FULL CIRCLE 2013: Reflections

For more on Full Circle, see pages 4-5.

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In July 2011, Matheny received a $300,000 grant from the New Jersey Health Initiatives Program of the Robert Wood Johnson Foundation to develop, with the cooperation of acute care hospital partners, a model to improve transitions to and from acute care hospitals for adults with chronic neurologic disabling conditions. The grant period ended June 30, 2013, but, based on the program’s success, Matheny will continue to fund and expand it, by creating a division within our nursing department which will integrate our specialized resources to improve transitions during all healthcare encounters. The program will also be broadened to include children.

The core of the existing program is the establishment of full-time transitional nurses who accompany patients transported to acute care hospitals, encourage full and effective use of information in the patients “mini-record”, follow patients throughout their hospitalization to facilitate discharge planning and foster development of resources needed for appropriate inpatient care and effective post-hospital transition. Our partners in this project are: Atlantic Health System’s Morristown Medical Center and Newton Medical Center, Robert Wood Johnson University Hospital and Somerset Medical Center.

The program is being continued beyond the grant period because we have strong evidence that our primary end goal – the reduction of re-hospitalizations within 30 days of discharge – was achieved. In the 10 months preceding the implementation of our transition program, six of the 24 patients who were hospitalized were re-hospitalized within 30 days (25%). During the project period -- September 2011 thru June 2013 -- four of the 65 patients who were hospitalized were re-hospitalized within 30 days (6.25%). In addition, satisfaction data were gathered from Matheny patients, staff and families showing positive results overall. And smoothness of discharge plans being implemented from the acute care locations back to Matheny was greatly improved, based on patient outcomes.

SAVE the Date
Miles for Matheny
June 1, 2014
Liberty Park, Peapack, NJ
Teaching a Non-Verbal Six-Year-Old to Communicate

Six-year-old Dylan Vongrej was born with Canavan disease, a disorder that causes progressive damage to nerve cells in the brain. Dylan is non-verbal and unable to walk, but, according to his mother Noreen, “He understands everything you’re saying.” He’s also learning to communicate, thanks to speech therapy he’s receiving from Matheny as part of our Solutions For Schools program.

Dylan is unable to physically attend school, but the Bridgewater-Raritan Regional School District has contracted with Matheny to have speech-language pathologist Jaclynne Dietrich visit Dylan twice a week. Dietrich is currently using two voice output switches to help Dylan communicate. “He’s pretty much mastered those,” Dietrich says. “We have programmed ‘hello’ and ‘goodbye’, and we make choices between music and books. And we have weather and numbers. His vision is pretty questionable, so we rely on his auditory abilities. We want to extend it beyond the two switches, so he can really lead his activities and tell us what he wants to do and how he’s feeling. The iPad allows for that. There are auditory scanning and switches that connect to the iPad that will make things more accessible for him.”

Before Dietrich began working with Dylan about three years ago, he was not able to communicate. “It was amazing what Jackie did with him,” says his mother. “He has really progressed with all of his therapists, but I’m partial to Matheny because they understand children like this more than anyone.” In addition to speech therapy through the Solutions program, the Vongrejs bring Dylan to Matheny’s outpatient clinic, the Matheny Center of Medicine and Dentistry, for both his seating and mobility and medical needs. “It’s great,” says his mother, “that everything is in one place.”

Dylan currently does not attend school because he’s too medically fragile. “We started him at a preschool when he was three, and he just became very, very sick,” Vongrej says. “We’d love for him to eventually go to school one day; we’re not ruling it out.”
“This was really awesome!” That comment by Heather Kosinski, a young woman from Kenilworth, NJ, was typical of the reaction to Full Circle 2013: Reflections, the 20th anniversary celebration of Matheny’s Arts Access Program. U.S. Congressman Leonard Lance (NJ 07), honorary chair of the event, described the artwork on display as “truly magnificent,” adding his congratulations to all of the artists and all of those who made this event possible.”

Eileen Murray, director of Arts Access, explained how the program works, “We provide the creative freedom for the artists to express themselves, but it is the artists who bring this work to life. The art you see today is a true reflection of 20 years of hundreds of individuals who have created thousands of personal reflections.” The true stars of the afternoon were the artists and their art — whether it was visual art such as “Flower Power”, an acrylic on canvas by Jess Evans, or Rasheedah Mahali’s moving tribute to the late artist Jason Christie or “Alone”, a dance piece choreographed and performed by Natalia Manning. More than 70 pieces of visual art, curated by former Arts Access facilitator Scott Beil, were on display in the gallery, and 14 performances of dance, drama, prose and poetry were presented in a

“Flower Power”, acrylic on canvas by Jess Evans.

Visual art curator Scott Beil and his wife Erin in front of an untitled acrylic on canvas by Chris Butler.

Dancer/choreographer Natalia Manning, center, with dance facilitator Corey Bliss, right.
multi-media stage presentation, which also visually traced the development of Arts Access from its beginnings in 1993 to the present-day. Steve Proctor, Matheny president, paid tribute to former Matheny medical director Dr. Gabor Barabas and former president Robert Schonhorn, who founded the program after asking the question: ‘Can people with disabilities create fine art?’

Arts Access received a $10,000 Challenge America Fast-Track grant from the National Endowment for the Arts to support the Full Circle celebration, and the program recently received an Excellence in the Arts award from the Somerset County Cultural & Heritage Commission and the Friends of Somerset County Culture & Heritage, Inc.

Writer and performer Jenny Durr, left, and Arts Access director Eileen Murray.

ON THE COVER: Actress Jessica Park brings performer/choreographer Isabell Villacis out for the finale. At far left, is actress Sarah Bethany Braun. At right is dancer/choreographer Natalia Manning.

Melia Moss, grants program manager for the Kessler Foundation, right, with artist and dancer/choreographer Cindy Shanks.

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From left, Linda Moore, executive director of the Morris Museum; Congressman Leonard Lance; and Morris Museum trustee Gerri Horn.

Garrett Alpaugh of Raritan, NJ, and Heather Kosinski of Kenilworth, NJ.
When he was around 2½ years old, Jacob Rolaf showed signs of bruising and was diagnosed with mild hemophilia. About 4½ years later, he began to experience gastrointestinal bleeding and, as a result, needed to be treated with high doses of blood coagulation factors. A resulting infection caused him to develop septic shock and multi-organ failure. “Before that,” says Lisa Cohen, social worker at Rutgers Robert Wood Johnson Medical School Hemophilia Center in New Brunswick, “he was an average kid. But he developed sepsis, multi-organ failure, central nervous system injury and seizure disorder. That really started all of his multiple medical issues.”

From that point on, Jacob was in and out of the hospital. At home in Toms River, NJ, he had special accommodations and lots of nursing support. Then, his mother, Carol Rolaf, became ill and was unable to care for him physically. He was placed in an institution that provided transitional care to infants and children with specialized medical needs.

“His hemophilia had stabilized,” Cohen says, “but we needed to find a long-term placement that had the therapies he needed and so he would not just sit all day.”

In December 2012, a representative of Child Protection & Permanency, CP&P (formerly DYFS) contacted Matheny regarding permanent placement for Jacob. CP&P was operating as a resource to help Jacob’s mother identify placement options, and the agency determined that Matheny was best able to meet his needs. He was eventually admitted as a resident in May 2013.

“He really needed a place like Matheny,” Cohen points out. “Seeing him there is wonderful. You can see it on his face. You can see the difference.”

Once he became a resident, Jacob also was enrolled as a student in The Matheny School. Students such as Jacob are provided with the opportunity to reach their highest level of academic achievement while also obtaining maximum independence. When Jacob was still living at home, he attended the Silver Bay Elementary School in Toms River and received therapies as part of the special education program.

At Matheny, related services are considered vital to the core of the program.

Occupational, physical and speech therapies are always integrated into the school through authentic tasks and settings.

Matheny students also benefit from the latest technology such as SMART Boards and Tables, iPads, iMacs, Powerbooks, HO-touch computers and much more.
Ryan O’Connor was born 10 years ago with a very rare chromosome deletion. His family was told that he would function at an extremely low level and would never walk or talk. Ryan’s mother, Debbie O’Connor, described the family’s initial reaction to this news. “As with most parents with special needs children,” she said, “to say we felt discouraged would be an understatement.”

Speaking at The Matheny School’s Open House this past October, the Annandale, NJ, resident recalled what happened when Ryan reached three years of age, time for him to go to school. The O’Connors visited Matheny, having learned about it through Ryan’s therapists and the Clinton Township School District. “I’ll never forget the first day I brought him here,” she said. “I was in denial and was so afraid to leave my special child in the care of strangers. But these strangers quickly became the people who would change his life and our lives. A child who could barely eat began to slowly learn how to swallow. A child with very limited gross motor skills began to learn how to move. A child with no fine motor skills began to learn to pick up his own food.”

And then, on Christmas Day 2008, “Ryan gave us a true Christmas miracle. With a house filled with family and friends, Ryan stood up and began to walk, completely unassisted, through our home. He wandered for several minutes from room to room, taking in his surroundings while we all watched in complete amazement.”

All of these milestones, O’Connor said, were reached because of Matheny. “There are no limitations here,” she added. “No one looks at our children and ever says the words, ‘They can’t do that’. Matheny is not just a school for our children. It’s a safe environment made up of amazing people who give everything they have to give our children a life that, as a parent of a special needs child, you may have thought would never be possible. Matheny is a place where miracles happen everyday.”

"Matheny is a place where miracles happen every day."
When Amanda Anastasia was about eight years old, she needed a new power wheelchair. “At the time,” her mother Sam recalls, “she had been driving her wheelchair with a scanner. It was a very slow process. The therapists at the Children’s Center for Therapy, where she was going to school, recommended that we visit the seating and mobility clinic at Matheny. They tested her out using head array, and she did fantastic. She learned to drive with her head. What a difference it made!”

Amanda, now 20, and her brother, Daniel, 15, have a condition called Aicardi-Goutieres, a syndrome that affects all of their motor functions. They have been in wheelchairs virtually their entire lives, but, since that visit about 12 years, all of their wheelchair and equipment needs are managed by Matheny.

“When Amanda got her first power wheelchair,” her mother recalls, “I didn’t feel the salesperson had good knowledge of the product. She just suggested a chair, and that’s kind of what we went with. At Matheny, they have expert knowledge about products and seating positioning. Because of the population that lives at Matheny, they have so much real life experience.” Her children, she points out, “live in their chairs. They may go to a different setting, but they’re still in their chairs.” The Matheny therapists, she says, “know their movements, their tone, where they’re tight, where they’re not tight. If there’s a problem, they find a way to solve it. They have creative ideas; they think outside the box.”

The transition from a manual to a power wheelchair, Anastasia emphasizes, is critically important. “A power chair,” she says, “gives them some independence, freedom. They can drive from room to room. The chairs elevate, they tilt, they recline. So, they can change their position themselves. They don’t have to wait for somebody or try to explain to somebody where they want to move.”

The seating and mobility clinic at Matheny is part of the Matheny Center of Medicine and Dentistry. The clinic team of therapists and rehabilitation technicians strives to meet the needs of each individual by providing the perfect match of assistive technology services and products to provide the highest level of health, function and quality of life. For more information, call (908) 234-0011, ext. 722.

"Because of the population that lives at Matheny, they have so much real life experience."
The annual Matheny talent show is a creative forum that enables students and patients to express themselves and feel empowered to share their gifts and talents. Nowhere was that more evident than in the performance this year by adult patient Natalie Tomastyk, who decided to sing “Brave”, a song made popular by singer-songwriter Sara Bareilles. Through the process of learning the piece, according to music therapist Megan Chappius, Natalie decided she also wanted to play the piano.

“Alternating between singing and playing was a new skill for her to learn,” said Chappius, “but she was determined and motivated to do it. Fortunately, she very quickly and easily mastered the skill. She never grew tired or frustrated, and she was very motivated.” In addition to learning the lyrics, Natalie had to work on her breath support and vocal phrasing. “It was important,” Chappius added, “that she identify with the artist in her and tap into her own unique personal creative expression. With that in mind, we focused on her emotional expression and connection to the message of the song when performing it. The song’s message is very empowering, about being brave and believing in yourself.”

In order for Natalie to learn the piano, Chappius marked off specific notes that she could play on the keyboard that were in the key of the song.

“Good eye-hand coordination was needed to play the marked notes with accuracy,” Chappius explained “Each week, she increased her speed and accuracy when playing.” Natalie was “a little nervous” before the performance, but afterwards, she said: “I am proud of myself, and I feel good.”

The talent show was held this past October in the Robert Schonhorn Arts Center at Matheny. Among other performances: Amanda Kochell’s rendition of Alicia Keys’ “No One” and Jessica Evans’ original poem, “My Memories are Painted in the Sky”. Music therapists at Matheny use various types of music to positively impact students’ and patients’ cognitive, physical, emotional and social skills, helping them realize their potential in society. Activities and techniques include improvisation, rhythm, songwriting, songs, chants, instrumental activities, live music and recorded music.
Twenty-one-year-old Matthew Detgen has cerebral palsy combined with several other medical conditions. When Matthew was three months old, he began receiving services from the early intervention program at Hunterdon Medical Center in Flemington, NJ. He subsequently attended the Bucks County Intermediate Unit in Quakertown, PA, and a Mercer County, NJ, regional school. But, by the time Matthew was 17 years old, the Delaware Valley Regional High School in Frenchtown, NJ, recognized the need for placing him into a private special education school. According to his mother Marie, a resident of Milford, NJ, the school district was “impressed with Matheny’s program and saw that it was perfect for Matthew.”

Last June, Matthew graduated from The Matheny School, and his mother says he has benefited from the way he has been, “consistently challenged and pushed to reach his full potential. The knowledge, opportunities and technological support that Matheny affords far exceed any class in a public special education program. No public school program could come close to all that Matheny offers.”

Matthew has moved on to Matheny’s Adult Services program, and he is benefiting from having been in The Matheny School’s transition class, which is designed to increase the independence of its students, both within the school and in the surrounding community. A key element of that program is the Tea Time Café, an in-house school refreshment stand equipped with an adapted cash register. It provides students with an authentic work environment, and Marie Detgen recalls the first time she and her husband Donald saw Matthew at work, “interacting with people. We had heard about it, but actually seeing how he was so excited and happy to be engaging with others made a lasting impression.”

The Matheny School serves students with multiple disabilities and provides them with the opportunity to reach their highest level of academic achievement while also obtaining maximum independence. For more information, call (908) 234-0011, ext. 237.  

"The knowledge, opportunities and technological support that Matheny affords far exceed any class in a public special education program."
During the first several years of his life, Sammy Heisler lived in a long-term care facility. He was medically complicated, and most doctors did not expect him to survive. “How shocked they would all be to see how he has flourished,” says his mother Doris Burman, a resident of Westfield, NJ. This past June, Sammy graduated from the Matheny School.

When Sammy first arrived at Matheny in January 1998, he was completely tube-fed. Since then, according to his mother, “Sammy has learned how to eat, handle a wheelchair and respond to familiar faces. But, by far, the greatest benefit Sammy received from Matheny is his self-confidence. The Matheny staff members have always treated Sammy and all the students with dignity and respect, and I strongly believe these interactions have enabled him to release his personality and develop into the charming young man he is today.”

Sammy initially came to Matheny, Burman recalls, because “he began to physically improve and soon became inquisitive about his environment. The long-term care facility was not geared toward development, but the Westfield School District knew about Matheny and was in complete agreement that this was an appropriate school for him.” Sammy has now made the transition into Matheny’s Adult Services Program, and Burman says she “will always be grateful to this organization of dedicated, talented people.”

"Sammy has learned how to eat, handle a wheelchair and respond to familiar faces. By far, the greatest benefit Sammy received from Matheny is his self-confidence."
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We sincerely appreciate all of our donors. Your generosity enables us to make a meaningful difference in the lives of those we serve. Thank you!

The donor listings below reflect gifts received during the period of July 1, 2012 through June 30, 2013.

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While every effort has been made to ensure accuracy of our donor lists, errors and omissions in this report may have occurred. Our supporters are assured of our appreciation for their generosity, and we apologize for any inaccuracies in this publication. We would kindly appreciate having them brought to our attention and we will make every effort to present corrections in subsequent issues of Matheny Matters.
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To learn more about bequests or the benefits of other planned giving options, visit the Planned Giving Page of our website at: Matheny.plannedgiving.org or contact Janice Kriegman at 908-234-0011 x 315 or jkriegman@matheny.org

This year Matheny proudly became an official partner of a movement intended to refocus the holiday season on giving back to those who need it most.

The Matheny campaign is raising money for the Matheny Center of Medicine and Dentistry, where our team of specialists focuses on providing more than 800 New Jersey kids, teens and adults with disabilities the best care possible. That means making sure we provide high quality, easy-to-access and comprehensive care – all in one place. Unfortunately, today, less than 50% of the cost of that care is covered by insurance.

You can help close that gap with a year end contribution to our Giving Tuesday Fund. The campaign will remain open through January 31, 2014 so there is still time to donate.

Just visit our home page and follow the link from the Giving Tuesday announcement, or if you would like to donate by mail contact Janice Kriegman at 908-234-0011 ext. 315.

Help us make certain that those with the greatest need continue to get the support and services they deserve.
Larry Thornton started out volunteering one day a week in a classroom at The Matheny School. That one day has turned into three. The retired paper manufacturing executive, who lives in nearby Gladstone, says, “Obviously, I enjoy this immensely. Coming here has been a real eye-opener for me to see this marvelous institution, what the staff members do to make the lives of these children as normal as possible.”

In addition to his classroom duties, Thornton had volunteered at Miles for Matheny, the annual fundraiser and community event; is a former member of the Board of Trustees at the now defunct McAuley School in North Plainfield, NJ; and is a past Grand Knight at the Knights of Columbus Council of Blessed Sacrament Church in Martinsville, NJ. The KOC Council recently donated $720 to Matheny. Earlier last spring, Thornton helped out at Matheny’s ‘Hoops for Heart’ event to raise money for the American Heart Association. During that event, Matheny’s front parking lot was closed off and transformed into several adapted basketball courts.

Since the majority of Matheny students and patients are full-time residents, volunteers such as Larry Thornton are needed days, evenings and weekends. Individuals can serve as classroom aides, recreation assistants, tutors or just friendly visitors. For more information, call (908) 234-0011, ext. 282; or email volunteers@matheny.org.