UNMC’s Munroe-Meyer Institute (MMI) for Genetics and Rehabilitation originated in the late 1950s as a place for children with polio to receive treatment. Today, Nebraska’s federally designated University Center of Excellence for Developmental Disabilities Education, Research and Service annually provides diagnosis and treatment to more than 14,000 children and adults with diverse developmental and physical disabilities and genetic disorders. In 2014 more than 55,000 patient services were provided across Nebraska by MMI faculty and staff.

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

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

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

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

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

MMI is committed to training future health care professionals who will provide care to children and adults with developmental disabilities and genetic disorders and their families.

**MMI’s Mission:**

To improve the quality of life for persons with disabilities and their families.
Dear friends of the Munroe-Meyer Institute,

A patchwork quilt is made of a variety of panels that combine to create a beautiful and comforting whole. In many ways, that also describes the Munroe-Meyer Institute – a collection of unique programs and professionals that, when pieced together, create a whole that is greater than the sum of its parts.

In this year’s annual report, we highlight the many ways in which MMI impacts Nebraskans across the state – and, more importantly, showcase how MMI’s many programs and disciplines work together to improve the lives of our patients and their families. Explore the groundbreaking work of the Center for Autism Spectrum Disorders, the evaluation programs being conducted across the state by our Education and Child Development Department, the outreach of our statewide network of behavioral health clinics, the cutting-edge research being done in the Developmental Neuroscience Department and in the Human Genetics Laboratory and a jobs program designed to help transition youth with disabilities to adult employment.

Bringing these world-class programs together, MMI stitches together an array of activities designed to improve the lives of families – in Nebraska, nationally and internationally – who are facing daily challenges. We are excited to share our stories with you.

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

Katie Schiefen is ready to go to work. And the Munroe-Meyer Institute is ready to help her.

Katie, a 28-year-old with developmental disabilities, is part of the first class to be enrolled in Project Search on the UNMC/Nebraska Medicine campus. She has received services at MMI and still takes part in the institute’s classes for young adults, such as gardening and cooking.

Project Search is a national program, created by the Cincinnati Children’s Hospital, which helps train young adults with developmental disabilities to enter the workforce. In Nebraska, it has 13 sites, including businesses such as Embassy Suites in Omaha, La Vista and Lincoln, Walmart’s distribution center in North Platte and St. Elizabeth Regional Medical Center in Lincoln.

Now, it has a site on the medical center campus, as well, the result of a collaboration with Madonna School, the Vocational Development Center Inc., Vocational Rehabilitation and Sodexo Inc., which oversees the food service operations for the UNMC/Nebraska Medicine campus.

MMI participated in the planning to bring the program to campus and the institute will be working with other units on the campus to develop additional internship training sites, said Wayne Stuberg, Ph.D., associate director of MMI.

Katie’s mother, MaryAnn Schiefen, is excited about the new program, which they learned about through the Madonna School, where Katie takes classes. Katie has worked before – at places such as Lakeside Hospital, where she sorted mail – but the new program offers her an opportunity to expand her job skills to move toward gainful employment.

Katie Schiefen practices making a bed during a day of classes at Project Search on the UNMC campus.
“We want to give her the opportunity to enhance her possibilities,” MaryAnn said.

That is where MMI comes in.

On a campus the size of UNMC, there are any number of potential internship sites – such as working in medical records, sterile supplies, or even in a mail room – and MMI will be working with directors and managers to develop internship sites in other areas.

“We want to give her the opportunity to enhance her possibilities.”

“We have gotten the information from the other health-based sites in the state and from Project Search as to which areas we should look at developing,” Dr. Stuberg said.

As skills for daily living are developed, most clients aspire to be employed, Dr. Stuberg said.

It’s a goal that faces daunting challenges. The Nebraska unemployment rate in December, the most recent rate available, was 2.9 percent, but the rate for persons with disabilities nationwide was 80 percent.

Having Project Search on campus, and providing as wide a range of internships as possible, could help cut into that statewide figure.

MaryAnn called the initiative wonderful.

“I see it providing better job opportunities for a lot of these young adults,” she said.

Katie, for example, would like to work in an office. As MMI begins to “recruit” more internship sites throughout the UNMC campus, the job possibilities expand not only for her, but for other future graduates of the program.

Paul Turner, executive director of Sodexo, said he has rarely been as excited about a program as he is about Project Search, which began at UNMC in early January. Three teachers are working with a cohort of between 10 and 15 students, with Sodexo providing learning space and the arena for on-the-job training.

“It’s a really meaningful endeavor, and I’m glad Sodexo can be part of reaching out to help people with special needs,” Turner said. He hopes to hire several of the program’s graduates, and he pointed out that even the students Sodexo doesn’t have positions for will have the training – and a Sodexo reference – to help them find work elsewhere.

That’s an attitude Dr. Stuberg hopes to find among other campus managers.

MaryAnn, who has worked in the field of special education for a number of years, said that employment programs such as Project Search help demonstrate that people with developmental disabilities can be contributing members to society.

“For a medical center of this caliber, this will enhance its reputation even more, knowing that Nebraska Medicine and MMI are taking part in this program,” she said. “It’s an honor and privilege for Katie to take part.”

And for the state of Nebraska, MMI and UNMC will be helping to train young adults with developmental disabilities in a variety of job skills.

“The institute has not traditionally been involved with employment,” Dr. Stuberg said. “But we are excited to have Project Search here on the campus, and we look forward to maximizing its impact by exploring internship possibilities that will match with students’ skill sets.”
They come to Nebraska from all over the country. From everywhere, they come to Omaha, to the little building with the yellow canopy.

In any given year, depending on budgets and grants, MMI’s psychology internship program may well be the biggest of its kind in the U.S. A few hundred annually apply, this year vying for a most-ever 19 spots.

They come because the program is fully accredited, and its graduates are thus in a good position to apply for licensure anywhere in the country.

And while they come from all over, many of them end their internships by staying in Nebraska.

Many of them know nothing about Nebraska, said Keith Allen, Ph.D., professor of psychology and director of the internship program. They’re coming just for this unique program, to follow their field of study and to be part of a well-respected academic medical center.

But they fall in love with the place, said Kristen Carson. Originally from South Carolina, she’s a current MMI psychology intern.

“I love Nebraska,” she said.

That’s good. Most of Nebraska is considered underserved when it comes to behavioral health care.

The next step is to get more psychologists out to Nebraska’s rural areas, and MMI and the state are working together to change that. In 2009, the Nebraska Legislature created Behavioral Health Education Center of Nebraska (BHECN), administered by UNMC. Leg. Bill 901, passed in 2014, helped BHECN beef up the psychology internship program, adding five more spots immediately. The bill called for increasing the number of interns by 10 within three years.

The interns are placed in communities that allow more access for rural and other underserved areas in the state. The program also emphasizes collaborative partnerships with other professions, institutions and agencies. Through this program, interns have been placed in the Rushville/Chadron/Gordon area, in Hastings, in Nebraska City, in Columbus, in Grand Island and in Kearney.

MMI-trained and affiliated psychologists now serve at primary care clinics in Columbus, Grand Island, Kearney and Hastings, and from there, can reach out to other communities.

MMI’s program is also unique in that it has pioneered the concept of integrating the behavioral approach into primary care offices. And the interns will be immersed in that as well, many throughout Nebraska, offering a valuable capacity in the traditionally underserved parts of the state.

“It is an approach based strongly in science,” Dr. Allen said. “The behavioral approach looks to the environment to understand best why people do what they do. It looks to how to make changes in the environment in order to support people in making the changes they want to make.”

This makes sense, Dr. Allen said, in part because you can make all the changes you want to make, but if you go right back into the same environment how likely are those changes to stick?

“We want to work ourselves out of a job,” Carson said. “We want to give these families the tools so they can basically be their own clinicians at home.”

That’s crucial, because MMI works in large part with kids. Some have behavioral challenges, health challenges, chronic illnesses or developmental disabilities. Putting them in an environment that helps them make and stick to changes is more effective than convincing them to change through talk, Dr. Allen argues.

“Frankly there isn’t a whole lot of convincing you can do with a 4-year-old,” he said.

Those who apply for these internships, who come here, have decided to specialize in the behavioral approach.

Dr. Allen likened it to doing a residency in, say, surgery. This is not a rotation. This is the direction in which interns have decided to take their careers.

It’s the final step before attaining their doctoral degree.

For example, MMI psychologists work a certain number of hours at primary care clinics throughout Nebraska. There, they work shoulder-to-shoulder with primary care providers, conversing over break-room lunches or trading anecdotes during workroom stops.
With this “What do you think?” approach, many problems are solved without patients ever being referred to psychologists.

But a pediatrician who does spot a greater concern can simply walk a child and parents down the hall to meet someone who specializes in this type of intervention. This is called a “warm handoff.”

Carson loves it. She relishes being asked, “Hey, can you meet a family?” During the introduction, she and her colleagues often are not referred to as psychologists, but simply, “part of the team.”

“It makes people feel more comfortable right off the bat,” she said.

Dr. Allen said: “These primary care docs, pediatricians, family-practice docs are our de-facto behavioral health providers. They can do their jobs so much better if they have people like us next to them, integrating behavioral health into primary care.”

“It’s a wonderful supervision model,” said Carson, who was coming up on six months in the program and will operate more and more independently as she goes. “They are in-session with me the entire time, but (her supervisor) gives me a lot of autonomy to be the primary provider.”

Carson was drawn to the primary-care model, and so far has enjoyed it as much as she thought she would.

“It’s happening in an office where children and families feel comfortable,” she said. “We’re reducing that stigma. They’re coming to the doctor just like any other doctor’s office.”

“There are other places that do some of this,” Dr. Allen said. “But we were a pioneer in this approach at the internship level.”

Carson came for the internship model. But, like so many before her, she fell for Nebraska.

“I’m hoping to stay here,” she said.
Hilary didn’t know where to turn.

Her 3-year-old daughter, Kennedy, was becoming increasingly violent, toward herself and others, particularly her older sister. She was pulling hair from her own head and eating it – which became even more frightening when her pediatrician told Hilary that eating hair can lead to a potentially life-threatening intestinal blockage.

“We kept her in her crib as long as we could for her safety,” Hilary said. “Kennedy would crawl out of the crib and throw things at her sister’s head. She would bite me. She would hit people. She was out of control.”

It’s a familiar and frightening scene to some parents of a child on the autism spectrum.

Frustrated, perhaps as the parents attempt to set limits on behavior, a child may resort to severe destructive behaviors, including self-harm. While functional communication training (FCT) has proven to be effective as a treatment – reducing problem behaviors by 95 percent – that is traditionally delivered in a tightly controlled setting.

Wayne Fisher, Ph.D., director of the Center for Autism Spectrum Disorders, and his team at MMI have received a grant from the National Institutes of Health for a program to target this type of behavior outside of a clinical environment, by helping parents deliver the FCT response that is best for each individual child and situation.

Over two years, Dr. Fisher and his team have developed an assessment to help refine FCT responses in a home, school or community situation.

“The preliminary data looks very good,” Dr. Fisher said. “We’re looking at how we control the motivating factors that make problem behaviors likely or unlikely to occur.”

The goal of FCT is to teach children the appropriate communication response for the attention they want, and to reach a point where the problem behavior – often self-injurious – no longer produces the desired effect.

The challenge for parents is that, in a day-to-day situation, they may not be able to provide the necessary response in a timely manner. Dr. Fisher’s project, funded by the NIH through 2018 at nearly $450,000, is designed to ensure that the gains made in a clinical setting won’t be lost in the real world.
Since she began receiving FCT treatments at MMI in the spring of 2014, Kennedy has made tremendous gains, Hilary said.

“She has reacted very well,” she said. “Her fits are subsiding, she’s starting to gain more control.”

Another goal of the treatment is to reduce what Dr. Fisher calls “extinction bursts,” increasingly intense outbursts of the bad behavior as the FCT treatment is initiated.

The child, realizing the behavior is no longer producing the desired outcome – immediate attention, access to a preferred toy or food – will increase the behavior in an attempt to force the desired response.

“You can’t always get what you want’ is a lesson all children have to learn,” he said. “It can be more challenging for some children on the autism spectrum.”

In conjunction with the funded project, therefore, Dr. Fisher and his team are developing and evaluating a method to bring the FCT response under the control of signals – a red card, for example, would signal to a child that access to his or her iPod was not available. When the card is changed to green, the child can have the iPod by signaling that he or she wants it.

“The people at MMI have taken a lot of time and energy to help us.”

“We lengthen the ‘red periods’ in a series of small steps,” Dr. Fisher said. “If we can get the child to where they will accept that the item is unavailable for five minutes, they will usually have lost interest and moved on to something else.”

For Kennedy, the transition from the clinical setting to the home went smoothly, as well.

“The people from MMI came to my home and instructed me on how to use the cards,” Hilary said. “The way they worked with her was incredible.”

When Hilary first began using the prompt cards at home, Kennedy used them all the time. Slowly, however, she has moved away from using the cards as often.

“Kennedy’s fits used to be severe and multiple times an hour,” Hilary said. “Now, they are maybe once a day and manageable.”

“She still has her tantrums, but nothing near the level that they were,” Hilary said.

There are still challenges ahead – Hilary has shaved Kennedy’s head as she continues to work with MMI specialists on her daughter’s compulsion to eat her own hair – but with the gains made with Dr. Fisher’s FCT training, Hilary feels optimistic about eventually coming to a solution there, as well.

“Kennedy’s therapists worked diligently at keeping me informed and reached out to me repeatedly, after the cards were administered for home use, to answer questions and coach me with their ‘real life’ application,” Hilary said.

“The people at MMI have taken a lot of time and energy to help us,” she added. “They took everything I said very seriously. When I think about the difference they’ve made, it almost makes me want to cry.”
Amber Carter is a genetic counselor at the Munroe-Meyer Institute. Her job is to educate patients on genetic conditions and familial risks of cancer, providing a risk assessment based on personal and family histories.

Genetic testing plays an important part in Amber’s role, and when it is needed, she works with the Human Genetics Lab at MMI.

But she’s not the only one working with the lab.

Within the last year, the lab has created seven new hereditary cancer panels, as well as other diagnosis-specific gene panels for indications such as autism, intellectual disability, multiple congenital anomalies, connective tissue disorders, and osteogenesis imperfecta, all of which have proven valuable for the clinical diagnosis and medical management of patients, according to associate laboratory director Jennifer Sanmann, Ph.D.

The new tests include a high-risk breast panel, a panel aimed at women’s hereditary cancers (breast, ovarian, uterine), and five additional panels designed for colorectal cancers, renal cancers, brain and central nervous system tumors, pancreatic cancers, and endocrine/neuroendocrine tumors.

The lab has been working closely with Sarah Thayer, M.D., Ph.D., associate director of the Fred & Pamela Buffett Cancer Center, chief of surgical oncology and program leader for cancer services at Nebraska Medicine, to ensure that physicians in many different disciplines find the tests offered by the Human Genetics Laboratory useful.

“Physician input is critical to our laboratory’s test development,” Dr. Sanmann said. “We continually strive to expand our laboratory services in ways that are meaningful for patient care.”

Dr. Thayer praised the collaboration between the Human Genetics Laboratory and the Fred & Pamela Buffett Cancer Center, saying the newly developed panels advance insights for people who may have familial cancers.
In 2014, the Human Genetics Laboratory launched the following expanded indication-specific gene panels, to include additional genes associated with the postnatal disorders.

**Autism/Intellectual Disability/Multiple Anomalies panel**
On Nov. 5, the panel was increased to 117 genes from 86

**Connective Tissue Disorders panel**
On June 1, the panel was increased to 33 genes from 24

**Osteogenesis Imperfecta panel**
On June 1, the panel was increased to 15 genes from 9

Comprehensive testing for each gene panel above includes gene sequencing and intragenic deletion/duplication analysis, to identify disease-causing changes in the genes tested.

“Genomic characterization of tumors, as well as patients who get these tumors, is really going to be at the forefront of cancer diagnosis and treatment, and hopefully prevention, as well,” she said.

Carter sees additional advantages from the patients’ points of view.

“Having the multiple testing options, especially on site, eases access for the providers and the patients,” she said. “The hereditary cancer tests include cancer site-specific panels, such as a panel geared toward colorectal cancer, which is a more targeted approach compared to some of the other panels available from commercial laboratories. The panels are targeted while also being broad enough to include rare genes that are often (financially) difficult to tackle on an individual basis,” she said.

Part of the reason for the lab’s record of success is the way its leaders actively seek collaboration and regularly participate in national and international case conferences. “Those conferences foster education and dialogue between specialties, which allows us to tailor our genetic menu to meet the clinicians’ needs,” Dr. Sanmann said. “We are also committed to meeting the specific requests from clinicians throughout the state.”

The hereditary cancer panels, developed at the lab to help identify mutations in well-characterized, high-risk hereditary cancer genes, are an example of how the lab gears testing toward clinical and patient utility.

Hereditary cancers make up 5 percent to 10 percent of all cancers, and a higher percentage in certain types of cancer, but all tumors have genetic components and most are not inherited. The lab is tackling this aspect of cancer care as well.

“Our understanding of the underlying genetic drivers of various cancers is continually growing,” Dr. Sanmann said. “Numerous technologies have transitioned from the research space to the clinical realm over the past few years, and these tools have proven to be invaluable diagnostic resources.”

Collaboration is key to maximizing the potential of these opportunities, she added.

“The collaboration with the Fred & Pamela Buffett Cancer Center, for example, has helped us bring more of these assays to the clinical diagnostic testing,” she said. “And we are actively participating in various tissue-specific cancer working groups to prepare our lab to meet future needs.

“One of the most important things coming out of these interactions is the ability to identify the future needs of clinicians,” Dr. Sanmann said. The lab is using feedback from physicians to ensure that it remains on the cutting edge of diagnostic genetic testing. “Genetics plays a tremendously critical role in the future of medicine. There is too much at stake for patients if we are standing still.”

Another test currently in development is a platform that allows investigators to look for changes throughout the entire genome in suboptimal tissues.

“This assay will be particularly useful for assessment of genetic abnormalities in tissues that have historically presented technical challenges, such as small pieces of tumor. Research studies are underway to validate this new assay, and we look to offer this test clinically in late 2015,” Dr. Sanmann said.
When Ted Stillwell, the CEO of the Learning Community of Douglas and Sarpy Counties, was looking for a way to evaluate the programs — Jumpstart to Kindergarten, family literacy programs, a liaison program for at-risk youth and families — he turned to the Munroe-Meyer Institute’s Education and Child Development department and its Interdisciplinary Center for Program Evaluation (ICPE).

“The Learning Community has been working with UNMC/ICPE for at least four years,” he said.

“High quality, independent third-party evaluations are critical to the core work of the Learning Community,” he said. “Our central value is in demonstrating promising, research-based educational solutions for children from poverty and establishing local proof of concept. This encourages others to adapt the central concepts from these successes to the benefit of students across the metro.”

The ICPE team has helped the Learning Community develop and implement evaluation plans for each of its funded efforts.

“As a result, we have high integrity results and, because ICPE’s evaluation approach is developmental, our funded programs can begin making improvements as soon as we get feedback on their initial results rather than waiting for the end-of-program results to be completed.”

The ICPE doesn’t just work with the Learning Community. Between 20 to 30 other programs, including the statewide Sixpence early learning programs for at risk infants and toddlers, keeps the ICPE team busy handling much of the independent program evaluation in the state.

“We have become a primary resource in the state for evaluation,” said Barb Jackson, director of the center, noting a push in education toward external evaluations and an emphasis on evaluating outcomes, rather than processes.

In fact, based on the center’s reputation, both the Learning Community and the Sixpence Early Learning Fund approached the department at MMI, Jackson said. Both entities provide grants to augment education, the Learning Community in the
Omaha area and Sixpence throughout Nebraska. The fact that both entities approached MMI, Jackson said, is a tribute to the reputation the department has developed with the evaluation work it’s doing throughout the state.

“The rigor of MMI’s evaluation process and the world-class caliber of the institution overall have been instrumental in providing scientifically credible evidence of the efficacy of targeted, high-quality early interventions,” said Amy Bornemeier, Sixpence administrator and associate vice president of early childhood programs at the Nebraska Children and Families Foundation. “These aspects of MMI’s involvement have not only played a crucial part in the ongoing improvement of Sixpence programs, but have helped substantiate these kinds of public-private investments as an effective, fiscally responsible strategy for closing the achievement gap that affects Nebraska’s youngest, most vulnerable children.”

Jackson attributed stakeholder input through a participatory evaluation approach as a key to successful evaluation.

“The reason the group has become so sought out is that it collaborates well with stakeholders,” said Lisa St. Clair, principal investigator for the evaluation study of the Learning Community.

“We respond to clients in terms of the analyses they request,” said Rosie Zweiback, project director for the evaluation of the Sixpence program. If a particular factor needs to be broken out for example, the MMI team – a staff of approximately 25, made up of psychologists, social workers, as well as educators – can tweak the evaluation process to examine additional programmatic questions.

“We don’t just deliver data, but we help programs use their data,” St. Clair said. “We model a strength-based, positive management style, highlight what is going well for them, and work with parents and the front line staff as well as administrators.”

For example, the data on the Learning Communities’ literacy coaching programs goes beyond rating the learning interactions that take place in the program. MMI’s Jolene Johnson, project director, also helps teaching teams debrief on the assessment information scoring, pointing out ways they can use the data to improve outcomes.

“We have become a primary resource in the state for evaluation.”

The evaluation process is two-tiered, Jackson explained, examining both implementation of the program and its outcomes. “If the outcomes are not as successful as were hoped for, we can look at the data and recommendations on how to improve the program.”

It’s important to the group that evaluations serve as building blocks, not sledgehammers. “Our approach is strength-based, but we tell the truth,” St. Clair said.

“Based on results, our collaborators might shift funding to programs showing stronger results,” St. Clair said. “At other times the evaluations offer next steps, and usually highlight areas that can be strengthened. Sometimes we offer broad recommendations, then work to take a deeper look at the possibilities.”

“Our goal is to help programs use their data to improve their programs,” Jackson said. “By helping programs improve their quality, we help them make a difference in the lives of children, families, and the communities in which they live.”
Measuring Courage

Alivia Wade likes to test her strength.

The 11-year-old sixth grader, daughter of Mindy McCoid, is at the Munroe-Meyer Institute’s Pediatric Neuromuscular Clinic this morning for a series of tests. Alivia, who takes dance and plays the guitar when she’s not attending classes at Anderson Middle School, has congenital muscular dystrophy, and today she will see a team of MMI health professionals, who work together across disciplines to track the progress of Alivia’s disease and help her cope with it. This clinic is made possible by a grant from the Muscular Dystrophy Association (MDA).

Alivia, along with occupational therapist Janice Flegle, is testing her grip strength on a tool called a dynamometer. As she tightens her grip, Flegle lets out a kind of primal not-quite-scream herself as a form of encouragement.

“I even do that with adults,” Flegle tells McCoid as Alivia switches hands. “It’s like, I can’t not do it.”

That’s fine with Alivia. She sees the visit, which has her seeing a pediatrician, a physical therapist, an occupational therapist, a dietitian and representatives from the local Muscular Dystrophy Association, as a way to test herself.

“There’s not really any pressure,” she says. “I kind of look forward to it.”

The MMI professionals will test her strength, her balance, talk to her about any challenges she’s facing, and discuss nutrition. It’s a long clinic, but McCoid and her daughter see it as a chance to confirm how well Alivia is holding off the progression of the disease.

Alivia has been coming to MMI for treatment since she was 2 years old; Mindy can’t really recall a time when the family wasn’t dealing with the degenerative disease.

The clinic visit starts with measurements and a short interview with the nurse – Have there been any concerns? Has Alivia needed any medication? Will she need a note for school?

“Oh, I haven’t even called them,” McCoid realizes.

As Alivia steps up on the scale, the nurse asks her about the MDA summer camp she attends, then sits her down to take her blood pressure, Alivia smiling at the buzzing noise the monitor makes.

When Flegle pulls out the hand dynamometer, Alivia smiles again.

She chats with her health care professionals throughout the visit. She’s doing well in school, and she likes science and English. She’s excited for the next summer camp. Her mother shares the news that Alivia has a boyfriend – mom’s met him, and he’s very nice.

Yes, she’s still dancing – in fact, she’s doing jazz now as well as hip hop.

The team is full of questions that have a serious purpose under the light tone. Is handwriting a problem? When does she use her wheelchair in school? Has she had any falls?

When Alivia admits to feeling tired at the end of the day at home or school, Robert Fuchs, the clinic physical therapist, zeroes in: How late in the day? In what part of her legs?

Alivia works with members of her interdisciplinary team at the Munroe-Meyer Institute’s Pediatric Neuromuscular Clinic.
Flegle and Fuchs prompt Alivia to talk about stretching in dance class. How does she get up from the floor? (She uses a chair to help pull herself to her feet.) They tell her that if getting up and down to stretch is too tiring, she should avoid it and save her strength for the dance class proper.

“You have to decide what is best to use your energy for,” Fuchs says.

Throughout the conversation, tests are continuing, and Alivia bears them without complaint. Fuchs asks the young girl to lie down on an examination table to check the flexibility in some of her joints, then take some muscle strength measurements, with Alivia, for example, flexing her foot upward against an instrument called a myometer.

“Do your feet get tired?” he asks.

The purpose of the interdisciplinary clinic, with Alivia seeing all manner of health professionals in one sitting, is not simply a matter of convenience for the family, says Flegle. With all of her team on hand, it’s easier to pool resources and share information.

“They all work together, they’re so familiar with the disease, they know what to look for and what to prepare us for,” she said. “I consider them part of our family.”

Zach, who will be attending college at UNO in the fall, comes to the clinic once every six months from his home in Wayne, Neb. He meets with a physician, occupational therapist, physical therapist and dietitian.

The appointments were initially very difficult, Shelley Jorgensen said. Now, the visits have become routine, “and it’s actually a fun day for us,” she said.

The team has helped with things as varied as recommending ways to adjust Zach’s wheelchair, suggesting the proper stretches and exercises that will help him maintain his strength, and referring the family to a cardiologist and respiratory therapist.

“Those are things we never would have done on our own,” Jorgensen said.

Working with the interdisciplinary team has also led to other connections, particularly other families who are facing similar challenges.

“MMI has led us to several types of support systems,” she said.
Serving the Community

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

This year, 16,639 participants attended workshops, conferences, teleconferences and other community education activities. This chart illustrates the broad spectrum of issues and services for which MMI provides evaluation, assistance in program development or implementation, continuing and community education and a variety of other community services.
Funds Leveraged

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

Interdisciplinary Trainees

MMI’s education program provided an interdisciplinary training experience for 192 students, interns, residents and post-doctoral fellows in 2014 for a total of 137,824 hours. Approximately 107 of these students were long-term trainees, receiving 300 hours or more of interdisciplinary instruction at MMI.
Fueling Our Mission

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

Products Developed

MMI faculty members publish extensively in professional journals, monographs, periodicals and books. In 2014, MMI faculty members developed 194 new products.
Nine years ago, the University of Nebraska Foundation launched the most ambitious fundraising effort in its history – Campaign for Nebraska Unlimited Possibilities. The goal: Raise $1.2 billion in support of the University of Nebraska’s commitment to becoming the best public university in America in terms of the impact it has on the people it serves.

At the conclusion of the campaign on Dec. 31, donors had contributed $1.85 billion, more than 50 percent beyond the goal. But most importantly, this support has transformed lives.

During the campaign, more than $8.8 million was raised for the Munroe-Meyer Institute, with 20 new funds created, including two endowed professorships. Of the 199 individuals and organizations making donations to MMI during the campaign, 181 were making their first donation to MMI.

This fall, UNMC Chancellor Jeffrey P. Gold, M.D., called the campaign an extraordinary success.

“The generosity of support has helped position UNMC for greatness as we seek a common goal to uplift the quality of life for Nebraskans and in so doing, lead the world in transforming lives for a healthy future,” Dr. Gold said. “This support and investment has given us further momentum to dream big and to seize opportunities.”

The University of Nebraska Foundation wishes to thank the Munroe-Meyer Institute campaign committee members: Chairman Steve McWhorter, Gail Werner-Robertson, Ted Friedland, Ken Bird, Ken Shafer, Curt Hofer, Carol Russell and Bob Kerrey.

For more information about the University of Nebraska Foundation and the funds supporting the work of the Munroe-Meyer Institute, contact Melonie Welsh.

melonie.welsh@nufoundation.org 402-502-4117