

matheny**matters**

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Why
Technology
Matters



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Technology for All

Technology, which has become integral to every aspect of American life over the last 20 years, is the theme of this *Matheny Matters* issue. At this point in time, most of us are beyond imagining our work-lives, home-lives, healthcare, education, and leisure pursuits without the many devices we have come to depend on, and value.

Technology, of course, is a tool, not an end, and as such has been important in extending our reach as human beings and creating new opportunities. The same technology impacting the general population is also changing lives at Matheny in positive ways. Computers, iPads, a variety of communication systems, and power wheelchairs are just some of the technologies transforming Matheny life. However, most at Matheny also need assistive technology, such as adaptive switches, to access their devices. Those switches are also exceptional technological advances.

Most Matheny clients communicate quite independently using

their communication systems. Many carry iPads everywhere they go. Communication devices and a variety of alternative means of accessing those devices have opened up big new worlds of expression and engagement.

One of our Matheny therapists pointed out that Alexa—the voice-controlled virtual assistant that was launched in 2014—can be used “to coordinate the functioning of a whole home or apartment,” vastly increasing our clients’ independence. While some Matheny clients can use voice commands, others activate Alexa from their communication devices.

All types of new technology are employed at Matheny, including “button” switches that can be activated by an individual’s head, hand, knee or foot; sensor-type switches that are placed on the skin to detect bioelectrical signals over a muscle; and eye-gaze technology. These adapted switches, and others, make it possible for individuals with limited use of their arms and hands to use tech devices.

These new devices are truly incredible, but so are our compassionate and highly skilled employees, whose consistent dedication Matheny counts on and values every single day. We are also celebrating the 30th anniversary of Matheny’s Arts Access program and the 40th anniversary of The Friends of Matheny. Both have made long-term and heartfelt commitments to better the lives of our students, patients, and residents. Without them, Matheny would not be the outstanding organization it is—where everyone can use new technology, and every other means imaginable, to live richer and more fulfilling lives.

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On the cover: Matheny resident Emma Webster with Donna Kelly, Director, Occupational Therapy, Matheny Hospital. Photo by Keith B. Bratcher, Jr.



Two Big Awards to Arts Access

The New Jersey State Council on the Arts (NJSCA) announced in September a \$72,732 award to Matheny for its Arts Access program, celebrating its 30th anniversary this year.

The program provides opportunities for individuals with developmental disabilities from across the state to express themselves through fine art and help define themselves by their accomplishments, building self-confidence while developing artistic skills, as well as breaking down barriers by showing the abilities of participants.

“The support Matheny receives from the New Jersey State Council on the Arts makes it possible for us to continue providing these artists the opportunity to do what they love,” said Eileen Murray, the program’s director. Since 1999, the NJSCA has awarded nearly \$750,000 to Matheny’s arts program.

Matheny also received a \$10,000 award from Grants for Arts Projects (GAP), the National Endowment for the Arts’ largest grants program for organizations, to support *Full Circle 2023: Reemergence*, the Arts Access program’s showcase of its artists’ works. The well-attended event took place on November 4th in the Robert Schonhorn Arts Center on the Matheny campus.

PHOTOS: IVETH MOSQUERA

MATHENY 2023 GRADUATES

A Year of Achievement

The Matheny School held two 2023 graduation ceremonies—one marking the advancement of four 8th grade students to a high school curriculum and the second celebrating the completion of high school by four students. Matheny’s 2023 high school graduates have all moved on to Matheny’s Life Enrichment Program for adults.



Graduate Trinity Rastelli with teaching assistant Mulu Kassa and Bill Kent, President and CEO

The ABCs of Transportation Safety

On September 13th, Matheny School experts presented a Transportation Safety webinar for parents and caregivers to raise awareness of the importance of proper wheelchair transportation safety, educate on proper and improper wheelchair securement, and provide training based on best practices. You can access this life-saving information using the QR code above.



Back to School Night

On October 4th, The Matheny School held its first in-person Back-to-School Night in four years. Staff happily welcomed parents and caregivers to talk with them about the collaborative team approach for educating the students, providing them with a wide array of therapies, and building a safe and socially stimulating environment. Participants were happy to be “back to school” on Matheny’s Peapack campus.



Dancing the Night Away

In early fall, the Matheny community gathered with friends and family members for its Fall Formals. Everyone showed off their dance moves and Disney-themed outfits, and enjoyed the evenings of fun and togetherness.





No Sounds of Silence @ The Matheny School

Here come the students making their way down the hallways to their classrooms. Some move fast, others more slowly, a few stop then go. All are in wheelchairs and most are nonverbal, yet the school's corridors are filled with sound and movement.

This is The Matheny School in Peapack, NJ, where the sounds of silence are never welcome. Well, maybe after school-hours.

Silence is not a virtue here. Nor is sitting quietly in a classroom absorbing a teacher's lecture on geography, waiting for the bell to ring. In fact, while rules of conduct are certainly in place, they are anything but obvious. This school is clearly different from the traditional schools that most of us know.

Here it's all about learning to communicate your thoughts and needs, and learning the subject matter "your way." In late Spring 2024, 10 students will proudly graduate from The Matheny School in a well-attended ceremony. They will wear caps and gowns and listen to messages from the class valedictorian and salutatorian; and as they receive their

hard-earned diplomas, their families and friends will cheer. All students will have learned the primary lessons that their teachers and parents strive to impart—culminating in the graduates' readiness to move into their young adult lives. And in today's world, that means learning to use technology to function as independently as possible.

The Matheny School, which teaches children from pre-school through high school graduation, was established in 1946 by a husband and wife, both educators, to provide a stimulating and effective learning and living environment for children with a wide range of medically complex developmental disabilities. At the time, Marguerite and Walter Matheny could not find such a place for their son Chuck—born with cerebral palsy in 1941—who became the inspiration for the founding of The Matheny School, and its decades-long development into a renowned specialized school, hospital, and community-based group residences. Students here complete all State requirements to earn their diplomas, like their peers in traditional schools, but generally at a slower pace, graduating at age 21.

Here students are mostly nonverbal, and most learn to communicate using an augmented, or alternative, communication system, which will allow them to learn new skills and information, engage more fully in their own self-care, and to socialize with those in their everyday lives. After graduation, many continue to take classes, volunteer in the community, and follow their interests, including sports activities, painting and sculpting, singing in Matheny's chorus, and advocacy on behalf of those with developmental disabilities.

Some graduates even start small businesses, like Brad Goldman who launched an online greeting card company called Bradesigns, featuring his original artwork. Other graduates sell their original visual art pieces created through Matheny's Arts Access program as well as products, such as scarves, ties, jewelry and tote bags, featuring their art. Still others have written and published books of poetry and essays that are available for purchase.

Learning to communicate, and continuing to develop communication skills throughout their school years, is certainly the top priority for students here. That



Calendar & Weather

Month	October	Year	2023	Season	Fall	
Days	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

Today: Monday
Tomorrow: Tuesday

Today's Weather: Sunny
Tomorrow's Weather: Sunny

- R'anee
- William
- Kai
- Eleri
- Angel
- Emma

- Yoshin S.
- Trinity
- Al-Jarwan



Christine Mayercik (left) with student Patrick Conmy

While all students use communication devices with voice output, “we teach total communication—to use everything at the student’s disposal to help them get their message across. **The goal is for the children to communicate and to be understood.**”

CHRISTINE MAYERCIK
SENIOR SPEECH-LANGUAGE
PATHOLOGIST, THE MATHENY SCHOOL

means they must first understand, then learn to be proficient users of, communication devices.

Christine Mayercik, the school’s senior speech-language pathologist (there are four speech-language specialists in the school) and a specialist in augmentative communication and swallowing, is passionate about her life’s work. During her more than 21 years at The Matheny School, she has covered the whole gamut of age groups, working with pre-school age and kindergarten kids as well as students preparing to graduate and move on.

Of those graduating from The Matheny School in 2024, she says, “Lots have been here a long time. Right now, they are all going through a transition program during their senior high school year, which will help prepare them for this huge step.”

For new students, a large part of Mayercik’s focus is on assessing which communication device is best for each child, then working with the student to master the skills needed to use it fully.

“These devices used to be large, heavy, brick-like stand-alone pieces of equipment,” she explains. “Now they are small, light-weight, portable wireless devices that are durable and tough.”

Some students even use iPads with dedicated communication apps as their primary communication tool.

“The technology has really improved,” she says. “Our kids are mobile, moving from classroom to classroom or to therapy sessions during the day. They need a communication device that moves with them—light enough to be mounted on their wheelchair or mounted to a classroom chair. For those that are ambulatory, the device needs to be light enough to hold in their hands or in a backpack. The weight of these devices has gone from 11 pounds to 3.”

While all students use communication devices with voice output, “we teach total communication—to use everything at the student’s disposal to help them get their message across,” explains the speech-language pathologist. That may include vocalizations, eye gaze, facial expressions, body language, gestures, and sign language, in addition to augmentative communication devices.

“The goal is for the children to communicate and to be understood,” she says, “and each needs to learn a variety of skills to do that.”

When a new student starts at The Matheny School, there is an initial evaluation of their language and feeding skills, according to Mayercik. “Then we design a program to move forward. Our goal is to help them become more functional, more proficient, more independent.”

She points out that the goal is for the student to take the skills learned in therapy and then use these skills outside of therapy—in the classroom, at home, with caregivers and out in the community. The therapist also works with teachers and caregivers to help facilitate the student’s communication and ensure their success.

Students often get 90 minutes of therapy each week, but never less than 60 minutes per week, according to Mayercik. She also works with students to practice their skills in bimonthly language groups. Like traditional schools, Matheny issues quarterly reports, evaluating each student’s progress toward their individual goals.

Access to technology, like the technology itself, has vastly improved, making progress more attainable. “Many students cannot use a touchscreen,” she explains, “but scanning technology has made access easier, and Bluetooth technology has improved over the last 5 to 10 years, and has become more reliable and consistent. iPads rely on Bluetooth access.”

In fact, says Mayercik, tech has improved so much that “you turn it on and it’s ready to go. You just need to be able to push one switch or two.” Many students use “jelly bean” switches, which are big colorful buttons that are easy to push. She explains that there are so many different switches now that you can usually find whatever is needed to match the student’s motor skills.

When in the classroom, students “are bringing iPads in more,” she says, “although iPads are not always the best choice.” Dedicated communication devices with speech output work better for many students. Mayercik collaborates with a school occupational therapist to develop visual skills for using eye-gaze to connect with devices, and points out that this can be challenging since many students at the school have cortical visual impairments.

In her current job working with soon-to-be-graduates, Mayercik says her primary goal is “to set up each student with the appropriate technology before the student leaves here.” The equipment she uses most frequently with the students are speech-generating devices developed by PRC, including the Accent 1,000; assistive technology by Tobii Dynavox; NovaChat; and the Unity language system.

“We match the device to the client’s needs,” she says. The school team looks at “the portability of the device, the environment it will be used in, what the student can work with, where the device will be mounted, the price, as well as taking into account input from families and caregivers.” If the student resides at Matheny’s hospital, she will work with the hospital staff to determine what works best.

The watchwords with students are always to help them be “as independent and as functional as possible.” This year’s seniors, like those before them,



Above: Physical education teacher Kim Drost with Matheny School students



Left: Many Matheny School graduates continue to take classes, volunteer in the community, and follow their interests, from sports to painting to advocacy on behalf of those with developmental disabilities. Some have written and published books.

are participating in the PCAST (Person-Centered Approaches in Schools and Transition) program. “We help each one to prepare for post high school life by identifying their likes and dislikes, their needs, the activities and things that make them happy, and their hopes and plans for the future.”

The students each put together a booklet talking about themselves, which Mayercik calls, “the Cliff Notes on who

the student is. What technology the student uses is part of that, since technology is part of their daily lives.” As one of the school’s speech-language specialists, her focus is always communication, particularly as graduates take their next steps into their future.

Sean Murphy, principal of The Matheny School, says: “The seamless integration of technology into Matheny’s school and hospital has been a top priority for a long time. Matheny’s Tech Committee has been working together to achieve this for more than 20 years.”

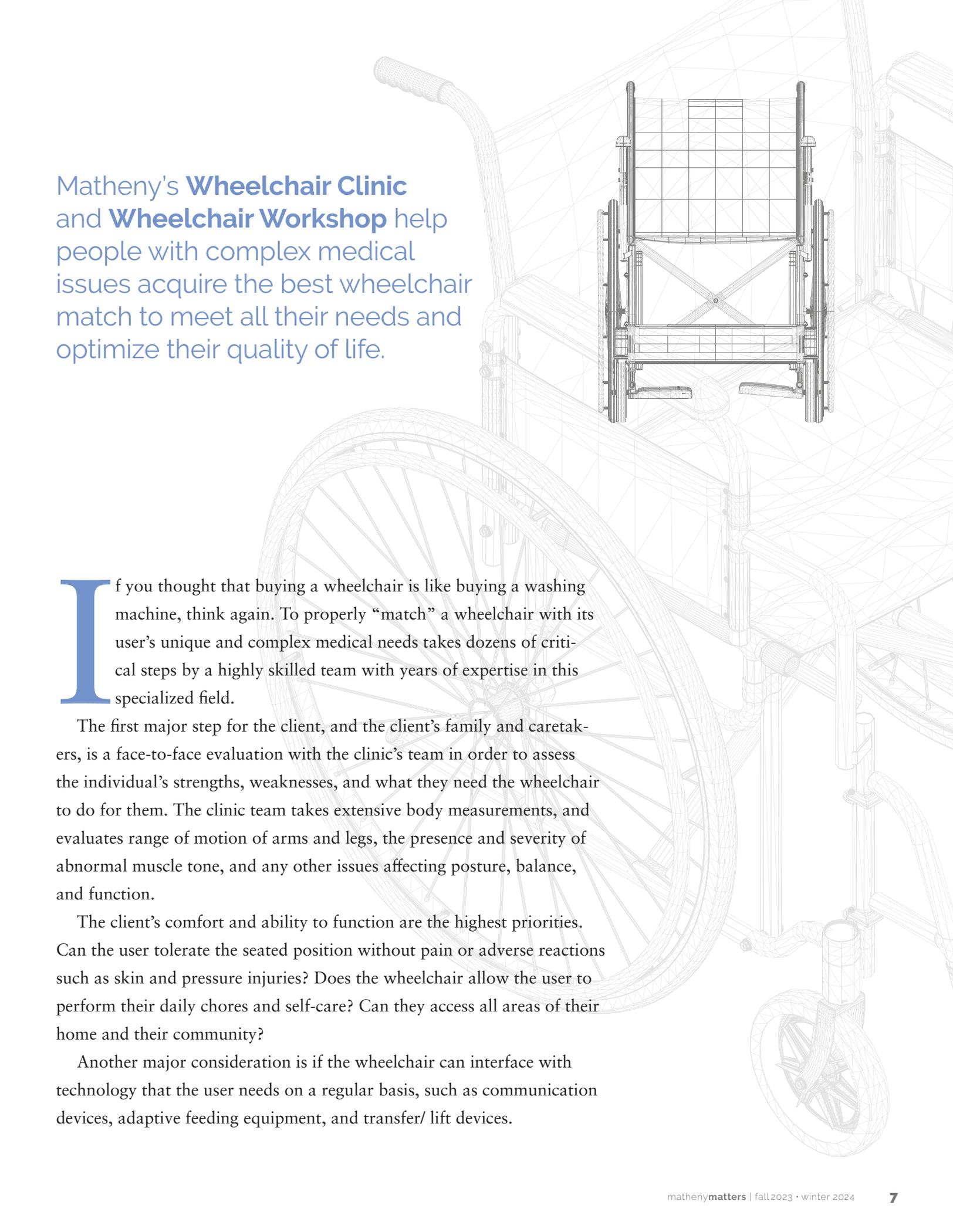
“Augmentative communication is a big part of that,” he continues, “so that when the students graduate from The Matheny School, and go out into the community, their voices go with them, and they will be heard.”

“Maximizing each student’s ability to communicate is a big part of what we do to maximize their independence, and that takes on even greater importance as they leave our school and enter adulthood.” **MM**



BUILDING A BEST-MATCH

Wheelchair



Matheny's **Wheelchair Clinic** and **Wheelchair Workshop** help people with complex medical issues acquire the best wheelchair match to meet all their needs and optimize their quality of life.

If you thought that buying a wheelchair is like buying a washing machine, think again. To properly “match” a wheelchair with its user’s unique and complex medical needs takes dozens of critical steps by a highly skilled team with years of expertise in this specialized field.

The first major step for the client, and the client’s family and caretakers, is a face-to-face evaluation with the clinic’s team in order to assess the individual’s strengths, weaknesses, and what they need the wheelchair to do for them. The clinic team takes extensive body measurements, and evaluates range of motion of arms and legs, the presence and severity of abnormal muscle tone, and any other issues affecting posture, balance, and function.

The client’s comfort and ability to function are the highest priorities. Can the user tolerate the seated position without pain or adverse reactions such as skin and pressure injuries? Does the wheelchair allow the user to perform their daily chores and self-care? Can they access all areas of their home and their community?

Another major consideration is if the wheelchair can interface with technology that the user needs on a regular basis, such as communication devices, adaptive feeding equipment, and transfer/ lift devices.



John Reck, Director Assistive Technology (center), and occupational therapists Maura Mirecki (l) and Kim Siara (r)

Welcome to the Matheny Wheelchair Clinic

Matheny's Wheelchair Clinic staff includes New Jersey licensed physical and occupational therapists: John Reck, long-time physical therapist and clinic director; and Maura Mirecki and Kimberly Siara, staff occupational therapists. All three are certified as Assistive Technology Practitioners (ATPs) through the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA). All clinic staff take continuing education courses regularly to keep up with changes in this highly specialized

field. The therapists work very closely with the wheelchair suppliers, who are responsible for selling and repairing the wheelchair equipment.

Gait trainers, shower commodes and tub chairs, mechanical transfer aides and lifting devices, and supported standing and other adaptive positioning devices are among the other equipment that the clinic can provide.

Cerebral palsy and spina bifida are two common primary diagnoses of Matheny's residents and students. Other less common diagnoses include genetic disorders such as Lesch Nyhan Disease (LND,) Rett syndrome, Angelman syndrome, Cornelia

De Lange syndrome, Wolf-Hirshorn syndrome and 4Q Deletion syndrome. These disorders may cause difficulties with muscle control, impact balance and the ability to maintain an upright posture, and can affect mental capacity and verbal communication. All of these need to be taken into consideration when matching a client with a wheelchair.

The Wheelchair Clinic also serves outpatients throughout New Jersey, including children and adults who have a neurological impairment from birth, disease, or trauma, such as stroke, or a traumatic brain injury that significantly affects their mobility and their posture when sitting.

Maximizing Independence and Special Abilities

There are many choices to be made by and for each client; and clients and their families and caretakers are at the center of all decisions and recommendations. "We set goals to maximize the client's function and health, and we work with the clients and families to identify and execute these goals," says Reck.

The wheelchair clinic stocks all kinds of demo equipment. The demo products allow the client to check sizing and to try out different types of wheelchairs, seat cushions, postural supports, and other adaptive equipment.

"After completing our assessments, the team will recommend certain products for the client to try," explains Mirecki. "The tryout helps determine what works best for the client before making a final decision to purchase." Demo trials, seating simulations, and training, for not only the client, but family and caregivers as well, are critical to a successful outcome.

Trunk support tops the list of considerations when designing a safe wheelchair. Postural deviations, length of the client's trunk, and width of the chest and hips are all part of the equation. "The goal is to identify the simplest item to meet the individual's needs, then go to more customization, when necessary," says Mirecki.

The Matheny team often designs and fabricates unique custom wheelchair parts. For instance, a patient with dystonia, which can cause legs and feet to move uncontrollably, might benefit from a custom foot-box manufactured in Matheny's Rehab Tech department, which would allow the feet to move freely, but still protect them from injury.

For those at risk for pressure ulcers, the clinic has a highly specialized "pressure mapping system" to identify at-risk areas of the body and to assist in product selection and optimal positioning needed for skin protection. Pressure injuries related to sitting can be very debilitating, and the best approach is to start with preventative strategies and interventions.

"For complex power wheelchairs we need to assess if the patient can access the controls needed to do all the things the power chair can do," says Mirecki. "For example, while some clients may have use of their hands and can operate a power wheelchair with a standard joystick control, others without good hand control may require alternative controls, such as a headrest switch system with embedded sensors activated by head movements."

Regardless of how you operate the power wheelchair, "Safety comes first," says Siara. "Can someone slow down, when necessary, maneuver around objects and people, change direction safely, determine when to stop? Access, safety, and consistency are all top concerns."

"Sometimes we recommend extended training for power mobility," says Siara. "We can recommend training on-site or where the client lives."

"Our assessments for complex rehab equipment reflect our therapists' extensive experience in this specialty," she continues. "It may take two or three visits to complete the evaluation and make recommendations; and another one to three visits at the end, when the recommended wheelchair is ready-to-go. Training to use the equipment safely and effectively is an integral part of the process."

"Everyone benefits when new technology for wheelchairs and assistive devices becomes more available, safer, and easier to use," says Reck.



Members of the Wheelchair Workshop team (l-r) back row: Tizazu Alamrew, Ed Muraski, Darrell Jones, Bill Seavey; front row: Sue Baumann, Christine Whitworth. Team members not shown: Sharon Brooks, Diane Converse, Patrick McCarthy, Karen Zaleski, and Jefferson Francisco

Welcome to the Matheny Wheelchair Workshop

When the "optimal" wheelchair cannot be created from ready-made parts, then uniquely crafted components are designed and fabricated in Matheny's Rehabilitation Technology Department.

Sue Baumann, long-time physical therapist and certified assistive technology professional (ATP), leads the 10-person Rehab Tech department, which does onsite repairs and custom fabrication of equipment components for wheelchairs and other durable medical equipment.

"We order the equipment recommended by the Wheelchair Clinic, put it together, make custom modifications, and make sure it fits as recommended," she says. "We collaborate with the team closely on all aspects."

It's in the workshop that technicians actually build the chair and upholster it, she explains. "We are our own durable medical equipment company. Everybody is hands on." The Rehab Technology Department consists of the suppliers who attend the clinics, the coordinator who works with the clients to obtain all the medical documentation required, and

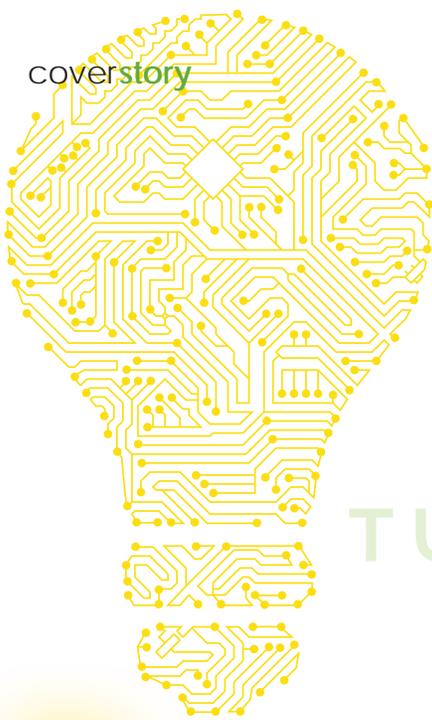
the technicians. The department provides services to Matheny's inpatients and outpatients through the Wheelchair Clinic, and also to various other facilities.

For the vast majority of Matheny's inpatients, most changes to manual wheelchairs within the past five years have been "low tech," such as improved fabrics used for custom fabrication, according to Baumann. "Improved fabrics mean better hygiene and comfort, more breathability, and greater affordability," she explains, "and can also enhance the client's positioning and safety."

Another advancement for manual wheelchairs is power assist technology. The power assist attachment for manual wheelchairs can turn a manual wheelchair into a power operated vehicle. These attachments are now smaller, lighter, and more portable.

For custom seating, the suppliers assist with the custom molding process and scan the image to send to the manufacturer for the fabrication of customized seating components. "The department's high-end molding machine adjusts electronically and can fine-tune seat cushions and back supports to wrap more comfortably

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TURNING THE SWITCH

Therapists are essential players on the Matheny team. An enormous amount of interdisciplinary teamwork and patience is needed to assess a client's ability to use any assistive technology. Therapists assess patients and then train the user, the caregivers, and the family how to use the technology in all settings of their daily lives.

Rapid advances in technology are positively impacting the lives of those with developmental disabilities who have physical and cognitive difficulties affecting their ability to access communication, leisure, and mobility devices. Matheny is a testing site for some of the newest advances in the burgeoning field of assistive technology.

“The goal is always greater independence,” says Cindy LaBar, Senior Clinical Director of Rehabilitation Services at Matheny’s hospital and group homes, whose 17-year-old daughter has developmental disabilities and medical complexities. While LaBar’s three children are all proficient technology users, she points out that, ironically, restricting time spent on electronic devices is sometimes a battle with her two sons, but the greater use of electronics by her daughter, who is nonverbal and has impaired mobility, is always 100 percent-supported by all members of her family.

“The communication device my daughter uses, Proloquo2Go, allows her to express her feelings more fully, including her sense of humor,” says LaBar, a physical therapist who has been practicing in the field for more than 20 years. Proloquo2Go is a “high tech” communication device that is programmed with more than 10,000 words.

“My daughter can now initiate conversations, rhyme words, get her point across. It’s been incredibly empowering. She has the ability to engage with her world—it has changed her life, and ours,”

LaBar says. “She has the ability to say ‘whatever,’ like any other 17-year-old. She can also tell me, ‘I love you,’ words I would not otherwise ever have been able to hear from her.”

Therapists are essential players on the Matheny team. “It takes an enormous amount of interdisciplinary teamwork and patience to assess the client’s ability to use any assistive technology. Therapists spend time assessing patients and then training the user, the caregivers, and the family how to use the technology in all settings of their daily lives,” says LaBar.

“I’m fortunate to be part of a team with so many talented clinicians and staff, who do amazing work every day for our clients. I’m inspired by their creativity and drive to continue to learn more, bringing the most current technology to our clients. Our team allows clients the opportunity to be as independent as possible, and engage fully with the world around them.”

Donna Kelly, an occupational therapist who holds a Master’s degree from NYU in assistive technology and is Director of the Occupational Therapy Department at Matheny’s Hospital, says that whether the new technology is a simple adaptation or a brand-new device, the “goal is always the same—to help our patients become more independent.” Kelly has almost 40 years of experience in the field, many at Matheny. She was also Director of Occupational Therapy at Children’s Specialized Hospital for 10 years and teaches a class on assistive technology each year at Mercy College.

“Technology that becomes available to the general population also impacts the disability community,” she continues. “Our patients use iPads, computers, various communication systems, and can access their equipment with assistive technology.”

She points to Amazon’s Alexa—the voice-controlled digital assistant that takes words and converts them into actions—as the new assistive technology star of the last five years. “It’s possible to coordinate the functioning of a whole home or apartment using Alexa,” she says. “A few of our clients can use voice commands, but patients can also activate Alexa from any of their communication devices.”

If an individual cannot access technology devices using “direct selection,” such as typing with their hands or using a joystick, we evaluate them for alternative access. Adaptive “switches,” electronic buttons that can be positioned wherever the individual has a controlled movement in their body, allow access to assistive technology devices, including iPads, communication aids, environmental controls, computer software, mobile devices, and power wheelchair mobility.

One of the most commonly used switches at Matheny is a “button” switch. The individual with motor control limitations activates the switch using their head, hand, knee, or foot to engage in activities or utilize communication or leisure devices. Other individuals may need a sensor type switch, which is placed on the skin over the muscle chosen to be the access point, according to Kelly. When someone



ON



moves that muscle, the device detects bioelectrical signals, and these signals allow the user to operate a computer, tablet, and other equipment. Another form of technology that uses more direct access is the “head mouse,” which translates movements of the head into the computer cursor.

Occupational therapists also work with individuals to use eye-gaze technology, which has vastly broadened the scope of possibilities for persons with neuromuscular restrictions. “Eye-gaze technology allows your eyes to do everything a mouse does,” Kelly explains, “but it can be exhausting for some individuals.” Speech recognition is another avenue for individuals, who can access their devices via voice control.

One of the more amazing devices is Tecla-e, “an assistive device that interfaces switches with high technology devices using blue tooth technology to control your whole world,” explains the occupational therapist.

“It’s incredible. Anyone who can control one muscle movement—a finger, the head, a leg or a muscle in any part of the body—can use it.” With the Tecla-e, a patient can send and receive emails and text messages, browse the Web, watch videos, launch and use apps, read books, turn on the TV, control the thermostat, turn the lights on and off, make (or hang up) phone calls, and enter commands using Siri.

How does it work? A sensor is placed on the skin over the muscle chosen to be the switch, according to Kelly. When someone moves that muscle, the device detects bioelectrical signals, and these signals allow the user to operate a computer, tablet, and other equipment.

There are also low technology adaptations that can make a big difference. “We make splints using thermoplastic material molded to a patient’s hand to make it possible for them to hold a pen, marker, paintbrush, or stylus,” says Kelly. “We also teach clients to use adapted keyboards with keyguards—so they don’t hit more than one key at a time.”

Kelly and her team are part of the current movement to create new quality of life products with the use of new technologies. They are working with engineering students from Raritan Valley College to develop “adapted computer games appropriate for our population. Leisure activities are a major part of individuals’ lives, especially as they get older. However, the disabled population has difficulty accessing typical computer games,” she explains. Raritan Valley College students have also worked on mobility technology for visually impaired individuals.

The occupational therapy department is also working on setting up a 3-D printer for fabrication of products for prevocational sale, and to make hand splints to attempt to keep patients’ hands open who have hand-contractures.

Getting the Message Across

Roughly 19 percent of the American population has disabilities impacting their mobility and communication. Recent technological advances promise new products to improve their quality of life.

Jackie Jardim, Director of Speech Therapy, started as a speech language pathology intern at Matheny 14 years ago and never left. She finds her position—leading a team of speech therapists who customize individual systems to establish a way for every client to communicate—to be extremely satisfying.

Many Matheny clients are nonverbal, while others speak but can be difficult to understand. Speech therapists work closely with the interdisciplinary team to evaluate the clients’ capabilities and postural supports, and assess which communication device fits their needs best, then teach them to use the device effectively. This can involve building skills over an extended period of time, according to Jardim.

She particularly values Matheny’s teamwork approach paired with its residential aspect, which fosters an atmosphere where clients live, learn, and participate in structured activities on site, allowing the same therapy team to follow and support them 24–7.

Communication devices range from “low-tech” boards, which can be programmed with a few messages, or a number of pictures and symbols to express messages, to “high tech” electronic equipment that offers hundreds, even thousands, of words and phrases to express complex thoughts and emotions. The Go Talk 4, a device commonly used at Matheny, is picture-based and has a 22-message capacity that is programmed on site, she says, allowing therapists to work with clients to expand their language skills and achieve more independence. Proloquo2go—at the high-tech end—is a communication application for the iPad and iPhone.



(l-r) Shannon Jones, physical therapy aide with patient Hamareeha Ibrahim and physical therapist Jill Budd

Jardim says that learning to use communication systems is often challenging for clients, and can be a gradual process. Assessing an individual's capabilities, and then choosing and helping the client learn to use the appropriate device, are among the primary responsibilities of Matheny's speech therapists.

Some clients touch an icon on a screen to express a thought, others use eye gaze, which Jardim says "can be very tiring and takes a lot of practice to master. You have



to have the ability to understand how the device works and you need to develop vision skills."

She explains that when learning how to use eye gaze, clients usually start by focusing on real objects, then move to picture symbols as they gain skills. "The client starts on a page with a few icons and then gradually increases the number of icons," she says. "The client's eyes control a mouse on the screen. They can stare at an icon for a certain amount of time or blink to activate it."

"We started eye gaze at Matheny years ago, but the Neuronode, which picks up movement or electrical signals from a muscle, is the newer technology that we are using as an evaluation tool to identify the best access method for

communication, mindful of the individual's unique skills," she says.

Like EMG, it recognizes a small electrical impulse made by the movement of just one muscle anywhere in the body—and transmits the impulse to a device as a command. "This takes a long time to learn," she says, "and is not widely in use. It's also very expensive."

"While not all clients can use all devices, our goal is always to find what gives the client the most independence."

"Our team allows clients the opportunity to be as independent as possible, and engage fully with the world around them."

CINDY LABAR
SENIOR CLINICAL DIRECTOR
OF REHABILITATION SERVICES
AT MATHENY'S HOSPITAL AND
GROUP HOMES

"Our Matheny therapists are highly specialized in augmentative communication and have a great deal of expertise in communication devices. They often have access to special communication devices that school districts may not have," Jardim says.

"Most Matheny clients are independent users of communication devices, and many carry their iPads everywhere they go," she continues. "Whether they use a low tech or higher tech device, most are able to communicate pretty independently. That's the success we work for."

While communication is at the root of this specialty, speech therapy also addresses some lesser-known issues such as dysphagia or difficulty swallowing; the use of G-tubes to deliver nutrition,

hydration, and medications directly to the stomach; audiological services; and oral healthcare.

The Colgate Hum—which has been in use at Matheny for two years—is a "smart" toothbrush that collects information on the user's brushing, assesses it and subsequently makes recommendations for improvements. "It's a really cool higher tech tool," says Jardim. "In this case it is the caregiver who does the toothbrushing so we use it as an educational tool to improve the client's oral healthcare."

Matheny Director of Physical Therapy Lisa Bauman says physical therapy (PT) equipment has not been as highly impacted by new technology. Most of the types of mobility equipment currently in use have remained the same, she says, with new features and materials that make them more comfortable and easier to use.

After 23 years working at Matheny, she is still hands on—in addition to overseeing the department. "Each day is different," she observes.

Matheny's physical therapists concentrate on positioning patients safely and comfortably in wheelchairs—in the most upright position possible—for their day's activities; and also positioning patients safely and comfortably in bed so they can "get the rest they need while protecting their skin," she says.

Bauman explains that the physical therapists also provide patients with opportunities for movement out of their wheelchairs—to stretch out on a beanbag, walk in a gait trainer, ride an adapted tricycle, and swim in the very popular Matheny pool.

"In our specialty, most of the types of equipment have stayed the same—with some features changing over time," says Bauman. "New designs and new materials have made our mobility equipment more durable, more comfortable for the patients, and much easier to use and adjust."

"But what always remains the same is the teamwork—the different perspectives of different professions coming together. All therapies work together here on a continuing basis, which means patients will learn to do more for themselves over time." **MM**

When Breathing's Not Easy



Jair Martinez, Respiratory Therapy Manager (left) with Senior Respiratory Therapist Elizabeth Ensminger

For most, breathing comes easy from the day they're born. But for some, breathing problems are chronic, persistent, and even life-threatening. More than 25 million people in the U.S. have asthma—the most common respiratory disorder. Chronic obstructive pulmonary disease (COPD), chronic bronchitis, and pneumonia can have long-range effects and sometimes shorten life.

Respiratory therapist Elizabeth Ensminger earned a Bachelor of Science degree in Finance and Managerial Sciences, then was inspired to make a switch into healthcare years later. “I had an older brother who had bad asthma attacks,” she says. “Seeing how hard he sometimes struggled to breathe made me want to learn how to help.”

So, she did, by going back to school to complete a two-year program in respiratory therapy, including clinical rotations at Children's Specialized Hospital, Overlook Medical Center, St. Peter's University Hospital, and Elizabeth General Hospital. She joined the Matheny Hospital staff in 2009, and still has a passion for her profession and also specifically for working at Matheny Hospital. “I have a special needs child—my older son,” she says. “I feel very comfortable working with special needs patients.”

Responding to respiratory emergencies,

and providing the everyday breathing therapies that some patients require, are a big part of the respiratory therapy department's job re-

“I had an older brother who had bad asthma attacks,” she says. “Seeing how hard he sometimes struggled to breathe made me want to learn how to help.”

ELIZABETH ENSMINGER
RESPIRATORY
THERAPIST



sponsibilities at Matheny. Right now, 21 of the hospital's 101 patients require this therapy on a daily basis.

“Patients with cerebral palsy—a primary diagnosis at Matheny—are prone to dysphagia, a swallowing disorder caused

when muscles in the throat and esophagus don't function normally,” Ensminger explains. “This can let food and drink go into the trachea when they swallow, and sometimes leads to aspiration pneumonia, which can be deadly.”

Respiratory disorders are a leading cause of death among people with developmental disabilities. So, heading off infections is always a primary focus of Matheny's respiratory therapists. “Because we know our patients so well, we are quick to recognize changes in the patient—even small ones—and we move in right away to stop the infection from taking hold.”

Respiratory therapists are integral to the increasing longevity of Matheny's patients, and to their ability to engage in so many active pursuits, from adapted sports to trips off campus, which so many can now count on as part of their day-to-day lives.

Among Ensminger's favorite responsibilities during her three-year stint as director of the department from 2020 to 2023 was teaching the CPR course to hospital staff—in order for them to keep their certification current. “I love teaching,” she says.

She was also in charge of the N95 (mask) fit-testing program, ensuring that

every staff member is properly protected from airborne infectious agents. “Not every N95 is the same,” she explains. “We need to find out which mask fits each person’s face best.” She also headed up the CODE Committee, which periodically reviews the department’s response to emergencies, and its emergency equipment, to determine which improvements, if any, need to be made.

In 2023, she retired from her Matheny position, but is still working hands-on as a respiratory therapist on a per diem basis. Among the tools in her respiratory therapist toolkit are “nebulizers, chest physical therapy, CPAP (Continuous Positive Expiratory Pressure), BiPAP (Bilevel positive airway pressure, a machine that delivers air through a mask on your face), and mechanical ventilation,” as well as a new piece of equipment she finds impressive.

“It’s the Volara System, which forces a patient’s lungs to expand and airways to open, dislodges mucus, and makes it easier to cough out; and delivers medication into the lungs, helping the patient breathe with less effort,” she explains. “I’ve seen some good results.”

Increased recognition of the link between dysphagia and pneumonia by respiratory therapists has been critical to identifying patients with respiratory infections earlier. When COVID-19 struck, Matheny’s healthcare workers were worried that their patients would be at higher risk of death. In general, says Ensminger, “Matheny’s patients pulled through COVID better than expected due to Matheny’s strict infection control protocol and because the clinicians quickly noticed even small changes of any status deterioration, prompting immediate intervention to prevent life threatening complications for most.”

When Ensminger began her career as a respiratory therapist, “I only expected to be hands-on for 10 years, then move into management,” she says. “But it’s so rewarding. You know that you’re making a difference—you can’t beat that feeling. I would absolutely recommend this profession to anyone considering healthcare—and there’s a real shortage of respiratory therapists now. There are a lot of openings.” **MM**

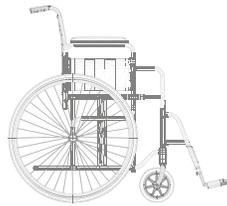
Best-Match Wheelchair

continued from page 9

around a client’s body,” Baumann explains.

“What’s really new and attention grabbing are the electronics for power wheelchairs,” she states. Switches that control complex multi-level positioning of the chair itself, such as the ability to change seat elevation; electronics that have pre-programmed custom sequenced positioning; and switches that control communication and other devices top the list of high-tech electronics.

“The evolution of iPads and speech-communication devices has also necessitated new holder-mounts. Many wheelchair users—including Matheny School students—need holders that secure their



“It’s in the workshop that technicians actually build the wheelchair and upholster it. We are our own durable medical equipment company. Everybody is hands on.”

SUE BAUMANN
DIRECTOR
MATHENY WHEELCHAIR WORKSHOP

devices to the wheelchair or wheelchair’s lap tray,” she says. “The mounts are evolving as the communication devices change.”

“We also work with the therapists and clients on positioning of switches,” she continues. “This is all done on site in our inhouse shop. It’s a unique opportunity we have—the ability to do all of this.”

DETAILS AND DEFINITIONS

Complex Rehab Technology (CRT) products include medically necessary, individually configured devices that require evaluation, configuration, fitting, adjustment or programming. These products and services are designed to meet the specific and unique medical, physical, and functional needs of an individual with a primary diagnosis resulting from a congenital disorder, progressive or degenerative neuromuscular disease, or from certain types of injury or trauma. CRT can refer to individually configured manual wheelchair systems, power wheelchair systems, seating and positioning systems, and other adaptive equipment such as standing devices and gait trainers (*Citation from National Coalition for Assistive and Rehab Technology; NCART*)

Another new and exciting development is creating wheelchair components, seating systems, and other custom items with 3D printing, she states. “3D printing technology could allow for more tailoring of wheelchairs and parts to the person in the wheelchair.”

What does the future promise?

“Heading the list are power wheelchair safety accessories—like safety alerts and accident avoidance for cars—that alert clients to curbs, inclines, and other tipping dangers, as well as obstacles in a wheelchair user’s path, and avoidance features that prevent collisions or drop-off events before they happen,” Baumann says. “The safety of wheelchair users—who risk collisions and tipping over in their everyday activities—is always a major priority.” **MM**

This Art Needs No Words

Celebrating 30 Years of Amazing Art

It was 1993—a time when adults with developmental disabilities were still generally thought incapable of expressing independent thought and creativity. But there were those who believed otherwise—among them Matheny’s then-President Robert Schonhorn and Medical Director Gabor Barabas. They shared a belief that those with complex developmental disabilities—many of them nonverbal and with very limited mobility—could create art if provided with alternative means of expression.

But what could be done to make this happen? First, they dealt with the practi-

“The client makes all the choices; the facilitator is neutral—with no preconceptions of what the artist creates and does not judge it in any way.”

EILEEN MURRAY
DIRECTOR, ARTS ACCESS

calities by applying for funding for a pilot arts program at Matheny, and won a generous grant of \$35,000 from the Blanche and Irving Laurie Foundation.

With the funds, they put an ingenious system in place whereby professional artists would act as facilitators for individuals with severe disabilities who wanted to create visual art but were not able to use their arms and hands to do so. This system proved hugely successful—and it has been further developed and finessed over many years.

Arts Access Program Director Eileen Murray has been asked many times to

explain the process: “The clients are primarily adults with complex disabilities, who may use wheelchairs for their mobility, have limited range of motion, and are often nonverbal. They need a conduit to enable them to paint on canvas, put words on the page, or dance on stage. Many clients have communication challenges, so they provide directives to the facilitators, who are all artists, primarily through eye movements, head motions, or communications devices. The facilitator asks questions in a yes or no format, and the client responds.

“The client makes all the choices; the facilitator is neutral—with no preconceptions of what the artist creates and does not judge it in any way.”

What started as a visual arts program in 1993 was adapted and expanded to include digital art in 2001, digital sculpture in 2006, a full-fledged dance and drama program in 2008, and creative writing in 2010. Many have participated in the Matheny Arts Access program for years, even decades, and have found deep satisfaction and a means of expression not available to them before. And the creative work—speaking to the world about experiences, thoughts, and feelings that no one had begun to imagine before—has been appreciated and praised by many.

As part of its 30th anniversary celebration, the program’s participants and supporters were asked to name the most memorable Arts Access painting exhibits across the decades. The Art of Choice at Sotheby’s in 2019 was voted number 1; the ABC World Headquarters Exhibit in Manhattan number 2; and Reflections at Grounds for Sculpture in 2014 and the Winter Blues Virtual Exhibit in 2022 tied for third place.

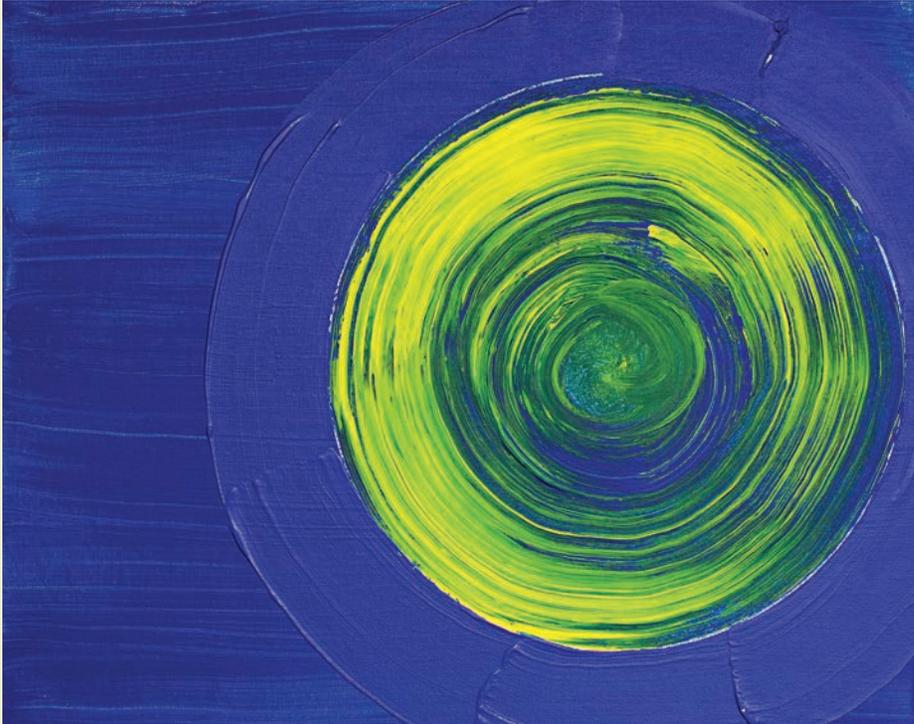
Without further words, we present a few artworks from these exhibits. We wish there was space to show all of them. **MM**



Title: *Untitled*
Artist: J Lane



Title: *Romantic Love*
Artist: J Evans



Title: *Untitled*
Artist: N Soto



Title: *Untitled*
Artist: E Kane

Happy 40th to the
Friends
of Matheny



When we think about the exponential growth of technology in our world over the last few years, it's not likely that a volunteer group that took root back in 1983 comes to mind. But it should.

The Friends of Matheny, founded 40 years ago, has raised almost \$4 million for Matheny since its inception—a staggering amount for a small group that always thinks big.

First a little history. While “The Friends” is currently comprised of close to 100 dedicated volunteers, there were just 15 in the 1980s who launched its ongoing, highly lucrative Second Chance Thrift Shop. That’s when Jean Wadsworth—The Friends’ longest serving volunteer, celebrating 38 years and counting—joined the group. She helped guide and build The Friends as a past president and as a member of its Board of Directors for many years.

Another long-term member, Linda Horton, headed up the Second Chance Thrift Shop for 25 years before retiring from that post in 2020. She joined The Friends in 1989, immediately started working in the thrift shop, and became its manager in the mid-1990s.

With hard work and intelligent direction, the shop thrived, and, along with various galas and other fundraisers, has been the source of most of the donated funds. But as Matheny grew, so did its needs and the cost of fulfilling those needs. The Friends never flinched, but set their fund-raising goals higher and dedicated whatever number of hours were needed to get the job done. Everyone pulled in the same direction.

So, what does technology have to do with The Friends of Matheny? The answer will stare you in the face if you take a casual walk through The Matheny School and Matheny Hospital, and the Adult Learning Centers and community residences.

Smart Tables and Smart Boards are an integral part of classroom learning. Students and residents use communication devices with voice output throughout the day. Computers and iPads with individualized switch access have become



(l-r) Current and former Friends of Matheny presidents Liz Geraghty, Gail Cunningham (staff liaison), Karen Thompson, Debi DeLorenzo, Dorothy Carpenter, Jean Wadsworth, and Linda Horton

commonplace in the school, Adult Learning Center, and group homes. There are several 3D printers in current use at Matheny. All of these, and more, have been purchased with funds from The Friends’ allocations.

A wheelchair washing machine; adaptive sports equipment; a five-day excursion to Disney for several students and their care providers; a kiln; the swimming pool as well as the system for getting swimmers into and out of the water safely, and a large canopy to shelter them from the sun; musical instruments and choir robes; Rocky the therapy horse; and tickets to major league sports events and live theater are just a few of the many other purchases made by The Friends to benefit Matheny’s kids and adults. The Friends also wrap hundreds of holiday gifts; and they provide refreshments after the Halloween parade, at the annual Miles for Matheny event, and after The Matheny School’s graduation ceremony; and sponsor a Staff Appreciation Day.

Like Rumpelstiltskin’s ability to weave straw into gold, The Friends take donated treasures that are no longer needed or wanted, and with a seeming magic touch, turn them into dollars for Matheny. A wish list submitted each year by staff

members alerts the volunteers to what is needed to enhance the everyday lives of Matheny’s residents and students; and The Friends try to fulfill every one of those wishes each year. This year’s requests include technology items and some things that are just pure fun. This highly effective form of recycling is also good business. Thrift shop sales generate more than \$100,000 each year.

Gail Cunningham, Matheny’s Public Relations and Volunteer Coordinator, is the link between The Friends and Matheny. “It has been my pleasure to assist The Friends with all of the many things they do for Matheny. During the 23 years that I’ve been lucky enough to be part of The Friends, I’ve been continually amazed by the overwhelming generosity and dedication of this wonderful group.”

On October 10th, The Friends of Matheny gathered to celebrate their 40th anniversary and to introduce new friends to their mission. Let’s hope they continue their work and their generosity for many years to come. **MM**

The Honor Roll of Donors

Individuals, corporations, organizations, and foundations generously helped support every aspect of life at Matheny during Fiscal Year 2023.

Because of our donors' compassion and support of Matheny's mission, the lives of hundreds of students, patients, residents, as well as their families and friends have been enriched in so many ways. We thank all contributors for their extraordinary generosity.

This donor list includes gifts received between July 1, 2022 and June 30, 2023.

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Matheny welcomed esteemed Hyde and Watson Foundation leaders, Bernie Moriarty and Bill Engel. Mr. Engel also represents the Union Foundation and EJ Grassmann Trust.



The Summit Foundation's President, Dana Turk, second from right, observes a Matheny Arts Access facilitation session with artist Paul Santo.

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A special thanks to all of our donors who wish to remain anonymous

A LOOK BACK

Pioneers in Research and Innovation

Research moves knowledge forward; and over the years, Matheny has made notable research contributions that have improved the healthcare, as well as mental health and general quality of life, of those with medically complex developmental disabilities. The aim of this research has always been to make life better for these individuals and their families. Also, by helping to educate a broad spectrum of students and interns training in the healthcare professions, Matheny helps to ensure that its expertise in this field is far-reaching, well beyond the bounds of its own campus.

A LITTLE BIT OF HISTORY

In the early 1990s, Matheny founded The Matheny Institute for Research in Developmental Disabilities to advance studies related to developmental disabilities. The Institute was renowned for its work on Lesch-Nyhan disease (LND), a rare genetic disorder causing an overproduction of uric acid, and neurological, cognitive, and behavioral disturbances. Dr. William Nyhan, who discovered LND with Dr. Michael Lesch, was the keynote speaker at the first-ever LND conference, hosted by Matheny on its campus in 1994. While the Institute is no longer an entity, Matheny's research continues to be well-received, and cited, by professionals in this field.

MATHENY'S RESEARCH LEADER

Dr. Kenneth Robey served as Director of Matheny's Research Institute for more than 20 years, and during his 29 years at Matheny has published often-cited research in the field of developmental disabilities. He now works with other members of the quality improvement and patient safety department to improve care for Matheny's patients and residents. Robey was founding President and a



with developmental disabilities, who often experience disparities in health outcomes beyond those caused by their primary disabling conditions.

Matheny has provided training experiences for: medical students from Rutgers

New Jersey Medical School; residents from Morristown Medical Center; nursing students from Raritan Valley and Passaic County Community Colleges, Seton Hall University, and Somerset County and Union County Vocational Technical High Schools; occupational, physical, speech, music and recreation therapy interns from 32 U.S. colleges and universities; social work interns from several universities; and biomedical engineering students from Rutgers School of Engineering. Beyond training provided at Matheny for healthcare professionals, Matheny's published work and training materials have influenced and supported training of healthcare professionals throughout the U.S. and abroad.

THE REACH OF MATHENY RESEARCH

A recent search found that published work by Matheny's staff has been cited by other researchers in their own peer-reviewed publications over 1,300 times, including articles published in English, German, Turkish, Russian, Malay, Bulgarian, Portuguese, Spanish and other languages.

Matheny's researchers have presented their work at conferences in the United States, Canada, England, Norway and Spain and in invited addresses throughout the United States.

Approximately 170 third-year medical students from Rutgers New Jersey Medical School train at Matheny for a total of 1,112 "student-hours" annually during their pediatric clerkship.

Resident physicians in Adolescent Medicine at the Morristown Medical Center visit Matheny to gain exposure to best practices in caring for individuals with developmental disabilities. **MM**

former member of the Board of Directors of the Alliance for Disability in Health Care Education, Inc., a national nonprofit of medical school and nursing school faculty, and others committed to incorporating disability-related content and experiences into their curricula. In 2015, he was selected by the Fulbright Program (U.S. Department of State and Council for International Exchange of Scholars) to lecture at Norwich Medical School and School of Health Sciences in Norwich, England; and to work with their faculty and administrators on strengthening the integration of disability-related experiences into their curricula. His research has focused primarily on the readiness of community-based healthcare professionals to serve persons with disabilities; psychosocial processes in disability, such as "implicit infantilizing attitudes held toward people with disabilities"; and Lesch-Nyhan disease.

RESEARCH IMPROVES QUALITY OF CARE

Matheny has applied research in this field to provide better care for patients. Matheny experts have guided future healthcare professionals on how to interact more effectively with individuals



What a Day

The 26th Miles for Matheny walk, run, and bike ride, held at the J. Malcolm Belcher Fairgrounds in Far Hills, welcomed Matheny residents and students, their families and friends, and members of surrounding communities. The day's events included 12.5, 25, 35, and 50-mile, and "Hills of Attrition," cycle rides, and a 5K Run, Kids Fun Run, and the beloved Lu Huggins Wheelchair Walk. Breakfast was provided by The Friends of Matheny.

"Miles" is a big fundraiser for Matheny, with proceeds helping to support its high-quality medical care, education, therapies, including recreational therapy activities and trips, adult day care, fine arts, and independent living.

John Elliott from CBS2 New York, who attended the June 3rd event, interviewed many of the volunteers and participants on-air, including: CEO Bill Kent; Coordinator of Volunteers Gail Cunningham with members of The Friends of Matheny; Matheny School principal Sean Murphy; VP of Life Enrichment Therapies and Community Living Sean Bielefeldt; Matheny School nurse Vanica Eldridge and her husband, Ken, with their adopted daughter India, an alum of The Matheny School and a long-time Matheny resident; and Visual Arts Coordinator Andrew Edge from Matheny's Arts Access program. The video, which is almost 15 minutes long, is well worth viewing using the QR code here.





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