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

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

Parents, teachers, therapists and community service providers are involved in the provision of services, which includes 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’s research, education, services and statewide technical assistance training have been a source of hope for patients with developmental disabilities and their families.

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 provide care to children and adults with developmental disabilities and genetic disorders and their families.

The UNMC Munroe-Meyer Institute (MMI) for Genetics and Rehabilitation originated in the late 1950’s 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 to more than 10,000 children and adults with diverse developmental and physical disabilities and genetic disorders.
Director’s Message

The theme of this year’s annual report is IMPACT. As we at the University of Nebraska Medical Center’s Munroe-Meyer Institute go about our daily work, it’s easy for us to remember why we’re here: to improve the lives of individuals with disabilities and their families. Whether that be from the lab, in the classroom, in the clinic or even in the community, we get to see first-hand how our work affects and impacts the individuals we serve every day. We wanted to share these stories with our audience who may only get that chance once every year. No matter if this is your first time reading about the Institute or if you know our rich history of serving individuals with polio, we hope you are inspired and impacted by the words and photos in this annual report. In the pages that follow, you’ll find a story about four women with disabilities making a living working at MMI. You will read of a patient whose family finally learned of his genetic diagnosis when he was 26. There is an article on a former student who now has her dream job because of her education at MMI and another on a collaborative clinic that is helping alleviate the long-list of children waiting to be screened for autism. It’s incredible to be a part of such a powerful mission, one that we plan to uphold for many years to come. Just as our actions have impacted those around us, the special population we serve has impacted us, and hopefully, at the conclusion of this report, you, too.

J. Michael Leibowitz, Ph.D.,
Hattie B. Munroe Professor
Director of UNMC’s Munroe-Meyer Institute

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Like our page to stay in touch year round.

MMI Annual Report 2013
Editor: Nicole Lindquist
Designer: Tom Waples
RPS6KA3. It looked more like alphabet soup than a diagnosis of a mutated gene. To Yolanda F. Johnson, it was so much more. It explained everything about her little brother. His looks. His past. His future.

Growing up, Johnson always knew Anthony was different. When doctors offered the blanket “mental retardation” label (now known as intellectual disabilities), she would wonder, “Is there more to the story?”

She finally got her answer in the form of genetic testing performed in the Human Genetics Laboratory at UNMC’s Munroe-Meyer Institute (MMI). Anthony, now 26, has Coffin-Lowry Syndrome.

Coffin-Lowry Syndrome is a rare genetic condition (about 1 in 50,000 people) that can cause cardiac problems, progressive curvature of the spine, smaller head size, short stature and other skeletal problems, according to Amber Carter, certified genetic counselor at MMI. It typically affects males and causes developmental delays during childhood and severe to profound learning problems later.

For as many answers as the diagnosis gave, it also raised a question. Since Coffin-Lowry is passed through the X chromosome, could Yolanda be a carrier who simply showed no symptoms? She hoped to have children someday. Would they be at risk for developing this same syndrome?

Genetic testing for the same gene mutation was offered to Yolanda. She accepted and underwent a blood draw. A few weeks went by and finally the call came.

“About 70 to 80 percent of the time it’s a new mutation, but 20 to 30 percent of the time it’s inherited through the family,” Carter said.

While RPS6KA3 was the answer, it was not the definition of Anthony. It turns out that the mutation found on Anthony’s X chromosome was most likely spontaneous and not hereditary, though there’s no way to know for certain since the Johnsons’ mother wasn’t tested.

“I would highly recommend genetic testing to others,” Johnson said. “But you have to have faith that it’s not going to put you in a checkbox.”

Anthony may have Coffin-Lowry, but that doesn’t change that he’s spontaneous, funny and kind. “He’s endured so much and when I call and talk to him, the first thing he says is ‘good morning,’” Johnson said. “He’s amazing. He’s my hero.”
Kathlene greets families in the psychology department. Tina is an associate in the business office. Amanda conducts intake interviews with moms and dads from her phone in the patient information department. Sheila escorts clients to their appointments in the social work clinic. The four women are all hard-working college graduates, and each of them uses a wheelchair as a primary means of getting around.

Employing individuals with disabilities was a primary focus of the AmeriCorps program when Joe Evans, Ph.D. brought it to UNMC’s Munroe–Meyer Institute in 2003. Similar to the Peace Corps, AmeriCorps members commit to hours of service in exchange for a stipend. They’re left with valuable, employable experience.

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Joe Evans, Ph.D., and Kathlene Egbers

She now has her master’s in social work and is happy to be putting her people skills to use at MMI. For Egbers, receiving that first paycheck was unlike anything else.

“It was awesome,” she said.

Going out for dinner. The occasional concert. Giving to charity. These are the things she girls save up for. Just like everyone else.

“Without a job, we wouldn’t be able to do stuff. It’s gives us a life,” Egbers said.

More important than what they can buy with their money is how earning it makes them feel.


“It’s all about being independent” Tina said.

Said Shanle, “I want to make a difference and contribute to society. I didn’t go to school to sit at home.”

Amanda did just that for nine months while she searched for jobs.

“My God it was boring,” she said.

Clearly, these women want to work. And MMI has given them that opportunity.

“What we need is more people like Dr. Evans to give people like us a chance,” Shanle said. “There are not enough Joe Evanses in the world.”

While flattered, Dr. Evans doesn’t think there’s a need to clone him.

“Sometimes people just need to overcome their preconceptions about what a person can and can’t do,” he said. “These four women have proven they do very valuable work.”
They gather around the table in the second floor conference room of Children’s Hospital and Medical Center. Their handwritten notes and laptops are at the ready in front of them.

Dr. Lois Starr, a clinical geneticist at UNMC’s Munroe-Meyer Institute and director of the multidisciplinary diagnostic autism clinic (MDAC) is the first to speak.

“So, Candee, what did you think?”

Candace Lake, Ph.D., is a board certified behavioral health practitioner and the question she’s about to answer is a big one. Per her evaluation, does Gabe have autism?

Ten-year-old Gabe was one of three children seen by a panel of experts in the new autism clinic held at the hospital and partially staffed by MMI faculty the second Friday of each month. The goal of the clinic, funded in part by the Autism Action Partnership, is to provide a multidisciplinary evaluation for children suspected of having autism.

“Being seen by multiple specialists on the same day who are able to discuss with one another their assessments and tailored approaches for each child is a great advantage to our patients and their families,” Dr. Starr said.

Following Dr. Lake’s observations, Howie Needleman, M.D., a developmental pediatrician with decades of experience, offers insights from his perspective. Next, Dr. Starr chimes in from a genetic standpoint and discusses whether testing would yield an underlying cause.

Last but not least is Jen Schrage. Schrage’s viewpoint cannot be matched by anyone else at the table. She is the parent of a child with autism and one of two advocates who make this clinic unique. Schrage is there to advocate for Gabe’s mom.

“I don’t want parents to feel alone when they receive a diagnosis of autism,” she said, “because that’s exactly how I felt when my son was diagnosed. They handed me a book.”

Schrage had to seek out services on her own. It was very unlike what she does for the parents who visit the MDAC. She researches sign language courses and respite options, but most of all, she relates to them.

“I live it at an organic level,” Schrage said, “so parents know that I get it, and they almost immediately relax when I come in the room.”

When Dr. Needleman recommends follow-up appointments for Gabe, Schrage makes sure she gets names and contact information for the best in the business for Gabe’s mother.

Using the recently released guidelines for diagnosing autism from the Diagnostic and Statistical Manual – Fifth Edition, the team reached a consensus after going around the table. Gabe has Level Three autism, which means he will need substantial support.

Having a diagnosis will put focus on his neurodevelopmental needs, rather than just his medical ones.

Dr. Starr credits Children’s for their support of the clinic and is hopeful it will soon expand to serve more patients like Gabe. She’s uncertain of exactly how many, but one things for sure: There’s one less child on the waiting list.

“I don’t want parents to feel alone when they receive a diagnosis of autism.”
Mary Kaleta didn’t have to apply for jobs. Following her year-long pediatric physical therapy residency at UNMC’s Munroe-Meyer Institute, jobs applied for her.


“They were all knocking on my door and asking me to come for interviews,” Kaleta recalled. “It was a crazy position to be in.”

She eventually chose Gillette Children’s Specialty Healthcare in Minnesota. Although she deserves all the credit for her good fortune, Kaleta is quick to recognize her residency training and more importantly, her mentors at MMI.

There was Amy for outpatients. Sandy in the NICU. Tammy for early intervention. Amber in the schools. Wayne in the gait lab. Each of them has shaped the physical therapy residency, now in its fourth year.

“When we received accreditation from the American Physical Therapy Association, our goal for the residency was to provide students with an intensive, well-rounded learning experience in pediatric physical therapy," said Wayne Stuberg, Ph.D., former director of the physical therapy department and current associate director of MMI.

The comprehensive experience was exactly what drew Kaleta in. The Marquette University grad worked at a hospital-based clinic for two years in Washington State before she decided to go back to school. There are few pediatric physical therapy residency programs and all are prestigious.

“One of the biggest draws to Omaha and Munroe-Meyer was the gait lab and the opportunity to study under Wayne Stuberg,” Kaleta said. “I love biomechanics.”

The state-of-the-art gait lab uses multiple, high-speed cameras and reflective muscle markers similar to video game technology to analyze abnormal walking patterns pre- and post-surgery. Performing gait assessments, completing clinical work, supervising students in the schools and collaborating with the early intervention program kept Kaleta very busy.

“It was phenomenal,” she said. “I feel like words can’t do it justice, but I wouldn’t give up my experience for the world.”

The residency is offered in conjunction with the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program, which means the opportunity to do research. Kaleta worked on a case study on crouch gait. She’s now considering tackling her Ph.D., but for now loves being in the field.

Kaleta works four 10-hour days at Gillette where she sees pediatric patients. The youngest she has treated was 54 days. The oldest, 18 years.

“I see the full spectrum of diagnoses, from various forms of neurodevelopmental, musculoskeletal, genetic and orthopedic conditions,” she said. “Two kids who are the same age with the same diagnosis can still present completely differently, so I’ve never had a dull day.

“I definitely love my job and am happy and thankful to be where I am today.”

In her down-time, Kaleta rows and runs marathons in between studying for the Pediatric Clinical Specialist exam she’s scheduled to take in March of 2014. If history is any indication, she won’t be taking the test. The test will have to take on her.
On a chilly, winter day, the preschoolers at Kellom Elementary School can be found zooming around the halls on their tricycles. Since they can’t go outside, they work on gross motor skills indoors.

Lisa St. Clair, an assistant professor in the education department at UNMC’s Munroe-Meyer Institute, observes this and beams. It’s because of her that some of these children are here.

St. Clair evaluates early childhood education programs. Through the generosity of funding from organizations like the Buffett Early Childhood Fund, she looks at how efficiently and effectively they prepare children for school. Believe it or not, how prepared children are for kindergarten can often tell you a lot about their future.

Over the years, researchers have found that children who are born into poverty often start school behind. They fall farther back as the years go by. Studies show that if there’s a gap in fourth grade, it’s most likely going to be wider by 11th grade.

“It’s like starting a marathon a mile behind. It makes it hard to catch up,” said Ted Stillwell, chief executive of the Learning Community in Omaha. “But if we intervene early, we don’t have as much ground to make up.”

It is Stillwell’s and St. Clair’s belief that proper early childhood education can prevent achievement gaps from forming in the first place. Although some research has shown any gains made in early childhood level off after a few years, St. Clair’s 2012 study of Educare showed what could make those gains long-lasting.

Her findings: The average reading score for a child in third through seventh grade who attended an early education program for less than one year was 80 (with 100 being an average score). The average score for a child in the same age range who attended an early childhood education program for 1-2 years: about 85, an improvement, but hardly substantial.

The average score for a child in third through seventh grade who attended more than two years of early childhood programming: 111. Way above average. For the record, math scores also jumped significantly after two years.

These findings were ground-breaking.

“It’s sort of an ‘oh, duh’ result, but it was really powerful,” St. Clair said. “To make those gains last, you have to have children in the program for two or more years. The results made others sit up and take notice.”

They didn’t just take notice. They acted.

The Learning Community and Omaha Public Schools came together to form the Early Childhood Partnership Program with pilot preschool programs at Kellom, as well as Conestoga, elementary schools in north Omaha. They launched in August and the model will soon expand to other schools. Not only was the program designed to be two years long, but professional development and parent engagement components also were added.

“What is compelling about MMI’s data is that it was able to isolate what made the difference: two years,” Stillwell said. “We were able to transfer that knowledge into our program and we wouldn’t have known that without the data.”

Both Stillwell and St. Clair are quick to acknowledge that individual children from disadvantaged backgrounds can succeed despite their circumstances, and that reading scores aren’t everything. However, for the majority of children in poverty, early intervention can change their life trajectory.

“It’s sort of an ‘oh, duh’ result, but it was really powerful.”

Good reading skills are the leading prerequisite to success in middle school, high school and college, Stillwell said. Low reading scores are often later linked with dropping out, criminal arrests and teen pregnancy.

One of the questions St. Clair asks parents during the course of an evaluation is, “What level of education do you see your child completing?”

“Some of them respond and say that they don’t see their kids graduating from high school,” St. Clair said. “But by the end of the program they’re saying, ‘My kid is going to college.’ And that makes St. Clair beam.
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, 18,645 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.

Fueling Our Mission

MMI’s complex mission requires that we seek support from a wide variety of sources. Patient revenues continue to be the largest part of our budget with state funds and contracts from public schools and state agencies providing a great deal of support. Private donations continue to be a very important part of our program as we develop cutting-edge programs to benefit Nebraskans with disabilities.

Products Developed and Disseminated

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 2013, MMI faculty members developed 84 new products and disseminated 167 different products to benefit professionals, students, parents, people with disabilities and the general public.
Funds Leveraged
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 and address emerging issues.

Interdisciplinary Trainees
MMI’s education program provided an interdisciplinary training experience for 177 students, interns, residents and post-doctoral fellows in 2013 for a total of 122,750 hours. More than half of these students were long-term trainees, receiving 300 hours or more of interdisciplinary instruction at MMI.

Nebraska Foundation
The University of Nebraska Foundation is involved in a comprehensive fundraising campaign to address university priorities across its campuses. As part of this campaign, the Munroe-Meyer Institute has embarked on an unprecedented effort to raise $20 million to fund critical initiatives. To date, generous friends have donated nearly $8 million.

Pulitzer Prize winning journalist Hodding Carter said “There are only two lasting bequests we can hope to give our children. One is roots; the other, wings.” Private support enables families to find hope in the diagnostic and treatment programs at MMI. It also provides critical support needed to reach families throughout our community, giving them the opportunity to soar past perceived boundaries.

Your gift to support programs, services, research and policy provides hope and direction to families who otherwise could not receive the tools necessary to empower their family members to have the same opportunities to lead healthy and productive lives as anyone else.

For more information about the campaign, contact Melanie Welsh mwelsh@nufoundation.org | 402-502-4117.

MMI’s Mission:
To improve the quality of life for persons with disabilities and their families.
UNMC Munroe-Meyer Institute for Genetics and Rehabilitation

A university center for excellence in developmental disabilities education, research and service.

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