



People First: Inside IBR

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



October 2011

Mark Your Calendar! Works For Me on October 26

OPWDD is holding its fourth annual Works For Me event on October 26 from 10 am to noon in the Hart Lounge at The Egg at the Empire State Plaza in Albany. This event coincides with National Disability Employment Awareness Month, and honors businesses that employ people with developmental disabilities and the employees who are succeeding in these positions.

The unemployment rate for individuals with developmental disabilities is 85 percent. OPWDD is committed to helping people with developmental disabilities gain employment, and our goal is to double the number of people with developmental disabilities who are employed. Businesses that hire individuals with developmental disabilities are tapping into a pool of dedicated and hardworking employees who will improve their bottom line. Individuals with developmental disabilities who are employed are contributing to their community, improving their own quality of life, and becoming self sufficient by earning a paycheck.

This year, OPWDD will honor five businesses in the following categories: small business, medium-sized business, large business, corporate partner, and government/nonprofit business. Albany FOX23 news anchor John Gray will serve as master of ceremonies.

Reserve your seat online! Go to: www.opwdd.ny.gov/cee/wfm_save_the_date.jsp.



Fire Prevention Week: October 9-15, 2011

October 9, 2011, marked the beginning of Fire Prevention Week in the United States. Fire Prevention Week was established to commemorate the Great Chicago Fire, the tragic 1871 blaze that killed more than 250 people, left 100,000 homeless, destroyed more than 17,400 structures, and burned more than 2,000 acres. The fire began on October 8, 1871, but did most of its damage on October 9.

According to popular legend, the fire broke out after a cow belonging to Catherine O'Leary kicked over a lamp, setting first the barn, then the whole city on fire. People have been blaming the Great Chicago Fire on the cow and Mrs. O'Leary for more than 130 years.

To mark Fire Prevention Week, please take the time to review fire safety practices at home and in your workplace. The New York State Office for People With Developmental Disabilities has several procedures on fire safety that must be practiced. Fire evacuation plans, fire drill procedures, and other fire safety-related topics should be reviewed.

Remember: fire doubles in size every minute. Fire prevention depends on all of us.

A Letter from the Commissioner



October 12 officially marks the first six months of our administration—and it is important that amid the reforms taking hold throughout our system that we track our progress and continually review the changes we have made in order to demonstrate that we are achieving our goals. Progress has been substantial, but a long road remains ahead, as we all partner to develop a system that really puts people first and makes New York the national model for care of individuals with developmental disabilities. And I am very pleased that we continue to receive all of the

ideas, concerns, and suggestions that we do. Individuals, family members, advocates, OPWDD staff, nonprofit providers, and other stakeholders are committed to the difficult but necessary task ahead.

Next month's newsletter will discuss the critical reforms already in place, which have focused heavily on the health and safety of individuals in our care, as well as workforce excellence.

As one of our next steps, we have an obligation to recruit the best employees possible, and provide our great workforce with the tools and resources they need to succeed.

This administration will be developing and implementing new training programs and seeking innovative opportunities for employees. We will be working hard to educate all stakeholders on how the reforms affect them, and also focusing strongly on culture change: rebuilding morale throughout the field, and creating a positive environment of trust.

This is a long process. It is important that we all have realistic expectations and recognize that change does not happen overnight, but we are successfully putting the pieces in place to continue our progress—with your help.

Sincerely,

Courtney Burke, Commissioner



Issue Highlights

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Shine the Light on Domestic Violence



W. Ted Brown, MD, PhD

IBR Receives \$2.2 Million Grant for Fragile X Syndrome Research

Commissioner Courtney Burke has announced that IBR has received a \$2.2 million grant for research on Fragile X syndrome. The four-year cooperative agreement grant has been awarded by the Centers for Disease Control and Prevention (CDC), through its National Center on Birth Defects and Developmental Disabilities (NCBDDD).

IBR Director W. Ted Brown, MD, PhD, will serve as principal investigator for the project. An internationally recognized expert on Fragile X syndrome, he will provide overall supervision of the project and maintain close cooperation and contact with the CDC and the project's collaborators: the Fragile X Clinical and Research Consortium (FXCRC), the National Fragile X Foundation (NFXF), and the Data Coordinating Center at Columbia University. *Continued on page 2*

Shine the Light on Domestic Violence

Throughout October, OPWDD is participating in the statewide "Shine the Light on Domestic Violence" initiative coordinated by the state Office for the Prevention of Domestic Violence (OPDV).

OPWDD launched its *I Spoke Out* campaign earlier this year to ensure that people who witness abuse report it. October as National Domestic Violence Awareness Month is another opportunity for everyone to recommit themselves to preventing abuse.

OPWDD will be featuring information on its website about domestic violence awareness and is encouraging people to wear purple, the symbolic color for domestic violence awareness, on October 19.

For more information about domestic violence awareness and OPWDD's *I Spoke Out* campaign, visit www.opwdd.ny.gov throughout October.

"Like" us on Facebook

The New York State Office for People With Developmental Disabilities is on Facebook. New media has proven to be one of the most effective means of distributing information to employees and other stakeholders, and the agency will be using its Facebook page to distribute press releases, share stories about people in our care and the employees who have dedicated themselves to service, and more.



IBR Receives \$2.2 Million Grant for Fragile X Syndrome Research

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The grant will be used to develop a comprehensive approach to large-scale collection and analysis of structured, longitudinal data for patients with Fragile X syndrome and will bring better care to the more than 100,000 Americans affected by the condition. 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.

Approximately 4,000 males in New York are affected by Fragile X syndrome, and 1 in 250 women are carriers of this gender-linked condition.

This project will build on the infrastructure that was established with funding from a previous CDC contract that is now in its final year. It will have a greatly increased focus on data collection: more data, better data, and data analysis. Collection of pilot longitudinal data will be based on direct interaction with, and medical evaluation of, patients who receive services at clinics in the FXCRC. The FXCRC currently consists of 25 clinics in the United States, including the Fragile X Center at IBR's George A. Jervis Clinic.

"This collaborative grant will provide the resources necessary to improve the care, health, and lives of individuals with Fragile X syndrome, with potential benefits to other groups affected by intellectual disabilities," said Commissioner Burke in announcing the award.

Dr. Brown said, "We will now be able to develop a data collection and analysis approach that will lead to a greater understanding of this syndrome, co-occurring conditions, and associated risk factors, and conventional treatments. This approach could provide valuable information for targeted interventions."



Boy with Fragile X syndrome and his mother

IBR Hosts 9/11 Memorial Blood Drive

IBR hosted a blood drive on September 8th in commemoration of the 10th anniversary of the September 11th attacks. Employees of IBR and the Staten Island Developmental Disabilities Office and community members participated. The event, conducted by the New York Blood Center, was organized by Bruce A. Patrick, MS, a research scientist in IBR's Humoral Immunology Laboratory.

The drive was one of many Patrick has organized at IBR. Employed at IBR since 1979, he has spearheaded its quarterly blood drives since 1986. Patrick organizes the drives with the help of blood captains throughout the three Institute buildings.



Bruce A. Patrick, MS

"With their help, and support from the IBR administration, we have been quite successful," he said.

An estimated total of 3,000 pints of blood have been donated at the drives he has led. As many as 80 pints have been donated at a single drive, he recalled.

"That happened in the summer of 1990, during the Gulf War."

"I get a feeling of satisfaction out of running a successful drive. And I enjoy helping my coworkers, a dedicated group of donors, to donate in a convenient and congenial setting," he said. Participants in the drives have attested to the witty repartee Patrick provides while they rest and replenish with beverages and snacks after their donations. "Bruce's sense of humor makes the donation process pleasant," one donor said.

With the smaller employee base at IBR now, donations have decreased. "We and the New York Blood Center have also noticed," said Patrick, "that younger people are less likely to donate. We hope to come up with ways to encourage them to participate."

"Donating blood is a great way for IBR employees to support our community."



Love Knows No Boundaries: Bill and Taneesh's Story

Bill Mannion and Taneesh Anderson met in the summer of 1996 at a Lexington Center ARC pre-vocational program in Gloversville.

After becoming close friends they began dating and their relationship grew. After two years, the possibility of marriage came up. Uncertain about how to proceed, they asked for support from family and people at Lexington.

Lexington staff provided Bill and Taneesh the information and support they needed to help them along the way. They went through the agency's couples counseling program to learn what to expect and to discuss their mutual goals and aspirations.

They decided to first live in the same supported house and once there was an available room, Taneesh moved into Bill's home. While they maintained separate bedrooms, it gave them the opportunity to be closer and spend more quality time together. Going to the movies, dinner, and shopping became easier and Bill would even occasionally surprise Taneesh with a candlelight dinner at the house. Their love and commitment to each other continued to grow and they were certain they wanted to take the next step.

In April 2010 they were able to move into a newly-constructed supported home in neighboring Johnstown, NY, with four of their friends. Each of them was involved in the planning,

design, and decorating of their new home. Bill and Taneesh had special adjoining rooms, which let them be close to each other but still allowed for some privacy and accommodations for their special needs. Since everyone living there uses a wheelchair, everything in the house was designed to support their independence and active lifestyles.

Bill and Taneesh announced their engagement on April 4, 2010.



On August 20, 2011, on a beautiful summer day, the glowing bride was escorted down the aisle by her father. What made this even more special was that Taneesh was able to "walk" down the aisle. Taneesh was determined to fulfill this dream, and after months of tenaciously working with her Lexington physical therapist, she was able to gain the strength and skill to get out of her wheelchair and walk a short distance.

Her dream became a reality in front of a gathering of teary-eyed family and friends.

An elegant reception followed the nuptials, which included food, dancing, and amazing memories. Bill and Taneesh Mannion's story of devotion and commitment has inspired everyone who knows them.



Villa Lombardi's
877 Main Street
Holbrook, NY 11741,
October 27, 2011
6:45 P.M.

The LIDDSO Employee Recognition Dinner: the Must Have Ticket of the Season

The red carpet will roll out once again on October 27 for the Long Island DDSO Employee Recognition Dinner. The dinner will be held at Villa Lombardi's in Holbrook. This is the premiere Long Island DDSO event of the fall when the organization says, "thank you," to its veteran employees with 25, 30, 35, and 40 years of service. The event is routinely sold out, as more than 300 attendees dress to the nines to step out and celebrate what it means to be a member of this family and to be engaged in our inspired line of work. Those who are not being honored come out in droves to support their colleagues.

This gala is financed through the Human Relations Committee's fundraising efforts and by donations from CSEA and PEF. As a result of these endeavors, ticket prices are kept very low. The celebration will be the result of the collaborative efforts of members of the Recognition Committee, 10 key staff who began planning the details of the occasion in August.

Everything from the printing of tickets to the photography is done by volunteers from the committee.

The party will begin with a cocktail hour that includes hot and cold buffets. A cash bar will be available throughout the evening. Award presentations will coincide with dinner, dancing, and dessert.

There is a reason why this celebration is historically such a huge success. Every year, Yolanda Sahagun, director of Human Resources, works tirelessly behind the scenes to coordinate and synchronize all the hundreds of isolated details into a balanced, joyous, and festive occasion.

It is likely the Employee Recognition Dinner will sell out early, so in order to avoid disappointment, it is recommended that interested parties reserve tickets without delay. Tickets are \$45. Please call 1-631-493-1839 for your ticket reservation.

In raising our glasses to salute our employees, we also celebrate our vital and essential work: Vivat crescat floreat—"may it live, grow and flourish."

Long Island Advocates Share their Stories in Albany

In August, the "FREE Your Mind" Speaker's Bureau, a program of the Family

Residences and Essential Enterprises, Inc. (FREE), visited Albany to share their stories and aspirations with Commissioner Burke and OPWDD's central office leadership. Members of the Speaker's Bureau, which is made up of several individuals with developmental disabilities—regularly visit communities throughout the state to share their stories and spread awareness about living with developmental disabilities, the importance of advocacy, and the power of positive language. Those who presented in Albany were Monique Medina, Anthony Urbano, and Sean Stuber.

They shared their experiences of living with a developmental disability and provided an inside look into their lives. Monique, Anthony, and Sean shared powerful and moving examples of what it means to persevere through the stigmas often attached to people living with developmental disabilities and to achieve their goals.

Anthony told his story of growing up in a family where he was taught that he was no different than anyone else, and he was expected to do all the things everyone else did. He now works at FREE as a full-time employee in the accounting department. Monique, who not only is a strong self-advocate, also advocates for others, and is an active member of the Bethpage Theater Program and Choir. Sean, who has overcome homelessness, had traveled to Albany as a member of the Legislative Action Committee at FREE, and recently has been asked to represent Best Buddies New York as a Community Hero. He joined the Speaker's Bureau to remind the world not to assume that everyone who has a disability is the same.

Lisa Caffrey, FREE's volunteer and advocacy coordinator, noted that "the speakers are self-advocates—the message has a much greater impact on the community when the stories come from them."

Honoring Direct Support Professionals

Marking National Direct Support Professional (DSP) Recognition Week in September, OPWDD used the opportunity to promote and support the work of some of the great dedicated direct support professionals who provide care for the 126,000 individuals with developmental disabilities in our state.

In all, 27 professionals who work on the service front lines were honored by Commissioner Courtney Burke and the agency's 13 Developmental Disabilities Services Offices (DDSOs). Similar ceremonies occurred around that state that recognized the work of nonprofit provider DSPs, as well.

The celebration comes amid vast reforms at OPWDD, which include:

- Providing good employees the supports and services they need to succeed;
- Improving workforce morale and confidence throughout the agency; and
- Developing a comprehensive values-based workforce recruitment plan based on dignity, equality, and respect for every person, and a commitment to enriching the lives of people with developmental disabilities.

Commissioner Burke said, "Direct support professionals are the heart of our workforce. It is an extraordinarily challenging profession, which has incredible rewards for those committed to this service. Every day, direct support employees at OPWDD and our nonprofit providers selflessly serve others. A shared value among these professionals is a commitment to putting the interests of others above their own, as we saw with the evacuation of nearly 1,500 individuals ahead of Hurricane Irene and subsequent continuous rainfall, which resulted insignificant flooding and widespread power loss across the state."

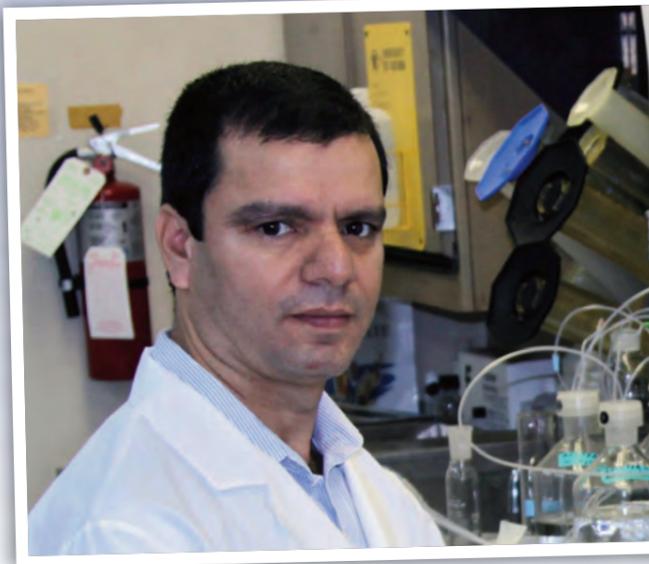
"I am pleased to celebrate the direct support professionals honored this year, and am committed to creating an environment in which every employee receives the supports and resources they need to be successful," she added.

This year's honorees, who are featured on the agency's first-ever online DSP Hall of Fame, are (by DDSO):

- Bernard Fineson: Michelle Pierre and Jacqueline Torrington
- Brooklyn: Kersendria Cosby and Paulette Manhertz
- Broome: Piper Ashton, Virginia Colon, and Phyllis Smith
- Capital District: Mary Hall and Robin Peacock
- Central: Paula Haley and Larry Schad
- Finger Lakes: Angie Smith
- Hudson Valley: Rebecca Konikowski and Robert Sellers
- Long Island: Jean Bien-Aimee, Alexa Brown, and Daryl Williams
- Metro NY: Jacqueline Crawford and Tracy Harris
- Staten Island: Carole Leslie and Cheryl Walker
- Sunmount: Melissa Fowler and Donna Nicklaw
- Taconic: Juanita Beals, Milissa Mahoney, and Robert "Bob" Prusakowski
- Western: Doris Engel



IBR Scientists Report the Effects of Excessive Folic Acid Supplementation on Gene Expression



Mohammed A. Junaid, PhD

Scientists from IBR have reported in the journal *Biochemical and Biophysical Research Communications* that excessive amounts of folic acid cause widespread changes in the expression of genes. Changes in the normal levels of genes can affect genes' function and have deleterious effects. Lymphoblastoid cells, which are derived from human white blood cells, were studied and are commonly used to investigate the regulation of gene expression in response to various environmental factors.

Folic acid is necessary to prevent a group of neurological disorders called spina bifida or neural tube closure defects in newborns. It is required in our diets. Federal guidelines have stipulated supplementation of cereals and grains with folic acid to augment the deficiency that in the past was responsible for neural tube closure defects. Neural tube closure occurs within the first trimester, when adequate levels of folic acid are

needed. However, high doses of folic acid are given to women throughout pregnancy, and the potentially abnormal physiological consequences of this supplementation are unknown.

The research study, led by Mohammed A. Junaid, PhD, head of IBR's Structural Neurobiology

Laboratory, showed that folic acid supplementation of lymphoblastoid cells dysregulated (either increased or decreased) expression of more than 1,000 genes by four-fold or more in comparison to untreated cells.

"These findings indicate that excessive folic acid supplementation may require careful monitoring," said Dr. Junaid. He is in the process of applying for funding to further explore these findings in laboratory animals, where, in addition to gene expression changes, behavior abnormalities can be studied.

One of the prominent genes whose expression was found to be decreased by folic acid is FMR1. This gene produces the protein FMRP, reduced levels of which cause 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. The research team hypothesizes that such abnormal expression of genes during early brain development may have lifelong adverse effects or lead to

neurodevelopmental defects, such as autism.

Senior author of the article is IBR Director W. Ted Brown, MD, PhD. Co-authors are Salomon Kuizon, BS, Juan Cardona, Tayaba Azher, and Raju K. Pullarkat, PhD, of IBR's Department of Developmental Biochemistry, and Noriko Murakami, PhD, of IBR's Department of Molecular Biology.

Dr. Brown said, "Our finding that excessive folic acid may cause abnormal gene expression has important public health implications. Because pregnant women are prescribed additional folic acid to prevent neural tube closure defects, there is a greater likelihood that the developing fetus will encounter folic acid concentrations high enough to alter gene expression."

Commissioner Burke said, "This study's findings will lead to further research on how excessive folic acid can lead to developmental disabilities, including autism, and how appropriate folic acid levels during pregnancy may possibly help prevent these disabilities as well as neural tube closure defects."

The study, "Folic Acid Supplementation Dysregulates Gene Expression In Lymphoblastoid Cells—Implications In Nutrition," was published in *Biochemical and Biophysical Research Communications* 2011; 412:(4):688–692.

IBR's 9/11 Memorial is Rededicated



Employees gathered for the 9/11 memorial rededication ceremony.

Sixty IBR employees gathered the morning of September 12 to rededicate the 9/11 memorial, relocated to the visitors' entrance of the main building of the IBR campus. Constructed with funds donated by employees to IBR's Human Relations Committee (HRC), the memorial features a circular, walled bed containing a memorial stone flanked by two emerald arborvitae and American flags. Solar lights illuminate the memorial.

HRC chair Violet Nealy, administrator of the Specialty Clinical Laboratories, welcomed attendees, thanking them for their donations toward the memorial. "It was an effort by all of IBR," she said. She extended special thanks to John Romano, a mason in the Maintenance Department, and Pamela Esposito, principal lab supervisor in the Animal Colony, for their efforts to build the memorial.

"This is IBR's chance to express our feelings about the 9/11 attacks," said IBR director W. Ted Brown, MD, PhD, to attendees. "It was a terrible event for New York and the US. It changed things. We probably all

knew people who passed away that day or assisted with the recovery." "Staten Island played a large role in the recovery from the World Trade Center attacks," he recalled. "The debris from the site was brought to the Fresh Kills Landfill on the island for recovery and identification of human remains, personal possessions, items of historical and scientific interest, and recyclable materials."

The original IBR 9/11 memorial had been located outside the east wing of the research tower. It was created with funds raised in 2002 from employees by Janis Kay, a secretary in the Department of Developmental Neurobiology, now retired, and the late Danuta Dobrogowska, BA, a research scientist in the same department. Dedicated on the first anniversary of the attacks, that memorial was relocated to the

visitors' entrance in time for the 2011 commemoration so that it would be more visible to the public.

"9/11 is an event that will be with us always and that we will never forget," concluded Dr. Brown. "This is IBR's way of remembering."

A moment of silence followed.



IBR's 9/11 memorial was relocated for its rededication.



Program Helps Homeowners with Disabilities Access Public Transit

Continuing a commitment to help individuals with disabilities live independently, OPWDD and the Capital District Transportation Authority (CDTA) have announced free, unlimited bus passes to Capital Region residents with disabilities who purchase a home through the agency's Home of Your Own (HOYO) program.

HOYO is open to income-qualified parents or legal guardians of people with developmental disabilities or mental illness, and to direct support professionals who provide care. The agreement, dubbed the "Homeowner Transit Use Incentive Program," will provide free, unlimited access to CDTA transit passes, as well as travel training assistance.

OPWDD Commissioner Courtney Burke said, "We are committed to giving individuals with developmental disabilities the support and resources they want and need to be successful in their day-to-day lives. Owning a home is not for everyone, but for those who make that decision, having ready access to reliable public transportation opens up new opportunities. I thank CDTA for their partnership and commitment to help people with disabilities to fulfill their dreams of owning a home."

Holly Pelkey of Albany, whose family has participated in this program said, "I lived in an apartment that was falling apart. My son lived in three rooms, he is wheelchair bound and the doorways were so narrow that he could not fit through them. When I found out about the housing program, it was the most amazing thing ever—it feels like a dream. This program made my son's dream of a safe and comfortable home come true. He also received a small transportation vehicle from the Make-A-Wish Foundation, which he can ride throughout the house thanks to its open space. I look forward to participating in the transportation aspect of this program as well, and thank CDTA and OPWDD for this much-needed assistance."

Participants must be 18 years of age or older, be a first-time homebuyer, have an income and be credit worthy. OPWDD and the state Office for Mental Health (OMH) are the only agencies determining eligibility for participation in HOYO. All eligible borrowers are referred to M&T Bank, which oversees a mortgage product specifically designed to meet the needs of these target populations.

For more information about HOYO or the transit program, call 1-866-946-9733.

Sidney Harper: Living a Richer Life in Brooklyn

Sidney Harper lives with his mother in a brownstone in Brooklyn. He is a Willowbrook class member and recently started receiving Medicaid Service Coordination services through the Brooklyn DDSO.

Sidney uses a wheelchair, but has challenges getting around, as he lives in a home with multiple sets of stairs, including steep front steps, which makes it difficult for him to get out into the community.

In August, Sidney took action and visited Frank's Mobility System in New York to get an estimate for a Scalamobil, a device that will assist him in successfully navigating the stairs in his mother's home.

Sidney has not been in a day program for more than 10 years, but he recently went on a screening for a day program. He is being referred for Saturday recreation opportunities, and modification proposals for his restroom and backyard are being made so he can move about and even sit outdoors when he wants.

According to Keeva Jackson-Breland, director of service coordination at the Brooklyn DDSO, the joy that Sidney has in being able to negotiate the stairs and leave his home using the Scalamobil is incredible. And although the chair is costly, being able to be a part of the community is priceless.

