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# Wish granted, Coral Springs boy greets the world



Yasmin Black with son Ewan Black, 4, and Ewan's nurse Cindy Goldberg. The Coral Springs boy is unable to speak, point, or gesture on his own. (FPG Photo/Anna Collins)

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## SHARELINES

- Ewan attends ARC Broward, a school in Sunrise that serves children and adults with developmental disabilities

For four years, Ewan Black remained trapped in his own world, unable to step out or to let others in.

The Coral Springs resident has Freeman-Sheldon syndrome, a rare congenital condition that makes communicating with others next to impossible. As he does not have the ability to speak or move his limbs, Ewan's family members and therapists have had to depend on his breathing and eye movements to peep into his mind.

Just when it seemed that there was no way to knock down the barriers that the disease had placed between Ewan and the world around him, Make-A-Wish stepped in. Less than three weeks since he had his wish granted in the form of an eye-gaze device that enables him to communicate with the world, Ewan is busy enjoying his new-found freedom.

"He really enjoys the device; he has a very good tolerance level for it," said Alain Laferriere, who represents Forbes Rehab Services, the company that makes the device. "He has gone far beyond the parameters that we initially set for him; in fact, he has even started showing off."

Ewan attends ARC Broward, a school in Sunrise that serves children and adults with developmental disabilities. At a lunch celebration organized last week at the school by Yasmin, his mother, Ewan's schoolmates, teachers, and Timothy Sykes, the donor, cheered as he demonstrated the device and thanked all those who made it possible.

It was pediatric gastroenterologist Enrique Hernandez-Sanchez who first told Yasmin about Make-A-Wish and the potential impact it could have on her son's life. "He told us that his office manager, a wish giver with the organization, would like to sponsor Ewan. That set the ball rolling," she said. "A lot of special people came forward to make this happen; we are very grateful.

"This will open up a lot of doors for Ewan," Black said. "It is not that he couldn't communicate earlier, but it was very limited. He is figuring out things on his own these days; it's really amazing to watch him come out of his shell. This will allow him to have a conversation with his big brother; that is huge for us."

Ewan has made plenty of progress in the short period that he has had the device, said Black. "We work with him every day, and he also takes it to school. The device offers a lot of possibilities; there is quite a bit in there for us to explore."

WinSlate 13, the \$20,000 device that Ewan uses, is a computerized system that makes communication possible using an eye-gaze module and two types of software. The Ohio-based company has a range of products that is used by people with medical conditions, such as cerebral palsy, amyotrophic lateral sclerosis, autism and multiple sclerosis.

"The eye-gaze module is like a camera with a special infrared light," Laferriere said. "The device also has a mounting system. 'Look to Learn' software is used to train the eyes to use the device, while the Grid software helps in communication."

Apart from helping Ewan with the device, Laferriere is also training those who will work with him at the school. "I expect him to read and write with the device," he said. "He will also be able to control the environment, including turning the lights or the TV on and off, using his eyes and the device."

Make-A-Wish Southern Florida grants a wish every 16 hours to a child with a life-threatening condition, said Richard Kelly, executive vice-president of brand advancement and chapter operations. "We helped 525 children last year. We don't just grant a wish and leave; we change lives.

"Once we know what the wish is, we look for funding to make it happen," Kelly said. "There is a price tag to every wish; some wishes are more expensive than the others. This wish was on the more expensive side, but the cost of saving a life sometimes isn't cheap."