



MUNROE-MEYER INSTITUTE

for GENETICS AND REHABILITATION

2018 Annual Report

The Munroe-Meyer Institute's mission is

to be **world leaders** in **transforming the lives** of individuals with intellectual and developmental disabilities, their families and communities through outreach, engagement, premier educational programs, innovative research and extraordinary patient care.



The Patient Experience Pledge

We pledge: To pursue the following concepts in all our activities and to work with each individual's unique attributes – particularly their strengths – in order to personalize care that makes a meaningful difference.

We will promote:

FUNCTION by

- Partnering to work with you rather than on you.
- Respecting your way of doing things.
- Empowering you to understand your health care needs and make informed decisions.
- Providing support to reach your potential at school, work and throughout the community.

FITNESS by

- Recognizing physical activity is important to health and wellness and comes in many different forms.
- Reducing individual and community barriers to movement and fitness.
- Advocating for policies to build a healthy inclusive community.

FUN by

- Recognizing that EVERYONE wants to have fun.
- Promoting inclusive accessible leisure activities in the community.
- Expanding opportunities to enjoy time with the people you choose as friends.

FAMILY by

- Supporting you and your family as you meet life's challenges and opportunities.
- Following your lead.
- Providing services and resources that are meaningful to you and your family.

FRIENDS by

- Providing tools that promote and enhance meaningful healthy relationships.
- Encouraging peer connections.
- Recognizing you as a fellow citizen and neighbor.

FUTURE by

- Valuing independence, inclusion, privacy, self-determination, employment and education.
- Keeping your expectations and dreams in view at all times.
- Challenging and supporting you in raising your own expectations in life.
- Embracing people-first language and principles.
- Embracing technology to improve services.

A Shared Dream of Building



The theme of this year's annual report is building, but not only a physical sense – even though we're excited about our new home. Rather, we look at "building" as an action, a commitment to our community: building a new home, a community, an organization. We are establishing new services, starting partnerships, building on legacy – and building a future together.

Masterful building is always a joint endeavor. It is a long process – the philanthropists of our community started to shape the foundation of today's MMI a century ago. It's my sincere hope that building of the Munroe-Meyer Institute also is an endless process, one that will continue long after our grandchildren leave this earth.

What is needed to build an amazing enterprise? The building blocks are philanthropists, providers, visionary leaders, community organizations, patients and their families, and many, many others. But the critical mortar that glues them all together is trust and a shared vision. This is an amazing community – we have it all.

I am always astonished when I think about this process. I cherish the thought that we are part of a growth trend that will go on for many centuries. We stand on the shoulders of visionaries who came before us, and one day the torch will be taken from us by new shapers of our future. Yet this is our time, and we must do our part, and we will.

I hope that one day all of us who contributed at this point in our rich history – philanthropists, MMI staff, community leaders, patient families, organizations – will be considered master builders.

A handwritten signature in black ink, reading "K. Mirnics". The signature is stylized and cursive.

Karoly Mirnics, M.D., Ph.D.
Director of UNMC's Munroe-Meyer Institute

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MMI Annual Report 2018

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Diego plays a video game in the MMI Virtual Reality Lab.



BUILDING INNOVATION

Making physical therapy more fun – that’s the strategy behind a new project by the Munroe-Meyer Institute’s Jamie Gehringer and Max Kurz, Ph.D., of the physical therapy department.

Inspired by the annual Hand-Arm Bimanual Intensive Therapy (H.A.B.I.T.) Camp run by MMI, Dr. Kurz and Gehringer, a soon-to-be graduating Ph.D. student, are developing immersive video games that will promote bimanual activity in children and youth with cerebral palsy.

With the project beginning in August of 2018, the work already has produced several video games – including a “shoot the space aliens” adventure – designed to draw clients into performing therapeutic movement in the virtual-reality environment.

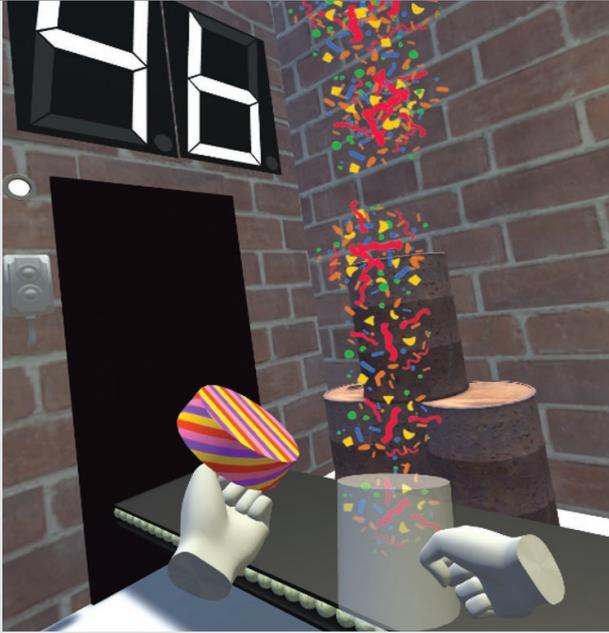
The project is funded through the department of physical therapy, an MMI Guild grant and with MMI institutional resources.

“At the H.A.B.I.T. Camp, the children do all these therapeutic tasks that are bimanual,” Gehringer said.

“But after doing those for hours on end, the tasks become boring. In contrast, the activities we designed are fun, and they’re play, achieving the same therapeutic movement without the monotony of the endlessly repeated movement.

“We tried to ‘game-ify’ the situation. We thought that virtual reality would provide the most immersive experience, but also lend itself to work with bimanual tasks using two controllers, one for each hand. The idea is that we can achieve the same therapeutic outcome as the more traditional habilitation approaches by blending the game and the therapy together.”

Bimanual activity is important for children with cerebral palsy because they tend to have a side that is weakened by the condition and typically favor use of their dominant arm and hand.



These games, designed by Jamie Gehringer, let children open jars as they try to keep up with frantic factory work (left), battle a space alien invasion (top right), and scoop ice cream for demanding customers (bottom right). All three are designed to promote bimanual activity in children and youth with cerebral palsy.

"All the games are inspired by tasks that they do in the H.A.B.I.T. Camp, and the game tasks are designed to create functional improvements for those individuals," said Gehringer, who is writing the computer code for the games. "We design the games with specific types of movement in mind, but the games also are made so that the physical therapist could manipulate them to change the type or amount of movement needed."

One of the requests from the physical therapists, for example, was to further adapt the "alien" game so that in order to fire lasers at the aliens, the client has to both pull and push back on a plunger, two distinct and cooperating movements. Another was to create a game where the player is a giant, protecting a city from invading robots by stomping on them, so that a young client could work on leg strength.

"We're working on making the games customizable to the individual, essentially," Gehringer said, "and we're collaborating across different services at MMI, including occupational therapy."

"We come together in group meetings to talk about the tasks," Dr. Kurz said. "We review the tasks to see if they are meeting the key requirements of the movement therapy. The description of desired movements comes from our clinicians. In most universities, it's just engineers sitting around thinking about how the therapy should work. We're getting insights from the therapist, and we can personalize the tasks to have the greatest impact for the patient."

Dr. Kurz mentioned MMI's Janice Flegle, director of occupational therapy, Sandy Willett, M.S., director of physical therapy, physical therapist Brad Corr, D.P.T., and occupational therapist Jacy VerMaas-Hannan, M.A., as being integral to the project.

"This is revolutionary and groundbreaking because the technology is now more accessible to the common user," he added. "All the equipment needed to run these therapeutic games can be purchased from retail stores. It's just a matter of creating the appropriate therapeutic games. Our goal is to make this technology accessible to everyone who could benefit from it. The games can be applicable to individuals with other conditions, as well."

BUILDING THE PIPELINE



Mark Shriver, Ph.D., speaks with Alex Hansen, a student in the applied behavior analysis (ABA) master's degree program.

In 2018, the Munroe-Meyer Institute added two master's degree programs: a degree in applied behavior analysis (ABA) in collaboration with the University of Nebraska at Omaha's Department of Psychology, and a degree in genetic counseling in collaboration with the UNMC College of Allied Health Professions.

The UNO collaboration is not new, said Mark Shriver, Ph.D., who oversees the new ABA master's program for MMI. Indeed, MMI has had a collaboration with UNO psychology for the past 10 years for an ABA master's degree program. ABA applies behavioral science in real-world settings, with the goal of improving behavioral issues and learning skills.

Collaboration will grow the provider pool, potentially impacting underserved areas of Nebraska and potentially create a pipeline of students from rural areas who will then return to rural Nebraska to practice. Nebraska historically has a dearth of behavioral health providers – of its 93 counties, 88 of them are considered by federal government to be underserved areas in terms of behavioral health.

"Increasing the pipeline of qualified providers is a benefit for the state, impacting countless families," Dr. Shriver said.

The program is jointly administered and has been approved by the Board of Regents and the Nebraska Coordinating Commission for Post-Secondary Education, so that the program is now literally housed at both campuses.

"Before, it was administratively at UNO, and MMI was teaching a number of courses," Dr. Shriver said.

Students can apply and matriculate through either campus in a program run by an overarching program committee that will include faculty from MMI and faculty from UNO.

“This is the first ABA degree program in Nebraska at the master’s level that leads to a board-certification in behavior analysis,” Dr. Shriver said. “Recruitment and retention of program graduates to underserved areas of Nebraska is a priority of MMI. The upcoming relocation of MMI strengthens this collaboration and provides a robust learning environment.”

MMI staff who will be members of the teaching faculty and serve on the ABA master’s program committee include Mark Shriver, Ph.D., Billy Higgins, Ph.D., Sara Kupzyk, Ph.D., and Regina Carroll, Ph.D.

“We also have quite a few faculty that supervise practicum throughout the institute, most in psychology and the Center for Autism Spectrum Disorders,” Dr. Shriver said.

“Previously, based on the collaboration, if either one of us said ‘We can’t do this anymore’ for whatever reason, the program would go away. Now, if for some reason UNO said we can’t do this – or we said it – the program still exists.

“So the sustainability of the program is assured over time, where is a benefit for Nebraska.”

MMI staff who will be members of the teaching faculty and serve on the program committee include Dr. Shriver. Billy Higgins, Ph.D., Sara Kupzyk, Ph.D., and Regina Carroll, Ph.D.

“We also have quite a few faculty that supervise practicum throughout the institute, most in psychology and the Center for Autism Spectrum Disorders,” Dr. Shriver said.

Meanwhile, through a unique partnership between the College of Allied Health Professions and several community partners, MMI will participate in a genetic counseling education program – the anticipated start date for the program is fall 2019

“We now have an accredited program by the Accreditation Council for Genetic Counseling (ACGC)” said Omar Rahman, M.D., who has a dual role as director of genetic medicine at MMI and the medical director for the program. “It will be a 21-month program.”

The program’s first year will be focused on didactic learning to include counseling theory, genetics knowledge, and clinical application. Experiential learning will be incorporated throughout the curriculum and will include in-class role-plays, standardized patients, and service learning opportunities. As students enter the spring of the first year, they will begin getting more involved in the clinical realm. Their second year includes clinical rotations in the major areas of direct patient care: prenatal, pediatric, cancer, and adult genetic counseling.

“The course instructors will include faculty from Genetic Medicine, the Human Genetics Laboratory, Genetics Cell Biology and Anatomy, and the College of Allied Health Professions. We are even exploring interest from faculty in Clinical Psychology here at MMI and Social Work at UNO,” said Holly Zimmerman, M.S., director for the new program. “It is truly a collaborative approach to training the next generation of genetic counselors.”

Clinical supervisors must be board certified geneticists or genetic counselors, so MMI geneticists and genetic counselors will be the clinical faculty for this new program, Dr. Rahman said.

The genetic counselors trained by the program will help MMI address the shortage of genetic counselors in the state. MMI will play a major role in the education and training component of this program. For the first time, MMI genetic counselors have been appointed as faculty at MMI, which has not had faculty appointments for genetic counselors prior to the establishment of the formal training program at the institute. This prestigious honor rewards the recipient, while ensuring the students that the educators are bound to the mission of the institution.

The program will be housed at the College of Allied Health Professions, where Zimmerman and associate program director, Sara Fisher, M.S., have led the planning and implementation. The administrative support within the college has been invaluable in this process, including directing course development, managing program budgets, supporting accreditation requests and guiding admission processes.

“Genetics is a growing specialty,” Dr. Rahman said. “In the future, as genetics starts to impact other disciplines and other specialties – like cardiology, neurology, endocrinology – we’re going to look at embedding genetics experts within those clinics, because they really bring a unique aspect to those disciplines.”

The result of both programs?

“We need behavioral health providers and genetic counselors in Nebraska,” said Karoly Mirnics, M.D., Ph.D., director of MMI. “These new educational programs will help us develop trained professionals right here, which increases our chances of keeping them here to help serve people across the state of Nebraska.”

BUILDING **A LEGACY**



When the new Munroe-Meyer Institute building opens in 2020, visitors can expect to see the image of a phoenix prominently displayed.

The eternal and fiery bird will stand as a symbol of former MMI Director Bruce Buehler, M.D., who died in 2018 at the age of 75.

During a visit with Dr. Buehler shortly before his passing, MMI Director Karoly Mirnics, M.D., Ph.D., and Associate Director Wayne Stuber, Ph.D., asked Dr. Buehler for his message to the MMI community, of which he had been a part for more than 35 years.

“Four things should never be forgotten, and they represent the fabric of who we are,” Dr. Buehler said. “MMI is the best. MMI is a launching pad for opportunities. MMI is where dreams are made. And MMI is the beginning of the future for our patients.”

That MMI is any of those things is largely due to Dr. Buehler, an inspiring leader and a passionate advocate for children with disabilities.

“Amazing leaders like Bruce emerge once in a generation,” Dr. Mirnics said. “We lost a giant, a visionary, a passionate advocate and an amazing friend. This loss hurts deeply, at a visceral level, yet we also must celebrate his extraordinary life and amazing contributions to our community.”

**“MMI is the best.
MMI is a launching pad for opportunities.
MMI is where dreams are made.
MMI is the beginning of the future for our patients.”**

– Bruce Buehler, M.D.

Dr. Buehler began his career working with individuals with disabilities at the University of Florida. He later spent time in Utah before leaving in 1981 to become the director of genetics and, eventually, MMI at UNMC. He was the second full-time director at MMI, succeeding Paul Pearson, M.D.

“The legacy of Bruce Buehler will never be forgotten,” said UNMC Chancellor Jeffrey P. Gold, M.D. “It was his leadership that took the Munroe-Meyer Institute to the next level. His mind was incredible – he was knowledgeable about every facet of medicine, but it was in genetics where he really left his mark. Bruce traveled across the state countless times providing his expertise to children with developmental disabilities and their

families. He made a huge difference for these families by bringing the services to them and not making them have to come to Omaha.”

In 1994, Dr. Buehler also was appointed chairman of the UNMC Department of Pediatrics, serving until 2007.

That year also is when he stepped down as MMI director, after a 24-year term spent forging relationships with state agencies and providers that left MMI with a statewide footprint and mission.

He helped MMI establish a world-class human genetics laboratory, as well as working with the Hattie B. Munroe Foundation to expand the Meyer Rehabilitation Institute into its current form as the Munroe-Meyer Institute for Genetics and Rehabilitation.

“This is the house that Bruce has built,” Dr. Mirnics said, pointing out that, during his tenure, Dr. Buehler oversaw a remarkable period of growth for MMI – from 70 employees in 1983 to 250 in 2007, with a budget that went from \$3 million in 1983 to \$21 million in 2007. “He put the institute on its feet, and then he expanded it and made it a world-class institution. We stand on his shoulders, his grand vision and achievements. We will continue to carry the torch that he has lit and make him proud.”

“He was a visionary in so many ways,” said Brad Schaefer, M.D., former associate director of MMI and currently the founding director of the division of genetics at the University of Arkansas for Medical Sciences. “Integrating medical genetics into the bigger arena of children with special health care needs was decades ahead of everyone else. His ability to develop a vision and then share it with others was a skill few have. This allowed him to take a fledgling program and develop it into a flagship program that leads the way in genetics and disabilities.”

“He was a leader, a visionary and a passionate advocate for children with disabilities,” said Steve McWhorter, president of the Hattie B. Munroe Foundation, which supports many initiatives at MMI. “Bruce created many programs intended to enhance the quality of life for children and their families. We owe him a great debt of gratitude for that.”



Bruce Buehler, M.D., seated, was joined by Munroe-Meyer Institute Director Karoly Mirnics, M.D., Ph.D., and many other friends and colleagues at his May 2018 retirement celebration.

BUILDING NEW OPPORTUNITIES



In 2020, the Munroe-Meyer Institute will open the doors to its new home inside the former First Data building near the University of Nebraska at Omaha Scott Campus.

The move will include the complete renovation of the building, moving Aksarben Drive to open up space on the east side of the building for a newly built aquatic center and playground, redesigning traffic flow, and creating a new main entrance. This will accommodate the rapidly expanding programmatic needs for clinic, therapy, education, research collaboration and office spaces.

Although the move comes with a hefty increase in space – from 98,851 square feet in the former building to 215,882 square feet in the new one – the main attraction of the new building is that “it allows us to better serve our patient population and their families,” said Karoly Mirnics, M.D., Ph.D., director of the institute.

“It’s a building serving a purpose,” he said. “And that purpose is to improve, expand and develop new educational, research, clinical and community engagement programs – to dream big.”

The building will house new programs, such as the Caring For Champions Program, a collaboration with Special Olympics that will provide vision and dental services and a weight management program. There will be a redesigned and integrated Center for Autism Spectrum Disorders (iCASD), where MMI professionals will provide

interdisciplinary care, pulling together the various services to streamline the clinical experience for patients.

As part of increased adult services, the new facility will house a one-bedroom “apartment,” where occupational therapists can help individuals with intellectual or developmental disabilities learn hands-on life skills.

“I’m ecstatic about our budding assistive/adaptive technologies program and our close proximity to the Peter Kiewit Institute, which will allow us to work with University of Nebraska at Omaha engineering students on developing and implementing novel technologies along the lines of mobility – basically movement and assisted movement – virtual reality, and communication for individuals who are non-verbal,” Dr. Mirnics said.

“Ultimately, we can never forget the importance of patient experience, and the new building will better serve that purpose,” he said. “It is being built and organized with an idea of being patient- and family-centric. Clients will not be running from department to department – their care will have no departmental boundaries.

“Honestly, if someone has to run around, it should be the provider, not the patient.”

The building is designed and the services are reorganized to facilitate seamless “soft handoffs” between the many types of assessments and treatments. A centralized scheduling system will ensure

Proposed architectural design of the Munroe-Meyer Institute building, as of December 2018, courtesy Altus Architectural Studios, Inc.



“This is an amazing philanthropic community, and I cannot put into words how much their support means to us. Their generosity made this dream possible, and our shared vision is something we greatly cherish. On behalf of MMI staff, patients and families – THANK YOU.”

– Karoly Mirnics, M.D., Ph.D.

families don't get a speech-language appointment on Tuesday, only to have to come back on Thursday for a developmental and behavioral pediatric appointment. Dr. Mirnics also plans to have patient care coordinators in the building who will guide families through their treatment visits, serving as integrators of the various services and advisers to the families.

“As we integrate patient care across services, the care coordinators will be an essential glue between the providers and families,” Dr. Mirnics said.

The MMI teams also are diligently working to educate and empower parents. “We want to engage newly diagnosed families in comprehensive parent-child interaction and in an education workshop, which would allow parents to become treatment providers for their children,” Dr. Mirnics said.

“We can provide hours of treatment during the day, but after that the child goes home,” he added. “If parents don't know what to reinforce and how to reinforce it, the treatment will be much less successful. The parents should be able to apply the newly learned skills and techniques at their homes, and interact with their children the way the therapist does.”

Everyone at MMI has worked hard to move out of their comfort zone and away from “business as usual” in an effort to design a unique, world-class facility and care framework, he said.

To achieve this, departmental boundaries will be broken down. “We're getting away from the so-called ‘mine’ syndrome – ‘It's my space, my patient, my department,’” Dr. Mirnics said. “Change is hard, but necessary in these ever-evolving times. We can't wait to occupy our new facility and deliver a one-of-a-kind experience for the population we serve.”

Dr. Mirnics thanks supporters who have made MMI's new home possible.

“This is an amazing philanthropic community, and I cannot put into words how much their support means to us. Their generosity made this dream possible, and our shared vision is something we greatly cherish. On behalf of MMI staff, patients and families – THANK YOU.”

BUILDING KNOWLEDGE



MMI surveys a representative sample of more than 400 people receiving DD services and nearly 750 receiving Medicaid services annually.

The Munroe-Meyer Institute is helping build knowledge as part of The National Core Indicator Project, a statewide survey designed to assess the satisfaction of individuals with the developmental disabilities services they receive.

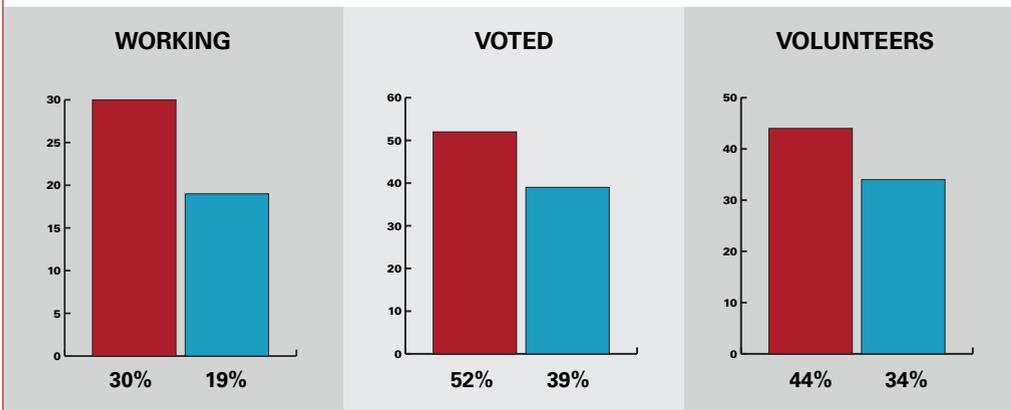
MMI contracts to collect the information through the University Center for Excellence in Developmental Disabilities Education, Research and Service (UCEDD), with the Nebraska Department of Health and Human Services, Division of Medicaid and Long-Term Care.

"We administer the adult consumer satisfaction surveys on a statewide basis to a specific group of people who are receiving developmental disability (DD) services and Medicaid services," said Wayne Stuber, Ph.D., associate director of MMI and director of the UCEDD.

The National Core Indicators collects performance and outcome metrics in service areas including employment, friendship, community inclusion, social engagement, choice and decision-making, and self-determination.

Nebraska vs. National Average

services and supports provided to individuals with developmental disabilities



Data provided by National Core Indicators

MMI's Rachel Ray is the statewide coordinator for the project, and MMI has nine surveyors throughout the state to collect the information. MMI surveys a representative sample of more than 400 people receiving DD services and nearly 750 receiving Medicaid services annually.

The National Core Indicator survey collects performance and outcome metrics in service areas including employment, friendship, community inclusion, social engagement, choice and decision-making, and self-determination. It measures all of those things from the perspective of the individual receiving services.

The information is used by the governor's office to look at quality improvement for both Medicaid and the DD system.

MMI has held the state contract since the 2016-17 fiscal year and in 2019 will be collecting data for the third year of a year-to-year contract paying approximately \$250,000 a year to the institute.

"Our connections statewide and our commitment to serving the needs of individuals with disabilities make this a good fit for us," Ray said. "We have the UCEDD, and we understand the community. We understand how to correctly ascertain information – in fact, our surveyors go through a lengthy training process to effectively interview individuals with disabilities."

The state was proud of the outcome of the previous survey, with a 2018 press release noting that Nebraska ranks highly in services and supports provided to individuals with developmental disabilities, including work (where at 30 percent, Nebraska was significantly above the national average of 19 percent for individuals who had a paid job), voting (52 percent of respondents voted or had the opportunity to do so, compared to 39 percent nationally), and volunteerism (44 percent in Nebraska compared to 34 percent nationally).

Nebraska was one of 39 states to participate in the study. The data is available on a website, www.nationalcoreindicators.org.

"Our work with this survey ties in with MMI's mission perfectly," Ray said. "In addition, if we identify an area that needs additional supports – such as transportation, for example – as a UCEDD, there may be ways we can partner with other agencies or provide input to improve transportation issues. That would be a win-win."

"So it's identifying not only what those needs are, but then plugging it into what we do as a UCEDD," she said. "It's not about a survey and what it shows. It ultimately is about using the information we gather to improve the lives of the individuals and families we serve across the state and to guide our future efforts, building on objectively collected data."



BUILDING ACCESS



 *The comprehensive genetics clinic at Gordon (Neb.) Memorial Hospital, is under the direction of (pictured left to right) Omar Rahman, M.D., director of the Munroe-Meyer Institute Department of Genetic Medicine at UNMC; Shanna Rosentrater, licensed mental health practitioner; Catherine Jones-Hazledine, Ph.D., who owns Western Nebraska Behavioral Health in nearby Rushville, Neb.; and Doris Brown, CEO of Gordon Memorial Hospital.*

In December 2018, a comprehensive genetics clinic opened at the Gordon (Neb.) Memorial Hospital, through a partnership between the hospital and the Munroe-Meyer Institute (MMI) Department of Genetic Medicine at UNMC. The clinic is funded by the Medically Handicapped Children's Program (MHCP) through the state of Nebraska.

The clinic, which will increase access to genetic counseling services in rural Nebraska, is the latest success for a longstanding collaboration between MMI and MHCP.

"The Munroe-Meyer Institute has had a collaborative relationship for providing services for children with special health care needs with the MHCP for years," said Wayne Stuberg, Ph.D., associate director of MMI. "The program is funded through Title V Block Grant monies that come to the state of Nebraska, and we have had a long-term relationship with them working with that specific population."

MHCP provides support for genetics clinics on a statewide basis, both in-person and via telehealth, allowing MMI experts to provide genetics evaluations, diagnostic information and then genetic counseling information in areas such as Scottsbluff, North Platte and Kearney.

The collaboration also supports MMI efforts to provide developmental pediatric services outstate, as well as MMI's teratogen hotline, a service where families can call in if concerned about a possible exposure to teratogens, which are things in the environment that can cause a disability to take place – poisons, lead exposure, secondhand smoke exposure and other agents.



 The Munroe-Meyer Institute's partnership with the Medically Handicapped Children's Program funds a surveillance program for children who have graduated from neonatal intensive care units (NICUs).

In addition, the partnership funds a surveillance program for children who have graduated from neonatal intensive care units (NICUs).

"A number of these children do just fine, and they go on to have typical development," Dr. Stuberg said. "But the likelihood that a child is going to have a developmental disability if they were in the NICU increases. This is a service that is provided free to the families, a surveillance program to see that the kids receive the services as early as they can."

Another recent initiative of the partnership is the expansion of the Family Care Enhancement Project, which funds parent resource coordinators – on-the-job trained family members of special needs individuals who help shepherd other families through medical and non-medical issues.

The program, which started with the Nebraska Department of Education, originally was restricted to children eligible for early intervention, birth through age 2. Through the MHCP partnership, MMI can increase the number of locations where parent resource coordinators are providing services statewide and for children over the age of 2.

Through the partnership, MMI also has developed a health care transition project.

"Currently in the state of Nebraska, as you are transitioning out of pediatric services and moving toward adult health care, there have not been developed programs to help you get linked with adult providers,"

Dr. Stuberg said. "Children can receive services up until they're 19, and then the expectation is that they would go to an adult provider.

"With typically developing individuals, it's pretty easy to find someone in family medicine or internal medicine to transition to, but if you have an intellectual or developmental disability, the number of adult providers is limited. The purpose of the health care transition clinic is to have a physician who is a pediatrician and internal medicine boarded physician, working with a social worker and a parent resource coordinator to help families identify a medical home for adult services."

Staci Zuerlein, the Nebraska Department of Health and Human Services MHCP program coordinator, called the partnership with MMI "a great collaboration."

"One of the biggest reasons is the resources provided through the institute greatly impact the population that we're trying to make a difference with across Nebraska," she said. "So, when we're specifically tasked with making sure that those children and youth with special health care needs receive the services to help improve their health, we have to have a partnership in place to make that impact.

"I truly believe this collaboration has been a blessing to both the families we serve and this agency, because it helps these families live better lives," Zuerlein said. "It really speaks to what we're trying to do here at our agency."

2018 HIGHLIGHTS

Key recruitments:

- Matt Stelzer, M.B.A., was recruited for the position of director of MMI Business Services.
- Regina Carroll, Ph.D., was recruited as director of research and clinical services at the Autism Care for Toddlers Clinic.
- Zach LaBrot, Ph.D., was recruited as assistant professor, MMI Department of Psychology.
- Bethany Hansen, Ph.D., was recruited as assistant professor, MMI Department of Pediatric Feeding.
- Scott Smith, Ph.D., was recruited as associate director of the Human Genetics Laboratory.
- Dawna Daily, M.Ed., was recruited as transition specialist for the MMI University Center for Excellence in Developmental Disabilities (UCEDD).
- Five genetic counselors were recruited to expand pediatric, prenatal and cancer genetic counseling services - Alyssa Cady, M.S. (prenatal and pediatric), Kristen Fishler, M.S. (prenatal and research), Michael Gurtler, M.S. (cancer), Andrew Schmanski, M.S. (pediatric) and Brianna Zieba, M.S. (pediatric).
- The Nebraska Leadership Education in Neurodevelopmental and related Disabilities (LEND) program recruited its first two disability advocacy leadership trainees, Olivia Versaw and Nathaniel Allen.
- Tracy Kirianov, R.N., was recruited as a specialty care nurse by the MMI Department of Developmental Medicine.

Key promotions:

- Kevin Luczynski, Ph.D., was promoted to associate professor, Center for Autism Spectrum Disorders.
- Nicole Rodriguez, Ph.D., was promoted to associate professor, Center for Autism Spectrum Disorders.
- Lois Starr, M.D., was promoted to associate professor, MMI Department of Genetic Medicine.
- Janice Flegle, M.A., was promoted to clinical associate professor, MMI Department of Occupational Therapy.
- Howard Needelman, M.D., was promoted to professor of pediatrics, MMI Department of Developmental Medicine.

Key appointments:

- Keith Allen, Ph.D., was named director of academic affairs.
- Eric Evans, Ph.D., CEO for Disability Rights Nebraska, was appointed as adjunct assistant professor at MMI.
- Sara Fisher, M.S., was named assistant program director for the MMI/College of Allied Health Professions Genetic Counseling Program.

Awards and certifications:

- Joe Evans, Ph.D., received both the University of Nebraska's Innovation, Development, and Engagement Award, and the Behavioral Health Education Center of Nebraska Distinguished Service Award.
- Wayne Stuberg, Ph.D., received the UNMC Distinguished Scientist Award and was elected as vice chair of the Nebraska Board of Health.
- Wayne Fisher, Ph.D., received the 2018 Don Hake Translational Research Award from the American Psychological Association.
- Marne Iwand, M.P.T. (below), received the Golisano Health Leadership Award from the Special Olympics.



- Mark Shriver, Ph.D., received the UNMC Outstanding Teacher Award.
- Max Kurz, Ph.D., received the UNMC Outstanding Faculty Mentor of Graduate Students Award.
- Karoly Mirnics, M.D., Ph.D., received the 2018 Help is Hope Award, presented annually by Autism Action Partnership, and was appointed chair of the Pathophysiological Basis of Mental Disorders and Addictions Study Section by the National Institutes of Health.
- Cynthia Ellis, M.D., was appointed president of the Nebraska Chapter of the American Academy of Pediatrics.
- Amy Nordness, Ph.D., was awarded the endowed Scottish Rite of Nebraska Professorship in Speech-Language Therapy.
- Rashelle Hoffman, D.P.T., received the Patricia Leahy Award from the Foundation for Physical Therapy Board of Trustees.
- Cathleen Piazza, Ph.D., was honored with the Student Committee Mentorship Award of the Association for Behavior Analysis International.
- John Keenan, public relations, received the Gold U Award from UNMC.
- Warren Sanger, Ph.D., posthumously received the Pediatric Legend Award from Children's Hospital & Medical Center.
- Bruce Buehler, M.D., received the Lifetime Medical Education Award from Children's Hospital & Medical Center.
- Michael Crawford, Ph.D., received the 30-Year Fellow Award from the National Council for Therapeutic Recreation Certification.
- Lois Starr, M.D., achieved board certification in clinical cytogenetics from the American Board of Medical Genetics and Genomics.
- Jennifer Sanmann, Ph.D., achieved board certification in molecular genetics from the American Board of Medical Genetics and Genomics and was appointed president of the Great Plains Chapter of the Clinical Laboratory Management Association.
- Katy Menousek, Ph.D., achieved certification as a research reliable Autism Diagnostic Observation Schedule (ADOS) administrator.

Community Engagement & Media:

- The MMI Patient Experience Pledge was created.
- MMI established a Community Advisory Committee.
- The Student Alliance for People of All Abilities (SAPAA) was formed on the UNMC campus.
- Multiple new partnerships were established with the University of Nebraska at Omaha (UNO) College of Business Administration, College of Arts and Sciences, and College of Engineering, and the UNMC College of Dentistry, College of Allied Health Professions, College of Nursing and College of Medicine.
- The MMI University Center for Excellence in Developmental Disabilities (UCEDD) established a presence at UNO's Barbara Weitz Community Engagement Center.
- MMI staff participated in the Scottish Rite's Walk Rite for RiteCare, RiteCare Classic Golf Tournament and Friends of Scottish Rite Dinner; the Meyer Foundation for Disabilities' Walk & Roll for Disabilities, Owl Ride and Denim for Disabilities; and the Munroe-Meyer Guild's Garden Walk.
- MMI participated in approximately 40 events at schools, agencies and in the community.
- Halloween Trunk-or-Treat at MMI (below) welcomed more than 500 participants and numerous community partners.





- The Harlem Globetrotters (above) made an on-site visit to MMI.
- The Camp Munroe Theater Co. held summer and winter productions.
- The MMI Department of Recreational Therapy held an art sale featuring art created by MMI clients.
- MMI participated in the Rock Your Socks Project for World Down Syndrome Day.
- The inaugural Light it Up Blue event on the Bob Kerrey Pedestrian Bridge drew a crowd of more than 100. The state capitol, UNMC's Hope Tower, MMI buildings and UNMC's 42nd street walkway also were "lit up blue" for World Autism Month.
- Alison DeLizza, M.A., Amy Nordness, Ph.D., and Karoly Mirmics, M.D., Ph.D., all drew large crowds when each gave a UNMC Science Cafe presentation.
- MMI won the campuswide NE150 Challenge, logging 207,237 miles of exercise, more than any other college or UNMC team.
- MMI hosted the Chancellor's Board of Counselors on a tour of the institute.

Philanthropy and newly obtained funding for MMI programs:

- Joe Evans, Ph.D., and Brandy Clarke, Ph.D., were awarded a collaborative \$1.9 million Behavioral Health Workforce Education and Training grant.
- Jolene Johnson, Ed.D., received a \$1.68 million Buffett Early Childhood Fund grant to focus on development and implementation of social emotional and executive functioning programming in high quality early childhood sites across the U.S.
- Mark Shriver, Ph.D., obtained a \$1.2 million Department of Education grant to train graduate students to work collaboratively in interdisciplinary teams to address significant behavior issues in schools.
- MMI partnered with University Centers for Excellence in Developmental Disabilities (UCEDDs) in Iowa and South Dakota via a \$425,000 grant from the Kessler Foundation for a two-year project on direct service to providers and job coaches using telecommunication.
- A gift was given by Donald C. Scott for a collaborative project between the MMI Department of Psychology's Autism Detection Training Program and the Center for Autism Spectrum Disorders' Autism Quick Start Program.

Education and Research:

- Channabasavaiah Gurumurthy, Ph.D.'s novel Easi-CRISPR technology was licensed by Taconic Biosciences, a global leader in genetic engineering.
- The MMI Virtual Reality Lab was established under the leadership of Max Kurz, Ph.D.
- Max Kurz, Ph.D., partnered with Louisiana State University Health Sciences Center to examine the benefits of power training for children with cerebral palsy (below).



- Curriculum was developed and received provisional accreditation for a genetic counselor training program in a joint MMI/College of Allied Health Professions endeavor.
- A master's degree program in applied behavior analysis (ABA) was established in collaboration with the University of Nebraska at Omaha Department of Psychology.
- Under the direction of Bhavana Dave, Ph.D., current cytogenetics and molecular genetics laboratory fellowships were transitioned to a single Laboratory Genetics and Genomics Fellowship accredited through the American Board of Medical Genetics and Genomics.
- A Developmental/Behavioral Pediatrics Fellowship program was established.
- A Think College pilot program, enabling a student with developmental disabilities to attend college classes, was implemented at UNO.

- The Nebraska Leadership Education in Neurodevelopmental and related Disabilities (LEND) program graduated 34 long-term trainees who participated in the LEND interdisciplinary leadership training program, Autism Leadership Academy, board certified behavior analyst (BCBA), early intervention and the LEND Pipeline Training Program.
- The Project Search pre-employment training program for individuals with intellectual and developmental disabilities posted a 93 percent competitive employment record across the past three years of the program's graduates.
- The Nebraska LEND Program developed a leadership training track for self-advocates.

Clinical:

- MMI contracted with the Nebraska Department of Health and Human Services Title V Medically Handicapped Children's Program (MHCP) to expand the Nebraska Department of Education's Family Care Enhancement Project to allow parent navigators to support children ages birth-21 and their families.
- The MMI Health Care Transition Clinic opened as a partnership with the UNMC Department of Internal Medicine and the Nebraska MHCP program.
- The Respite Employer Engagement Program developed partnerships with more than 40 businesses across the state that are now sharing respite resources with their staff.
- The Respite Service Learning Certificate Project is recruiting and training certified nursing assistants and nursing students from Clarkson College and students from UNO to become trained respite providers.
- The Autism Care for Toddlers Clinic expanded as a result of a community partnership with the Autism Center of Nebraska.
- An integrated screening and diagnostic protocol for autism was implemented in collaboration between the MMI Patient Information Office, the MMI Departments of Psychology and Speech-Language Pathology and the Center for Autism Spectrum Disorders.
- A new partnership between the MMI Department of Psychology and Great Plains Health was initiated to place and integrate an MMI-trained behavioral health provider into a primary care clinic in North Platte.

- The MMI Department of Psychology, through its fellowship, developed a program to provide outpatient and community behavioral health services for adults with intellectual and developmental disabilities.
 - The Interdisciplinary Adult Behavior Medicine Clinic was established as a collaboration between the MMI Departments of Developmental Medicine and Psychology. The interdisciplinary clinic includes psychology, developmental medicine, nursing and social work.
 - The MMI Department of Physical Therapy expanded services to the Omaha Public Schools by adding provision of home-based Early Development Network services to patients with developmental delays ages birth-3.
 - The MMI Department of Physical Therapy contracted with Children's Respite Care Center to serve children in their day respite and outpatient program.
 - MMI services and programs expanded to the former JP Lord School facility.
 - The Human Genetics Laboratory developed clinical exome testing for mutations across the coding regions of the genome and expanded four postnatal indication-specific gene panels to include additional genes of interest.
 - The Human Genetics Laboratory enhanced its hereditary cancer test offerings through the expansion of three indication-specific panels and through the addition of a molecular assay for the detection of the Boland inversion (*MSH2* gene).
 - The Human Genetics Laboratory developed three new custom fluorescence *in situ* hybridization (FISH) probes for indications associated with solid tissue tumors.
 - MMI facilitated the NICUSeq study as part of a national collaboration, offering rapid whole genome sequencing of infants in the intensive care setting (NICU and PICU).
 - The MMI Department of Recreational Therapy expanded leisure education services to the Westside Public Schools special education transition program, serving students ages 18-21.
 - MMI partnered with Legal Aid of Nebraska to provide services for MMI families through the United Way of the Midlands Karnett Trust.
 - MMI's National Core Indicators Survey contract to measure quality of life and satisfaction for individuals receiving long-term services and support was extended.
 - MMI initiated a new cardiac genetic service at Nebraska Medicine.
 - MMI established a new inpatient genetic counseling service at Children's Hospital & Medical Center.
 - The MMI Departments of Genetic Medicine and Developmental Medicine expanded outstate telehealth services, funded by MHCP through the state of Nebraska and using specially designed telehealth carts funded by the Friedland Professorship. A new clinic was opened at Gordon (Neb.) Memorial Hospital, and clinical visit capacity in Scottsbluff was doubled.
 - Speech-language pathologist Jessie McMordie, M.S., partnered with Nebraska Medicine Music Therapy in the newborn intensive care unit to offer the pacifier-activated lullaby to support development of non-nutritive sucking skills.
 - A new speech-language screening was established to initiate first contact with families in a timely manner and ensure the most appropriate evaluation is scheduled.
 - MMI speech and swallowing services in the Nebraska Medicine Head & Neck Cancer Clinic were expanded.
 - The Lincoln RiteCare Clinic now offers a Hanen Parent Training Program for parents of young children (birth-5 years of age) with a language delay. The program provides parents with practical strategies for helping their children learn language naturally throughout their day together, practice and discuss strategies with their child and the speech-language pathologist and identify ways to adjust daily routines to support language development.
 - An enhanced fitness room was opened to serve patients and staff.
- Other:**
- The University of Nebraska Board of Regents approved the move and rebuilding of the Munroe-Meyer Institute for Genetics and Rehabilitation on June 28.
 - Bruce A. Buehler, M.D., third director of MMI, died Sept. 19.
 - The MMI Security Alert System was implemented.
 - MMI purchased two high-speed/high-capacity servers for secure file storage.

BOARD HIGHLIGHTS

Building on decades of support, MMI's supporting boards provided critical financial, organizational and public awareness support in 2018, with financial support of more than \$1.4 million. We are very grateful to them for their ongoing partnership and investment in those we serve.

Hattie B. Munroe Foundation

The Hattie B. Munroe Foundation donated 75 gift cards during the holidays that were delivered to MMI client families in need. The foundation also provides the funding for a psychology internship, Camp Munroe and related children's programs, a professorship for the Center for Autism Spectrum Disorders and the MMI director totaling more than \$800,000.

Meyer Foundation for Disabilities

The Meyer Foundation for Disabilities (MFD) held two fundraising events in 2018 – the Walk & Roll for Disabilities, which was held on March 4, with attendance of approximately 500, and The Owl Ride, which was held on August 4, with attendance of approximately 800. MFD provides more than \$50,000 to the recreational therapy department's adult programming, which in 2018 included such programs as MMI's Thursday Evening Respite Program, its Cooking Club, Wheel Club and other programs.

The Munroe-Meyer Institute Board of Directors

The board works closely with MMI leadership to inform the public of the breadth and quality of MMI's programs. The board annually awards the Rhoda Davis Blatt and Hattie B. Munroe Foundation scholarships. The board oversees the distribution of holiday gift cards to selected MMI families in need, as well as reviews and approves the MMI Recreational Therapy Department budget before it receives final approval by the Hattie B. Munroe Foundation board.

Munroe-Meyer Guild

The Munroe-Meyer Guild held its 50th Annual Garden Walk on June 10, with approximately 1,000 in attendance. Using the proceeds from the walk and a grant from the William and Ruth Scott Family Foundation, the guild was able to award nearly \$70,000 in grants to MMI for projects such as GoBabyGo!BIG and Embracing Women's Health. To celebrate the milestone of 50 Garden Walks, a tea was held to honor the people who brought the walk to this milestone. Ruth and Bill Scott were honorary chairs. An Excellence Fund was established to fund a special project at the new building, and \$16,000 of the \$20,000 goal was raised.

Scottish Rite Foundations of Nebraska

The Scottish Rite held its RiteCare Classic Golf Tournament on June 13 at Pacific Springs Golf Course. Twenty-one teams raised a record \$22,000 for the RiteCare Speech and Language Clinics. On June 23, nearly 150 walkers participated in the 11th annual WalkRite for RiteCare. The Friends of Scottish Rite Dinner was held on Oct. 19. In 2018 the Scottish Rite Foundation provided more than \$400,000 to support the RiteCare Speech and Language Clinics.

Community Advisory Committee

This year, the MMI Community Advisory Committee was formed to serve as a working partner in guiding the Institute's activities by representing the voice of the community and its local participants. They have provided a critical sounding board in shaping both the current and future path of MMI.

Scholarly Activities in 2018



87 publications in
scholarly journal

45 other publications



**Conference
presentations
and posters**



8 books/book
chapters

4

Doctoral dissertations
or master's theses

Educational Activities in 2018



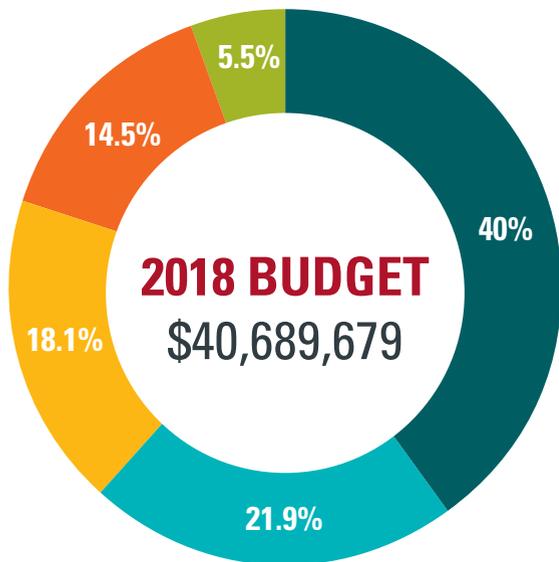
In 2018, MMI's education program provided an interdisciplinary training experience for

184 trainees

Students, interns, residents and post-doctoral fellows trained for a total of

211,749 hours

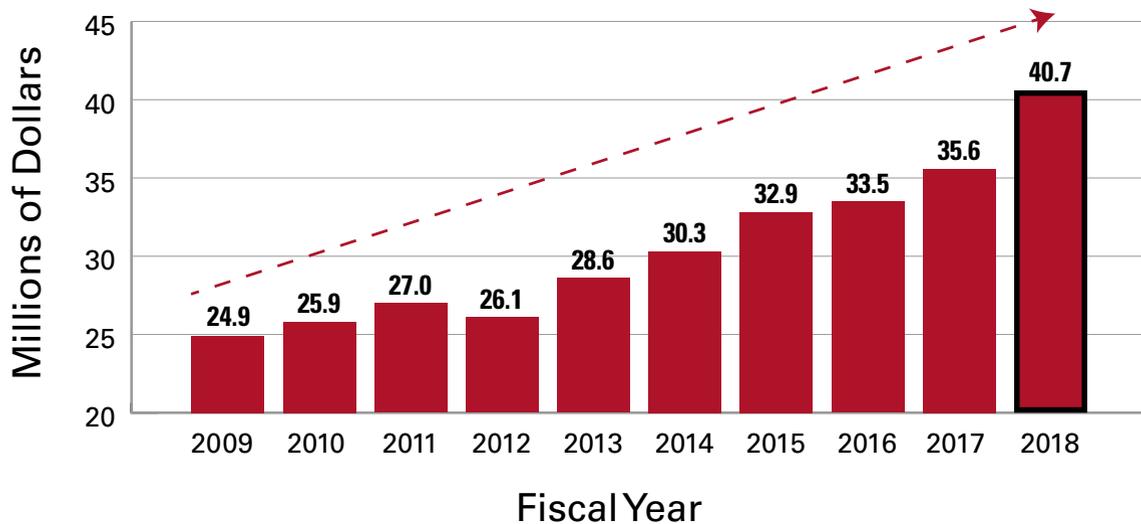
Financials



Revenue Sources

- Clinical service reimbursement
- State/local/school grants & contracts
- Federal grants & contracts
- State appropriation
- Philanthropic/other funds

MMI Budget 2009 – 2018



Community



9,107 HOURS
OF COMMUNITY ENGAGEMENT

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.

9,056 people

attended workshops, conferences, teleconferences and other community education activities.

MMI BY THE NUMBERS

History:

- 1919: The Society for the Relief of the Disabled formed a new charity dedicated to providing therapy and braces to children impacted by the polio epidemic.
- 1922: Founded as the Hattie Baker Munroe Home for Convalescing Crippled Children.
- 1997: The Meyer Rehabilitation Institute (MRI) and the Hattie B. Munroe Pavilion become the Munroe-Meyer Institute (MMI) for Genetics & Rehabilitation.
- 2009: MMI becomes an academic unit of UNMC.

Organization:

- 14 departments, approximately 500 employees.
- One of 67 federally designated University Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) and one of 52 Leadership Education in Neurodevelopmental and related Disabilities (LEND) programs.
- Five supporting philanthropic boards: MMI Board of Directors, Hattie B. Munroe Foundation, Meyer Foundation for Disabilities, Munroe-Meyer Guild, Scottish Rite Foundation of Nebraska.
- Annually, more than \$40 million budget, with more than \$16 million in federal, state and local grants and contracts, and \$2.2 million in philanthropy.

Clinical services:

- More than 70,000 yearly services serving clients across the lifespan (75 percent take place in the community).
- More than 40 provider locations across the state (more than 30 outside Omaha).
- More than 50 types of services provided.
- 22 recreational therapy programs and clubs serving more than 500 families annually.
- More than 440 volunteers providing 13,600 service hours annually.

Laboratory tests:

- Approximately 50,000 clinical genetics tests performed in 2018.
- More than 130 types of genetics tests have been provided to 49 states nationwide and to four international locations.

Education and research activities:

- Involved in education of medical students, residents, fellows, interns, allied health professionals, Ph.D. and M.S. students, college and high school students.
- More than 9,000 participants in workshops, conferences, teleconferences and other community education activities in domestic/international forums.
- 133 long-term trainees (doctoral, master's, interns) in 2018.
- Interdisciplinary training in 2018: 184 students, interns, residents and post-doctoral fellows for a total of 211,749 hours.
- More than 3,600 long-term students received training at MMI in the last 17 years.
- Students from more than 40 universities and colleges nationwide.
- More than 100 courses and seminars taught by our faculty and staff annually.
- Approximately 45 faculty involved in basic, clinical and translational research activities.
- More than 150 clinical and research fellows trained in the last 15 years.
- More than \$7 million in research funding annually.

Community and outreach activities:

- Annually, more than 90 technical assistance services (8,131 participants/1,846 hours) to community partners in LEND and UCEDD alone.
- More than 80 community training activities (9,056 participants/606 hours) institute-wide.
- 9,107 hours of community engagement across the entire institute.



“The true measure of any society can be found in how it treats its most vulnerable members.”

-Mahatma Gandhi

University of Nebraska Foundation

Approximately 230,000 Nebraskans live with a disability every day – Nebraskans like John, who was diagnosed with Autism Spectrum Disorder when he was four years old. His escalating behaviors led him to UNMC’s Munroe-Meyer Institute (MMI). Over the next four years, John received more than 2,400 hours of intensive therapy from MMI staff. Recently, John graduated from MMI’s early intervention program and is thriving at home and at his public school.

This year, MMI embarked on a fundraising campaign, “Changing Lives, Transforming Futures,” to meet the needs of so many like John. This campaign will move MMI to a new facility, expand its programming and recruit the most talented and innovative providers and researchers in the field. When completed, MMI will be positioned to become world leaders in transforming the lives of all individuals with disabilities and complex health care needs.

Exceptional programming and patient care are costly, but local, state and regional support has been encouraging. Gifts of any amount will have a lasting impact on MMI. Thank you again for all that you have done, and will continue to do, as we complete the philanthropic journey toward creating an exceptional patient experience at MMI.

To learn more about how to make a gift to MMI, please go to nufoundation.org/mmi, or contact Brian Anderson at brian.anderson@nufoundation.org or **402-502-4113**.

BREAKTHROUGHS FOR LIFE.®

UNIVERSITY OF
Nebraska
Medical Center



**UNMC Munroe-Meyer Institute
for Genetics and Rehabilitation**

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