Dear Friends,

At Marianjoy, we often speak about the rehabilitation journey of our patients. They typically begin with an illness, an accident, or the diagnosis of a medical condition. Each patient is unique, defined by their specific needs and treatment goals. Their journeys include a number of milestones, touchpoints, obstacles, and celebrations.

Our clinicians and therapists partner with each patient to develop individualized care plans designed to help them achieve their goals. In this issue of Marianjoy Matters, we highlight several young patients who are working to attain greater levels of independence and success, through the use of innovative technology coupled with the expertise of our physicians and clinicians. These stories demonstrate the distinctive nature of every patient’s rehabilitation journey, and serve as examples of how the combination of technology and compassionate care can help patients reach their functional and personal goals.

All of us at Marianjoy are humbled and inspired by the strength of spirit and perseverance our patients show every day as they continue along their paths to recovery. We are blessed to be able to accompany our patients on their rehabilitation journeys as they reach for their personal goals.

Many Blessings,

Kathleen C. Yosko
President, Marianjoy Rehabilitation Hospital

Jeffrey Oken, MD
VP Medical Affairs, Marianjoy Rehabilitation Hospital

"I want water," says two-year-old Graysen. Though it’s common to hear a youngster this age ask for something to eat or drink, for Graysen, who is non-verbal due to cerebral palsy, it’s especially profound. He is using a new augmentative communication device with eye-gaze technology to make his needs known.

Augmentative or alternative communication (AAC) describes various methods of communication that can help both children and adults who are unable to use verbal speech to express themselves. With AAC, individuals can communicate their needs and wants, which allows them to participate more fully in their environment.

"Augmentative or alternative communication is any technology that enhances or takes the place of verbal expression," explains Rima Birutis, speech-language pathologist at Marianjoy Rehabilitation Hospital. "Augmentative communication can range from low-tech, to light-tech, to high-tech. It can start as simply as offering a choice of two items for selection with touch or eye-gaze. As soon as a person can express a preference, he or she is ready to start exploring augmentative communication."

For a child like Graysen, the display on the device is arranged so he can find the picture and the word quickly. By keeping the words in the same location, he is developing motor memory and building a vocabulary that will ultimately lead to literacy. The eye-gaze technology detects the reflection of light coming from Graysen’s eyes, which activates a computerized spoken response, further reinforcing and encouraging him to practice his own verbalization. To date, he can say the word “more,” along with several other words.

"Because of his spastic muscle tone, Graysen has to overcome his natural tendency to pull back his lips tensely while trying to say a word like ‘more.’ His determination and understanding of how pictures on a screen can express messages demonstrate to me that he is very bright. His communication and cognitive skills will advance quickly as he uses this technology. It’s possible that with this opportunity to experiment with communication, he may even catch up cognitively to other children his age," Rima says.

AAC benefits both children and adults. Some children are born with inherent weaknesses or conditions such as cerebral palsy, autism, or a learning disability. These conditions can make it difficult for them to verbalize. Later in life, adults may lose their ability to speak due to a stroke, brain injury, or neuromuscular disorder like ALS, Parkinson’s disease, or MS.

"Augmentative or alternative communication is any technology that enhances or takes the place of verbal expression."

Rima Birutis
Speech-Language Pathologist, Marianjoy Rehabilitation Hospital

Speech-Language Pathologist Rima Birutis helps Graysen to read a book, using AAC.

For Graysen, this technology will grow with him. As he makes a selection, a new computerized page opens where more options are available. “This provides him with the opportunity to learn new words and phrases while actively engaging with his environment,” Rima says. “He can use his motor and visual memory through this device to begin developing sentence structure, as well as more fully expressing himself socially or in a classroom.”

When asked what the future might hold for those who need AAC, Rima responds, “I see more people coming to Marianjoy, because it is a center of excellence. We connect people with the tools that can help open their world to communication.”

To learn more, go to www.Marianjoy.org/Assistive-Technology.aspx
A Gold-Medal Journey: Twins with Cerebral Palsy Spread Activism on Road to Paralympics

Alex and Amanda Malawski have been on some incredible journeys in their fifteen years: Amanda is in the final stage of track and field pre-trials for the Paralympics to be held in Rio de Janeiro this summer; and her brother, Alex, is using his writing and public speaking skills to spread the word about the games and its participants. Together, the two have become role models and advocates for all people with disabilities.

Though they are achieving amazing feats now, their mother, Lori, says she was terrified when the twins experienced strokes after being born 11 weeks prematurely. They spent 38 days in the neonatal intensive-care unit (NICU), where their physician determined they both experienced “bleeds” on their brains. Alex’s condition was more serious than his sister’s, and they experienced “bleeds” on their brains. Alex’s condition was more serious than his sister’s, and they experienced “bleeds” on their brains. The twins have also received serial casting at Marianjoy, which involves putting a tightened muscle area—usually an elbow, wrist, knee, or ankle—into a cast for one to six weeks. The plaster or fiberglass cast stretches out the affected muscle group and is a non-invasive alternative to surgery. The twins have also received Botox injections to alleviate tension in their muscles. “When children grow, that’s when they experience the most spasticity,” says Dr. Keen. “It’s important to keep them flexible and strong to ensure proper development. Dr. Keen has recognized their athletic aptitude and recommended they get involved in community sports. Starting with Fox Valley Special Recreation, the twins have become involved with various adaptive sports programs, including an annual triathlon. For the last seven years, they’ve competed regionally and nationally through the Great Lake Adaptive Sports Association (GLASA). Amanda began excelling so much as an athlete she qualified to pursue the Paralympics, the portion of the Olympics in which athletes with physical disabilities compete. Ever the proud brother, Alex has reached out to numerous organizations to spread the word about his sister’s involvement, the Paralympics themselves, and disability activism in general.

Alex and Amanda’s athletic experiences have complemented their academic experiences as well. “They have their moments when they’re down on themselves, when things are difficult, but I remind them that if they had more ‘normal’ lives, they wouldn’t have these extraordinary opportunities and experiences,” says Lori. “They wouldn’t be traveling the world, being role models for people overcoming any sort of challenge. I think that’s important for all children and teens with disabilities to remember. My advice to parents is to teach your kids to remove ‘can’t’ from their vocabulary.”

The Malawskis have also found support in their schools. “Cerebral palsy hasn’t really limited me, but I have needed some adaptations,” says Amanda. “Many are simple, like leaving class early so I don’t have to navigate crowded hallways. My teachers are really understanding, adapting things without my even needing to ask.” My teachers are really understanding, adapting things without my even needing to ask. I think they like learning how they can make classes more accessible as well.” Alex agrees, and his school has adjusted his individualized education plan (IEP) as his accommodation needs have changed. They’ve found strong support from their fellow students who treat Alex and Amanda like any other classmate. Both love to write and contribute to their school newspaper. Alex participates in drama classes, and Amanda serves on the student council, in addition to being active on the track team. “My friends are very supportive,” says Amanda. “They think it’s great I’m not letting cerebral palsy stop me from what I want to do or define who I am.”

They are very clear when it comes to recognizing how they’ve both come so far at such a young age. “Never give up; there’s always a light at the end of the tunnel,” says Alex. “Keep reaching for your goals, even if you have to figure out a different way to get there.” Amanda agrees: “You don’t know you can’t do something unless you try it,” she says. “It’s about your mental attitude of being your best at it and not taking ‘no’ for an answer.”

For more information about Marianjoy’s Pediatric Program, please call 630-905-PEDS (7337).
Marianjoy Foundation Celebrates the Hospital’s Dedicated Volunteers

Volunteer Appreciation Luncheon

Accepting the “2016 Volunteer of the Year” award, Don Van Gelderen discussed the first moment he felt a connection to Marianjoy that would lead to his volunteer service. Recovering from a stroke in 2013, he recalled a moment waiting for an elevator when a member of Marianjoy’s Buildings and Grounds Department bent down to tie Don’s shoe.

“This wasn’t a nurse or a therapist. It was a maintenance man. That’s when I first understood the caring spirit of Marianjoy,” Don told the audience.

Don was among the 80 volunteers who attended the Marianjoy Volunteer Appreciation Luncheon on April 12 at Cantigny Park’s Le Jardin restaurant. Held during National Volunteer Week, the luncheon is a celebration of Marianjoy Rehabilitation Hospital’s committed volunteers—from new volunteers in 2015 to those who have made contributions for over 30 years. Marianjoy Rehabilitation Hospital relies on the dedication of over 150 active volunteers, whose contributions make a difference for patients and families. Volunteers share their time and talents by staffing the hospital’s gift shop, transporting patients to therapy, supporting the mailroom, and more in 32 hospital departments.

In Remembrance

The Marianjoy family is saddened by the loss of four distinguished volunteers in the past year, whose contributions made a lasting difference in the lives of children and adults with disabilities.

Kendra Aulich

Contribution award over 4,000 hours of volunteer service to Marianjoy, Kendra became a familiar face to thousands of patients, visitors, and volunteers as a volunteer with the dietary department since 2003.

June Jobgen

For 13 years, June offered a cheerful welcome to Marianjoy patients and visitors at the reception desk.

Don Van Gelderen

After becoming connected to Marianjoy as a patient, Don returned as a volunteer, and for six years, he interviewed patients as part of the “Living History” program that helps caregivers get to know their patients.

Marianjoy Volunteers Matter

Volunteer Appreciation Luncheon


Marianjoy Scholarship Program Celebrates Major Milestone

Scholar Update: Lauren B.

With a little patience and perseverance, 2015 Marianjoy Scholar Lauren Bryant got into her “dream school,” the University of Illinois at Urbana-Champaign.

Lauren, who has a rare congenital bone disorder, spent two years at the College of DuPage while also transitioning to an independent living arrangement.

Next fall, she will be enrolled at the University of Illinois to pursue a degree in human resources.

“One of my biggest achievements is getting into U of I,” Lauren said. “It means being independent like every other young adult and showing everyone that I am capable of living on my own.” The University of Illinois is widely considered among the most disability-friendly universities in the world and was notably the first school to provide disability access to all university services, curricula, and facilities.


Join many of the area’s most prestigious philanthropists, business leaders, and loyal friends of Marianjoy for the 28th Annual Marianjoy Foundation Golf Invitational on June 20 at Cantigny Golf. This signature fundraising event has contributed over $1.5 million for the programs and services of Marianjoy Rehabilitation Hospital.

Guests will enjoy 18 holes of championship golf at Cantigny; a buffet lunch; unlimited snacks and beverages on the course; and the 19th Hole Cocktail Reception. The Marianjoy Foundation Golf Invitational is also supported by a robust silent auction, made possible by donations from generous donors and community businesses.

Celebrate your philanthropic spirit on the golf course with other Marianjoy supporters! Learn more about the 28th Annual Golf Invitational, including event details and sponsorship opportunities, at www.MarianjoyFoundation.org or by calling 630-909-7390.
ABOUT MARIANJOY  Marianjoy Rehabilitation Hospital is a state-of-the-art facility with 127 beds for inpatient and subacute rehabilitation care. Marianjoy offers inpatient rehabilitation programs in stroke; brain and spinal cord injury; musculoskeletal and neuromuscular disorders; and pediatrics. Our Wheaton campus features uniquely designed accessible gardens, a labyrinth, a chapel, and a meditation room. Marianjoy maintains an extensive network of inpatient, subacute, and outpatient sites, as well as physician clinics throughout the Chicagoland area and is now part of Northwestern Medicine.

Coming Soon!
Tellabs Center for Neurorehabilitation and Neuroplasticity

The future of rehabilitation technology is being created now at Marianjoy. Some of the latest advances will be found in the Tellabs Center for Neurorehabilitation and Neuroplasticity opening this fall.

For more information, go to Marianjoy.org.