SHARENotes

SEPTEMBER 2023

VOLUME 38, ISSUE 2

SHARE and High School Engineering Students Design Adaptive Ride-On Vehicle Good for Miles of Smiles

A longtime electrical and computer engineering professor at UMASS Dartmouth, SHARE Executive Director Phil Viall is no stranger to advising students and overseeing academic assignments. Yet this past spring, SHARE received a special request that brought Viall to a new Southcoast campus to lend his expertise in the classroom. Working together, Viall and a team of Bishop Connolly High School students engineered a unique solution that has powered mobility and independence for one of the school community's youngest members.

As Thomas dos Santos was approaching his third birthday this summer, Megan and George dos Santos knew that their little boy would need a range of customized adaptive equipment to best support his learning and development. Thomas was born with a rare condition called congenital diaphragmatic hernia, which can impact the prenatal development of





Thomas takes his new ride for a spin as his younger brother Joey and his mom look on.

the heart and lungs. Due to complications from this condition, Thomas experienced a cardiac arrest at two months old that led to him having hypoxic-ischemic encephalopathy (HIE) and cerebral palsy.

"After Thomas sustained his HIE, he was extremely limited with his movement," said Megan dos Santos, Thomas's mom. "Developmentally, babies and toddlers learn about the world around them by exploring their environment. Thomas couldn't do that independently."

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SHARE Foundation Seeks Participants for 38th Annual Fun Walk on September 23

It's time once again to put on your sneakers or comfortable walking shoes and take part in the SHARE Foundation's 38th Annual Fun Walk on Saturday, September 23!

This year, the event will again be held at the Westport Point United Methodist Church located at 1912 Main Road in Westport. The walk kicks off at 10 a.m., and the route includes the town's scenic waterfront. Arrive early and enjoy coffee and doughnuts while you register at 9 a.m.—you're sure to see plenty of familiar faces and meet some new friends!

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SHARE walkers and wheelers enjoy the beautiful Westport Point waterfront during FunWalk '22.

SHARE's Classic Car Show Set for September 17

If you're a SHARE supporter, time travel just may be closer than you think! Save the date for Sunday, September 17th and flash back to yesteryear in style at our annual Antique Classic Car Show sponsored by the Downshifters Club of New England. This fan favorite will be held from 9 a.m to 2 p.m. at the Freetown Historical Society, located on 1 Slab Bridge Road, Assonet. Entrance is free; a donation jar will be available with all proceeds benefiting SHARE.

You'll definitely find longtime event organizer John Remedis behind the wheel of this successful fundraiser again this year. Providing the perfect soundtrack for the day, he'll also be spinning your favorite oldies from the 50s, 60s and 70s as the iconic DJ "Johnny Angel."

As always, the show will feature a stunning array of classic cars and trucks, along with contests, trophies, camaraderie and a generous dose of nostalgia. You can also enjoy a tour of the site's museum, grab a bite at the food truck, and check out the vendor tables carrying a colorful mix of



SEPTEMBER 17 9 AM TO 2 PM

Vendor space reservation — \$15

Call Sheila at SHARE
at 774-992-0674
or register online at
www.thesharefoundation.org

Classic Cars and Trucks registration — \$15 Drive-ins are welcome! For details, call John at 774-353-6625 treasures (all items except food and refreshments are allowed). With ample space on the grounds there, people are welcome to register their antique vehicles upon arrival at the event if they haven't already preregistered.

A good friend of SHARE founder Les Cory, Remedis was first moved to support SHARE after seeing a child with disabilities benefit from the foundation's services by operating a computer via facial movements. Nearly three decades later, Remedis remains committed to aiding SHARE's mission to offer adaptive equipment and training at no charge to children and adults with disabilities.

SHARE Executive Director Phil Viall said he is especially honored by the heartfelt dedication and generosity that Remedis has shown to the SHARE community.

"John is a true supporter of SHARE, both through the car club and personally," said Viall. "He is just a wonderful example of a very caring human being."







CALLING ALL TECHIES

SHARE is looking for technically oriented people willing to help us in our mission to serve children and adults with disabilities. Based on your skill level, volunteer jobs include:

- > Setting up equipment for clients
- > Building equipment
- > Training clients to use their equipment

If you are interested and would like to learn more, please call SHARE at 774.992.0674.

JOIN THE CONVERSATION

Whether you would like to talk to others or chat one-on-one, please consider joining SHARE's Director of Client Services Beverly Thorn and your fellow SHARE clients. It's not necessary to commit to each week, but join us as you are able!

Interested in joining or getting more information? Contact Beverly at SHARE at 774.992.0674 or email her at beverly@thesharefoundation.org.



Remember to like us on Facebook!

https://www.facebook.com/ people/The-SHARE-Foundation/ 100060850593949/

Ben Boyle/Ron Kostyla Golf Tournament Celebrates 40 Years

While it poured rain in the early morning hours of June 4th, by tee time, it had turned into a beautiful day to greet golfers at the Ben Boyle/Ron Kostyla Golf Tournament to benefit SHARE.

Special thanks go out to organizer Bob Bjorklund, his team,

Ernest DiMicco, President of the Pawtuxet Valley Rotary Club, and all club members for sponsoring the 2023 event,

which raised more than \$13,500. Over the last 40 years, the tournament has raised in excess of \$283,000.

The golf classic began in 1984 when a group called the "Sunday Morning Golfers" wanted to do some fundraising for their friend and fellow golfer Ben Boyle, who had been injured in an automobile accident and was confined to a wheelchair. After receiving services from the SHARE Foundation, Ben told his golf group, "I have

everything I need. Do something for SHARE." In turn, Ron Kostyla, with the help of the Sunday Morning Golfers, put together the first golf tournament. For the next 23 years, Ron would lead

the organization of the Ben Boyle Golf Classic.
After his death in 2006, Ron's "second in command," Bob Bjorklund, took up the reins and has led the charge for the

past 17 years.

"Bob and his entire team have given so much of themselves," said SHARE's Executive Director Phil Viall. "The number of people whose lives they have been impacted by their dedication is simply amazing."

The clients and staff of SHARE salute the many people who have made this annual event possible. Mark your calendars—next year's tournament is slated for June 2, 2024!



SHARE Fun Walk '23

Continued from page 1

"The Fun Walk is both a piece of history and a way that you and your friends can be a part of something bigger," said Phil Viall, SHARE Executive Director. "Not only are you having a good time, but you are bringing in donations that will help adults and children with disabilities achieve independence and a better quality of life."

The Fun Walk is one of SHARE's major fundraisers of the year and is crucial to keeping the 40-year-old nonprofit organization up and running. Since its incorporation in 1982, the SHARE Foundation has assisted approximately 4,000 people with disabilities such as ALS (Lou Gehrig's disease), spinal cord injury, cerebral palsy, multiple sclerosis, stroke and many other conditions.

Walkers and wheelers (wheel-chairs are always welcome!) will be treated to a pizza lunch and have the chance to win some fabulous prizes, including incredible gifts for the top three fundraisers. Prizes include a 32" TV, gift cards to restaurants, Zeiterion Theatre tickets, and tickets to a show at the Providence Performing Arts Center. Kids (and those young at heart) can enjoy face painting, pumpkin painting, and other activities.



Miles of Smiles

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To help Thomas interact with his surroundings on his own, his parents first purchased a small, wheeled chair specially designed for children with disabilities, but discovered that Thomas didn't have the coordination and strength to move it forward independently. As vice principal for academic affairs at Bishop Connolly prior to its closure this June, dos Santos turned to Ellen Russell, the school's STEM director, with the idea of enlisting her engineering class to build Thomas a motorized chair.

"I knew it would be a lot of trial and error because there were elements of the chair that had to be customized to Thomas's unique needs," said dos Santos. "I presented the problem to the students and asked if they could help us find a solution. I thought it would be such a great thing for Thomas, but also a way to show students that they can use their gifts and talents to do good for others."

The chair gives
Thomas the chance
to have fun and see
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different perspective.
It really is a gift to
him and our family.

Russell embraced the challenge, planning a custom vehicle design that would add both fun and functionality to Thomas's daily activities. "Thomas can practice and develop physical skills, while achieving a level of autonomy in exploring his environment," said Russell.

Starting with a Power Wheels Wild Thing commercially manufactured for kids, Russell and her students rewired and programmed the ride-on vehicle, adding a single joystick control for Thomas, as well as a safety switch for parental control. They also designed BELOW: Bishop Connolly educators
Megan and George dos Santos stop for a
family shot with their boys during
Thomas's test drive. TOP RIGHT: Prof. Viall
and BCHS senior Daniel Reynolds work
together to program Thomas's chair.
AT CENTER: Thomas watches as Prof. Viall
makes adjustments to the chair's joystick.
AT BOTTOM: Thomas and Reynolds,
a computer science major at Worcester
Polytechnic Institute this fall, are all smiles
after the successful test drive.



and mounted a container for Thomas's ventilator and oximeter that allows for visualization of the devices' readouts and protects the associated cords. The design team then installed custom seating and padding to ensure that Thomas could comfortably maneuver the vehicle on his own.

As the project progressed, Russell invited Professor Viall to share his engineering expertise as a consultant on the project. He visited Connolly's lab frequently, guiding the students' engineering work and troubleshooting as needed to ensure that Thomas would be able to operate his vehicle safely and easily. In late May, the entire design team kept close watch as—during the vehicle's test drive—they put the power of independent movement in Thomas's hands for the first time.

"Thomas was so excited and had the biggest smile on his face once he







realized what the chair could do," said dos Santos. "He was just ready to go. He actually cried when it was time for him to come out of the chair."

For Viall, the unique engineering project was a doubly rewarding one.

"It was a wonderful opportunity to introduce the field of rehabilitation engineering to students who are looking ahead to college and considering their career paths," said Viall. "Working with Thomas and having a part in bringing him joy was really inspirational for all of us."

With Thomas starting preschool this fall, his parents are excited that his custom set of wheels will allow him to explore new learning adventures all on his own.

"The chair gives Thomas the chance to have fun and see the world from a different perspective," said dos Santos. "It really is a gift to him and our family." **THANK YOU!** We extend our heartfelt thanks to the many supporters who have donated to SHARE over the past few months. Your generous gifts are making it possible for us to provide the opportunity for independent communication to more children and adults with disabilities.

The following donations were received from April 1, 2023 to August 17, 2023.

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Photography

Sheila Pereira, Karen and Claudette Roy-Viall

www.thesharefoundation.org

Looking back, looking ahead... By Phil Viall, Executive Director

A YEAR AGO IN THIS SPACE, I looked back 40 years, and at how things have changed since the early eighties. SHARE grew from two people working on a kitchen table with the goal of helping one person lead a more productive life to an organization that has helped nearly 4,000 people in 39 different states and eight foreign countries.

Today, I want to look forward. SHARE is now among the "over 40" crowd. Two of its three founders are no longer with us on this earth. What are my plans for the future? What is the future for SHARE? Who will lead SHARE into the future?

Over the last three years, I have led SHARE as executive director, but at some point, new blood and new ideas need to be introduced into the organization. SHARE needs to reach out to new funding streams and open doors to new donors so that we may expand the services we provide to our clients. The staff of SHARE will be changing over the next few years. New employees will need to be hired.

In a few months, I hope to step down as executive director into another role that I feel I am far more suited for...it is a technical role, as you might expect. There are some innovative products that could be developed and marketed to provide yet another revenue stream for the SHARE Foundation. This type of innovation is where my talents have always excelled. I am much more comfortable surrounded by technical books and nearly empty glasses of iced tea than I am in the executive wing of a business whose funding is being sought. Creating new devices with a potential market brings me back to doing the engineering design and implementation that I love to do. I would expect to be involved with SHARE in this role for some time to come.

The SHARE Board of Directors is currently in the process of selecting a new executive director. This new director will be responsible for day-to-day operations of the organization, all branding and development. He or she will hopefully be the one to lead SHARE to a new level of performance and professionalism that will continue our mission for years to come. SHARE grew into something none of its founders ever imagined. I hope that 40 years from now SHARE provides support to disabled children and adults in ways we never even dreamed.