

Matheny Mathens

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Miles Marches On

n Saturday, April 16, the rains came. On Sunday, April 17, much of Natirar Park in Peapack, NJ, was flooded. But, with some last-minute logistical maneuvering, the 14th annual Miles for Matheny withstood the elements and moved forward with the competitive determination so often exhibited by Matheny's patients and students. There were new routes and locations for the Lu Huggins Wheelchair Walk, 5K run and kids fun run, and despite the swampy conditions, approximately 1,900 supporters from the community showed up to walk, run, cycle, volunteer and cheer. Some volunteer walking partners had to lift wheelchairs over rough spots in the terrain; 5K runners were warned about a speed bump that was now part of the course; and makeshift planks were placed over the water so everyone could get to the portable bathrooms.





Miles of Support

unds raised at Miles for Matheny sustain the Matheny Center of Medicine and Dentistry, which provides medical, dental and therapy care to inpatients and people with disabilities throughout New Jersey. Approximately \$200,000 was generated from donations, sponsorships and in-kind gifts.

According to Steve Proctor, president, Miles is "as much a community event as it is a fundraiser. Our goal has always been to bring together the children and adults with disabilities with their ablebodied counterparts in a wonderful and uplifiting day enveloped by the strong community spirit of our neighbors."

That feeling was echoed by some of the participants and volunteers. "What I like best about the event," said Ridge High School student, Sarah Bush, who volunteered, "is the great spirit and that everybody was there to support Matheny." Eric Schapiro, a Basking Ridge resident whose family formed The Schapiro Team to raise funds, added: "We're participating in Miles for Matheny to show our support for the residents, families, patients and staff of this wonderful facility."

Thanks to our Sponsors, pages 10-11



From left, speechlanguage pathologist Brynna Cunningham. Matheny student Raven Bennett and teaching assistant Megan Schroeder.

Adult patient Chris Saglimbene



From left, Bernards High lacrosse players: Kelly O'Neill of Bernardsville; Lauren Crane, Peapack; Courtney Waid, Kate Wallace and Rachael Alberti, Bernardsville; and Sammy Martin, Gladstone.



From left, kids fun run participants Erin and Molly Parker and Sage and Samantha Rudolf with their mother Denise Rudolf, all of Bedminster.

and the NJ Devils Mascot.

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Bernardsville Rotary grilled hamburgers and hot dogs at the picnic.



Cyclists take off.



Start of the 5K race.



'We Moved to New Jersey to be Closer to Matheny'

ive-year-old Jack Harter has only been a student at Matheny since December 2010, but, according to his parents, Doug and Katie Harter of Madison, NJ, it already feels like home. "When we first came into the lobby, we felt comfortable right away," says Katie. "The teachers and administrators are all so warm and friendly." Jack was born with a rare neurological disorder called Pelizaeus-Merzbacher Disease (PMD). While the Harter family was living in New York

\$5,600, to help sustain the Matheny Center of Medicine and Dentistry, which provides medical, dental and therapy care for inpatients and people with disabilities in the community. "We are blessed with family and friends who want to do what they can to support us and Jack," says Doug. Miles for Matheny,



Working on bilateral skills by hugging the whale.



From left, Meghan, Doug, Jack, Katie and Caroline.

City, he received occupational and physical therapy as part of an early intervention program and attended preschool at the Roosevelt Children's Center. "We moved to New Jersey," says Doug Harter, "to be closer to Matheny."

To show their support for Matheny, the Harters formed Jack's Team to raise funds for Miles for Matheny, and Jack's Team generated more than he adds, "was a positive way to get our family and friends involved.

Doug describes Jack's progress at Matheny as "unbelievable". His most impressive accomplishment, according to Donald Pauselius, director of occupational therapy, is "his improving ability to lie in a prone position with his weight propped on his elbows. And, although it clearly requires considerable effort on his part,

he will reach for an object upon request. He knows when he is successful, and he gives a big smile when he has accomplished a requested task. Laura Sackerman, his teacher, has a stuffed whale in her class that Jack likes. Sometimes we work on bilateral skills by having him hug the whale with assistance. This is another time when he smiles a lot."

Physical therapist Jana Gebhard feels, "Jack has really adjusted well here and works hard because he loves his therapy. I have given his family some suggestions for alternate positioning at home and have helped them utilize some of our outpatient clinic services."

Although Jack is non-verbal, he is learning to use switches to activate voice output devices. According to speech-language pathologist Christine Mayercik, this allows him to participate in circle time and direct some activities.

The Harters appreciate the way Matheny has made the rest of the family feel at home. "We have two-year-old twin daughters," Doug says, "and they love being here. They talk about how much fun they have going to Jack's school."



After Early Misdiagnosis, Lesch-Nyhan Patient is 'Flourishing' at Matheny

Then he was a toddler, Zach Ludlow was misdiagnosed as having everything from Tourette syndrome to cerebral palsy. And when he began injuring himself as a little boy, his father, Tom, thought it was accidental or behavioral but never connected it with an illness. As his behavioral problems worsened and Mattituck, NY, schoolteachers were at a loss to deal with his diffiiculties, Tom Ludlow and Zach's stepmother, Melissa de la Puente, took him to

five psychologists, none of whom had a solution. They suggested punishing negative behaviors and rewarding good ones, but those efforts made Zach's symptoms worse.

It took a camp counselor working with Zach, then 16, to come up with the key to what was troubling him. The counselor had previously worked with a child who displayed similar behavioral characteristics resulting from a rare

genetic disorder called Lesch-Nyhan Disease. Blood tests revealed that Zach did suffer from LND, which is characterized by severe dystonia, spasticity, speech impairment, renal disease, varying degrees of cognitive deflicit and the hallmark symptom, compulsive self-injury. The diagnosis was confirmed by Buz Jinnah, MD, PhD, professor in the Departments of Neurology and Human Genetics at Emory University. Dr. Jinnah also referred the Ludlow family to Matheny. Lesch-Nyhan occurs in approximately

one out of 380,000 births. As with Zach, it is often misdiagnosed.

Today, Zach is 20 years old and a residential student at Matheny, which has been providing programs for individuals with this condition for two decades. Here, with medication and proper treatment, according to his family, he is flourishing. His family is also grateful to the Mattituck School District, which recognized Zach's needs and pays for his tuition at the Matheny School. Next year, Zach



Competing in the Somerset County Special Olympics.

will turn 21, graduate from school and transition into Matheny's Adult Services program. "It was a major turning point when we knew the cause of Zach's behavior," Tom Ludlow says. Zach's mother lives in North Carolina and visits her son as often as possible but agreed to let his father become the custodial parent when the couple divorced several years ago.

Zach is in a wheelchair, and his treatment involves the use of safety devices to prevent him from hurting himself or others. And, instead

Rock climbing at the Midland School.

of punishing negative behaviors, Ludlow says, those familiar with Lesch-Nyhan understand that they need to ignore the involuntary acts, while applauding the positives. Matheny calls this approach "selective ignoring". The

goal is to act as if the Lesch-Nyhan behaviors are not happening and to continue to conduct business as usual. If the behaviors are completely ignored, they may decrease.

While the Lesch-Nyhan diagnosis was devastating because there isn't yet a known cure, the fact that Zach is getting proper treatment at one of the few facilities in the world with staff who understand the disease is, according to Tom Ludlow, a relief.

(Adapted from an article that appeared in the Suffolk (NY) Times, April 28, 2011).



Matheny Student Raven Bennett Receives Special Honor

arole Reifsnyder, RN, HNB-BC, first met Raven Bennett two years ago when the Matheny student was a patient in the pediatric unit at Morristown Memorial Hospital. Reifsnyder is a holistic nurse in the integrative medicine department. She offered Bennett a hand and foot massage and reflexology treatment and remembers her being "a bit skeptical about it, but

she agreed to try a session." From that meeting, a true friendship developed. "At first she would just write in her notebook to communicate to me," Reifsnyder says, "but eventually she spoke and I listened carefully. Then we began to have real conversations.

"She shared her feelings about missing her mother who had passed away and about how hard it was to be in the hospital. She would show me the poetry she had written, and

I was amazed at her talent." Reifsnyder introduced Bennett to Megan Calabro, the music therapist on the floor, who worked with her to put music to the words of the poetry. Then, Reifsnyder recorded Megan singing one of Raven's songs and recorded it onto a CD.

Reifsnyder and Calabro, however, weren't the only MMH staff members captivated by Bennett. "She engaged everyone on the unit," Reifsnyder says. "Many nurses, techs, doctors and child life therapists became close to her and spent time with her whenever they could. My daughter, Lauren, who is a nursing student, was working at the hospital that summer

as a nursing tech, and she and Raven became friends as well. Raven captured the heart of everyone she met through her courage, bravery and positive outlook, despite her life and health challenges." Eventually, Bennett was discharged from the hospital and returned to Matheny. Reifsnyder kept in touch with her and was her walking partner in the Lu Huggins Wheelchair Walk at Miles for Matheny in 2010.

Clockwise, from left: social worker Valerie Marcketta, personal care assistant supervisor Sharon Davis, occupational therapist Veronica Armellino, Reifsnyder, Calabro, physical therapy aide Brittani Jones and Raven.

On April 30, the 17-year-old Bennett, thanks to Reifsnyder, honored by Advancing Opportunities/Cerebral Palsy of NJ, a Mercer County-based agency serving people with disabilities. At the organization's spring gala, held at Greenacres Country Club in Lawrenceville, NJ, she received the Andrew J. Murphy Award, given in honor of a young man who never let his physical limitations prevent him from being with and doing what able-bodied people were doing. Reifsnyder, who had attended the organization's gala for several years, sent a letter

to board member Jim Spano with a collection of Bennett's poetry and the CD, asking him to nominate her for the award. "Jim came to visit Raven and was impressed with her story and her talents; he nominated her for the award, and she was selected to receive it." Bennett celebrated the evening with her aunt and cousin, who live in Newark, and with several staff members from Matheny. The popularity

she had enjoyed in the hospital manifested itself at the event as she spun around the dance floor with a variety of partners. As the evening's program stated: "Raven has cerebral palsy and has some limitations with communication, but she is blessed with a brilliant smile; and it's never hard to know



Raven, with her aunt, Barbara Herbert, left, and cousin Asia Herbert.



Matheny Inspires Student's Major in Special Education

ami Weber first visited Matheny five years ago as a result of her family's friendship with the Desatnick family, whose son, Bryan, was a residential student. Initially she had "mixed feelings" about coming to Matheny, but as she got to know Bryan and some of the other students better, all that changed. "Bryan," she says, "was an inspiration, and now I realize the Matheny students are normal kids just like us."

"Bryan was an inspiration, and now I realize the Matheny students are normal kids just like us."

Because of her experiences at Matheny, Weber has decided to major in special education at the University of Delaware, and she is currently taking advantage of a special program at Ridge High School in Basking Ridge, NJ, known as Senior Option. Seniors who who are planning to major in education volunteer teach

four days a week at a local school. Most of her friends, Weber says, are teaching at a local elementary school, but she is volunteering in one of the classes at Matheny.

"Sometimes I help teach a lesson," she says, "and other times I may work oneon-one with someone. When I watch the teacher, Karen Deland, I realize how each kid has his or her own different way of communicating." The students in Deland's class are nonverbal, but she says Weber "has quickly learned how each individual child communicates, and she works



With Matheny student, Daeon Troutman.



Dancing with Bryan Desatnick at the Matheny Prom.

effectively with each one of them. She understands our students and their needs as if she has been here forever."

Weber is co-president of the Jr. Friends of Matheny, a student version

of The Friends of Matheny, an auxiliary group that has raised more than \$3 million for Matheny since its inception in 1983. The JFOM consists mainly of students from Ridge and Bernards High in Bernardsville, who raise funds and increase awareness about Matheny in the community. The highlight of her association with Matheny was her attendance at the Matheny Prom last year. "It was so amazing to see all the kids dressed up in tuxes and gowns," she says. "It was so nice to see they could participate in things that normal kids get to do," adding that, "Bryan was my date."

Deland recalls an assignment Weber was given to lead the class in a specific task. "She was given the topic of metamorphosis, as we were raising tadpoles

to frogs. Sami took the concept and created a game for the students to play, which was a perfect way to teach. She led the class, and played the game. It's inspiring and refreshing," Deland adds, "to find a young lady who is so focused and determined to help students like ours in the future. She is comfortable in her role here and in the community"



Clinton, Matheny Students Compete in 'Adapted' Sports

■ ighth graders at the Clinton, Clinton assistant principal Christine NJ, Public School recently Maines maneuvering a power wheelchair. ✓ played hockey and basketball while sitting in wheelchairs, bowled by pushing a button and participated in manual and power wheelchair races. All of these activities were part of a special physical education class that included six students from the Matheny School. Matheny staff and students demonstrated several adapted versions of traditional sports, and the two groups of students competed against each other. Goal of the program is to promote interaction between both groups, enabling them to compete as peers. There was also a personal connection between Sam Harrison of the Matheny and Clinton Clinton playing students. Thirteen-year-old adapted basketball. Matheny student, Sean Hartigan, is the twin brother of Andrew Hartigan, an eighth grader at Clinton. Sean Hartigan on a tricycle, assisted by Heather Birmingham of Clinton competing in adapted hockey. physical therapist Erin Guidera.



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Dear Friends,

I/M Carl Shirley

It is an honor for me to be able to thank you on behalf of all of us here at Matheny for your continued generosity. As a new member of the Matheny team it is both overwhelming and humbling to witness the special care and nurturing environment that define what Matheny is all about on a day-in and day-out basis. I want to thank all of you who have been so generous with your time, talent and treasure in support of Matheny's mission and the individuals we serve.

A special thank you goes out to all of those who supported this year's Miles for Matheny, which was held on April 17th in Natirar Park. Despite the wind and wet conditions, approximately 1,900 supporters from the community showed up to walk, run, cycle, volunteer and cheer. A listing of this year's sponsors can be found on the accompanying pages and all of the individuals and teams who made contributions in support of the event will be listed on the Miles for Matheny website. Please go to www.milesformatheny.org for the complete listing.

Thank you once again for your ongoing support of Matheny Medical and Educational Center and I look forward to receiving your feedback and ideas as we move forward with our efforts to support such a very special place.

Kevin Ralph Chief Development Officer

Miles for Matheny 2011

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We hope to see you again next year for Miles for Matheny 2012!

Upcoming Events!

FULL CIRCLE 2011 - Saturday, November 5th, Robert Schonhorn Arts Center





65 Highland Avenue, P.O. Box 339 Peapack, NJ 07977 (908) 234-0011•Fax: (908) 719-2137

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Chuck Matheny Turns 70

huck Matheny, whose parents, Walter and Marguerite Matheny, founded the Matheny School in Burnt Mills, NJ, in 1946, turned 70 years of age of March 30. On Friday, March 25, an early birthday celebration was held at Matheny for Chuck, as his sister, niece and aunt had all come in from out-of-town for some special weekend activities, including a special service on Sunday, March 27, at the Basking Ridge Presbyterian Church. Other visitors included 80-year-old Edward Johnson of Newark, who, as a 16-year-old, looked after six-year-old Chuck at the Burnt Mills location. Special tributes were read by Chris King, Matheny director of operations; Steve Proctor, Matheny president; and Tara Hopko, an occupational therapist. And the students at the Matheny School presented a special book to "Sir Charles, King of Matheny".

In lieu of presents, Chuck has asked that contributions be made to a scholarship he is establishing for college students majoring in a healthcare field that helps people with developmental disabilities. Anyone wishing to donate to this scholarship fund should make checks out to Charles Matheny and write 'scholarship' in the memo space. Checks can be sent to Chuck c/o Matheny Medical and Educational Center, PO Box 339, Peapack, NJ 07977.



Chuck is congratulated by a friend from the community, Claire Pratt of Basking Ridge.