MMI’s Mission:
To improve the quality of life for persons with disabilities and their families.
UNMC’s Munroe-Meyer Institute (MMI) for Genetics and Rehabilitation originated in the late 1950s 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 14,000 children and adults with diverse developmental and physical disabilities and genetic disorders. In 2014 more than 55,000 patient services were provided across Nebraska by MMI faculty and staff.

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 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.
Dear friends of the Munroe-Meyer Institute,

The fact that I am addressing you in this message demonstrates one of the many changes that took place at MMI in 2015. Some of those changes, such as the retirement of our longtime director Michael Leibowitz, Ph.D., were anticipated. Some, such as the passing of genetic lab director Warren Sanger, Ph.D., were unanticipated and heartbreaking. And as the human services and legislative landscape continues to change in Nebraska and beyond, some were challenging. Nevertheless, MMI’s committed professionals continued to work to provide world-class services to the children and adults with disabilities and the families we serve.

In times of change, connections provide not only support and stability but also opportunity. MMI works collaboratively on many levels, some of which we will highlight in this report. These collaborations, whether with fellow researchers at UNMC to explore possible treatment pathways for children with cerebral palsy, with officials of the state of Nebraska to ensure proper access to care for adults on the autism spectrum, or with universities and scholars from across the world who collaborate with or study at MMI to increase global understanding of developmental disabilities and treatment avenues, help keep MMI on course. These collaborations enable us to continue, even in times of change, to move forward with cutting-edge research, world-class education and, as always, compassionate clinical services to improve the lives of our clients and their families.

“Working together” is a core value of the University of Nebraska Medical Center. At the Munroe-Meyer Institute, this is more than a slogan – our collaborations are a source of both strength and resilience. By working with others, we become a stronger resource for the families we serve. We are excited to share stories of these collaborations with you.

Wayne Stuberg, PT, PhD, FAPTA,
Interim Director of UNMC’s Munroe-Meyer Institute
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**MMI Annual Report 2015**

**Editor:** John Keenan  
**Designer:** Tom Waples
Sarah Swanson could use a break.

She can’t have one, though, because she’s trying to make sure everyone else can.

Swanson is the lead in MMI’s respite education effort, in partnership with Jolene Johnson of the Interdisciplinary Center for Program Evaluation and Respite Employer Engagement Coordinator Kim Falk, UNMC/Nebraska Medicine. It is an effort that has a statewide reach.

“There is a significant need for respite in Nebraska, because families are caring for loved ones across the lifespan representing diverse needs,” said Sharon Johnson of the Nebraska Department of Health and Human Services, which collaborates with MMI to address statewide respite needs.

“Depending on circumstances, family caregiving can be financially devastating. Many families are unaware of respite resources and have no support for relief.”

The state’s partnership with MMI to address a growing need for respite providers makes sense for many reasons, Swanson said.

“We have a statewide focus, and one of our missions is training, and another mission that we have is supporting people who have disabilities and their families,” she pointed out. “It is kind of a win-win for both the state and MMI to partner on this.”

Jolene Johnson said that MMI’s first-year evaluation on the Lifespan Respite Subsidy Program shows clear benefits to respite.

“There is a significant need for respite in Nebraska, because families are caring for loved ones across the lifespan representing diverse needs,” said Sharon Johnson of the Nebraska Department of Health and Human Services, which collaborates with MMI to address statewide respite needs.

“One of the things we’re looking at is whether respite can change the trajectory of whether the individual with disabilities gets placed in institutional care, meaning a nursing home or other out of home placements,” Swanson said.

“We know that it’s less expensive to care for an individual in their home, and most people want to stay in their homes.”

“Through receiving respite care services, family caregivers reported a decreased level in stress as well as marked decreases in health symptoms including headaches, irritability, anxiety and chest pain. The respite care services helps ease the frustration and anxiety of caregiving for caregivers when they know a break is on the way,” she quoted from the report.

In addition to working with the respite coordinators throughout the state, MMI is starting to look at how respite is woven into other programs and how it’s meeting the needs of families.

“It’s very obvious that when people have access to respite, they feel better, they have more enthusiasm,” Swanson said.

What makes that important is that people are then more likely to continue providing care, usually to family members.

“Your kids are going somewhere where they are having fun, and you are able to go out and do what you need to do,” she said.

Assistant director of recreational therapy Kelley Coutts is a member of the MMI staff who is a respite trainer. She said many MMI families who use the recreational therapy programs often use them as an opportunity for respite.
Coutts, who is doing respite training as part of the MMI collaboration with the state, said trained respite providers allow caregivers to step away for a break.

“For a lot of caregivers, it’s a question of finding people that you can trust,” she said. “That’s really hard for families, especially families with adult children. And also, as individuals age, some of their physical needs require so much more.”

One of the reasons the state came to MMI is that the institute has some natural pathways to the developmentally disabled and aging community, through the physical therapy school, the UNMC College of Nursing and other programs, Coutts said.

Swanson’s team is trying to collaborate with other local and statewide entities to increase the awareness of respite, including the state unit on aging.

“We recognize that respite is a lifespan issue,” she said.

In addition to providing respite training, MMI is working to broaden the discussion on respite across the state. The institute provides respite resources to employees who are caregivers at UNMC and Nebraska Medicine, in part to determine if this work-based strategy makes a difference.

“Right now, caregivers are getting burned out,” Swanson said.

They need respite. And MMI is working with the state to try and help them get it.
Min-Hwee Yong attended the Oct. 28 game between Northwestern and Nebraska, another close Nebraska loss.

It was the first football game the scientist from Singapore had ever attended. But that wasn’t the reason he was in Nebraska.

Yong, a scientific officer at KK Women and Children’s Hospital in Singapore — one of the Munroe-Meyer Institute’s longtime international institutional collaborators — came to MMI to work with prenatal genetic arrays. To travel to MMI, he had to compete with other scientists at his center for a government-funded grant.

“I’ve been exposed to a wide range of tests being done here, some very advanced tests,” he said. “It’s a fantastic learning experience.”

Yong is just one of several international researchers and scholars who are collaborating with MMI. Developmental neuroscience has two international post-doctoral fellows and two international graduate students, while physical therapy is hosting a doctoral candidate from India. The genetics
department has sponsored a number of faculty members from universities around the world, while the Genetics Lab itself has ongoing research collaborations with hospitals in Singapore, including Yong’s institution.

In addition, Woo-Yang Kim, Ph.D., assistant professor of developmental neuroscience, serves as a coordinator and faculty advisor for the UNMC Asia Pacific Rim Development Program and has run a student exchange program between Chinese institutions and UNMC. Shelley Smith, Ph.D., has helped coordinate an international genetic study of reading and language with institutions in the Netherlands, England, Australia and other countries.

“In today’s scientific community, collaboration is key in both research and clinical efforts,” said MMI Interim Director Wayne Stuberg, Ph.D., who himself traveled to Oman in 2013 to help develop an MMI collaboration with the country’s Ministries of Education and Medicine. “The number of international collaborations that MMI is taking part in speaks to the universal effects of the developmental disabilities our organization researches and treats.

“It is an indication of the quality of our researchers and staff that so many high-quality scientists and health care professionals around the world have embraced these collaborations with MMI.”

International students also find a strong support network at the institute, said Swati Surkar, a Ph.D. candidate in rehabilitation science who has been at MMI for three years.

Surkar came to MMI to work in pediatric rehabilitation research, drawn by the cutting-edge work being done in neuroimaging and in rehabilitation of children with cerebral palsy and other neuromuscular disorders. But the India native, who had only brief experience with international study before coming to the United States, also found a lot of people willing to help her acclimate.

“There was great support from each and every person at MMI to help me to settle in during those initial days,” she said. From finding accommodations to getting an email account set up, MMI staff and faculty, including institute leaders, were on hand to help.

Yong said he also had enjoyed strong social support from MMI staff and co-workers during his one-month stay.

“Over the last decade, we’ve hosted visitors from Singapore five different times. We really try to introduce them to the American culture,” said Diane Pickering, manager of the Human Genetics Lab. “That’s really an enriching experience when we get to know them on a personal basis.

“We’ve had a lot of fun – despite the Husker loss.”
When the State of Nebraska, in the wake of a court decision that mandated Medicare coverage for children with autism, was seeking information on the types of services that could and should be provided, they met with a team of professionals from the Munroe-Meyer Institute.

That’s not surprising.

“We have been identified as a primary stakeholder for providing these services throughout the state,” said Terri Mathews, Ph.D., an associate professor of psychology at MMI who runs social skills programs for children with autism and is the director of Autism Care for Toddlers Clinic. “We provide a lot of teaching and research in this area, and we’re probably the most frequent referral source for providers who see children with possible autism spectrum disorders.”

Cynthia Ellis, M.D., associate professor of pediatrics and psychiatry at MMI and chair of the Nebraska State Autism Collaborative, was one of the MMI experts who met with state officials, along with Dr. Mathews and Wayne Fisher, Ph.D., director of the Center for Autism Spectrum Disorders, Joe Evans, Ph.D., director of psychology, and other MMI staff.

Through her work on the Autism Collaborative, Dr. Ellis has seen MMI’s effect on the state in a number of initiatives and collaborations with entities as diverse as universities, hospitals, non-profits and grassroots advocacy groups.
“We’re collaborating with many people around this issue,” Dr. Ellis said.

With MMI in a leadership role, the collaborative has received several grants and completed a number of projects related to autism awareness or treatment across the state.

The group, which includes what Dr. Ellis described as all of the major players in Nebraska related to autism, works to best pool resources and define optimal outcomes.

“We have been identified as a primary stakeholder for providing these services throughout the state ... we’re probably the most frequent referral source for providers who see children with possible autism spectrum disorders.”

Many MMI professionals also serve on different community boards related to health care and autism – in fact, interim director Wayne Stuberg, Ph.D., serves as chairman of the state board of health. Assistant professor Jennifer Burt, Ph.D., is the CDC ACT Early Ambassador for Nebraska, charged with educating primary care providers and pediatricians about autism awareness and the importance of screening for autism. Dr. Evans works with the Behavioral Education Center of Nebraska as well as with health care homes throughout the state to help provide ABA-trained clinicians not only to many of the primary care centers in Omaha, but in rural areas to provide screening, diagnosis, and clinical services for children with autism.

“We communicate with the schools sometimes on a daily basis,” Dr. Mathews said. “We do a lot of referrals with PTI Nebraska, which is an advocate for these families to help get the services that are needed in the school setting, too.”

“We extend our expertise from MMI outward,” Dr. Ellis agreed.

Collaboration is important because MMI serves as the academic center on autism for the state, receiving money through the federal Autism Cares Act to help build the workforce capacity, educate people and facilitate diagnosis and treatment of children with autism.

“We know that kids with autism have a different set of needs and different outcomes,” Dr. Ellis said. “It has put pressure on states, providers, health care networks and insurance companies, because now we have a lot more kids that are identified as needing services that, in Nebraska, we don’t have yet.”

While the collaborative has provided a way to bring all the state’s stakeholders together to create change, and while there has been improvement, there is still a long way to go.

And MMI must be a leader on that journey.

“The biggest problem right now is that we don’t have enough well-qualified service providers, especially out in the rural areas, who have early intervention training,” Dr. Mathews said. “That’s why programs like the ACT Clinic are so important. We need to educate early childhood providers to ensure that these children are not only getting diagnosed early and quickly, but receive those ABA services that are needed with the level of intensity that is recommended.”
It’s an instinctive response in infants: to suck, swallow and breathe.

That’s why it can be so frightening for parents and health care providers when the infants can’t do it.

Now, a new device called an NTrainer will help the Munroe-Meyer Institute and its collaborators at Nebraska Medicine’s Neonatal Intensive Care Unit (NICU) address this critical need among the hospital’s infant population.

At the medical center, the NTrainer is practically as new as the infants it is designed to help. Purchased in October, as of December it had not yet been used on a NICU patient. But Munroe-Meyer Institute Director of Speech Therapy Amy Nordness, Ph.D., and medical director of the NICU and the Newborn Nursery Ann Anderson Berry, M.D., foresee that not only will their collaboration help Omaha infants and their families, it will produce research results that may positively influence outcomes for infants across Nebraska and throughout the world.

The device, funded by a grant from the Munroe-Meyer Guild, currently is only the second NTrainer in the state of Nebraska. Both Dr. Nordness and Dr. Anderson Berry were excited to bring one to the medical center.

“NTrainer therapy has been shown to establish a coordinated suck-swallow-breathe sequence in preemies,” Dr. Nordness said. “This decreases length of stay in neonatal intensive care units, decreases the time to oral feeding, decreases the potential for g-tubes, improves secretion management and increases oral feedings.

“NTrainer therapy is being trialed across the country with children with neurological impairments and cardiac deficits,” Dr. Nordness said. The team will be conducting research with the NTrainer as well as providing clinical services.
“One of the advantages of working at an academic medical center is being on the front lines of innovative therapies such as this,” she said.

Drs. Nordness and Anderson Berry feel the device can help:

- Infants with hypoxic ischemic encephalopathy, or HIE, which occurs when there is in utero distress or distress during delivery that leads to brain injury. (These infants will be the first group the med center treats with the NTrainer.)
- Premature infants, without lung, heart or brain problems, who are not yet developmentally prepared to effectively tackle the task of oral feeding.
- Infants that have other medical problems, such as pulmonary or gastrointestinal problems.

“Learning how to effectively establish a pattern of ‘suck, swallow, breathe,’ is one of the critical milestones that a baby has to achieve prior to discharge from the NICU,” Dr. Anderson Berry said. Currently, the NICU has several strategies for assisting these infants, including lactation consultants and a specific staff member trained as a feeding specialist for this patient population. The NTrainer provides another option, one that both doctors feel has tremendous potential.

“This is the perfect example of why care is elevated and outcomes are improved when you pursue treatment at an academic medical center,” Dr. Anderson Berry said. “Collaborations like this are the epitome of what practice at an academic center is all about. We can impact care, and we can forward research in the area. This is a patient population that we’re investigating that NTrainer really hasn’t been evaluated in, and it’s an intervention that could potentially show great promise to these patients.”

The MMI Speech-Language Pathology Department is grateful to the Munroe-Meyer Guild for supporting its goals to help infants improve their swallowing skills, Dr. Nordness said.

“We are excited to provide such an advanced treatment to our patients, partner with the Nebraska Medicine NICU to invest in our infants’ future, and pursue our research goals for advancing feeding and swallowing therapy in infants,” she said.

What is the NTrainer?

The NTrainer is an FDA cleared device that provides synthetic patterned orocutaneous stimulation via a pacifier (small pressure pulses through a pacifier with the exact intensity and frequency needed for an effective non-nutritive suck (NNS). The NTrainer was developed to provide the ideal stimulation to establish the NNS in infants.

The NTrainer provides orocutaneous pulses, which expands the pacifier in a series of 6-cycle burst with a 2-second pause period after each burst. The expansion of the pacifier is approximately 135 micrometres. Real-time software in the system computes all the NTrainer data, which informs on how to obtain information on how strong an infant’s suck is, how frequently they suck, how many sucks are in a burst, and how consistent their sucking pattern is.
Max Kurz, Ph.D., and Tony Wilson, Ph.D., arrived at UNMC within a few months of each other in 2009. They’ve been working together ever since, using Dr. Wilson’s expertise in magnetoencephalography (MEG) and Dr. Kurz’s knowledge of biomechanics to study cerebral palsy in children with an eye toward improved treatment of the neurological disorder.

That effort got a huge boost this year with a National Institutes of Health grant that will allow the team to build on earlier work. Dr. Wilson called the new project “the capstone of about six years of research.”

For Dr. Kurz, his work with Dr. Wilson is unique because each researcher brings a different set of tools to the project.

“Where my background is far more related to biomechanical and human movement analysis, and I have the expertise in developmental disabilities that we see here at MMI, his expertise is more related to the inner workings of the brain and cognitive processes,” Dr. Kurz said. “So it’s a synergistic blend of our talents that allows us to
answer unique questions about how the brain is involved with control of the movements that we see, the production.”

Dr. Kurz focuses his expertise on the end point of the movement production; Dr. Wilson examines how the brain is working to generate those movements.

“That allows us to answer really unique questions that other research institutions cannot,” Dr. Kurz said. “Usually you either have expertise in one or the other, but not a blend of people that are working together.”

Drs. Kurz and Wilson first started working together under a grant from the Hattie B. Munroe Foundation, leveraging their research results to get a small NIH grant and from there roll it forward into the current, larger study.

But through it all, they haven’t lost sight of their real goal – helping children with cerebral palsy.

“What we’ve essentially shown is that often you can see abnormalities in the brains of these children before they actually start moving,” Dr. Wilson said. “We’ll have children in the MEG system performing motor actions, and we can actually see that the brain activity that precedes that action is abnormal.”

“We’re trying to figure out ways we can better teach those kids to learn new motor skills or overcome the barriers they potentially have, to improve their activities of daily living,” Dr. Kurz said.

Historically, people have believed that children with cerebral palsy had musculo-skeletal difficulties – that the problem was really in their muscles and skeletal system. But the thinking on that is changing, Dr. Wilson said.

“It’s now believed to be more a central problem, that the brain is potentially not programming these movements right, and it is this faulty programming that results in the movement impairments that we see outside the laboratory,” he said.

The way the MEG charts brain activity is the key to the clinical applications of their research.

“Planning occurs before you actually produce a motor action, and we would have no idea how that is occurring without these brain imaging tools,” Dr. Kurz said. “So if there are problems in planning, then we can focus on those therapeutically and try to teach that child to improve the way they orchestrate and plan motor actions.”

How the MEG works

The MEG, one of about 20 in the country, illuminates the neurons that provide motor control prior to and after gait training.

“Our results extend our understanding of how cerebral palsy influences the brain’s performance,” Dr. Kurz said.
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, 11,076 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.
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 additional funding sources to develop innovative programs and address emerging issues.

Interdisciplinary Trainees

MMI’s education program provided an interdisciplinary training experience for 192 students, interns, residents and post-doctoral fellows in 2015 for a total of 146,164 hours. Approximately 117 of these students were long-term trainees, receiving 300 hours or more of interdisciplinary instruction at MMI.
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
MMI faculty members publish extensively in professional journals, monographs, periodicals and books. In 2015, MMI faculty members developed 159 new products.
University of Nebraska Foundation

The Munroe-Meyer Institute performs huge miracles for small patients every day. The doctors, technicians and therapists at MMI and those trained there, now working in physician’s offices, schools and other agencies across the state, uncover the hidden potential of kids, teens and adults with medical and developmental disabilities. Last year, more than 10,000 Nebraskans were helped by services provided by MMI. For MMI patients and their families, success is measured in small steps, in bites of food and the ability to say monumental sentences like “mommy, I love you.”

Although MMI has the potential to expand its research, diagnostic, educational and outreach capabilities, to provide those it serves to surpass perceived expectations, much of this potential cannot be met with current allocations and require private philanthropy. Please consider making a gift to the Munroe-Meyer Institute. Through your generosity dreams can be realized.

“A dream you dream alone is only a dream
A dream you dream together is a reality.”

—John Lennon

To learn more, or to give, go to nufoundation.org/mmi or contact Melonie Welsh, melonie.welsh@nufoundation.org or 402-502-4117.