The UNMC Munroe-Meyer Institute (MMI) for Genetics and Rehabilitation originated in the late 1950’s as a place for children with polio to receive treatment. Today, Nebraska’s federally designated University Center of Excellence for Developmental Disabilities Education, Research and Service annually provides diagnosis and treatment to more than 10,000 children and adults with diverse developmental and physical disabilities and genetic disorders.

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

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

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

Since becoming a part of the University of Nebraska Medical Center in 1968, MMI’s research, education, services and statewide technical assistance training have been a source of hope for patients with developmental disabilities and their families.

MMI’s mission includes a dedication to basic and applied research conducted by faculty and staff members in all disciplines and programs.

MMI is committed to training future health care professionals who will provide care to children and adults with developmental disabilities and genetic disorders and their families.
In past annual reports, we’ve brought you in-depth stories on our vital services, our first-of-its-kind research and our extensive education programs. Last year, we showed you how the Munroe-Meyer Institute (MMI) serves people with developmental disabilities throughout their lifespan.

For this year’s annual report we wanted to do something different. We wanted to tell you more, and more importantly, show you more. When you’re finished reading MMI A–Z, we hope you have a greater understanding of what this Institute is all about, which is unlocking the potential of children and adults with developmental disabilities in all aspects of life. Whether it’s through greater Nebraska behavioral health clinics, genetic counseling, translational and clinical research or apps that help children with autism learn to communicate better, great things are happening here every single day.

I’m excited about where we’re headed in 2013 as well. With the Affordable Care Act now solidified, the opportunity for MMI to more fully support families of individuals with disabilities grows exponentially. Not only will there no longer be life-time benefits limits and exclusions based on pre-existing conditions for the individuals that we serve, but the emphasis that will be placed on early intervention and preventive-type services has the potential to greatly impact the disability community.

With so much possibility, there’s never been a more exciting time to be part of UNMC and MMI. I hope you enjoy reading about all the things we are doing to improve the quality of life for individuals with disabilities. While this report doesn’t come close to highlighting everything we do, we hope it offers a clearer picture of who we are, from A to Z.

J. Michael Leibowitz, Ph.D., Hattie B. Munroe Professor
Director of UNMC’s Munroe-Meyer Institute
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WEB EXTRAS
Look for this red bookmark throughout the report for exclusive web content such as YouTube videos, Facebook photo albums and other helpful links.

MMI Annual Report 2012
Editor: Nicole Lindquist
Photographers: David Hussey, Nicole Lindquist Malone & Co., Scott Dobry, iStock Photography
Designer: Tom Waples
Autism Treatment for Children of Troops

Thanks to a $1.5 million grant from the United States Army, Wayne Fisher, Ph.D., director of MMI’s Center for Autism Spectrum Disorders, and his team are recruiting children with autism whose parents serve in the military to test the effectiveness of telemedicine treatment for autism. Since military families are often stationed all over the world, the model—if successful—could allow for access to services anywhere in the world. “And hopefully, it will lessen the overall stress on these families as they continue to serve our country,” Dr. Fisher said.
Behavioral Health

Who’s the first person parents turn to when their children exhibit behavior problems? If you guessed their pediatrician, you’re probably right. However, pediatricians often aren’t trained to deal with such issues. That’s why a model developed by Joe Evans, Ph.D., director of MMI’s psychology department has been so successful. In just 15 years, Dr. Evans has helped recruit, train and place behavioral health professionals such as psychologists, social workers, psychiatric nurses and counselors into 30 rural and urban primary care pediatric practices throughout the state. Those clinics have served patients from more than 225 communities and towns in Nebraska.

Camp Munroe Celebrates 30 Years

The only camp of its kind in the region, Camp Munroe, celebrated its 30th anniversary in the summer of 2012. For three decades, MMI has offered the typical summer camp experience with arts and crafts, swimming, cooking and plain old fun to children and teens with disabilities like autism, cerebral palsy and Down syndrome. Volunteers are a big part of camp. “Before I always thought that people with disabilities weren’t able to do much,” said volunteer Jessica Dang. “But coming here, I realize they’re like us. They just need a little extra help.”

Disability Awareness Day Flash Mob

On March 14, 2012, a group of MMI employees donned the color burgundy and strategically placed themselves around a corridor of the University of Nebraska Medical Center. At the conclusion of a disability related puppet show, the group gathered in the center of the room for a flash mob dance. Katy Perry’s “Firework” played over the speakers as the group attracted attention from onlookers and passersby. They danced and simultaneously signed the lyrics in sign language. “We wanted to draw attention for people with disabilities to show that they can be active and do things in the world,” said organizer Reggie Harbourne, Ph.D.
**EPIC Changes for Health Records**

It seems like everything is going electronic these days and health care records are no exception. The Munroe-Meyer Institute launched The Nebraska Medical Center’s new comprehensive system called “OneChart” in a few clinics this past spring and then throughout the Institute in late summer. Not only does OneChart allow MMI to go paperless with charts, it also sets providers up for the future in regards to health care reform. Soon, the data also will be accessible for research purposes as well as for patients to more easily monitor their own medical records.

**Fun on the Run for Foster Care Siblings**

Brothers and sisters often are taken for granted. For siblings separated by foster care, though, just seeing one another is a big deal. The Munroe-Meyer Institute’s “Fun on the Run” program brings together brothers and sisters who may not spend any time together throughout the year if it weren’t for the once a month outings. It had been nine months since Cherrell Davis last saw her 6-year-old sister, so when they got to hang out at SkateDaze last fall, it was heaven. “We’re really close, so just seeing her for those two hours makes my whole month. I just wish it were more.”

**Guild Garden Walk**

The Garden Walk is a major annual fundraiser hosted by the Munroe-Meyer Institute Guild. In the 45 years of its existence, the event has helped raise well over $1 million for grants and research projects at MMI. Past proceeds have funded adaptive communication devices, stipends for trainees and most recently sophisticated eye tracking equipment to test for developmental delays. The 2013 Garden Walk will be held on June 9 and feature five fantastic Omaha area gardens. Tickets can be purchased for $15 in early May at local Hy-Vee stores and nurseries.
Whether it’s an autism diagnosis or a cancer finding, there’s one question that bubbles to the surface. What caused this? The Human Genetics Lab at the Munroe-Meyer Institute tries to answer that very inquiry with its genetic testing capabilities. The staff provides more than 14,000 diagnoses a year, using state-of-the-art equipment and experienced clinical staff to do so in a fast, but personal, manner. Director of the lab, Warren Sanger, Ph.D., has been at the helm for more than 25 years as his team has grown from three to 67.

**Human Genetics Lab**
Infant Lab

Although they might not be able to vocalize it other than by crying, babies and toddlers dislike unfamiliar surroundings. This gave MMI’s Reggie Harbourne, Ph.D., an idea. Rather than conduct research on sitting in the gait lab that features stark white walls and wide open spaces, why not create a “lab” that felt more like home? With the help of some paint, soft lighting and comfortable furniture, fewer tears are now shed when wee ones come in for a research study or treatment. Their surroundings look like your average American living room, just the way they like it.
Licensure for Genetic Counselors

Genetic counselors assist families in understanding complex genetic information and implications for appropriate medical management. Earlier this spring, Nebraska lawmakers passed a bill that will provide formal licensure for genetic counselors. “Not only will LB831 protect the public, as currently anyone can call themselves a genetic counselor,” said MMI Director, Mike Leibowitz, Ph.D., “but licensure also will allow for our genetic counseling staff members to be reimbursed for their services.” All nine of MMI’s genetic counselors meet the training and certification requirements necessary for licensure.

K-12 Education and Youth Development Evaluation

There are numerous pre-school and after school programs designed to complement and support K-12 education, but how effective are they? That’s what the education department at the Munroe-Meyer Institute seeks to answer through its program evaluations. Key components of evaluations include everything from measuring teaching quality to studying the program’s effect on short- and long-term student achievement. Evaluations include input from educators, parents, community partners and other important stakeholders. Ultimately, the evaluations are designed to continuously improve all programs and to close achievement gaps.

Jack

Six-year-old Jack Moser never got to have the “cake smash” on his first birthday, a defining moment that parents love to photograph. Unfortunately, Bill and Tina’s only son had only been fed liquids through a tube in his stomach prior to coming to MMI. Following a small intestine, liver and pancreas transplant, he slowly learned to eat again with the help of the Pediatric Feeding Disorders program. Now, therapists are working with the kindergartner to increase the amount of table-textured foods he eats. His parents look forward to one of life’s simple pleasures, dinner around the table.
MySocius App

A smartphone application that has potential to help children with autism communicate more effectively is now available for download. Developed by Keith Allen, Ph.D., professor of psychology at MMI, the app uses evidence-based naturalistic teaching procedures to foster communication between parent and child. “We wanted to help parents do more to help their children learn basic communication skills. We wanted to develop something that could assist parents right in their homes. We wanted something that was supported by research,” Dr. Allen said. “We” is Dr. Allen and BehaviorApp, LLC—a Lincoln-based smartphone app development company. The app is available for download in the App Store.
Nebraska Neuroscience Alliance

While it may not seem like Alzheimer’s has anything to do with autism or that epilepsy and multiple sclerosis have anything in common, each of them involves the performance of neurons in the brain. Physicians and basic research scientists at MMI and UNMC are working to improve the quality of life for these individuals in a new venture called the Nebraska Neuroscience Alliance. The NNA hopes to develop state-of-the-art approaches to diagnostics and therapeutics of neurodegenerative diseases with an emphasis on translational research—research that translates from the researcher’s bench to the patient’s bedside.

OwL Ride

The Omaha with Lights (OwL) ride has become a premiere cycling event in the city since its inception in 2010. Organized by the Meyer Foundation for Disabilities, the fundraiser has garnered more than $100,000 for programs for adults with disabilities, such as the Thursday Night activity program at Munroe-Meyer Institute. The casual 16-mile bike ride (or 7-mile shortcut) begins at 10:00 p.m. with several stops built in along the way. With more than 2,000 riders, it is the largest biking event between Denver and Chicago. The 2013 OwL ride is on July 13.

PoNS

A device that could be a difference maker to individuals with neuromuscular disorders continues to prove itself in research studies at the Munroe-Meyer Institute. Developed by researchers at the University of Wisconsin, the PoNS uses the thousands of nerve endings on the tongue to send messages to the healthy areas of the brain. The idea is that the stimulation helps the brain form new neural pathways for functions like balance and movement, skills vital for those affected by cerebral palsy, multiple sclerosis and traumatic brain injuries. At this time, MMI has approximately 27 subjects at various stages of the clinical trial.
Quality Assurance

Quality assurance is a routine part of most organizations, but for the clinical services committee at the Munroe-Meyer Institute, those in charge of monitoring it go above and beyond. The team disseminates satisfaction surveys and when the results come back team member Sarah Swanson does more than forward the information to the appropriate department. She makes a personal follow-up call to gain a clearer understanding. While quality assurance may be mandated by the Association of University Centers for Excellence on Disabilities, MMI employees make it more than that. “We want to make sure feedback from our families benefits everyone,” Swanson said.

Research

For those who have ALS—better known as Lou Gehrig’s disease—the decline in cognition occurs before anyone notices it is happening. That’s why Mili Kuruvilla’s research into brain function and cognitive decline is so important. Dr. Kuruvilla uses a device called the fNIRS, short for functional near-infrared spectroscopy, to study the relationship between prefrontal blood flow changes and the degree of cognitive, speech and language loss. Her research also incorporates genetic testing to study gene-brain-behavior interactions in Lou Gehrig’s disease. This work is done in collaboration with the Human Genetics Lab at the Munroe-Meyer Institute.

Symposium on ADHD

For the fifth straight year, the Munroe-Meyer Institute symposium brought health care providers and parents together to talk about disabilities. The topic was ADHD and featured presentations on genetics, behavior management and ADHD’s effects on loved ones. Attendees enjoyed hearing the latest trends on evaluation and treatment directly from the experts themselves. Thanks to an endowment from the Nebraska Fraternal Order of the Eagles, the symposium will continue for years to come, covering topics like autism, Down syndrome and cerebral palsy from a multi-disciplinary standpoint. The 2013 symposium on amyotrophic lateral sclerosis is set for May 17.
Telemedicine for Epilepsy

Lack of access to medical specialists is a major health issue in rural Nebraska. Residents frequently experience high travel costs and long wait times seeking health care. Rather than make those individuals come to us, the Munroe-Meyer Institute is taking a “let’s take health care to them” approach using telehealth to deliver specialist care. For instance, children with epilepsy can meet “face-to-face” with a pediatric neurologist in Omaha from a clinic near their hometown. MMI is working to expand their telehealth services, which already include behavioral and speech therapy as well as treatment for autism and pediatric feeding disorders.
Update Newsletter

A resource designed for families. That’s what community/family coordinators at the Munroe-Meyer Institute, Mark Smith and Sarah Swanson, set out to create with their e-newsletter, MMI Update. Distributed quarterly, it includes everything from the latest in the Nebraska legislature to events geared toward families of individuals with disabilities. It also contains links to community resources and advocacy organizations. “We want it to be a resource that families value,” Swanson said. To submit a story idea or to sign up to receive the e-newsletter, just visit unmc.edu/mmi or e-mail sswanson@unmc.edu.
Fragile X Research

Fragile X syndrome is the most common form of inherited intellectual disability in boys. And it’s the goal of Dr. Anna Dunaevsky’s to figure out why. The researcher in the developmental neuroscience department at Munroe-Meyer Institute uses a mouse model with altered genes that mimic Fragile X syndrome to study their brain development. She and her team create cranial windows into the brains of the mice to see how the animals’ synapses change when the mice learn a new motor skill. The team hopes their research can lead to better understanding of Fragile X syndrome and in turn impact diagnosis and treatment.

Validation

Validation is something that has to be done on every new machine that performs genetic tests. To make sure the new machine returns accurate results 100 percent of the time, it must be compared to tried and true methodology. The Human Genetics Lab at the Munroe-Meyer Institute is nearing the completion of validating the Next Generation Sequencer. The machine can process multiple genes at a time as well as multiple patient samples, something the former sequencing system was unable to do. Because of this, costs for genetic testing could become more affordable.

WalkRite for RiteCare

This annual fall fundraiser is held by the Scottish Rite Masons of Nebraska, whose mission is to provide speech services to children with communication disorders. Because of the group’s generosity, Munroe-Meyer is able to offer preschool speech services free of charge to hundreds of children per year. “For every dollar we spend on the RiteCare clinics, it saves three to five dollars in special education costs,” said Curt Edic, general secretary of the Omaha Valley Scottish Rite Masons. With fundraisers like WalkRite for RiteCare, the Masons hope to provide the priceless gift of communication for years to come.
You Can Help

Munroe-Meyer is beyond grateful to all those who, generously, support its mission of improving the lives of individuals with developmental disabilities. Through the University of Nebraska Foundation, an “Unlocking Potential” fund, a “Train the Brain” fund and a “Big Splash” fund to have been set up to provide critical resources that advance its initiatives. If MMI has touched your life in some way, please consider giving back. All gifts make a big impact. For more information on donating, as well as an update on the NU Foundation’s campaign for MMI, see page 22.

Zzzz – Sleep Study

The Center for Autism Spectrum Disorders at the Munroe-Meyer Institute is recruiting children with autism for a study on sleep disturbances. Problem bedtime behavior, delayed sleep onset and nighttime wakings are frequent issues for children with autism spectrum disorders and related disabilities. Sleep disturbances not only have negative effects on the children, but also on their caregivers. The study will evaluate the independent and combined effects of behavioral therapy and melatonin, a natural compound that regulates sleep cycles. MMI professionals will monitor nighttime sleep, train caregivers to implement treatment and provide expert feedback so that everyone can get more zzzzzz. For more information, call Dr. Tara Loughrey at 402-559-3560 or e-mail tara.loughrey@unmc.edu.
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, 20,787 participants attended workshops, conferences, teleconferences and other community education activities. This chart illustrates the broad spectrum of issues and services for which MMI provides evaluation, assistance in program development or implementation, continuing and community education and a variety of other community services.
Fueling Our Mission

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

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Products Developed and Disseminated

MMI faculty members publish extensively in professional journals, monographs, periodicals and books and also disseminate best practices through reports, manuals and other informational materials. In 2012, MMI faculty members developed 134 new products and disseminated 139 different products to professionals, students, parents, people with disabilities and the general public.
Funds Leveraged

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

Interdisciplinary Trainees

MMI’s education program provided an interdisciplinary training experience for 171 students, interns, residents and post-doctoral fellows in 2012 for a total of 128,659 hours. More than half of these students were long-term trainees, receiving 300 hours or more of interdisciplinary instruction at MMI.
Nebraska Foundation

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

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

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

For more information about the campaign, contact Melonie Welsh mwelsh@nufoundation.org | 402-502-4117.
**MMI’s Mission:**
To improve the quality of life for persons with disabilities and their families.
UNMC Munroe-Meyer Institute for Genetics and Rehabilitation
A university center for excellence in developmental disabilities education, research and service.

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