

# matheny**matters**

Summer 2017

## **Nurses** Make All the Difference



THE ARTS ABOUND | TOP GRADES FOR OUR SCHOOL | VOLUNTEERS WITH VISION

Kendell Sprott, MD, JD  
President and CEO



## Getting to Know You

Expertise in any profession encompasses far more than proficiency in a particular skill set. An expert is an authority in a specific subject or activity, as well as a master of problem-solving in that field.

At Matheny, where many of our clients have complex physical disabilities and are nonverbal, expertise means so much more. Our experts are well-trained and experienced in their areas of specialization, and are always pursuing additional education and training. But they are also highly motivated leaders, compassionate teachers and caregivers, innovative and creative individuals, and, above all, passionately dedicated human beings, who want to provide every opportunity for our students, residents, and patients to live full and satisfying lives.

In this issue, we introduce you to just a few of our many experts. Because Matheny is composed of a school, a specialized hospital, and group homes, we've

tried to cover a range of employees and volunteers who contribute to the well-being of the entire enterprise. You will read about our school principal; our recreation therapy director; the medical and nursing directors of our hospital, and a fairly recent recruit to our nursing department; a volunteer who has headed up our highly successful thrift shop for more than 20 years; and another volunteer whose community outreach activities have engendered amazing results. Each of them is a standout, and together, they constitute an extraordinary team.

We also present to you some of the exciting happenings of the first six months of this year, including: Matheny's earning of The Joint Commission's Gold Seal of Approval for Hospital Accreditation for its special hospital; the highly successful 20th anniversary Miles for Matheny event in early June, which raised more than \$110,000; the \$150,000 gift donated by the extraordinarily dedicated Friends of Matheny volunteers; and our school's graduation of six stellar students in June. You can read more about these events inside this issue.

In future issues, you will have the opportunity to meet more of our experts and get to know some of our patients, students and alumni, who credit their ability to engage in everyday activities, as well as achieve long-term goals, to the spirit and efforts of so many members of Matheny's staff and dedicated volunteer group.

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On the cover: Matheny nurse Kacey Zane with patient Rasheedah Mahali

## mathenymatters

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## Community Counts

In late February, an “army” of Home Depot volunteers converged at Matheny, armed with paint brushes, ladders, tape, and paint, and set to work. In just a few hours, the adult instruction area, three bathrooms, and four classrooms had fresh coats of paint. Volunteers also cleared the nature trail of winter’s residue, opening the path for parents, students, and clients to amble through. Home Depot’s



first volunteer project was in 2011. Their continuing generosity—and hard work—has touched everyone at Matheny.

Top: (l-r) Home Depot volunteers Paul Lundhol and Store Manager Mike Urenko, and Matheny volunteer Larry Thornton.



Left: Home Depot Store Manager Jeff Pemberton (second from right) leads a group of Home Depot volunteers. Center: Sean Murphy, principal of Matheny School.

## Birthday Wishes for Chuck Matheny

On March 29, friends, staff, students, and residents turned out to celebrate Chuck Matheny’s 76th birthday—remembering his pivotal role in the founding of Matheny.

In 1941, when Chuck was diagnosed with cerebral palsy shortly after his birth, his parents, Walter and Marguerite, made up their minds to change the “landscape” for their son and others with complex physical disabilities. At the time, the outlook for these children was very bleak. Five years later, they opened the Burnt Mills School for Paralysis Correction with three students and an operating budget of \$3,000 obtained through a GI loan. However, word spread and enrollment in the school increased, as did the need for more staff and additional space. On March 14, 1954, there was a groundbreaking on the



Chuck Matheny blows out his candles with Lynn Coyle, director of Matheny’s music therapy program.

hillside in Peapack, NJ, for the first building of what is now the Matheny Medical and Educational Center. As CEO and President of Matheny, Dr. Kendell Sprott, points out: “His parents’ love for Chuck created all we have here today.”

## Going for the Gold



Matheny’s special hospital recently earned The Joint Commission’s Gold Seal of Approval® for Hospital Accreditation, reflecting its commitment to providing safe and effective patient care.

During a rigorous onsite visit, Joint Commission experts evaluated compliance with hospital standards in emergency management, environment of care, infection prevention, infection control, leadership, and medication management. Surveyors also conducted onsite observations and interviews.

“Our patients are our highest priority. Staff from this organization work together to continuously improve the quality and safety of patient care and to develop and implement approaches that will potentially improve system reliability for our patient-community,” says Dr. Vincent Barba, Chief Medical Officer and VP of Patient Care and Safety.

## Save These Dates

*Matheny schedules special events throughout the year. Here are a few you won't want to miss.*

### **Matheny School's Second Annual Golf Outing • Par-Tee on the Links2 Tuesday, September 26**

Oak Hill Golf Club, Milford, NJ. Go to <https://events.matheny.org> to sign up.

### **Arts Access Full Circle 2017: Art of Possibility Saturday, November 4**

Robert Schonhorn Arts Center, Peapack, NJ. Visit [www.artsaccessprogram.org](http://www.artsaccessprogram.org) for more information.

### **Second Season of Art Garden CSA Ongoing until year's end**

Go to [www.artgardencsa.org](http://www.artgardencsa.org) to purchase a share of art or individual pieces created by artists with disabilities.



## Has Never Looked So Good

**T**he Second Chance Thrift Shop in Gladstone, NJ, is a labor of love and a concrete testament to the ongoing dedication of 142 volunteers with a mission—to earn as much money as possible for a cause close to their hearts. For the past 10 years, they have raised more than \$100,000 annually to support a broad array of projects at Matheny.

You might think of their work as spinning straw into gold—not unlike the Rumpelstiltskin fairytale—but in this case taking new and “gently used,” high quality donated items and selling them to a devoted clientele for prices that move most merchandise out the door quickly. The cash then goes through a second transformation—purchasing items and services to enhance the lives of Matheny’s students and residents from a “wish list” submitted by teachers and staff.

Leave your prior notions of thrift shops at the door—this one is unique in many important ways. Merchandise is artfully displayed and meticulously organized, not tossed hodge-podge in bins. Visit once, and when you return, you’ll know exactly where to go for children’s games, men’s jackets, jewelry, books, or women’s shoes, to name just a few categories. Special holiday and seasonal displays are eye-catching and colorful; and you won’t trip over merchandise or other shoppers. There is plenty of space.

Go on vacation and you risk missing out on the evening gown you’ve been yearning for or maybe a baseball card table you were never before able to locate. Older items are moved out regularly and shelves are continually replenished.

At the helm of this enterprise is Linda Horton, the manager for 20 of the 33 years that the shop has been in operation. When she and her husband moved



Linda Horton

to Peapack in 1989, she knew next to nothing about Matheny. She quickly rectified that situation, joining the Friends of Matheny volunteer group and signing up to work in the thrift store. In 1997, she assumed her current challenging position. An enterprising individual, she looked for

**One way or another, every donation raises dollars, and that’s the point. “This is recycling at its best,” she says.**

ways to improve the business in order to make it more lucrative.

Trained as an elementary school teacher, she nevertheless has excelled in the world of small business, making operational changes that have yielded impressive results. She opens the doors six mornings each week, works an hour or two, then leaves and comes back for an hour or so before closing. “Every volunteer knows how to open and how to carry on without me,” she says humbly. The

well-trained staff is comprised of men and women of all ages, some 90 and older.

Linda’s goals include accepting and then selling all items that will “fit” into the store size-wise—and even some that don’t; and maintaining an ongoing relationship with clients. She sends out a weekly newsletter via email that features the store’s newest items to a mailing list of 400. In addition, a monthly newsletter displaying photos of “some of the more interesting donations” is emailed to more than 200 regular clients. “The quirkier the item, the better it sells,” she observes. Add to that a lively and frequently updated Facebook page and you know some of the ingredients of the store’s success.

In addition to her emphasis on communicating, the manager’s philosophy of “recycling” is critical. She believes that every donation can be put to use. Clothing that doesn’t sell after several weeks of price reductions is sold cheaply in bulk. Damaged silver and gold jewelry can be melted down and sold by weight. “We sell to dealers with stores, and also to dealers with a special niche who sell our items

*continued on page 12*



# A Perfect Ambassador

**W**hen Larry Thornton speaks, people evidently listen. Just witness the impactful changes that his work has created. With an unassuming demeanor, he has gone forth into the surrounding community to tell Matheny's "story," making new "friends," who, in turn, have contributed their time and money.

Large corporations, small businesses, individuals with big hearts have all answered his calls. He believes in the "old-fashioned" business practices of face-to-face meetings and a firm handshake, indicating goodwill going forward. And he always does his homework.

His career in marketing spanned almost five decades. You know those standing displays that are strategically placed up and down the aisles of drugstores such as Walgreens and CVS? He was part of their initial design and launch in the 1960s and '70s, and their persistence in the marketplace thereafter. "All products in stores were placed on shelves before that time," he explains. "These displays moved the products off the shelves—a radical change in retail marketing."

Eye-catching designs and colors; lightweight materials; and easy mobility drove the growing trend of wooing pharmaceutical customers with these displays. Thornton was a driving force in this industry—with large clients such as Novartis and Johnson & Johnson. He won a POPAI award (from the international organization for creative retail marketing) and holds a patent for a display he designed for the pharmaceutical industry.

His career and family life (he and his wife raised four children) kept him busy. However, in 2008 he was looking for a meaningful retirement opportunity close to home. Matheny caught his attention.

He started out by volunteering for several hours one day each week in the science classroom; that quickly grew to two days, then three. "Initially, I didn't know if I could do this," Larry remembers. "But I developed such a love for the students."

His positive classroom experiences

fostered a growing sense of connectedness with the students and staff, and led him to think about additional ways his particular skills could be of use. First, he was invited to take a seat on Matheny's Board of Trustees, and he accepted. Then he was invited to join Matheny's School Board, which he also gladly took on. But he still wanted to do more. That's when he hit upon the idea that his background in marketing and sales might make him a perfect "ambassador."

**"Matheny provides a unique nurturing environment that allows the children, and adults, to thrive and reach their full potential."**



Larry Thornton and Matheny student James Wild tend the Science Garden.

He looked around the Matheny campus and saw that the nature trail was difficult to navigate; the path to the Arts Center was treacherous for wheelchair-travel in bad weather; the pool deck needed repairs. These were just a few of the projects needing funding.

As an ambassador, Larry starts by doing research on a small local business or a large corporation with a local presence. "I enjoy finding out about these companies."

Next he formulates an individualized letter, packaging it with selected brochures and a book about Matheny, entitled "On Top of the Hill." He then delivers the package personally to someone he has identified in the company, always looking for a fit between each company and a particular project.

His strategy is simple: If he can connect with someone and get inside the door,



Larry Thornton

he talks with them about Matheny—a neighbor that many only know in passing. Larry then invites the company-representative to tour the campus and meet its CEO, Dr. Kendell Spott. "To know Matheny is to love it," is his motto.

And his strategy has worked. In just a few years, several Somerset County businesses have "adopted" projects and, in so doing, have changed the face of Matheny. First to respond was the Home Depot in Bridgewater, which donated three raised planters for the science class; undertook the renovation of the front patio by providing and laying down 1,000 square feet of pavers, so that wheelchairs can easily move across the surface and visitors can comfortably sit on the five new benches; and connected Matheny with Tilcon—a large company that paves highways and runways. "They brought in huge equipment," Larry says, "and pulled out roots of trees before paving a quarter-mile

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Sean Murphy, in the hallways of Matheny and (opposite, top) with student Joshua Rincon and speech therapist Jaclynne Jardim

**A** day in the life of Sean Murphy is a day chock-full of nonstop activity and awesome responsibility. It is a life he could never have imagined for himself while growing up in Chesterfield, England, in the late 1970s and '80s. As principal of the Matheny School and Vice President of Education at Matheny Medical and Educational Center, he is the end-stop for the safety, well-being, and top-flight education of a student body with multiple complex disabilities.

Like many in today's work world, Sean's day has no clearly defined beginning or end. The early mornings are filled with demands that require answers before the students' classroom activities can even begin. Classes start promptly at 10 A.M.; and more than 200 staff need to be accounted for, and coverage provided for unforeseen staff absences. In this highly specialized educational environment, the principal must act quickly to ensure that every student is appropriately cared for.

Sean, whose parents owned a corner shop and ran a pub until he was 11, was often put in charge of caring, and cooking, for his two siblings. After his parents

split up, he was part of a "big, modern family, excellent training for my future career," he says.

His high school business studies, after-school work in nursing homes, and a sabbatical year spent running the student union all added to his practical knowhow, as did the four high school summers spent working, and directing, Easter Seals camp programs in Hackettstown, NJ.

Let's just say that Sean found the U.S., and the care and teaching of children with disabilities, to be a great fit. In September 1994, he landed his first full-time job after high-school as a personal care assistant (PCA) at Matheny, where he has been

# A Day

employed happily for the last 23 years. At the time, he wanted to learn more about Lesch-Nyhan syndrome, a genetic disorder causing an overproduction of uric acid, and subsequent neurological, cognitive, and behavioral disturbances that become apparent in early childhood. The Matheny Institute of Applied Research was recognized as a center of investigation into the disorder.

Sean remained in that position for several years, living in Matheny's residential quarters, and taking on desk and driving duties on some nights and weekends. While working full-time, he completed the training to become a "certified residential assistant" as well as an emergency medical technician (EMT), and then earned an associate's degree from the County College of Morris.

With the first steps of his career ladder in place, Sean set himself the goal of completing a bachelor's degree in special education—working all day and then driving to New Jersey City University in Jersey City for classes and back to his home in Warren County most nights, a round trip of 150 miles. "In order to retain my full academic scholarship, I had to go to school full time and maintain a high GPA (grade point average)," he explains. After graduating, he immediately began coursework leading to a Master's degree in Urban School Administration.

With his hard-earned degrees in hand, he began looking for an opportunity to apply his new knowledge and skills, and that opportunity quickly surfaced. At the end of 2004 and in early 2005, Matheny was creating its first formal set of policies and procedures. Sean took on the project, finishing in just three weeks, while also assisting the new principal at the time with successfully completing a survey from the State.

From that point on, there was no stopping him. His obvious talent as a leader propelled him forward in the school's administration—from supervisor, to vice principal, to acting principal, then princi-



# in the Life

pal, principal and director, and finally to his current position of Principal and Vice President for Education.

The scope of his responsibilities is wide. Not only does he “run the school,” but oversees all aspects of its finances, as well as the education and therapy of all of its students. Just recently, he says, Matheny passed its compliance monitoring with “zero areas for recommendations.” What exactly does that mean? “That we are in the top 1 percent of schools,” he responds proudly.

As if this isn’t enough, he and his team run parent seminars to inform a wider audience about what the school offers, and he serves in a broad spectrum of roles outside Matheny as well. He is an adjunct professor of psychology at the College of St. Elizabeth; a member of the

advisory board for Centenary University; and holds leadership roles in the Alliance of Special Education Schools of New Jersey and the Division for Physical, Health and Multiple Disabilities of the Council for Exceptional Children (CEC). The sharing of ideas, he says, helps him do his job even better.

And all of these activities support the school’s primary goal: “To put what we do here under the microscope so that we can maximize the independence of all of our students,” he says.

He has been working with Matheny’s Technology Committee for more than 10 years to “seamlessly integrate the newest and best assistive technology” into the lives of the students; and his efforts reach well beyond their classroom years “to the time after the students graduate from the



**Instead of students remaining in a self-contained classroom all day with one teacher teaching every subject, students started moving from classroom to classroom for different subjects. Sean calls it “moving for a purpose.”**



school and go out into the community.” Like any school in our country, this one is charged with preparing students for adulthood.

In July 2013, “we instituted a monumental change here,” the principal says. Instead of students remaining in a self-contained classroom all day with one teacher teaching every subject, students started moving from classroom to classroom for different subjects. Sean calls it “moving for a purpose.”

The trial period was two months. Did chaos ensue? Not at all. “The feedback was good,” he says, “and the teachers and paraprofessionals interacted more than ever. It sharpened everyone’s sword.”

As Sean conducts a whirlwind tour through the school, his pride in all that it offers the students is evident. He points to the new SMART-Boards in every classroom, the lively bulletin boards in the hallways, and the expanded space in the science classroom that necessitated taking down and moving walls. With students ages 3 to 21, all with complex conditions, it’s hard for a principal to know what to focus on next.

But Sean knows the school is on the right track. The teachers are “exceptionally dedicated and tend to stay here,” he says, and the school promotes from within for all positions.

Like his own hard-won, but deeply satisfying professional movement into his current leadership role, “we are all on a conveyor belt of success,” he says.

And that’s the primary takeaway from a chat with Sean Murphy: He believes that this is a school where everyone wins, regardless of limitations. And he is willing to work around the clock to make that happen.

# Empathy in Action

**K**acey Zane did not make a beeline for her current career in nursing, nor was she even aware of the existence of Matheny and its highly reputed hospital and school during her college years. A ballerina from age 5, her passion for dance led her to win a spot on the NFL cheerleading team in 2013, performing in front of crowds of 80,000. However, despite her exciting “career” in the limelight, she was quick to name empathy as the personality trait she values most in herself.

It was witnessing empathy-in-action that drew her to consider nursing as a profession, but she was already in her last year of college at the time—too late to switch majors. Her mother had shattered three vertebrae in her back, and was hospitalized for a long period. “I was so impressed with the nurses. They took such good care of their patients and the patients’ families,” she says. “My mother was so well cared for.”

So, in the fall of 2013—following her college graduation in May—she jumped into an accelerated Clinical Nurse Leader (CNL) Master’s program at Seton Hall University. She was headed for a career in pediatric nursing.

However, in the last semester of her graduate studies, she did her capstone project at Matheny “and that changed everything,” she recalls. Kacey was charged with “finding a problem in the institution and fixing it. I focused on trying to reduce patient-anxiety before a surgical or medical procedure through education.”

While this may not sound like rocket science, the project proved to be both challenging and rewarding. “Many of the patients at Matheny have problems communicating,” she observes, “but they get scared just as we do. Most of our patients just learn in a different way.” Her project

Nurse Kacey Zane with patient Chris Saglimbene



demonstrated that more communication with patients lessens their anxiety.

In 2015, after earning her Master’s degree, Kacey married and moved with her husband, a Marine on military assignment, to Hawaii. But when they returned to the East Coast one year later, it was to Matheny she gravitated. “Unfortunately, there were no open positions in nursing,” she remembers. Starting as a per diem in June 2016, she worked on all three units—pediatric and adult—and got to know all of the patients. In October, she applied for an open position as a nurse manager on a 30-patient adult unit called the Red Zone, and was hired.

What drew her back to such a specialized, and clearly demanding, position? “The patients are amazing,” she says. “I feel like this is where I am meant to be.”

The type of nursing required by patients at Matheny, who have complex physical disabilities, rely on wheelchairs

for their mobility, and often have difficulty communicating, is “not something we learned about in nursing school,” she says. “It’s such a small community, but such an interesting one.”

What amazed her is “how intelligent, creative, and funny the patients are. It’s eye-opening and humbling—the lives they live with the challenges they face.”

Which qualities does this kind of nursing call for? “Compassion and patience,” she answers unhesitatingly. “When someone communicates with an eye-gaze board, one sentence can take 20 minutes. We live in such a fast-paced world. We generally don’t stop to listen.”

One of her patients, she says, “is the funniest person I’ve ever met. He’s hysterical—but you wouldn’t know if you didn’t take the time to listen.”

Matheny’s nurses do take the time to communicate. But all of the routine—and unexpected—care still needs to get done.



Many patients get nutrition through feeding tubes. “And many have seizure disorders,” she explains. “Seizures are so frequent, but our nurses respond quickly and do the right thing. I had never seen a seizure before coming here.”

Patients also frequently have respiratory issues. “Their muscle tone is low and it’s difficult for them to clear excretions,” she says. Suctioning is common to prevent infections, particularly pneumonia.

“Because you see the patients every day, you can pick up on any little changes,” says Kacey, who explains that sometimes those little changes indicate larger problems. “Our nurses observe changes quickly—many have been here for years and know the patients well.”

“Nurses at Matheny like having the same patients for years,” she states. “You grow attached. The patients become extensions of your family. Many are here for most of their adult lives. This is their home—even those who go out to adult day care centers return here in the evening.”

“What Matheny does for its patients makes such a difference in their lives,” she concludes. “Patients paint and dance; they surf, ski, and bowl. They live exciting lives. It’s awesome.”

## Who's Who?

Vincent Barba, MD, Vice President of Patient Care and Safety, and Chief Medical Officer and Safety Officer at the Matheny Medical and Educational Center, and Denise Micheletti, RN, chief nursing officer, are recognizable faces at this “special hospital,” providing long-term care for 101 children and adults with medically complex developmental disabilities. Patients generally range in age from 8 to the 60s, although the hospital is equipped for anyone age 3 and older.

The goal, says Dr. Barba, who also serves as a trustee on the Matheny Board of Trustees, is to return clients to the most independent environment they can live in—back home to their families, or to a group home in the community or assisted living. “Most have cerebral palsy as one of their primary diagnoses,” he explains.

“Many have seizure disorders.”

While most parents want their child with developmental disabilities to live at home, in some cases that’s not possible. For instance, aging parents sometimes can no longer take care of a teen or adult son or daughter. In years past, “these diagnoses pertained to children. But now, patients often have normal life expectancies,” he says. “Johnny grows to be 6 feet, 3 inches tall and 200 pounds, and his parents may not be able to manage anymore.”

Denise says that kids with these complex disabilities get great benefits through the educational system, usually to age 21. “But it’s not enough,” she says. “They need access to many therapies their entire lives. For instance, they need to do walking and biking some of the time, even if they are primarily in a wheelchair.”

“We strive to deliver the volume of therapies needed by these patients. There is no other place like Matheny in New Jersey,” she says.

Denise has long experience as a critical care nurse, as well as a teacher of nurses who are specializing in the care of patients with complex developmental dis-

abilities. She came to Matheny six years ago. “Nurses use all of their nursing skills here. Patients can have up to 10 diagnoses; we have 55 patients with feeding tubes; many patients have respiratory and seizure issues. Most are nonverbal,” she states. “There are not many nurses in the world who are specialized in this field.”

“In addition, patients often have atypical presentations of disease patterns,” she

**“We strive to deliver the volume of therapies needed by these patients. There is no other place like Matheny in New Jersey.”**

explains. “It takes a lot of experience to know what you’re seeing when a patient behaves differently but may not be able to tell you what’s wrong.”

What attracted her to this field? “There are fewer formulas,” she states. “You have to observe closely and think it through to understand what you’re seeing.” She also likes the long-term care aspect and working closely with families, patients, other caregivers, and school personnel. Forty patients of the hospital attend the Matheny School.

“We ask our nurses to do more coordination of care,” she explains, “and more support of families, particularly communicating with parents who may be releasing control of their children after taking care of them at home for years. Many parents want to stay involved; and some nurses email parents every day.”

“The secret ingredient for a Matheny nurse is their humanity,” she says. “We want to attract the right people for the job—and retain talented nurses. We encourage nurses to attend conferences and to continue their education. And we always foster teamwork.”

Matheny employs about 70 registered nurses, 58 of them full-time and some per diem. Some students do their clinical training here through one of the two-year, affiliated programs—at Raritan, Passaic,

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Denise Micheletti and Dr. Vincent Barba





# Delighting in a World of Dance and Disney

Recreational therapy at Matheny is going the distance.

For Sean Bielefeldt, the annual Matheny Spring Prom is a serious matter. However, despite the myriad details to be resolved each year prior to the event, a broad smile lights up his face as he talks about the special May evening. He's recalling the glimmering lights, the sounds of music coming from the large ballroom, the gorgeous decorations created by Matheny's staff, the food and flowers, and the prom-goers' enormous delight. This once-a-year occasion feels more like a once-in-a-lifetime fantasy. Sixty-eight inpatients ages 16 and older, 30 group-home residents, including alumni, and 200 to 250 family members and friends participated this year at Skylands Manor in Randolph.

"This is a formal event, one of the most special nights of the year. Participants feel pampered," Sean comments. "This is just like any other prom, from selecting a king and queen to deciding which songs to add to the playlist."

Festive party attire adds to the evening's ambiance. Don't have the proper clothing? That's not an issue! The mall is just a 10-minute drive away and multiple pre-

prom shopping excursions allow time to find the perfect outfit. Everyone has fun; there are no wallflowers or naysayers. And for those ages 14 and 15 who can't attend, there is a "pajama prom" right at Matheny on the same night.

Sean, who has served as the hospital's Recreation Therapy Director since 2007, and has recently added the position of Director of Adult Day Health Services for the hospital to his responsibilities, is not one to cower at the hundreds of details facing him each day. This is part and parcel of the job that seems to have found him, and that he has taken on willingly and fulfills with enormous energy.

He's an old-hand by now at pulling off this kind of thing, although still young in years and spirit. He came to Matheny right out of college in 2002, and he hasn't stopped improving and expanding his department's scope of services.

If you've ever arranged a prom, or a trip to Disney with your kids, you can appreciate the extensive planning involved. Now imagine planning a five-night, six-day excursion to Orlando for children with multiple complex physical disabili-

ties and you can begin to appreciate this director's job. Normalcy, fun, camaraderie are all high on his list; however, the safety of the children must come first, and that's no easy feat. Getting to the airport and through security; getting the children safely and comfortably seated for the flight to Florida and back to New Jersey; taking care of the hotel, food, and medical necessities; as well as experiencing the many highpoints the theme park has to offer are all major challenges—and preparing for the unforeseen.

Sean, who earned a bachelor of science degree in recreational therapy from East Stroudsburg University of Pennsylvania in 2002, and a Master's degree from the University of Illinois, Urbana-Champaign, in 2010, could not have anticipated this job's many challenges. But he also could not have foreseen its many joys.

And "joy" is the right word for his expression as he recalls the group's adventures last November. Wheelchairs did not stop these students from enjoying fast-moving rides, being wowed by spectacular sights, and hugging their favorite Disney characters. Physical challenges made it difficult, but not impossible, to engage with the entire Disney World experience that all children dream about.

And, of course, every step of the way a team of committed care providers were there. It also takes money to make a trip like this happen and the Friends of Matheny volunteers stepped up to raise the funds, which the Friends of Matheny's Board allocated to the trip. The undertaking took a full year of planning, as well as a leader willing to shoulder the ultimate responsibility for the children, while also supporting their normal-kid desire for fun.

While the Disney trip presented unique challenges to the staff, off-campus excursions are certainly not unique. "We do multiple vacations each year and rotate which kids and residents go on the trips," explains Sean. Residents go to the Kalahari Resort in the Poconos, the Museum of Natural History in New York City and other Manhattan sites, to Broadway plays, the Special Olympics at the College of New Jersey, and they even enjoy a beach vacation in Wildwood. "We rent a condo for a week from a family that has



children with special needs,” Sean says, “and split the week—take three adult patients for four nights and three kids for three nights.”

Like any New Jersey beach vacation this includes “evenings on the Boardwalk playing games and eating junk food, as well as cooking at home and heading over the sand and into the ocean on beach

**“We believe that leisure activities help with relaxation and pain management, and enhance a person’s overall quality of life.”**

wheelchairs, and swimming in the pool.”

Day trips also figure prominently in Matheny’s offerings. “Community integration is a large part of what we do here. It sets us apart from other facilities similar to Matheny,” the recreation therapy director explains. He and his team organize more than 40 trips each month. Adventures in the last few months have included the Duke Farms in Hillsborough Township, multiple concerts, the Morris Museum, the Raritan Valley Community College Planetarium, Peppa Pig Live at NJ PAC, Wednesday night out-to-dinner, sporting events, including New Jersey Devils and New York Red Bulls games, and, of course, the mall to shop for prom-wear.

“Our calendars are unbelievably busy,” Sean states. “My colleagues at other places take just one or two trips a month. Matheny embraces community integration and our residents benefit from all of these experiences. We are part of the community; and we know how to deal with the complex developmental disabilities.”

“Matheny sees value in recreation therapy as a tool in the health care process,” he continues. “We believe that leisure activities help with relaxation and pain management, and enhance a person’s overall quality of life.”

At Matheny, “we have individuals who define themselves as athletes,” he says proudly. “We go water skiing, snow ski-

Opposite page: Matheny students and staff in Orlando, Florida

From top: Patient Cindy Shanks on water skis. Rasheedah Mahali with Colleen Leschinsky, recreation therapist at the Matheny prom. Sean Bielefeldt. Daeon Troutman competing at the Somerset County Special Olympics.



ing, camping; we have people who have earned their black belts in karate.” All of this is accomplished by a department consisting of just six recreation therapists, including its director, and four recreation assistants.

“We ask patients what they want to do, and then we figure out how to get that for them,” Sean says. “A lot of parents are actively engaged in our programs and we hear them say their children are able to do things that the parents thought they would never be able to do.”

Despite his often-long days, the director also teaches Recreation Therapy at Kean University, and conducts a 15-week internship program at Matheny for those wanting to enter the field. “I love to teach,” he says. “It’s vitally important to educate future professionals.” Many students from Kean and Temple universities have trained here.

Now that summer has finally arrived,



activities include a pool program, water skiing, surfing trips, campouts at Matheny, trips to the beach, kayaking, and bike riding at the park. This past spring, residents took part in track and field, bocce, power lifting, and baseball.

“Our athletes participate in sports in every season—they even go ice-skating in winter,” he says. “We are committed to giving our patients every opportunity we can possibly give them.”





Arts facilitator Keith Garletts with Matheny artist Cindy Shanks

# The Artist Within

**W**ith vivid descriptions that come alive with color and light, Eileen Murray remembers her immediate emotional connection with Matheny. It was more than 15 years ago that she first visited the campus, but her memory of that day is still vibrant and highly charged. That's no surprise: she is an artist, after all. Storytelling, poetry, painting, sculpture, music, dance, theater—she admires and appreciates all of them.

Her professional path took a whole new direction in 2001, and it has impacted her personal one, too. After graduating from The College of New Jersey, she had built a career in corporate advertising, graphics, and Web design for well-known clients that included Hershey's, Hunter Douglas, and Lucent Technologies. All the while, she continued pursuing her own art—working as a painter, printmaker, encaustic (hot wax) artist, and jewelry-maker. “But I was ready for something different,” she remembers.

Fortuitously, she spotted a classified newspaper ad for a part-time “arts facilitator” for Matheny's Arts Access

program—and she responded. Had she ever heard of Matheny before that? “No, never,” she says. But when she did a little research, she was intrigued. And when she came to the campus for her interview, “I fell in love with the program,” she says. “I felt I was meant to be here.”

That “feeling” proved to be spot-on. Eileen—whose own art has been exhibited in a variety of solo, juried, and group shows—is now the director of the Matheny Arts Access Program. “I knew what making art had meant to me,” she says. “Our clients have art, creativity, vision inside them. They just need another tool to enable them to express that.”

The clients are primarily adults with complex disabilities, who use wheelchairs for their mobility, have limited range of motion, and are often nonverbal. “They need a conduit,” she says, “to enable them to paint on canvas, put words on the page, or dance on stage.” There are 10 full- and part-time program staff, all of whom are artists.

A Matheny arts facilitator must be completely neutral, not influencing the art or artist in any way. “The facilitator is a

conduit, another tool,” Eileen explains. “It's ingenious.” This process, used by artists and facilitators, was developed at Matheny and introduced in 1993.

Eileen explains how it works: the facilitator must be completely “neutral”; the facilitator and artist have a peer-to-peer relationship, one artist assisting another artist (not a teacher and student relationship); there are no restrictions imposed by the facilitator—the artist makes all the choices; the facilitator should have no preconceptions of what the artist creates and does not judge it in any way. “The facilitators provide the tools and methods so the client can create art.”

Because most clients have communication problems, the artists provide directives to the facilitators through a board with words and pictures, as well as using head motions. “The facilitator asks questions and the client gives a yes or no response,” Eileen says. “If you can make a choice, you can make art.”

Color, shape, form, line, texture are all choices made by the visual artist, as well as types of paper, canvas, cloth, and other materials to work on. Color charts, shape charts, and brushes provide options; clients also choose from a variety of alternatives for applying color. The chart system was created by Matheny's facilitators, and they have trained others to be arts facilitators.

Arts Access offers clients the opportunity to express themselves in all of the artistic disciplines. “So, how does a participant in a wheelchair choreograph a



Eileen Murray



dance, or how does someone who cannot read create a memoir?" the director asks. It's all possible, accomplished through charts that have been created for that particular artistic discipline, and a system of questions and answers.

For instance, says Eileen, the Matheny writing facilitator created a system of choices. "The writer chooses pictures from the chart and builds words, sentences, whole poems." Three books of poetry by Matheny-poets have been published.

"Some of the work created here is amazing," she says. "I look at it and say, 'I wish I had done that!'"

As you might imagine, Arts Access is a very popular program. The weekly schedule—with half-hour time slots blocked off and four different disciplines ongoing at one time—looks overwhelming. There are even evening classes.

"We conduct 220 sessions per week to accommodate everyone who wants to take part," Eileen explains. Group home residents—who have lost their "access to art" after moving off Matheny's campus—are welcomed back to participate.

"One of the incredible things that we've noticed is that signature styles emerge over time," Eileen says. "That reaffirms the integrity of the process by demonstrating that it does not matter who the facilitator is. It's always the artist's unique style coming through."

## It Takes a Village

While artists take great joy in the process of creating art, most also enjoy presenting their art to an appreciative audience. Matheny artists put on quite a show each year for their families, friends, and the public. This year's theme is "The Art of Possibility" and the event is scheduled for Saturday, November 4, from 3 to 6 PM.

"It takes a village to do this," says Eileen Murray. "There is a new exhibit every year."

Choosing which pieces of art to display is a huge undertaking in itself. Curator of the exhibit, Haeree Park, who is also Arts Access project and events coordinator, examines more than 2,000 artworks in the digital database, choosing 50 pieces by

40 or more artists for the event. All of the artwork exhibited is for sale; and some has been beautifully reproduced on ties, silk scarves, and high quality mugs. "For some," Eileen says, "this is their vocation and a means to earn money."

In prior years, the events have included dance performances choreographed by Arts Access participants; readings of poems and plays they have written; music; and good food, donated by local restaurants and bakeries. This is a celebration of the creative process, and there is a lot of creativity to celebrate here. The event draws a "standing-room only" crowd of 250 to 300.

"People have said to me that this has been a life-changing event for them," says the director. "It is a great bridge linking the larger community with the community of artists with disabilities. Every artist expresses a unique viewpoint. Art can change our perspective, or sometimes give us a whole new one."

## Sharing the Bounty

Buying shares in the Art Garden will not pile a plentiful summer harvest of strawberries, tomatoes, and melons on your table or quell the appetites of hungry guests. What it will do is open up doors to the artists' world of color and light, innovation and imagination.

A business model called CSA (Community Supported Agriculture) was introduced in farming about 20 years ago. It counts on consumers to buy "shares" in a particular farm's harvest; and builds bridges between clients hungry for fresh produce and farmers appreciative of a committed clientele.

The same concept, recently adapted in New Jersey for the art community, connects those interested in purchasing artwork to a spectrum of artists with unique styles and perspectives. Not only do buyers benefit from acquiring sophisticated pieces of art, but they have the satisfaction of supporting talented artists with complex physical disabilities. Art Garden CSA is the only such organization worldwide supporting artists with disabilities trying to launch professional careers.



This ingenious concept was conceived and begun by two nonprofit organizations, the Matheny Arts Access program and Arts Unbound in West Orange, and was launched with a generous grant from the Kessler Foundation and \$5,000 from the Friends of Matheny. Started in 2016, the program took off rapidly and had a sold-out first season. Ten new artists are participating in 2017.

There are 50 available shares in the art garden, and each artist creates 50 pieces of original or limited edition fine art for the program, including paintings, jewelry, photography, and wearable art, such as scarves and ties. That means 10 artworks for each full share or 5 for a half share. The CSA not only makes unique artworks accessible at modest prices, but teaches artists entrepreneurial skills, including how to build a website and create a presence on social media, and the art of nurturing relationships.

"This is the first art garden dedicated to providing vocational opportunities to artists with disabilities," says Eileen. Full shares cost \$450 and half shares \$225. Buyers can purchase individual pieces.

For more information on this venture, contact Heather Williams at [heather@artsaccessprogram.org](mailto:heather@artsaccessprogram.org) or call her at 908-234-0011, extension 412.



Friends of Matheny volunteers  
Bottom (l-r): Sandy Harrison,  
Linda Horton, Seena Frankel  
Top: Kathy Sisto, Catarina Sandin,  
Gina Kalvin



## Thrift

*continued from page 2*

online,” she explains. “And we sell some large items by placing a photo in our newsletter.”

One way or another, every donation raises dollars, and that’s the point. “This is recycling at its best,” she says. “We take things people no longer want and make money from them.”

For each of the last two years, Second Chance has donated \$150,000 to Matheny. “Every department submits wishes,” explains Linda. The Friends of Matheny Board of Trustees decides how the money will be spent.

“We are careful to choose the projects that will benefit the largest number of students and patients,” she says, “and in the end, we purchase most of the items requested.” Recent purchases include a wheelchair washing machine; Smart Boards; Smart Tables; a LiteGait walker; and adaptive sports equipment.

The wishes-fulfilled list goes on and on,

and includes such things as financial help for parents traveling from out of state for a child’s surgery; and plane fare for a student, and her aide, to attend a brother’s wedding.

In the realm of nursery tales, fairy godmothers often grant wishes using magical powers. The volunteers of Second Chance Thrift Shop—with real world commitment and steady, hard work—have created their own magic for Matheny with more than \$3 million in donations.

## A Perfect Ambassador

*continued from page 3*

nature trail last year. Now students and residents can come out there in their wheelchairs.”

“Home Depot also donated paint and \$2,500 worth of light bulbs, and painted five classrooms and three bathrooms,” he says. In addition, the company donated trees, flowers, mulch, and the manpower to restore the memorial garden dedicated to Walter and Marguerite Matheny (the founders of Matheny).

Also quick to respond was the Lowe’s in Flanders, which donated all of the makings of a 50-foot by 50-foot garden and many employee-volunteer hours to make it happen as part of their annual Heroes Project.

Larry’s “ambassadorship” has also reached to a fellow Knights of Columbus member—Dominick Rizzitiano, whose company, American Consolidated, Inc. in Carlstadt, NJ, is in the business of warehousing, packing, and shipping. He donated designer purses, sport jackets,

and more to sell at Matheny, raising significant funding. In addition, the owner of Caesar’s Corner Deli in Gladstone, who also manages a landscaping business, volunteers staff to weed and clean up the garden twice monthly.

Thornton’s ideas continue to bubble. His newest venture involves a collaboration between Rutgers’ biomedical engineering students and Matheny. “The students want to apply their learning to real-world problems,” he observes. “Matheny can provide them with opportunities to make life better for people with complex disabilities. There are many problems of everyday living to be solved here.” The first meeting took place in early May and the new relationship is beginning to take root.

“Before coming to Matheny, I never understood how hard it is for these really intelligent students to communicate with other human beings,” he says. “I’m so impressed with the dedication of the staff, their compassion for the children, and their striving every day to give some normalcy and happiness to their lives.”

## Empathy in Action

*continued from page 7*

or Warren county colleges—and Seton Hall’s Master’s degree program. “Some fall in love with the work and return here as employees,” says Denise.

While she is charged with heading up hospital-nursing care, recruitment, and education, Dr. Barba leads, directs and serves as administrator for all patient care services. These include overseeing medical and nursing services, psychological care, as well as the rehabilitative and therapeutic service departments. He also is charged with ensuring quality care, patient safety, fiscal management, and clinical competency of the staff. It’s a huge responsibility but one that he is certainly equipped to handle.

He earned his MD from New Jersey Medical School (NJMS), where he also completed a residency in internal medicine and served as chief medical resident. In addition, he holds a graduate certificate in public health from Rutgers School of Public Health and a graduate certificate in Health and Hospital Law from Seton Hall University School of Law. He is a 1989 Seton Hall College of Arts and Sciences alumnus.

Before coming to Matheny in 2015, Dr. Barba was chief quality officer at University Hospital in Newark and assistant professor of medicine and preventive medicine and risk management steward at NJMS. He still holds a clinical faculty appointment at the medical school.

Matheny was recently awarded the Gold Seal of Approval for Hospital Accreditation by the Joint Commission on Accreditation of Hospitals, confirming the hospital’s high standards of performance in several critical areas. The seal is a confirmation of all that the patient care leader has worked for since coming to Matheny, and he’s proud of the accomplishment.

But the beat goes on: Matheny’s reputation is based on performance. Every day, 24/7, the staff and leaders of Matheny work in tandem to provide extraordinary care to the patients, students, and clients who count on them.



## The Art of Possibility

Early this year, the National Endowment for the Arts (NEA) announced that Matheny's Arts Access Program is one of 134 not-for-profit organizations nationwide to receive an NEA Challenge America grant. Arts Access was awarded \$10,000 to support **Full Circle**, an annual event showcasing original artwork by artists with disabilities; and a multimedia production of the artists' original choreography, plays, and spoken word performances with professional guest artists.

great big mountains  
covered in snow

sunshine  
the blue sky  
sunsets  
beaches  
gray, purple  
winter  
spring  
fall  
fields & pla



"Nightlight" by Chet Cheesman



## Oh No, Don't Let the Rain Come Down

June 4th marked the 20th anniversary of **Miles for Matheny**, and nothing could dampen the participants' exuberant spirits. The event featured 10, 25, 35, and 50 mile bicycle rides; the Hills of Attrition bike ride; a kids' fun run; a combination fitness and Lu Huggins wheelchair walk; a Breakfast of Champions provided by the Friends of Matheny; and Latin cuisine from La Fe, Inc. The event raised more than \$110,000. We are especially grateful to the many generous donors, volunteers, and this year's major sponsors:

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To see a full list of Miles donors, visit our website.

### Save the Date!

21st Annual Miles for Matheny, Sunday, June 3, 2018

## In the upcoming issue:

Read about our devoted personal care assistants; five group homes; wheelchair clinic; rehab technology services; and the illustrious 2017 donor honor roll.



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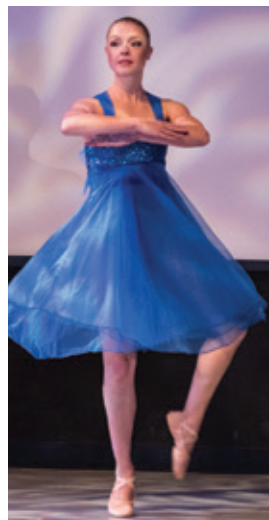


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## ART OF POSSIBILITY



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[www.artsaccessprogram.org](http://www.artsaccessprogram.org)

Painting: *Untitled* by Jessica Evans



All event proceeds will benefit the Arts Access Program at Matheny. Arts Access is a unique fine arts program where individuals with disabilities can fully express themselves in the creative arts.



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