

## ‘He’s Surrounded by People Who Love Him’

**T**he toughest moment for parents of a disabled child is the realization that child might be better off living away from home. Kelly Hartigan-Love and Martin Love of Clinton, NJ, have reached that conclusion about their 11-year-old son, Sean, but that doesn’t make the decision any easier.

Sean, who has athetoid cerebral palsy, is a day student at the Matheny School. He is in his second year, having started in the summer program in 2007. After aging out of the Jerry Davis Early Childhood Center in Manville, NJ, and spending two years in a special program in the High Bridge Elementary School, the Clinton Public School District recommended he attend Matheny full-time. The Loves have placed Sean on the waiting list for residential placement, and Hartigan-Love acknowledges that, “As a parent, to make that kind of decision is extremely difficult. But I know he loves it here, and I know when the time comes that he has to go somewhere else and not home, he’ll be safe here because he’s surrounded by people who love him.”

Both Sean and his twin brother, Andrew, were born prematurely when their mother was only 26 weeks pregnant. “Sean was

one pound, 3 1/2 ounces,” Hartigan-Love recalls, “and Andrew was one pound, 8 ounces. So, just living day to day for them was a struggle.

When they came home from the hospital, “Andrew started



Sean Hartigan and his mother, Kelly, in his school classroom.

making developmental milestones, and Sean didn’t. Andrew went from rolling to grabbing things. Sean wasn’t doing that. Sean never played with any toys. That should have been an early indication, but I wasn’t sure; I was just so appreciative he was alive.”

Although he has had several surgeries, Andrew today attends the Clinton Public School. One of the reasons Sean adjust-

ed so well at Matheny, his mother says, is that, “the nurses all remembered him from when he was two years old and here for respite.”

An example of the progress Sean has made at Matheny manifested itself on a recent family trip back to the Syracuse area. “Sean was lying on the floor, and he got up on all fours; and he was rocking like he was going to crawl. He had never done that before. He was never able to tolerate anything on his hands because he was tactile defensive. Putting his hands on the floor without having them in a fist was very difficult for him.”

Getting Sean to open his hands has been a major objective of Matheny’s physical therapy department, according to JoAnna Skripak, DPT. Sean has also been helped, she says, by a new wheelchair. “He’s been growing,” she explains, “so he has a completely new frame, and we’ve changed the angle of his tilts, and he has a new seat cushion.” A ‘peanut ball’, a therapy ball that, “looks like a peanut”, is helping strengthen his stomach muscles.

The staff at Matheny, says Hartigan-Love, “go above and beyond. When I walk in here, I get such a warm feeling. This is where he belongs.”

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# Full Circle 2008: The First 15 Years



"Untitled"  
by Kevin White

Matheny's Art Access Program began 15 years ago with a question: "Can people with disabilities create fine art?" Anyone who attended Full Circle 2008, the 15th anniversary celebration of Arts Access, which was held Saturday, November 15th in Matheny's Robert Schonhorn Arts Center, knows the answer to that question.

In the auditorium, following an art reception in the gallery, Lyn Sanders, director of Arts Access, introduced a presentation that included dramatic interpretations of poetry, wheelchair dance performances, a multimedia collaboration

between an Arts Access artist and an able-bodied dance company and a preview of a documentary being produced by P3 Entertainment that clearly demonstrated the art facilitation process.



Therapy administrative assistant, Lynne Wagner of Somerset and 17-year-old student, Natalie Tomastyk, perform in 'Good People' dance number.

While there may have been setbacks and obstacles along the way as Arts Access developed, Sanders, said, "the word, 'impossible', is not a word that ever described Arts Access. A better description, she said, would be, 'pure imagination'... These amazing artists have taught me to take the time to listen to them as they speak their unique language. They have more to say than anyone would ever have dreamed."



Dance facilitator Andrea Kramer of Califon and adult patient, Chet Cheesman, dance 'A Fond Farewell'.



Drama facilitator Brian Pollack of Millburn reads Jenny Durr's poem, 'Food Names'.

Barbara and Craig Powderly of Freehold.



Chris and Holly Bormann of Flemington.

From left, Mark Gatzke, Patti Bennett and Kerry Shannon of Basking Ridge.



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Jim Mersfelder and Sandy Stark of Manhattan and medical director Gary E. Eddey, MD, of Morristown. Stark is a past chair of Matheny's Board of Trustees. Behind them is an untitled painting by Mark Riddle.

Emory University alumni volunteers, Jody Rosenzweig of Warren, James Turteltaub of Kinnelon and 11-year-old Jacob Turteltaub.



## Daniel McLaughlin Named Chair of Matheny Board of Trustees

**D**aniel F. McLaughlin has been named chair of the Board of Trustees of Matheny, succeeding Anne L. Brady. McLaughlin, who lives in New Vernon, NJ, with his wife, Lynn, and four children, is an executive in the Morristown office of Willis Group Holdings, a London-based insurance brokerage firm. Earlier this year, WGH acquired Hilb, Rogal & Hobbs, which, in 2002, had acquired McLaughlin & Company, an insurance brokerage firm founded by McLaughlin.

He has a BA from Boston College, is a member of the Board of Trustees of St. Benedict's Prep in Newark and is a former assistant basketball coach for St. Anthony's High School in Jersey City. A trustee since 2003, McLaughlin said he is, "honored to be affiliated

with a nationally renowned facility such as Matheny."

Two new members have been added to Matheny's Board of Trustees: Kenneth Alter and Gary A. Squires. Alter, a resident of Short Hills, NJ, is director of the Deron School of New Jersey, Inc., a private school for the disabled with campuses in Union and Montclair. The Deron School was founded by Alter's parents, Ronald and Diane Alter, more than 41 years ago. He has a BS degree in business administration with a concentration in economics from Monmouth College and an MA in



Daniel McLaughlin, visiting recently with 15-year-old Matheny student, Raven Bennett.

educational administration from Kean College. Squires, who lives in North Caldwell, NJ, is a founding partner of Squires Goldberg, LLC, a financial consulting and insurance firm based in Cedar Grove, NJ.



## Vanica Eldridge Has Wanted To be a Nurse Since Third Grade

**V**anica Eldridge, RN, has known she wanted to be a nurse since she was in the third grade. And, after working as a volunteer for Special Olympics as a teenager, she decided she wanted to work with patients with developmental disabilities.

When she was studying for her associates degree in nursing from the County College of Morris, in Randolph, NJ, Eldridge and other student nurses did a rotation at Matheny. "In nursing school," she recalls, "they said to go out and get the acute care experience first before you start anywhere." But she couldn't get Matheny out of her head and started on the night shift in 1998. Eventually an



Vanica Eldridge checks on 7-year-old student, Katherine Gaudio.

opportunity surfaced for a primary nurse, and Eldridge switched to days.

Recently, the Denville, NJ, resident received her 10-year-service pin at

Matheny and is now nurse manager for Matheny's yellow pediatric zone. Under Matheny's unit-based model of care, a nurse manager oversees the overall functioning of each residential unit.

Eldridge is currently pursuing a bachelor's degree in nursing at The College of Saint Elizabeth in Morristown and hopes to continue on to obtain a master's degree in healthcare administration.

"The best thing about working at Matheny," Eldridge says, is, "having the opportunity to experience the many different interdisciplinary teams in order to provide the optimal care for our patients."





# ‘No Doubt in Our Mind: Matheny was the Right Place’

When he reached 18 months of age, Bryan Desatnick began having seizures and was diagnosed with Angelman syndrome, a genetic disorder that causes developmental delays and neurological problems. Today, at age 17, Bryan dances at his school prom, competes in Special Olympics and has dinner out with his friends.

During January 2003, Bryan was admitted as a day student at the Matheny School. He had attended the Mount Prospect School in Basking Ridge through the middle of fifth grade, when his medical condition and seizures became unmanageable. His mother, Edana Desatnick, recalls that, “he went into significant seizures and didn’t wake up for three weeks. It was not going to be possible for him to continue school in an inclusion environment. Ultimately, the school district decided we should come and visit Matheny. We all came here and loved it. As these medical issues got more complex, there was no doubt in the school district’s mind or in our mind that Matheny was the right place.”

Then, says Desatnick, “we were offered one of the 12 new beds in the yellow zone, a new residential wing at Matheny.” Now a member of Matheny’s Board of Trustees, Desatnick feels, “We happened to have been one of the lucky

ones. Our lives and his life are so much better. But there are just not enough options for children who have multiple handicaps.”

Bryan’s health since he’s been at Matheny, has been, “transformational. Every year he’s gotten bigger and stronger. At Matheny, he can be supported, day in and day out, because of having things like the seating and mobility

An important part of Bryan’s progress, though, has nothing to do with medicine. He has a full social life that his parents could never have imagined. “He was at the Olive Garden recently on a field trip,” Desatnick says, “and I went to pick him up. There were 30 to 40 kids in their wheelchairs sitting at the Olive Garden having lunch. It’s a picture you can’t ever dream of. There’s the Matheny

prom. It’s the most magnificent night of the year because you not only see him and all of his friends celebrating, but you see normal kids from the community helping. There is Miles for Matheny [Matheny’s annual fundraiser and community event] and the Special Olympics. He’s involved in so many things, and each one of them build on each other to create a completely different life than he would have had.”

But the lifestyle Bryan is able to lead at Matheny, Desatnick emphasizes,

“is only possible because of the outstanding medical care he receives on a daily basis. Matheny is licensed as a special hospital, and the doctors, nurses, teachers, therapists and aides are all specially trained to treat children and adults with developmental disabilities – they are like angels who understand Bryan’s challenges, medical complexities and his wonderful possibilities. We are grateful to have Matheny in our lives.”



Bryan Desatnick with his parents Edana and Lloyd and service dog, Ben, at Miles for Matheny.

clinic and the orthotics clinic. We used to have to travel just to do a wheelchair alignment. Now he has a custom-made wheelchair. Because of the creativity of the therapists, he’s using a completely different kind of walker than we thought possible. He’s had a variety of orthotics made for him. He has a stander that he uses in the classroom. Every little component of what his life was all about has been enhanced because of the talent of the people who are at Matheny.”

Photo by Tizazu Alamein

# Childhood Illness Motivated Beverly Bain to Pursue Therapy Career

When she was six years old, Beverly Bain was stricken with rheumatic fever. “I lived about a block from my school in Trinidad, Colorado,” she recalls, “and I was completely bedridden. I used to see all the children going to school, and I always thought if I could only do something to help a child who was in bed, it would mean a lot to me.”

A dean at Colorado College suggested she consider becoming a therapist. So she applied to the University of Southern California and was accepted. Dr. Bain began working as a consultant at Matheny in 1998, after a distinguished career as an educator and

al therapy masters degree students here. “I would come two or three days a week to supervise the program,” she recalls, “and then, in 2000, I had knee surgery, and I couldn’t go to NYU anymore. So, I started working as part of the OT department at Matheny two days a week. The main thing I’ve brought to Matheny,” she explains, “is my expertise in assistive technology. I realized that these children and adults can use technology to make themselves more independent – from pushing a bell in the morning to call a nurse to riding in a wheelchair to doing something with a computer.”

She points to one student at Matheny, eight-year-old Kevin Long, who had been holding his head down. “We outfitted him with a switch, which means that when he brings his head up, he can listen to music or operate a toy. You should have seen his face!”

“I still feel I’m kind of a teacher, the 79-year-old Bain says, “even though, physically, I can’t get on the floor. But I still can use my mind and my experience.”

That experience is quite impressive. She graduated from USC with a certificate of occupational therapy, after having received her BA in psychology from Colorado College. She then accepted

a position as director of the physical disabilities section at Los Angeles County Hospital. From there, she became director of occupational therapy for the Kessler Institute in West Orange and the New Jersey Orthopedic Hospital in Orange. After spending five years in private practice and serving in a variety of positions at both the NJOH and the New Jersey Rehabilitation Institute in Orange and Union County Technical

Institute in Union, she received an MA in learning disabilities from Montclair State and proceeded to develop and coordinate the occupational therapy program as an associate professor at Kean College in Union. She joined NYU in 1983 as a clinical assistant professor and received her Ed.D in educational leadership from Fairleigh Dickinson University in Teaneck in 1985.

Dr. Bain only works one day a week at Matheny now. “My goal,” she says, “is to improve a child’s potential. If they can do at least one thing for themselves, I hope that will lead to other things.”

Using a walker to get around now, she recalls that she and her husband moved to Bernardsville, NJ, 33 years ago and, “built our house accessible to wheelchairs for our parents; now I’m using it. As a matter fact, when I was at Kean College, I used to have my students come to our house at the end of the year and go through the house in a wheelchair.”

**“My goal is to improve a child’s potential.”**



Eight-year-old Kevin Long learns to hold his head up, under the watchful eye of Dr. Beverly Bain.

occupational therapist at such institutions as New York University, Kean College and the Kessler Institute.

She initially became connected with Matheny because NYU had received a grant to train its occupation-



# Celebrities Support Matheny Golf Classic

Professional athletes and TV personalities mingled with other golfers at the eighth annual Matheny Golf Classic, held October 21, at the Somerset Hills Country Club in Bernardsville. And while everyone had a great day of golf and camaraderie, they were reminded of the real reason they were there by Jim and Ruby Yedloutschnig of Cedar Grove, parents of 22-year-old Matheny patient, Alicia Yedloutschnig.

**Nine years ago**, the Yedloutschnigs made a decision to admit their daughter as a resident at Matheny. It's a decision they've never regretted, although it was very difficult at the time. Speaking to golfers and other guests before dinner, Jim Yedloutschnig recalled the initial interview with staff at Matheny. "I was very impressed with the respect we and Alicia were shown and the way the staff listened to us." His wife, Ruby, remembers, "being stressed to the max. We couldn't let go." But, now, when they visit Alicia, "we are no longer crying; we leave with a smile. Our relationship with Matheny is a family relationship."

Among those showing support for Matheny were five cast members of the CBS daytime drama, "Guiding Light", New York Jets Kellen Clemens and Jay Feely, retired New York Giants Brian Kelley and Brad Van Pelt, retired New Jersey Devil Scott Stevens and TV actor Jay Thomas, who conducted the live auction for the third consecutive year. The dinner speaker was legendary high school basketball coach Robert Hurley, Sr., who, despite his incredible oncourt success at St. Anthony's High School in Jersey City, indicated "the relationship to the kids" is what makes his job special.

**Double Eagle Sponsor** for the event was Village Office Supply, Somerset. Funds raised will help support the Matheny Center of Medicine and Dentistry, which provides much-needed medical, dental and therapy care to Matheny inpatients and about 600 outpatients from the community.



Clockwise from bottom center: Matheny adult patient, Gerald Tavares; "Guiding Light" cast members Robert Newman, Mandy Bruno, Robert Bogue, Kim Zimmer and Bradley Cole; and Dan McLaughlin, chair of Matheny's Board of Trustees.



Shotgun start.



From left: retired NJ Devil Scott Stevens, 13-year-old Matheny student, Shane Szott; and golfer Fred Frisco of Hillsborough.

From left: Matheny president, Steve Proctor, Jim Yedloutschnig and NY Jets placekicker Jay Feely.

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A tribute to recognize occasions like birthdays and anniversaries, to honor a friend, or in memory of a loved one takes on special meaning when it also helps the many children and adults at Matheny.

When you make a gift, the honored person or the

family of the deceased receives a personal letter acknowledging your gift. The amount is never mentioned. You, as the donor, receive an official receipt for your tax deductible contribution. For more information, call Robert B. Budelman, III at 908-234-0011, ext. 744.

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For your convenience, a self-addressed envelope has been provided in this newsletter.

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Gifts to Matheny Medical and Educational Center provide a wonderful opportunity to honor the memory of a family member, friend or colleague, or to recognize an individual or a life occasion.

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Your company may have a matching gifts program. Matching gifts can double or even triple your contribution.

Please contact your company's Human Resources Department to see if you are eligible.

### CORPORATE GIVING

There are many ways your corporate employer can support Matheny, including becoming a Miles for Matheny sponsor or forming a corporate team to participate in the event, supporting our annual Matheny Golf Classic or by making a corporate contribution in support of a patient or student program. Employee volunteer projects are also a way for your company to make a difference and support the important care provided by Matheny.

**If you have any questions about making a gift, please contact Robert Budelman, Director of Philanthropy, at (908) 234-0011 ext. 744 or by email at: [rbudelman@matheny.org](mailto:rbudelman@matheny.org)**

### Special Note:

The Charitable IRA Rollover was extended by Congress for two-years and may provide you with many tax benefits. The provision will be made retroactive to Jan. 1, 2008, and will apply to gifts made from that date through Dec. 31, 2009. The provision exempts from taxable income any funds transferred ("rolled over") from an Individual Retirement Account (IRA) to a charitable organization. The following limitations apply:

- The donor must be age 70½ or older.
- The cap on annual IRA rollovers is \$100,000.
- The contribution must be a direct gift to a charity (no planned gifts).

## Philanthropy Notes

Dear Friends,

As the end of the year approaches, many of us will use the next few weeks to decide to which nonprofits to give our charitable dollars. Without question, faced with the current turbulent economy, many Americans will be more thoughtful this year about which charities to support. I, of course, encourage you to keep Matheny at the top of your giving list.



Your charitable gifts to Matheny directly benefit the patients, residents and students under our care. In fact, you are welcome to visit us anytime and witness first-hand the care and programs we provide on a daily basis, 365 days per year. Please remember that it is because of your support that Matheny is able to offer innovative programs such as Community Connections, which helps better our patients' quality of life and creates opportunities for them to interact with able-bodied children and adults in the broader community. In addition, your support directly impacts the specialized care Matheny makes available through its Center of Medicine and Dentistry, which presently has a waiting list of more than 100 disabled persons seeking dental care.

Thanks to you Matheny is at the forefront of providing medical care and educational programs for children and adults with medically complex developmental disabilities. However, as Matheny's reputation has grown, so too has grown the demand for our services and expertise. Only with your steadfast support can we continue to meet the needs of these special children and adults.

On behalf of the patients, students, families and staff of Matheny, I thank all the individuals, corporations, local businesses, and foundations that gave their time, talent and financial support to Matheny this past year. I look forward to the good we will accomplish together in 2009!

With sincere gratitude,



Robert B. Budelman, III  
Director of Philanthropy

## Matheny PCAs Participate in Career Path Pilot Program for Direct Support Professionals

Matheny's patients need a maximum amount of assistance in many areas, including eating, transferring, bathing, dressing, oral hygiene and toileting. These functions are carried out by Personal Care Assistants (PCAs), who play a unique role in providing for the most basic care of the patients. PCAs and patients develop a strong bond of trust and companionship, and PCAs are vital members of Matheny's interdisciplinary team. Their input and observations are essential for effective care planning.

At Matheny, all PCAs are required to complete a Paraprofessional Career Ladder Curriculum, which consists of 30 classes focusing on insuring a basic understanding of anatomy, the impact of disabilities on various body systems, medical interventions and their role in prevention and care provision.

Now, through a federally-funded project aimed at strengthening the workforce of those who provide direct support to people with disabilities, Matheny's PCAs are also able to partic-

**“It’s that fulfillment and that joy that you’re doing something worthwhile with your life.”**

ipate in a special Career Path Pilot Program for DSPs (Direct Support Professionals) via online courses at the College of Direct Support, an internet-based college for direct support professionals. Intent of the program is provide

incentives to people who want to remain in direct care, contributing to a reduction in turnover and the enhancement of professional skills. Courses include instruction in such as areas as: safety at home and in the community; maltreatment of vulnerable adults and children; positive behavior support; and

don't have a professional background.”

“There are people who came to this job and said, ‘I’m just going to be here for six months’ and are now here 15 years,” says Ethridge Hansen, who has been a PCA for three years. “It’s that fulfillment and that joy that you’re doing something worthwhile with your life,”



From left, PCAs Hana Said, Ethridge Hansen and Senait Lesfaye with 15-year-old student, Jordan Pullian. In background is Nadine Thompson.

individual rights and choices.

Sixteen members of Matheny's PCA staff have already graduated from the first level of instruction, and many are proceeding to more advanced levels. The PCAs who have gone through the program are enthusiastic about the fact that it gives their positions a more professional status. “It’s a very good course,” says Toyin Akinpoleyoy, who has been a PCA for 4½ years. “The course makes us more professional, which is important because most of us

she adds. “All of us try to give Matheny patients the best life we can. All of us really care for them deeply. But we don’t know everything; we want to know more. That’s why this career path is very important to us. Now we will be more knowledgeable.”

Nadine Thompson, who has been a PCA for 14 years, adds, “I still feel good about coming to work. You get attached to the clients. Even if they can’t talk, they smile when they see you. You know that they really appreciate you.”



# Matheny Recognized as Leader In Care of Lesch-Nyhan Patients

Lesch-Nyhan Disease (LND) is a rare X-linked, recessive genetic disorder associated with cognitive impairment, high levels of uric acid in the blood, kidney involvement and the hallmark symptom – severe and involuntary

behaviors usually begin between ages three and six and often escalate as the patient ages and becomes more physically able to cause self-injury.”

Treatment, Dr. Eddey says, should include:

- Judicious use of protective devices.
- Utilization of a behavioral technique commonly referred to as ‘selective ignoring’ with redirection of activities.
- Occasional use of medications.

Protective devices, Dr. Eddey emphasizes, are, at times, controversial, but, “they are essential. When protective devices are requested by the patient and used to safeguard the patient from him or herself, the outcome is an extraordinary feeling of comfort and safety. Not allowing the use of protective devices would violate

the autonomous rights of the patient.

“Selective ignoring is designed to extinguish self-destructive emotional or physical behavior in the LND patient. It requires the caretaker to ignore such behavior by the LND patient toward the caretaker so the behavior decreases or ceases. Along with selective ignoring, the use of redirection is also found to be helpful.


“The use of medications for treating the behavioral component of Lesch-Nyhan Disease is controversial, yet most children and adults with LND are treated with different medications. No medication has been found, however, to reverse the so-called ‘Lesch-Nyhan

behaviors’.”

Most of Matheny’s Lesch-Nyhan patients are adults who have been here for several years. However, this year, Matheny has admitted two teenage LND patients from out-of-state [New York and Indiana] because there was no facility in their respective states that could effectively care for them. As a result, Matheny has formed a new Lesch-Nyhan Committee, headed by John Reck, PT, MPT, PCS, ATP, director of assistive technology services. Mission of the committee, says Reck, “is to look at the care model that’s being used for individuals with LND. We have an interdisciplinary team of people who have multiple years of hands-on experience working with people with LND, and we need to re-educate all staff in order to maintain the most consistent continuity of care around that model.”

Lesch-Nyhan patients, he explains, “are very high-functioning in an intellectual way. Their self-injurious behavior

**Matheny has nine LND patients, believed to be the largest concentration in one place.**

goes against what they want to do. So, the behaviors they exhibit to staff and to themselves can be very difficult to observe. Staff need support on how to best cope and how to best care for those individuals in order to promote the positive aspects of the person.” 



Gary E. Eddey, MD, with adult LND patient, Jason Christie

self-injurious behaviors. Matheny has nine Lesch-Nyhan patients, believed to be the largest concentration of LND cases in one location, and is recognized as the leading source of information on care issues.

Gary E. Eddey, MD, medical director of Matheny, points out that LND is usually diagnosed in the first few months of life as a developmental delay, “and may be diagnosed initially as cerebral palsy.” The behavioral aspects of Lesch-Nyhan, such as self-mutilation and aggressive behavior, are, he says, “generally involuntary in nature. The self-injurious behavior is not under the patient’s control, nor does the patient desire it. These self-destructive behav-

# Healthy Competition

Matheny's adaptive phys ed demonstration at the Clinton Public School in Clinton, NJ, last year was so well-received that school administrators asked for an encore presentation in 2008. Seventh grade students were shown by Matheny therapists and teachers how to operate manual and power wheelchairs and how to participate in adaptive bowling, soccer and foot-

ball. Several Matheny students attended in the demonstration, and both groups of students competed in wheelchair races.



Rose Burach races in a power wheelchair.



Lauren DiNapoli tries her skill at adaptive soccer.



George Hervey, left, and Jacob Versprille compete in adaptive soccer.

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