

Mathens



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Matheny Grant Will Ease Hospital Transitions

atheny has received a \$300,000 grant from the Robert Wood Johnson Foundation through its New Jersey Health Initiatives program to develop,

implement and test a model for improving the quality of transitional care for persons with chronic health issues and medical complexities associated with developmental disabilities. Matheny's partners in this project are Morristown Medical Center in Morristown, NJ, and the Robert Wood Johnson University Hospital in New Brunswick, NJ.

For Matheny patients, the Lisa transition to and from acute care hospitals is difficult. Over the past several years, Matheny has developed two primary mechanisms to help acute care staff members understand and address its patients' needs better: a trip nurse and a mini medical record.

The RWJF grant will enable Matheny to partner with MMC and RWJUH to formalize those two mechanisms and provide an unusual degree of interaction between Matheny staff and acute care hospital staff through the establishment of a nursing position dedicated just to the transition process. These two acute care hospitals were selected for this project because they treat the majority of Matheny patients who require acute care hospitalization. Grant funds have allowed Matheny to hire a full-time transitional nurse who will accompany

patients transported to these two acute care hospitals, encourage full and effective use of information in the patients' "mini-record", follow the patients throughout their hospitalization



New transitional nurse Jeanne Lavelle, RN, center, confers with Lisa McKenna, RN, left, and Dr. Surbparkash Singh, staff physician.

to facilitate discharge planning and foster development of resources needed for appropriate inpatient care and effective post-hospital transition.

The new transitional nurse is Jeanne Lavelle, RN. The project's goal is to reduce the number of

More on Matheny's new transitional nurse, page 2

hospital readmissions of patients with developmental disabilities. In evaluating the results of this project, Matheny's Institute for Research in Developmental Disabilities will examine the length of time between hospitalizations, numbers of re-hospitalizations and number of emergency room visits in the target population during the course of the project. That data will be compared with data derived from clinical records

of persons served in the 12 months preceding the project.

Communication on a day-to-day basis between Matheny and the staff at the participating acute care hospitals

will be managed by Lavelle. Key Matheny personnel at the administration level are: Dr. Gary Eddey, chief medical officer, and Cathy Church, RN, director of nursing services. Primary contacts at MMC are: Dr. Stanley Fiel, chair of the department of medicine, and Trish O'Keefe, RN, director of nursing and acute care services. At RWJUH, the primary contact is Dr. Alfred Tallia, chair,

department of family medicine.

The RWJF focuses on the pressing health and health care issues facing our country. As the nation's largest philanthropy devoted exclusively to improving the health and health care of all Americans, the Foundation works with a diverse group of organizations and individuals to identify solutions and achieve comprehensive, meaningful and timely change. For more than 35 years, the Foundation has brought experience, commitment and a rigorous, balanced approach to the problems that affect the health and health care of those it serves. When it comes to helping Americans lead healthier lives and get the care they need, the Foundation expects to make a difference in your lifetime. For more information, visit www.rwif.org.



Wheels for Whitney: Adaptive Wheelchair Helps Young Woman Navigate Around Campus

In April 2001, nine-year-old Whitney Weldon was diagnosed as having Fibrodysplasia Ossifcans Progressiva (FOP), a rare genetic disorder characterized by the abnormal growth of bone in soft tissue. FOP is the only known condition where one organ can transform into another, where muscles, tissues and ligaments develop into bone. The disease progressively disables the body as new bone fuses joints and creates immobility.

In March of this year, Whitney and her parents, Bill and Hilary Weldon, of New Vernon, NJ, visited Matheny. Whitney was getting ready to enter Georgetown University in the fall, and her parents were hoping therapists and rehab technicians could evaluate her for adaptive equipment that might make her life a little easier.

Since Whitney's mobility was extremely limited, Matheny recommended the Permobil C500, a front wheel drive power wheelchair with a standing feature. Whitney was not able to use a

conventional wheelchair, but this model, according to Jon DaSilva, Matheny rehab technician, "allows the seating system to come up to meet her. And we added a custom foam in place to help with her comfort level."

DaSilva recalls that Whitney, "was real resistant to using a wheelchair." But that has changed. "I'm doing great," she says. "The wheelchair has worked out real well for me. I can get around faster than if I was on foot, and I have the freedom to get out of it if I want to." Some of her early resistance, she admits, was because "I was worried that I wouldn't have a lot of friends because it was different." but the wheelchair, she says, has actually contributed to the fun of the college experience. "I can get places quicker. People don't have to wait on me. I have to wait on them now."

DaSilva says Stephen Burke, Permobil's representative in northern New Jersey, "has been a huge resource for us, not just with Whitney but with

other clients as well." Whitney is appreciative that Matheny has



Whitney Weldon in her power wheelchair.

given her a Permobil contact in the Washington, DC area. "If I have a problem now," she says, "they will send someone who's closer to me to make adjustments and stuff."

There is tremendous need for FOP research funding. The Weldon family, through the Weldon FOP Research Fund (www.weldonfop.org), has raised awareness and millions of dollars for the FOP Laboratory at the University of Pennsylvania School of Medicine.

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Matheny's New Transitional Nurse

Jeanne Lavelle, RN, a resident of Morris Township, NJ, has been a member of the Matheny nursing staff since February 2010. She has previously worked in the CNIII outpatient clinic and chemotherapy area at Memorial Sloan Kettering Cancer Center in New York City and has been a grant reviewer for Susan G. Komen for the Cure North Jersey. In her new position, she will accompany patients transported to Morristown Medical Center and Robert Wood Johnson University

Hospital, encourage full and effective use of information in the patients' "minirecord", follow the patients throughout their hospitalization to facilitate discharge planning and foster development of resources needed for appropriate inpatient care and effective post-hospital transition. She is "looking forward to being an advocate for our patients. The whole plan is cutting edge and exciting. It's an opportunity to provide better care and support for the families of our patients."



Full Circle 2011 Showcases Talent And Passion of Artists with Disabilities

ull Circle 2011 Dimensions, the annual celebration of Matheny's unique Arts Access Program, highlighted all the different dimensions of the program's artists. "They may be painters." explained Eileen Murray, Arts Access director. "They may be playwrights; they may be dancers or choreographers. Arts Access gives them the opportunity to sample all that and to find their one passion or several different passions." Arts Access enables people with disabilities to create fine art, assisted by professional artist-facilitators. At

Matheny patients often have great difficulty communicating, but, "Arts Access provides them with an opportunity for creative expression." It reflects, he added, Matheny's efforts, "to enrich their entire lives, to provide them with a full spectrum of life experiences." Pamela Cembrook, a resident of Bernardsville and Matheny trustee, was honorary chair of the event.

Right: Untitled by Shaleena Tomassini.





Jessica Evans performing her dance, "My Brain's on Fire" with professional dancers and actors.

Full Circle 2011, more than 40 pieces of visual art were exhibited during a reception in the gallery. The exhibit was curated by Madison-based artist, Dan Fenelon. A stage presentation showcased dance, drama and poetry created by the artists. Professional dancers and actors, some Arts Access staff members, performed with the Arts Access artists.

Speaking to a packed theater prior to the stage presentation, Steve Proctor, Matheny president, pointed out that

Arc of Mercer adapts
Arts Access system, page 7



Exhibit curator Dan Fenelon and his wife, Kadie Dempsey.



Ann Painter, CEO of the Visiting Nurse Association of Somerset Hills, and her husband, Robert.

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At Matheny, Physical Therapy is Measured by Long-Term Goals

rin Leach remembers sitting in her advanced biology class ✓ during her senior year at Jefferson Township High School in Oak Ridge, NJ. "My classmates were bored," she recalls, "but all I could think about was how fascinating all this information was. I thought, 'Wow, this is what your body is made of, and this is what makes it move." That interest led her to pursue a career in physical therapy, earning both master's and doctor of physical therapy degrees from the University of Scranton. The Sparta, NJ, resident worked in sports medicine and then tried a nursing home setting before moving on to work with children with developmental disabilities - first at Cerebral Palsy of North Jersey's Horizon High School in Livingston and, since November 2008, at Matheny.

"I've ended up enjoying Matheny more than anything else I've ever done," Leach says. "In a nursing home, you can improve somebody's function pretty significantly, but here, with the kids, there is just so much more energy. I started to realize that what I do can really help them forever. With this population, even though the change doesn't happen quickly, I always know I'm doing something with them they wouldn't otherwise get the opportunity to do - like sitting up or standing up by themselves. I've learned to shift my focus and think more long-term. I can look back and say, 'Wow, they're doing this much better' - even if it may just be the smallest little thing."

Leach's dedication has been recognized. She was voted the Related Service Provider of the Year by her

peers at the Matheny School. Saying she was "surprised when I won this," Leach acknowledges that integrating physical therapy into classroom activities requires creativity. One



Physical therapist Erin Leach works on sitting balance and reaching skills with eight-year-old student Niara Holmes.

example, she points out, involved a classroom lesson about where different articles of clothing belong on the human body. "The teacher had a big cutout of a person, and the students were working on where the shirt goes, where the shoes go, things like that. They had Velcro clothing and shoes. So, when it was my student's turn, I helped her walk up to the big cutout and put the shoes on. It was the perfect activity for what she was working on."

At Matheny, physical therapy provides therapeutic interventions to

help students and patients attain their optimal level of function. PTs take a personal and client-specific approach to addressing each person's individual needs. Leach is part of a relatively new concept called the Professional Learning Group (PLC), which is a group of teachers, aides and a physical, occupational and speech therapist. "We talk about what we want to do to enhance the lives of the students." she says. "There are little things about the students that some people know and some people don't know. We thought it was a really good idea to make a communications card that they could have on their wheelchairs. So, when somebody new comes in and wants to have a conversation with them, it would be good to know where their visual field is or if they have a 'yes/no' response or if they're hard of hearing."

One of the most difficult aspects of Leach's job, she says, is, "finding out what motivates the students. You really have to try to understand that from the child's perspective. 'What does this mean to him/her?' 'Is this something he/she really wants to do?' 'How can I change it so he/she will want to do it?' It's hard, and I think everyone struggles with that. You just have to take the time to get to know the child. You have to pay attention to the nuances and the communications cues. Sometimes. you just have to shift your focus and take a step back." Leach would be the first to admit that she receives lots of help. "I feel like the staff is really, really supportive," she says. "There are people here with a ton of experience, and everyone is pretty open-minded. There's an easy exchange of ideas." We



Flexibility and Patience are Keys to Matheny Teacher's Success

aren Deland first taught at The Matheny School in 1979, and she remembers one of the non-verbal students using an autocom, a monotone oral speech device. "Matheny was a forerunner in technology then," she says, and "Matheny is still doing it. It is still

top-of-the line technologywise for the students, and everybody's treatment," she emphasizes, "is different and individualized." Deland, who is a resident of Berkeley Heights, left Matheny in 1980 to accept a teaching position in the Franklin Township Public School District, in Quakertown, NJ. After earning a law degree and raising a family, she returned to Matheny in 2009 and last year was named the school's Educator of the Year. In her classes she uses a Smart Board, which helps

some of her students with low vision follow along "because it's so large and bright, and you can change the background and meet their needs. Without the technology, we would be doing textbook learning, which isn't really appropriate for our population."

After spending time as a teacher in both public and private schools and practicing law, Deland came back to Matheny because she missed the "special students". Today's Matheny students are much more medically complex than the students she taught 30 years ago, but the keys to success, she says, are flexibility and patience. "You have to be flexible in all

aspects – in scheduling, in progress, in communication. You just kind of have to roll with it. Nothing is set in stone. You may be working on phonetics, and a student will blurt out something that you did yesterday. That is great gratification. We were working on compound words," she continues,



Karen Deland with one of her students, 15-year-old Daniel Gaudreau.

"and then the next day we were doing something else, and one of the students said, 'bedroom'. Wow! She remembered it."

"It's very heartwarming and enlightening to see that my own kids can walk in here and feel at home."

One of Deland's students is quasiverbal; another says a few words; and the other four are non-verbal. "Adapting to their different modes of communication is challenging," Deland admits. "This morning we had a great big Scrabble board up there, and all the students were playing. We played Scrabble using phonetics and vocabulary words, and they can do it. If you take the time and break things down into teeny, tiny task analysis steps, they can communicate.

You just have to be patient and flexible." Having spent a lot of time educating her students about the impact the Americans with Disabilities Act has had on their lives, Deland also feels very strongly about helping her students be part of the community and part of society. "If we cannot provide our population with the ability to be out in public, we have done a disservice to them." Her class recently played miniature golf at Hyatt Hills, a handicapped

accessible course in Clark, NJ. "I can put a student on a bus and take her to Shoprite or take her to a golf course. I can't think of any day that goes by that somebody doesn't warm my heart."

Deland received her BS degree in elementary education and special education from Vanderbilt University's College of Education and Human Development and her JD from the Seton Hall University Law School.

Her students are all teenagers, and she has two teenagers at home, who are the same age. "It's very heartwarming and enlightening," she says, "to see that my own kids can walk in here and feel at home."



Recreation Therapy Intern Benefits from Unique Matheny Experience

hat's really good about the recreation therapy program at Matheny," says Leah Friedman, "is that the students and patients aren't identified by their disabilities; they are identified by their likes and dislikes. You don't just look at someone and say, 'Oh, he has cerebral palsy.' You look at him and say, 'He likes to play soccer.'"

Friedman, who grew up in Short Hills, NJ, enrolled in the fall of 2007 at Ithaca College as a freshman majoring in therapeutic recreation. "Most people don't do that," she says, "but my mom was an alumnus of Ithaca, and my senior year of high school she had gotten this alumni DVD, and rec therapy was on it. So, I was watching it with her and said, 'I'd really like to do that.'" Friedman received her B.S. degree in therapeutic recreation in May 2011, which included an internship requirement. And since she had been a volunteer at Matheny during the summer of 2010, 'this was on the top of my list of places I wanted to intern."

She spent 15 weeks at Matheny last summer, splitting her time between working with adults in the Adult Services program and spending time in the classroom with children in The Matheny School. What really

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impressed her in the school was the interdisciplinary teams of therapists who worked together with the teachers. "In the classroom," she says, "I would be working directly with occupational therapists, speech therapists and physical therapists." One of the keys to Matheny's educational philosophy is its interdisciplinary approach - integrating therapy treatment, social services and psychology into the educational program. The expertise of speechlanguage pathologists, physical and occupational therapists, social workers and psychologists is always available and is provided in collaboration with the

Throughout her college years, Friedman had done field work, but it was mostly with an older population, often with recovering stroke victims. So, the summer she volunteered at Matheny was her first experience working with a young population and with people whose disabilities had been with them from birth. "My first day volunteering at Matheny," she recalls, "I was with some of the adults, and they immediately struck up a conversation with me. They were asking about me and school and everything. I was the shy one." The students and patients at Matheny, Friedman says, "are just so special." She remembers a moment during her internship when, "one of the kids looked at me and grabbed my hand. He said, 'I'm really glad you're here. You're my best friend.""

Friedman completed her internship in September, and "if there had been an opening in recreation therapy at Matheny, I'd have done it in a heartbeat." Instead, she is interviewing at other organizations and says, "I'll go anywhere where I can be hands on." As for Matheny, "It's just a great place. I think everyone should know about it and visit."





Arc of Mercer Adapts Arts Access Program

ver since he first heard of Matheny's Arts Access Program, Steve Cook had dreamed of somehow adapting it for clients at The Arc of Mercer, which provides a variety of services and programs for adults with developmental disabilities in Mercer County. Cook is executive director of The Arc of

artistic backgrounds to influence the artists' work. The two key traits they must have are: complete neutrality and patience.

Zimmerman is a practicing artist with a BFA degree from The College of New Jersey. He describes his own work as "minimalist surrealism". He participated in an intensive two-week Acceptance and popularity of the program at The Arc has come quickly. "It has been amazing," says Joe Gleason, director of day programs. "People are always asking, 'When is it my turn?" Adds Zimmerman: "I get bombarded when I come in the door." Acceptance has also come quickly in the community. The artwork has already been exhibited



Mercer, whose mission is to empower all people with developmental and intellectual disabilities to choose and realize their goals. "I cold-called and invited myself up to Matheny for a tour," he recalls, "so I could learn how the program worked. I knew I wanted someday to bring it here." When some funding became available, Cook hired an artist, Eric Zimmerman, and had him trained in the Arts Access method of facilitation. Facilitators carry out the physical functions that disabled artists cannot do on their own, but facilitators must not allow their own professional

training program with Arts Access staff members and artists. Although Arc clients can often hold their own paintbrushes and speak (something many Arts Access artists cannot do), the philosophy, Zimmerman says, is the same. Keith Garletts, Arts Access facilitation manager, agrees that, "the core principles are the same," adding that, "Eric was great to work with. He was very receptive to learning the process, and the experience of learning with our clients forced him out of his comfort zone. It forced him to think in a different way."

at the Ewing Municipal Building, and there are plans for other exhibits at The Grounds for Sculpture in Hamilton Township and Artworks in Trenton.

But perhaps most important of all is the impact the program has on the artists, allowing them a new method of self-expression and self-esteem. As Zimmerman asks typical questions such as, "Do you want tape on the inside or outside?" and "How big do you want the triangle to be?", Wayne Sallie, the artist answering him, adds a statement of his own: "I'm happy," he says. "I'm an artist."



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A Message to Our Supporters

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On behalf of our patients, students, families, and staff, we cannot say, "Thank You" enough for your generosity in backing all the critical programs and services Matheny provides to improve the lives of the children and adults we serve.

Mr. and Mrs. Paul Simms, Jr.

In our efforts to communicate our messages and accomplishments to a broader audience I am pleased to announce Matheny is now fully engaged in a social media program that

includes Facebook, Twitter, Blogs, and YouTube! You can connect to these channels from links on our website homepage, www.matheny.org. Thank you once again for your ongoing support and I wish you all a Happy New Year!

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Miles for Matheny Returns to Liberty Park

Save the Date: Sunday, April 22, 2012



We are so pleased to be returning to Liberty Park in downtown Peapack for the annual Miles for Matheny community event. This fun-packed day includes Bicycling routes through rural Somerset Hills, a Kids Fun Run, a USATF 5K race and our signature event, the Lu Huggins Wheelchair Walk. The 5K and Wheelchair Walk will begin at noon so that road closures will not disrupt services at the local houses of worship and so that all community members can join in the festivities. The schedule of events and registration information will be issued soon!

Congratulations to the top fundraisers at Miles 2011:

The Desatnick Family (Bryan's Team) of Basking Ridge, NJ

The Goroff-Friedlander Family (Team L'Equipe Louise) of Brookline, MA

The Harter Family (Jack's Team) of Madison, NJ

Andrew Lash (Team Andy "Flash" Lash) of Franklin Township, NJ

The May Family (Team Mason) of Bridgewater, NJ
Sarah Malzberg (Sarah's Mitzvah) of Pottersville, NJ
Beth Misener of Succasunna, NJ
The Schapiro Family (Team Schapiro) of Basking Ridge, NJ

Stephanie Young of Bridgewater, NJ