Raising Awareness About Autism Spectrum Disorders

by Ann Bird

Autism is a developmental disability that affects a person’s ability to communicate and socially interact with others. More people are affected today by autism than Down Syndrome, juvenile diabetes and childhood cancer combined. The Center for Disease Control estimates that the number of individuals with Autism Spectrum Disorders (ASD) is between 1 in 150 and 1 in 166 people. More than 1.7 million individuals live with autism in the United States. These read like mere statistics until a family member or friend is directly affected by ASD.

Such is the case for Gail Werner-Robertson and her husband Scott Robertson. They are parents of four children, two of whom have been diagnosed with ASD. The Robertsons served as general chairpersons for a successful benefit dinner and auction on June 5th at the Durham Western Heritage Museum. UNMC Chancellor Hal Maurer and his wife Beverly served as honorary chairpersons for the event that (coupled with a June 6th golf tournament at Shadow Ridge Country Club) raised nearly $675,000 to benefit the Munroe-Meyer Institute’s Center for Autism Spectrum Disorders.

Dr. Bruce Buehler, MMI Director and Chairman of the UNMC Department of Pediatrics, applauded the efforts of the Robertsons and the committee responsible for the two-day event. More than five hundred people attending the dinner became aware of the needs of individuals with autism and their families. Charlie Weis, Notre Dame head football coach, and father of a daughter with autism, and Jerry Newport, an individual with Asperger’s Syndrome, a form of autism, spoke from their personal experiences with ASD.

Proceeds from the benefit dinner and auction will provide support for MMI’s Center for Autism Spectrum Disorders, and will specifically provide funding for the Autism Diagnostic Clinic, Project BEST-CASE, the Apraxia Diagnostic Clinic and a post-doctoral trainee in autism. The MMI Center for Autism Spectrum Disorders is being developed to meet the needs of children and youth with ASD, as well as the needs of their families. The Center will expand the autism services currently offered at MMI, and will focus on older children and young adults in transition from elementary to middle school, middle school to high school and from high school to higher education or the world of work. The Center will provide multidisciplinary training for both parents and professionals to help adapt middle and high school programs for individuals with ASD, with particular emphasis on providing opportunities in the acquisition of socialization and self-management skills.

Ann Bird, Coordinator for the MMI Center for Autism Spectrum Disorders, said the Center will provide a means for MMI to:

• hire highly qualified professionals in the fields of ASD, research science and related fields;
• coordinate behavior analysis with molecular genetics to identify therapies and treatments for individual differences in the autism spectrum;
• develop and present state-of-the-art seminars for teachers and parents;
• provide ongoing professional development opportunities for school personnel working with children and youth with ASD;
• collaborate with local school districts in providing high quality services to students with ASD; and
• conduct cutting-edge research in the areas of applied behavioral science and autism spectrum disorders.

Ms. Bird said MMI is fortunate to be bringing Wayne Fisher, Ph.D. to serve as Director of the Center for ASD. Dr. Fisher is a highly respected research scientist, who currently serves as the Executive Director of the Marcus Behavior Center at Emory University in Atlanta, Georgia. He is a professor of Psychiatry at Johns Hopkins University School of Medicine. Dr. Fisher plans to assume his position at MMI in the fall of 2005.

The MMI Center for ASD provides the opportunity to take Nebraska’s programs in autism to a new level. Through the strong commitment and support from the community, such as the efforts of Gail Werner-Robertson, MMI can help Nebraska become a national leader in the innovative research and treatment of autism spectrum disorders.
Awards and Noteworthy People

UNMC Chancellor’s Silver Award Winners:

January 2005
Amy Vrchlavsky
Munroe-Meyer Orthotics and Prosthetics

February 2005
Torri Smith
Psychology - Project BEST-CASE

April 2005
Janet Henry
Education and Child Development

June 2005
Amanda Volkmer
Psychology

New Additions to MMI Staff

Ann Bird
Administration

Shirley Dean
Administration

Karen Olechnowicz
Developmental Medicine

Brigette Vaughan
Developmental Medicine

Chris Holley
Genetic Medicine

Kristi DeHaai
Genetic Medicine

(From left: Jennifer Sanmann, Jadd Stevens, Mariela Castillo and Pamela Althof)
Human Genetics Laboratories

Jennifer Haire and Sonja Harris
Nursing

Kirsten Fernau
PIO

Rosario Goodwin
PIO

Juanita Tarsikes
PIO

Stephanie LeMunyon
Psychology

Victoria Stewart
Psychology
In the past month, MMI has received amazing support from the citizens of Nebraska. Lead by the efforts of Gail Werner-Robertson and GWR, a successful fundraising/golf tournament netted nearly $675,000 to develop the next step in our programs for autism. The efforts put in by GWR were Herculean and the public awareness of autism was greatly enhanced throughout the state of Nebraska. The funding will greatly help in advancing services through MMI for families, children and adults with autism. Much of the effort will be put into developing transition programs in cooperation with the schools.

In order to accomplish the next step in developing our autism program, we have added to the expertise of Dr. Susan Wilczynski and her team with the addition of a new coordinator, Annie Bird. Annie has had 30 years of experience as a major administrator in the Department of Education and Special Education at the state level and her expertise is invaluable. We’ve also successfully recruited Dr. Wayne Fisher and Dr. Cathleen Piazza, both faculty at John Hopkins University and presently based at the Marcus Center in Atlanta, Georgia. Their expertise is nationally recognized in the area of behavioral management and their efforts are now directed toward Autism and specific areas, such as feeding and swallowing in children with special needs. These recruitments enhance the existing BEST CASE program, but also allow us to expand our clinical role, our research role, and our educational role. Dr. Fisher presently has a NIH grant and Dr. Piazza is just completing a K Award. These are two outstanding professionals who will be bringing doctoral and post-doctoral students with them.

These accomplishments are not just due to our commitment to autism, but our long history of developing programs as needs arise and identified. It is critical that MMI remain on the forefront in developing new programs and translating those programs into the community. It has always been my attempt to develop programs that have a finite time at MMI and are then translated and absorbed into the community and perpetuated. To be an Institute at an academic medical center, it is critical that we do the necessary research and education, as well as service, for those populations that we serve. Every day I feel the excitement of the new challenges, the development of new programs and our commitment to all individuals with special needs.

Strategic planning and action steps continue to be a critical part of MMI and I look forward to our next challenge.

Congratulations to staff who received outstanding performance stipends. These individuals should be applauded for their efforts!

Brace Place
Jean Jackson
Jim Littleton
Mary Littleton

Business Office
Mark Conlin
Lola Peterson

Core Group
Pat Gromak
Erni Steele
Wayne Stuberg
Amanda Volkman

Education and Child Development
Carol McMorris

Gene Genetic Medicine
Gwen Reiser
Christy Williams

Human Genetics Laboratories
Denae Golden
Kristi Horeis
Susan Kolb
Chestnut Livermore
Marilu Nelson
Melissa Nipper
Kimberly Wichman

Molecular Genetics
Melanie Schrack

Occupational Therapy
Theresa Levy
Emily M’Dermott

PIO
Deb Brumley
Becky Gilbert
Connie Kelly
Karen Mruz
Connie Tostenson
Linda West
Emily Ziskovsky

Physical Therapy
Amy Beyersdorf
LaRue Dyczek
Kathy Volkman

Psychology
Vicki Morrison
Torri Smith
Rachel Valleley

Recreational Therapy
Nicole Norlin-Giron

Recreational Therapy/Social Work
Karol Warchola

Speech
Karen Anderson
Dyanne Rupp

Congratulations also goes out to Bob Fuchs of MMI’s Physical Therapy Department. Bob received the 2005 SAHP Teacher of the Year Award. Bob is a physical therapist and assistant professor in physical therapy education in the School of Allied Health Professions (SAHP). SAHP is a school within the College of Medicine at UNMC.
Interdisciplinary Education Poster Session

MMI’s sixth annual poster session was held in the Durham Research Center on April 13. 13 student posters and 15 faculty posters were judged by Michael Leibowitz, Ph.D., of Administration, Bhavana Dave, Ph.D., of Human Genetics Laboratories and Dr. Foad Salama, of Pediatric Dentistry.

Winners were: 1) Interdisciplinary Research - Holly Roberts, Corrie Davies, Emily Warnes, and faculty Judy Mathews; and 2) Research - Jenny Burt, Brandy Clarke, and faculty - Connie Schnoes and Cindy Ellis.

The poster session is part of the education and research activities of Munroe-Meyer which are supported (in full or part) by Project #8188 from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services. The poster session is organized and coordinated by Pat Gromak, Education Director, and Erni Steele, Education Coordinator.

MMI Supports American Heart Association

MMI actively participated in the American Heart Association walk-a-thon, held on May 7. Again this year, MMI exceeded their goal and raised $1,600 for this worthy cause. Thanks to everyone for their generous support.

Special thanks go out to Joanne Johnson (Chairperson and Team Captain), Tina Mendel, Becky Gilbert, Hugh Kam, Gabriella Castro, Deb Reay, Michelle Wiggins, and Pat Gromak and family.

Arts for Hearts

The 4th annual MMI Recreational Therapy Arts for Hearts Art Show and Silent Auction took place on May 11 and 12. Arts for Hearts is sponsored by the C. Louis Meyer Foundation. The show featured artwork created by the children, youth and adults with developmental disabilities who participate in the various Recreational Therapy Programs at MMI, as well as works by local artists. The art show and silent auction raised $4,200.

Special Olympics

A banner displaying the logo of Munroe-Meyer Institute welcomed athletes of all ages and spectators to the gymnastic events for the 2005 Summer Games for Special Olympics Nebraska on May 19. Athletes from around Nebraska competed in floor exercise, vault, all around, uneven bars, balance beam, parallel bars, horizontal bar, and the pommel horse.

The gymnastics events, held in Cahoy’s Gymnastic Training Center in Ralston, were sponsored again this year by MMI. People were so appreciative of MMI’s sponsorship that participants, parents, volunteers, and staff said “thank you” throughout the competition.
**Golf Tournament Held**

The C. Louis Meyer Foundation’s annual “Tee-Up for Disabilities” golf tournament took place on May 20 at Tregaron Golf Course. Over 60 golfers gathered for this four-person scramble. The weather was perfect and a wonderful time was had by all.

The tournament’s honorary chair was Nebraska golf legend, Susan Marchese (*pictured at the left with Sarah Gardells and Greg Blake*). Again this year, Susan conducted a golf clinic before the festivities began.

The event raised several thousand dollars to benefit the adult evening respite and habilitation programs at the Munroe-Meyer Institute, serving adults with developmental disabilities.

**MMI Picnic is Again a Rousing Success!**

On a pleasant spring day, the Institute’s staff (*pictured at the right*) gathered to enjoy another Munroe-Meyer picnic. This event, featuring chicken and drinks provided by Administration and a myriad of salads and desserts brought by employees, was held on MMI’s outdoor playground on June 1.

Planned by the Distinction Through Quality Council under Barb Jackson’s leadership, the picnic welcomes new employees, as well as thanking everyone at MMI for their continuing dedication and hard work.

**Garden Walk Celebrates Its 38th Year!**

Shady retreats and sun soaked landscapes shared the limelight this year with the first annual Garden Faire on May 12. This year’s garden walk participants enjoyed garden walk workshops, demonstrations, the latest garden advice and were able to purchase wonderful gift items.

The annual walk is sponsored by the Munroe-Meyer Guild. Proceeds from the Garden Walk allows the MMI Guild to support scholarships, grants, holiday gifts, student work programs, and a staff appreciation event.

Again this year, the Garden Walk was a great success, raising over $25,000.
Neurobehavioral disorders are the largest group of conditions in the health care of children in developed countries today (~15%). Many neurobehavioral conditions such as autism and attention-deficit-hyperactivity disorders appear to be increasing in number. Adult onset neurobehavioral disorders are becoming increasingly identified. These conditions require disproportionately large amounts of resources for families and practitioners in their care and management. The genetic basis of these conditions have recently come to light. Large amounts of new information about the molecular pathogenesis of these conditions have been published over the past few years. Pioneering work in therapeutics targeted to work at the basic molecular defect of these conditions has begun.

In this light, UNMC/ MMI has one of the top clinical behavioral genetics programs in the country. The scope and outreach of our programs are unparalleled. The breadth and scope of these programs provides an unmatched basis for behavioral genetics interventions. We conduct seven unique multidisciplinary clinics for persons with neurobehavioral disorders. Many of these clinics provide services that can not be found in a ten state area. These clinical services in neurobehavioral genetics are also provided as outreach services to a huge geographic area including Kearney, Winnebago, and Scottsbluff, Nebraska and Rapid City and Pierre, South Dakota. In addition, telehealth for these services has recently been implemented in Scottsbluff. UNMC/MMI already has solid programs in the molecular genetics of neurogenetic disorders. Active programs in the genetics of learning disabilities, ADHD, and neurosensory disorders are in place. All that is needed to ‘complete the circle’ in developing novel interventions is a program in translational therapeutics.

The objectives of the new behavioral genetics program are: 1. To develop one of the top programs in behavioral genetics in the country at MMI. 2. To increase existing basic science research in behavioral genetics. 3. To implement transitional research/therapeutics in behavioral genetics.

The recent recruitment of Dr. Wayne Fisher is the first step in expanding the program to accomplish these goals. Two additional recruits will begin shortly:
1. Genetic epidemiology in conjunction with multiple units on campus
2. One to two additional molecular genetics laboratories doing work in behavioral genetics - with an emphasis in translational research.

**Developmental Medicine**

by Dr. Cindy Ellis

On July 1, Brigette Vaughan, M.S.N., A.P.R.N., became a member of the Department of Developmental Medicine. She will join Drs. Ellis and Needelman on a part-time basis and will provide comprehensive developmental/behavioral pediatric evaluations of patients and follow-up care.

Brigette is originally from Southern Colorado and moved to Omaha in 1990. She received a Bachelor of Science in Nursing Degree from Creighton University in 1995 and completed her training as an advanced psychiatric nurse practitioner at UNMC last December. She is currently a nurse coordinator/investigator in the Psychopharmacology Research Unit in the UNMC Department of Psychiatry and she plans to continue in this position, part-time in conjunction with her clinical work at MMI.

Brigette has extensive experience in pediatric mental health having previously worked as a staff nurse at Uta Halle Girls Village, Cooper Village, and the Mercy Hospital Children & Adult Acute Behavioral Services. She was also the charge nurse at the Child/Adolescent Residential Treatment Center at the St. Joseph Center for Mental Health from 1997-1999. In addition to her clinical expertise, Brigette is an experienced researcher and has been a co-investigator on over 20 research grants and projects in the Department of Psychiatry.

The addition of Brigette will expand the clinical capacity of Developmental Pediatrics to provide comprehensive, expert, family-centered evaluative and management services for children and youth with complex developmental, behavioral, and emotional disorders.
**MMI AmeriCorps and a Day in the Park**

by Dave Burgess

AmeriCorps is a national organization created in 1993 by President Clinton. The AmeriCorps program at Munroe-Meyer received its initial funding from a seed grant from the National Service Inclusion Project, and now receives its funding through the federal government and the Munroe-Meyer Institute. MMI AmeriCorps is one of 48 AmeriCorps projects and programs within the state of Nebraska. The goals of AmeriCorps are to: 1) strengthen the community through community service and volunteerism, 2) bring people with disabilities to the Munroe-Meyer Institute, and 3) help provide services to people with disabilities within the community. Areas within MMI that are utilizing AmeriCorps members are: Psychology, Recreational Therapy, Project BEST-CASE, The Brace Place, and Pediatric Dentistry. AmeriCorps members are also working in MMI’s outreach behavioral clinics and the Columbus Community Hospital.

On May 21, MMI AmeriCorps sponsored its first annual picnic for the kids, parents and members of the Ollie Webb Center. The picnic was held in Omaha’s Hanscom Park at 32nd and Woolworth. With plenty of fresh air and sunshine, add to that kids, games, food and a park, mix well and you have the perfect recipe for fun. There were plenty of games and activities for everyone to try their hand at. The day’s activities included: decorating name tags and coloring goodie bags; a fish pond for kids to win different prizes. A very large parachute that the kids and parents ran underneath; and basketball, sack races, horse shoes and musical chairs. While participating in the activities everyone was welcomed to a large assortment of cookies, cupcakes and other treats.

Taking advantage of the picnic were over 50 kids and parents as well as 40 volunteers from two local Boy Scout troops, Project BEST-CASE, friends, families and more. Volunteers helped with setting up and tearing down the area, serving lunch, and helping out with the different activities. Lunch was provided by HyVee and all the treats for the picnic were donated by staff members of Munroe-Meyer and UNMC.

*All in all, the day, the food, the games and time spent together couldn’t have been any better.*

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**Do You Know About...**

**The Very Special Person Club “The VSP Club”**

The VSP Club is a recreation club located in northwest Omaha for teenagers (from age 12) and young adults with developmental disabilities. The VSP Club is a place where people with developmental disabilities can enjoy leisure time activities with their peer group. Individuals can enjoy a movie theatre, a dance club, a sports bar, a game room, and an exercise room. The club was designed to feel comfortable and inviting and not institutional. The VSP Club provides a safe environment where individuals can be dropped off, and parents and guardians can enjoy respite time when needed.

*For more information call (402) 991-9588 or visit their website at: www.vspclub.org*
Grants

Barb Jackson - Education and Child Development:
1. Received $314,640 - Real Choice Quality Assurance, and $221,000 - Real Choice C-Pass - both funded by Nebraska’s Department of Health and Human Services.
2. Received $50,984 - DD Council Needs Assessment - funded by Nebraska Health and Human Services DD Council.
3. Received $15,673 - Evaluation Promising Models - funded by the University of Nebraska at Lincoln.

Warren Sanger - Human Genetics Laboratories: received $12,359 - Genetic Causes of Childhood Lymphoma - funded by the National Children’s Oncology Group (NIH).

Brad Schaefer - Genetic Medicine: received $81,521 - EPST Portals to Adulthood (Transitions) - funded by Nebraska’s Department of Health and Human Services.

MMI’s Adopt-A-School Activities

Fundraiser Helps JP Lord School

Again this spring, MMI’s support staff organized the 4th Annual Plant Sale, which was held on May 6. The sale raised $230 with the proceeds benefitting MMI’s adopt-a-school, JP Lord. Thanks to everyone at Munroe-Meyer for your generous support. The support staff would like to extend a special thanks to Gwen and Jim Reiser for providing the plants.

Congratulations Class of 2005!

Friday, May 20, 2005 was a very special day for three JP Lord students. Clifton Lipkins, Jordan Nelson and Benjamin Stange were presented diplomas as they rolled across the stage. Members of the MMI’s support staff were on hand to participate in the celebration.

The Media Department would like to extend our thanks to all of those who responded to our satisfaction survey included in the last issue of MMInfo. We would like to share with you our survey results:

Survey Demographics:
- MMI Staff Members = 49
- MMI Students = 2
- MMI Board / Guild Members = 4
- Parent / Consumer of MMI Services = 1

Survey Results:

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**Getting to Know You**

**Becky Gilbert**

Job title: Programmer Analyst

Department: PIO

Years at MMI/UNMC: 10 years

Hometown: Baudette, Minnesota

**The best part of my job is:** There are many parts of my job that are enjoyable. I have the gratification of seeing a project from inception to completion. It is technical, yet there is also a degree of creativity. I truly enjoy working at MMI, the interaction with Project BEST-CASE is a wonderful experience. However the best part is the work environment provided by our boss. She encourages independence, personal growth and is always open to suggestions.

**Tell us about your family:** I am celebrating six months of marriage to Bob. I have two sons, Cole 16 and Sean 14 (Aug 22) and of course our dog Heidi, a Gordon Setter.

**If I could have two or more careers, I would:** I have always wanted to write whether it be novels or articles.

**The accomplishment I am most proud of:** Above all else raising my sons.

**If I had to carry my most prized possession on my back, I would take:** My pictures, they become more important the older I get.

**My favorite book and/or movie is:** Not sure - I enjoy Kay Hooper, Ken Follett, Patricia Cromwell and as far as movies I love the classic Disney movies.

**Not everyone knows that I:** I was a big scaredy cat…I am much better now.

**My favorite way to relax is:** Enjoying a good conversation with family or friends, walking.

**I most admire:** Those people who rise above adversity.

**Three adjectives that best describe me are:** Kind, hard-working, sensitive.

**My greatest pet peeve is:** Rude and inconsiderate people, people who throw their cigarettes or other trash out of their car windows!

**If I could interview anyone - living or dead - it would be:** Madame Marie Curie.

**One day I’d like to:** Travel extensively.

**A defining moment in my life was:** The births of my sons.

**If I could convince people of one thing, it would be:** Communication is the key to the happiness and success of your life, communicate to your significant other, your children, your family, your friends, and in your workplace.
Happy Summer to all. It’s been a busy six months over the first half of ’05. A lot has been accomplished in all of our work in support of individuals with disabilities and their families, but challenges still remain. Fortunately, a number of exciting opportunities have emerged in response to these challenges, but more on that in a minute. Among the activities MMI has had involvement in regarding advocacy and systems change over this period includes:

- Activities in support of addressing gaps and barriers in the area of transportation for individuals with disabilities have been ongoing, with an informational teleconference occurring most recently on June 29th. MMI staff will be working with other stakeholders in order to develop a work plan regarding next steps in this critical area for this next year.
- MMI staff will be participating and participating in the planning for a Transition forum for past and present students in Special Education with the Omaha Public schools.
- MMI staff along with representatives from the DD Council and Nebraska Advocacy Services, have participated on the state team assembled to assist in the planning for the Alliance for Full Participation Summit this coming September, a collaborative effort of the National Consortium for Citizens with Disabilities with the goal of helping chart the national and state course for disability policy and practice for the foreseeable future.
- Institute staff have participated on a number of cross-cutting disability work groups involving, for example, DD Service funding (the Objective Assessment Process), the Maternal and Child Health Statewide Needs Assessment Committee, person-centered planning, and the HHS Real Choice initiatives on quality assurance and self-directed personal assistance services.

Some projected goals for this coming year include looking at opportunities to support the development of leadership and systems change skills in family and self advocates, providing information on the reauthorization of the Individual with Disabilities Education Improvement Act (IDEIA), and varying ways to further support the consumer perspective at MMI. While this may appear an ambitious agenda, help is on the way, so to speak.

I want to take this opportunity to introduce to our new Consumer/Family Coordinator, Shirley Dean (pictured at the right). Shirley brings a wealth of skill and experience to our work, but I’d like to get out of the way and allow her to introduce herself a bit further:

I am very pleased to have the opportunity to work at MMI as a Consumer/Family Coordinator, a position which, as part of our University Center grant, is to address the areas of advocacy, system change and capacity building. These are all areas of great interest to me. I consider working with people with developmental disabilities and their families to be my life’s work. I have been involved in the self-advocacy movement, the parent-to-parent movement, and community services. Some of the places I have had the privilege to work have included: ENCOR, League of Human Dignity, and most recently, Metropolitan Community College. Here at MMI, I am working with Mark Smith to:

- Provide mentoring to families and adults with disabilities,
- Develop means of providing added support for families and consumers involved in MMI,
- Develop ways to infuse the adult consumer and family perspective into MMI,
- Assist MMI staff in identifying ways to reach traditionally underserved populations, and
- Enhance student training on issues surrounding family-centered care.

Some of the projects I will initially be working on include: providing resources and support to teens and families who come in to the new “transition” clinic (Portals Project), which will be starting soon; the development of leadership training for parent and self-advocates on systems change; developing educational sessions for students within MMI.

I look forward to meeting and working with consumers, students and staff of MMI.

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Bridges For Families

by Mark Smith

The mission of the Munroe-Meyer Institute is to improve the quality of life for persons with developmental disabilities and their families.

The MMInfo Newsletter is developed and distributed on a biannual basis by the Media Center Munroe-Meyer Institute

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Thank you to all who contributed to this issue of Munroe-Meyer Institute’s MMInfo Newsletter.