

matheny **matters**

Summer-Fall 2024

We Are the
Advocates

Matheny resident and advocate Amy Myers



Bill Kent
President and CEO

Advocacy is a word in common usage right now, but few are as passionate about advocacy as our Matheny clients and their families and friends. The rights of those with severe developmental disabilities are just now moving into the forefront of our American consciousness. Why did it take so long?

One reason is that most individuals with developmental disabilities struggle to communicate. Many are nonverbal. They have not been able to speak out on behalf of their own interests. However, in recent years, an array of communication devices—both low and high tech—have been developed, and educational and therapeutic practices have steadily progressed, making communication possible for everyone. And lo and behold, we’ve discovered that all of our clients have a great deal to tell us. Their thoughts, observations, concerns, their feelings, locked in their brains for so long, are being unlocked. And it’s time for us to listen.

Matheny has a long history of advocacy. Its founders were early advocates for the rights of individuals with developmental disabilities, and their advocacy impacted the education, health care, mobility, and living situations not only of Matheny’s clients, but many others nationwide—from the 1940s onward.

Today, Matheny is still home to many pioneers, who advocate for their own welfare, as well as the rights and happiness of those in their community. These self-advocates live and learn at Matheny.

In addition, there are many at Matheny who have found a voice by creating visual art; writing plays, poetry, and essays; and through choreography and dance performance in our Arts Access program. The most interesting point is that now—with a whole new toolbox in hand—our clients can speak out for themselves in a variety of ways.

In this magazine, you will meet several Matheny self-advocates who want you to see them as they really are—individuals with knowledge, brainpower, talents, unique personality traits, and the ability to communicate about their own issues and those of their community.

Our residents have a lot to say, and they want you to hear what they say. They want your respect and attention, and they want to change the perception of persons in wheelchairs whose speech may be slow and hard to understand.

As one of our advocates, T.J. Christian, says so cogently: “When people look at me, they see someone who has been in a wheelchair his whole life. But I’m more than that...I hope you can see that my life is more than my disability.”

mathenymatters

Summer • Fall 2024

The magazine of
Matheny
Peapack, New Jersey
www.matheny.org

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contents

What's In the News	1
Matheny's Advocates	2
The Art of Advocacy	8
Meet the Pharmacy Team	12
Self Advocates Are Grown Here	14
A Family of Advocates	18
Honor Roll of Donors	20
Miles for Matheny 2024	24

On the cover: Matheny resident and advocate Amy Myers • Photo by Keith B. Bratcher, Jr.



5 Matheny Artists Show Their Stuff

Paintings by five talented Matheny artists—Jessica Evans, Bari Kim Goldrosen, Karen Frascella, Paul Santo, and Tammy Heppner—were showcased in a new exhibit, “Art Without Boundaries,” at the renowned Sotheby’s in New York City from March 29th through April 7th. Read more about Matheny’s artists on page 8.



BRAD GOLDMAN



Watch Our New Video

A video entitled, *Unlocking the Soul of Matheny*, which was produced and donated by Cannon Design, discusses the creation of a long-term plan for Matheny’s future that will “better serve the individuals in their care while inspiring positive change on a broader scale.” The Cannon team collaborated closely with Matheny to ensure residents’ voices were prioritized in the master planning process. See the video now by scanning the code above.



A Grand Winner

Congratulations to Zanib Akhtar, a Matheny nurse chosen as the winner of the 2024 Disability Advocates Award (Individual category) by the Somerset County Office on Aging and Disability Services in recognition of her “advocacy on behalf of, or other exemplary support of, Somerset County citizens with disabilities” and for “outstanding service demonstrating significant impact in meeting the needs of Somerset County citizens with disabilities.” She works with pediatric and adolescent patients with complex developmental disabilities and serious medical conditions who reside in Matheny’s hospital. The award was presented at the Somerset County Commissioners Meeting on September 24.

They Make Such a Big Difference

The Friends of Matheny, a nonprofit that raises funds for Matheny’s programs and special events, recently presented their 2024 donation of \$125,000, a \$25,000 increase over recent years. \$100,000 will go to support Matheny’s Durable Medical Equipment (DME) and \$25,000 will go to the Arts Access program.

The Rehabilitation Technology Department focuses on clients’ positioning and safety needs,

fabricating custom positioning equipment, safeguarding equipment, and bed and wheelchair replacement covers, to name a few. It also modifies sleepwear, stabilizes toys and communication devices, and provides repaired parts for patients’ wheelchairs.



The Friends donated additional funds to be used to support ongoing programs such as Matheny’s annual Wish List and the Student Family Support Fund.

Matheny staff are invited to submit wish list requests to benefit their students and patients, such as supplies and equipment for programs, and trips for patients and students not covered in Matheny’s budget.

Over the years, The Friends have donated more than \$3.5 million to Matheny, most of it generated through sales at the Second Chance Thrift Shop. A gathering was held there on June 20th to thank The Friends, who enjoyed a visit and remarks from former New Jersey Governor Christine Todd Whitman.



The Friends present their annual check to Matheny, a tradition established 40 years ago.

Matheny welcomes two Board of Trustees members to new positions—**Paul Frascella**, retired Sr. Corporate Counsel, Cisco Systems, will be Matheny’s new Board of Trustees Chair and **Nancy Hamstra**, Consultant, Bergen New Bridge Medical Center, the new Board of Trustees Vice Chair/Board Secretary. Read more about them in the next issue of *Matheny Matters*.



When Matheny's Advocates Communicate



People Listen




What motivates advocacy?
At the top of the list:
the human desire and need
to be heard



Advocacy drives change. Being able to communicate a concern or state an issue is crucial to advocacy, but getting a message across is difficult for some.

For most of Matheny's adult residents living on the Peapack campus and in its community residences, "speaking out" is challenging. Many communicate differently, using words, communication devices, body and sign language, or often a combination, to express their thoughts and needs. Even those who are verbal often struggle to make themselves understood. The history of those with severe developmental disabilities is a history of being sidelined, not part of the mainstream, not even expected to articulate concerns and take a stand.






Josh Handler

Member of advocacy group at Matheny's Adult Learning Center at Hillsborough, longtime resident of Matheny's community residence in Frelinghuysen, participant in Matheny's Arts Access program since its inception in 1993

Josh came to live at Matheny in 1968—just before his second birthday. He came to know Chuck Matheny, son of the Matheny School's founders, who was born with cerebral palsy and lived with his parents on the Matheny campus. Josh has very good memories of his time spent with Chuck. Josh is an advocate for everything Matheny does on behalf of its residents and students.

"I love Arts Access, where I learned to be a painter, choreographer, and dance performer. I'm working on a dance to the music of Mordecai Ben David, a Jewish singer and songwriter. Arts Access has helped me build confidence in myself. I go to the Adult Learning Center, where I particularly like the computer lab and fitness programs. I've done a lot of traveling with Matheny—I even went to England and Florida. I would love to travel some more. I attend religious services at the Flemington Jewish Community Center. I have good friends at Matheny. I'm happy with my life."



The History of Advocacy at Matheny

Matheny's founders, Marguerite and Walter Matheny, were educators and early pioneers in fighting for the rights of developmentally disabled children, among them their son, Charles (Chuck) Matheny, who was born with cerebral palsy in 1941. Because they could not find a school able to teach their son how to achieve and function in the world, they founded their own school in 1946 in Burnt Mills, NJ, which later moved to its current campus in Peapack.

The founders believed that children with developmental disabilities could be educated and should be educated just like their peers, and they dedicated their lives to making that happen. The Matheny School's founders changed the lives of many children and their families with their powerful advocacy.

From 1946 until his death in 1977, Walter Matheny advocated for the rights of individuals with developmental disabilities and their educational needs. Simultaneously, he headed up The Matheny School with his wife, Marguerite, leading its daily operations and overall direction and growth.

As the years went by, Matheny formed close ties with its surrounding communities and opened its doors to the public, inviting them to visit and volunteer their time on campus. Matheny's staff taught physicians, dentists, nurses, teachers, and therapists how to work with students and adult clients with complex developmental

disabilities. The staff also took students and residents on trips to town libraries, restaurants and malls, and to speak at local elementary schools, providing stimulating activities for the residents, and fostering a new awareness among the public of the abilities of their clients.

This was happening while the students, including Chuck Matheny, flourished in the school, while the medical staff learned how to better maintain the health and wellbeing of patients and extend their lifespans, while communication devices improved, and Matheny's staff worked to teach every student and resident how to communicate using these devices. In 1993, the Arts Access program opened, providing clients with new avenues for self-expression, and clients' mobility steadily improved with the development of new equipment.

Over time, major societal changes regarding the rights of those with disabilities took root. On July 26, 1990, the Americans with Disabilities Act was passed, allocating federal funds for facilities like Matheny to take the next step and support independent living for adults with disabilities.

What's Up Now?

The current focus on self-advocacy at Matheny follows long years of societal changes. In 1992, Matheny opened its first community residence in Basking Ridge, followed by a second in Franklin Township in 1995, and five more subsequently. Each is designed to make it



Amy Myers

Member of the advocacy group at Matheny's Adult Learning Center in Hillsborough, resident of Matheny's community residence in Franklin Township, participant in Matheny's Arts Access program, focusing on digital art, drama, dance, and writing

Amy is an active member of the Hillsborough Adult Learning Center's advocacy group. She likes to play games, read books, watch and play sports, particularly football and basketball. She loved watching the Olympics this past summer and has participated in NJ's Special Olympics and also attended games "to support our team." Arts Access is an important part of her life.

"In our advocacy group, we are making podcasts. The first one, on respect, is finished. The staff loved it. Now we'll show it to a bigger audience. We're working on a second podcast—on courtesy and privacy. It's a big topic for us. Everybody in our group helps with the podcast in some way. We have a long list of topics for future podcasts."

possible for four to six adults 21 and older, who do not require ongoing intensive medical care, to live more independently.

Matheny also established two adult learning programs, so that developmentally disabled persons who cannot hold jobs, can still live active, purposeful lives—attending classes, participating in athletics, and interacting with their communities and other adults like themselves. Now, when students graduate from high school, it's not an ending, but a jumping off point for a productive adult life with purpose and social connections. And Arts Access opened up a whole new world of self-expression and self-advocacy.

What has been firmly established over the years is that early and ongoing education are key to the progress and wellbeing of those with developmental disabilities. It's hard to imagine a time when children with developmental disabilities were thought to be uneducable, not capable of understanding language or communicating their thoughts. Now these children make great progress in school, and become adults who are active in their communities and in the world. Unfortunately, the general public still largely holds on to outworn beliefs and misperceptions, because many people have never interacted one-on-one with an adult with developmental disabilities.

Self-Advocacy Is Powerful

Many of Matheny's adult residents are strong self-advocates. They've learned to ask for what they need and want, know

their rights and speak up for themselves, and make choices that affect their lives.

The Matheny residents' self-advocacy groups generally meet once per month in each of three zones at Matheny Hospital, where individuals with complex medical issues, requiring one-to-one attention and care, live; and also, at the Adult Learning Center at Hillsborough, which provides educational, athletic, and social activities, 9 AM to 4 PM weekdays. Most who come to the Center live at one of Matheny's group homes.

During advocacy meetings, participants express concerns about their everyday lives, and specify what they think needs to change. Social workers serve as facilitators. Amy Kappmeier, a social worker at the Hillsborough Center who started facilitating in 2010, says the Hillsborough advocacy meetings draw 20 to 25 participants. "But if we have a large activity, we try to involve everyone in the program."

She says the ongoing, consistent theme is that participants want their voices to be heard and their concerns to be addressed; and the group's primary goal is to foster a broad awareness of their need to be seen and treated as equals. Members have made several videos expressing this need, and have visited local elementary schools to show the videos.

The hospital advocacy groups draw about a dozen very active advocates across residential zones. "Our advocates consistently emphasize how important it is that their concerns are heard. They want to feel safe and respected," says

continued on page 17

We Are the **Advocates**



TJ Christian

Member of advocacy group at Matheny's Adult Learning Center at Hillsborough, lives at Matheny's community residence in Frelinghuysen, a longtime member of Matheny's Arts Access program

TJ is deeply religious, attends church online, is part of a telephone ministry, where he ministers to people online, and studies the Bible online as part of a group called "Relationship University," which has a structured curriculum focusing on relationships among people. He is also an active participant in Arts Access, where he paints and creates scriptural art.

"When people look at me, they see someone who's been in a wheelchair his whole life. But I'm more than that. I feel that I have a calling to help people. I've ministered to people over the phone for a long time. Several people have told me how much I've helped them. I also reached out to a woman who published a book and told her she should make it accessible through other media. She agreed and said she would add a dedication to me. That made me feel good. I hope you can see my life is more than my disability."



Cheryl Chapin

Joined the Matheny community in 1998, lives in a Matheny community residence in Basking Ridge. A participant in Arts Access since it began in 1993, she has a passion for writing and creating visual art.

Cheryl is an active participant in the Hillsborough Adult Learning Center's podcast project as a writer. She has also written short plays. One, entitled "Tea & Venom," was performed as part of the New Jersey Theatre Alliance's Plays by People program, featuring works by writers and dramatists that are performed by professional actors from Premiere Stages at Kean University. She particularly likes to write comedy. "I like to lighten the mood," she says. She is also an avid reader.

"Courtesy is the subject of our next podcast. I came up with the idea—what courtesy means to us. It means being polite. It means being kind, helping out, being nice. For the staff, it means understanding our need for privacy. It means knocking on a door first before coming in."



Andy Lash

Longtime resident of Matheny, avid New York Yankees fan and participant in Matheny's Arts Access program. The subjects of his painting range from commentary on sports and society to more personal matters. He created a painting shortly after 9-11, entitled "I'm Sorry New York," as a tribute to New York City.

Now in his 50s, Andy came to live at Matheny at age 6. He's a dedicated advocate for all nonverbal residents of Matheny, and uses an E-Tran [eye-transfer] board to get his message across. His board has 500 words and symbols that he picks out, one by one, using eye gaze to communicate to his communication partner. He has a lot to say.

"Sometimes people communicate in different languages in front of residents. They need to talk to me. Sometimes people don't understand me." Andy has made a simplified communication board to address this issue—he can indicate which clothes he wants to wear, which TV shows he wants to watch, and whether he wants to stay in his room or go out. He hopes this will improve communication.

cates



Mike Cornely

A founding member of the Matheny resident advocacy group on the Peapack campus, outspoken advocate on behalf of all Matheny residents, participant in Matheny's Arts Access program as a writer and painter, longtime Matheny resident.

Mike's artwork is often playful and comical. He likes to make people laugh. His short play entitled "AMY FINALLY VISITS MIKE" was performed in 2022 as part of the New Jersey Theatre Alliance's Plays by People, featuring works by writers and dramatists that are performed by professional actors from Premiere Stages at Kean University. His visual art often reflects his current life experiences and emotions.

"In trying to be helpful, staff sometimes turn off our devices. Then voice control won't work. They need to ask if we want the device turned off. I like participating in Arts Access—I think my art can change the way people see me."



Melvin Rhett

Graduate of Elizabeth High School in NJ, resident at Matheny's Peapack campus since 2000, active member of resident advocacy group since it started, enjoys sports, chess, computers, movies, competitive gaming, and being an advocate.

Melvin is a great communicator. He often speaks to staff on behalf of other residents. He sees his role at Matheny as "giving voice" to other Matheny clients living on the Peapack campus, and says that staff fix complaints right away. His goal is to help bring everyone together. Melvin loves the "cool trips" for residents organized by Matheny's Recreation Therapy Department and enjoys going home on weekends to visit with his mom and brothers.

"This is a close community of residents and staff. Residents want to be respected and well cared for. Our advocacy group works for solutions for issues of residents and staff. We talk for patients who can't talk. We try to represent everyone. A few residents have gone to staff meetings to talk about how to fix things that bother us. We got a good response. The staff respected what we told them."



Dr. Vincent Barba

Among Matheny's top leaders is its Vice President-Patient Care & Safety, Vincent Barba, MD, who came to Matheny in 2015 with more than 20 years' clinical and leadership experience at Newark's University Hospital and New Jersey Medical School (NJMS), and eight years as its Chief Quality Officer. He leads all clinical services for Matheny, including the Special Hospital and Outpatient Center for Medicine and Dentistry. He is also Clinical Associate Professor of Medicine at Rutgers NJMS, and a Fellow of the American College of Healthcare Executives.

"An essential part of our patient safety campaign is empowering those we serve to speak up. We encourage them to advocate for things they feel impact their health and clinical care at Matheny. Our Advocacy group is a powerful tool for our Special Hospital inpatients and Group Home clients to help us improve the quality of care we deliver. Matheny serves individuals with medically complex developmental disabilities and we are very sensitive to their medical health as well as their behavioral well-being. Our Quality and Safety teams take our clients' concerns very seriously, thoroughly investigating issues they bring forward."



THE ART OF

Advocacy

You may be wondering what it takes to be an advocate. While there is no definitive answer, advocacy is propelled by a passion for a cause and requires a means to communicate that passion to the world.

Growing up with developmental disabilities often means verbal communication is difficult. However, tapping into alternative means of expression can open up a world of opportunity and meaning. That's precisely the purpose of Matheny's Arts Access program—to provide the tools for self-expression and advocacy to individuals with developmental disabilities and teach those interested in the arts how to use those tools. For many, it's a chance to be recognized for their unique dreams and goals and talents. And an opportunity to advocate for themselves, to tell the world what it looks like from their perspective.

Matheny's Arts Access program was founded in 1993 and has built momentum over the years, developing strong links to the world beyond Matheny's campus. Participants create visual art, written works, and dances, and exhibit and perform at venues throughout the State and beyond. Arts Access also invites friends and family to its Full Circle events in the Arts Center on the Peapack campus to celebrate the achievements of participants.

The program gives individuals with complex disabilities the opportunity to express themselves in the arts. Assisted by professional artist-facilitators, the participants use specialized systems, methodologies, and assistive technology that have been designed to enable them to clearly communicate their ideas.

Participants work side by side with staff facilitators. Most provide directives to the facilitators through computer-driven

communication devices; boards with words, pictures, and numbers; eye movements; and head motions. The facilitator asks questions in a yes or no format, and the client responds. The artists make all the choices, from paint color to the steps of a newly choreographed dance. The facilitators maintain "neutrality" throughout the creative process, never criticizing or judging the artists' choices, or even making suggestions.

"What the Arts Access facilitators and staff do is based on client advocacy," explains Heather Williams, the program's director. "We give our clients a voice—help them tell people about themselves."

"A lot of people don't understand the capabilities of our clients," she continues. Williams went to Washington recently to speak to elected officials about Arts Access. Her presentation included press packets, visuals, and links to dances and plays created by, and often performed by, Arts Access clients. "They were blown away by this program and its participants," she says. "Those who have never experienced the multifaceted talents of the Arts Access clients are often stunned by what they see."

The talents of Matheny's artists have recently been showcased at a world-renowned gallery in New York. The paintings of five Arts Access participants—Jessica Evans, Bari Kim Goldrosen, Karen Frascella, Paul Santo, and Tammy Heppner—were featured in an exhibit entitled "Art Without Boundaries" at Sotheby's in Manhattan from March 29th

Premiere Stages

When it comes to successful long-term partnerships, Matheny's Arts Access and Kean University's Premiere Stages know how to do it. Their ongoing, successful relationship has been growing for close to a decade.

Premiere Stages is a professional theater group in residence at Kean whose mission is to bring high quality professional productions of new plays to New Jersey residents, and in partnering with



Matheny aims to help stage original dramatic pieces, poetry, and prose, created by individuals and groups whose writing rarely gets the opportunity to be presented to more than a narrow audience. The program receives written scripts from clients, choosing some to cast with professional actors and to produce before an audience.

"In 2015, Premiere Stages partnered for the first time with Matheny's Full Circle—an arts festival on Matheny's Peapack campus featuring visual art, original dances, and staged plays and other written works," says Nick Gandiello, the Education and Play Festival Manager of the Kean program. John J. Wooten, the company's Producing Artistic Director, directs the dramatic staging for each Full Circle show.

"In Full Circle, often the clients want to perform in their own pieces, and some

perform all of their own roles or shadow the professional actor when it's staged. Some of the writers use communication devices," says Gandiello. "The actors get feedback from the clients, which they use to adjust their performances to more closely match the writer's vision."

The partners also work together on an annual presentation of "Plays by People," a reading series featuring short dramatic works of prose, monologues, theatrical scenes and poetry by Arts Access contributors. These script-in-hand presentations have been part of the New Jersey Theatre Alliance Stages Festival. "Plays by People" was last held on March 28th of this year.

"Our mission is to provide New Jersey audiences with high quality, socially relevant, topical theater; and we have an educational arm which focuses on including more students from marginalized communities. We work to ensure equity in artistic expression, diversity, and accessibility," he says. "As part of this mission, we make sure that theater in this State includes individuals with developmental disabilities."

"We work to ensure equity in artistic expression, diversity, and accessibility."

NICK GANDIELLO

"From our collaborations with artists, we honor and embrace that they are differently abled," continues Gandiello. "We include them as artists in all processes. Because of the partnership with Arts Access, we are more inclusive and more representative. We are honored to be part of that process."

through April 7th. A portion of the exhibit displayed the works of "rising artists," says Williams, who create art in a variety of forms, including sculpture and digital pieces. Matheny previously collaborated with Sotheby's in 2019 for a well-attended exhibit entitled "The Art of Choice."

Partnerships are integral to the mission of Arts Access—to introduce the world to the works of multitalented artists with disabilities. This was a banner year for expanding partnerships between Arts Access and local New Jersey art galleries.

Among its newest, exciting projects is a relationship developed last winter with the law firm Barnes & Thornburg. Michael Zogby, the partner-in-charge of the firm's New Jersey and Philadelphia offices, has volunteered and helped organize the annual Miles for Matheny running and biking events for several years.

"When the firm's Morristown office opened, Mike reached out to us to curate a selection of artwork to adorn their new space. He and the rest of the Barnes & Thornburg team are passionate about supporting Arts Access. Not only did they acquire 17 paintings, they also mounted displays with information on Matheny and Arts Access to showcase the story behind the artwork to their clients," says Julia Halsey, Exhibits and Collections Coordinator for the Arts Access Program.

"An artist reception to celebrate the collaboration is in the works, and we plan to rotate new pieces to keep the office display fresh and exciting," she says.

Other new and ongoing community partners showcasing Matheny's Arts Access artists include:

- the **Center for Contemporary Art** in Bedminster, which invited Matheny artists to do an exhibit at their gallery;
- the **Mayo Center for the Performing Arts** in Morristown, where Arts Access artists proudly displayed their work in the Starlight Gallery from May 22nd through July 8th;
- **Middlesex County College**, which brought dancers from the college to Matheny's campus for its Full Circle extravaganza in fall 2023 to perform dances on stage, which were choreographed by Arts Access choreographers;

Matheny artists proudly display their work at Sotheby's in New York—a collaboration that has resulted in two well-attended and exciting exhibits in 2019 and 2024.

- **Madison Mostly Dance Festival**, which presented works created and performed by participants in Matheny's Arts Access Choreography Program on April 29th;
- **Premiere Stages at Kean University**, which is among the longest running partnerships for Arts Access. "This program gives our artists the opportunity to work with professional, equity actors, who come to Matheny and learn the work of our artists," says Williams. "It also gives our clients the opportunity to go out into the community, to get out of Matheny and have new experiences that inspire art." (See sidebar)
- **The Heidi Gallery in Livingston**. Its "Summer Symbiosis" show, which ran



from July 22nd to August 18th, featured the first Matheny Arts Access/WAE Center exhibit, where the works of each organization's artists were co-mingled in a single space. Fifty artists participated. The WAE Center is an art learning program for adults with developmental and intellectual disabilities. The Arts Access and WAE Center partnership has been

ongoing for 14 years and is supported by the Essex County Department of Cultural Affairs, a partner of the New Jersey State Council on the Arts.

- **The Riverdance Festival in New Hope**. Last summer, Josh Handler, a long-time Arts Access participant and resident of Matheny since childhood, created, and performed in, a dance for four dancers, including himself. The festival, organized by the Roxey Ballet Company, provides opportunities to choreographers and dancers of many varied backgrounds. It offers three days of dancing with three different programs, as well as feedback after each performance. The festival also offers a virtual option.
- **The Arts Council of Princeton**, which will hold an exhibit at the end of November featuring works of Arts Access artists.

"The work done in Arts Access serves as an advocacy tool, informing the public that those with disabilities are highly capable of doing many things," says Williams. "It gives our artists the opportunity to express themselves. Their pieces are often chosen for shows, and they can feel proud about that. The program is also a vocational tool, an opportunity for them to earn some money. Their pieces are exceptional—they speak for themselves. But we help them market their work. We serve as their agents."

Williams calls Arts Access an "untapped gem. We are always looking for new ways to showcase the artists and their work," she says, "so we can bring more awareness and more funding to this program, particularly from philanthropic

ISABELL VILLACIS

Eye on Arts Access Artist and Outspoken Advocate

Since 2011, Isabell Villacis, who was born with cerebral palsy, has worked consistently on her paintings, writing, 3-D sculptures, digital art, and choreography through Matheny's Arts Access program. She is an accomplished abstract visual artist, and an outspoken advocate for greater inclusion of people with disabilities in the art world. She works to change mainstream thinking about individuals with developmental disabilities.



She has also written and published a book in 2022 entitled, *My Life as an Abstract Artist*, available on Amazon. "Writing allows me to come out of my shell," she says. "I express a lot of my feelings in my writing."

Villacis appreciates that Arts Access also provides a place for artists to go and the opportunity to meet and interact with other artists, as well as furnishing the artists with performance and exhibition space and the chance to show, and sell, their work. The program, she says, is a perfect fit for her. "The professional team believes in me, and I believe in myself as an artist and a person."

Even during the worst of COVID, Villacis worked on her art through the virtual program offered by Arts Access. She describes the program as her "spiritual lifesaver." Her painting, entitled "I'm a Survivor of the COVID-19 Virus," speaks volumes about her fight to regain her health so she could return to "the joy of creating art."

Villacis often writes about her perceptions of what's going on in the world. "Sometimes, I can't find the words when I talk, so through my artwork I create my own language. I'm very astonished at how far I've evolved as an artist."

"Art is freedom," she says.

continued on page 17

This Pharmacy Team Always Answers the Call

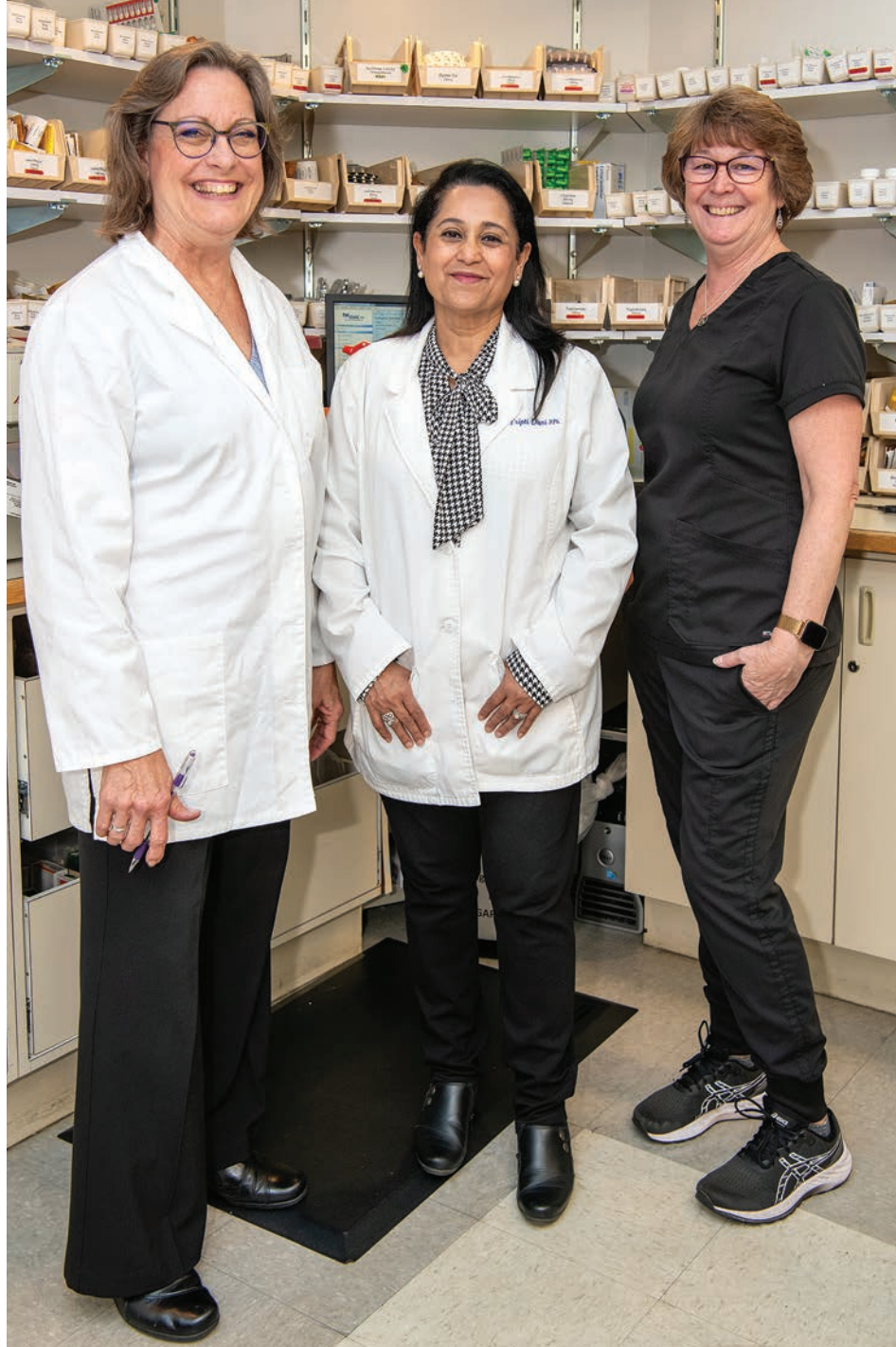
Matheny's Pharmacy team is tiny, but mighty. Its four staff members prepare all of the medications and refills for Matheny's 101 hospital patients on a daily basis; and deliver medications that will be needed over the next 24-hour-period to the floors. They also prepare doses that will be needed for the next 10 days.

There's no doubt that this team, which includes Director Tripti Dani, Denise Bettinger, Donna Mustillo, and Claire Caruana, are all highly motivated, efficient, and very detail oriented, since there's no room for error in drug dosing and packaging. "Everything is checked closely. Everything needs to be very clean. Quality control is so important," says the director.

With such a small staff, there is always one member of the pharmacy team on call 24-7. Emergencies come up suddenly—sometimes at night or during a snow storm—and a member of the pharmacy staff is always "on the case".

The variety and complexity of the hospital residents' conditions make filling medication needs on a daily and emergency basis a particularly challenging task. While the majority of Matheny's inpatients have cerebral palsy as their primary diagnosis, the hospital also cares for patients with spina bifida, Lesch-Nyhan Disease (LND), and a broad range of uncommon neurological conditions that include Rett syndrome, Angelman syndrome, Cornelia de Lange syndrome, Wolf-Hirshorn syndrome, and 4Q deletion syndrome.

Adults with intellectual and developmental disabilities generally have more health problems than others. These can include seizure disorders; vision and hearing loss; psychiatric disabilities; obesity;



Above: the pharmacy team (l-r): Claire Caruana, RPh; Tripti Dani, RPh; and Denise Bettinger, pharmacy technician. Not shown: Donna Mustillo, RPh. On page 13: Denise Bettinger, pharmacy technician; Tony Wong, Rutgers intern (inset)

a high rate of falls; and dysphagia, which can cause aspiration problems. They also experience more health issues associated with aging. Residents of Matheny Hospital range in age from 6 to 50 plus. While the average life expectancy of those with medically complex developmental disabilities has increased in recent decades, early death is not uncommon.

Keeping Matheny Hospital patients healthy is always a challenge, but even more so when bouts of infectious diseases, such as COVID-19 and flu, are in high gear. COVID-19 brought new demands

to all Matheny Hospital staff members, including the pharmacy team. "COVID came without information, and we needed to create emergency guidelines," says Dani. "We had to customize how we would provide everything and not get sick ourselves."

With new guidelines in place and constant dedication to every patient's safety and well-being, the team managed to stay healthy and to care for the patients, some of whom contracted COVID. Pharmacy staff delivered and inspected medications right on the floors, and disinfected

everything in the hospital corridors—even the carts—before bringing things back to the pharmacy.

In addition to being always-watchful not to spread COVID from one zone to another in the hospital, pharmacy team members also had to contend with drug shortages. But the pharmacy had stocked up on many things before the shortages, according to Dani, who had done advanced planning—for almost a year ahead. “And when vaccines came out, the picture changed. We were involved in getting everyone vaccinated quickly,” she says.

“The Pharmacy staff bring years of experience to the job, and are so competent in providing excellent pharmacy service,” states Dani, who is also an adjunct faculty preceptor for the Rutgers Ernest Mario School of Pharmacy. She teaches Rutgers pharmacy students during rotations on Matheny’s campus.

Dani explains that the condition of Matheny’s patients is very dynamic—things can change suddenly. And some of the patients are very young and very vulnerable. “We need to ask right away, ‘Does the patient need medication changes?’ We have to watch the dosing very carefully.”

But the pharmacy team—and nurses and medical staff, headed up by Vincent Barba, MD, Vice President for Patient Care and Safety and the Chief Medical Director—know the patients so well that they can quickly spot changes in a patient’s health, she observes. Each patient’s care is highly specialized and highly individualized, which has likely saved many patients from worsening illnesses, and even death.

For Dani, her job with Matheny is a dream come true. After working for Omnicare, a division of CVS that provides pharmacy services for long-term care and post-acute facilities, for more than 20 years, “I wanted to be more involved with patients and I wanted to make a difference every day,”



she says. She saw the opportunity to do that at Matheny, as well as being able to “apply every skill that I had learned up to that point—patient management, medication management, financial planning, and team collaboration—to do my job.”

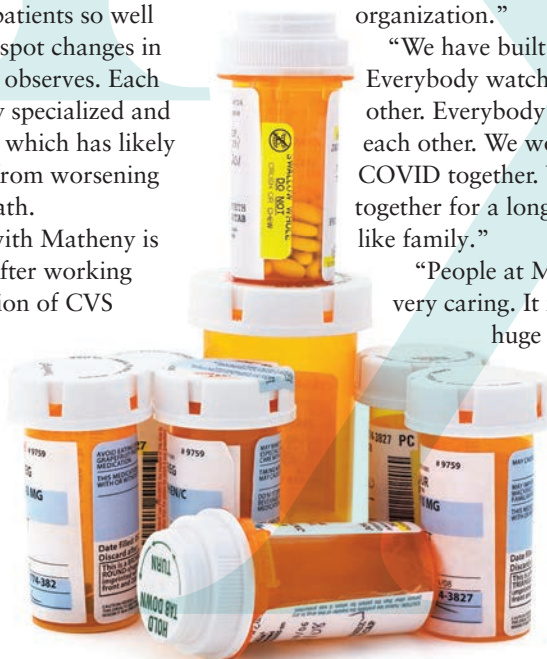
She has not been disappointed. “Here I know all the hospital residents and look forward to coming to work every day. When I leave for home, the residents say, ‘See you in the morning.’ And when I return to work, they are so glad to see me,” she says.

“I love my pharmacy team, I love my clinical team,” she continues. “You see nurses and doctors here making such a difference in people’s lives. This is so different from working for a large organization.”

“We have built a great team. Everybody watches out for each other. Everybody covers for each other. We worked through COVID together. We’ve worked together for a long time—we’re like family.”

“People at Matheny are very caring. It makes such a huge difference.” MM

“I wanted to be more involved with patients and I wanted to make a difference every day,” says Tripti Dani. She saw the opportunity to do that at Matheny.



**WE ARE THE
2024 MATHENY SCHOOL
GRADUATES**

Self-Advocates Are Grown Here

On June 18, 10 students moved proudly up to the podium to accept their hard-earned diplomas before an enthusiastic audience of family, staff, and fellow students. They are 21 years old; and many have been at The Matheny School for the majority of their lives. Some live on Matheny's Peapack campus, in the hospital that manages the complex medical issues that frequently occur with serious developmental disabilities; others live at home, and have traveled to The Matheny School each day by bus, returning home in the late afternoon.

What sets these new graduates apart from most high school graduates is that the majority are in wheelchairs and almost all are nonverbal, and have learned to use communication devices to express themselves. In addition, the array of symptoms and behaviors that characterize their particular syndromes or conditions make everyday life more difficult. Many cannot function without the help of 24–7 caretakers to assist them in their most basic functions. They have all been well prepared to take that giant step from high school student to young adult, and are eager to move into their new role.

These graduates will not go on to college or employment, but will participate in Matheny's Adult Day Program, which offers classes and a wide variety of daily activities, or a

day program in or near the community where they reside. Matheny's transition program, which is part of a New Jersey Education initiative entitled "Person Centered Approaches in Schools and Transition," or PCAST, helps students identify their likes and dislikes, and which activities they enjoy, and start to plan for their future. PCAST meets weekly during the last two high school years.

Despite their communication and mobility challenges, know that these graduates are warm and talented human beings, capable of learning new information and skills, of making friends, loving their families, understanding humor and complex ideas, and of communicating in many different ways. Come November, most will exercise their right to vote for the next President and Vice President of the United States, as well as other elected officials. They will consider the awareness and actions of politicians in regard to their own needs and interests, in addition to the nation's future as a whole. These graduates have learned a vital lesson at The Matheny School—the power of self-advocacy.

Matheny School students graduate high school at age 21, much the same as other students in programs for those with complex developmental disabilities. Not only do they complete the standard public-school curriculum, they also focus in their final school years on how they will make

a successful transition to the next stage of life post-graduation.

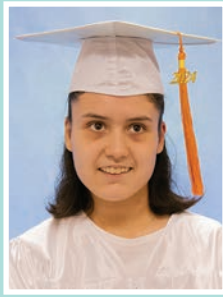
There are many questions for each one to ponder and try to answer: What is important to me as an individual? How will I connect to my community? What will I do with my life once I finish school? The students create brochures about themselves that will serve as a means of introducing themselves as they meet new people when moving on to their next program, living situation, or any other social opportunity, according to occupational therapist Christine Horvath.

This year's group is among the largest graduating classes in Matheny's history, and they will enter their adult lives using technology on a daily basis. The computer skills that they've built over the years, and new communication technology which they've learned to use, can help them express their needs, communicate with others, function more independently, and link them to people and places far beyond their immediate locale, opening up a world of new experiences. In their new roles as adults, their ability to make the case for changes in their immediate environments, and more globally, will enhance the lives of all those living with developmental disabilities.

These are snippets from the PCAST brochures of this year's 10 Matheny School graduates, who tell their stories in their own words.

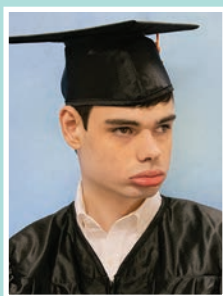
Juliana

I am super social and love interacting and engaging with others. I prefer playing with others versus solo play, so anything interactive like throwing/catching a ball, stuffed animals, or playing simple games are some of my favorite things to do. I also like coloring, bike rides, swings, and listening to audiobooks...I like having my iPad with music, story apps or videos...I use sign language as my primary form of communication...I will definitely come up to you to start a conversation. I'm doing better at asking for what I want using up to three signs spontaneously. I can use picture symbols as well by pointing to them and picking them up...I like going for walks—inside, outside. But especially on the nature trail or at the mall.



Patrick

I love music, listening to books, holding your hand, and spending time with my family and favorite staff. I hope to be included in the conversation, and will often interject with my own voice or one of my communication modalities...Tech is everything...I use an Easy Stander and adapted bike during school...I use Little Mack communicators, Little Step by Steps, a jellybean switch, a Blue2 Bluetooth switch, and of course my 12-inch iPad...Movement is super important for me. I get around in my manual wheelchair.



Yasim

I really enjoy music, especially if it's live. I like a lot of different kinds, like rock, dance/ techno and classical, and Michael Jackson is always awesome...I used to do karate and loved it. Have you seen my kicks and punches? Overall, I just love to be involved and engaged in activities with other people...I love to be a part of the group or just sitting in the hallway so I can chat with everyone. I also love to be hands-on doing things like crafts, cooking, games, sensory play, throwing/catching...I enjoy being active versus calmer activities, but I'll be ok listening to a book or a video...I get around in my manual tilt in space wheelchair...I have a jellybean switch on a modular hose that gets mounted near my left knee. I can access my Little Mack communicator with my knee or a Bluetooth interface so I can use an iPad and communication app.



Jenna

I love baseball... I enjoy music, male voices, and folk/rock like Cat Stevens are some of my favorites. I also love classical and particularly enjoy the harpsichord...I communicate in a lot of ways. I can use two Little Mack communicators on my lap tray...I can do partner assisted scanning with fields of up to 4 [an alternative or augmentative communication technique in which the communication partner presents messages or letter choices to the individual, who makes their selection. Scanning means items are presented one after the other for the communicator] I can also answer yes/no questions by looking down to my left for no and up to the right for yes. I have a dark sense of humor—give me all the monsters at Halloween!



Nicholas

I use my head to access a jellybean switch to control a Little Mack communicator. I can use partner assisted scanning. I do best when you give me two to three choices at a time. I'm also a great nonverbal communicator...I love music, especially Bachata, Soft Rock, and Shakira...I enjoy listening to books, so we can always read together. Or we can take a walk, preferably outside in the nice weather. I get around in a manual wheelchair and have a lap tray that I use for activities and work.



Jameir

Don't let me fool you into thinking I'm the strong silent type. I have a pretty big voice and can use it when I want to... If I'm having a really quiet day, I can use picture symbols in a field of four to five. I prefer using manual language boards to communication apps. I have used Sounding Board on my iPad...I'll help you do just about any task. Got some mail or supplies to deliver? I'm your guy. Laundry to deal with or dishes for the kitchen? I've got it. Plants to water? Consider it done. Need to organize your space? Sign me up. And there is no better sous chef than me.



Aidan

I love to be out and about and doing things... I like going for walks in my chair or being on the swings... I get around in a manual tilt in space wheelchair.

I have two Little Mack communicators that can be on the front corners of my lap tray. I also love being on the bike or getting up in the gait trainer...My fave people include Mom and Dad, my sisters Ellie and Lia, Grandma and Pop Pop Pauch (and their pool), Grandma Mac, and a whole lot of extended family. I also really love our dogs Chloe and Archie. My Matheny family is pretty awesome, too.



Marina

I use a lot of non-verbal communication...I'm learning to use my right hand to reach out and access two Little Mack communicators, but I still need a lot of cues and support under my elbows. I don't like sitting in my wheelchair all day, so I really like getting out. I enjoy sitting on a bench or getting in a shallow comfy chair...Let's put on some music—Disney is always a hit or a book on tape and I'm happy. If you have sensory lights or videos, I'm down for those, too...And I love walks, especially outside when the weather is nice.



Ari

Let's have a dance party! I love some classic rock (A little Ram Jam anyone?), but anything with a beat will do. I have a great sense of humor, so I really like shows like Impractical Jokers, or listening to audiobooks. I like being with the group and doing hands-on things... I use a jellybean switch mounted to my (manual) wheelchair and positioned near the left side of my head to access my Little Mack communicator. I can use Partner Assisted Scanning with up to four choices. I also use my eyebrows/smiles and sometimes an eye blink to indicate yes answers...I'm a pretty easygoing guy, so there isn't much I don't like.



Matthew

I really enjoy exploring, so let's take a walk. If there's a door, I want to see what's behind it...I like to move! I enjoy going for walks in my stroller, riding the bike and I can walk on my own... I also enjoy walking more when I can be outside in the sunshine...I can use a PECS book and have my own with my most preferred activities as well as some other icons that I can use to participate. [The Picture Exchange Communication System, or PECS, is an alternative communication system for nonverbal people to communicate using cards with pictures, symbols, words or photographs.]



Teacher Christine Gonella with recent graduate Yasim



Now you have a glimpse into the lives of the graduates. They've met weekly for two years to think about, and discuss, who they are now and what they hope for in the coming years. Christine Mayercik, the school's senior speech-language pathologist, works closely with main PCAST teacher Christine Gonella and occupational therapist Christine Horvath to guide students through this transition period. Essential to their team are physical therapists, para-professionals and social workers.

"PCAST helps students develop their sense of self," says Mayercik, whose focus is improving language skills and communication. "I think this program works to make the transition from high school into adulthood easier for students and their families."

Learning to communicate is certainly a top priority here. Mayercik sets up each student with the appropriate technology before graduation, matching devices to the client's needs.

"Technology is part of their daily lives. Maximizing each student's ability to use technology to communicate will maximize our graduates' independence," she says.

"Teaching students how to communicate their thoughts and their needs may be the most important thing we do here," states Sean Murphy, principal of The Matheny School. "When students finish their high school education, they need to be ready to advocate for themselves, and also to be effective advocates in their larger community." **MM**

Matheny Advocates

continued from page 5

hospital social worker Shannon Curry. “The residents have come up with a variety of ways to communicate with staff about these concerns, including emails, letters, posters, and face-to-face meetings with caregivers and administrators.”

The social workers help to present residents’ concerns at Matheny’s monthly town hall meetings. These concerns might include conditions within the facility, and how staff help residents with activities of daily living (ADLs), including eating, dressing, getting into and out of a bed or chair, taking a bath or shower, and using the toilet. The social workers also report when the clients’ issues have been resolved.



“There is a lot of respect at Matheny for the advocates and their efforts within Matheny. People listen,” Curry says.

“Many of our advocates live in community residences, and their concerns vary,” explains Kappmeier. “The advocates think about how they can approach problems in a broader context, so that specific concerns can be addressed more universally.”

“Sometimes the identified issues can be complicated to navigate,” she says. “Our residents choose specifically who they want to communicate with and how. They are understanding that the process to respond may be slow but their concerns are respected.”

Prior to COVID, representatives of Matheny’s advocacy groups attended the annual national advocacy conferences for those with developmental disabilities in different states throughout the U.S., including Minnesota, Alabama, Ohio, and

Kansas. “We traveled to many different places for these three- to four-day conferences, and also did some sightseeing,” she says. “There were breakout meetings focusing on different topics, and advocates chose which to attend. They were able to meet with advocates from other states. Matheny advocates shared how valuable it was to them to have the opportunity to participate in these different levels of advocacy.”

Many of Matheny’s adult residents are registered voters, and regularly vote for elected officials, first informing themselves about national and local issues, particularly those affecting people with disabilities. “Being a part of organizational, state, and national level advocacy projects is huge,” says Kappmeier. “Historically the advocates chose to take on projects that promoted well-being in the community in significant ways. They hosted fundraisers for organizations they chose to support and sought opportunities to make a difference in local and larger communities, like writing letters to soldiers serving overseas and sending stuffed animals to kids facing difficult circumstances.”

Right now, members of the Hillsborough advocacy group are working on a series of podcasts, which they intend to present to staff and residents of Matheny, to administrators at town hall meetings, and then to a broader audience. Each episode will focus on a particular topic of concern; the first is about respect.

“Everybody participates in some way,” Kappmeier says, “with some people doing the writing, and others offering creative ideas, performing in the production, typing, creating music, using computers to provide closed captioning and credits, anything it takes. A lot of people work behind the scenes. It’s serious and it’s also fun.”

“A lot of the advocates express the importance of being heard,” says Curry. “They want to make a difference in their own lives, the lives of their peers, loved ones, and community. Come meet our advocates. They have a lot to tell you.” **MM**

The Art of Advocacy

continued from page 11



and government agencies.” She gives special mention to the New Jersey Council on the Arts, which Williams says has been their biggest supporter over the years.

Arts Access will hold a new one-day special event in October, which Williams describes as “an all-ability art fest.” Artists will be set up in Matheny’s Robert Schonhorn Arts Center gallery beside their artwork, which will be on display for sale. Several arts organizations will participate.

“The idea is to sell the artwork,” Williams says. “We are trying new things. We are trying to target new audiences.”

In addition, artists will be invited to the Peapack campus to “sit outside on the hill and paint the beautiful foliage. A professional artist will guide the outdoor workshops,” she says. Writing workshops will also be offered.

Looking ahead, Williams sees more and more opportunities opening up for artists with disabilities, as the awareness of their exceptional artwork grows. Just a few months ago, she was invited to speak to the Robert Wood Johnson Foundation Resident Council. The topic? How art and health care work together.

“We’re working hard to include more diversity in all aspects of the arts and gain the recognition that the work deserves,” she says. “These works need a far wider public audience in the future.” **MM**

Advocacy Gives Eleni Manwaring a Voice



What does it take for a family to support, educate, encourage, and provide care and shelter for a child for 18 years? Add to that constant advocacy on her behalf. It takes a lot—and way more if that child has complex developmental and medical issues. It can take a commitment that puts most of life’s previous commitments deeply in the shadows.

That is precisely what happened in the lives of Athena and Derek Manwaring and their children Leo and Eleni. Athena and Derek met during their undergraduate

senior years. Athena was at Barnard College and Derek at Columbia College, both part of Columbia University in New York. They both went on to establish careers in international business after earning MBA degrees. The couple married in Athens in 1999, following nine years when they saw each other on and off while establishing their careers in far flung locales. Their future together held challenges they could never have envisioned, and never have prepared for.

After marrying, they moved together to Santiago, Chile, and two years later

to Mexico City, where they lived for three years for Derek’s job with Colgate-Palmolive. Their first child, Leo, was born there in 2003.

Leo arrived and started his life with no drama. The family moved back to the U.S. and lived in Chappaqua, NY, for two years. Their second child, Eleni, was born in Westchester County six weeks early, in December 2006, and arrived with no noticeable complications. “Initially, everything looked OK,” remembers Athena. But early on, Eleni’s parents noticed that “her body seemed stiff and things just didn’t feel right.”

The worried parents brought Eleni repeatedly to doctors, asking what could be wrong. They were assured that Eleni was normal and developing nicely. But Athena and Derek’s observations and instincts told them otherwise.

When Eleni was five months old, Derek accepted an assignment with Colgate-Palmolive in Geneva, Switzerland, and the family moved there. Within months, doctors there discovered that Eleni had periventricular leukomalacia (PVL), a brain injury in which the cells of the white matter around the ventricles of the brain die. It’s due to a lack of oxygen or blood flow to the periventricular area of the brain and affects nerve fibers that carry messages from the brain to the body’s muscles. Symptoms, which include motor disorders, delayed cognitive development, coordination problems, and vision and hearing impairments, range from mild to severe.

Due to PVL, along with a variant on one of her two copies of the DHX37 gene, Eleni has spastic quadriplegic cerebral palsy, an associated seizure disorder, cortical visual impairment, and she is nonverbal. The Manwaring family’s lives changed. Living overseas posed its own challenges, but navigating special needs waters in a foreign country became a whole new challenge.

They lived in Switzerland for three years, Geneva for two years and Basel for one, where Athena and Derek say

the doctors and therapists were good. However, both cities did not have a large special needs population and treatment was not aggressive. There were not many programs or resources available for Eleni. When she was ready for pre-school, “There was only one special needs school in all of Geneva, it was very small, and served all special needs kids of the city,” says Athena, who had given up her career to become Eleni’s full-time caregiver.

Colgate-Palmolive transferred Derek back to the U.S. “The company was wonderful—very supportive,” says Athena. The family settled in Ridgewood, NJ, in 2010. Eleni started pre-school at age 4. The environment was warm and nurturing, and Eleni was happy there for many years, according to her parents.

Eventually they felt Eleni needed to be challenged, and hired an educational consultant, who conducted tests to determine what Eleni was capable of, then searched for the right school for her.

“Eleni’s receptive abilities far outweigh her expressive abilities,” Athena explains. “She understands almost everything, but she has a very limited ability to express herself. Eleni needed to be challenged more. Communication was a huge issue.”

“We were really struggling to pull Eleni’s voice out of her,” says Derek.

The Matheny School was identified as a good place for Eleni to make progress. The school specializes in teaching students to communicate—using whatever means the student is capable of mastering. Therapists are well versed in how to use and teach students to use devices ranging from simple picture boards to advanced technology.

Eleni started virtual schooling in 2020 as a middle school student in the Matheny School’s summer program, while COVID was raging all around. After trying several communication systems, she learned to use Touch Chat on the iPad, an augmentative communication app that opens the door to communication for many nonverbal individuals.

Starting at the Matheny School proved to be a giant step forward for Eleni. Then in October 2020, a spot became available at Matheny’s specialized hospital, and COVID hastened a decision that Athena



The Manwaring family (l-r): Derek, Leo, Eleni, and Athena

and Derek knew they would eventually have to make.

“We knew the day was coming when we could no longer care for her at home,” says Athena. “The seizures were awful—long and severe. Eleni needed to be cared for 24–7, especially overnight when she would have her seizures. Because of COVID, we could not get nursing help at our home, and caring for Eleni became extremely hard.”

A Matheny behaviorist and a social worker helped prepare Eleni for the move. Athena and Derek were able to explain to her that she would have two homes, and that they would see her often. The transition was hard for the whole family, but Eleni adapted and felt at home at Matheny rather quickly.

“She is such a social person—she gets energy from other people,” says her mother. “At home, there was not enough of a social environment no matter how hard we tried to provide it. She loves everyone at Matheny. She’s always part of the action—always happy.”

Her parents point out that the connectedness between the school and hospital is a huge plus. “What she learns in school, such as communication skills using her device, she practices in the hospital. The speech, occupational, and physical therapy teams run separately, but they work together and are all fantastic. There’s continuity.”

“At school, they really challenge her,” says Athena. “She’s learning. Her comprehension is high, they treat her as a typical child and expect a lot from her. She’s able to express herself better—it’s working.”

“They love her. She’s a happy girl,” her mother continues. “Eleni is a flirt. She loves boys, and she loves music, picks out movies and TV programs, and likes to play games. Matheny provides varied and fun recreational activities.”

“And the hospital care is top notch,” says Derek. “We have every confidence that they take good care of her. The nurses are amazing and the whole staff provides great 24–7 care. She also has access to specialists and the equipment department always makes sure that she has just what she needs.”

Eleni uses a walker, wheelchair, and stander, and has benefited from all types of therapy. She enjoys getting off campus with Matheny to do activities such as eating at different restaurants, bowling, and even adapted skiing. She “loves to be as active as possible. She loves rollercoasters,” says Athena. “She’s a bit of a daredevil.”

The Manwarings are active contributors to Matheny and participate in the annual fundraiser and community get-together, Miles for Matheny. Their hope is that Matheny’s facilities will soon be expanded in order to reach more people who need them.

“The staff is so wonderful here. Teachers, therapists, administrators, social workers, nurses, DSPs [direct support professionals], everyone,” says Derek. “They’ve helped Eleni to thrive.”

“Yes, they do everything,” agrees Athena. They “even dress her up, do her hair nicely, she loves it. Her one-to-one aide, Katie, is just extraordinary and like a second mother to Eleni.”

“We’ve been so lucky,” says Derek. “Eleni is very happy.”

The family’s constant advocacy on behalf of Eleni, whom they Facetime every night and visit often, has ensured that. She will turn 18 in December, a cherished member of her family, and a beloved member of the Matheny family as well. **MM**

The Honor Roll of Donors

Individuals, corporations, organizations, and foundations generously helped support every aspect of life at Matheny during Fiscal Year 2024.

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.

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Team members from new partner **Daichi Sankyo, Inc.** came out in full force to make Miles for Matheny a great success.



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Cannon Design, partnering with Matheny, created a video entitled, "Unlocking the Soul of Matheny." The video's creators say: "Holistic care, education, and inclusion remain elusive for those with medically complex developmental disabilities. Matheny is dedicated to addressing this issue, providing coordinated services to enhance the quality of life of these individuals." Matheny is grateful to Cannon Design, which has donated so many employee-hours to create this video for educating and informing Matheny's many constituencies about its planning for the future.





Matheny Advocates Go the Extra Mile

It was a banner day for Miles, still going strong after 27 years. On a beautiful Saturday in June, hundreds of Matheny advocates—students and residents, families, staff, volunteers, community members, friends and local businesses—came together to celebrate, raise funds, and have some good, old-fashioned fun. What made this year a particular standout? It was the first ever Miles for Matheny event to take place right on the Peapack campus.

Funds raised for Matheny topped \$58,000, but the amount of fun was immeasurable. The ever-popular Kids Fun Run—this year with an added obstacle course, a Trail Run and Fitness Walk, the

beloved Lu Huggins Wheelchair Walk, the traditional Breakfast of Champions, sponsored by the Friends of Matheny, a big BBQ with delicious food, music, interactive games, and free snacks all made the day memorable. In addition, cycle rides were held off campus.

We want to give a big thank you to all our sponsors who make this event possible, from new partners to longtime supporters, small businesses to large companies, families to organizations. And a special thanks to Anthony Melillo, who extended a warm welcome to Miles for Matheny participants to walk and run on the beautiful Blairsdens Mansion grounds.







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