

matheny **matters**

A photograph of two women in a brightly lit hallway. One woman, with red hair and glasses, wearing a maroon plaid shirt, stands behind another woman. The second woman, with long pink and black braids and glasses, wearing a pink and white plaid shirt, is seated in a black motorized wheelchair. Both women are smiling warmly at the camera. The background shows a modern office or hospital hallway with glass doors and warm lighting.

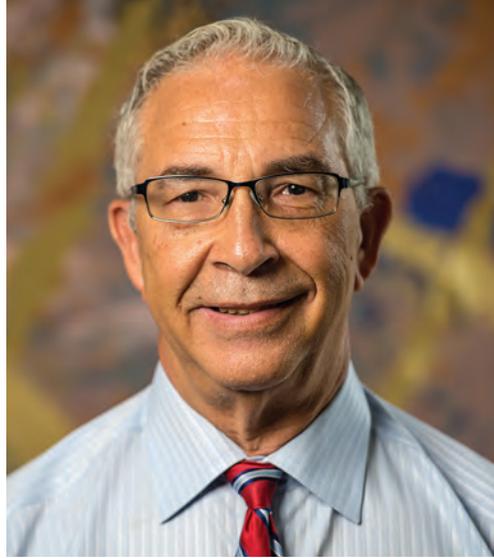
Summer/Fall 2019

SPECIAL ISSUE:
Social Services
at Work

Adopting India

A Dream Come True for Matheny Nurse

Kendell R. Sprott, MD, JD
President and CEO



Matheny Looks Forward

While social workers often work almost unnoticed behind the scenes, what they accomplish on a day-to-day basis at Matheny is very much front and center. This issue of *Matheny Matters* shines a light on our six social workers, who together with their director, form a small, but highly effective, team. All have been here for 12 years or more, and some have moved from clinical internship programs onsite directly into staff positions. That speaks to their dedication to our students and residents, and to their cohesiveness as a professional group. It exemplifies their commitment to Matheny's goals and environment, making it what it is today.

Social worker Mari Cote describes some aspects of the job: "When residents come to live at Matheny, we help the

client and family or guardians adjust to their new home. When residents move from child services to adult services, we help the young adult and their family with their transition. When a group home becomes available, we help make sure it's a good match and assist the resident and family to adjust to the new residence. We meet with clients and provide supportive counseling; we help clients and parents and guardians do problem-solving."

Social worker Valerie Marcketta says, "I think what's most important is that our social workers bring a sense of stability to the client and provide an ongoing relationship. The social worker knows the patient and knows the family and may be the only one who knows the whole picture."

That touches on just some of the priorities of our Social Services Department. Facilitating adoptions is another. Read the uplifting stories of two adoptions of Matheny patients by Matheny employees, which would not have come about without the hard work of our social workers.

Also be sure to read about Matheny's chaplain, Martisha Kanard-Dwyer, who brings a whole new dimension of communication, spirituality, and support to our community and is an integral member of the Social Services Department.

And last but not least, two esteemed members of Matheny's Board of Trustees, Edana Desatnick and Patrick Scaglione, tell readers how they are working to help realize Matheny's continued role and vitality in our State's and country's future healthcare and education systems.

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On the cover:
Vanica with adopted daughter India
Photo by Keith B. Bratcher, Jr.

mathenymatters

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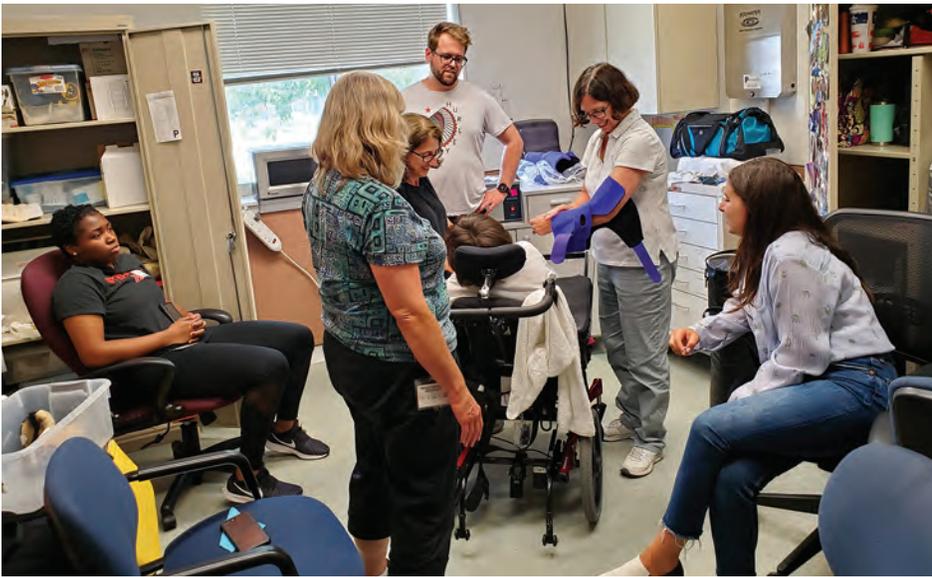
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 **matheny**
enriching lives. growing abilities.



Matheny Residents Come to the Rescue

Matheny patients in the adult day program like to give as well as receive and get great satisfaction from the ties they establish with local community groups. They recently coordinated a donation drive for Eleventh Hour Rescue in Rockaway, collecting much-needed pet food, treats, toys, blankets, cleaning supplies, and more. Eleventh Hour Rescue saves dogs and cats from high-kill shelters. The animals are cared for by volunteers and staff in foster homes, in the organization's kennel, and in adoption centers, and are provided with needed medical attention. The organization also tries to find permanent homes for them. Several Matheny patients even turned out for Eleventh Hour Rescue's 15th annual fall Puptoberfest to show their support of the group's mission.

Year 3 for Rutgers-Matheny Partnership

The third class of Rutgers Biomedical Engineering Department students to intern at Matheny kicked off their experience in September with an immersion program, introducing them to daily life at Matheny. The 23 undergraduates make up the largest class of Rutgers interns at Matheny since the program's 2017 inception. The internship aims to help the Rutgers students better understand

"Most of these students become biomedical engineers because they want to help people. That's really the essence of being a biomedical engineer, and this program is the epitome of that."

the daily challenges faced by Matheny's residents, who have medically complex developmental disabilities, and to teach the interns how best to use their academic training to impact real world problems.

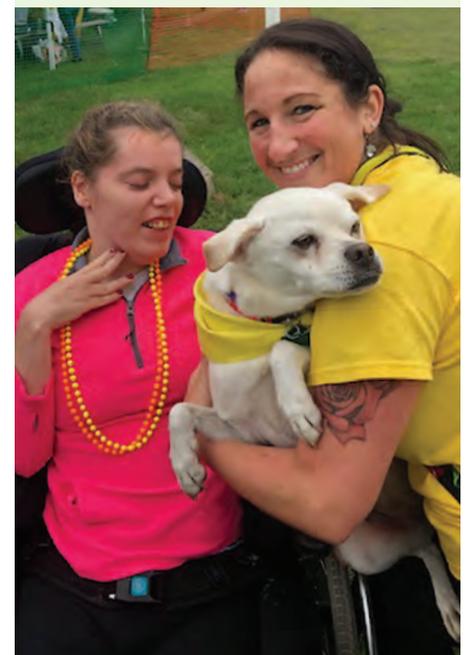
The interns are asked to envision, plan, design, and fabricate devices and equipment to improve the independence, and

quality of everyday life, of Matheny's residents. The device-ideas serve as the basis for the Rutgers students' senior design projects and can be developed in the Rutgers' department's new labs.

Examples of devices created by student-teams in prior years of the program include: a motorized headrest for wheelchairs to give people with cerebral palsy a greater range of vision and reduce their reliance on caretakers; adjustable lateral support arms to give patients greater mobility with their bodies; and a self-sterilizing intravenous pole for wheelchairs that is retractable, and includes a cover with LED lights that emit ultraviolet light to kill bacteria.

"Most of these students become biomedical engineers because they want to help people. That's really the essence of being a biomedical engineer, and this program is the epitome of that," says Kristen S. Labazzo, MBA, PhD, an assistant research professor in the Rutgers Biomedical Engineering Department.

The Rutgers-Matheny partnership was the brainchild of Larry Thornton, who, after a successful career as Vice President of Sales and Marketing for International Paper, retired and dedicated countless hours to volunteering at Matheny. He died last April, but the program he founded continues to grow and thrive.



Arts Access Video Takes Best in Show

“We are so much more than what we’re sitting in,” says Chris Saglimbene, a prolific Arts Access artist, who is sitting in his wheelchair in the opening seconds of an impactful video that recently won much acclaim.

“Some of us may not be able to speak,” he says. “Some of us may not be able to move our arms or legs. But that doesn’t mean our minds are not intact.”

The video, “Matheny Arts Access: 25 Years of Art Without Boundaries,” captures what Matheny’s Arts Access program is all about. It touched a chord for judges and general viewers alike, winning two first place awards and Best in Show at the 51st Annual Jersey Awards sponsored by the NJ Ad Club on June 5th. Produced by Awakened Films in Basking Ridge, the video introduces a few of the talented artists working in the Arts Access program, and demonstrates their process of creating art, along with commentary by members of the program’s staff and parents of the artists.

The mission of Arts Access at Matheny is to provide individuals with disabilities the freedom to create in the visual, literary, and performing arts. Their

artwork has been exhibited in galleries at Sotheby’s in New York, Pfizer, Bristol-Myers Squibb, ABC World Headquarters, the Newark Museum, Johnson and Johnson headquarters and several other notable venues. Arts Access has been featured on CBS Sunday Morning, CBS Evening News, Fox 5 NY, NJTV, and other media outlets.

The Jersey Awards celebrate creative excellence in advertising. The 21 judges, who are advertising, marketing, and public relations professionals, reviewed 600 entries. Matheny’s Arts Access video was the night’s big winner.

The Arts Access video ends with some powerful words from Chris Saglimbene: “I have cerebral palsy. But one thing I like to say to people is, ‘I have a disability but the disability doesn’t have me. It’s never had me. It never will have me. And that’s something I’ve learned from working with Arts Access. There really are no limits to what I can do as an individual.’”

Take a few minutes to view the video on Matheny’s homepage. And visit the Arts Access program website at artsaccessprogram.org to learn more about their programs and services.



Making Beautiful Music Together

The Matheny Choir, led by Matheny’s Music Therapy Department, performed at the induction of restaurateur, musician, and long-time volunteer and friend of Matheny, Tim McCloone, into the New Jersey Hall of Fame on Sunday, October 27, at the Paramount Theater in Asbury Park. The choir performed with McCloone’s band.

The 4th Annual Matheny School Golf Outing

on September 24th was a great success. A special thank you to all our valued sponsors: BCB Bank; Medline; Partlow Insurance; Autosport Acura of Denville; Innovative Benefit Planning; Torsilier Inc; The Tustin Group; Porzio, Bromberg & Newman PC; Patrick’s Pals; Paycheck; Lincoln Financial Group; Cavanaugh’s Inc; Binsky Service.

NOTABLE EVENTS

December 8

Holiday Express Concert on Matheny’s campus. Tim McCloone is the founder and leader of Holiday Express, which “delivers music, food, gifts, financial support, and friendship to those with the greatest need for the gift of human kindness...” The Holiday Express band has performed at Matheny since 2001. *(invitation only)*.

Matheny choir members add holiday spirit to Peapack’s annual holiday celebration *(invitation only)*

April 24

Casino Night in the Robert Schonhorn Arts Center to raise money for Matheny’s Adult Services



Arts Access artist Chris Saglimbene



Six Questions for Patrick Scaglione

First-generation American, Patrick Scaglione, Vice Chair of Matheny's Board of Trustees, served as a Somerset County Freeholder for nearly a decade and has also volunteered countless hours serving on the boards of a long list of nonprofits. And that's what he does in his "free" time. A serious accident in his 20s left him partially paralyzed, but he has become the personification of the term "mover and shaker," and a welcome addition to the leadership guiding Matheny into the future.

Can you tell *Matheny Matters* readers about your childhood?

My parents came to this country from Argentina and I grew up in North Plainfield with my twin sister, Vanessa. My mother was the eldest of ten children and my father the youngest of eight so we have a large extended family who still live in Argentina. My father was a tailor, and my mother was a registered nurse who worked at Overlook Hospital and Som-

erset Medical Center. I was always good in math and science, and was interested in technical things, so after high school I chose to go to college to study engineering. I graduated from Rensselaer Polytechnic Institute with a major in Electrical Engineering and a minor in Economics.

What did you do after college?

I did research for Bell Labs in Murray Hill, the pre-eminent research facility in

the world at the time. I had been working there for one year when I had a very serious motorcycle accident on my way to work on a Saturday morning. I should have been dead, but an amazing trauma surgeon literally saved my life. It took a full year of rehab until I could get back to work and return to Bell Labs. In order to gain more of a business background, I decided to get an MBA in Real Estate and Finance from Rutgers. While in grad school, I started a side business in independent financial trading.

What did you do after receiving your MBA from Rutgers?

I went back to AT&T, working in the Management Employment division of the company for a year or so. Then I started a company specializing in computer installations for small businesses. The Internet was just getting started at that time. Three years later, I made the decision to close up shop to concentrate on financial trading. I founded several more businesses over the years, but I've continued doing trading. This past summer, after more than 18 months of research, planning and construction, my wife Kimberly and I were excited to open Ultimate Xscape Rooms, a new entertainment venue in Downtown Somerville. It's a place where anyone age 8 to 88 can come to play live-action escape games in a variety of uniquely themed rooms, such as Dragon Castle, Wizarding School, and Sherlock Holmes. The challenge is for players to collaborate as a team to complete a specific mission or objective by finding all the hidden objects, solving the puzzles, and cracking the codes before time runs out.

How did you get involved in public service?

In the 1990s, I bought a house in Bridgewater, and started getting involved in the community. I served as a councilman for 12 years and became Council President. Then, in 2009, I was elected to the Somerset County Board of Chosen Freeholders, a position I held until 2018. At both the municipal and the county levels, I worked hard to preserve the quality of life we enjoy in our communities without raising

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Parent Leader

Edana Desatnick

Edana Desatnick has a story to tell and she is passionate about telling it, both to those who have been touched by the world of complex developmental disabilities, and those who have not. That world has touched her over and over again in life-changing ways, taking her in directions she could not have foreseen when she was growing up in Philadelphia.

As the first person in her immediate family to go to college, Edana entered the academic world with drive, first earning a bachelor's degree from Tulane University, where she met and started dating her husband, Lloyd, at age 18, and then returning to her hometown to earn an MBA degree from the University of Pennsylvania's Wharton School of Business in 1988. "I was very focused on a career," she remembers. "I thought I had my life mapped out."

The couple married and moved to Manhattan. "We had our first child, Bryan, when I was 30," she says. "Although he was not able to breastfeed as a newborn, we did not know there was a medical problem when he was born or during his first months. Everything seemed perfect, we both had good jobs and now had our beautiful son."

But around five months of age, everything seemed to change. "We saw that Bryan wasn't eating right and we thought he wasn't hearing well; and at his check-up, the doctor suggested testing to determine what was going on," she explains. That was the beginning of a line-up of frustrating doctor and medical specialist visits that determined that Bryan's hearing was fine. However, he was developmentally delayed. Months and months of testing to find a diagnosis followed.

At about this time, Edana's sister, Melissa, noticed a child on a flight she took with distinctive similarities to Bryan, and spoke with the parents. The child had been diagnosed with Angelman Syndrome



Bryan Desatnick (seated) with his family (L-R): Lauren, Lloyd, Edana, and Sarah

and the parents provided her with information. Strangely, it turned out Bryan was affected with the same disorder.

"I was just married and had a new career, and simultaneously we had an infant diagnosed with this very serious disorder," states Edana.

"At the time, there was little known about Angelman Syndrome," she continues. "We saw so many doctors and they were all so negative. They said, 'Send him away and don't have any more children.' And I thought, 'Oh my God, will life ever be simple for us again?'"

At 18 months, Bryan began experiencing "very significant seizures," Edana says, and they registered to attend their first Angelman Syndrome conference in

Orlando, Florida, hoping to better understand what she could do for their son. There were some positives: she connected with other families whose children were similarly affected and they exchanged information, and she learned about a specialist in New York City. She also learned that the medications Bryan was being treated with were the wrong ones and exacerbated his seizures. "He was in the hospital all the time," she states. "We were regulars in the emergency room."

A rare genetic disorder, Angelman Syndrome primarily affects the nervous system, causing delays in development, intellectual disabilities, severe communication problems, and often serious difficulties with movement and balance. Seizures

are a predominant part of the disorder and of Bryan's life.

In 1996, the Desatnicks moved to New Jersey, where Edana had gotten a new job and where she became actively involved in awareness initiatives through The ARC of New Jersey, an organization "promoting and protecting the human rights of people with intellectual and developmental disabilities and actively supporting their full inclusion and participation in the community throughout their lifetimes."

Their home in Basking Ridge was located just a quarter mile from an elementary public school, and Edana set her sights on promoting inclusion in their hometown for Bryan and others like him. She helped win a model grant through the State of New Jersey to design a program of inclusion at this school.

"It was very early on in the inclusion movement in New Jersey," she explains. "I worked closely with the town and the school, and all necessary accommodations were made before Bryan started there, and he was able to attend classes with an aide for second through fifth grades. He was the first child with severe developmental disabilities to attend the school. The other kids were wonderful to him and took turns being Bryan's buddy."

However, by fifth grade, Bryan's seizures got much worse. "He experienced nonstop seizures and did not wake up for almost three weeks; he was having a seizure every second and a half," Edana recalls. "I didn't leave the hospital. Neither the doctors nor my husband and I knew what to do. The doctors' only recommendation was to put him into a drug-induced coma."

Luckily, at the very last moment, and using an experimental medication being used in Europe, Bryan woke up. It was during this life-threatening episode that Edana crossed paths with John Garrity (currently Matheny's Director of Social Services, who was then working for St. Barnabas Medical Center; see story on page 6). "We had explored Matheny for its excellent school, with the possibility of placing Bryan in the school in sixth grade, but we knew very little about its hospital at that time," she says.

While the Desatnicks had never thought

of placing Bryan in a residential facility, it became apparent that after weeks of unremitting seizures, he needed more medical attention than they could provide for him at home. It was at this time that Matheny was renovating a wing of the hospital—the yellow zone—and "the timing was perfect. Bryan was so medically fragile and they were able to accommodate him. It felt like a miracle moment," she tells.

"These kids are so vulnerable. Emergencies can come on so quickly, and you have to react so fast. There's no doubt that our son is alive because of the dedicated and amazing staff here at Matheny."



Bryan with his parents and grandmother. Debra Heller

The Desatnick family made the wrenching decision to move Bryan from the family home to Matheny. "It was devastating," remembers Edana. "I had never imagined leaving my child somewhere. He's the love of my life and I wanted him home with our family."

"But you go through a process," she continues. "You have to learn to count on other people's care, you learn to trust."

At that time, Edana was Executive Director at Merck with worldwide responsibility for the Organizational Development function. She showed interest in Matheny's Board of Trustees and was invited to join the Matheny Board.

"Today, there are so many ways for parents to participate in ensuring the continued existence and well-being of Matheny. For instance, fundraising is so important and parents can make such a big difference in that area," she explains.

Edana has been a member of Matheny's Board of Trustees since 2003, co-chairing the Board from 2016 to 2018. Bryan graduated from the Matheny School in 2012 at age 21 (students with complex developmental disabilities graduate at 21), and continues to live on campus, attending Matheny's Adult Day Program in Hillsborough and on the Matheny campus. He is now 28.

Matheny has become a second home, not only for Edana, who has also been active in fundraising and other volunteer activities, but for their entire family. She visits Matheny frequently to spend time with her son, but also as a friend and familiar face to all Matheny residents.

Bryan's two sisters, Lauren, now 24, and Sarah, 20, have also spent a great deal of time on the Matheny campus, visiting with their brother and volunteering during their high school years. "The kids have had the most amazing experiences here," Edana says. "Both girls have served as presidents of the Jr. Friends of Matheny," an active volunteer organization for high school students, and both have had "incredible life-expanding moments here." Both girls have also earned Girl Scout Gold Awards through their volunteering at Matheny.

For Bryan, Matheny has truly become a second home. "He went from being in the ER all the time to being so well taken care of that there have been very few ER visits over the last few years," she tells.

Bryan's life is very full. "He's done so many extraordinary things," says Edana, "and he has become so integrated into the community." Among his mother's happiest moments has been watching Bryan's happiness as he participates in the

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The Social Work team (l-r): Michele D'Amico, Kelly Henry, Amy Kappmeier, John Garrity, Mari Cote, and Valerie Marcketta. Not shown: Bonnie Wilkenfeld, a longtime member of the department, who began working for the Matheny School in September.

A Job Well Done

It's evident that Matheny's six social workers and the department's director love their jobs. All of them have been in the department for at least 12 years, some for as many as 16 years, and several began their careers at Matheny and have not considered moving on.

"There is an esprit de corps here," says John Garrity, Director of Social Services, who started at Matheny in 2003. "We have the right people in the right place, and there's a synergy. Everybody is competent, everybody is highly skilled, everybody has an MSW and is licensed by the State of New Jersey, everybody is assertive and brings a unique approach to the job, but everyone here respects each other. Each social worker has his or her own style."

When asked what the social work team does, Mari Cote, a 12-year member, gives an overview: "When residents come to live at Matheny, we help the client and family or guardians adjust to their new home. When residents move from child services to adult services, we help the young adult and their family and guardians with their transition. When a group home becomes available in the community, we help make sure that the group

home is a good match and then we assist the resident and his or her family with adjusting to the new residence."

"We meet with clients and provide supportive counseling, or visit with clients to give them additional social interaction and communication practice. We help clients and parents and guardians do problem-solving," she continues. "Of course, it varies greatly with the client and the family or guardians. For example, one client might be worried about a relative's health and another might want help skyping with a friend; or a family might need information on respite care or support groups for siblings."

Valerie Marcketta, who worked for years as a social worker in various locales in the U.S. and abroad before coming to Matheny 12 years ago, says, "I think what's most important is that our social workers bring a sense of stability to the client and provide an ongoing relation-

ship. The social worker knows the patient and knows the family and may be the only one who knows the whole picture."

John agrees that bringing stability to the clients' lives is a top priority: "Each individual has a social worker assigned to him or her. The more stability, the better. All individuals need reassurance, encouragement, support, and to know that they are significant."

"We are the liaison between the patient, family, and professional team," explains Kelly Henry, who started at Matheny as a graduate intern in 2003 and was hired in 2004. "We attend team meetings to discuss each patient on our caseload, to obtain information from other members of the team, and share information with the team. We provide supportive counseling one to two times a week for some of our clients; and maintain communication with families as needed. We help facilitate patients being able to communicate with their families and friends."

Kelly and fellow social worker Michele D'Amico co-facilitate the patient advocacy group, which meets monthly to discuss issues that could be related to living at Matheny, as well as State or Federal disability issues. Amy Kappmeier, social worker at the Hillsborough Program, facilitates an advocacy group for the group home residents. These social workers take the patient advocates to various events and conferences throughout the year, including the *New Jersey Self-Advocacy Project* (NJSAP) conferences; and Kelly and Amy have taken advocates to the Self Advocates Becoming Empowered (SABE) National Conference, which is held every two years in a different city and state.

"It has always seemed like no matter what we want to do for our patients to enjoy their lives despite their challenges, we do it. For instance, we've taken residents to the National Advocacy Conference for the past 10 years. Many of them had never been on a plane before," says Kelly. "It's remarkable that staff always volunteer to attend and make this a trip of a lifetime for many residents."

Kelly also works closely with a specialized group at Matheny with Lesch Nyhan Disease (LND) and helps train staff at Matheny and other facilities about how best to work with this population and manage behaviors associated with the disease.

“There are many patients with Lesch Nyhan Disease here. They may have varying intellectual abilities, involuntary self-injurious behaviors and a dystonic movement disorder. For some, accepting and living with this disease can be challenging on a daily basis. It’s a struggle to know you hurt yourself and others but do not have any control over it. This disease truly limits the abilities of those with the disease and that is difficult for them to accept.”

“We help clients adjust and work with their challenges to have a full life,” explains John, whose prior positions include working as the social work supervisor in the pediatric oncology/hematology service at Saint Barnabas Medical Center in Livingston, as a clinical social worker in the traumatic brain injury unit at Mount Sinai Medical Center in New York City, and as a clinical social worker at Johns Hopkins Hospital in Baltimore. “Many clients live with their disabilities but also struggle against them. We help them find some reality to what they can do and what they can’t do.”

“Clients also experience so many losses,” comments Valerie, “and because of their losses, they are often attention-seeking. Staff come and go, and clients get so attached to them. Also, the clients experience many deaths. We find a way to comfort them when they experience feelings of sadness and loss. And another part of our job is to advocate for each client. Sometimes the sensitivity to what the individual is experiencing gets lost.”

John chairs the human rights subcommittee. “Social workers bring a different perspective to these meetings,” he states. “At Matheny, the Social Service and Psychology departments work together closely, and value each other’s input,



which doesn’t happen everywhere.”

“Social workers are also facilitators for discharge,” he adds, “which is an important and complicated process that takes a long time. Social workers do not control this process. There are seven entities involved in each patient’s discharge: the patient, family, Matheny staff, the group home they go to, the Division of Developmental Disabilities (DDD), the support coordination agency, and the adult day program. And social workers help with adoptions.” (See articles on Matheny adoptions, pages 8 and 10.)

Clients are reviewed for discharge annually, he continues, and the input from a multidisciplinary team is reviewed. “For instance, we might review 40 adult patients, 30 could go to medical group homes, 10 could go to (general) group homes. Some children could go to medical group homes, but there are none built for our children now. DDD is informed of patient eligibility for community placement. DDD sends non-identifying information to group home agencies to obtain possible placement resources for our patients.”

Each social worker at Matheny “has about 25 clients and each faces many big challenges on a day-to-day basis,” he states, “but meeting these challenges is a large part of what keeps the social work staff going. Families have such a high level of trust in Matheny.”

“The staff here works well together as a



Above: Mari Cote chats with Tammy
Left: John Garrity

team and when that happens in a workplace, it’s a beautiful thing,” adds Valerie. She credits John with the ability to have built, and to sustain and lead, such an effective team. “It’s not arduous to do our jobs well. The staff is so easy to work with, it’s wonderful.”

“When we work with clients, we assess, affirm, and facilitate,” she states. “We get to know their needs and how we can assist. We don’t let their needs get overlooked. We always advocate for our clients.”

“I enjoy learning how to communicate with people and our clients have such diverse communication styles,” comments Mari. “When I meet with someone for the first time, often it’s very challenging. They might not be able to talk, so I have to learn their unique way of communicating. Or they might not be able to make certain sounds when they talk, so it could take me a few meetings to learn their ‘accent.’ But soon, it becomes easier for both of us. There is always a variety of job tasks, so I am always learning something new.”

“Matheny is an amazing place. It’s foundation from the Matheny family has always been inspiring to me and, I think, many of the staff who work here,” adds Kelly. “But it’s the patients who keep us all going. They are amazing individuals with strength and resilience I often think I would never have.” **MM**

Adopting India

The Making of a Family

It looked like India would not be adopted. Her medical complexities were certainly a deterrent, and as time went on, so was her age. Toddlers and young children with special needs have a chance at adoption. But it appeared that India, who was 17 in 2015, had missed the window of opportunity.

Not so. When Vanica Eldridge moved to Denville, NJ, from Florida in 1993, she brought with her several dreams that she was intent to realize. She came to live with her aunt and attend the County College of Morris (CCM). “I always wanted to become a nurse,” she recalls, “and I always wanted to work with children with disabilities. And I wanted to adopt a child.” Growing up near the Shriners’ Hospital in Tampa, and being hospitalized herself for multiple eye surgeries as a child as well as helping nurse her mother through complications of diabetes, she knew the underbelly of these dreams. But she was determined.

She earned her degree and became an RN in 1998, completing several clinical nursing rotations along the way, including her final rotation, which she did at Matheny. That experience was critical to her future in many ways. “It was a match,” she says simply. She applied for a job in Matheny’s hospital, and had a seamless transition from nursing student to staff nurse.

“October 19th was my first day on the job, although I actually worked on the night shift,” she remembers.

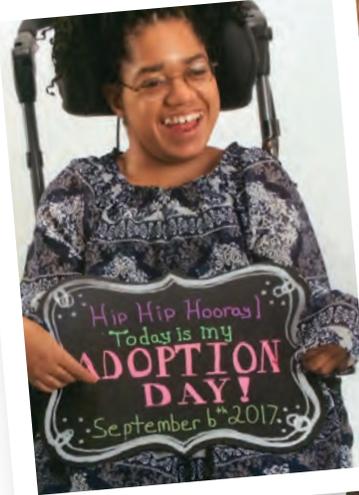
Over the next few years, Vanica focused her efforts on learning to provide the

highly skilled hands-on care that those with developmental disabilities and medically complex issues require. It’s challenging work, and sometimes patients become acutely ill quickly, needing an immediate and knowledgeable medical response. “Learning to do my job well came first,” she says.

But she had not forgotten her dream of adopting a child. “I used to talk about adoption with my mother when I was growing up in Florida,” she remembers. “It was something I thought about doing for a long time.”

However, life did not happen in the order Vanica had anticipated. In 2013, she was ready to adopt when “almost simultaneously” she met her future husband, Kenneth. At that time, she was 43 and no longer working at Matheny. (She has since returned.)

India came to live at Matheny in 2001 at age 4. Vanica had known her since that time and had been thinking about adopting her for many years. There were other families also interested in



adopting India over the years, but for various reasons it had never happened. When Vanica discussed the possibility of adoption with her future husband, and brought him to Matheny to meet the teenager, “he said yes right away,” she recalls.

Bonnie was India’s social worker, and she helped her understand the process and what adoption would mean for her. India liked the idea, and happily served as flower girl at her soon-to-be parents’ 2015 wedding. “We announced our plans to adopt India at our wedding,” Vanica recalls.

“India and I had a previous relationship, so she felt comfortable with me,” says Vanica. “Ken and I took foster care

classes, had several home inspections, and met with India's social workers at Matheny and her therapists for equipment training before India could come home with us to try things out. We felt well prepared."

When all of the groundwork had been covered, India's long-awaited first overnight visit took place on Christmas Day 2015. "We first took India to Ken's house, then my aunt's house; the family met her and we all had a wonderful time. When we took her home and she saw her own bed for the first time, she had a face filled with awe," remembers Vanica. "This was her first time having a private room. It was our norm, but not her norm."

While Vanica and Ken's excitement surrounding the upcoming adoption was in high gear, things seemed to be moving too fast for India. So, they slowed things down "and eased into the process" of making India a member of the family, and "by the time of her adoption, India was used to our home."

Since the adoption process is lengthy and complex, India turned 18 before her court date came up. But by then she was ready to sail. Vanica recalls the large group of well-wishers who filled the courtroom on adoption day, including social workers and lawyers, teachers and friends, and others who had helped India along the way. Her new parents were very happy, but also nervous. They had taken a giant step that would have major repercussions for their entire family and their future.

How did India's life change after adoption? She continues to live at Matheny during the week, where she is provided with her medical care and an active social life and "everyone knows her name," but she comes home almost every weekend. She has participated in the family's car trips to Florida four or five times to visit extended family. Perhaps best of all, she is experiencing "all of her firsts" with loving parents, even though those firsts were much delayed.

"We celebrated her first Christmas with the family, her first birthday, her first grocery shopping. We also go to church together, and India has been baptized and had her first communion," says Vanica.

"And just this past June, she graduated from Matheny's high school. We've had so much fun together."

India, who has cerebral palsy, is "completely dependent for all care," explains Vanica. "She can't stand or eat by herself, goes everywhere in her wheelchair, has a feeding tube, although she can also eat by mouth, and communicates using a device. But she is basically a healthy, strong person," says her adoptive mother.

What counts is that India, who will turn 22 in November, loves to go out and about with her family on weekends and holidays, "doing Challenger baseball, walking in the park, going to the mall

Vanica's words of advice for anyone thinking of adopting a special needs child: "There are always going to be obstacles, but all things are possible with a little creativity and knowing what the obstacles are."

and the zoo, volunteering, visiting family and friends, and participating in religion classes and church activities. And we have days at home, when we play cards and do art projects, and then go out to eat," relates Vanica. India often picks the restaurants.

"We take a hand chopper and chop all her food, and she can eat, and drink, anything," Vanica says. "She's learned to communicate with waitresses."

India and her family communicate a lot. "She is verbal," says Vanica, "and her speech has blossomed since we adopted her. She is very determined to tell you what she wants. She also uses Proloquo [a symbol-based communication app] and is learning to use an iPad."

The biggest obstacle the family has encountered is getting India up and down

the stairs leading into their home. "I can't take her in and out of the house by myself," Vanica explains. "It takes both of us." However, once into the house, all living areas are on the first floor and the family has purchased a lift.

A conversion van with a ramp makes their travels easier. "We do a lot of thinking ahead when we're planning a trip. We find out where the nicest family bathrooms are, or sometimes use hotel bathrooms. We find a way."

And what about the future? This is the most serious and disturbing question for every parent of a child with special needs. Who will take care of our child when we can no longer do that?

Since India is already a resident of Matheny, her parents hope she will transition into an active group home. "This is a wonderful option. As we age, India will be well taken care of and we will still have the benefit of having India in our lives," Vanica explains. "This is the optimal situation for a child with special needs. Of course, like other parents we worry about her: What activities will she have? Will she be happy there? But we have the security of knowing that Matheny knows how to do this so well."

Does Vanica have words of advice for those who may be thinking of adopting a special needs child? "There are always going to be obstacles," she says, "but all things are possible with a little creativity and knowing what the obstacles are. Eventually, society will catch up and understand the obstacles, and make changes to accommodate those with special needs."

In the meantime, life for India is good. In addition to Vanica, Ken, and her extended family, she has her Matheny "family," and the newest additions to her world—a Pekingese dog named Rosie and a kitten named Charlie, whom she cherishes. The family also has another dog named Hunter.

There's no doubt that dreams do come true sometimes, and certainly this is a dream-come-true story that was a very long time in the making.

"India has completed our lives," says Vanica, "and I think we have completed hers." MM

Adopting George



Mom & Me

George's adoption by Matheny physical therapy assistant Donna Hoehn has been an unequivocal success by any measure, but it has come at a personal cost that few can imagine. The everyday demands of raising a child with developmental disabilities and complex medical issues are big, the long-term challenges even bigger. But Donna says she has never regretted the adoption for a moment. George has given her life great purpose; and she has given George a mother and a home.



Life Before the Adoption

Donna is a "Jersey girl" who grew up in Millington and then Gillette, where she is the fourth generation to reside in their family home. Health care has been a recurring motif in her life, from learning to relieve her mother's back pain through massage as a child, to a 10-year stint with the local volunteer rescue squad starting at age 16, to her first job as a physical therapy assistant at the Hunterdon State School, where she discovered her affinity for working with children and adults with intellectual and developmental disabilities.

She earned Associate of Science and Bachelor of Science degrees from Fairleigh Dickinson University, and became licensed as a physical therapy assistant in the state of NJ. After completing a clinical internship at Morristown Memorial Hospital, she joined the staff there and realized her aptitude for working with traumatic brain injury, stroke, and spinal cord patients. She was employed there from 1983 to 1995.

It was in 1995 that Donna's life took several unforeseen twists and turns. She earned a tractor trailer license to team-up with her husband, driving the big trucks from New York to Tennessee and Ohio. "It was



awesome!" she remembers. However, in 1998, she contracted Lyme disease.

"The onset was insidious," she describes, "and it took a long time to diagnose." She experienced haloes, memory loss, and extreme fatigue, and couldn't drive at night any longer. Finally, she was diagnosed correctly and treated with the appropriate antibiotics, and "it was like night and day." She recovered, applied for work at Matheny, and started there as a physical therapy assistant in March 1999, "just over 20 years ago," she says proudly.

A New Chapter for Donna

Working at Matheny was "like coming home," says Donna. Her grandfather had grown up in Peapack, and she had volunteered at Matheny when she was in high school. "Matheny was a big part of the town," she says.

When she returned as a physical therapy assistant in 1999, she worked at the school, helping students to sit, stand, walk, and maintain their balance, "so they could achieve the highest of their abilities." For the past several years, she's worked with adults in the hospital, using manual therapies to "keep these patients in motion," she explains. She has always loved her work.

In 2002, life changed radically for Donna when her husband passed away suddenly. They had no children. But in June 2004, her life changed radically once more when 6-year-old George came to Matheny, and then came home with Donna in 2005. "He was brought to me," she says. "This was nothing that I had planned."

George was just 3 weeks old when he was rushed to the emergency room and diagnosed with shaken baby syndrome, "a serious brain injury resulting from forcefully shaking an infant or toddler, which destroys a child's brain cells and prevents his or her brain from getting enough oxygen. Shaken baby syndrome can result in permanent brain damage or death," according to the Mayo Clinic website.

"George had two skull fractures, multiple hematomas, and several broken bones," Donna tells. "He had experienced

a huge amount of trauma, and he was placed in foster care when he was released from the hospital.”

“He lived in 10 different places before he came to live with me,” she says sadly. George had been put up for adoption at age 4.

George Comes Home

This is what Donna saw when she met George: “a little boy who couldn’t walk or talk; he screamed. He was self-abusive. You had to watch him constantly. He couldn’t express himself.”

“But his will to live was unlike anything that I’ve ever seen,” she says. “He was a fighter and he had an infectious smile. He was adorable.”

So, Donna fell in love with George, and George with Donna. “We started going home together months before he actually came to live with me. He was 7 years old, and he did fine,” she says. “I’ve always had dogs, and George loves dogs. That helped.”

“At first, it was difficult for me,” she says. “The first three months were stressful when we were alone.” But her parents lived in town, and her brother not far away, and they helped when she needed them.

“I wasn’t intending to do this at all,” she explains. “I had an old house with lots of stairs, and I don’t have a lot of money.”

“I put in the application to become a foster parent,” she remembers, “then went through the foster care training and the DYFS [Division of Youth and Family Services] home visits. But I never thought I would actually let it happen.”

Living with George

George weighed 35 pounds when he came to live with Donna. “I could carry him easily up and down the stairs then,” she says, “and he could also bunny hop.”

The new mother and son bonded almost immediately. She says: “I have been Mom right from the beginning. He was in the courtroom for the adoption and he knew that this was it. It’s always been ‘Mom, Mom, Mom.’” George also



immediately gravitated to the photograph of Donna’s husband in their living room, “almost as if he knew him,” she says.

In the years since his adoption, George has made enormous progress, according to his mother. He attended public school from 2006 to 2008, and then moved to the Midland School, where he’s been very happy. “He texts, he’s on the computer a lot, and he has been walking on his own since 2009, when he had femoral osteotomy surgery that corrected the position

of the upper part of the thigh bone,” she explains.

“He still walks crouched and has braces, but he also runs, dances, jumps, and plays soccer and baseball,” she continues. “He’s part of a challenger league in Branchburg, he’s been a member of the Boy Scouts, and he’s made friends at school.” Donna also had an addition put on the house, so George could live on the first floor following surgery.

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The Dancing Pastor

Reverend Martisha Kanard-Dwyer's journey of exploration and self-discovery has taken her to far-flung locales and back to her roots in New Jersey, where she has raised four children, battled some tough personal challenges, and learned how to connect spiritually with a wide spectrum of humanity.

If you walk by her side as she strides down Matheny's hallways on an early weekday morning, cheerfully engaging with even the most communicatively challenged residents, you'll quickly get the picture of how effectively this strongly spiritual woman does her work.

First you should know that Martisha is relatively new to Matheny, but has worked many years in health care and critical care environments. She spent her first five years in Chapel Hill, North Carolina with a great aunt who was a holiness preacher, then came to join her parents in New Brunswick, NJ. Both parents had moved away from large families in the South (her mother had 13 siblings, her father 15) to take job opportunities in New Jersey, her father with Squibb, her mother with the Job Core. "As a child, I was lonely for family," she tells.

A graduate of the city's public-school system, a dedicated volunteer in her high school years, and a sheltered child with a keen desire to get out in the world, Martisha "was wooed by the military." At age 18, she signed up for the Navy (unbeknownst to her parents) and left for her four-year stint of duty in Greece and Italy two days after graduation. "My hair had never been out of braids before," she remembers.

She also recalls discovering during her teen years that "I loved listening and

talking with the people I met in the senior program at the YWCA, where I volunteered. They would tell me their stories and I was fascinated to hear them."

Communication was already a theme in her life when at age 18 she was assigned to monitor ships' messages in the Mediterranean. In looking back at those years, she says, "The experiences I had in the Navy are a big part of who I became...the shock of being in the military, the need to learn how to read people and read situ-

ations quickly, the need to always watch and observe people closely. I had to be hyper-vigilant in reading my surroundings. It was very intense."

"This was more than 30 years ago, and it was a difficult time for many in the military," she relates. "In general, women were still struggling in the military, and there were so few people of color in the Navy and Air Force in the occupation of communications."

Honorably discharged in 1993, Martisha came home and focused on what to do with the rest of her life. She became reacquainted with the man who later became her husband, whom she had met when she was in high school and who had been very supportive during her military years. She also completed two semesters at the Rutgers College of Engineering, and



was about to declare a major in chemical engineering when she discovered her love of dance, and took four dance classes before “finding my niche in public health policy,” she says.

In her new major, she participated in efforts to retain first-year college students through drug and alcohol education; and safe sex, pregnancy, and dating violence programs. She also helped launch Scream Theater, “a gorilla theater group that uses skits and role-playing to teach students about sexual assault, domestic and dating violence, stalking, sexual harassment, and bullying. It’s still going strong at Rutgers,” she says proudly.

By 1995, Martisha was married and halfway through her undergraduate years when she gave birth to their first child. She had her second child shortly after earning her degree. “I became an at-home mom,” she says. “I also became a certified personal trainer and did training with women who wanted to continue exercising during pregnancy and after childbirth, and I was always the go-to person in the neighborhood for afterschool care.”

After having her third child, she felt it was time to redirect some of her efforts beyond family life. “I decided to start seminary,” she recalls. She had gone to Sunday church services regularly when she was growing up and continued to attend religious services abroad. “In the military, I wasn’t concerned about the denomination. I went to find the connection to God. It was time out for reverence.”

In 2007, she entered the seminary, but it was not until 2013 that she received ordination. Along the way, she explored several different religious groups. “I became deeply involved in the African Methodist Episcopal (AME) Church, which connects so many people of color around the world and is very educationally oriented.” Founded in Philadelphia in 1816, the church has persistently advocated for the civil and human rights of African Americans.

Wherever she went, Martisha developed deep relationships that helped her form her personal identity. “I learned so much about me,” she says. “When I left the AME Church, I left knowing I was someone special.” Top among her

“lessons” was the realization of “how important it is for someone to receive your story, to be entrusted with it, someone who cares, someone in your community.”

In the middle of her spiritual journey, she was hit with her own crisis. In 2009, Martisha was diagnosed with Stage 3 breast cancer. “I needed lots of chemo, radiation, and surgeries,” she tells. “When you get sick, you go back home for comfort.”

For her that meant a return to the Tabernacle Baptist Church in New

needed something,” Martisha relates. She started volunteering with the hospital’s pastoral care department, working closely with Reverend John DeVelder, who created the residency program in Clinical Pastoral Education at RWJUH with Rabbi Bennett Miller. The internationally reputed program “accredited more than 1,000 chaplains across many different faiths in the hospital setting. We did some amazing work,” she says.

After her ordination, she recalls Reverend DeVelder asking: “Why don’t you



Brunswick, the church of her childhood. “At first, I didn’t tell anyone about my religious background. I hid out, relaxed, and healed.” She then returned to the seminary and finished her studies, but remained with the Baptist Church.

“I was one of the first women ordained in that church,” she says, smiling, “and then there were three right behind me.”

And what followed her ordination? Given her own cancer struggles, her ability to reach out to others, and her strong spiritual commitment, her decision to do hospital work at Robert Wood Johnson University Hospital (RWJUH) in New Brunswick was not surprising.

“When I finished treatment in 2010, which included seven cancer operations, I

stay and create something?” And she did.

Martisha went out into the community—to Starbuck’s, Elijah’s Promise, under bridges, anywhere people in need of her services would gather. She became intimately familiar with the homeless population, and also with community organizations, and helped to train others to do the same work. “Reverend DeVelder gave me such latitude,” she remembers.

In 2013, the position of trauma chaplain/community liaison was created by Reverend DeVelder and Martisha at the hospital and she was hired full-time into the job. “Homeless people came into the ER all the time, and when they came in, they saw me. Many recognized me. I was the frontline for adult and pediatric

trauma, providing pastoral care for all religious faiths. It was very hard work,” she remembers. “My mentor also convinced me to teach. I taught and I taught and I taught.” That was also the year Martisha graduated from the seminary and was ordained.

In 2017, Reverend DeVelder collapsed at a conference and died shortly afterwards. “I sat with his wife Linda for three days. I watched what the family went through in the ER, and gave them whatever support I could,” she recalls. “This is what it means to be a clinical chaplain. I realized how important my hospital experience had been in my life. It was a game-changer.”

Martisha stayed on at Robert Wood Johnson for one more year. (She has continued serving on the hospital’s ethics

Then Martisha really got started. She began by reaching out to families, talking with them about their religious practices. “Are there rituals you want me to honor?” she asked them. “What can I do for your family?”

Then she started visiting with the students and residents, coloring with them, playing games, talking with them about concepts of well-being and about God, and with some of them about stress. She started holding interfaith services, talking with participants about the divine in communities, about belonging and caring.

“I also did funerals. I scrambled around, trying to make these occasions more meaningful and more connective,” she says. “It took a lot of work. And I let everyone understand that I would do this work with great care.”

see people here as so fragile,” she says. “I see their abilities.”

Always challenging herself to do more, Martisha is finishing a master’s degree in social work. “Whatever work I do, I want to maintain people’s confidence that I will support their emotional and spiritual concerns,” she says, “that I will focus on their spiritual pulse.” As part of her focus on her own and others’ “spiritual pulse,” she adds entries to her journal every day, and is an avid photographer of the world around her, taking at least one photograph each day, which she often posts on social media. “I do this to connect people to a thought, to connect people to each other, and to remain open and vulnerable to my communities.”

She also continues to prioritize teaching in her line-up of ongoing activities. This

“I want to maintain people’s confidence that I will support their emotional and spiritual concerns,” she says, “that I will focus on their *spiritual pulse.*”

board for the past eight years.) However, she was not without a job for long. Just a few months later, Dr. Norma Fair Brown, a colleague and the former chaplain at Matheny, reached out to her, looking for someone to fill her own position before she moved out of the state. In April 2018, Martisha joined the Matheny staff 20 hours a week.

“How do I do this job?” she asked herself worriedly. It was very different from anything she had ever done before.

“I love people; I know how to get close to people, to be with people,” she reassured herself. “I just have to figure out how to do this.”

So, she sat on the units, in the dining room, in the classes. “I got to know everyone, and got familiar with everything,” she says. “I spent a lot of time in Matheny’s group homes and at the day program at Hillsborough.”

“I even use the bulletin board by the cafeteria to post messages, reminding everyone about the need to care and the need to receive care, to give kindness, to receive and give our humanity. That’s what it means to me to be a chaplain and to be human.”

“Religion is never supposed to do harm,” she continues. “It’s about how people experience the divine. It’s sharing the self, sharing in the community.”

Martisha weaves music and dance into her chaplaincy. “I go from zone to zone in the hospital. I say prayers at the bedside and in the hallways. And I’m always here for the staff, to support their well-being, too. My door is always open. I keep an eye out for the staff, and often I have to be the one to make the approach,” she explains.

“And I have overcome one of the biggest hurdles to doing my job. I no longer

fall, Martisha will welcome Maci Sepp, Matheny’s first chaplain intern completing her studies at Princeton Theological Seminary, who will join Martisha in providing pastoral care. “This work is important,” says Matheny’s pastor, “because we are called to tend to the spiritual care of the community, and not just in places where we feel most competent. We should always be willing to learn.”

As a mother of four, a wife of 24 years, a graduate student, Matheny’s chaplain, and a photographer and “journaler” who also values her extended, on-line community, Reverend Martisha Dwyer carries a full load. In December of this year, she will celebrate a decade of being cancer free; and lucky for everyone at Matheny, she remains passionate and energized to support the well-being of her newest community through the often-challenging circumstances of their lives. **MM**

Six Questions

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taxes. I also focused on promoting the economic development of Somerset County. We have dozens of large corporations here, like Sanofi, Verizon, and Nestlé, which employ thousands of people.

How did you become involved at Matheny?

I met Dr. Sprott several years ago at a local event and he asked if I would be interested in joining the Matheny Board. Unfortunately, I didn't have the time at that point as I was already serving on several nonprofit boards. Three years later, however, some of my commitments changed and in 2016–2017, I joined the Matheny Board. Currently, I chair the Building and Facilities, and Governance, subcommittees as well as serving as Vice Chair of the Matheny

Board. The campus is now more than 50 years old, and Matheny also runs five group homes, so we are working on the best way to maintain these buildings and plan for the future.

What do you hope to contribute to Matheny in the future?

Matheny is unique, serving those in our state with the most severe disabilities—our dedicated staff and volunteers do an absolutely phenomenal job of enriching their lives. We need to work on a strategy for the sustainability of Matheny to ensure that in 20 years we are still fulfilling that mission. Matheny now has an opportunity to expand its presence into other parts of the state. I see a real need to increase the number of group homes and provide quality services to populations who are not currently well served. I'm looking forward to helping guide Matheny in the years ahead. **MM**

Edana Desatnick

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many activities offered by the Recreation Therapy Department, including adaptive snow and water skiing, adaptive surfing, adaptive skating, and camping out over night, to name just a few.

"Matheny believes so much in these residents that they create the most amazing activities," she observes. "We're so touched that Matheny's staff and leadership have the courage to try so many of these incredible activities."

No story about Bryan and his family is complete without mention of "one of the most important people at Matheny, a PCA (personal care assistant). Mulu has been there since Bryan came here," says Edana, "and she is like an angel, always checking on him, always going above and beyond. All of the PCAs, the nursing staff, the therapists, the kitchen team, etc. are angels. They always go above and beyond, helping in every detail of the patients' lives, taking on more work, and they do it from the heart, with love."

"People often don't realize how hard it is to take care of these children and adults, how physically intense it is, and how medically, emotionally, and mentally challenging it can be. It's a huge process just to dress Bryan in the morning," she explains. "So much of this work is really hard work for the employees and yet they do their work with so much love."

"These kids are so vulnerable," she continues. "Emergencies can come on so quickly, and you have to react so fast. There's no doubt that our son is alive because of the amazing staff here. We are deeply grateful every minute of every single day for everything the wonderful Matheny team does for our children. We love our children so much and we thank everyone who cares for them so well."

Edana also praises the Board of Trustees, whose members are "such a dedicated group of leaders who volunteer so many hours to ensure the well-being of Matheny. Many Board members have been serving for a long time."

The Matheny Board, she says, wants to "position Matheny to continue to be

successful and sustainable for many years to come. We need to ensure that we can support all of these wonderful patients long into the future."

Fundraising is key, she states, because the many "extras" that Matheny provides to its students and patients are not covered by the State and other funding sources. "In some ways, we've done a disservice, because Matheny makes it look so easy. We've never shared with the parents and other stakeholders how much it costs to run Matheny. We need to continuously raise funds so that we can maintain the high quality of our services."

Strong engagement of parents and the community for Matheny's fundraising is crucial, according to Edana. "I would like to see everyone, including every parent, volunteer, and caring person connected with Matheny, go out and communicate our need for both large, and small, donations. Every donation is important and appreciated. Our future financial stability and growth depend on it."

"I can say—as a parent and a Board member—that I have looked at comparable institutions, but haven't been able to identify another organization like Matheny that provides the high quality of services from early childhood right through the adult years. There is no match anywhere for the breadth of experiences, the medical support, the educational components," she states.

Edana believes that the Board and leadership team at Matheny are thinking about its future strategically and that Matheny will come to be nationally recognized as the pre-eminent organization in its field, and offer its services to more people and touch more lives.

"Come to Matheny's campus," she says. "Take a tour. You can come for a tour anytime. I will meet you and take you around. Walk the floors and meet the angels who take care of our kids. There is such goodness happening here. It's such an important place."

"The other day, I asked two women patients what they would like. 'Lipstick,' said one. 'Visitors,' said the other. They both smiled."

"Come and visit," Edana concludes. "And bring some lipsticks if you can." **MM**

Mom and Me

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Donna herself experienced some health issues, and she says school vacations have been challenging, “but Matheny has been so good to me as an employer and when I needed help, my co-workers have come to the house to help us. Everyone has been so good to us,” she says.

George graduated from the Midland School in June 2019 at age 21. (Developmentally disabled students generally graduate high school at age 21.)

“George loved school,” Donna says, “but now it’s time for something new.”

A New Phase of Life

With each phase of parenting come new challenges, and those challenges are multiplied when the young adult is developmentally disabled. First and foremost, George continues to need a host of medical and social services; and ensuring that those services continue into adulthood requires a large amount of paperwork.

Donna is also wrestling with keeping George’s life on track with as few changes as possible. “Communication is still an issue for him. Change is frustrating and frightening for George. His frustration levels rise, and he can have anger issues,” she explains.

Keeping George on at Midland’s adult day program is the right way to go, Donna thinks. He’s been going there for 11 years and has made friends, and he can participate in a job training program from 9 am to 3 pm, Monday through Friday. However, the school is 22 miles from home, and someone needs to be there when George is dropped off. Donna’s parents passed away in 2012 and 2013, and she says that a reliable aide to wait for George at their home in the afternoons is difficult to find.

“Matheny has been awesome. You need an employer who is flexible and understanding, and recognizes the parenting challenges,” she says. “This is not for the faint of heart.”

“But you have a love for your child, and you do whatever your child needs you to do,” she says.

What is George’s life like as a young adult? “In some ways, he’s like others his age,” Donna explains. He loves music; fiddles with his computer to find his favorite programs, such as “America’s Got Talent”; loves Snap Chat and YouTube and “somehow manages to find the videos with kids with disabilities,” enjoys bowling, swimming, and playing with the dogs.

But George still has many challenges. “He’s a complicated young man who communicates using a combination of a communication device and sign language because his speech is garbled. We use a lot of visuals. He sometimes doesn’t understand what’s said to him. He needs

If you’re thinking of adopting a developmentally disabled child, Donna says, **“Go with your heart. It felt right to me. When my parents met George, they fell in love and he immediately became part of the family.”**

help showering and dressing, but he’s able to feed himself if the food is cut in small pieces. He needs toileting help. When George gets sick, which has not happened often, he needs a lot of Mom-time, a lot of reassurance. He’s never going to be completely independent,” she says.

Donna and George both find peace in church, where Donna plays the organ, and George helps the Sunday School teacher. He enjoys working with an occupational therapist on yoga-based exercises. George also loves to go for a week during the summer to the Elks’ Camp Moore in Haskell, which offers a

program for developmentally disabled children and young adults. It gives him a taste of independence, and both mother and son a breather for a few days.

What’s Next?

Donna wrestles with that question every day. She wants her son’s life to continue with as few changes as possible. She wants him to be with friends and have an active social life. She wants him to keep learning, to have a job in line with his abilities, to have an interesting life outside his home. And she hopes to be able to provide a warm and stable home for George for a long time to come.

Right now, he participates in prevocational classroom experiences and community outings, including shopping, providing Meals on Wheels, yoga, social skills, all part of the Midland Explores Adult Program. “He loves it and it’s a good learning experience,” she says. “It works for him right now.”

But like other parents of developmentally disabled children and young adults, she worries about what will happen to George if she gets sick and can’t take care of him any longer. That’s a big question, and one she has not yet resolved.

But if you’re thinking of adopting a developmentally disabled child, Donna says, “Go with your heart.” When she was contemplating adopting George, her mother had said, “No, we could never deal with a child like that.”

“I did not have their support,” says Donna, “but it felt right to me. And once my parents met him, they fell in love. George immediately became part of the family.”

So, George has found a home and a loving mother, and Donna a loving son. “I try to give George the opportunity to be as independent as possible. I give him choices, but it’s very hard to do, hard to let go. A child with special needs is so vulnerable,” she says. “A little part of you has to go out on a limb.”

What’s next for “Mom and me”?

Donna says she’ll manage to figure it out, much like she has figured out all the other challenges they have shared along the way. **MM**

A Day at The Matheny School

“Busy” is the word that comes to mind moving through the halls of this private school for students with medically complex developmental disabilities. Silence is not a virtue here; communication is a top priority. And there is a lot of communication going on here all the time. Teachers engage students to learn subject matter, and, at least equally important, to work toward their maximum level of independence.

Elementary school students are introduced to the arts; and physical, occupational, speech, and music therapies are threaded through the curriculum, which is based on the New Jersey Student Learning Standards. Despite being faced with unique, and sometimes tough challenges, teachers devise activities that capture students’ attention, and help them achieve specific and measurable goals. Teachers also collect data to measure the success of the programs.

In the upper grades, students move from classroom to classroom for their classes, and choose electives, building skills in journalistic writing, for instance, and photography. Developing practical skills is also emphasized, including activities of daily living (ADLs). Students progress through the Novice Level, where they develop skills inside purpose-designed transition rooms, to the Journeyman Level, where they practice skills out in the community. Some students reach Mastery Level, where job coaches support their progress to independence.

Technology, including SMART Boards and Tables, iPads, iMacs, Powerbooks, and HP-Touch computers, spur students’ abilities and confidence. Various communication devices allow nonverbal students to build vocabulary and express their thoughts and needs more quickly and effectively.

Parents participate in the school’s planning processes and are invited to contribute to curriculum design. Staff and parents communicate often, and the classroom-doors are always open to public-school districts that want to partner with Matheny staff.

When students graduate from The Matheny School at age 21, they do so proudly, and with skills, abilities, plans, and dreams to further their learning into their young-adult lives. **MM**





Recreation Therapy's

fun

The busy season for Matheny's recreation therapy department runs April to December and features a dizzying number of activities, including baseball, track and field, bowling, bocce, yoga, surfing, kayaking, bicycling, karate, swimming, water skiing, campouts, restaurant and theater trips, and overnight vacations to Wildwood, New York City, and beyond.

The department actually provides two kinds of programs: recreation therapy, which is aimed at enhancing the functioning of clients, and leisure programs, which focus on social and community interaction and support interests outside of Matheny. One such leisure program is the annual prom, a night of music, food, and festivities that everyone anticipates happily for months.

It is recreation therapy and leisure activities that link Matheny residents most closely with the outside world. "There is no typical patient here; each individual's needs are unique," explains Sean Bielefeldt, Director of Recreation Therapy and Adult Day Health Services

at Matheny. Improving the client's ability to use a power wheelchair, to get on and off a van lift, to navigate sidewalks, to use automatic door openers, to order food in a restaurant, and to shop and have money skills to make a purchase are all part of the program.

"It is the goal of Matheny to integrate clients back into the community, to help prepare them to live in group homes, by working with them on skills that will maximize their independence," he continues. "Matheny is unique in the numbers of activities that enhance community integration—we average 40 trips a month in our programs, which is pretty much unheard of in similar programs."

"We work as a team and parents are part of the team," says Meghan Walsh, a senior recreation therapist. "They trust that we can provide the opportunities that they never thought their kids would have." MM



Miles for Matheny 2019

It was a bright and beautiful day on Sunday, June 9th, for the 22nd Miles for Matheny annual fundraiser, and spirits were soaring. Matheny's students, patients, friends, families, supporters, and volunteers gathered at a new venue—the Far Hills Fairgrounds—for a busy day of music, food, children's games, camaraderie, outdoor fun, and physical challenges. The day's line-up of events included: the Lu Huggins Wheelchair & Fitness Walk; Kids Fun Run (ages 3–10); 12.5, 25, 35, and 50-mile cycling rides; the "Hills of Attrition" endurance cycle ride; and the 5K run, which was a great hit.

"Miles" gives people with special needs the opportunity to interact with members of the community and raise awareness of the challenges they face each day. The event raised more than \$130,000 to help support programs and services, such as medical care, education, physical therapy, music therapy, adult day care, recreational therapy, and fine arts, which better the quality of life of Matheny's patients and students.

So many individuals, teams, and corporations participated to make the day a success. The Friends of Matheny kept everyone moving with a delicious Brunch of Champions. Thank you to everyone who contributed to help make this a wonderful day.

This year's sponsors include: Poses Family Foundation; Herb and Phyllis Bachelor; Peapack-Gladstone Bank; Bedminster Flyers Cycling Club; the Golub family; Partlow Insurance Agency; Petrucci Family Foundation; Porzio, Bromberg & Newman PC; Mariner Wealth Advisers; Pfizer; Bank of America Merrill Lynch; Day Pitney LLP; Patrick's Pals Foundation; Medical Express; Total Lubricants USA, Inc; Pave-Rite, Inc; The Tustin Group; Unitex; Summit Associates Inc; Baker Tilly Virchow Krause, LLP; Atra Janitorial Supply; RWJ Barnabas Health; Affinity Federal Credit Union; Imperial Dade; Fairclough Propane; ShopRite; Maffey's Security Group; Hunterdon Healthcare; Village Office Supply.

The 2019 top five team fundraisers are: Rolling-With-Scott • Team Bryan Desatnick • Team Andy Flash Lash • Team Porzio • Danny Ambroziak

This year's top individual fundraisers are: Justin Lash • Julie Gordon • Richard Ambroziak • Diana Correia • Lloyd Desatnick

SAVE THE DATE

Saturday, June 13, 2020

Miles for Matheny at the Far Hills Fairgrounds





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