The Munroe-Meyer Institute for Genetics and Rehabilitation originated in the early 1960s as a place for children with polio to receive treatment. Today, Nebraska’s federally designated University Center of Excellence for Developmental Disabilities Education, Research and Service annually provides diagnosis and treatment for more than 10,000 children and adults with diverse developmental and physical disabilities and genetic disorders.

With approximately 230,000 people with disabilities living in the state of Nebraska, the need for specialized programs and support services to improve their quality of life and unlock their potential is evident.

By utilizing professionals who specialize in more than 15 disciplines and programs, MMI provides an interdisciplinary team approach that assures a family-centered, diagnostic and treatment program.

Parents, teachers, therapists and community service providers also are involved in the provision of services, which include the development of innovative ways to promote inclusion of individuals with disabilities and their families into the community.

Since becoming a part of the University of Nebraska Medical Center in 1968, MMI has offered research, education and technical assistance training to programs statewide. MMI’s mission includes a dedication to basic and applied research conducted by faculty and staff members in all disciplines and programs.

MMI is committed to training future health care professionals who will supply care to children and adults with developmental disabilities and genetic disorders and their families.

On the Right > Occupational therapist Kristin Didier assists Ethan Petersen on the playground at Picotte Elementary School. Story on page 5.
Dear friends of the Munroe-Meyer Institute,

This year’s annual report can be likened to the Munroe-Meyer Institute: extraordinary people and their incredible stories can be found on the inside.

As you read the following pages, keep in mind that these are just a handful of stories about people whose lives have been touched by MMI, Nebraska’s federally designated University Center of Excellence for Developmental Disabilities Education, Research and Service.

Everyone who passes through our doors, whether a family member, a faculty member, student or community advocate, has a story. It could be about a research discovery, an interdisciplinary training session or a unique clinical service, everything we do leads to improving the quality of life for persons with disabilities and their families.

None of our activities would be possible without the leadership of University of Nebraska Medical Center Chancellor Harold M. Maurer, M.D., and the guidance and support of our community boards and benefactors, including the Hattie B. Munroe Foundation, the MMI Board, the C. Louis Meyer Rehabilitation Foundation, the MMI Guild, the Autism Action Partnership, the Enrichment Foundation and the Scottish Rite Masons of Nebraska. A heartfelt thank you goes out to all of them.

Additionally, to help secure MMI’s future and develop new programs to impact the lives of all Nebraskans, the University of Nebraska Foundation has started an “Unlocking Potential” fund to aid future children and adults with disabilities.

I invite you to read the following stories and fill out the attached comment card. Your feedback helps us to shape our goals and exceed our expectations. We welcome any requests for additional information about MMI programs.

If you are interested in receiving our bi-annual newsletter, please send us your e-mail address. I hope you enjoy the 2008 MMI annual report.

Sincerely,

J. Michael Leibowitz, Ph.D.
Interim Director

Find it online at www.unmc.edu/mmi

This report can be viewed online along with web extras that are identified throughout the report by the web extra icon.

You can also provide feedback about this report online by visiting the Web site listed above.
This annual report highlights only a few of the programs, activities and services offered by MMI. For more information about our center, we welcome you to visit our facilities on the UNMC campus, our clinics and other programs across the state, or our Web site at www.unmc.edu/mmi.
For Ethan Petersen, it’s just another day in physical education class at Picotte Elementary School in Omaha. Just like his classmates, he scatters when those who are “it” get near him, inevitably gets tagged and eventually manages to tag someone else.

But 7-year-old Ethan isn’t just like his classmates. One of triplets, Ethan, and his sisters Emma and Katelyn, were born 14 weeks early and spent three months in the neonatal intensive care unit. When Ethan was just 6 weeks old, the neonatologist diagnosed him with periventricular leukomalacia, or lesions on the brain, which indicated he would have motor problems, most likely cerebral palsy.

Despite multiple surgeries to fix his unsteady gait and several Botox injections in his hamstrings to help him stand up straighter, nothing has slowed him down.

Watch a video of Ethan in action at www.unmc.edu/mmi
Ethan keeps up with his classmates thanks to the efforts of his physical and occupational therapists, Jenny Kronberg-Haire and Kristin Didier.

Employed by UNMC’s Munroe-Meyer Institute (MMI) Kronberg-Haire and Didier spend their days in Omaha Public Schools (OPS) where they observe, evaluate and recommend adaptations for a caseload of about 70 students with special needs.

MMI has provided PT/OT services for OPS since 1999 and this year began providing PT services for Bellevue Public Schools. MMI will provide OT services to Bellevue Public Schools next year.

“It’s a valuable service for our students and their families to be able to receive direct therapy in the schools as part of our contract with MMI,” said Julia Allen, director of special education for OPS. “Without MMI, it would be challenging for us to recruit the number of therapists we need as we have 668 students who receive physical therapy and 976 students who receive occupational therapy this school year.”

Like Ethan, some students receive both services. Kronberg-Haire, Ethan’s physical therapist, evaluates his basic motor skills, such as walking form and posture. She ensures Ethan is physically able to get where he needs to go, whether it be with the help of his walker or using handicapped accessible ramps, and limits barriers that prevent him from participating with his peers once he gets there.

Didier, Ethan’s occupational therapist, focuses on fine motor and self-help skills as well as visual and sensory processing abilities. She works with teachers to modify the classroom and adapt learning materials to facilitate successful participation. Outside the classroom, Didier makes recommendations so that Ethan can complete tasks, such as putting on his coat, using the restroom and eating lunch more independently.

“Every kid, regardless of disability, wants to have fun, make friends and do the things other kids are doing,” Kronberg-Haire said. “We try to figure out what we can do in collaboration with the school system to support children in those goals.”

“We want kids to feel as successful as possible and give them the confidence that they can do anything their peers can do,” Didier said. “Our job is to teach them they can do it, show them different ways they can do it and help train and educate teachers and families on how to adapt their classrooms and homes so children can be successful.”

An adapted desk and chair, pencil grips, a clipboard that holds his homework while he writes and a sticky pad that keeps the clipboard from sliding off his desk have resulted in vast improvements in Ethan’s handwriting. Ethan uses assistive technology including a keyboard device with enlarged letter stickers when writing demands become too much. And a basket attached to the back of his walker with shower curtain rings has given Ethan more energy for playing instead of lugging around his coat and helmet.

Ethan’s increase in strength has improved his posture and allowed him to accomplish his goal of kicking a soccer ball.

“He’s amazed everybody by participating in activities that all the other kids are doing,” Didier said.

And that’s all he ever wanted. 😊
au·tism \\o-,tiz-əm\\ n: the diagnosis given to toddler Ryan Long, who was always late in reaching developmental pediatric milestones such as walking and talking

A new diagnosis for Ryan

It just didn’t make sense. Autism is often characterized by social difficulties such as avoidance of eye-contact and tactile sensation. Ryan Long was a happy-go-lucky kid who had no problem engaging and locking his baby blue eyes with others. He also loved to hug, wrestle and be tickled.

“We didn’t want to be in denial, but we didn’t want to just accept what had been handed to us either,” recalled his father, Brian Long, who along with his wife, Arla, read several books on the behavioral diagnosis of autism.

Amid the frustration of not knowing whether their only son had autism, hope arrived in the form of a magazine article.

A colleague of Long’s had read a story in People magazine about a child who was misdiagnosed with autism after genetic testing revealed the child actually had Angelman syndrome. Like autism, Angelman syndrome is characterized by intellectual and developmental delay.

Long immediately went to the Internet to research Angelman syndrome and genetic testing. While there, he came across articles by genetic gurus from UNMC’s Munroe-Meyer Institute (MMI), one of which was written by Warren Sanger, Ph.D, professor and director of the human genetics laboratory at MMI. The paper discussed a newer, more sophisticated form of genetic testing called microarray.

MMI’s Human Genetics Laboratory processed 10,543 clinical specimens in 2007. That’s almost 3x times the number of clinical specimens processed in 1997.

BBB

MMI’s Human Genetics Laboratory serves as a clinical diagnostic genetic testing center for children with disabilities, genetic disorders and birth defects. Microarray enables cytogenetic technologists to compare DNA sites from specimen samples such as blood or tissue, with a control sample injected with fluorescent markers to see if there are any missing or extra chromosome segments in the patient’s genetic composition.

Only about 12 labs in the country offer microarray technology for clinical genetic diagnostic testing.
“Microarray is an extension of fluorescent in situ hybridization or FISH, which is used to confirm suspected genetic defects,” Dr. Sanger said. “But instead of testing one or two DNA sequences at a time as with FISH, microarray can test 44,000 DNA sequences at once. Its analysis is much more complete and efficient and has a 10 percent higher detection rate of genetic imbalances.

“If you’re looking for a specific gene form, FISH is the way to go, but if there are unknown causes for delay, microarray is extremely powerful.”

Brian Long refers to microarray as the “Lamborghini of genetic testing.” In March 2008, MMI’s microarray technology helped to diagnosis his son with a missing piece of chromosome 22Q in region 13, better known as Phelan-McDermid Syndrome. A FISH test confirmed those results.

Suddenly, Ryan’s low muscle tone or hypotonia, and gross motor developmental delays made sense. There was an explanation for his reduced perspiration and decreased perception of pain, both common features of children with Phelan-McDermid Syndrome, a rare disorder that has been diagnosed in fewer than 500 individuals worldwide. It occurs when a piece of the chromosome breaks off in the formation of the egg or sperm.

The Longs learned all about Phelan-McDermid Syndrome through MMI’s genetic counselors.

“We have eight genetic counselors at MMI and their primary roles are education and support services,” Dr. Sanger said. “Our cytogenetic technologists can do neat things in the lab, but if a diagnosis is not adequately explained to the patients, it doesn’t matter. Genetic counseling is a critical component.”

While a medical diagnosis does not cure genetic disorders, it can help guide treatment plans, prevent a disease from running its course and garner coverage from insurance companies.

According to Dr. Sanger, in 80 percent of cases, families change the management of the disability following a genetic diagnosis, which is why fast turnaround times in the lab (see timeline below) are so important. The Long family of Kansas City, Mo., was no exception.
They’ve also attached what is called a “P-grabber” to his overalls. It serves as an oral therapy tool to encourage jaw and tongue movement. It is common for children with Phelan-McDermid syndrome to have a strong desire to chew.

“The diagnosis wasn’t a silver bullet,” Long said. “Ryan’s future is still uncertain, but eliminating all the guesswork has allowed us to focus on him as a person.”

This past July, the Long family attended the international Phelan-McDermid Syndrome conference in Greenville, S.C., where families gathered to network, learn more about the medical and genetic aspects of Phelan-McDermid and offer each other support and friendship. Long now contributes to the monthly Phelan-McDermid newsletter and offers tips and suggestions for other parents. He also has spoken directly with Katy Phelan, Ph.D., for whom the syndrome is named after, about his son’s diagnosis.

“There’s still plenty more to discover,” Long said. “But it all started with hearing that diagnosis because we had been in a battle with the unknown. The diagnosis was validation that we hadn’t been crazy. Our son didn’t have autism.”

“The diagnosis from MMI was a turning point for our entire family,” Long said.

“For the first time in Ryan’s life, we received the answers to the question all families ask: Why? Those answers have allowed us to refine Ryan’s treatment, therapies and educational programs. We can now provide him with every possible opportunity to succeed. For all of this, we are extremely grateful to the entire staff at MMI.”

The Long family now work with Ryan to help him express pain by touching where it hurts and watch him carefully in the summer time to regulate his temperature.

9 a.m.
The patient DNA and reference DNA are labeled with fluorescent dyes. This takes about 2½ hours.

1 p.m.
Label reactions are purified and measured for label efficiency.

2 p.m.
If label reaction passes quality control, the labeled patient and reference DNA are mixed together with a “hybridization” mixture and placed on a slide. Each slide contains four arrays which contain 44,000 spots, each representing a separate human gene region. The slides are then hybridized in a rotating oven for 20 to 24 hours.
“Parents often don’t know what a genetic diagnosis means for their children,” Dr. Buehler said. “A genetic counselor can explain exactly what is missing and why, and inform parents about any helpful services or resources.”

Bruce Buehler, M.D., clinical geneticist and professor, speaks with the tenBensel family about their daughter Joslyn’s genetic diagnosis at a clinic for children with special health care needs in Kearney, Neb. MMI participates annually in more than 30 such clinics sponsored by the Nebraska Medically Handicapped Children’s Program. Also pictured are genetic counselor Shelly Nielsen, right front, and fourth-year medical student Melissa Marohl. Nielsen draws pictures of chromosomes to illustrate genetic disorders for families.

1:30 p.m.
The array is removed from the oven and placed in a slide holder, which is dipped in a series of washes and dried.

1:45 p.m.
The slide is scanned using a dual-laser scanner that measures the intensity of the dyes on the microarray spots.

2:15 p.m.
The image is then loaded to the software and analyzed for differences between the patient and reference DNA. If there is a discrepancy between the two, the software flags the region. Cytogenetic technologists then interpret and verify a deletion or duplication in that region. If the gene is abnormal, FISH studies are done to confirm the results and parent specimens are requested.

3:15 p.m.
A report is written and three certified technologists review and sign it. Dr. Sanger reviews the report and any other completed clinical tests. The test results are then faxed to the referring physician and Dr. Sanger follows up with a telephone call to answer questions about the findings. Dr. Sanger also provides physicians with genetic consultation and clinical geneticist or genetic counselor information to explain the findings and implications to the patients and their families.
It’s Valerie Gortmaker’s job to work with speech, occupational and physical therapists, as well as primary care physicians, nurses and social workers on a daily basis. As a school counselor and psychologist for Lincoln Public Schools, she serves children with developmental disabilities.

LENDing leadership

But it is her unique experience with Munroe-Meyer Institute’s Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program that helps her successfully collaborate with these professionals.

Gortmaker is a graduate of the LEND program, which offers interdisciplinary training to graduate level trainees to prepare them for leadership roles in the provision of interdisciplinary health and related care, continuing education, technical assistance, research and consultation.

LEND emphasizes the development of leadership skills and a knowledge base that includes neurodevelopmental and related disabilities, family-centered and culturally competent care, community outreach and the translation of research to practice skills.

Funded by the Health Resources and Services Administration’s Maternal and Child Health Bureau, LEND programs are an integral part of national and international efforts to improve the health of infants, children and adolescents with, or at risk for, neurodevelopmental disabilities.

While a 2005-2007 trainee in the LEND program, Gortmaker worked as an intern and post-doctoral fellow in the MMI Department of Psychology where she provided behavioral therapy and consultation to children and families with a variety of behavioral, emotional, social and academic difficulties.

It was there that she learned the importance of communicating and collaborating with professionals from different disciplines.

“In the real world, you’re constantly working with professionals from other disciplines,” she said. “If I didn’t have the background I have, I would not work with them as well.”

In her current position with Lincoln Public Schools, Gortmaker determines students’ eligibility for special education services as well as their academic and behavioral programming. She frequently works with children who have chronic health care needs, physical and developmental disabilities and mental health disorders.
While enrolled in LEND, Gortmaker also collaborated with families. As part of her LEND project activities, she worked with parents to devise individualized interventions for their children.

She gained leadership experience by presenting her research and projects to professionals, which led her to give a series of presentations to parents of Lincoln Public School students about how to deal with children’s mental health issues including ADHD, anxiety and depression.

“LEND graduates are uniquely qualified to address the needs of children and adolescents with neurodevelopmental and related disabilities through clinical services, program development, policy administration, teaching and research, said Kellie Ellerbusch, MMI’s LEND training coordinator. “Across the national LEND network, graduates have accomplished much, including research findings that have been disseminated worldwide.”

LEND also provides continuing education and technical assistance to graduates as they move into the workforce and to professionals already practicing in the field to keep them up-to-date with the latest research and practice.

Currently there are 38 LEND programs nationwide, and while all programs have the same overall mission, each LEND has a unique focus and individual strengths.

Under the direction of Cindy Ellis, M.D., MMI’s LEND program was one of only 18 LEND programs to receive much needed additional funding this year under the Combating Autism Act. These funds will be used to develop specific, autism-related interdisciplinary training opportunities to address the critical shortage of appropriately trained personnel and services in the area of autism and related disabilities.
Jodie Flanagan tried to find a job. But even with a double major in psychology and criminal justice, no one would offer her work and she knew why.

Flanagan is blind and has been since the age of 16, when a car accident broke every bone in her face, crushed a vertebra in her neck and left her with a damaged optic nerve in her left eye and a detached retina in her right.

The Dodge, Neb., native had always dreamed of being a veterinarian. As a multi-sport standout in high school, she had the notion she could do anything. But when she lost her eyesight, she didn’t know what she would do with the rest of her life.

“I didn’t even know how I was going to get from the couch to the bathroom,” the now 26-year-old Flanagan recalled.

Following her high school graduation, Flanagan pursued a bachelor’s degree at Peru State College in Peru, Neb. It was there that she met her husband, Sean, and discovered her passion for counseling.

But passion wasn’t enough to get her hired as Flanagan soon found out.

“It is so tough to find work when you are visually impaired,” she said, noting potential employers were hesitant to hire her due to concerns about accommodations.

A friend recommended Flanagan join the AmeriCorps program at the University of Nebraska Medical Center’s Munroe-Meyer Institute (MMI). Similar to the Peace Corps, members commit to one year of service, working between 300 to 1,700 hours, and in some cases complete a second year of service.

The mission of MMI’s AmeriCorps program is to promote and enhance community awareness and inclusion of individuals with disabilities and their families.

“AmeriCorps represents an opportunity for people with and without disabilities to show that they have valuable skills and are productive citizens,” said Stacy Bliss Fudge, Ph.D., AmeriCorps coordinator at MMI. “It gives them a chance to add real-world work experience to their resumes and receive recommendations from employers who can speak to their job skills and eliminate future employers’ concerns about hiring people with disabilities.”

MMI has helped Flanagan complete her advanced practicum for a master’s degree from the University of Nebraska at Omaha by putting her counseling skills to use in group therapy sessions at UNMC’s Weigel Williamson Center for Visual Rehabilitation as well as family therapy sessions at MMI.

While some might see Flanagan’s inability to observe patients as a hindrance, Flanagan, ever the optimist, views it differently.

“Sometimes people feel more comfortable and are more at ease when they find out I can’t see because then no one is judging them,” she said, adding that she uses her sense of hearing to pick up on things that others may miss due to visual distractions.
Prior to the formation of MMI’s AmeriCorps program, few people with disabilities were employed at MMI. Now, three former members are working in programs and positions begun during their AmeriCorps service.

Kathleen Egbers, who has cerebral palsy and uses a wheelchair, is one example. She recently was hired by the MMI Psychology Department as a customer service specialist. Egbers is the first person people meet when they call or check in. She helps clients make appointments, contacts psychologists and provides weekly reminder calls to patients. Egbers brings a cheerful attitude to the job and has increased productivity in the department. She is currently learning Spanish so that she is better able to communicate with Spanish-speaking patients.

“One of the things we are most proud of is our success at increasing the percentage of people with disabilities who work at MMI and on the UNMC campus,” said Joe Evans, Ph.D., founder and director of MMI’s AmeriCorps program.

This year nine out of 19 AmeriCorps members have a disability. Four work at UNMC; the five others provide services in community agencies including Girls Inc., YWCA, Apollos School and the Nebraska Humane Society.

Though Flanegan practices in the city of Omaha, the MMI AmeriCorps program serves people statewide. Funded by a grant from the Nebraska Volunteer Service Commission, the program has placed members in Nebraska urban and rural communities to increase the quality of services for people with disabilities in underserved areas.

Each member is required to participate in a minimum of five volunteer/community service activities and five leadership and personal development trainings per year on topics that relate to people with disabilities.

In exchange for their service, members receive a monthly living allowance and an education award that can be applied to existing student loans, current school expenses or future education costs.

But perhaps the most valuable take away for those with disabilities is the self-assurance that they can prove themselves when given a chance.

“Once I can show people all I can do, they realize I don’t need extra help,” said Flanegan, who plans to pursue a career in counseling. “But some of us first need the opportunities provided by AmeriCorps.”
Tanya Roland never had to worry about her young daughter putting anything and everything in her mouth.

In fact, it was just the opposite. Torshaya was born with gastroschisis, a congenital condition that left her intestines protruding from her abdomen. Dependent on a feeding tube for nourishment, she never experienced being fed as a baby.

After losing 95 percent of her small intestine, Torshaya underwent a life-saving small bowel transplant in 2006 at The Lied Transplant Center, operated jointly by UNMC and The Nebraska Medical Center. While recovering from her operation, the 3-year-old was referred to the Munroe-Meyer Institute’s (MMI) Pediatric Feeding Disorders Program at UNMC.

In a video recording of her first appointment, Torshaya screams and cries as she bats at the hand of her mother trying to feed her with a spoon.

“She wasn’t used to chewing, swallowing or the taste or texture of food,” Roland said. “If food did get in her mouth, she would spit it out or if she did swallow it, she would instantly throw up.

“She was terrified of food.”

Less than 18 months later, feeding time is closer to normal. Today, the 5-year-old is no longer dependent on intravenous feeding. Instead, she chats with her mom between tiny bites of hot dog, sweet potatoes and green beans.

“She’s made an incredible amount of progress since she’s been here,” said Cathleen Piazza, Ph.D., director of the Pediatric Feeding Disorders Program. “It’s quite impressive given how ill she was.”

Torshaya was practically on her deathbed when her mom, dad and two sisters pulled up stakes in Oklahoma and moved to Omaha to save her life.

Physicians in Oklahoma had recommended she have a Do Not Resuscitate order and doctors there had taken out her feeding tube.

“At 14 pounds, you could literally see every bone in her body. It was bad, but I always had faith that she would get bigger and better,” Roland said.

And she has, with the help of the UNMC transplant team, Dr. Piazza and the MMI feeding team. Getting a little girl who had never eaten to accept food required a customized treatment plan.

“We start off by making eating as easy as possible,” Dr. Piazza said. “We might start out feeding the child baby food, which is easier to eat than regular-textured food, or we might start by simply having the child touch the food with his lips.

“We also make eating as fun as possible, so we might allow the child to play with toys during the meal. It’s a process that’s broken down in small steps.”
She compares the task to training for a marathon.

“If you’re going to run a marathon, you start by running one mile, not 25 miles. That discourages success. We set children up for success.”

Dr. Piazza says that most preferences for flavors are learned and that children who go through the treatment program are ultimately better eaters than their peers without feedings disorders.

“The only way to tell if a child has been in our program is that they eat their vegetables,” she said. “We teach them to eat all the food groups.”

There are six observation rooms with one-way mirrors in MMI’s Pediatric Feeding Disorders Program. It’s where data is collected for about 40 patients per week, some of whom receive outpatient treatment for one to three hours per week and others who receive therapy all day, all week for about eight weeks.

Parents are actively involved in the process, and practice feeding their children with the program-developed treatments.

“A lot of our research is focused on how the caregiver’s responses during meals affect a child’s behavior,” Dr. Piazza said. “By systematic testing, we’ve found that if the parent allows the child to get out of eating or pays attention to the child during meals by coaxing or reprimanding, the child’s eating behavior will get worse, not better. It is important to teach parents how to feed their children properly and how to react when they refuse or accept food, Dr. Piazza said.

Dr. Piazza, who headed a successful pediatric feeding disorders program at the Kennedy Krieger and Marcus Institutes at Johns Hopkins University School of Medicine where she worked for 19 years, ensures that children succeed with a therapist before putting parents back into the equation. Once goal-oriented treatments work consistently, they are then implemented in the home.

“Generally, most children who come to our program have not succeeded with other programs,” Dr. Piazza said. “We are usually a parent’s last hope for helping their child become an age-typical eater.”

Said Roland: “That’s our plan – to get her to eat like every other kid.”

This story was originally featured in UNMC’s Discover magazine, Spring 2008. To read or download the full article visit www.unmc.edu/discover.
As a toddler, Hope Kircher would make a sucking noise like Maggie Simpson of “The Simpsons” TV show when she wanted a drink of water. When she wanted ice cream, she’d touch her finger to her tongue. If she wanted more, she’d say so in sign language.

Born with apraxia, a motor planning speech disorder that affects coordination of the tongue and lips, Hope had trouble talking. She knew what she wanted to say, but couldn’t get the words out, hence the sound effects, gestures and facial expressions she used to communicate.

Young Ajay Kalra’s small chin, caused by facial femoral syndrome, made it difficult for him to enunciate speech sounds. He had a vocabulary of about four words and gestured and pointed for everything else.

Both sets of parents could understand what their children were trying to say, but the rest of the world could not. As caregivers, they wanted their children to better communicate with their peers, grandparents and siblings.

Enter UNMC’s Munroe-Meyer Institute (MMI) and the Nebraska Scottish Rite Masons’ RiteCare speech therapy programs, which are designed to enhance the expressive communication abilities of preschool children.
For more than 30 years, the Nebraska Scottish Rite Masons have supported RiteCare programs in Omaha, Hastings, Lincoln and Alliance, Neb.

“It is so gratifying to meet someone who went through the RiteCare clinic as a child and has become a successful adult,” said Curt Edic, general secretary of the Omaha Valley Scottish Rite Masons.

Through songs, books, art and interaction at the RiteCare preschool clinic, Ajay can now say more than 100 words. With the help of RiteCare individual speech therapy, Hope now speaks in three- to five-word sentences.

“When Hope first came, we worked on just getting her to use basic consonant and vowel sounds,” said Korey Stading, a speech therapist who along with fellow therapist Beth Hughes, teaches the preschool classes. “Apraxia makes it difficult to produce speech sounds and words are a combination of speech sounds, which makes them even more difficult, but Hope has progressed a lot since coming here.”

Stories like Hope’s and Ajay’s are an inspiration to Edic and the reason the Scottish Rite Masons continue to support the RiteCare clinics.

If paid out of pocket, speech therapy would be a huge financial burden on families whose children have encompassing disabilities. Without the Nebraska Scottish Rite Masons’ support, some families wouldn’t be able to afford speech services at all, as insurance companies will not always cover the cost.

“For every dollar we spend, it’s estimated to save up to $7 in special education or behavioral management costs,” Edic said.

Still, financially difficult times are making it difficult for the Nebraska Scottish Rite Masons to hire speech clinicians in rural areas like Alliance, Neb., which was forced to close when the last clinician left.

“Our vision is to add a second clinician in Hastings as soon as possible and then open another clinic in Alliance or a mobile clinic so it can cover a lot of miles in rural areas like Chadron, Scottsbluff and Kimball, Neb.,” Edic said.

Funds from this year’s fundraiser will enable the Scottish Rite Masons, with the help of a new clinician, to slightly decrease the number of children on the waiting list for the RiteCare clinics.

The more children like Ajay and Hope who attend the RiteCare preschool programs and receive individual and group speech therapy, the more children who can learn to communicate in ways others understand.

“We can see results from the services provided to these children. The communication skills they learn may be among their most important life skills as good communication between two or more people creates understanding, peace and harmony.” —Curt Edic, Omaha Valley Scottish Rite Masons
In the Community

Nebraskans with disabilities benefit from the therapy and diagnostic services MMI provides in rural and urban counties across the state. MMI also provides services on Indian reservations in Nebraska and South Dakota and through its video telehealth network. Last year, more than 10,000 individuals received clinical services and almost 50,000 clinic visits were provided. The following clinics address a variety of disabilities and disability-related needs for both children and adults. In many of the clinics, services are conducted in a collaborative manner with other hospitals and programs.

Center for Autism Spectrum Disorders

• The Severe Behavior Program, which provides highly specialized services to children with developmental disabilities who display destructive behaviors, has a joint clinic with a developmental pediatrician at MMI. The clinic is unique in that doctors coordinate their treatment development and medication modifications so that the most optimal treatment package is provided to clients.

Developmental Medicine

• MMI employs two of the four pediatricians in Nebraska who are board certified in developmental/behavioral pediatrics.

• The developmental medicine department completed an industry-sponsored drug trial in children with autism.

Education

• MMI is among the founding partners of the Nebraska Parental Information and Resource Center (PIRC), a statewide parent involvement project supported by a $2.7 million grant from the U.S. Department of Education. The PIRC partners with organizations and agencies to carry out the work of sharing parental information and resources.

• Developmental TIPS (Tracking Infants Progress Statewide) is the largest standardized follow-up program of its kind in the country. The program enrolls infants statewide who were in a neonatal intensive care unit for at least 48 hours, regardless of the child’s perceived risk for neurodevelopmental disability. The children — more than 8,900 infants to date — are followed through age 3. TIPS resulted in early identification of numerous children who are in need of early intervention services.
**Human Genetics**
- MMI geneticists played a key role in providing the genetic testing for a major scientific breakthrough in which scientists for the first time successfully derived embryonic stem cells by reprogramming the genetic material from skin cells while studying Rhesus Macaque monkeys. The study was reported in the journal Nature.
- Research collaborations with Singapore General Hospital and with the Children’s Oncology Group.

**Nutrition**
- MMI’s nutrition coordinator is the only dietitian in Nebraska to be certified by the Commission on Dietetic Registration as a specialist in pediatric nutrition.
- Provides services to rural areas of the state through contracts with the Nebraska Department of Health and Human Services’ Medically Handicapped Children’s Program. Two contracted dietitians provide services to children with diabetes in the North Platte Outreach Clinic and the Norfolk Outreach Clinic, while MMI’s nutrition coordinator provides services in the Child and Adolescent Clinic in Hastings.

**Serving the Community**
MMI provides technical assistance to other university departments and programs, community organizations and governmental agencies to transfer new knowledge from the academic setting into the community. This year, 28,110 participants attended workshops, conferences, teleconferences and other community education activities. This chart illustrates the broad spectrum of issues and services for which MMI provides evaluation, assistance in program development or implementation, continuing and community education and a variety of other community services.
Occupational Therapy
- Collaborative research with MMI psychology faculty to evaluate the efficacy of specific intervention strategies used with Omaha Public School students served by MMI.
- Launched a 12-week pilot-feeding group that systematically introduces new foods to kids with rigid food preferences.

Pediatric Feeding Disorders
- One of the only pediatric feeding disorders programs in the world to collaborate with an intestinal rehabilitation program for children with intestinal failure.

Physical Therapy
- In collaboration with Children’s Hospital, MMI’s Reggie Harbourne received a federal grant to start a pediatric clinic residency that would be the second of its type in the United States.
- A unique summer clinical program — PEDALS — teaches children and adults with coordination disorders to ride a bicycle.

Psychology
- The prestigious American Psychological Foundation Cummings Psyche Award was presented to MMI Psychology Director Joe Evans, Ph.D. The award is presented nationally to the one psychologist who most effectively promotes the integration of behavioral and physical health care in primary practice.

Fueling our mission
MMI has a budget of more than $20 million which supports more than 250 faculty and staff. Funding sources are diverse and include federal, state and local grants and contracts, revenue from services, and generous support from numerous boards, foundations and individuals across Nebraska.
Interdisciplinary Trainees
long-term trainees / all other trainees

MMI’s education program provided an interdisciplinary training experience for almost 200 students, interns, residents, and post doctoral fellows in 2008. Approximately one-quarter of these students were long-term trainees, receiving 300 hours or more of interdisciplinary instruction at MMI.

Funds Leveraged
patient revenues / grants and contracts

Over the past five years, MMI has been successful in maintaining grants and contracts with existing partners in the community, and also in identifying new partnerships and funding sources to develop innovative programs to address emerging issues.

Recreational Therapy

- Recreational Therapy boasts the largest service learning program for youths in Nebraska with over 350 volunteers from over 75 different junior and senior high schools providing some 13,000 service hours to programs for youths and adults with developmental disabilities.

- Recreational Therapy programming ranked among the top ten in the nation according to the National Institute for Recreation Inclusion (NIRI). The department provides programs year round in community inclusion, school-based and center based services to over 500 families each year.

Social Work

- Received a $10,000 Nebraska Planning Council on Developmental Disabilities grant to improve the health and wellness of young women with developmental disabilities.

- Developed unique psycho-educational therapeutic services for children and adolescents in foster care to help stabilize their behavior and normalize their environment.

MMI psychologists annually collaborate with six additional agencies as part of the Nebraska Internship Consortium in Professional Psychology. With 29 interns in 2007-2008, the Nebraska program is the nation’s largest internship consortium site. MMI was home to nine interns in the 2007-2008 academic year along with five post-doctoral fellows and 12 graduate trainees.
Products developed and disseminated
all products disseminated
new products developed

MMI faculty members publish extensively in professional journals, monographs, periodicals and books and also disseminate best practices through reports, manuals and other informational materials. In 2008, MMI faculty members developed 130 new products and disseminated more than 127 different products to professionals, students, parents, people with disabilities and the general public.

Speech-Language Pathology

- Provided a telehealth training program for speech pathologists in Nebraska on treatment techniques for children with apraxia. Teleconference presentations were provided to speech pathologists in McCook, Hemingford, Lincoln, Millard Public Schools (Omaha), Homer, Winnebago, Lyons, Decatur and Wayne.

- Participated in the development of new augmentative communication device interfaces for people with physical and language disabilities. The Rehabilitation Engineering Research Center grant involves Duke University, Temple University, Penn State University, Children’s Hospital-Boston, University of New York at Buffalo and the University of Nebraska-Lincoln.
Unlocking Potential Fund
www.nufoundation.org/mmiunlockingpotential

Private support from patients, families and friends plays a critical role in the success of the University of Nebraska Medical Center’s Munroe-Meyer Institute. UNMC has challenged itself to achieve world-class excellence in patient care, medical research and education and the University of Nebraska Foundation is proud to represent this mission to friends of MMI.

Although, MMI has the potential to expand its research, diagnostic, educational and outreach capabilities, much of this potential cannot be met with current allocations and will have to be realized through private philanthropy. With your help, the Unlocking Potential Fund will provide the funds necessary so MMI can better serve families with disabilities through advocacy, education, outreach, patient service and research. Through your generosity, the pledge to improve and “unlock the potential” in the lives of these children, youths, adults and their families will be realized.

For more information about the fund or to make a donation, please contact m welsh@nufoundation.org or (402) 502-4117.

Sincerely,

Melonie S. Welsh
Director of Development for MMI
University of Nebraska Foundation

In service to our community

As part of its federally funded mission, MMI must secure additional funds which can then be used to provide interdisciplinary long-term training, conduct technical assistance and outreach to community programs, develop materials for dissemination and publish the outcomes of our research efforts. The charts presented highlight these efforts.