The Power of Fun

A chance meeting between an engineering professor and an 11-year-old boy with cerebral palsy led to the creation of five devices that enhanced the child’s life.

by Becky Rodia

On a June day in 2008, Dr. John Enderle, director of the biomedical engineering program at University of Connecticut (UConn), stopped at the Ashford, CT plant nursery, Sean Patrick’s Plants, to buy plants for his garden. While there, he met Sean Patrick Stenglein, an 11-year-old boy living with cerebral palsy. Sean works at the greenhouse with his parents, Brenda and Patrick Stenglein, who own the business they named for their son, “in honor of the miracle of his life.”

“I saw Dr. Enderle watching Sean,” Brenda Stenglein remembered. “Then he asked me if Sean had ever ridden a go-kart. Of course, he hadn’t. There aren’t any go-karts that meet Sean’s needs.”

Dr. Enderle saw possibilities for Sean, and had access to resources that he extended to the Stenglein family. Each year, UConn biomedical engineering students create devices for people with disabilities under the auspices of Research to Aid Persons with Disabilities, a program funded by the National Science Foundation. Dr. Enderle asked Brenda if Sean could be the recipient of the projects made in the upcoming school year.

“I started to cry right there. I couldn’t believe what he was saying,” Brenda said.

Dr. Enderle gave the Stengleins reports and photos of projects UConn students had completed in previous years, and asked them to choose devices that would enhance Sean’s life.

“The family chose 5 projects that were difficult, but a good challenge for the students,” Dr. Enderle said. “The initial ideas for the projects came from the photos, but then the devices were specially tailored for Sean.”

On May 8, 2009, after a year of working closely with Sean, his family, his physicians and therapists, as well as experts in the field of cerebral palsy, the group of UConn seniors delivered their final projects to Sean. The 5 assistive devices included a trampoline, a “Standing Gardener” that helps Sean in the family’s greenhouse, a device that allows Sean’s communication unit to be mounted in a car, an all-terrain wheelchair, and the go-kart. Dr. Enderle mentioned to Brenda on that first fateful day.

The trampoline is for the whole Stenglein family, thanks to a hydraulic crane arm that holds a special harness for Sean. “The team of students that made the trampoline had to set a 3-by-3-foot concrete block down into our yard, for installing the steel support and I-beam that holds the harness,” Brenda said.

The harness itself was designed to include supportive aspects of Sean’s car seat; the students had to purchase one of the car seats to work with, cutting it apart and adapting the design of it. After all that hard work, the results were magical: “They made a trampoline for my child who can’t stand up on his own,” Brenda Stenglein said. “Now he gets to experience the sensation of jumping on his own, and flying through the air.”

Sean stands with the help of a Leckey Freedom Stander. Brenda points out that it’s very important for Sean to bear weight every day, and the Freedom Stander allows him to do that. The UConn students adapted the design of the stander to create the Standing Gardener, a standing device that not only supports Sean’s feet, knees, hips, and trunk, but also features storage for soil and other gardening supplies that he needs for his work at Sean Patrick’s Plants.

The stainless-steel Standing Gardener has a semi-circular tabletop, a rotating “Lazy Susan” type device to hold various sizes of pots, and handles that Sean can hold for balance. UConn engineering students Robert Knapp, Fryderyk Karans, and Peter George, who designed and built the Standing Gardener, also took the future into consideration when they designed the device – it’s made to extend as Sean gets taller.

Sean is mostly nonverbal. He is able to communicate a few essential words on his own, and mainly expresses himself with the aid of a DynaVox augmentative and alternative communication device (AAC). "Sean can access the DynaVox in his wheelchair or from a chair at home, but there was no way for him to talk to us in the car," Brenda Stenglein said.

The UConn students solved this problem by researching the DynaVox as well as Sean’s positioning in the car, and designing an Augmentative Communication Mounting Device—a mounting system that allows the DynaVox to be placed in the car. "It’s very exciting for everybody," Brenda said. "Now Sean can communicate with family and friends while we’re in transit."

The last two devices UConn students made for Sean will also help keep him in transit. The team who made the Standing Gardener also designed a portable all-terrain wheelchair for Sean. And James Paolino, Alex Jodczak, and Eric Leilmes made Sean his very own go-kart, with adaptations that support his body and allow him to drive and steer by himself.

"The wheelchair solves my challenge of what to do with Sean in the winter," said Brenda. "I didn’t have a sled that could support Sean. We had the..."
same problem at the beach. It's difficult to carry Sean onto a beach in the hot sun. The UConn students designed a wheelchair with inflatable tires that pop off, and the wheelchair folds up. It's portable, and the inflatable tires can handle snow and sand. Sean thinks it's the greatest thing. He feels like he's in a big monster truck!

The go-kart has been a source of great joy for Sean and his entire family. It features interchangeable seats—a family member can sit in a typical go-kart seat and drive, but if Sean wants to take the wheel, that seat swaps out and Sean's 5-point-harness car seat fits in its place. The go-kart can be operated by a family member via remote control, or Sean can drive it himself using a joystick and headstick.

The first time Sean got into his go-kart was a momentous occasion. As his family, two of his physical therapists, and UConn students watched, Sean grasped the steering wheel with both hands (a tremendous achievement, according to Brenda) and drove all the way down the Stenglein's long driveway by himself.

"We were all in tears," Brenda recalled. "Sean was so excited and happy."

In addition to delivering the devices, the UConn students also wrote instruction manuals for each device, so the Stenglins can maintain and repair the devices as needed. Brenda Stenglein pointed out that the students also provided their e-mail addresses.

"They said that if we needed anything, they'd come back and help us," she said. "These kids are so committed. They made themselves part of our world."

For more information on the University of Connecticut's work with the National Science Foundation's Research to Aid Persons with Disabilities, visit http://nsf-pad.bme.uconn.edu

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