

matheny matters

Winter • Spring 2018



Remembering
**Charles H.
Matheny**

1941 - 2017

Kendell R. Sprott, MD, JD
President and CEO



Year in Review

This past year proved to be particularly impactful for the Matheny community. Charles (Chuck) Matheny, whose parents Marguerite and Walter founded the Matheny School in 1946 for their son and all children with cerebral palsy, died at his home on the Matheny campus on December 14.

Chuck was educated here; grew into adulthood, held a job, and made good friends here; served as a role model and mentor for our students and patients; and lived out his life here until his death at age 76. He demonstrated to others at Matheny how to live a fulfilling and full life, how to be joyful and how to share joy with others, and how to be an integral part of a community while living with developmental disabilities. We will all miss

him and all remember him as a vital part of Matheny and what it stands for and achieves on a day-by-day basis.

Also, at the end of last year, Matheny and the Borough of Peapack-Gladstone ended years of litigation with the approval of a settlement by both sides. Matheny can now move forward to develop a site plan that will address its needs for the future.

In this issue of the magazine, you can read about a few of our many remarkably dedicated individuals. Meet two extraordinary volunteers, both Matheny Board of Trustees members; read about the incredible work of our personal care assistants (PCAs); take a peek into the classroom of our talented art teacher and see how she helps prepare students for life after graduation; and learn what it really takes to fashion a wheelchair that answers the unique and changing needs of each client.

In 2018, we celebrate the 25th anniversary of our amazing Arts Access program, which you will read about in the summer issue of *Matheny Matters*.

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matheny
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Chuck Matheny, Remembered

Charles H. Matheny, age 76, died on December 14, 2017 in his home on the Matheny campus in Peapack. He will be remembered as a pivotal force in the development of the Center that bears the Matheny name.

Not only was he well educated at Matheny, and supported to reach his full potential, but he helped create the “personality” of this compassionate and cohesive community that has served so many so well. According to Amanda Kochel, a 13-year Matheny resident who misses

“He was a father figure to me and a really funny man,” says Amanda Kochel.



seeing Chuck moving around the hallways, “I knew him for 13 years. He was a father figure to me and a really funny man.”

Josh Handler, currently a resident of one of Matheny’s group homes, first met

Chuck in 1968, just before Josh’s second birthday. “He was my babysitter and he was very kind and friendly and funny,” says Josh. “He was a good teacher.”

“He was very kind and friendly and funny. He was a good teacher,” says Josh Handler.



His best memory? “Watching *The Mickey Mouse Club* show together,” Josh answers without hesitation. “It was fun. He was so good with children. We had a good trusting relationship.”

Chuck grew up to be a warm, kind, positive person, a “storyteller,” a man with a wonderful sense of humor who had many friends and loved life, according to those who knew him. He became “the face” of Matheny and the model of possibility for all those growing up, or coping, with limitations.

Chuck finished high school, earned a driver’s license, mowed the lawns of Matheny’s main campus, participated in all of Matheny’s events, and was a devoted

member of the Basking Ridge Presbyterian Church for more than 50 years. He will be remembered as a beacon of achievement and a caring friend to so many.

On January 26, about 200 family and friends attended a memorial service on the Matheny campus to honor and remember this remarkable man. He will be missed by many.

Save These Dates

**Somerset County
Special Olympics Event**
Saturday, May 5, Bridgewater

2018 Matheny Prom
Thursday, May 17

**Matheny School's
Graduation Ceremony**
Wednesday, June 20

**Matheny School's
Third Annual Golf Outing**
Tuesday, September 25
Oak Hill Golf Club in Milford

A Growing Partnership

Biomedical engineers design prostheses, surgical instruments, and implantable devices; devise new imaging methods; and invent therapeutic devices and pharmaceutical products.

So, what were 13 undergraduate students from the Rutgers Department of Biomedical Engineering (BME) doing at Matheny several months ago? They were doing exactly what biomedical engineers do: looking for opportunities to improve quality of life by applying engineering practices to real-world medical and health problems. Matheny and Rutgers launched a program in 2017 to enhance medical device development that could help those with developmental disabilities. The



ROY GROETHING

idea was conceived by Matheny Board of Trustee and school volunteer, Larry Thornton.

As part of the pilot program, the Rutgers seniors met with a group of Matheny patients and students with medically

complex developmental disabilities in order to better understand their challenges; and Cindy Shanks, a long-time Matheny resident, presented to students attending a biomedical engineering conference how assistive technology has improved her life. The Rutgers students will envision devices that could improve the daily life of individuals with disabilities, which will be the basis of their senior design projects.

This may yield benefits for Matheny’s students and residents, as well as for the Rutgers students, who will learn how to best apply their academic training to impact real world problems. Matheny School Principal and VP of Education, Sean Murphy, Vice Principal James Hintenach, and volunteer Larry Thornton have been instrumental in developing the program.

A Visionary Dentist

Gerald Sydell, DDS, feels a great sense of accomplishment as he looks back over the course of his more than 40-year career as a practicing dentist, his long and productive term as Chairman of the Board of Trustees of Delta Dental of New Jersey, and his current work as a Board of Trustees member at Matheny Medical and Educational Center. Born at Newark Beth Israel Hospital, raised in Newark, and a graduate of Newark's Weequahic High School, he went on to earn a Bachelor of Science degree in three years from Southern Methodist University in Dallas, Texas, and a Doctor of Dental Surgery (DDS) degree from Temple University College of Dentistry in Philadelphia, later returning to his home state to set up a general dental practice in Cranford.

Why did he go so far away to college? "The tuition was \$64 a year," he laughs. "Can you believe it?" There was never a question in his mind about how he would make his living. "It was always dentistry." He went into the Air Force immediately after graduating and served as a practicing dentist in Okinawa during the Korean conflict for two years.

Establishing and running a dental practice, and later going "back to school," this time to NYU Dental School half-time to specialize in orthodontics, were exactly what he had always had in mind. Although specialty practice could have kept him busy full time, Sydell decided not to abandon his general practice. "I couldn't leave my patients," he explains.

He worked at the Cranford office, doing both general dentistry and orthodontics, for 42 years. "I enjoyed every day of it," he remarks. However, when he retired from practice in 1998, big new challenges awaited him.

Sydell was named Chairman of the Board of Trustees of Delta Dental of New Jersey. Founded in 1969, Delta Dental of New Jersey is part of a national nonprofit dental insurance network that was created by dentists to expand the public's access to oral health care. As the largest dental insurance provider in the country,

it covers more people-- individually and through company plans--and has more participating dentists than any other dental insurance program in the U.S.

"I had been involved with Delta Dental prior to retiring from my practice," he states. As the Board of Trustees chair, he participated with the company's CEO in making major decisions, made and sup-

"My passion for Matheny has been my primary hobby for years. There's no place like it."



Gerald Sydell and his wife Roz

ported company-contacts, and helped to lead major committees.

During his early years in that role, Sydell was part of a decision to give a grant of \$1,500 to Matheny to provide orthodontic work for several of Matheny's residents. "However, those funds were never used because it was impossible to do the orthodontics without the proper equipment," he remembers.

But rather than walk away from the project, he worked with Delta Dental to come up with the funding to create a spe-

cialized clinic on Matheny's campus that could answer the needs of its residents. "We created a dental clinic there that could accommodate patients with special needs, and then Delta Dental made an annual contribution to provide new equipment and take care of renovations," he says. The UMDNJ (now Rutgers) dental school provides a specially trained dentist to staff the clinic.

As Sydell's interest in Matheny and concern for its students and residents grew, so did his involvement. When he was asked to serve on the Board of Trustees, he readily consented. He has given particular attention to decisions related to the dental clinic. "The clinic serves not only Matheny residents but others who need this kind of special care and cannot get it elsewhere," he explains.

Many years after his initial introduction to Matheny, Sydell is "still on board. After my first walk-through, I knew I had to help wherever I could," he says. He has brought people to visit. He has encouraged visitors to Matheny to donate time and money. "And I made sure that Delta Dental has stayed involved," he says.

He served on the Board of Delta Dental until two years ago, participating in and helping to guide its growth. Contributing to Matheny was a pervasive theme at Delta Dental throughout his tenure there. "Our entire Board has been so enthusiastic about Matheny," he says. "If you have ever visited, you know why."

Among his wishes for Matheny is to have a full-time dentist on staff. "Patients have to wait such a long time for treatment," he says. "The waiting list is long."

Sydell tells the story of bringing his 13-year-old granddaughter, Jacki Rosenzweig, to visit Matheny one Sunday years ago. The teenager was so moved by the experience that she decided to visit Matheny patients every weekend for a year. "This was her Bat Mitzvah commitment," he explains. "But she never stopped visiting until she went to college when she was 18, and now she's a second year resident in pediatrics."

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Leading “The Friends”

Kathy Sisto’s commitment to her most recently acquired role is certainly on par with that of top administrators of major international companies. As president of the Friends of Matheny, the highly successful volunteer fundraising arm of the Matheny Medical and Educational Center, she is determined to lead the group to first meet, and even exceed, its notable results of prior years. “The Friends,” as they are so aptly nicknamed, composed of dedicated volunteers of all ages, most but not all from the local communities of Peapack, Gladstone, Bedminster, Bernardsville, and Mendham, have contributed thousands of hours over many years to earn the funds that underwrite the “wish lists” of Matheny’s teachers and program leaders on behalf of their students and residents, as well as many other important projects.

“The group has raised, and contributed, \$3.1 million since our inception in 1983,” she states. These funds have purchased many items and services that support a better quality of life for students and residents of Matheny. Among the most recent purchases are a wheelchair washing machine; Smart Boards and Smart Tables to help students communicate; adaptive

sports equipment; a LiteGait walker; and, of course, the trip of a lifetime—the six-day, five-night excursion to Disney for several of the students and their care providers in November 2016. And that’s just the short list.

Like many of Matheny’s deeply devoted volunteers, Kathy did not have priorities to Matheny before being invited by a friend to visit the campus and attend a Friends Board of Trustees meeting. A “Jersey girl,” Kathy grew up in North Plainfield, and returned to her home state after graduating from the University of Richmond in 1986 with a degree in English. She lived in Westfield before purchasing a home in Bernardsville with her husband in 1990, where they raised their three boys, now ages 26, 23, and 21. From 1986 to 1992, she worked in mortgage banking for a small savings and loan institution, then took on part-time jobs while the boys were growing up. Two years ago she was hired as a relocation specialist by Turpin Real Estate, where she initiates and fosters relationships with relocating corporate transferees, providing them with information about local housing, amenities, transportation, and schools. The position is a good fit for a

person with her friendly and outgoing demeanor, sense of calm, and organized and knowledgeable approach to solving problems.

Those same skills and positive, can-do mindset are also a good fit for her role as the Friends of Matheny’s top leader and a member of Matheny’s Board of Trustees. She has been an active member of the Friends’ Board for 10 years and is in the second year of her term as president. “I had a brother who, because of an accident, was brain-damaged,” she discloses. “I always wanted to do something related to special needs.”

The Friends of Matheny was founded in 1983 as a “community-based auxiliary, just like a hospital auxiliary,” she states. “Its purpose is to raise funds. And it has some very long-term members.”

However, just like other volunteer groups, its membership has declined over the years “in large part because so many women are working and don’t have the time to volunteer,” Kathy observes. “And other factors need attention, too.”

All funds raised by the Friends of Matheny are currently brought in by Matheny’s Second Chance Thrift Shop in Gladstone and donations from our members, Kathy points out. “We used to host

“I’ve spent a lot of time at Matheny over the last 10 years and it’s been well worth it.”

an annual gala, a dinner dance that raised a lot of money,” she explains, “but we haven’t been able to do that recently.” She would like to reinstate that popular event.

However, before she can do that, Kathy needs to bring in more volunteers. “We need to communicate more widely,” she says. “There are still many people who don’t know about Matheny.”

The Friends’ president will focus some of her efforts on getting the word out. “If people knew more about it—the complexity of what Matheny does and how well they do it—they would be

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Matheny Made the Difference

With a newly awarded University degree in biology and chemistry in-hand, Peter Longa packed his bag, left all that was familiar to him, and traveled alone to the New York metropolitan area in 1993. Civil war was raging in his country. “I had to leave,” he says.

His first job offer in the U.S.—after a nine month-course of computer training in bookkeeping and accounting—was in a bank, an opportunity to earn a living, but not one that was ultimately satisfying. However, a friend from South Sudan, who was a personal care assistant (PCA) supervisor, told him about Matheny and encouraged him to apply as a teacher’s aide to get his foot in the door.

“There was no opening in the school and I had no training in special education,” he explains. “But there was a job opening as a PCA in the hospital.” That was 23 years ago and Peter got the job.

“I loved it right away,” he says. “I loved caring for patients and I was able to live on the campus.” (Matheny provides on-campus housing that is utilized by about 50 PCAs and other staff, making it possible to provide 24-hour care to Matheny’s residents.)

Peter started thinking about earning a degree in physical therapy or nursing so that he could provide direct patient care at a different level. “I saw patients with skin wounds, and then I saw how the wounds healed with the proper attention. I saw a patient with severe breathing dif-

“The PCA does for the patient whatever the patient cannot do for him — or herself,” says Peter Longa. “If not for the PCA, that patient could be lying in bed all day.”

ficulties. The nurse was called and within minutes, the patient was fine again,” he tells. “I wanted to work on something where I could see the positive results.”

So, he started on what was to become a decade-long path to advance his education in providing patient care. First, he took six credits toward a nursing degree

at Raritan County Community College, followed by additional prerequisites. He then completed the associate degree in nursing in two years, winning a Matheny Nursing Scholarship Award, and quickly afterwards passed the national exam, earning his registered nurse (RN) licensure in July 2004. He was also awarded the Joanne Nitchecky Sergeant Award for excellence in clinical nursing while at the school.

On July 7, 2004, Peter started working in the nursing department in Matheny Hospital’s Red Zone—taking on double shifts on Fridays, Saturdays, and Sundays so he could attend classes and study during the week. “I offer the same to my staff now who want to further their education,” he says, “as long as they don’t abuse it.”

His desire to advance his education motivated him to complete a bridge program to UMDNJ (now Rutgers)–School of Nursing and start the Masters of Science in Nursing (MSN) degree program in 2005. He earned his degree in three years, and, along the way in 2006, was honored with the Governor’s Nursing Merit Award in the Registered Nurse Post Acute category.

In fact, Peter's life was all coming together--awarded the MSN degree in 2008, he married in 2009, had his first child in 2010, and started that same year to work on his doctorate. Also in 2010, he stepped up to the position of night nursing supervisor, which he held for five years.

And that was just the beginning. Peter went on to earn a doctor of nursing practice degree in just two years, going to school full-time while continuing to work full-time. "It was very hard," he remembers, "and some of the students dropped out. I thought of dropping out of the program, too, but my friends encouraged me to stay."

In 2015, the position of director of personal care assistants (PCAs) and community resident assistants (CRAs) opened up, and Peter moved into the position that he currently holds. The life and responsibilities of PCAs and CRAs are very familiar to him. After working as a PCA at Matheny for an entire decade, it's a profession that he deeply respects.

"The PCA does for the patient whatever the patient cannot do for him- or herself," he says. "If not for the PCA, that patient could be lying in bed all day."

Dr. Longa directs the work of 150 PCAs and 50 CRAs, all of whom are responsible for the 24-hour care and function of Matheny's students, and hospital and group home residents. The ratio of caregiver to client is generally one to three or four, he says, and coverage is provided around the clock.

New hires are trained at Matheny, generally over a period of three weeks. "Some are CNAs (certified nursing assistants), some come with experience and others are totally green and need longer training," says Peter. "I prefer the green ones. We train them well here." Shifts run eight hours over five days or nights, or twelve hours over three or four days or nights.

What is he looking for in a new hire? "Someone who is patient, caring, and compassionate. This job is all about caring," he answers.

A day in the life of a PCA or CRA is busy. "If your shift starts at 7 AM, you would go directly to the unit and get a

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Family Ties

For Brenda Hoagland, choosing a career and deciding to work at Matheny were both no-brainers. It was "all in the family." She, her parents, and four sisters all treated Alex, her younger brother who has cerebral palsy, "just like a normal child when he was growing up and living at home. My sisters and I rigged up the vacuum cleaner so he could vacuum from his wheelchair," she recalls, laughing. "We expected him to do everything we did."

At age 12, Alex became a student and resident at Matheny. (Alex is 53 now and lives in his own apartment in Tewksbury.) Brenda, who is seven years older than her brother, answered an ad for a child care worker (now called a personal care assistant or PCA) at Matheny when she was 19 and got the job. More than four decades later, she still works there.

"I came here," she recalls, "to learn all I could about cerebral palsy." And in doing so, she also learned all she could about how to care for and help Alex.

Feeding, clothing, assisting in bathing, helping residents to get up from the bed and move about in wheelchairs and walkers are all part of the PCA's job at Matheny. The daily tasks of living are challenging, and frequently impossible,

for most residents and students to do without help, and that's where the PCA steps in.

Brenda, now a PCA supervisor from 7 AM to 3 PM in the Red Zone of Matheny Hospital, says she loves all aspects of her job, including the hands-on work of stopping into each room in the morning to offer her assistance to the PCAs she supervises. She also loves to work with new employees. "I have a great desire to teach," she says, "and a great desire to learn." She's in charge of 12 to 15 PCAs.

While scheduling, coordinating, and monitoring the activities of Matheny's residents and their PCAs, and working closely with the nurses on the unit, take up much of her day, Brenda rarely spends a lot of time at a desk. "I move around, going from room to room each morning, helping out," she says. "I wear a Fitbit and at the end of every day, I've done 11,000 to 15,000 steps, meaning I've walked more than five miles." (10,000 steps equals five miles)

Residents do not stay in their rooms unless they're ill. Most go to the dining room for breakfast, and then move on to classes, the Arts Access program, the Hillsborough day program, doctors'

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Brenda Hoagland reads with Matheny resident Kimberly Alarcon

Matheny Made the Difference

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report from the nurse on how the patient did at night and what is scheduled for the day,” he says. “Then you would help the patient get up and get dressed, take them to breakfast, assist them with their grooming, and get them to class or appointments by 10.” The PCA then straightens up the room, picks up laundry, and sends the dirty laundry out to be done.

Lunch for the PCA staff at Matheny is scheduled for 11 to 11:30 or 11:30 to 12, and lunch for the patients starts at 11:30 or 12:05; and the PCA helps the client at lunch, and after, helps with “ADLs” or activities of daily living, such as chang-

ing a wet diaper, and gets the patient back to class or an activity. Residents are given showers every day, generally in the evenings.

“The personal care assistant may have four patients, two of whom eat by mouth and two who may get their nutrition through a G-tube,” he explains. “PCAs always have a PCA partner, and they work together to coordinate patient care.” Throughout the day, patients often have appointments at one of Matheny’s many clinics, such as dental, orthopedics, podiatry, and seating. Some adult patients go to the Hillsborough day program, leaving Matheny around 9 AM and returning between 3 and 4 PM. Some PCAs accompany these patients to the program.

While the duties of a PCA and a CRA overlap in many areas, the CRA generally works at a group home, and has

some additional duties, such as preparing meals, administering oral medications, doing general housekeeping, and driving residents to various appointments and recreational activities.

“Many of our staff stay on the job at Matheny a very long time—10, 15, 25, 30, 35 years,” Dr. Longa says. “One of the PCA-supervisors has been here for more than 40 years.”

Why? “There are some who say, ‘This is not for me,’” he says. “Those people know very quickly it’s not a good fit.”

“But for the others, they just love it. They understand the importance of their work to the lives of the patients.”

“As one of our PCAs said so well, ‘I can’t be late for work. My patients need me. They can’t get out of bed alone. We are their legs; we are their hands.’”

Family Ties

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appointments, and social and recreational trips. “I have a master board,” says Brenda, “to make sure that everyone gets where they’re going at the right time every day.” And, of course, the PCAs accompany, help, and ensure the safety of all residents as they go about their daily activities.

Training new PCAs is part of Brenda’s job. What does it take to do this job well? “You have to be flexible. No two days are ever the same,” she says. “And you have to be able to work in a team. And, above all, you need to be a caring person.”

“And you need patience,” she continues. “That’s very important. Many residents and students can’t speak; they use communication boards and head movements. It might take five or ten minutes for them to communicate their message. You have to hang in.”

While PCAs are not required to earn certification or licensure, there are educational programs available to them. According to Brenda, the State of New Jersey offers a “direct support professional program,” which can be completed

entirely online. About six years ago, she was among the first in the state to complete levels one and two of the program, and become State-certified. She then became nationally certified through the University of Minnesota—one of just 20 PCAs in the country

“There’s no place like Matheny anywhere in the state. It will always be a part of me.”

(at that time) to complete the rigorous requirements, including demonstrating competence in nine out of twelve specified areas. This is done by submitting a portfolio showing knowledge, skills, and experience in each of the areas, which is then reviewed by a panel of experts.

“The more I can learn, the better I can serve the individuals I work with,” she says.

While most of those individuals reside at Matheny, Brenda’s expertise has also



been critical in caring for family members. Several years ago, Alex was hit by an SUV and he was severely injured. Brenda stayed by his side, managing his rehabilitation. “I learned a lot from working at Matheny; and those skills all came into play,” she says. Now, she and one of her sisters, who is a paramedic and works at Matheny’s Lakeside Group Home for medically frail individuals, are dedicated to helping Alex maintain his independent living situation.

Brenda and her husband have also raised two daughters, now ages 24 and 35. The older one has had epilepsy since she was 12. “Because I learned so much about seizures while working at Matheny, I could handle this so much better,” she says.

For Brenda’s brother Alex, who continues to rely on Matheny for dental and medical services, including the wheelchair seating clinic, the school and hospital have been central to his well-being for decades.

And that holds true for Brenda, too. “There’s no place like Matheny anywhere in the state,” she says unabashedly. “It will always be a part of me.”

A Labor of Love

In Felicia Querrey's classroom, at Matheny Medical and Educational Center, creativity "rules." Art pieces line the walls and shelves, speaking volumes to those who enter the room. Drawings, paintings, sculptures, photographs, individual and group projects are all outpourings of students who often cannot talk and whose everyday communications take great effort. Here, a teacher with enormous enthusiasm for her job, and teeming with ideas of how to inspire and encourage her students, guides them to express themselves in inventive and telling ways.

Felicia is midway through her fifth year as a teacher at Matheny, but already she has learned a great deal. First and foremost, this is a profession she did not necessarily foresee for herself and she is still a bit surprised that she took to it like the proverbial "duck taking to water." She cannot even imagine herself in a different place or with other students.

Born in West Virginia, and raised in High Bridge and Somerville, NJ, Felicia always had an interest in teaching children. During her junior and senior years in high school, she was one of 12 students selected to run a half-day preschool on

the high school's campus. It was there she learned how to craft a lesson plan, create a positive environment for learning, and manage a classroom on a daily basis.

When she graduated from Ramapo College in 2007, it was with a bachelor's degree in visual arts and a certification to teach art. "But it was a tough time and I could not find a job," she remembers.

In 2008, through networking, she found out about a teaching assistant position at the Matheny School, and applied for and landed the job. "I had no experience with special education, but I needed a job and it was a foot in the door," she remembers. "What I found out is that I love it."

In her time at Matheny, the school has moved away from the self-contained classroom, where teachers and teaching assistants taught all subjects to a particular age group of students who stayed put in one classroom. It was in this type of classroom that Felicia says she learned an



enormous amount about teaching from her co-workers. "I love collaborative teaching," she says. "Teachers work together and learn from each other."

Felicia went back to school part-time and earned special education certification from Centenary University and, in September 2013, moved into a teaching spot at Matheny. Initially, she taught only writing, and concentrated on "giving students a lot of voice and a lot of choice." As part of her writing curriculum, she launched the *Bulldog Bugle*, Matheny's lively student newspaper, written and produced by the high school students. "From writing to peer editing, the students work very hard to put this together," she says.

In her second teaching year, Felicia added "Life and Community Skills" to her roster. This course covers topics such as health and wellness, practical money skills, community and safety awareness, and service learning projects. While all students at the Matheny School have complex medical conditions, they still want to reach out to assist others in challenging situations. Felicia and her co-teachers Shannon Hanrahan and Alisha Barreiro help students research the various options for projects, collaborate to raise funds, and then donate the funds to such organizations as the Red Cross, UNICEF, and the American Society for the Prevention of Cruelty to Animals (ASPCA).

Currently, the students are focusing their efforts on Operation Gratitude, an organization that sends care packages filled with entertainment, hygiene

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Wheelchair supplier, Ed Muraski, ATP, and occupational therapist, Maura Mirecki, OTR, ATP, with school student Nicholas Barros Perez.

Going the **Extra Mile**

This morning, like many mornings, the Matheny Wheelchair and Assistive Technology Clinic is abuzz with purposeful activity. This is the place where new wheelchair users—and also those who have new or changing needs—come to be evaluated, fitted, and trained to use their equipment by highly skilled professionals. This clinic not only specializes in wheelchairs, but also many of the associated devices that help those with complex physical disabilities stay active and perform necessary self care.

Life in a wheelchair presents challenges unimaginable to most. However, when a wheelchair is the “right fit” for its user, everyday barriers are minimized, and mobility and capacity to function independently are maximized. The connection between chair and user is an intimate one.

For director of assistive device technology John Reck, PT, who has worked at Matheny for 23 years, each day presents

new and unique challenges. The physical therapist’s enormous enthusiasm for his job is immediately evident.

He heads up a team of highly trained occupational and physical therapists, who work alongside “durable medical equipment” (DME) suppliers with explicit knowledge of the newest device parts. Taking care of each client involves a many-step process requiring input from multiple sources. With a 60-year history of serving those with complex physical disabilities, Matheny’s depth and breadth of experience and knowhow are hard to duplicate.

Cerebral palsy and spina bifida are among the more common primary diagnoses of Matheny’s residents and students, but they also have less common genetic disorders such as Lesch-Nyhan Disease (LND), Rett syndrome, Angelman syndrome, Cornelia De Lange syndrome, Wolf-Hirschhorn syndrome and

4Q Deletion syndrome. The clinic also serves outpatients, including children and adults who have incurred severe accidental injuries or stroke, or have progressive neurological or muscular disease that impairs their mobility.

But naming a disorder does not begin to suggest its many variations in expression. “Each of these clients presents unique challenges to our professional staff,” says Reck. “So, the approach is highly individualized.”

The director moves determinedly down the clinic’s hallway, pointing to shelves of equipment-pieces lining the walls—manual and power wheelchair parts, custom seating, specialized positioning devices—and comfortably furnished examination rooms. “That’s one of our great strengths here,” he says. “We stock so many wheelchair demo products. After we do our assessments, we recommend certain products for a client to try out; we determine what works best before any final decisions are made.”

“And we can make our clients comfortable when they need to get out of their chair,” he comments, pointing out a young woman reclining on a beanbag chair while her wheelchair goes through some fine-tuning.

Ensuring proper analysis, fitting, delivery, and training in the use and care of manual wheelchairs, power wheelchairs, and custom seating support systems are a big part of the work here. But clients can also try out a long list of other specialized equipment, including walkers, gait trainers, canes, shower commodes and tub chairs, mechanical transfer aides and lifting devices, supported standing and other adaptive positioning devices, and special needs car seats.

There are a host of considerations when determining the right fit for a wheelchair, with trunk support right at the top of the list. “Is the client’s trunk short or long, are the chest and hips narrow or wide?” asks Reck. “We need to identify the simplest item to meet the individual’s needs, and go to more customization when necessary.”

Postural deviations, skin protection (cushions can be filled with fluid, foam, gel, air, or a combination of these),

whether the client requires an IV pole or a gastric feeding tube to be attached, safety issues, and activities of daily living must all be considered and addressed. “For instance, we have a client with dystonia, causing her legs and feet to move a lot. We made her a custom foot-box, which allows her feet to move freely, but they are still protected from injury,” says Reck.

“Someone relies on that wheelchair 10 to 12 hours per day, and it needs to be there to do everything they do,” says John Reck, PT.

The clinic has clients of all ages; and the range of abilities is broad. “Some are more mobile, some are employed, some live in assisted living, others live independently. We see some individuals with intellectual disabilities,” the director explains.

While some clients have hand skills and can operate a power wheelchair with a standard joystick control, others may need alternative controls, such as a head array system with sensors placed inside a headrest for control of a power wheel-

chair. These alternative controls can be used for individuals with cerebral palsy or anyone who has difficulty with motor control or coordination.

Why does someone seek out the services of a wheelchair clinic? According to Reck, the individual’s current equipment may be aging or not meeting their needs anymore because “the client has significant changes in body shape or size, or may have a progressive illness, new or worsening postural problems, feeding issues, skin problems, or discomfort. Someone relies on that wheelchair 10 to 12 hours per day, and it becomes an extension of their body. It needs to enable their independence and support all their activities. That wheelchair needs to be there to do everything they do.”

The clinic team is composed of NJ licensed occupational therapists and physical therapists who are certified as assistive technology practitioners and seating mobility specialists. “Assessments for complex rehab equipment are best performed by therapists with knowledge and experience in this specialty area,” he says. “That is one of our greatest strengths.”

The clinic specializes in severe scoliosis; pelvic issues; windswept deformities (hip and lower limb deformities often seen in cerebral palsy); abnormal body shapes;



Above: Matheny resident, Anthony Santia, receives custom foam-place molding for wheelchair back support. **Bottom:** Assistive Technology team members (l-r): Maura Mirecki, OTR, ATP; occupational therapist Kimberly Siara, OTR, ATP; wheelchair supplier Ed Muraski, ATP; John Reck PT, MPT, ATP/SMS; and Lisa Tumminelli, PT, Director of Physical Therapy, with Anthony Santia

and postural instabilities. “It usually takes two or three visits to complete the evaluation and make recommendations; and another one to three visits at the end, when the recommended chair is ready-to-go,” he explains. “We have all the tools to evaluate and also to simulate what we think will work.”

The clinic also has a highly specialized “pressure mapping system” to identify areas at risk for pressure ulcers, a common skin breakdown that can be painful and sometimes causes massive infection. Those who are bedridden, use a wheelchair, or are unable to change position are particularly prone.

Matheny has also purchased “a high end molding machine that is housed in the wheelchair workshop, which adjusts electronically and can fine-tune seat cushions and back rests to wrap more comfortably around a client’s body,” the director says. This latest technology helps the team provide the right wheelchair for each individual.

“The complexity and importance of wheelchairs is vastly under-recognized. We are asking pieces of metal, plastic, wood, and foam to address and compensate for the physical limitations of an individual,” Reck states. “When we do it right and there is a good outcome for the wheelchair user, it is truly rewarding.”



A Wheelchair Like No Other

When is a wheelchair not simply a wheelchair? Don't know the answer? Well, like most Americans, you likely have no reason to know. But for the 2.2 million people in the U.S. who depend on a wheelchair for their all-around mobility, knowing where to go for the "right one" is crucial. And for wheelchair users and their families in New Jersey, Matheny's rehabilitation technology department is certain to meet their needs.

Kevin McCormick, director of rehabilitation technology at Matheny, knows wheelchairs from the ground up. He came to Matheny in 1976 as a personal care assistant (PCA), left for two years in 1979, and came back in 1981 "because I fell in love with the kids." When he returned, it was as part of a newly developing rehabilitation technology program, which included rehabilitation engineering. "We were part of a growing movement to make independent living more possible," he says.

McCormick explains that wheelchair manufacturers mass produce the parts, such as seat cushions, back cushions, headrests and other components. "However, no one seating system comes out of the box and is OK for an individual," he says. "We work closely with occupational and physical therapists, and make modifications for each individual to meet their unique needs."

For many students and residents at Matheny, and others in the state who have complex physical disabilities, the department's workshop can build a unique wheelchair. "We compile parts from five, six, seven manufacturers," says McCormick. "We may use a seat cushion from one, a back cushion from another, a chest vest from a third." The department serves approximately 400 clients annually.

However, for some clients, the compilation of ready-made parts doesn't do the job. In those cases, the department's workshop fabricates some, or all, of



Kevin McCormick

the wheelchair's components. "Clients' bodies may be contorted and they may have deformities in their spines and need special support. They may also need special padding for their feet in order to keep upright and well-positioned," explains McCormick. "And sometimes everything needs to be customized for the protection of the client."

The department has two certified assistive technology professionals (ATPs) and one in training, who are part of each client's evaluation process. According to the Rehabilitative Engineering and Assistive Technology Society of North America (RESNA), the ATP certification "recognizes demonstrated competence in analyzing the needs of consumers with disabilities, assisting in the selection of appropriate assistive technology for the consumer's

needs, and providing training in the use of the selected device(s)."

Matheny's students and patients have diagnoses with many serious associated clinical conditions, such as vision and hearing deficits, seizure disorders, and dysphagia, which often require accommodation when planning a client's wheelchair. Clients' conditions also change over time and these changes may impact the comfort and functionality of the wheelchair.

Insurance coverage, based on input from many sources, will ultimately govern what can be provided; and working with the insurance companies to help determine the outcome is a responsibility of the department. "This is very complex," says McCormick, "and involves looking at how a person is sitting; looking at the

current wheelchair; determining what is working and what is not; collecting input from parents, the bus driver, teachers, therapists, caregivers—from the client’s entire team. We need to understand how this wheelchair will be used.”

There is a large amount of paperwork to be completed, including the collection of all documentation relating to the client’s wheelchair needs, as well as prescrip-

For many students and residents at Matheny, and others in the state who have complex physical disabilities, the department’s workshop can build a unique wheelchair.

tions for medications and other medical necessities. This information, along with the proposal for a new or revised chair, is sent to the physician for sign-off. After all the required documentation is received, the request is sent to insurance and if approved, the turn-around time from the authorization to delivery is generally 30 to 60 days.

“It’s tough for people to find a place that can do these evaluations, especially for Medicare,” he explains.

The department and its workshop, while handling the required paperwork for each project, is really a small manufacturing plant, where highly skilled technicians do the hands-on work required. The staff make custom cushions from molds taken of the individual’s body; cut cushions to accommodate leg-length discrepancies; fabricate custom pads and custom foot-boxes with padding; configure reinforcement plates for head rest attachments; devise belts to hold the client in place; and construct all kinds of safe-guarding equipment and devices to prevent injury to the client.

“We have a full shop of technicians and tools to do whatever accommodation is needed,” says McCormick, “and we even

have a full-time upholsterer.” When the new or modified wheelchair is ready, a therapist is there with the client to make sure all concerns have been addressed and it works properly for the individual.

The shop also does repair work, even “a quick repair whenever possible,” says McCormick. “We can adjust brakes in just a few minutes and return the client to his activities.” The technicians are all busy, “but they can be flexible to fit in repairs.” Everyone here knows that to be without your wheelchair for even a day may necessitate staying in bed, since those with complex physical disabilities often cannot swap out another wheelchair, even for a short time.

A quick tour of the workshop reveals the intricacies of the technical and creative processes that result in a functional, comfortable wheelchair. Staff even invent wheelchair pieces to fill new, as-yet unfulfilled needs.

Such was the case of the custom “iPad holder” invented by the workshop’s upholsterer. Students and residents often rely on the iPad to link to the internet; but the iPad frequently drops to the ground or slips from eye-level and comfortable reach. An innovative new product was born out of this observation and a professional staff member’s ingenuity.

Also housed in the shop is the wheelchair washer, a piece of equipment purchased with funds raised by the Friends of Matheny. Wheelchairs are in almost constant use, necessitating a periodic thorough cleaning. Every Matheny resident’s and student’s wheelchair finds its way into this large stainless steel machine.

“This is a field where products are constantly changing, and staff is always seeking out training to keep on top of all innovations,” says McCormick. It’s the goal of helping every client achieve freedom and independence that inspires staff members to always go the extra mile.

Top: Patrick McCarthy repairing a client’s wheelchair; second from top: the rehabilitation technology team; bottom: Christine Whitworth creating assistive equipment



A Visionary Dentist

continued from page 2

Did her visits to Matheny have anything to do with her choice of a profession? “I’m sure it did,” he responds.

“I know that anyone who is thinking of volunteering or giving a charitable donation will find this place hard to resist,” he says. “My passion for Matheny has been my primary hobby for years.”

“And to think it all came about over the \$1,500 donation from Delta Dental many years ago that we couldn’t give away because we couldn’t find a dentist who could do this work there. So we visited the campus and realized that patients could not get the dental care they needed here or anywhere on the outside,” he remembers. Now they can.

“Matheny is God’s gift to New Jersey,” he says. “There’s no other place like it.”

Leading “The Friends”

continued from page 3

astounded,” she says. She is making a personal appeal to previous members, as well as to families of students and residents, to join the Friends of Matheny and participate in the activities. “We already have six parents on the Friends Board,” she says.

Also among her priorities is continuing the Friends’ tradition of funding a major facility-improvement project. The group is currently underwriting the renovation of the family dining room. “It’s a space for a visiting family to have a meal with their child,” she explains. “We want to make it more comfortable, more of a lounge with a couch, comfortable chairs, a TV, plus a table, where a family can spend some time.”

“We always try to take on a big project,” Kathy continues. “I would love to be able to fund more projects like this

one.” Fundraising to furnish future group homes is just one of the projects she’s thinking about.

Of course, that’s in addition to the many “smaller” activities and events that the group supports, including wrapping hundreds of holiday gifts, providing food after the Halloween parade, sponsoring the Staff Appreciation event, holding a Day of Beauty for the women residents and older students, ordering breakfast for participants in Miles for Matheny, and working to keep the thrift shop running.

What the Friends’ president would like best is to communicate her personal satisfaction and joy in volunteering at Matheny to others who might have a few hours to spare. Those hours could be well spent volunteering at Matheny in any number of different capacities, she says. “I’ve spent a lot of time at Matheny over the last 10 years and it’s been well worth it. My kids got involved, too. It’s always so inspiring to be here.”

A Labor of Love

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products, handmade items, non-perishable snacks, and personal letters of appreciation to U.S. Troops, First Responders, veterans, military families, and wounded heroes and their caregivers. The students are collecting items and assembling packages that they will send out.

“Through Service Learning Projects they learn to do research on computers, the SMARTBoard, and iPads, finding out about a charity’s history and goals,” she explains. “The students also design flyers and posters, use email to interest family and friends in their fundraising efforts, and learn many other skills as they collect the donations,” she says.

In her third teaching year, Felicia added art to her teaching line-up, firing up her own and the students’ creativity. “I love sketching and I love lettering—graffiti style,” she says. “I enjoy experimenting.”

Teaching elementary through high school students, she tailors her art classes to the age-group. She introduces the youngest students to different materi-

als and styles, and encourages them to experiment. Upper elementary classes participate in the Festival of Living Art. Students research famous artists and create displays to bring the artists’ work to life in Matheny’s hallways. “This is the Festival’s third year and the students love it,” she says.

At the high school level, Felicia challenges students by offering different topics each marking period, including photography, sculpture, drawing and painting, digital art, and mixed media. The individual portfolios of each student’s work display the breadth and depth of their accomplishments in this class. A pop-up exhibit of the students’ work at the Morris Museum each winter is an exciting testament to their achievements.

As if all those courses weren’t enough, Felicia added PCAST—or Person-Centered Approach in Schools and Transition—to her teaching specialties last year. The focus is on “Person-centered planning” and is another co-teaching opportunity, pairing Felicia with speech-language specialist Brynna McGinnis. The course-content is aimed to prepare 18- to

21-year-olds for life after graduation from the Matheny School.

The transition from school to adult services and group home living is a big one, producing anxiety for many parents and students, Felicia explains. This course is designed to lessen that anxiety. As part of the curriculum, participants prepare an “All About Me” brochure, which includes photographs and information that will serve as an introduction, and present guidelines, for students in their post-secondary life.

The feedback has been so positive, and so gratifying for the teachers as well, that Felicia would like to introduce PCAST in the eighth grade, and maybe even in lower grades.

With a crowded “job description” that would send many teachers into a tailspin, or maybe even out the door, what keeps Felicia in her classroom? “I love the kids and I can be creative,” she answers. “And I am always supported in my creativity by the school administrators. I can go to them with any idea for something new,” she says unhesitatingly. “That is very valuable.”



Remembering Chuck Matheny

It's no exaggeration to say New Jersey's educational landscape would be vastly different if not for Charles (Chuck) Matheny and the visionary outlook and incredible tenacity of his parents, Marguerite and Walter. Born in 1941 with cerebral palsy, Chuck died on December 14, 2017, at age 76 in his home on the campus of the Matheny Medical and Educational Center in Peapack, NJ, where he lived for most of his life.



A look back to the early 1940s discloses how little there was in the way of educational opportunities, medical therapies, and living accommodations for children with complex developmental issues, and also how little was understood about the mental capacity and learning potential of children born with cerebral palsy. This was the arid landscape that Chuck's parents, both educators and both deeply committed to their son's well-being, saw when they explored available opportunities for him.

There were few. So they stepped up to the plate, so to speak, eventually setting many wheels in motion. Originally from Minnesota, they left their home in the Midwest when Charles was very young, moving around the country for Walter's work as a U.S. Air Force Civilian Consultant and to search for a therapeutic and educational program that would meet their son's needs. They settled in New Jersey when Walter became the manager of a newly established school in the State.

Just a few months later, Walter and Marguerite made the decision to found their own school. Walter had experience working with physically disabled children and severely injured GIs returning home after World War II. They both had ideas for what a new school could, and should, provide; and both had the drive and commitment to make it happen.

In 1946, they founded the Burnt Mills School for Paralysis Correction with just three students and an annual operating budget of \$3,000, which they obtained through a GI loan. While the school's first years were fraught with significant financial and operational challenges, Matheny's founders were determined; and as word got out about their endeavor, students came from across the U.S. and abroad to matriculate. By 1949, the school had enough students to support a move to larger quarters in Far Hills; and in 1954, the school moved again, this time to its current site on "the hill" in Peapack.

Creating a school that would provide the breadth of services needed for Chuck and others with cerebral palsy became his parents' passion; they lived on the campus and worked very long hours, he as director of the school and she as associ-

ate director. It was here that Chuck grew up and it is where the family brought Chuck's adopted sister, Mary Ann, 11 years his junior, when she was a month and a half old. "He was part of the family's decision to adopt me," says Mary Ann Bents, now an IT Project Manager at NASA Goddard Space Flight Research



top photo: Marguerite and Walter Matheny;

bottom: (l-r, standing): Gregg and Mary Ann Bents; Zoe, Mary Heather, and Maggie Noble; and Chuck Matheny (seated)

Center. "He helped pick out my coming-home clothes and helped build blocks for me. All of that speaks to who he was."

"He was funny, really funny, and he knew how to make people feel at ease,"

she tells. "He adored children and animals, and they adored him." She remembers him riding around the campus as a teenager in the evenings on a motorized buckboard. "After the buckboard, he had a series of golf carts. The neighbor's dog rode in the golf carts with Chuck—as his sidekick. It was very funny to see."

"The school was a 24-7 job for mom and dad," she recalls, but nonetheless, both she and her brother were given "unique and personalized time with our parents. They made each of us feel very special."

"As I grew up, Chuck and I spent a lot of time at the school together—hanging out with students," she says. She remembers that Chuck and some of the other students improvised a baseball game in which crutches and wheelchairs played a prominent role.

A graduate of Bernards High School, where Chuck attended football games when his sister played in the school band, Mary Ann thinks that "growing up at Matheny gave me a different perspective from most kids on many things. I learned acceptance and appreciation for different people and I learned about inclusion at an early age."

When Mary Ann started college at the University of Arizona, "the whole family flew out to deliver me, Chuck, too," she recalls. She says he could walk with crutches, feed and bathe himself, talk quite clearly, and enjoyed every aspect of this independence. He loved to do many things, she says, including "going out to eat, listening to music, going into New York City to see Broadway shows and the Ice Capades, and traveling to see new places. He would come to visit us on his own when I first got married and lived in Arizona."

Those who met Chuck later in his life saw a man with the same zest for life, the same positive outlook and sense of humor, but with progressively waning physical abilities. His niece, Mary Heather Noble, says her uncle was a "fixture in my life." She grew up in Ohio but visited her Matheny family in New Jersey once or twice each year.

When she was 7, Mary Heather remembers a summer visit when her uncle

could still walk well with crutches and would push his own wheelchair stacked with soda cans for refilling the machines around the campus. “Everyone would stop and talk with him. Walking with him, I would feel so special,” she says. He was also in charge of mowing all the lawns at Matheny with his tractor mower—not a small undertaking since the grounds are quite extensive. He took his jobs seriously.

A golf cart became his primary mode of transportation around the hilly campus. Mary Heather remembers riding in the golf cart with Chuck to the Blairsden Mansion, “one of his little adventures.”

“In his late 40s, when I was a teenager, he earned a driver’s license, and proudly drove a van (locally) that everyone fondly called the Chuck wagon,” she recalls.

She remembers his love of music, his desire to “venture out in the world,” his enduring attachments to friends, and his devotion to the Basking Ridge Presbyterian Church, where he was a member for more than 50 years. “His faith was so strong and he was an everlasting optimist,” she observes. “He was never discouraged. And he was very patriotic.”

He was also a successful fundraiser, taking huge satisfaction when he raised money for his adopted causes, chief among them the CROP Hunger Walk, a worldwide effort to fight hunger globally with events at the local, community level.

During his last weeks of life, Chuck and Mary Heather watched *The Sound of Music* together in his hospital room. “He enjoyed the movie so much,” she says. “Chuck was singing along with it, even as he was suffering in the hospital. It just captures the kind of spirit he had—enjoying all the things that life gave him until the very end.”

“He had such a big inner spirit, he was such a joyful man with a tremendous internal drive,” she comments.

Did he mind being in the limelight? “No,” she answers. “He believed he was put on this earth and given his condition so his parents would start the school and he could show others by example. He always had such a sense of purpose.”

In addition to family, friends, and students, Chuck also inspired many Matheny staff members. Trisha Matheny, age 25,



“He had such a big inner spirit, he was such a joyful man with a tremendous internal drive. He believed he was put on this earth and given his condition so his parents would start the school and he could show others by example,” says his niece, Mary Heather.

was born and raised in Minnesota, and yes, she is Chuck’s relative, but a distant one. She had never met Chuck and did not even know if he was still living before she arrived in New Jersey for a job. She had another relative who was developmentally delayed, and became interested in working in this field. She was strongly attracted to Matheny “for what it encompasses and strives to do,” she says.

“I met Chuck on prom night in 2015. ‘You must be Mr. Matheny,’” she remembers saying. “Guess what? I am a Matheny, too. I just moved here from Minnesota.”

Chuck was instantly intrigued and took Trisha in as his “baby cousin.” With most of her family in the Midwest, Chuck always reminded her that she was “home”

with him. “He took me under his wing and loved me like only family could,” she says. Because of the relationship shared between Chuck and Trisha, the “Minnesota Mathenys” and the “New Jersey Mathenys” were reconnected and “they have shared the joy of getting to know each other,” she says.

What would she like people to know about him?

“He loved life and he cared about the world. He had a wonderful sense of humor. He never gave up, never got frustrated if you couldn’t understand him. His patience was astounding. Every person he met touched his life and he was special to so many people. He loved people and had so many friends,” she says. “He was a great man.”

Tara Hopko, an occupational therapy assistant, met Chuck Matheny on her first day on-the-job in 2004. Like Trisha, she says, “I always wanted to work at Matheny. I was drawn to the place.”

What drew her? “I loved the story behind Matheny. I loved the family orientation of the place,” she says. When she arrived, she found exactly what she was looking for.

What she hadn’t banked on was meeting Chuck Matheny and forming such an indelible friendship with him. “We just adopted each other,” she states.

What did she notice first about him? “His sense of humor. He had such a great sense of humor,” she answers. “He was such a cool person.”



top photo (l-r, standing): Maddie, Tara, Matt, and Lexie Hopko; and Chuck Matheny (seated)



“He never asked, ‘Why me? Why do I have these burdens?’ He had such grace, such courage, and gratitude.”

Their relationship started in Matheny’s hallways. “I would stop and chat every time I saw him in the halls,” she remembers. “Sometimes he was difficult to understand. You needed to take the time to sit and listen. He had a lot to say.”

Chuck told her about his parents, his sister, his niece; and as the friendship progressed, she would spend time talking with him at her lunch break or after work. “It made me feel good and it made him feel good, too,” she says simply.

As Tara’s friendship with Chuck grew, she invited him to spend time with her family. It started with Easter, grew to include his birthday and Thanksgiving, and finally Christmas, too, when he could no longer make the trip to Las Vegas to visit his close friend Linda. “My two girls started calling him Grandpa Chuck and my mother did, too,” she remembers. “He would come to my kids’ school concerts and the school would save him a seat in the front row.”

Tara’s daughters were born in 2006 and 2008, and by 2009, Chuck was spending all holidays with Tara’s family. “He was like a father to me,” she says. “We needed each other.”

Professionally, she saw that he had capabilities that were not being used. “He did not want to be seen as a patient; he wanted to be seen as a mentor. Independence was a huge thing for him,” she observes.

But she knew he loved the water; and she encouraged him to swim with her twice a week in Matheny’s pool in warm weather. In cold weather, he joined a senior aerobics class at the YMCA and he would try to do all the exercises. She went with him. “We had a blast. It was such fun!” she says.

Tara also encouraged him to ride the adaptive tricycles available at Matheny. “He biked every week religiously,” she remembers. “He rode around the hallways like a mayor.” She also attended clinics with him sometimes, so she could help make his needs known.

Chuck maintained a great deal of his independence until a few years ago, when it was decided that he needed 24-hour care.

“But his aides were like family to him. They just wanted him to be happy,” she says. The aides, too, joined Tara’s family to celebrate holidays.

Chuck loved music and he liked to show his gratitude to those who were kind to him. About four years ago, he bought tickets for Tara, her family, for Marta, the caregiver, and for himself to attend a concert given by an ABBA trib-

ute group at the Mayo Performing Arts Center in Morristown. It is one of Tara’s best memories.

“When everyone in the audience stood up near the end of the concert, Chuck couldn’t see the stage. My husband and I stood him up at the end of the concert, and held him there, so he could see too. My husband’s a big, strong guy, but even he was moved to tears,” she recalls.

Even at the end of his life, “until his last moments, he was joking with me. He had so much grace,” Tara says.

“Knowing Chuck makes you want to be a better person, more grateful, more gracious. He has transformed my husband and me. He has had such an impact on us.”

“Chuck was such a great spirit,” she concludes. “My life is never going to be the same.”

The compassion, determination, and hard work of Walter and Marguerite Matheny, on their son’s behalf and on behalf of all children with cerebral palsy, laid the solid foundation for the sophisticated special hospital, educational facility, and group homes for children and adults with medically complex developmental disabilities that make up the Matheny Medical and Educational Center today. That compassion and commitment are still at the very heart and soul of the education and care provided.

In 1966, 20 years after the school’s founding, Walter Matheny said, “Time and time again I hear parents ask the same question I asked 25 years ago—‘Why me?’ I had no answer then, but I believe I have one now. If our son Chuck had not been born with cerebral palsy, Marguerite and I never would have gone into this work, the school never would have been built, hundreds of children never would have been helped by the wonderful staff we have been able to assemble.”

Matheny Medical and Educational Center will continue as a living tribute to Chuck Matheny, his family, friends, and all of the staff and volunteers who have had the foresight, devotion, and, above all, the love to help build and sustain the Matheny-vision.

The 2017 Honor Roll of Donors

Individuals, corporations, organizations, and foundations generously helped support every aspect of life at Matheny during Fiscal Year 2017. 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, 2016 and June 30, 2017.

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In 2017, the **Friends of Matheny** once again donated \$150,000 to Matheny for projects that benefit students and patients. More than 140 volunteers generously give their time to support the Second Chance Thrift Shop, the group's primary source of earnings. "The Friends" have donated more than \$3 million to Matheny.



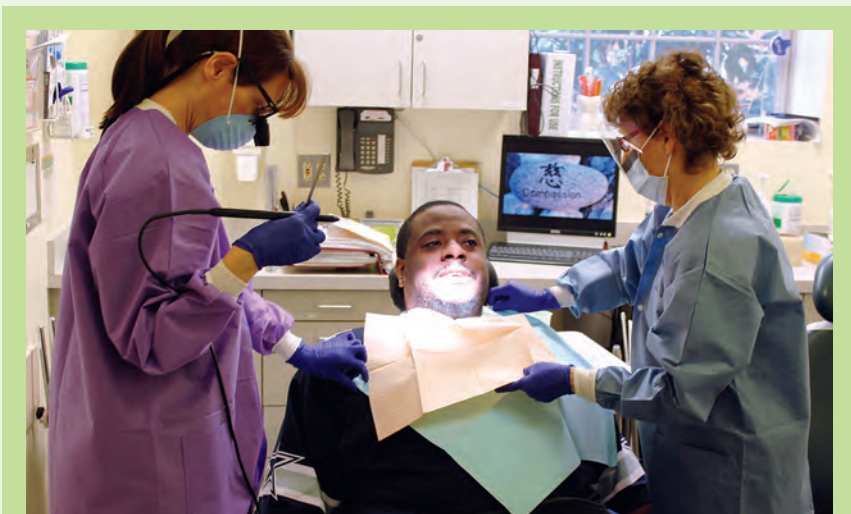
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The **Delta Dental Foundation of NJ** recently donated \$50,000 to support the hiring of a new assistant for Matheny's specialized dental clinic. They provided the initial funding to help Matheny build the clinic that is part of its Center of Medicine and Dentistry. Through the years, Delta Dental has donated substantial funding to help make dental care accessible to individuals with disabilities.



The Investors Foundation generously donated \$10,000 to help support Full Circle, the annual multidisciplinary arts event showcasing the work of participants in Matheny's Arts Access Program, which encompasses painting, digital art and sculpture, dance, drama, and creative writing. The Foundation also provided key funding support for the newly redesigned Arts Access Website. Arts Access is currently celebrating its 25th anniversary.

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For more information on how to join Matheny's Honor Roll, contact the development office at development@matheny.org.

Her Art Speaks Volumes

On Thursday afternoon, January 11, Laura Pittman excitedly entered the Robert Schonhorn Arts Center on Matheny's main campus in Peapack. She was on a mission.

On her mind was the large painting she had recently purchased from artist Cindy Shanks, a long-time participant in Matheny's Arts Access program. Laura would be traveling back to Washington, DC, soon, where she is a second-year student in American University's Master of Arts Management program. Her passion is fostering the abilities of disabled artists. She recently returned from the University's Arts and Business semester at Sotheby's in London.

Laura was concerned about the size of the artwork and how to safely transport it to her home. As a high school student, she volunteered at Matheny and continues to be interested in the Arts Access program and how disabled artists work. She is always on the lookout for pieces that grab

her; and Cindy's painting did just that.

Cindy, a resident of Matheny for more than 25 years, spends hours each week working on her paintings, choreography, dramatic work, and creative writing. She often works on more than one painting at a time.

A Page County, Virginia, native, she was born with cerebral palsy, and is unable to speak or walk. She came to Matheny at age 12 and graduated from high school at age 22.

"As far as colors, I pick one and go from there," she explains. "I choose them based on how I'm feeling. When people look at my paintings, I want them to really look at them. My style of painting has changed a lot over the years. When people see my work, I want them to feel good. I like to take risks."

Cindy's work is on display in her home state, and also has been shown at the University of Medicine and Dentistry of New Jersey in Newark, Rutgers Uni-



versity, Johnson and Johnson, and the Monmouth Museum, among others.

"Cindy is an incredible artist, in the sense that any time she works on something, whether it is art or choreography, she has a clear vision," says Heather Williams, a performing arts coordinator with Matheny's Arts Access program.

That vision speaks strongly to Laura Pittman, who safely transported Cindy's painting to her home and feels lucky to be able to enjoy it every day.

Brave Bag Launch

Teddy bears are cute, cuddly, comforting creatures that can calm, soothe, and cheer a troubled child. When children are scared, a teddy bear can come to the rescue.

This simple knowledge led residents of Matheny's Adult Services Program to create the "Brave Bag" project. Nicole Araujo and Deanna Willard, program staff members, met with residents of the Adult Services program, explaining that police officers always ride with teddy bears in their cars, because the bears comfort frightened children.

That understanding inspired the launch of a unique project. The Matheny participants wanted to provide an additional support to children in an emergency situation who are scared and need help to feel brave. And so they came up with the



name "Brave Bags" for a gift that comes from their community, whose residents understand how hard it is to stay strong when facing tough challenges.

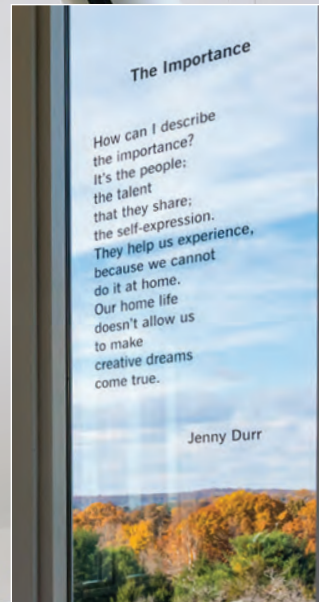
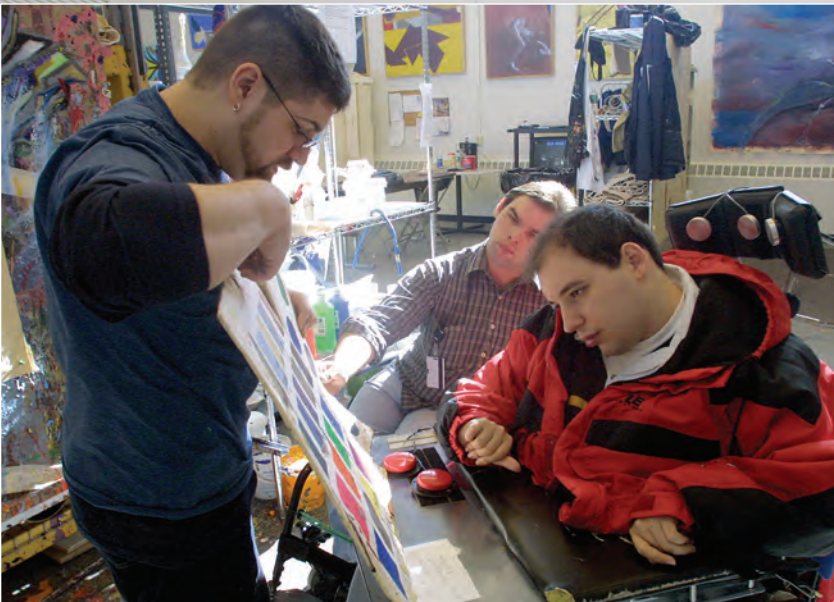
All Matheny Adult Services residents are able to play a role in some facet of preparing, assembling, and decorating the small, drawstring bags, which are filled with crayons, a coloring book, bubbles, a bouncy ball, and a small game or toy. The

bags themselves are hand-decorated with flowers, super heroes, sports team logos, and other lively images.

Each bag comes with an important message from those who know: "From your friends at Matheny, 'You are braver than you believe, stronger than you seem, and smarter than you think.'" (A.A. Milne, *Winnie the Pooh*)

A small ceremony was held to present the Brave Bags to the Peapack Gladstone Police Department. Matheny residents took enormous pride explaining how the bags are created and what role each resident plays in the process. The Brave Bag project continues to expand its reach. Bridgewater, Middlesex, Chester, Mount Olive, Somerville, and Hillsborough police departments have all agreed to partner with Matheny.

Meanwhile, the project not only keeps Matheny residents engaged and more connected to their community than before, but provides a most welcome gift to children in distress.



Arts Access Turns 25

Matheny's Arts Access Program turns 25 this year and, oh, what a lot it has to celebrate. Just look at the vibrant life-size paintings lining the walls of the Robert Schonhorn Arts Center, contemplate the cutting-edge choreography and dramatic works played out on the Center's stage, and savor the powerful poetry and other literary pieces created by participants. All of the art is the unique work of individuals with complex developmental disabilities who, in 1993, were given new and unique tools, allowing them to fully participate in the creative process.

This was a pioneering experiment, resulting in great successes. Communication systems were developed, using "facilitators" as conduits, enabling even non-verbal and wheelchair-bound artists with limited range of motion and mobility, to fully express themselves. The facilitators, working professionals in their areas of expertise, have been trained to be the arms and legs of the disabled clients. They consciously maintain a sense of neutrality throughout the creative process so that the client-artists' work is completely their own.

What started in 1993 with visual art grew to include digital art, sensory painting, choreography, creative movement, creative writing, and drama, each with a unique communication system developed by Matheny Arts Access staff.

Each year in November, friends, family, fellow artists, neighbors, and art-lovers gather at the Arts Center on Matheny's main campus to view and celebrate the artists' work. Called *Full Circle*, the event features a visual art exhibit and on-stage performance pieces by Arts Access participants.

Arts Access helps change perceptions about the capabilities and talents of people with developmental disabilities, and fosters an environment of creativity among the participants. The program was recently approved to receive a **\$10,000 Challenge America grant from the National Endowment for the Arts (NEA)**. The grant supports projects that extend the reach of the arts to underserved populations. The award will help Matheny honor and celebrate the achievements of its artists with disabilities at its annual fine arts showcase, *Full Circle 2018: Then and Now*, on **November 3, 2018**.

For more information, go to www.artsaccessprogram.org



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A collage of four photographs: top-left shows cyclists in green and black gear; top-center shows a group of military personnel in camouflage uniforms with one man in a wheelchair; top-right shows a group of children in yellow shirts running a race; bottom-left shows a man in a red and white striped costume interacting with a child; bottom-right shows a man in a yellow shirt and white cap sitting in a wheelchair.

#celebratechuck

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For more information contact us at info@matheny.org or call (908) 234-0011, ext. 260