



## IBR: Breaking ground, saving lives

In quiet anonymity, scientists at the Willowbrook facility are penetrating the mysteries of developmental disabilities

By **STEPHANIE SLEPIAN**  
STATEN ISLAND ADVANCE

How early can autism be detected?

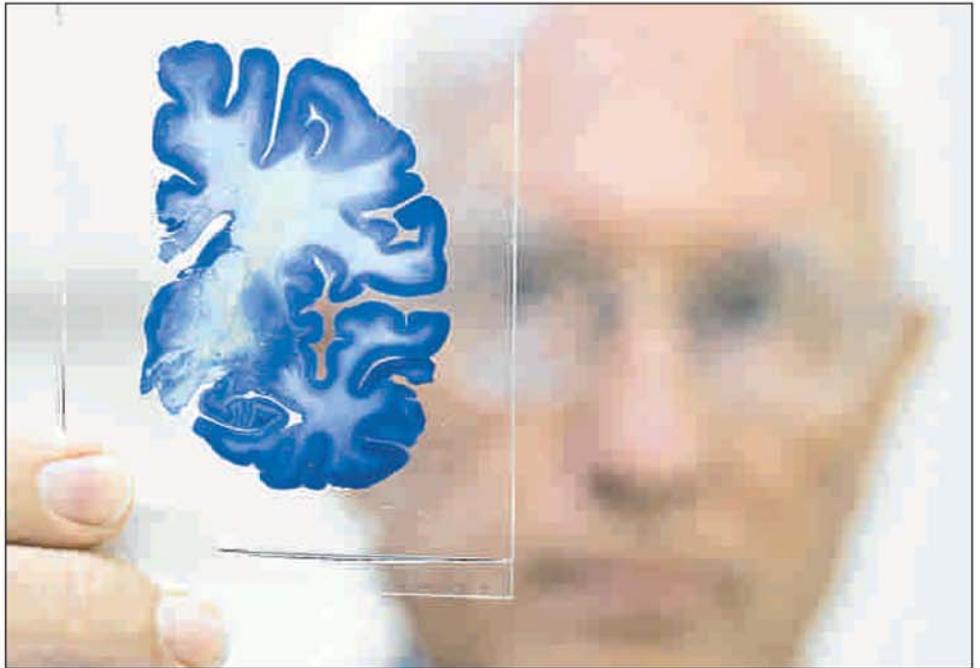
It's a question the world's leading scientists are seeking to answer — and many of those scientists can be found on Staten Island in the labs of the New York State Institute for Basic Research in Developmental Disabilities (IBR) in Willowbrook.

IBR's findings routinely put it at the scientific community's international forefront. On the Island, however, it exists in a quiet anonymity.

Its four low-slung buildings are nearly obscured by a row of trees on Forest Hill Road and the backside of the sprawling campus of the College of Staten Island.

But inside those buildings, scientists in seven research departments and 45 labs are pushing the limits of what is already known about autism and other developmental disabilities.

Simply put: Their research can



STATEN ISLAND ADVANCE/MICHAEL McWEENEY

Dr. Jerzy Wegiel, IBR's neurobiology director, displays a sliver of a human brain.

help families who are living with autism by uncovering more effective means to diagnose, treat and determine the cause of the disorder that affects one in every 150 children to varying degrees.

"Some of our studies could potentially suggest autism in the first months of life versus a diagnosis

that is usually made between 2 to 3 years of age," said Dr. W. Ted Brown, IBR's director. "It would be really helpful to know which children are at risk at one month of age.

"The earlier we diagnose it, the earlier we can treat it. With inten-

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Dr. Janusz Frackowiak, head of the Laboratory of Cellular Pathology, looks at proteins while working in one of IBR's labs.



STATEN ISLAND ADVANCE PHOTOS/MICHAEL McWEENEY

Cross-sections of human brains are placed in a tray before being studied at the New York State Institute for Basic Research in Developmental Disabilities.

# Penetrating the mysteries of developmental disabilities

sive behavioral therapies at a very young age, [children] can be mainstreamed in school."

IBR, the research arm of the state Office of Mental Retardation and Developmental Disabilities (OMRDD), has been making scientific headlines since it was founded in 1967, as the first facility to study mental retardation.

Work done there has led to the first pre-natal screenings for Fragile X syndrome — the most common known cause of inherited developmental disabilities and the most common known single-gene cause for autism — and the discovery of PKU, the only form of mental retardation that can be treated at birth.



Dr. Jerzy Wegiel, director of IBR's Department of Developmental Neurobiology.



Karen A. Amble, director of Clinical Services for IBR's George A. Jervis Clinical Institute.



Dr. W. Ted Brown, director of the New York State Institute for Basic Research in Developmental Disabilities, Willowbrook.

The postmortem tissue — which is age-matched from donors both with and without autism — allows scientists to see directly into the brain's most remote regions in search of structural and chemical abnormalities.

## NERVE CELLS SMALLER

"The nerve cells are smaller and very compact," said Dr. Wegiel, department chairman, pointing to images on a computer screen brought up when the violet-stained sections of an autistic brain are placed under a microscope's lens.

The smaller neurons, he said, may reduce the capacity of different regions of the brain to communicate with each other.

"As we learn what the structural changes are, we can start working on treatments. We can translate the basic research into practical application."

IBR scientists have also identified a gene that may determine the severity of autism, are analyzing the DNA of autistic siblings and their parents and are studying the use of an experimental drug that has increased development of new brain cells and improved cognitive function in a small sampling of patients.

They have also found that infants admitted into neonatal intensive-care units are at an increased risk to develop autism — about 2.5 times the population norm.

Much of this research will be shared among scientists as part of the New York State Autism Consortium, a partnership of the state's leading research and clinical centers that will be coordinated by IBR.

## A TROUBLED PAST

But for all its successes, IBR's history has hardly been trouble-free. Throughout the 1990s and earlier in this decade, the state and IBR maintained an adversarial relationship.

Tensions peaked in 2003 when then-Gov. George Pataki threatened to close the facility for good.

Even the previous commissioner of its parent agency was ready to lock the doors.

But elected officials and the community passionately argued that IBR was a lifeline for thousands of families who have loved ones with developmental disabilities.

Because of the public rallies and bipartisan support for IBR's continuance, the state Legislature passed a budget over Pataki's head that spared the facility.

"From my perspective, what's changed, is we have looked very carefully to understand what the value of IBR is and how it absolutely adds to our mission," said Diana Jones Ritter, commissioner of the state Office of Mental Retardation and Developmental Disabilities, whose tenure began after IBR was spared.

"We are expecting extra results from our Autism Consortium and the research we're doing on all developmental disabilities. We are just continuing on our journey."

## FACES NEW CRISIS

But IBR faces a new crisis in that journey: Cutting costs as the state's fiscal resources shrink.

IBR, which employs 307, including more than 100 Ph.D.-level scientists, receives \$24 million from OMRDD, and another \$7 million in grant money.

"Every operation within my organization, and IBR is not exempt, is being challenged to and required to come up with really good cost savings to contribute," Ms. Ritter said.

For IBR, that means more aggressively pursuing grant dollars.

"I believe IBR is one of the best-kept secrets and we don't do enough to make sure people understand the real exciting groundbreaking research being done there, especially with autism," said Gary Lind, OMRDD's deputy commissioner of policy and enterprise solutions.

"We're very much encouraged that good science will lead to other good science and that it will be recognized by the grant and funding community."

It's a hope IBR scientists, like Dr. Janusz Frackowiak, more accustomed to geek-speak than money matters, cling to as they work every day.

Still, as he looks for research dollars, Dr. Frackowiak never loses sight of why he is doing what he is doing.

As he prepared to dissect the peanut-sized brain of a genetically altered mouse, which exhibited the memory and learning deficits associated with developmental disabilities, he could speak only of the possibilities.

"Does the mouse remember where its food is?" asked Dr. Frackowiak, the head of the Laboratory of Cellular Biology, describing the changes he looks for in the mice.

"Did it go from finding its platform in six seconds to finding its platform in 30 seconds?"

"It's impossible to do this on patients, but if we can fix it in mice," he said, "who knows what we can do someday?"

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## BREAKTHROUGHS

Over the years, they've made breakthroughs in Down Syndrome, Alzheimer's disease, Batten disease and fetal alcohol syndrome. An outpatient clinic offers sophisticated diagnostic tests to catch things routinely missed on a pediatrician's exam.

Among IBR's educational programs is the Center for Developmental Neuroscience and Developmental Disabilities, run jointly with the College of Staten Island.

The institute's commitment to finding the causes of all developmental disabilities continues today, although there has been a shift in IBR's research.

"I've been focusing more and more on autism because it is being recognized as very prevalent in the community," said Dr. Brown, an internationally recognized expert on Fragile X and progeria, a premature aging disease.

In IBR's Department of Developmental Neurobiology, Dr. Jerzy Wegiel catalogs slides that contain life's most delicate matter: Cross sections of human brain tissue.