



People First: Inside IBR

The Institute for Basic Research
in Developmental Disabilities



News and Information from the New York State Office for People With Developmental Disabilities

June 2012

A Letter from the Commissioner



Dear Friends and Colleagues:

The tens of thousands of direct support professionals (DSPs) across the state are the backbone of this organization. These are incredibly dedicated and caring people who often forgo time with their own loved ones to make a difference in the life of an individual with a developmental disability.

Knowing the challenges that come with a career in direct support, especially in light of the intense scrutiny and many changes that have been occurring at OPWDD, I was very proud to learn that one of our own

was honored as the 2012 DSP of the Year by the American Network of Community Options and Resources.

Some of you may know this year's honoree, Lynda DiPressi, a DSP at New Horizons Resources, Inc., in the Hudson Valley. Lynda is certainly deserving of this distinction. She is one of fewer than 300 people in the state who have earned certification as a direct support professional from the National Alliance for Direct Support Professionals, which required an extensive classroom and online training program of more than 200 hours of instruction, as well as a portfolio project demonstrating her proficiency in at least eight core competencies of being a DSP. She did all of this while working full time.

I am humbled by DSPs like Lynda—and there are thousands of you in both state and nonprofit service—who, day after day, enrich the lives of the individuals we serve. You know our individuals well; their strengths, their health needs, their interests, their personalities, and their loved ones. You keep them safe, and help them to explore their communities and experience new things.

You are also continually engaged in efforts to improve our system and our quality of care, and I thank you for that.

Please join me in congratulating Lynda DiPressi on her incredible achievements. I also wish to extend my deepest appreciation to all DSPs who, like Lynda, inspire me each and every day.

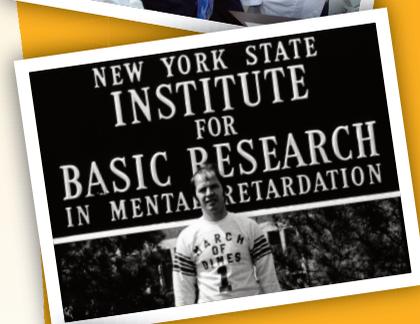
Sincerely,

Courtney Burke
Commissioner



Governor Cuomo Introduces Legislation to Protect Vulnerable New Yorkers

Governor Andrew M. Cuomo has introduced legislation to establish the strongest standards and practices in the nation for protecting people with special needs and disabilities. His bill will create a new Justice Center for the Protection of People with Special Needs, an initiative that will transform how the state protects over one million New Yorkers in state operated, certified, or licensed facilities and programs. *Continued on page 3*



Issue Highlights

IBR Receives Three-Year Grant to Study the Effects of Prenatal Folic Acid

Women's History Month Celebration

IBR Employees Walk the Walk for the March of Dimes

IBR Receives Three-Year Grant to Study the Effects of Prenatal Folic Acid on Brain Development



Left to right: Principal investigator of the newly funded March of Dimes project, Mohammed Junaid, PhD; and co-investigators W. Ted Brown, MD, PhD, and Kathryn Chadman, PhD.

IBR has been selected to receive a three-year grant from the March of Dimes Foundation to conduct research on the effects of excessive dietary folic acid intake during pregnancy on newborn brain development.

The grant will be used to conduct studies in laboratory mice to determine whether excessive folic acid intake by mothers during pregnancy has any effect on the behavior of their babies. Folic acid is an essential vitamin prescribed to pregnant women to prevent the occurrence of neural tube defects in newborns. Mandatory fortification of dietary foods with folic acid was recommended and mandated by the Centers for Disease Control and Prevention and the U.S. Food and Drug Administration in 1996. Folic acid can promote heritable changes in gene function that occur without a change in the underlying sequence of the DNA. These epigenetic changes are responsible for controlling the amounts of genes that are copied from the DNA. The IBR study will evaluate whether too much folic acid causes any undesirable changes in the developing brain, and whether these changes are responsible for abnormal behaviors.

The principal investigator and lead researcher of the project will be Mohammed Junaid, PhD, head of the Structural Neurobiology Laboratory in IBR's Department of Developmental Biochemistry. Additional co-investigators, both from IBR, will be Kathryn Chadman, PhD, head of the Behavioral Pharmacology Laboratory in the Department of Developmental Neurobiology, and W. Ted Brown, MD, PhD, IBR director and chair of the Department of Human Genetics. Dr. Chadman will evaluate the behaviors of the mice that are born to dams fed various levels of folic acid during pregnancy. Dr. Brown will provide expert advice on the regulation of brain-specific imprinted genes and their involvement in neuropsychiatric conditions.

Over the last decade, investigators have conducted studies to identify the genetic factors responsible for autism. So far, less than 5% of the autism cases that have been identified have contributing genetic factors. The IBR researchers reasoned that environmental factors might play a wider role in the cause of autism. They found that a potential environmental candidate was the vitamin folic acid, which has hitherto been considered a safe, water-soluble

vitamin. The IBR scientists carried out a pilot study of the effect of folic acid on human lymphoblastoid cells, and to their surprise, found widespread changes in gene expression. Prominent among the genes whose expression was decreased by folic acid was the *FMRI* gene, down-regulation of which causes fragile X syndrome in humans. Fragile X syndrome is the most common known cause of inherited intellectual or developmental disability as well as the most common known single-gene cause of autism. In response to these findings from their pilot study, the IBR researchers submitted their grant proposal to the March of Dimes Foundation.

This study of the nature and the severity of the effects of prenatal folic acid exposure is expected to have far-reaching public health implications. It will be the first study to investigate the dietary levels of folic acid necessary to cause deleterious epigenetic modifications.

Dr. Brown said, "Through this award, IBR will continue its commitment to improving methods for identifying the risk for autism spectrum disorders and neuropsychiatric disorders."



Mohammed Junaid, PhD, explaining his newly funded research project at the 35th Annual Tina Russo Student Convocation, sponsored by the Staten Island Division of the March of Dimes.

Governor Cuomo Introduces Legislation to Protect Vulnerable New Yorkers

Continued from page 1

Since the bill's introduction, more than 120 organizations have joined a coalition in support, and thousands of people have attended nearly a dozen public presentations on the bill.

The Justice Center will have a special prosecutor and inspector general for the protection of people with special needs who will investigate reports of abuse and neglect and prosecute allegations that rise to the level of criminal offenses. It will also include a 24/7 hotline run by trained professionals, a comprehensive statewide database that will track all reports of abuse and neglect, and a statewide register of workers who have committed serious acts of abuse who will be prohibited from ever working with people with disabilities or special needs.

"This bill puts forth unprecedented reforms that will transform how New York State protects and cares for people with special needs and disabilities," said Governor Cuomo. "This is exactly the type of agency that the patients and their family and friends deserve."

Governor Cuomo's proposed Justice Center for the Protection of People with Special Needs will have primary responsibility for tracking, investigating, and pursuing serious abuse and neglect complaints for facilities and provider agencies that are operated, certified, or licensed by the following six agencies: OPWDD, the Department of Health (DOH); the Office of Mental Health (OMH); the Office of Children and Family Services (OCFS); the Office of Alcoholism and Substance Abuse Services (OASAS); and the State Education Department (SED). The Justice Center will also absorb all functions and responsibilities of the Commission on Quality of Care and Advocacy for Persons with

Disabilities, with the exception of the Federal Protection and Advocacy and Client Assistance Programs, which will be designated to a qualified nonprofit.

The proposed legislation will also replace confusing and inconsistent definitions of abuse and neglect in various laws and regulations with a single consistent standard applicable to human services systems.

New Yorkers can learn more about the Justice Center at www.Justice4SpecialNeeds.com.

The governor's legislation was developed in part from recommendations outlined in *The Measure of a Society: Protection of Vulnerable Persons in Residential Facilities Against Abuse and Neglect*, a special report prepared by Clarence Sundram, the governor's special advisor on vulnerable persons. A copy of this report is available at: www.governor.ny.gov/assets/documents/justice4specialneeds.pdf.



Request a Cutting Board

As part of the system-wide plan for consistent food preparation, OPWDD has produced lightweight, flexible, and machine washable cutting boards. Cutting boards will be distributed to all state and nonprofit group homes. If you prepare food for a person with a developmental disability outside of these settings, you may have a cutting board mailed to you—just email your name and address to communications.office@opwdd.ny.gov with "cutting board request" in the subject line.

Grill Season Recipe: Easy Grilled Pork Chops

Ingredients

- 8 (1/2-inch) bone-in pork chops (about 3 ounces each)
- 1/4 cup honey
- 2 tablespoons vegetable oil
- 1 tablespoon apple cider vinegar
- 1 teaspoon ground cumin
- 1/2 teaspoon red pepper flakes
- Salt and freshly ground black pepper

Directions

Begin by making the marinade. In a small bowl, whisk together the honey, oil, vinegar, cumin, and red pepper flakes.

Sprinkle both sides of the pork chops with salt and pepper and place in a resealable plastic bag with the marinade. Let rest on the counter for 1 hour.

Heat a grill or grill pan over medium heat. Remove the pork chops from the bag and lightly sprinkle with salt and pepper. Place on the grill and cook until the pork chop releases from the grill, about 4 minutes. Flip and cook on the other side for another 3 minutes. If using a grill pan, be sure to do in batches so you don't steam the chops.



Women's History Month Celebration

IBR employees gathered in the seminar room on March 28 to celebrate the accomplishments of 10 of their colleagues on the occasion of National Women's History Month. The honorees were:

Maureen Gavin, BSN, RN-BC, CDDN, George Jervis Clinic
Iyabide Labinjo, Business Office
Elizabeth Lennon, PhD, Department of Infant Development
Sangita Mehta, Department of Molecular Biology
Deborah Pang, MPH, Department of Psychology
Eugenia Sajery, Department of Molecular Biology and Jervis Clinic
Valerie Schwenk, Digital Microscopy Laboratory
Diane Troyano, Payroll Office
Mary Sheelagh Vietze, Department of Psychology
LingLing Ye, Department of Human Genetics

The honorees have worked at IBR an impressive combined total of 210 years.

The event was organized and hosted by the IBR Affirmative Action/Human Relations Committee (AA/HRC), chaired by Jeanette Mitchell. IBR Director W. Ted Brown, MD, PhD, made opening remarks, providing a background of the history of Women's History Month. He noted that this year's theme was 'women's education—women's empowerment.'

Each honoree was introduced by her supervisor, who shared an appreciation of the honoree's contributions to IBR. Fuller biographies of honorees were provided in a brochure distributed at the event. After each introduction, honorees spoke, almost unanimously of their gratitude for working at IBR. Perhaps Labinjo spoke for all the honorees when she said, "I have to say thank you. It's a pleasure to work with all of you!"

The celebration concluded with a hot luncheon prepared by the Lifestyles Café, at Lifestyles for the Disabled, which was served by AA/HRC members.



Pictured with Dr. Brown and Jeannette Mitchell (far right) at IBR's celebration of National Women's History Month were honorees (left to right) LingLing Ye; Deborah Pang, MPH; Iyabode Labinjo; Valerie Schwenk; Diane Troyano; Eugenia Sajery; Maureen Gavin, BSN, RN-BC, CDDN; Mary Sheelagh Vietze; and Elizabeth Lennon, PhD. Not pictured is honoree Sangita Mehta.



Dr. Brown welcomes attendees to IBR's celebration of National Women's History Month.

IBR Employees Walk the Walk for the March of Dimes

On April 29, IBR employees participated in the 5-mile-long March for Babies on Staten Island to support the March of Dimes' (MOD) efforts to prevent birth defects, premature births, and infant mortality. Robert Freedland, PhD, Director of the Programs in Neuroscience and Developmental Disabilities, and Maureen Gavin, BSN, RN-BC, CDDN, Nurse Administrator of the Jervis Clinic, served as co-captains of Team IBR. Together, they organized a kick-off breakfast and raffles on April 27 and marshaled colleagues' support for the walk. Freedland also prepared Team IBR-branded items as incentives for participation, as he has been doing since 2003.

This year marked the 37th year IBR employees participated in the walk. It was Jimmy LaMantia, retired IBR chief electrician, who first solicited the support of IBR staff for the walk. He became involved at the suggestion of his sister, the late Rosalie Flanagan, an executive board member and chair of the MOD Staten Island Division, and remained involved for more than 30 years.

"Back in 1975, when we started doing the walk," LaMantia recalled, "we walked more than 20 miles around Staten Island!"

Also lending a hand to the walks has been Karen Amble, LMSW, Director of Clinical Services in the Jervis Clinic. For the past 5 years, she has served as a sensitive issues spokesperson for the walk and worked at the MOD family tent on walk day, helping staff and volunteers with any issues that may present themselves.

In addition to supporting the annual March for Babies, several IBR staff



At the MOD March for Babies on April 29, Mohammed Junaid (third from right), and Kathryn Chadman (third from left), received a ceremonial check for the grant Dr. Junaid was awarded this spring from the MOD. Also pictured, left to right, are Team IBR co-captains Robert Freedland and Maureen Gavin as well as two representatives of the MOD Staten Island Division.

members have been sharing their expertise on MOD committees. Amble and Nancy Zellers, MS, CGC, genetic counselor and coordinator of the Jervis Clinic's Fragile X Center, have served on the Staten Island Division's Program Services Committee. Anne Gordon, MS Ed, head of the Early Intervention Evaluation Center, is currently chair of the Staten Island Division's Program Advisory Committee and is a member of the Greater New York State Chapter's Program Services Committee. All three women have reviewed community grant applications on the Staten Island committee, and Gordon also on the state committee.

From 1990 through 2009, Gavin, Gordon, Zellers, and the late Marie Goepel individually collaborated with the MOD Staten Island Division to organize its annual Fetus at Risk Conference, which addressed prenatal health and development. Evelyn Nesbitt, currently a secretary in the Department of Human Genetics, provided administrative assistance in the conference planning.

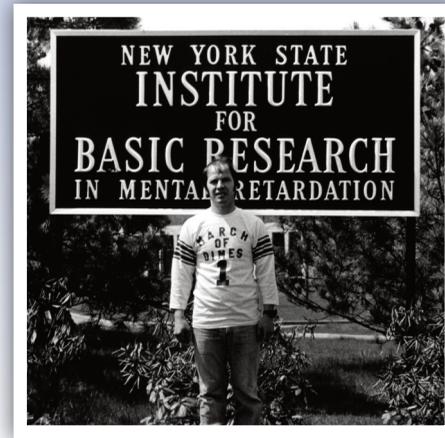
In 2011 and 2012, Zellers and Gordon served on the planning committee of the division's Mothers-to-Be educational program. Gordon also presented a workshop on newborn development at the 2012 event, which was hosted by IBR.



Team IBR at the March for Babies (left to right): Maureen Gavin, Karen Amble, Mohammed Junaid, Kathryn Chadman, Victoria Mariocca, Stephen Chan, Jimmy LaMantia (now retired), Evelyn Nesbitt, Glenn Heaney, Ashfaq Shiekh, Julian Freedland, and Robert Freedland.

Since 1995, IBR has hosted the annual Tina Russo Student Convocation, sponsored by the MOD Staten Island Division to increase awareness of the health sciences among local high school seniors. Goepel and Gordon individually organized several of the events. Thousands of students have attended the convocations, named in memory of a long-time volunteer and chairman with the MOD Staten Island Division. IBR Director W. Ted Brown, MD, PhD, was the keynote speaker at this year's event, held on April 19. His presentation, on new developments in genetics research, proved quite engaging for attendees and elicited insightful questions.

Several IBR researchers and clinicians have received grants from the MOD recently. Among those awarded Greater New York Chapter MOD



IBR chief electrician Jimmy LaMantia (now retired), pictured here in 1976 in front of IBR, initiated IBR employees' support of the March of Dimes Walk for Babies.

Community Grants are Gavin, to help enhance resources in the Jervis Clinic for families and healthcare professionals, and Jervis Clinic genetic counselor Jacquelyn Krogh MS, CGC, to develop fact packs on genetics, reproductive genetics, and pediatric genetics. MOD national research grants were awarded this spring to Mohammed Junaid, PhD, Department of Developmental Biochemistry (see related article), and Nanbert Zhong, MD, Department of Human Genetics.



Dr. Brown presents the keynote address on April 19 at the 35th Annual March of Dimes Tina Russo Student Convocation, hosted by IBR.

Katie Beckett, Who Inspired Health Reform, Dies at 34

Reprinted from the May 22, 2012 edition of the *New York Times*.

Katie Beckett, who was 3 years old and had been hospitalized almost since birth when President Ronald Reagan invoked her case as an example of irrational federal regulation in 1981—a crucial moment in the movement toward government support for home health care—died on Friday in Cedar Rapids, Iowa, in the hospital where she was born. She was 34, more than three times the age her doctors had predicted she would reach.

The cause was a digestive disorder not related to the brain inflammation that led to her lifelong respiratory difficulties, her mother, Julie Beckett, said.

On Monday, the secretary of health and human services, Kathleen Sebelius, called Ms. Beckett “an inadvertent pioneer in the civil rights movement for people with disabilities” and the inspiration for regulations that have allowed more than 500,000 disabled children to live at home since 1981.

Four months after her birth at St. Luke’s Hospital in 1978, Katie contracted viral encephalitis, leaving her partly paralyzed, unable to swallow and barely able to breathe on her own. Her parents found themselves in a bureaucratic trap. They wanted to manage her care at home with a ventilator and began lobbying politicians and bureaucrats.

The case led to what is known as the Katie Beckett Waiver.

Katie qualified for Supplemental Security Income, a Medicaid program run by the Social Security Administration. Under the old rules, if she had been taken home, her parents’ incomes would have been counted against her, and she would have lost eligibility for the aid. Yet her hospital care was costing \$12,000 a month, six times as much as home care would have cost.

President Reagan heard about Katie from Vice President George Bush, who been told about her by Thomas Tauke, a Republican congressman from Iowa. At a news conference on Nov. 10, 1981, Mr. Reagan cited Katie’s case as an example of “hidebound regulations” that caused “tremendous expense to the taxpayers.” The rules, he said, forced her to stay in the hospital even though she would be better off at home.

A day later, the secretary of health and human services, Richard S. Schweiker, waived the rules to let Katie return home without the loss of federal support. He also created a review board to handle similar cases. When she left the hospital a week before Christmas in 1981, Katie received a rag doll from the Reagans and a note wishing her and her family “the loveliest holiday ever.”

Ms. Sebelius said that “thanks to her mother, Julie’s, tireless advocacy, in



1982, Medicaid policy fundamentally shifted” toward supporting home health care.

Mary Katherine Beckett was born in Cedar Rapids on March 9, 1978, to Julie and Mark Beckett. Besides her parents, she is survived by a stepsister, Chelsea.

Home care worked for Katie Beckett, her mother said. Although Ms. Beckett required nursing care an hour a day, five days a week, and 12 hours a day on a ventilator, she graduated from Mount Mercy University in Cedar Rapids in 2001 with a degree in English and creative writing. She held several jobs over the years, including one as a secretary in a homeless shelter.

There were extended hospital stays, but she had applied to graduate school and was writing a novel. “She wouldn’t let me read it,” her mother said, “but she loved young-adult romance novels.”

She added: “She lived a fairly normal life. She wasn’t homebound.”

AHRC’s New Video on Giving Back – Volunteering in the Community



Did you know that over a thousand individuals served in AHRC New York City adult day programs spend part of every day helping others at more than 200 volunteer sites in the community?

Not only is volunteering a meaningful activity for the people who participate, but the many nonprofits, nursing homes, hospitals, public parks, and organizations dedicated to helping people in need appreciate the assistance.

Check out a touching video produced by AHRC NYC about their volunteer programs on YouTube by searching: “Volunteers AHRC New York City 2012 Event Video.”

DDSO Creates Homes any Family Could be Proud of

The following article was written by the office of State Senator Tom Libous.

It's a busy 7:30 am in the house on Columbus Street in Binghamton. Neil is getting in his morning walk in the treadmill; Todd is pulling on his coat to head to work. Chris and Ryin are listening to the television as they get their things together, and Fred is outside smoking his pipe.

Kevin Williamson has to keep them organized. His job? Soccer mom.

But not just any soccer mom. Williamson oversees the house for the Broome Developmental Disabilities Services Office. His charges are six men in their middle ages, so if the minute-to-minute tasks are similar to anyone trying to keep a house organized, the work he and the nine people he supervises require some advanced skills.

One of the residents is blind; another uses a wheelchair. A strobe light and mechanical bed-shaker had to be installed because another resident can't hear a fire alarm. One has epilepsy so severe he once broke a leg during a grand mal seizure.

Williamson must cope with all of that.

"This house—as far as community access and independence goes—is as close as we get to them living on their own," Williamson said.

Still, "The mornings are busy for me. People are getting up, getting ready for work," said Williamson, who typically starts his day about 5 am, and sometimes at 3:30 am. "They pack their lunches the night before. They know the routine; they get it done."

Neil and Chris snipe at each other as they get their coats on, more like brothers than housemates. They have a busy day ahead.

Neil, Chris, and Fred get into the back of the van, and Todd walks the several blocks to Country Valley

industries in Johnson City, where he'll catch a ride to his job with NYSEG. Williamson loads Ryin and his wheelchair into the van.

Williamson drops Chris and Neil off at Achieve's facility in downtown Binghamton. They have jobs and they need to contribute to the household. They get to keep the first \$65 they earn, but pay a portion of the rest for household expenses.

Ryin and Paul are dropped off at the Chester B. Lord School on the West Side for day habilitation, and another housemate is dropped off at Achieve's facility on Upper Front Street.

Williams checks the mail at the headquarters on Airport Road and chats with his boss, Carla Simpson. Then it's back to the house, where he has his own chores. He meets nurse Mary Alice Luce, who's stopping by to update medical records—each chart is a three-ring binder that tops 10 pounds.

"A good share of my work is oversight," said Luce, who monitors 30 residents at several homes. "It's a lot of paperwork."

While she checks the charts, Williamson checks the house. Weekly inspection—check the fire and carbon monoxide detectors, water temperature (no more than 110 degrees), the utensil drawers to make sure the knives and forks are where they should be. He reviews the emergency exit plan.

"Our neighbors, Chet and Kay, are the nicest people," he said. Their house is the rally point during the repeated drills. By regulation, Williamson and his staff must get the residents to safety in less than 3 minutes—a challenge when one considers the physical challenges a wheelchair and hearing and vision impairments present. Typically, they're out in a minute and a half.



Then it's on to some paperwork in his "office," a corner of the living room. Williamson can't complain. His office has a couch, easy chairs, television, and a kitchen in the next room. It's done in pleasant earth tones, soft carpet, and quaint trim—much of Williamson did himself.

But his thoughts drift to his charges. He's not sure what's for supper yet. It'll have to be something quick done by the next shift because tonight is grocery shopping night. Special Olympics was last night, and there will be more social activities on a nightly basis.

And he does have to build in some unstructured time. "The guys who come here—they're like a family," Luce said. "They talk around the table."

Each home is different, Williamson said. One home may have residents with behavior issues; another with related health issues. His brother runs a home a couple of blocks away where the residents—all young men—tend to wander, so locks have to be set on the doors.

"Every person placed in a house is placed there for a reason," Williamson said.

"These people weren't dealt a fair hand in life. It kind of makes you appreciate what you have," he said. "Sometimes I feel I'm missing something because I see how happy they are."

Strengthening OPWDD Services and Supports

Join the movement to:

-  **Empower** individuals and families to have a stronger voice and more flexible services.
-  Provide the most **person-centered**, integrated services possible.
-  Ensure that all of an **individual's needs** are met in a coordinated way.
-  Measure quality of care based on an individual's **personal outcomes**.
-  Ensure **effectiveness** and efficiency in OPWDD operations.

Since April 2011, thousands of individuals, family members, advocates, and employees have come together to develop OPWDD's People First Waiver.

Join the discussion.



Find your local waiver contact at www.opwdd.ny.gov/2011_waiver.