



# PARTNERSHIPS



**Munroe-Meyer Institute**  
*for Genetics and Rehabilitation*  
2017 Annual Report



## MMI's Mission:

The Munroe-Meyer Institute's mission is to be a **world leader** in transforming the lives of all individuals with disabilities and complex health care needs, their families and the community 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.



## ***Winds of Change***

I always liked a quote, often used by UNMC Chancellor Jeffrey P. Gold, M.D:

*"If you do not like change, you're going to hate when you become obsolete."*

The world around us is constantly shifting and swirling, and we have to adapt to it. What was the standard of care 10 years ago is now obsolete, and if we indeed want to be world leaders in our activities, we must keep up with and implement the best evidence-based treatment modalities and training tools.

We are changing, growing, exploring and collaborating. This all starts with a look in the mirror and an understanding of who we are and who we want to be.

As we prepare to design our new MMI replacement facility, we must not forget that a shiny new building is a home, but its providers make up the soul of MMI. We are reorganizing MMI, always guided by our mission statement, and positioning ourselves to provide the best and most cutting-edge care. We will streamline our operations, establish new department and services, eliminate redundancies and GROW!

Our reorganization is not a top-down process. It is a grassroots endeavor, as we heavily rely on the opinions and suggestions of patients and their families, community health care organizations, advocacy groups, educators and philanthropists.

Importantly, plans cannot be only on paper. We are already growing! In this annual report you can read about the expansion of the Autism Clinic for Toddlers, new telehealth efforts and other collaborative initiatives taking place at MMI.

There are, and there will be challenges and obstacles on the road. The challenges facing the special-needs community are virtually endless, yet resources are becoming more and more limited. However, thanks to all of you, when challenged, we become stronger. Please, partner with us to be all we can be!

A butterfly emerging from a cocoon is beautiful. The new, fully evolved MMI will be amazing.

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

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## **MMI Annual Report 2017**


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Genetic counselor  
Sara Fisher, right,  
meets with a client.

# COLLABORATION OVER COMPETITION

When Omar Rahman, M.D., became the director of the Munroe-Meyer Institute's Department of Genetic Medicine, he immediately moved to increase the number of genetic counselors on staff.

That's tougher than it sounds. Genetic counseling, as a health care profession, is a growing field, and qualified counselors are relatively scarce and highly sought after.

That's one of the reasons that the Munroe-Meyer Institute and the College of Allied Health Professions are teaming up to create a new master's in genetic counseling program at the University of Nebraska Medical Center.

The program was developed through an innovative partnership between the UNMC College of Allied Health Professions (CAHP), MMI, and a number of community partners, including Blue Cross Blue Shield of Nebraska, Boys Town National Research Hospital, Children's Hospital & Medical Center and Nebraska Medicine.

The program will be administered in the CAHP, which also will grant the degree. MMI will provide clinical training, and MMI geneticists and genetic counselors will serve as training faculty.

The clinical partners offered crucial support in the form of clinical education experiences and collectively contributed full funding support – at no cost to the state of Nebraska – through the first five years of the program to facilitate start-up.

“Our community is fiercely loyal, passionate and committed to providing the highest caliber of patient care,” said Karoly Mirnics, M.D., Ph.D., director of MMI. “Our shared vision allowed us to step over perceived institutional boundaries to partner to achieve a common goal. Together we achieved something amazing that will impact lives for generations to follow.”

Kyle Meyer, Ph.D., dean of the CAHP, said his college is honored to join MMI’s decades-long commitment to genetic counseling.

“The program is a legacy to the late Dr. Warren Sanger, former director of clinical genetics at MMI, whose vision shaped its development,” Dr. Meyer said. “The unparalleled teamwork that created the program is a fitting tribute to a man known for his generous and collaborative spirit.”

With financial support from the clinical partners and funds from the CAHP and MMI, the program required no additional state funds and is projected to be self-sustaining at full implementation at year five. The 24-month master’s program projects to enroll its first students in 2019, with full ongoing enrollment set for 20 students at full implementation.

Holly Zimmerman, the newly recruited director of the new program, said genetic counselors are becoming more commonly accepted by the health care community.

“Genetic testing is being implemented in almost every aspect of medicine,” she said. “Genetic counselors can be the liaison between complex genomic medicine and patient care – supporting both the provider and the patient.”

Dr. Rahman has worked with Zimmerman before and is excited to collaborate with her again.

He also is pleased to be adding a teaching component for his genetic counseling staff.

“Having an educational program elevates the clinical care that you provide – you have to stay on top of information in order to be able to teach it,” Dr. Rahman said. “Students stimulate you to learn more yourself as a faculty member. It can be very rejuvenating.”

**“Our community is  
fiercely loyal, passionate  
and committed to  
providing the highest  
caliber of patient care.”**

MMI has been aggressively recruiting genetic counselors; with 10 at the institute and two others working at UNMC, the campus has 75 percent of the total number of genetic counselors in the state of Nebraska.

The new program at UNMC also may give the institute an edge in future recruitment in a state that needs more genetic counselors, Dr. Rahman said.

The Bureau of Labor Statistics estimates that the number of genetic counselors in the U.S. will increase 29 percent by 2024, in part because of the incredible advances in genetic testing over the past decade. According to Dr. Rahman, that expansion has been fueled by the health care industry’s recognition of the value of genetic counseling.

That makes the new program especially timely.

“This will be a unique program in many ways, and I am very excited that we will be finally able to meet the demands of our community for these services,” Dr. Mirnics said.





# Science in the Summer

*From left to right, Shalise Cline, Melina Harlan, chaperone Brittany Strong and Chalette DeCora during the SHPEP-WISH program.*

**The Munroe-Meyer Institute's Maurice Godfrey, Ph.D., has been working with Native American tribes in Nebraska and South Dakota since 2005.**

Dr. Godfrey is the principal investigator on the National Institutes of Health Science Education Partnership Award (SEPA), a federal grant, through which he and his collaborators attempt to spark an interest in science among Native American youth.

His program has worked with the urban Native American community in Omaha through the Native Indigenous Centered Education Program in the Omaha Public Schools; the Ponca tribe's urban population, which includes Omaha and Lincoln and Norfolk, Niobrara and Sioux City; Nebraska reservation communities, including the Omaha, Winnebago and Santee tribes; and in South Dakota with the Yankton, Sisseton-Wahpeton and Rosebud communities.

In 2017, Dr. Godfrey decided to build on the successful summer science camps that he has been holding for middle school students for more than a decade. He invited four Native American high school students to attend the first week of UNMC's Summer Health Professions Education Program (SHPEP).



Although the UNMC program is designed for college students, Dr. Godfrey felt SHPEP – which offers a look at various health professions and the educational pathways to achieving professional status – would be aspirational for his high school students.

“I thought, why don’t we give them a vision of what’s possible if they’re interested in health careers?” Dr. Godfrey said. The four young women – two students from Omaha through Omaha Public Schools, one from Winnebago and one from Arizona – were integrated with the college students, providing near-peer mentors that might help them “envision themselves as SHPEP scholars in a year or two, depending on where they are in high school.”

Cheryl Thompson, Ph.D., one of the co-principal investigators of the Robert Wood Johnson Foundation-supported SHPEP program, was pleased to open it up to Dr. Godfrey’s students. The effort was called SHPEP-WISH – “Weeklong Institute for Students in High School.”

“All four students were excited about being here,” she said. “Most exciting is the students’ intent to apply to the SHPEP program when they become eligible for participation. We look forward to this being another strong pipeline into the health sciences for Native American students.”

Hannah Butler Robbins came all the way from Arizona to take part in the program.

“I intend to go to medical school, and I wanted to gain a better understanding of what it takes to get into medical school, and what the medical school experience is like,” she said. “I found the most useful and enjoyable part of the experience to be the Q-and-A session with current medical students. The week-long institute served to reinforce that the medical field is where I belong.”

Shalise Cline, from Walthill, Neb., is a member of the Winnebago tribe.

“I enjoyed getting to experience all of the different programs that were offered,” she said. “I got to see a lot of careers that I didn’t even know existed.”

Frances Bullshoe, a science teacher in Marty Indian School in Marty, S.D., and a member of the advisory board which oversees grant activities such as SHPEP-WISH, said Dr. Godfrey’s program is valuable

in preparing Native American students for higher education.

Bullshoe, a member of the Blackfeet Nation who married into the Yankton Sioux tribe, is a product of educational pipeline programs herself, attaining degrees in chemistry and biology.

“The largest thing for us, as native people, is that we are a minority, so when we go into a classroom or college, we’re often by ourselves,” she said. “SEPA exposes us to other things – other cultures, other places – so that when we go to college, we’re ready to succeed. Dr. Godfrey and Dr. Sam Kumar respect our Native American culture and language.”

The history of Native Americans with Europeans makes it hard to trust outsiders, Bullshoe said.

“We have a lot of historical trauma,” she said. “Europeans came in, took our land, cut our hair, told us to stop speaking our language, beat us, committed genocide. We have a hard time trusting people.

“Sometimes, people come in and think they’re going to ‘save’ us,” she said. “That is not what Maurice is doing. He is very respectful of us as Native people, and before he does anything, he wants to be sure it’s culturally appropriate.”

Roger Bordeaux, Ed.D., superintendent at Tiospa Zina Schools in Sisseton, S.D., agrees that Dr. Godfrey is always willing to listen.

“If an idea is worthwhile, he’s willing to try it,” he said. The SEPA program has “made a big difference with our students and their desire to try to explore science in a lot of different ways.”

Feedback and culturally respectful collaboration is integral to the program’s success, Dr. Godfrey said.

“SEPA stands for Science Education Partnership Award, and we always underscore that word partnership. It’s very important that the communities and schools we work with know that we are true partners in working with them.”

MMI leadership also met with Ponca tribe leaders this fall during an outreach tour to explore further avenues of involvement with the native American community.

“MMI is committed to expanding such programs,” said MMI Director Karoly Mirnics, M.D., Ph.D.

# Taking ACTion

## For William Higgins, Ph.D., it's a matter of volume, not space.

Dr. Higgins is the director of the Autism Care for Toddlers Clinic, and beginning in 2018, the clinic is inhabiting a large new space at the Autism Center of Nebraska at 9012 Q St.

The MMI ACT Clinic has been at the Autism Center of Nebraska since 2012, when Terri Mathews, Ph.D., and Joe Evans, Ph.D., from the department of psychology at the Munroe-Meyer Institute, started it with just a few graduate students and only about 700 square feet of space.

"The space we previously occupied will be converted into a conference and community training room, and what used to be a church sanctuary is now going to be an autism sanctuary of about 8,300 square feet," Dr. Higgins said.

Before the shift, the clinic was "maxed out" at 14 young children diagnosed with autism, Dr. Higgins said. Now, the clinic plans to serve a total of 40 children.

"Currently, about half of our patients receive 18 hours and the other half receive up to 12 hours of treatment per week," he said. "Research suggests that all of these children would benefit from 25 to 35 hours per week. One of our first goals is to get our current patients up to 25 hours, and then we're going to continue to build our staff and capacity to serve more children."

**"What used to be a church sanctuary is now going to be an autism sanctuary."**

The agreement to be community partners and lease a larger space to the ACT Clinic was a simple one, said Rene Ferdinand, president and CEO of the Autism Center of Nebraska.

"We've seen children being served here, and it is remarkable to see the progress they've made," Ferdinand said. "I know they were overcrowded, and when we learned there was a waiting list, we started talking."

The Autism Center of Nebraska spent more than \$550,000 renovating the space.

"We were making the most of the room we were in," Dr. Higgins said. "But now we're going to have toddler toilet-training bathrooms, we will have multipurpose clinic rooms, and a laundry room, a kitchen, space for temporary staff . . .

"It's going to be a far less constrained environment for our intervention strategies," he said. "The extra space will allow for more clinical services and additional training opportunities for our graduate students and trainees. We hope to use the space to better integrate MMI's autism services across disciplines, including speech, feeding, occupational, physical and recreational therapies."

It's also allowed the MMI Department of Psychology to ramp up recruitment for the ACT Clinic. Regina Carroll, Ph.D., will now join the ACT Clinic staff as associate director of research and clinical services for the clinic. "We also are actively recruiting graduate students, interns and postdoctoral fellows who want to join us in making our expansion vision a reality," Dr. Higgins said.

And as the new clinic space takes shape, that vision – under the guidance of Dr. Higgins and MMI Director of Psychology Keith Allen, Ph.D. – includes other potential community partnerships that could expand MMI Autism Services throughout the region.





From left, Rene Ferdinand, William Higgins, Ph.D., and Regina Carroll, Ph.D., look over plans for the redesigned Autism Care for Toddlers Clinic.

1 Dr. Higgins has identified possible community partners in Papillion and north Omaha, and MMI is interested in expanding the services to South Omaha, Council Bluffs and more rural locations.

2 “As a provider who used to work in Beatrice, ultimately I’d like to be able to recruit people born and raised in rural communities to come to MMI to get expert training and eventually go back and either be affiliated with us or start their own program. These services are greatly needed in communities across the state,” Dr. Higgins said.

3 The clinic has also received funding from Americorps, allowing it to bring in community members who learn to carry out early intervention services and take that knowledge out into the community.

4 “This also has been a promising collaboration as we work toward our vision,” Dr. Higgins said.

5 An important lesson from the collaboration with the Autism Center of Nebraska, he added, was this: People want to be community partners.

6 “People are motivated to help solve problems of social significance in our community, and they want to work together,” Dr. Higgins said. “So, don’t be shy.”

7 “Additional expansion is still in its infancy, but we have identified other potential community partners and there is a great need for additional early intensive autism services,” Dr. Higgins said. “We are recruiting current trainees that could function in a professional role at additional locations. So we’re starting to work on the logistics.”

8 And in the meantime, there’s still planning for the grand opening of the refurbished Autism Center of Nebraska space.

9 “The collaboration has been such a pleasure,” Ferdinand said. “The staff of MMI is just a joy to work with.”





# The Westward Expansion



Telehealth, says Wayne Stuber, Ph.D., is the future.

And at the Munroe-Meyer Institute, the future is now. MMI professionals, from pediatric feeding and the Center for Autism Spectrum Disorders to genetic medicine and psychology, are using telemedicine as MMI leverages the technology to expand its reach in the state, the region and even the world.

Subspecialists such as those found at MMI are a limited resource, and it is difficult to recruit these professionals into smaller, rural communities, said MMI Director Karoly Mirnics, M.D., Ph.D.

"Small communities should have the same right to receive the highest quality of care, in their own environment, as patients living in big cities," Dr. Mirnics said. "Telemedicine is the way to achieve this."



*Telehealth technology can let professionals from various Munroe-Meyer Institute Departments, such as the Center for Autism Spectrum Disorders, meet with clients who are in their home environment.*

Traveling many hours to a major health care center is inconvenient and often prohibitive, especially when you have to make the appointment months ahead of the visit, Dr. Mirnics continued.

“Our patients are individuals with special needs, as well, and traveling long distances may represent significant challenges.”

In the pediatric feeding program, Cathleen Piazza, Ph.D., and her staff use the technology to conduct follow-up sessions with families whose children have graduated from the feeding program.

Chris Engler, behavioral specialist in pediatric feeding, has been surprised at how open families are to using telehealth.

“Once you get the technology set up, it’s a click of a button,” he said. “It’s easier for the families.”

Wayne Fisher, Ph.D., grew the Center for Autism Spectrum Disorders’ telehealth program from a U.S. Department of Defense grant that was exploring how the technology could help the families of service members.

The goals included training parents to implement early intervention procedures in the home, training behavioral technicians to implement procedures with the child in the home, and then managing the early intervention program remotely.

Today, Dr. Fisher’s program is serving families as far away as Italy.

“What that research has shown is that we can train technicians just as well as if they come to the building, and we can do the same for parents,” Dr. Fisher explained. “We can manage early intervention programs effectively such that children never have to actually come into our building.



“Based on evaluations, parents are implementing the procedures at about 90 percent accuracy – which is about as well as we do in-house, although we haven’t had a systematic comparison.”

The department of psychology uses telehealth for clinical supervision, said department director Keith Allen, Ph.D. “Our interns, postdocs or students can see a family in a remote location with a supervisor ‘present’ through telehealth,” he said.

For example, Josh Turek, Ph.D., though based in Norfolk, Neb., supervises Fran Rieken, who is providing services in York, Neb. “He probably does 10-12 telehealth sessions a month,” Dr. Allen said.

**“Our patients are individuals with special needs, as well, and traveling long distances may represent significant challenges.”**

The key to successful telehealth is cutting-edge technology, according to Omar Rahman, M.D., director of genetic medicine.

His department has two telehealth “carts,” portable units that can be moved from place to place. One is stationed at Scottsbluff, while a destination is being determined for the other.





*New portable telehealth carts, such as the one shown above, will increase the institute's versatility and ability to serve clients in different areas while allowing them to avoid long trips into Omaha.*

"You can actually do a pretty decent genetics exam, as long as the camera is of good quality, because most of what we look for is the facial features, the palms, the fingers, the toes," he added. "We don't need to do any sort of hands-on exam in the majority of instances."

Working with families while they are in a home setting actually brings advantages, according to MMI experts.

"Sometimes a child will show skills or a reduction of problem behavior here in the clinic, but not the same degree of behavior change at home," Dr. Fisher said. "Having the parents implement the procedures in the home while we're watching through televideo conferencing allows us to see the behavior as it occurs in the natural environment, and that provides insights."

Engler agreed.

"The cool part about them being in the home is that's their natural environment," he pointed out. "The family is going to respond to kids running around in the background, mom's phone is going to go off – it's very real-world for families."

Reimbursement and licensing issues provide a challenge for some services delivered via telehealth, which can hamper expansion. But Dr. Stuberg, MMI associate director and director of clinical services, envisions an important and expanding future for telehealth at MMI.

His vision?

"I would like to see every department that provides clinical services be able to offer them on a statewide basis via telehealth."





# Department Highlights

## Administration

- Munroe-Meyer Institute leaders visited Fremont, Columbus and Norfolk as part of a listening tour to determine the accomplishments and needs of the intellectual/developmental disability community in each location and to explore possible collaborations.
- Omar Rahman, M.D., was named director of genetic medicine.
- Keith Allen, Ph.D., was named director of academic affairs for MMI.
- Matt Stelzer was named director of business services for MMI.
- Jennifer Sanmann, Ph.D., was named director of the Human Genetics Laboratory.
- Wayne Stuber, Ph.D., was named a Distinguished Scientist for 2017 by the UNMC Office of the Vice Chancellor for Research.
- Cindy Ellis, M.D., received the Interprofessional Education Scholar Award from the UNMC Office of the Vice Chancellor for Academic Affairs.
- An external advisory committee of national disability experts was formed.
- A community advisory committee was formed.
- Consultants conducted 50 interviews to assist in organizational structure evaluation.
- Four national autism spectrum disorder consultants reviewed MMI's current service structure.

## Center for Autism Spectrum Disorders

- Wayne Fisher, Ph.D., was asked to chair a grant review panel for the Autism Pilot Program Study for the Department of Defense.
- The department's Ph.D. program has grown to 24 students. Four students graduated in 2017,

and each of these graduates received national recognition for their scholarly research.

- Dr. Fisher served on a national steering committee working with the American Medical Association (AMA) to develop Current Procedural Terminology codes for applied-behavior-analysis services.

## Developmental Pediatrics

- Howard Needelman, M.D., was appointed to the executive board of the Provisional Section of the Child Death Review of the American Academy of Pediatrics and also received a Special Achievement Award for Distinguished Service and Dedication to the Mission and Goals of the Academy.
- Brigette Vaughan was appointed to a three-year term as the vice chair of the UNMC Institutional Review Board.
- The department initiated the Complex Case Support Board, a group that meets monthly to brainstorm and collaborate on the care and management of complex patients. Representatives from various agencies in the Omaha metro area also participate in the meetings to connect patients and families with community services.
- Developmental Medicine expanded its professional staff with the addition of a social worker, an LPN, and a third nurse practitioner.

## Developmental Neuroscience

- Woo-Yang Kim, Ph.D., and his colleagues at MMI and Creighton University made a major breakthrough in understanding the cause and potential treatment for a form of autism and intellectual disability. Mutations in the ARID1B gene are known to cause autism and developmental delays, and Dr. Kim's group defined the alterations in brain development that underlie these difficulties. This work was published in the journal "Nature Neuroscience."



*Staff turned out in force (and in costume) as MMI held its first Trunk or Treat event in 2017. More than 200 children with disabilities and complex health care needs attended the October event.*

- Anna Dunaevsky, Ph.D., received a grant from Nebraska Health and Human Services to study the changes in brain development caused by Fragile X Syndrome.
- C.B. Gurumurthy, Ph.D., developed an improved method for creating precise genetic changes in laboratory mice so they can represent the genetic alterations that cause diseases and disabilities in humans. He has taken the CRISPR-Cas9 system, which has revolutionized this field, and improved it even further to make it easier and more accurate. The methodology was published in journals "Genome Biology" and "Nature Protocols."
- Sung-Ho Huh, Ph.D., and his postdoctoral fellow, Michael Ebeid, Ph.D., were invited to publish a paper, "FGF signaling: Diverse roles during cochlear development," which covers a group of genes that are important for the development of the inner ear, specifically the cochlea, the organ in the inner ear that transfers sound to the brain.

- Shelley Smith, Ph.D., received five-year National Institutes of Health renewal funding for the Learning Disabilities Research Center, focusing on the causes, diagnosis, and treatment for reading disability (dyslexia).
- The laboratory of Jyothi Arikath, Ph.D., is publishing a paper, "Intracellular Amyloid Beta Expression Leads to Dysregulation of the Mitogen-Activated Protein Kinase and Bone Morphogenetic Protein 2 Signaling Axis," in collaboration with the laboratory of Surinder Batra, Ph.D., examining a novel functional role for a signaling pathway that is highly relevant to Alzheimer's disease.

### **Education & Child Development**

- The department evaluated 19 local, state and regional projects that focus on early childhood, closing the achievement gap, home visitation, after-school programs, parenting and expanding access to genetic services and supported them to improve their programs through the use of data.
- The department contracted to complete 12 trainings statewide on the Classroom Assessment Scoring System (CLASS) to help teachers and schools improve the quality of classroom interactions.
- Jolene Johnson, Ph.D., received a grant aimed at helping parents and teachers have a better understanding of how to support young children's executive functioning. Materials were distributed to 885 families at four Educare in Nebraska and New Orleans. In addition, teachers at these same sites received training from national experts.

### **Genetic Medicine**

- The department successfully recruited three new genetic counselors, one specializing in cancer genetics and two in pediatric genetics.
- The department initiated an adult genetics program that will collaborate with a cardiac genetics clinic in 2018 and has identified a dedicated genetic counselor to provide services to this new population of patients.
- The department introduced technology in order to improve clinical services, such as the Face2Gene app and the expansion of telegenetics services.

## Human Genetics Lab

- Jennifer Sanmann, Ph.D., passed the board exam in the subspecialty of Clinical Molecular Genetics and Genomics through the American Board of Medical Genetics and Genomics to become the only geneticist with this certification in the State of Nebraska.
- Marilu Nelson, laboratory supervisor, was presented with the Margaret Barch Memorial Workshop Presentation Award and Evan Roberts, molecular genetic technologist II, was the recipient of the New Horizons Award at the 42nd Annual Meeting of the Association of Genetic Technologists.
- The lab developed one new test, updated three existing assays, and validated new equipment to meet evolving clinical needs and to reduce turnaround times for clinical results.

## LEND

- The Nebraska LEND Program provided training in the use of ADOS-2 in diagnosing autism spectrum disorder to 48 students, faculty and practicing professionals.
- Graciela Sharif joined LEND as the first cultural diversity coordinator to improve cultural accessibility and diversity training.
- Nebraska LEND collaborated with five community agencies to provide community learning and leadership opportunities for nine long-term LEND trainees and partnered with Legal Aid of Nebraska to support training for two additional long-term LEND law trainees.

## Occupational Therapy

- The Munroe-Meyer Guild funded a collaboration project between OT and the University Center for Excellence in Developmental Disabilities to start the "Oppourtunity Brew" coffee cart, which will be a training site for Project SEARCH interns.
- Mekenzie Keenportz started in July as the department's inaugural American Occupational Therapy Association Pediatric Fellow. She will be on site through June 2018. This is a collaboration with MMI LEND and Children's Hospital & Medical Center.

## Pediatric Feeding Disorders

- The department submitted to a new behavior analytic journal, "Behavioral Development Bulletin."
- Department director Cathleen Piazza, Ph.D., joined by Wayne Fisher, Ph.D., gave invited presentations in Oslo, Norway, to a diverse group of about 100 attendees that included behavior analysts, dieticians, occupational therapists, parents, psychologists, and speech therapists.
- "The Journal of Applied Behavior Analysis" presented its Contribution of the Year Award to an article authored by Kathryn Peterson, Dr. Piazza and Valerie Volkert.

## Physical Therapy

- Brad Corr, D.P.T., was hired as director of adult physical therapy programming.
- Amy Beyersdorf was recognized by the American Physical Therapy Association Academy of Pediatric Physical Therapy as the Outstanding Pediatric Clinician of 2017.
- Max Kurz, Ph.D., and his team were selected as the September 2017 APSselect Recipient, an award from the American Physiological Society for "distinction in scholarship in the Journal of Neurophysiology."
- The PT department organized and sponsored the first "Pediatric Physical Therapy Special Interest Group" seminar. More than 50 area physical therapists attended the event.

## Psychology

- Joe Evans, Ph.D., and Brandy Clarke, Ph.D., were awarded a \$1.9 million Behavioral Health Workforce Education and Training Grant from the federal Health Resources and Services Administration to increase the number of behavioral health providers, including psychologists, therapists and nurse practitioners, being trained within primary care medical practices in rural and inner-city underserved areas.
- Jenny Burt, Ph.D., was part of a team of clinical researchers from UNMC awarded a \$315,000 three-year Clinical Scholars grant from the Robert



Wood Johnson Foundation for their innovative program for at-risk youth. The program, called Dusk to Dawn, is the only hospital-based, youth violence prevention program in Omaha.

### Recreational Therapy

- More than 550 volunteers provided 13,000 service hours in 2017.
- The department saw increased funding – more than \$15,000 in new funds – to adult community inclusion programs by both the Enrichment Foundation of Omaha and the Meyer Foundation. The funds will provide a dozen new field trips in 2018.
- The department teamed with Westside Public Schools for a new leisure coaching program for special education transition students.

### Speech-Language Pathology

- The department secured the full Nebraska Medicine contract for inpatient speech language pathology services at its main Omaha campus and at Bellevue. The department doubled in size to meet this need.

- SLP researchers received an \$85,000 grant from Women Investing in Nebraska to expand pediatric feeding and swallowing services across Nebraska and bring fiberoptic endoscopic evaluation of the swallow to central Nebraska.
- The department developed a collaboration with the MMI Department of Psychology to provide interdisciplinary services within the Autism Care for Toddler (ACT) Clinic to improve SLP services for children with autism and presented their approach to providers across Nebraska at the Nebraska Speech-Language-Hearing Association Annual Conference.

### University Center for Excellence in Developmental Disabilities (UCEDD)

- The 2017 employment rate for the Project SEARCH class was 100 percent and class size was increased to 14.
- The National Core Indicator project with the Department of Health & Human Services (DHHS) was expanded to include Medicaid long-term care programs in addition to the developmental disability adult consumer satisfaction project.
- The Nebraska Council on Developmental Disabilities funded three UCEDD projects: a statewide family training program for leadership and advocacy; a task force to expand statewide respite services; and a kennel technician certificate training program.
- The UCEDD collaboration with the DHHS Lifespan Respite Program expanded to include services in Lincoln and the surrounding area.
- UCEDD members piloted and developed the Respite Employer Engagement Initiative in collaboration with the Nebraska Lifespan Respite Network to encourage employers to provide Respite Resources to their employees.
- UCEDD staff, partnering with The People First of Nebraska project, provided leadership development and training and support in self-advocacy to more than 250 Nebraskans as one of four state partners in the Heartland Regional Self-Advocacy Resource Network.



*Speech-Language Pathology researchers received an \$85,000 grant from Women Investing in Nebraska to expand pediatric feeding and swallowing services across Nebraska and bring fiberoptic endoscopic evaluation of the swallow to central Nebraska.*

# Board Highlights

MMI's supporting boards provided critical financial, organizational and public awareness support in 2017, with financial support of more than \$1.8 million. We are grateful to them for their ongoing partnership and investment in those we serve.

## Hattie B. Munroe Foundation

The Hattie B. Munroe Foundation donated 86 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.

## Meyer Foundation for Disabilities

The Meyer Foundation for Disabilities' Walk & Roll for Disabilities event was held on March 5, 2017, with attendance of approximately 500. MFD supports the recreational therapy department's adult programming, which in 2017 included such programs as MMI's Thursday evening respite program, its cooking 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 49th Annual Garden Walk on June 11, 2017, with approximately 1,000 in attendance. Thanks to the proceeds from the walk and a grant from the Scott Foundation, the guild was able to award more than \$72,000 in grants to MMI for projects such as the MMI "Oppourtunity Brew" coffee cart to train Project SEARCH students and to measuring executive functions for NICU grads.



*Project SEARCH intern Ulysses Hernandez and Luann Rabe, president of the Munroe-Meyer Guild.*

## Scottish Rite Foundations of Nebraska

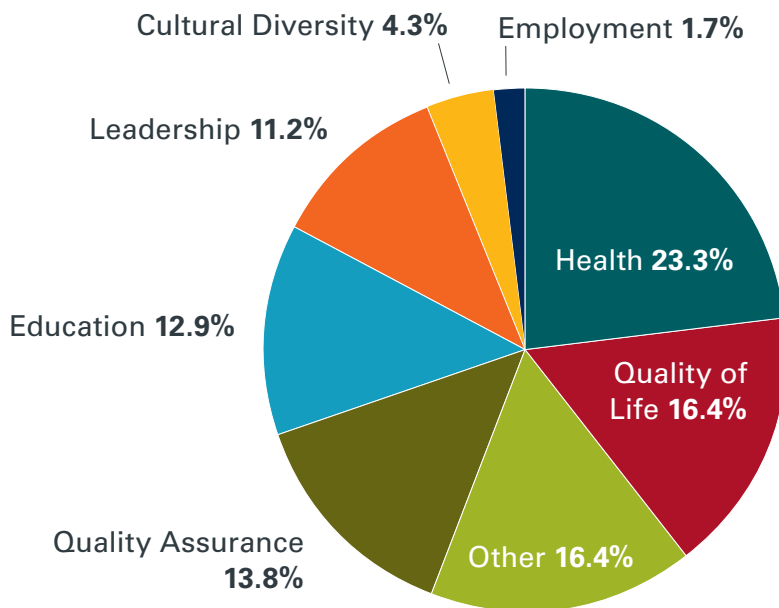
The Scottish Rite held its RiteCare Classic Golf Tournament on June 21, 2017, at Pacific Springs Golf Course. Nineteen teams raised \$16,685 for the RiteCare Speech and Language Clinics. On June 4, 2017, more than 100 walkers raised \$8,400 at Lake Zorinsky for RiteCare in the 10th annual WalkRite for RiteCare. The Friends of Scottish Rite Dinner was held Oct. 13, 2017, with 190 guests. The event honored Annie Bird for her commitment to children with disabilities and raised \$60,000 for speech therapy across Nebraska.

# Facts & Figures

## Serving the Community

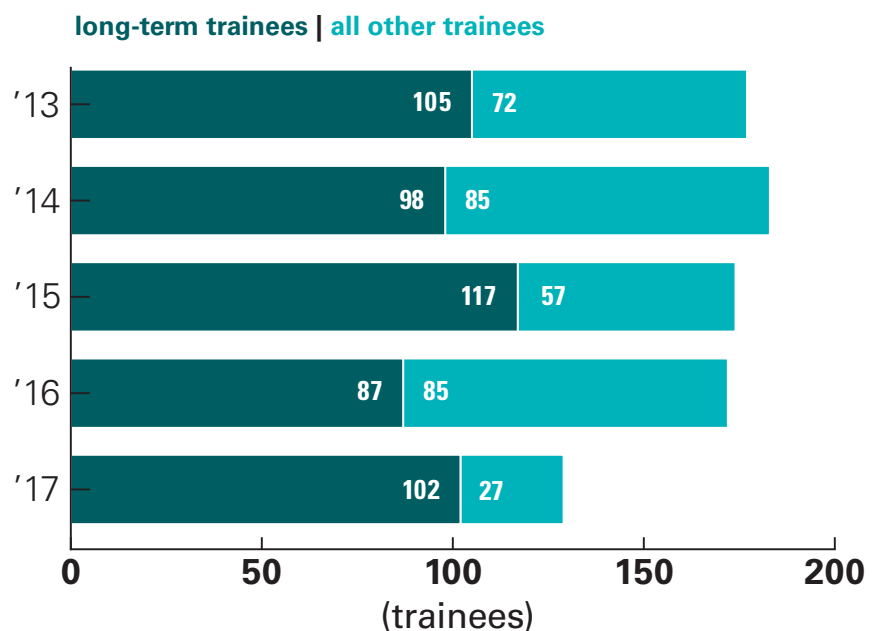
MMI provides technical assistance to other university departments and programs, community organizations and governmental agencies to transfer new knowledge from the academic setting into the community.

This year, 7,415 participants attended workshops, conferences, teleconferences and other community education activities. This chart illustrates the broad spectrum of activities and services for which MMI provides evaluation, assistance in program development or implementation, continuing and community education and a variety of other community services.



## Interdisciplinary Trainees

MMI's education program provided an interdisciplinary training experience for 129 students, interns, residents and post-doctoral fellows in 2017 for a total of 142,747 hours. Approximately 102 of these students were long-term trainees, receiving 300 hours or more of interdisciplinary instruction per person at MMI.

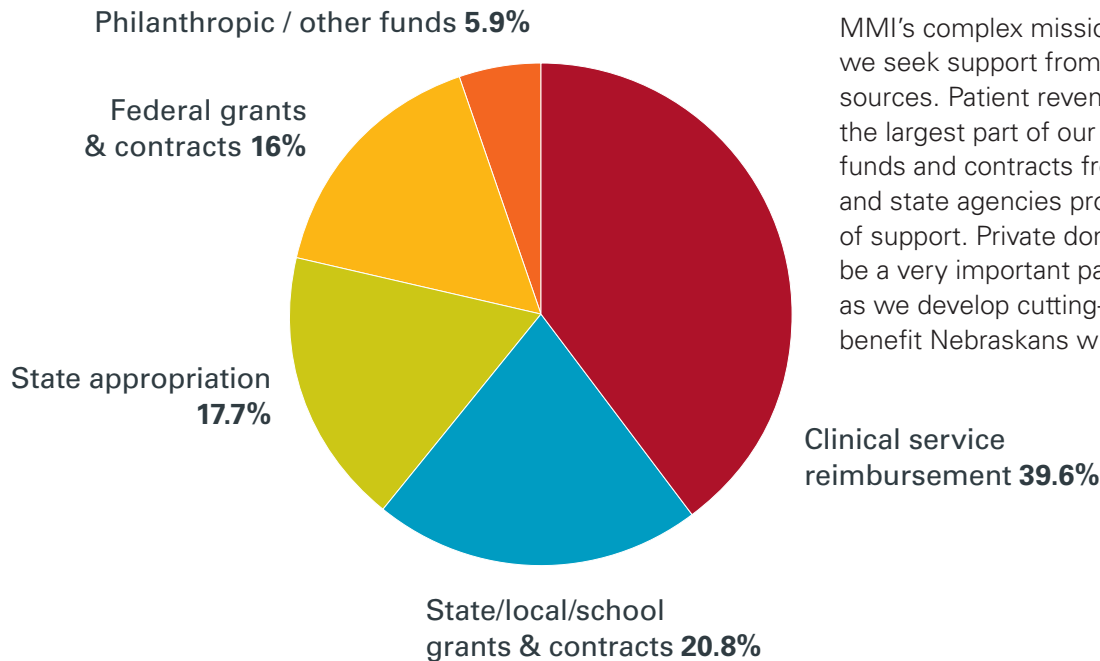




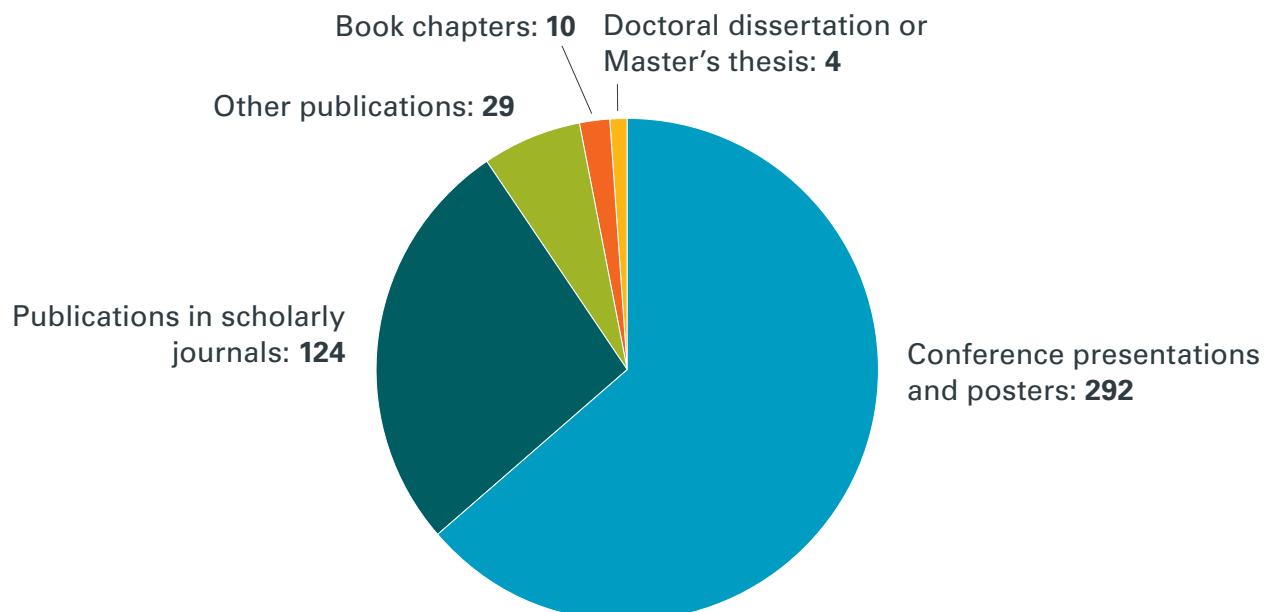
## OVERALL BUDGET: \$35,644,615

### 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 services to benefit Nebraskans with disabilities.



## SCHOLARLY ACTIVITY IN 2017: 459 PRODUCTS



# Points of Pride

## History:

- 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:

- 15 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 \$35 million budget, with over \$13 million in federal, state and local grants and contracts, and \$1.8 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 550 volunteers providing 13,000 service hours annually.

## Laboratory tests:

- Approximately 50,000 clinical genetic tests performed in 2017.
- More than 130 types of genetic 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 9,040 participants in workshops, conferences, teleconferences and other community education activities in domestic and international forums.
- 102 long-term trainees (doctoral, masters, interns) in 2017.
- Interdisciplinary training in 2017: 129 students, interns, residents and post-doctoral fellows for a total of 142,747 hours.
- More than 3,600 long-term students received training at MMI in the past 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 40 faculty involved in basic, clinical and translational research activities.
- More than 150 clinical and research fellows trained in the past 15 years.
- More than \$5.7 million in research funding annually.

## Community and outreach activities:

- Annually, more than 70 technical assistance services (1,899 hours) to community partners in LEND & UCCED alone.
- Approximately 27 community training activities (2,442 participants/776 hours) in LEND & UCCED.



## University of Nebraska Foundation

Small steps. Bites of food. Short sentences. And finally, a smile.

At the Munroe-Meyer Institute, these small accomplishments are huge victories in the lives of patients with intellectual and developmental disabilities and their families. Doctors, technicians and therapists at MMI, including those trained here who now work in physicians' offices, schools and other agencies across the state, uncover the hidden potential of children, teens and adults every day. Annually, more than 70,000 services are provided to Nebraskans by MMI.

While MMI provides more than 50 types of services and more than 50,000 genetic tests were completed in 2017, there is tremendous potential to expand its research, diagnostic, education and outreach services capabilities. However, current allocations barely cover existing expenses. Expansion of services and staff, and an upgrade of facilities and equipment to allow MMI clients to surpass perceived expectations can only be realized through private philanthropy ... your generosity. Please consider a heartfelt gift to the Munroe-Meyer Institute.

***"Take your victories, whatever they may be, cherish them, use them, but don't settle for them."***

—Mia Hamm,  
*retired soccer player, two-time Olympic gold medalist,  
two-time women's FIFA World Cup champion*

To learn more, or to make a gift to help expand MMI's services to more individuals in need, please go to [nufoundation.org/mmi](http://nufoundation.org/mmi), or contact Brian Anderson at **[brian.anderson@nufoundation.org](mailto:brian.anderson@nufoundation.org)** or **402.502.4113**.



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