

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.



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

April 2012



A Letter from the Commissioner

Dear Friends and Colleagues:

April is National Autism Awareness Month. This month, along with the many events that will be occurring across our state to foster autism awareness, I will be releasing a one-year progress report documenting the improvements that have already taken hold throughout the OPWDD system, as well as initiatives and reforms that will better position us to meet current and future needs.

One area of progress that I am pleased to share is how we are continuing to build on OPWDD's *I Have What it Takes* workforce recruitment campaign, which is designed to reinforce the values held by OPWDD—dignity, equality, and respect for every individual—to attract direct care applicants into the developmental disabilities field.

As our next step, we have finalized a new partnership with the state's higher education opportunity programs to attract graduating students to our field who are looking to make a difference in someone's life. We're also planning to expand this in the future through partnerships with local Boards of Cooperative Educational Services (BOCES) and others.

Direct care is one of the most meaningful positions available today, and as advancements continue in the developmental disabilities field, our employees become even more important in the lives of the people we serve. This partnership with education is a common sense approach to helping capable, committed applicants join our field.

The partnership includes:

- Higher Education Opportunity Program (HEOP), which serves 5,500 students at 51 private colleges statewide.
- Education Opportunity Program (EOP), which serves more than 9,000 students throughout the State University of New York (SUNY) system.
- Education Opportunity Centers (EOC), which serve more than 15,000 students in 12 centers across the state.

As always, I welcome your thoughts and suggestions on any initiatives you believe will help us strengthen our services and supports.

Sincerely,

Commissioner Burke



Issue Highlights

IBR Student Volunteer Wins NIH Travel Award

Neurotrophic Antiviral Research Laboratory

A 'Joyous Occasion': IBR Celebrates Its 25-Year Employees

10th Annual Spring Luncheon Delights



IBR Student Volunteer Wins NIH Travel Award

A high school student who interned for two summers at IBR recently received a National Institutes of Health Travel Award to present his research in Norway.

Mark Alexander, a senior at Mamaroneck High School, Westchester, served hundreds of hours volunteering in the Laboratory of Cellular Immunology in the Department of Developmental Neurobiology during the past two summers. There, he conducted research on profiles of taurine in preterm placenta exposed to oxidative stress, under the guidance of laboratory head Eunkyue Park, PhD.

Mark has been enrolled in his school's Original Science Research Program since his freshman year. The project he developed is examining placental tissue from babies born too soon and at risk for long-term neurodevelopmental poor outcome to determine the role of taurine in the developing fetus. Last fall, he was invited to travel to Geilo, Norway, as a National Institutes of Health Travel Awardee to present his research—entitled "Culture negative prematurity is associated with

decreased placental taurine independent of the clinical indication for preterm birth"—at the meeting of the International Federation of Placenta Associations (IFPA) in association with the European Placenta Group (EPG). Mark is the youngest recipient of this award at this international student conference. He traveled with his mother, grandmother, and twin sister.

While interning at IBR, Mark excelled in the technical aspects needed to work in an immunology laboratory. "I found Mark to be hard-working, a fast learner, and extremely reliable," said Dr. Park. "He showed that he has the ability to work well in a complementary fashion that has added to the lab's projects."

The volunteer also developed skills in critical thinking and analysis, organization and time management, and professional behavior and public speaking. According to Dr. Park, he was able to move quickly in his project from the basic level of research tasks to an advanced level requiring higher levels of abstraction and understanding.

The project has a potential impact on



Mark Alexander with his IBR mentor, Eunkyue Park, PhD

individuals with developmental disabilities, Mark explained. "Taurine is an essential amino acid responsible for healthy neurological development and brain function in children. Low plasma neonatal taurine is associated with low scores on the Bayley mental development index at both 18 months and 7 years of age." It is hoped that levels of taurine in the placenta may be a potential biomarker of the level of risk of neurodevelopmental disorders.

While his research skills are advanced far beyond his age, in other ways, Mark is a typical high school senior: he likes playing soccer and listening to the Smashing Pumpkins, for example.

Mark is considering pursuing a career in science and will attend New York University in the fall.

IBR Laboratory Working to Develop Strategies to Reduce Incidence of Premature Births

For 16 years, a laboratory at IBR has been working to develop treatments that prevent an important cause of preterm births. Preterm births, which occur after less than 37 weeks of pregnancy, often result in complicated medical or developmental problems, and they account for approximately 50% of long-term handicaps in children. Preterm births double the risk of autism. Other disabilities that can result include cerebral palsy, intellectual disability, and blindness.

The rate of preterm birth has been increasing, despite the widespread use of preventive strategies. Therefore, the number of children with long-term handicaps caused by preterm birth is also increasing. The rate of premature births in New York State has increased by 13% between 1995 and 2005. On average, 549 babies per week are born preterm in the state, according to March of Dimes' statistics.

To address this problem, the Neurotrophic Antiviral Research Laboratory in IBR's Department of Developmental Biochemistry has been developing ways to prevent a leading cause of the majority of early spontaneous preterm births: clinically silent infections in women's upper

genital tracts. These infections play a major role in preterm labor and delivery, probably not as a direct effect of the infectious agent, but instead as the inflammatory response of the mother to the infection.

Led by Charles E. Isaacs, PhD, the laboratory is conducting two research projects. Both of these projects are supported by OPWDD and the National Institutes of Health and are being conducted in collaboration with research groups at Magee-Womens Research Institute at the University of Pittsburgh and the University of Washington in Seattle.

The aim of the primary project is to develop a topical microbicide that will reduce inflammation caused by infections in the female genital tract, thereby preventing premature births. Dr. Isaacs and his research group have established that several antimicrobial compounds can reduce the concentration of infectious herpes simplex virus (HSV) as well as HIV and a number of bacteria and can be used as active components in a topical microbicide. They are now planning to formulate several other antimicrobial compounds and to evaluate their



Charles E. Isaacs, PhD, with members of his laboratory staff, Weimin Xu (left) and Anna Parse (right).

effectiveness *in vivo* and develop them as practical treatments.

The laboratory's other project is focused on the development of new antimicrobial compounds that can reduce the transmission of infections from mother to infant during birth. Neonatal HSV infection results most commonly from exposure to HSV in the genital tract during delivery. While neonatal HSV infection develops in less than 1% of infants delivered vaginally to women with HSV infection, it remains one of the most serious neonatal infections. Future research efforts will entail the development of combination microbicides (i.e., containing more than one active ingredient) that can potentially inactivate more than one infectious agent at a time.



Honoree Arthur Dalton, PhD, with W. Ted Brown, MD, PhD



Honoree Steve Holburn, PhD (center), with (left to right), Anne Gordon; W. Ted Brown, MD, PhD; Judith Gardner, PhD; and Jeanette Mitchell



Below: Honoree Narayan Ramakrishna, PhD (second from left), with (left to right), Yu-wen Hwang, PhD; W. Ted Brown, MD, PhD; and Jeanette Mitchell



Honoree George Morris, PhD, with W. Ted Brown, MD, PhD

A 'Joyous Occasion': IBR Celebrates Its 25-Year Employees

The IBR seminar room was packed with employees on February 2, as they gathered for a luncheon to celebrate the 25-year anniversaries of four of their colleagues:

Arthur Dalton, PhD, Center for Aging Services, Department of Molecular Biology

Steve Holburn, PhD, Intervention Research Laboratory, Department of Infant Development

George Morris, PhD, Graphic Resources and Media Services (GRAMS)

Narayan Ramakrishna, PhD, Biochemistry Laboratory, Department of Molecular Biology

The luncheon, hosted and organized by the IBR Affirmative Action/Human Relations Committee (AA/HRC), started off with welcoming and opening remarks by AA/HRC chair

Jeanette Mitchell and IBR Director W. Ted Brown, MD, PhD, respectively.

"This is a joyous occasion to celebrate the milestone of 25 years here at IBR for our honorees," said Dr. Brown.

Each honoree was introduced by his supervisor and/or a colleague, who shared their appreciation of the honoree's contributions to IBR. Afterwards, a hot luncheon prepared by the Lifestyles Café, at Lifestyles for the Disabled, was served by AA/HRC members.



Honoree Arthur Dalton, PhD, addressing colleagues at the luncheon.

10th Annual Spring Luncheon Delights

IBR employees gathered on March 19 for the 10th annual spring luncheon, held in the old library of the main building. The event was organized by Chien Wang, Head of Information Services, and Violet Nealy, Administrator, Quality Assurance and Quality Control, Specialty Clinical Laboratories. They started the luncheon in 2002 as a celebration for employees on the first floor of the main building.

"While other areas of the main building and IBR campus have winter gatherings in December, the first floor hasn't, because some staff members are on vacation for the holidays," said Chien. "So we decided to have our area's celebration in the spring." The event, now open to all IBR employees who wish to participate, is always held on a Monday to allow more time for food preparation.

More than 25 employees participated in this year's event, held appropriately enough on the last full day of winter. One featured dish that made quite a hit was the barbecued-beef appetizers, called 'Uglies,' prepared by Martha Soto, secretary to IBR Director W. Ted Brown, MD, PhD. You can enjoy the recipe here.



Spring Luncheon organizers Chien Wang and Violet Nealy. In the background (left to right) are Valerie Jenkins, Mong Chang, Mirosław Mierzwa, and Theresa Troiano.

UGLIES

"These savory barbecued-beef treats aren't pretty, but they are delicious."

INGREDIENTS:

1 pound ground beef chuck	1 1/2 cups barbecue sauce
1/2 cup chopped onion	1 (10 ounce) package refrigerated biscuit dough
1/2 teaspoon garlic powder	2 cups shredded Cheddar cheese

DIRECTIONS:

1. Preheat oven to 400 degrees F (200 degrees C). Lightly grease 8 muffin cups.
2. In a large skillet or frying pan, cook ground chuck with onion and garlic powder until evenly brown; drain off the grease. Stir in the barbecue sauce and simmer for another 3 minutes.
3. Roll out each biscuit on a floured surface so that each biscuit is 6 inches across. Put the biscuit in the muffin tin and fold up sides to create a cup shape. Fill each biscuit almost to the top with the meat mixture; top with cheddar cheese.
4. Bake in preheated oven until biscuits are baked, cheese is melted, and tops are golden brown, about 15 minutes.

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Better Assessing Individual's Needs

Critical to achieving a more person-centered system of services with the People First Waiver is a uniform needs assessment process. OPWDD recently selected a new assessment tool called interRAI Integrated Assessment Suite, which will form the foundation for a reformed system that:

- Informs the care planning process for every individual;
- Involves individuals, families, caregivers, and others in designing their services;
- Ensures the most appropriate supports and services for every individual we serve; and
- Assists in the development of quality measures to ensure that the goals in each individual's life plan are being achieved.

Use of the interRAI Integrated Assessment Suite will be phased in over many years, beginning with small case studies and pilot projects, and later carefully implemented throughout the service system to ensure that people's lives are not disrupted and their needs remain fully supported. The case studies and pilot projects will inform us about the effectiveness of this assessment tool, and we will provide opportunity for input from all stakeholders so that appropriate modifications to the assessment tool can be made.

OPWDD

HEALTH & SAFETY
ALERT!

Subject: Preventing Carbon Monoxide Poisoning

March 2012

Carbon monoxide (CO) is a colorless, odorless gas known as the "silent killer." According to the Centers for Disease Control and Prevention, it is the leading cause of accidental poisoning deaths nationwide, with more than 400 deaths and 20,000 hospital visits every year. People are often unaware they are experiencing CO poisoning until it causes physical symptoms such as:

- Headache, dizziness, and nausea.
- Weakness, vomiting, chest pain, and disorientation.

Sources of CO can include any solid, liquid, or gaseous fuel-fired appliance, fireplace, etc., or motor vehicle. While everyone is at risk, infants and people with chronic heart disease, anemia, or respiratory problems are particularly susceptible.

Ways to prevent CO poisoning:

- Ensure that CO alarms are installed in your home and in all buildings containing a potential CO source. It's the law. Alarms must comply with Underwriters Laboratories (UL) 2034 or Canadian Standards Association (CSA) 6.19.
- Alarms should be checked regularly to ensure they are operational. A good practice is to replace batteries every spring and fall.
- Never burn charcoal inside a home, garage, or tent.
- Have your heating system, water heater, and any other gas, oil, or coal burning appliances serviced by a qualified technician every year.
- Never operate fuel-burning appliances without proper ventilation.
- Do not use portable flameless chemical (catalytic) heaters indoors.
- Regularly examine vents and chimneys for improper connections, rust, soot, or other debris.
- Never run a vehicle, generator, or other fuel powered motor indoors or in an attached garage.

Always remember that carbon monoxide alarms are not substitutes for smoke alarms. Smoke alarms should also be installed on every level of a home as well as in or outside of all sleeping areas. The National Fire Protection Association recommends that CO alarms be installed in a central location outside each sleeping area and on every level of the home.

If you suspect poisoning or your CO alarm sounds:

- Ensure that everyone exits the building to the outdoors quickly and safely.
- Call emergency services (your local fire department or 911) for further assistance.
- See a physician for proper diagnosis.

For additional information, please visit www.cdc.gov/co, contact your DDSO, or OPWDD's Office of Safety & Security at 518-474-9897.

HSA08 – 03/12



Exhibit Honors Letchworth History

To commemorate the centennial of Hudson Valley's Letchworth Village, famed photographer Margaret Bourke-White's poignant and fascinating 1933 photographs of Letchworth are on exhibit at the Thiells, NY branch of the King's Daughters Public Library.

Letchworth Village, once home to thousands of people, was established in 1911 as an institution to care for individuals with developmental disabilities. It survived as a largely self-sustaining farm village for more than 50 years.

The institution that was Letchworth Village closed in 1996. Letchworth now serves as the Hudson Valley regional office for the New York State Office for People With Developmental Disabilities (OPWDD), supporting individuals with developmental disabilities through community-based services and operations in Orange, Rockland, Sullivan, and Westchester counties.

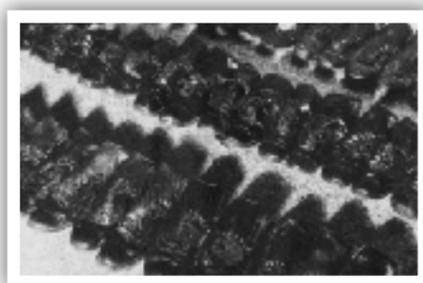


Commissioner Burke said, "This is an exciting opportunity for the individuals we serve, some of whom used to call Letchworth Village home, as well as the larger community, to enjoy an historical perspective of what the developmental disabilities field was like in the 1930s. I applaud Michael Kirchner, our local director, and his team for helping to make this exhibition a reality and success."

Margaret Bourke-White was a pioneering figure in 20th century documentary photography and is famous for her scenes of modern industry, of the Great Depression, and of political and social movements in the 1920s through 1950s. She studied with renowned photographer Clarence White at Columbia University before graduating from Cornell in 1927. In 1929, Bourke-White became the first staff photographer employed by *Fortune* magazine, and in 1936 she was one of the founding photographers of *Life* magazine. It was her groundbreaking work on *Fortune* that opened the door for Bourke-White in 1930 to be the first Western photographer allowed to enter the Soviet Union to document industrialization under the Communist regime. Upon her return in 1931, she compiled these photos into a book entitled *Eyes on Russia*.



In 1933, after returning from photographing Russia, and before *Life* magazine was launched, Bourke-White spent two days photographing Letchworth Village. The collection chronicles life at Letchworth during the Great Depression. This body of work is a fine example of the point in Bourke-White's career when her style moved from industrial and geometric to include more candid and humanistic images.



Sunmount Special Olympics Snowshoeing Club Makes a Difference

Sunmount DDSO's Special Olympics training club, the Mountaineers, boasts a rich history of year-round training and competition that spans more than two decades. Over that time, participation in Special Olympics has helped hundreds of athletes to refine their maturity and self-discipline. It has also helped them adopt a healthy, happy, successful lifestyle.

Each December, the Mountaineers don skis, snowshoes, skates, and hiking boots, and embark on four months of training. They hit the gym, the hockey rink, and the practice field. They participate in timed heats and competitions on campus, too. But the real adventure begins when the Mountaineers head for the backcountry and the High Peaks region of the Adirondacks.

While the breathtaking vistas, pristine surroundings, and shared positive experiences are fringe benefits, the Mountaineers know that there's nothing quite like challenging terrain and a backpack to help build speed, strength, and stamina.

In March, the athletes attended the Special Olympics Area 27 State Winter Games, hosted by Paul Smith's College, home of respected USCAA Nordic racing team, the Bobcats.



The Bobcats, many of whom pursue majors in recreation, adventure travel, and ecotourism, are also wonderful student volunteers. Nine Mountaineers participated in this year's Nordic competition.

One might think that following the mildest Adirondack winter in recent history, the absence of snow might put a damper on a Nordic event. But given the indomitable spirit of the athletes and the enthusiasm of coaches, volunteers, and family members, nothing could have been further from the truth. It turned out that unfettered by heavy parkas, boots, and snow pants, many of the athletes actually achieved personal bests!

After a memorable awards ceremony, the Mountaineers congratulated their rivals, thanked the faculty and students for their gracious hospitality, and returned home to begin preparing for the upcoming track and field season!



Helping Brian Reach His Goal of a High School Diploma

Brian McGough, a resident of AHRC New York City's Dixon-Goodman Apartments (a residential setting and alternative to a nursing home that provides 24/7 nursing care to its residents) attended Christ the King High School in Middle Village, Queens, 30 years ago. But due to a serious illness, Brian was forced to leave school without his diploma.

"I attended classes from 1979 to 1981, but I wasn't able to graduate," Brian said. "I never went back."

Brian mentioned his regret to Nancy Felicitta, his AHRC occupational therapist. Nancy, who has worked with Brian for about a year, contacted Peter Mannarino, the principal of Christ the King High School.

"The principal was receptive and said he would meet with the school's board to inform them of Brian's situation," Nancy said. "They were very accommodating."

Recently, Nancy and Brian had the opportunity to visit his former school, where Brian received his high school diploma. "When we got there, the cap and gown were already waiting for me," Brian explained. "I got my picture taken for the alumni paper, and it really made my day!"

"A representative of the school's alumni group even named Brian as an official alumni group member," added Nancy.

When Brian returned to the Dixon-Goodman residence, his loved ones and members of the AHRC-NYC community held a reception to congratulate him.

