridge, so this is what I do and I love it.”

Mia and her parents are optimistic, too.

“Mia hopes to keep working hard and to be her own star in all that she is able to do,” Michelle said. “It is our hope that Mia can train herself to use the system to be able to learn her alphabet and numbers, read books and be able to tell us what she is thinking – all over time, of course. We see this is a tool that should bring much reward to her life. The possibilities are honestly endless.”

Rett syndrome usually is diagnosed in the first year of life when a child isn’t meeting developmental benchmarks. Characterized by a compromised gene on the X-chromosome, it most often affects girls. Mia experienced seizures, eating and growth difficulties, gastrointestinal problems and scoliosis.

“Dr. Andreas Rett is the one who identified this disorder in the early 1990s. The medical community only recently began doing a lot of research on it,” Michelle said.

Annual walkathon

The Zerials have met many other Detroit-area families through the Rett Syndrome Research Trust. “Mia has opened our eyes to a whole other world,” said Michelle. The fourth annual Walkathon for Rett Syndrome Research is set for 9:30 a.m. Sunday, Oct. 6, at Inglenook Park, 20901 W. 12 Mile Road, Southfield. “We would love to have a corporate sponsor,” she said.

“We’re happy we can share our story and let others know there is help out there,” Michelle added. “Keep looking for it.”

She encourages interested individuals to visit www.michigan.wish.org, www.questforacure.net and www.opportunityfoundationofamerica.org for more information.

“Meeting with Mia and her family was great,” Williams said. “They are a wonderful, warm family who love their daughter and want her to have every opportunity to succeed. That’s evident in the hospitality and love felt in the home. Mia was an absolute delight to work with. She’s used this technology at school and we could tell she was so excited to have it at home to show her family where she is cognitively and to interact with them in a way she’s never had the opportunity to do before.

“This is a major step,” he added. “It’s an amazing feeling to watch a child experience true independence, doing something for herself. Mia is just starting out; she’s barely scratched the surface. From here, it all depends on her and where she wants to go with it.”