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'Everyday We Thank God That He's Here'

I n May 2009, Matthew Detgen was hospitalized for six weeks as the result of a decubitus ulcer, a bed sore that develops from lying or sitting in one position too long, so that the circulation in the skin is compromised by the pressure. "It was sort of God's way of telling us we couldn't handle his medical problems anymore," says his father, Don Detgen, a resident of Milford, NJ. "He needed a facility that

could." Matthew has cerebral palsy, combined with several other medical conditions. In September 2009, the 17-yearold was admitted as a resident at Matheny. "If Matthew had been at Matheny," his father says, "they would have picked up on the skin breakdown. We just thought it was some kind of diaper rash."

Matthew had been on a waiting list for residency at Matheny for about 2 ¹/₂ years. The Detgens were driving their daughter home from school in Texas when

they received a call, telling them there was a bed at Matheny for Matthew. "I was in the backseat," recalls Marie Detgen, Matthew's mother, "and I started sobbing, saying, 'no, no, it's too soon.'" But, as painful as the decision was, she knew residency was the correct decision because, "all of his medical issues were becoming more evident, and he was getting older." For four months, the Detgens brought their son home every weekend, but now, says Marie, "we feel more comfortable. We don't have to bring him home every weekend. I think he's more alert because of all the stimulation. He wants to know everything that's going on. I can really see a difference in him." Less than 24 hours after Matthew was born, he started began in the early intervention program at Hunterdon Medical Center in Flemington when he was six months old. He attended a Mercer County regional preschool and also attended the Bucks County Intermediate Unit in Quakertown, PA. His parents would bring him to Matheny in the summers for respite. "When we would leave him for respite. "When we would leave him for respite," Marie recalls, "I would feel at peace because they did such a wonderful job. It wasn't easy having him admitted as a resident, but we know this is where he needs to be. It's just a phenomenal place."

"From the president to the PCAs [personal care assistants], everybody's just so professional, caring and competent," says Don Detgen. "It seems that everybody knows Matthew's name. We can't believe it. The staff has genuine love for what they do and for the children." "Everyday," says Marie Detgen, "we thank God that he's here and for the people who

work here and for the passion they have for our child and everyone else. His medical needs prepared us. He had many prior surgeries, but they were all scheduled. This was totally different, and it showed us that we needed to place him here.

"Now, when we spend time with Matthew, it's relaxed, more fun. When he was home, we were so exhausted from taking care of him."

Don and Marie Detgen with their 18-year-old son, Matthew, in his Matheny classroom.

having seizures. Testing showed that he had some brain damage and the eventual diagnosis was cerebral palsy, which had been caused by lack of oxygen at birth. "Anybody who has a disabled child," says Don Detgen, "knows that you go through all kinds of different emotions – you're angry, you're resentful of others." Matthew



New York Jets, Bloomingdale's Hold Shopping Fundraiser for Matheny

our years ago, Andrea and Dave Szott made "a painstaking decision, deciding that someone else would care for our child." That decision was to admit their son, Shane, who has cerebral palsy, as a residential student at Matheny. The move to Matheny, Andrea Szott said, "has transformed Shane's life. He is the happiest young man that you can imagine. Matheny met a need that we weren't able to do." Matheny, she added, makes it possible "for these kids to have a normal lifestyle. Shane went to his first prom; he's been camping, fishing, skiing, canoeing and rock climbing."

Szott made these remarks at a brunch and private shopping event held November 11 by the Atlantic Health Jets Women's Organization at Bloomingdale's in The Mall at Short Hills. Dave Szott is director of player development for the New York Jets. The brunch kicked off a four-day shopping event from November 11-14 during which Bloomingdale's donated 10% of total group sales made with its At Your Service Manager to Matheny. During the brunch, wives and girlfriends of Jets players and staff modeled fashions from the store for select customers including several members of The Friends of Matheny, an auxiliary group that raises funds for Matheny. The shopping event raised more than \$3,200.



Friends of Matheny shoppers, from left: Helen Fallone, Nancy Hojnacki, Lisa Lee and Nancy Wojton.

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Katina Taylor, wife of Jets linebacker Jason Taylor, modeled "Game Day" fashions.

Andrea Szott, center, with Michelle Ryan, wife of Jets head coach Rex Ryan, left, and Michelle Tannenbaum, wife of Jets general manager Mike Tannenbaum.

SAVE THE DATE: Miles for Matheny, April 17, 2011.



Full Circle 2010: The Human Condition

⁶⁶ These are artists who refuse to be defined by their disabilities. Their art helps to communicate who they are." With those words, Steve Proctor, president of Matheny, prepared his audience for the multi-media stage presentation that was an integral part of Full Circle 2010: *The Human Condition*, the 17th annual celebration of Matheny's Arts Access Program, held in the Robert Schonhorn Arts Center. Arts Access makes it possible for people with disabilities to create fine art, assisted by professional artist-facilitators.

The presentation of dance, drama and poetry was preceded and followed by a 57-piece exhibit of fine art, consisting of acrylic paintings, digital images, pigment prints and digital sculpture created by artists in the program. Guest curator for the visual art exhibit was Madison-based artist, Dan Fenelon.



From left, Kay and Glenn Dunn of Bernardsville and Celia Maietta of Basking Ridge.



Barri Tabak of Marlboro, left, purchased a painting created by artist Alex Stojko, right.



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"Nightlight" by Chet Cheeseman.

Dance facilitator Heather Johdos, left, and Arts Access dancer/choreographer Natalia Manning performing "I Am Ready"



With Matheny's Help, Maria Tetto Got the Wheelchair She Needed

hen she was 13 years old, Maria Tetto of Budd Lake, NJ, was struck by a pickup truck, an accident that resulted in traumatic brain injury. She spent a month in Morristown Memorial Hospital, several months at Children's Specialized Hospital in Mountainside and 17 months as an inpatient at Matheny.

Maria returned home to her family in April 2000, and although no longer able to walk, resumed as normal a life as possible and graduated from Mount Olive High School in 2006. Currently, she works at Presents of Mind, a gift shop in Flanders, NJ, operated by Community Options, an organization that develops residential and employment supports for people with severe disabilities.

Shortly after Maria had graduated from high school, her power wheelchair had broken, and having only a manual chair seriously hampered her ability to be as independent as she would like. Familiar with Matheny from her stay there, Maria's family brought her to Matheny's Seating and Mobility Clinic in August 2009.

Maria's previous wheelchair, according to John Reck, PT, MPT, PCS, ATP, Matheny director of assistive technology, was a power chair with a standing function. "We did an initial evaluation," Reck recalls, "and we recommended the Permobil C500," a front wheel drive power wheelchair with a standing feature. We trialed her, and she was able to drive it. It's important to her to be able to stand up and drive around her kitchen and access cabinets. She has her own apartment adjacent to the family home, and this chair allows her to participate in activities of daily living. And it also strengthens her bones and joints."

Matheny therapists and rehabilitation technicians worked very hard to get the chair approved by the insurance companies and were able to deliver it to Maria in June of 2010. "Matheny," says Frank Tetto, Maria's father, "was very good with following up with the original denials from the insurance companies. They did the paperwork and handled the appeals. They documented the



necessity of the chair. Maria can use this chair as a stander. It allows her to speak to people at eye level. It helps prevent blood clots and skin breakdowns, and it allows her to be more independent."

At the Presents of Mind gift shop, the front desk counters are high, and Maria's manual chair was low. "So," says Tetto, "they had her working at a table in the back. Now, ever since she's had the new chair, she can work upfront." A bonus feature of the chair has been its ability to generate social interaction for Maria. "What's unique," explains her father, "is that when people see her in public, they will approach her and ask her about the chair. So, it opens up a whole world of social possibilities."

Matheny's Seating and Mobility Clinic is a highly specialized professional service. The clinic team strives to meet the needs of each individual by providing the perfect match of assistive technology services and products in order to create the highest level of health, function and quality of life.

Left, Maria, using the standing feature in her Permobil C500 front wheel drive power wheelchair.

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Basking Ridge Teen Raises Money to Fund Power Wheelchair for Newark Student

aniela Duarte is a nine-year-old student at the Belmont Runyon School in Newark. Fourteen-year-old Callum Slater, a resident of Basking Ridge, NJ, is an eighth grader at the Far Hills Country Day School in Far Hills, NJ.

Daniela moved to the United States from Brazil when she was five years old. She was in a motor vehicle accident in October 2008 and was ejected from the car, landing on Route 22. She had no health insurance at the time, but was treated at the UMDNJ Trauma Center. She has been through

many surgeries, both lifesaving and reconstructive. As a result, she can eat and talk again. Through charitable donations of doctors and friends in the community and the patience of her parents, Daniela is now able to sit upright in a wheelchair, read enlarged print and interact with her peers, using her own voice.

Callum, as a project for his Bar Mitzvah earlier this year, decided to raise money to fund a power wheelchair for someone who couldn't afford it. He visited the rehab technology department at Matheny to learn more about power wheelchairs and how they help people with disabilities. Matheny's rehab department works closely with staff serving medically fragile children in the Newark School District, and Marda Herz, who is a physical therapist



From left, Marc Galli, rehab product specialist, Pride Mobility Products (manufacturer of the wheelchair); Maria Moco, Daniela's mother; Marda Herz, PT in the Newark School District; Bob Williams, Matheny rehab technician; Daniela Duarte in her new power assist wheelchair; Callum Slater; Fiona and Dr. James Slater, Callum's parents.

in the district, identified Daniela as a worthy recipient of Callum's project, which raised nearly \$8,000.

Daniela was presented with her new power assist wheelchair on Thursday afternoon, September 23, at the Belmont Runyon School. Her mother and sister-inlaw were present along with Callum and his parents, Dr. James Slater and his wife, Fiona, Marda Herz and members of the Matheny rehab technology staff. M



BOB WILLIAMS

Bob Williams, Matheny rehab technician (in photo at top of page), passed away in November. Bob was personally involved in Callum's project and was devoted to the patients at Matheny and people with disabilities in the community. He will be greatly missed.



Smart Board Helps Non-Verbal Student Express Himself

ike most teenagers, 17-yearold James Wild is very social. Unlike most teenagers, James, who has cerebral palsy, is non-verbal.

In individual speech therapy sessions at Matheny, James, a residential student, has learned to communicate using interactive symbols on an electronic augmentative communications device. However, because James requires oneon-one supervision and tends to be very physical with equipment, it was not possible to use the DynaVox speechgenerating device in his classroom. To solve this problem, the speech therapy department was able to transfer the software program from the DynaVox onto a computer so that James could

communicate on a Smart Board, which is projected on a big screen in his classroom. So, the Smart Board became a large DynaVox. Pretty much everything the DynaVox does can be recreated for him on the Smart Board. This has opened up doors for James that previously didn't exist.

Before this was accomplished, the frustrations experienced by James were also frustrating for his teacher, Peggy Zappulla. "All of our kids need a way to communicate," she explains.

"James uses mostly sign language, but, for people who don't understand sign language, it's difficult for him to tell them what he wants. So, speech came up with this idea, and he uses it very effectively during speech group."

For example, "We were doing an activity that required the students

to identify a part of speech and come up with a word for that part of speech. We set the board up so James would have to choose the part of speech, and then the board would open into another board. We gave him four choices, and he would have to choose the word. For him, it's very effective. When he touches the board, he folds his arms and waits for the next question and then goes back to the board. It's really helped him a lot. He's able to focus because everything is big, and he can see the visuals. He can touch it, and he can draw."

As part of a collaborative team, the speech-language pathologists at Matheny provide a complete assessment of each student and patient's individual needs. The method being used by James is one example of how technology is adapted to address a specific challenge. Educationally, the school works to improve the ability of all students to develop independence in life, and communication is a necessary skill to develop this independence. "My objective," says Zappulla, "is to get James to write sentences, putting the words together using picture symbols. He's a very smart kid. He picks things up very, very quickly. This improves his ability to express his needs and express his knowledge. It's just fantastic!."

James Wild points to a symbol on the Smart Board screen, assisted by speech-language pathologist Brynna Cunningham.





Integrating Physical Therapy into the Classroom

n a typical day, Diane Tavares, MS, PT, conducts about eight 30minute physical therapy sessions for children in the Roxbury, NJ, Township Public Schools. But it's what those children do after they leave Tavares that's really important.

"It's not just physical therapy once or twice a week -it's physical therapy all the time."

"What happens," says Patricia Hovey, Roxbury director of special services, "is that she'll teach the teacher those skills that she's teaching individually, and that continues all day. So, now it's not just physical therapy once or twice a week – it's physical therapy all the time. It's an important piece of what Diane does. She's not just working with the child; she's working with the teachers and the aides."

Tavares works in the Roxbury district as part of the Therapy Solutions program at Matheny. As part of Solutions, physical and occupational therapists, speechlanguage pathologists and rehabilitation technicians from Matheny help public and independent schools enhance education and communication for their special needs children.

One of Tavares' star pupils is five-year-old William Miller, a student in a self-contained preschool class at the Jefferson Elementary School in Succasunna. When William first started school two years ago, Tavares recalls that he had very weak trunk control. "He was falling all over the place. I had to reassure his teacher that he was going to fall and that what she had to do was make the environment the best that she possibly could. We worked

on how to give him the support in the classroom so he was safe, being that one step ahead so that if he turned a corner and was going to trip, we'd be there ahead of him." When William came into the therapy room for his individual treatment, Tavares says, the teachers and aides were willing to have someone come with him. "It's a collaborative effort," says Patti Klein, William's teacher. "We're lucky because

it's a partnership."

Thirty minutes twice a week, says Tavares, "was not going to fix someone like William. It has to continuous be all day long. His teacher and the aides gave him the support. A big part of his success is that they carried it over into the classroom. As a result, he's very motivated. He wants to keep up with other children in Helping William the classroom. When navigate the first started, balance beam. he



Stretching William's hip flexors and quadriceps.

he wanted to do the balance beam, and we'd be a nervous wreck. He can do it now without assistance. It's incredible how much he's improved in two years. He'll play catch with me now. He'll throw at a target. These are things he had no interest in doing because it was too hard."

A resident of Randolph, NJ, Tavares has been working in the Roxbury district on behalf of Matheny since March 2007. During that time, she has become an integral and valued member of the staff. Hovey describes her as "an advocate for the needs of her students and a collaborative partner with our district's staff. Her dedication to her profession and to her students is apparent every day that she works with us." Cheryl Miller, William's mother, says her son is doing, "wonderfully." The great thing about Tavares, she says, is that, "she goes out of her way to keep me posted. She follows through with everything."

For more information about Matheny's Therapy Solutions program, call (908) 234-0011, ext. 751, email Solutions@Matheny.org or log onto www.Matheny.org/Solutions.



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For additional information, please contact: Janice Kriegman, Acting Director of Philanthropy 908-234-0011 ext 315 or jkriegman@matheny.org

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Matheny Parents Form Foundation To Help Families of Special Needs Kids

hree years ago, friends and family members approached Jim and Kerry Conmy about having a golf tournament to raise funds for their son, Patrick, who has several undiagnosed special needs and attends the Matheny School. "They

people came to dinner. We raised more than \$25,000."

The golf tournament, now held every August, is the primary fundraiser, and Patrick's Pals is now a 501(c)3. "We work with Matheny as well as the Hunterdon Medical Center, the Arc of Conmys are also planning to fund some adaptive laptop computers for Matheny students. Other projects have involved paying the medical bills for a young spina bifida patient whose family's house was in danger of being foreclosed and buying a wax machine

were just looking for a way to help us out with Patrick," Jim Conmy recalls. "The more Kerry and I talked about it, we loved the idea of a fundraiser, but there was no way that we could have accepted the money, because we knew that we could provide for Patrick."

So, instead, the Conmys decided to help other families with special needs children that *did* need financial help.

They formed a foundation called Patrick's Pals and established a golf tournament in 2008 at the Stanton Ridge Country Club in their hometown of Whitehouse Station, NJ. "We said to the people who had come to us that we would do the golf tournament with one caveat. We didn't want to take anything. We wanted to set the money aside to help other people. When we held the first tournament, in August 2008, we really weren't a 501(c)3 yet, but the response was amazing. It was the biggest golf tournament they ever had at Stanton Ridge. We had more than 190 golfers, and 200



Kerry Conmy with Patrick at Matheny's Halloween celebration.

Hunterdon County and the Somerset Hills Handicapped Riding Center,"

Matheny has benefited from a \$2,500 donation to help expand its adaptive phys ed department.

Kerry Conmy explains. "Those four places have helped us identify families who need the help."

Matheny has benefited from a \$2,500 donation to help expand its adaptive phys ed department. The

for a young girl who needed it at home for physical therapy. "Then," adds Jim, "there's the single mother whose child is severely autistic. She couldn't afford to send the child to a summer camp that would fit his needs. She was ill. and she needed him to be at camp to get things straightened out in her life. So, we wrote a check to the camp, and he went two years in a row." Patrick

has two siblings, 12-year-old Seamus and 10-year-old Catherine. "They love their brother," Jim says, "but we wanted to teach them a lesson that you take something like Patrick's disability and make a positive out of it. Don't feel sorry for yourself; make this into something good." For example, Catherine and four of her friends all have birthdays in April. According to Kerry, "They got together, and, instead of having five birthday parties, they had a big outing at one of the roller rinks, and, instead of receiving gifts, they asked for donations and raised \$2,000 for Patrick's Pals." M



Veteran PCA's Reward: 'Having Someone Trust You With Their Loved Ones'

66 From the outside. Get from the outside. Get to know them." That is the greatest lesson that Safy Diedhou has learned from her 11 years as a personal care assistant (PCA) at

Matheny. Diedhou, who emigrated to the United States from Senegal in 1996, remembers when a friend first referred her for a position at Matheny in 1999. "When they called me," she says, "I thought: 'I don't know if I'm ready for this job.'" But, after working for a year, "I knew that I just had to do this."

PCAs provide basic care for Matheny students and patients and are vital members of Matheny's interdisciplinary team. Diedhou, a resident of Hackettstown, NJ, is one of the PCAs chosen by Matheny to take online enhancing the professional skills of people who want to remain in direct care. Courses include instruction in areas such as safety in the community and at home; mistreatment of at risk adults and children; positive somebody's life different."

She has already taken the first two levels of the CDS instruction and is going on to level three. The classes, she says, have enabled her to become better at communicating as well as



Safy Diedhou applies night splints for one of the students under her care.

classes from the College of Direct

"When I go home, at the bottom of my heart, I know I have helped somebody, made somebody's life different."

Support at the Boggs Center for Excellence at UMDNJ. The mission of the CDS is to serve as a learning gateway for direct care workers, behavior support; and individual rights and choices.

When Diedhou was growing up in Senegal, she hoped to one day become a nurse, but her family did not have the money to send her to nursing school. Now she hopes to eventually make that dream come true. In the meantime, she receives a great deal of satisfaction from her current job as a PCA. "To have someone trust you with their loved ones," she says, is what makes her work so gratifying. "When I go home, at the bottom of my heart, I know I have helped somebody, made

more knowledgeable about safety issues. Of particular importance, she adds, has been the improvement in her ability to communicate with the parents of her patients, "knowing how to approach them and make them feel more comfortable." She recalls the early days of her career when she wasn't so sure she could be an effective caregiver. "But I decided that if I was scared of these kids, if I was too emotional, I wouldn't be any good to them. It's interesting around here how you can learn a lot of stuff and just grow." Me





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New Friends President Puts Emphasis on 'Quality of Life' Gifts

June Cioppettini's master's degree in business administration came in handy five years ago when she was asked to modernize the financial record keeping system for the Friends of Matheny. She was soon asked to join the Friends' board of directors and serve as treasurer. June's service to the Friends reached a new height when she was elected president of the 30-member board at the Friends' annual luncheon in June 2010.

Cioppettini's goal is to "try to give the residents and day students more of a life like our own children." The Friends

of Matheny has funded many initiatives that enable the children and adults to participate in everyday activities such as adaptive ice skating, skiing and other sports. This year, the Friends provided the funding for a therapeutic cello and harp, choir robes, switch-activated cameras, therapeutic equipment, weekend entertainment, waffle makers and a pasta maker. The Friends also funded a Smart Table and a Smart Touch computer -- equipment used to enhance the educational experience. "Why shouldn't these children have a prom and every opportunity we can give them?" Cioppettini asks. "It is an honor to be asked to be president of the Friends of Matheny and be able to help them achieve their goals."

For more information about the Friends, please visit www.friendsofmatheny.org, call 908-234-0011, ext. 282, or email friendsofmatheny@matheny.org.



June Cioppettini, 3rd from right, flanked by other Friends officers, from left: Pam Cembrook, Kathy Sisto, Lisa Novella, Karen Thompson, Cathy Wild and Edana Desatnick.