

# THE ROSE F. KENNEDY CENTER AT 50 YEARS

## BIRTH OF HOPE

In 1961, President John F. Kennedy challenged the nation to address the issue of intellectual disability through research and quality clinical care. A network of Intellectual and Developmental Disabilities Research Centers (IDDRCs) was established.\* Our own Rose F. Kennedy Center was one of the first. On the center's 50th anniversary, we reflect on some of our most significant accomplishments. We also look toward the future as we continue our work to advance treatments that will promote the well-being of people with intellectual and developmental disabilities (IDDs).

\* Originally referred to as Mental Retardation Research Centers. The term "mental retardation" is used in this brochure only in its historical context; the phrase used today is "intellectual and developmental disabilities."

Rose and Robert Kennedy at the center's groundbreaking ceremony in May 1966.



# HOPE DEFINED



“ Although we have attacked on the broad front the problems of mental illness, although we have made great strides in the battle against disease, we as a nation have for too long postponed an intensive search for solutions to the problems of the mentally retarded. That failure should be corrected. ”

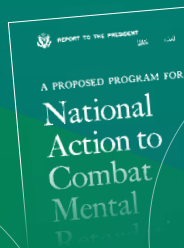
—John F. Kennedy, October 11, 1961

President Kennedy commissions a panel to support research on the neglected field of intellectual and developmental disabilities. Much of the ensuing research done at the Kennedy Center and clinical work undertaken at Einstein and Montefiore have greatly advanced the field and spurred treatments for many IDD, including autism and language and communication disorders.



Hope for Retarded Children  
By Eunice Kennedy Shriver  
1962

At a time of little hope for individuals with intellectual disabilities, the courageous openness of the Kennedys gives hope to countless other American families. Eunice Kennedy Shriver writes an article for the *Saturday Evening Post* in 1962, revealing her sister Rosemary Kennedy's intellectual disability.



In October 1962, the president's panel recommends the development of 12 research centers to advance understanding of the causes of the condition. It also supports the creation of university-affiliated diagnostic and treatment facilities to improve clinical care for children with IDDs.

President Kennedy signs PL 88-164 on October 31, 1963, turning the panel's recommendations into reality. The research centers are to be funded by the newly created National Institute of Child Health and Human Development (NICHD) of the National Institutes of Health (NIH).

Through the efforts of Dr. Harry Gordon, a professor of pediatrics and a pioneer in neonatology and child development, one of the coveted research centers is awarded to Einstein.

“ Fifty years ago when I was seeking help for my own daughter who was retarded, there was no place to turn. I was bewildered, frustrated and heartbroken to learn how little was known and how little could be done.... I hope my name, as a mother of a retarded child, may bring faith and hope and confidence to other mothers, as they realize the perseverance and zeal, the self-sacrifice and devotion, of scientists and doctors working here. ”

—Rose F. Kennedy, at the center's groundbreaking, May 1966



Public Law 88-164  
31, 1963  
1576]  
To provide assistance in combating mental retardation through grants for the construction of research centers and grants for the construction of facilities for the retarded and assistance in improving mental health centers, and for other purposes.  
AN ACT  
Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That this title may be cited as the "Mental Health Centers Construction Act of 1963."  
TITLE I—CONSTRUCTION OF RESEARCH CENTERS  
FACILITIES FOR THE MENTALLY RETARDED  
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# PICKING UP THE MANTLE OF HOPE

Dr. Gordon is named founding director of Einstein's Rose F. Kennedy Center.

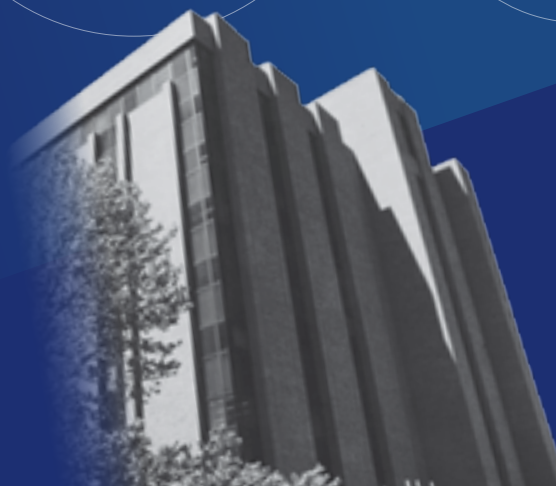
At Dr. Gordon's direction, the Children's Evaluation and Rehabilitation Center (CERC), which offers services to patients with IDD's, moves into the first two floors of the Kennedy Center. This continues the 1957 vision of Einstein's founding chair of neurology, Dr. Saul Korey, of a "bench-to-bedside" translational research model.

In 1972, Dr. Gordon transfers the directorship of the center to Dr. Dominick Purpura. Two years later, Dr. Purpura establishes one of the nation's first departments of neuroscience, located in the Kennedy Center. Dr. Herbert Cohen is named CERC's director in 1974, replacing the program's founder, Dr. Lawrence Taft. Though it later expands beyond the Kennedy Center, CERC retains space within it until 2015, when it is consolidated in the Van Etten building.

Also in 1974, a University Center for Excellence in Developmental Disabilities (UCEDD) is established in the Kennedy Center, fulfilling another part of the 1963 legislation. To this day, Einstein remains one of the few medical schools to receive funding for IDDRC, UCEDD and LEND (Leadership Education in Neurodevelopmental and Related Disabilities) programs.

Over the next 50 years, the Kennedy Center will train many hundreds of scientists and clinicians who will go on to populate labs and clinics around the world.

Dr. Robert Terry, chair of pathology, helps the center develop one of the world's strongest teams of neuropathologists, neurologists and neuroscientists.



# TRANSFORMING HOPE INTO ACTION

The 1970s bring significant developments in research and clinical care. Highlights include work on hearing, neuronal communication, neurometabolic diseases and neurotoxicology.

Dr. Joseph Arezzo

Dr. Yonatan Fishman

Dr. Herbert Vaughan and colleagues develop noninvasive multichannel electroencephalogram (EEG) recordings from the human scalp, deepening our understanding of how the human brain works. By the 1990s this work provides advances in high-density electrophysiological mapping of human brain activity that paves the way for imaging of brain function in autism and other neurodevelopmental disorders.



Dr. Mitchell Steinschneider

Drs. Peter Spencer and Herbert Schaumburg establish the field of neurotoxicology and later set up the Institute of Neurotoxicology within the center.

Dr. John Foxe

Dr. Charles Schroeder

In 1974, Dr. Murray Bornstein performs pioneering work on neuronal cell cultures using the "hanging drop" method. Neurophysiologist Dr. Stanley Crain will later collaborate with him to study the electrophysiology of embryonic rat neuron cultures.

Child neurologist Dr. Isabelle Rapin and colleagues use techniques developed by Dr. Vaughan to record auditory-evoked responses to diagnose hearing loss in infants with brain damage.

Dr. Daniel Javitt

Dr. Michael Kraut

Dr. Walter Ritter



In 1978, Drs. Robert Ruben and Thomas Van De Water study inner-ear structures in culture, paving the way for innovative research on hearing disorders in infants.

Dr. Ted Bargiello

Dr. Felix Bukauskas

Dr. Michael Bennett pioneers the investigation of intercellular communication within the nervous system. Einstein becomes and remains world renowned for the study of gap junctions.

Dr. Andy Harris

Dr. Elliot Hertzberg

Dr. Vytautas Verselis

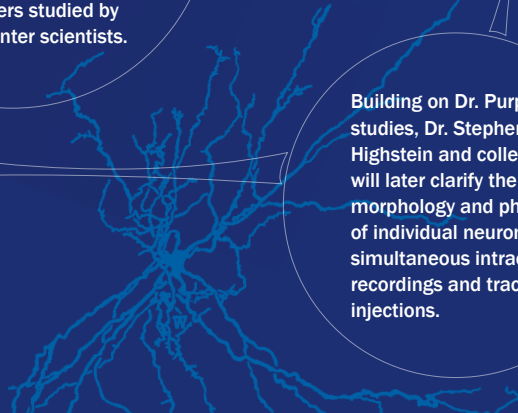
Dr. Harold Nitowsky begins Operation Gene Screen. Using a mobile lab, he identifies Tay-Sachs carriers in the Ashkenazi community, with the goal of reducing the incidence of this lysosomal disorder, one of many such disorders studied by Kennedy Center scientists.

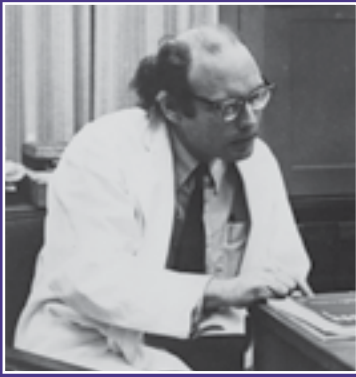
Dr. George Pappas

Dr. David Spray

Dr. Purpura describes abnormal dendrites in people with intellectual disabilities, revealing underlying structural changes that may be responsible. Modern efforts to link changes in the neuronal connectome to autism and IDD's rest on his work. He also finds ectopic dendrite growth in Tay-Sachs; this is later tied by Dr. Steven Walkley to lysosomal dysfunction.

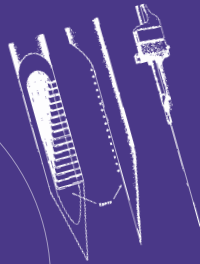
Building on Dr. Purpura's studies, Dr. Stephen Highstein and colleagues will later clarify the morphology and physiology of individual neurons using simultaneous intracellular recordings and tracer injections.





# BASIC SCIENCE IN TRANSLATION

In 1982, Dr. Vaughan assumes directorship of the center. Discoveries in basic science and their applications to clinical settings continue under his leadership.



Drs. Vaughan, Joseph Arezzo and colleagues develop a new multi-electrode array that allows a detailed mapping of intracranial electrical field potentials, providing a bigger picture than single-cell recordings and expanding our ability to understand how the brain functions.



CERC opens the Adult Literacy Program as part of its Fisher Landau Center for the Treatment of Learning Disabilities. Founded by Dr. Ruth Gottesman, the program is the only one of its kind in the New York metropolitan area providing ongoing one-on-one therapy to adults with learning disabilities.

Dr. Herbert Cohen

Dr. Gary Diamond

Dr. Dennis Dickson

Einstein's clinical researchers identify and describe neurodevelopmental consequences of congenital HIV. In 1988 they team with Kennedy Center neuropathologists to define the phenotype of pediatric AIDS. This leads to the establishment of a treatment clinic for children with AIDS and research into preventing such transmission.

Drs. Nitowsky and Robert Marion identify an association between low levels of maternal serum alpha-fetoprotein and fetal chromosome anomalies. This observation leads to the creation of maternal serum biochemical screening tests.

Dr. Andrew Wiznia

Dr. Cecelia McCarton and her team find that premature babies with low birth weight are more likely to exhibit cognitive delays in childhood. This is the first sign that intrauterine growth restriction can adversely affect cognitive function.

Dr. Dikran Horoupian

Dr. Arye Rubinstein

Dr. Robert Marion

Drs. Solomon Moshé and Shlomo Shinnar, later joined by Dr. Aristeia Galanopoulou, establish the field of developmental epilepsy, expanding seizure research on adults to infants and children.

Gathering neuropathologists, neuroscientists and clinicians, Dr. Cedric Raine builds one of the world's strongest research groups focused on multiple sclerosis. He later establishes the field of neuroimmunology, exploring how the immune system works in the brain.



# A CENTER WITHOUT WALLS

In 1993, Dr. John Kessler is named director of the center. Envisioning a “center without walls,” he develops a program embracing faculty in genetics and cell biology. At the same time, CERC clinics continue to expand out of the center and into the Rouso building on Einstein’s Jack and Pearl Resnick Campus.

In the early 1990s, Dr. Judith Gravel spearheads advocacy for universal newborn hearing screening, leading to the passage in 1999 of New York State’s Public Health Law §2500-g establishing such a program.

Dr. Pablo Castillo

Dr. Rapin earns renown as one of the world leaders in the systematic study of autism and developmental language disorders, influencing countless colleagues. To this day, Einstein-Montefiore researchers and clinicians maintain a critical role in advancing understanding and developing best clinical practices for these disorders.



Dr. Anna Francesconi

Dr. Donald Faber becomes center director and chair of neuroscience in 1999 and expands the focus on cellular and molecular mechanisms of neural plasticity and the neural basis for learning and memory.

Dr. Alberto Pereda

In 2006, Dr. Marion, chief of genetics in the department of pediatrics, is named director of CERC.

Dr. Jean Hebert

Dr. José Luis Peña



The Gruss Magnetic Resonance Research Center, established in 2000 with a generous gift from the Gruss-Lipper Foundation, provides state-of-the-art imaging for IDD-related studies in humans and animals. Drs. Craig Branch and Michael Lipton assume leadership positions in 2008.

Dr. Bryen Jordan

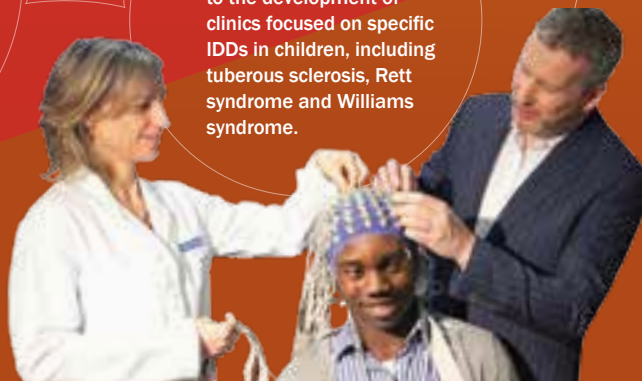
Dr. Saleem Nicola

Dr. Kamran Khodakhah

Dr. Adam Kohn

The Children’s Hospital at Montefiore (CHAM) opens in 2001, leading to the development of clinics focused on specific IDDs in children, including tuberous sclerosis, Rett syndrome and Williams syndrome.

Dr. John Foxe is recruited to Einstein and becomes research director of CERC in 2010. He and his colleague Dr. Sophie Molholm bring a major program of autism and communication disorders research, establishing the Cognitive Neurophysiology Laboratory in Van Etten.



# A KENNEDY CENTER RENAISSANCE

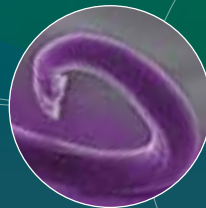
In 2010, Drs. Walkley and Foxe are named director and associate director of the Kennedy Center. The “center without walls” concept is dramatically expanded to include more than 100 IDDC investigators and clinical partners from 15 basic science and clinical departments. Funding increases for scientific cores in human clinical phenotyping, cell and brain imaging, animal behavior and neurogenetics.

Researcher-clinician collaborations abound. In the Tri-State Rett Syndrome Clinic at CHAM, clinic director Dr. Aleksandra Djukic works with Dr. Susan Rose to examine fundamental aspects of attention in children with Rett syndrome, using eye-tracking methods.



Drs. Elyse Sussman and Mitchell Steinschneider collaborate to show that basic deficits in processing of the auditory environment may contribute to language impairment.

Dr. Elizabeth Ridgeway, director of occupational therapy at CERC, and Drs. Molholm and Foxe later initiate NIH-sponsored clinical trials to test the efficacy of a novel sensory integration therapy for the treatment of autism.



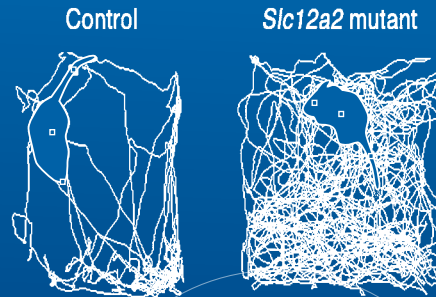
Drs. Scott Emmons and David Hall report on the “connectome” of the neural network in *C. elegans*, showing how neurons execute behavior based on inputs from multiple sensory neurons. Their paper wins the 2012-13 AAAS Newcomb Cleveland Prize for the most outstanding research article published in *Science*. Earlier, Dr. Hall and Dr. Zeynep Altun had published the “*C. elegans* Atlas” (known worldwide as the “Worm Atlas”), a complete anatomical guide to the roundworm.



# EINSTEIN-MONTEFIORE COLLABORATIONS EXPAND

Dr. Judy Aschner is recruited as chair of pediatrics at Einstein, expanding efforts on premature-birth issues and increasing collaborations between pediatrics at Montefiore and the IDDR. CERC oversight moves to Montefiore, and Dr. Theodore Kastner is named its director.

Dr. Aschner recruits Dr. Melissa Wasserstein to be chief of the division of genetic medicine at CHAM, bringing enhanced clinical investigations of neurometabolic disorders and programs in prenatal screening, as well as—with Dr. John Greally—whole-genome sequencing for IDs.



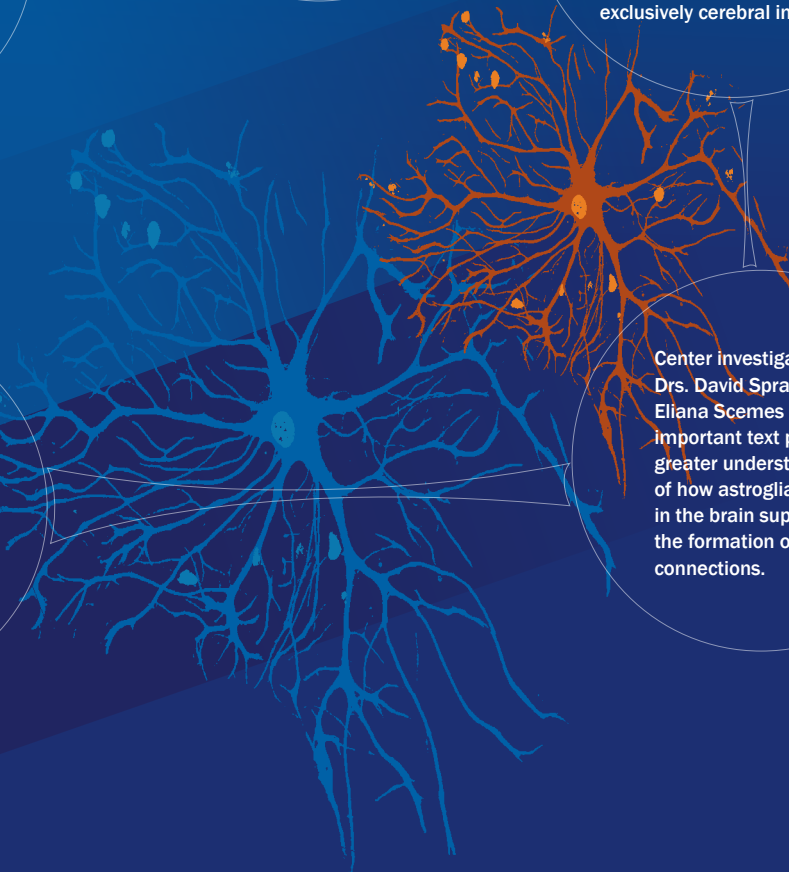
Advances in basic science continue as neuroscientists in the Kennedy Center pursue research critical to understanding the atypical wiring and neural communication underlying IDs.

Dr. Mark Mehler, chair of the Saul R. Korey Department of Neurology, fosters increased collaboration to further bridge research and clinical efforts.

Dr. Jean Hebert and colleagues find that inner-ear defects cause motor hyperactivity in mice, showing that sensory impairment can cause maladaptive behaviors through molecular changes in the brain. Until this report, it was thought that hyperactivity was exclusively cerebral in origin.

Expanding earlier research on gap junctions, Dr. Vytautas Verselis reveals the critical role these structures play, when defective, in keratitis ichthyosis deafness syndrome, a major cause of syndromic hearing loss.

Center investigators Drs. David Spray and Eliana Scemes publish an important text providing greater understanding of how astroglial cells in the brain support the formation of neural connections.





# COMING FULL CIRCLE

Successful renewal of funding for the Rose F. Kennedy IDRC in 2016 ushers in the beginning of its second half-century. Dr. Molholm becomes associate director of the IDRC.



During the 1990s, Drs. Bernice Morrow and Raju Kucheralapti advanced the study of the inherited disorder known as 22q11.2 deletion syndrome, a condition originally identified by Dr. Robert Shprintzen at Montefiore. Known for its association with craniofacial and cardiac anomalies and high incidence of schizophrenia, this disorder can also result in intellectual and developmental disability (IDD). The IDRC leadership initiates a five-year multidisciplinary research project as part of the renewed NIH funding to explore the genetic basis of the IDD related to this syndrome. Through collaboration between the IDRC and the departments of pediatrics and genetics, the Montefiore-Einstein Regional Center for 22q11.2 Deletion Syndrome opens in 2017 to serve the needs of this population.

Dr. Jean Hebert

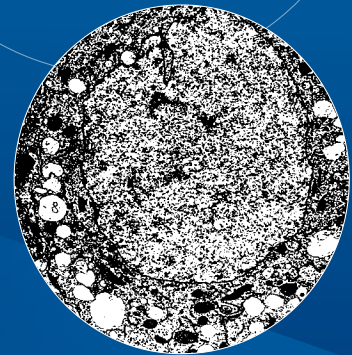
Dr. Noboru Hiroi

Dr. Herbert Lachman

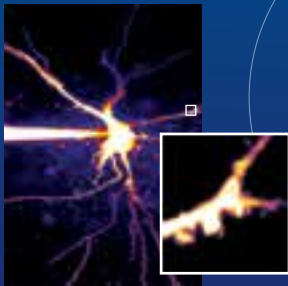
Dr. Deyou Zheng

Dr. Sophie Molholm

IDRC investigators develop therapies for lysosomal disorders affecting the brain. Following their earlier work showing efficacy of bone marrow transplantation for correcting brain pathology in alpha-mannosidosis, Drs. Walkley and Kostantin Dobrenis are joined by Drs. Mark Zervas and Cristin Davidson to develop two drugs, miglustat and cyclodextrin, for treatment of Niemann-Pick type C disease.



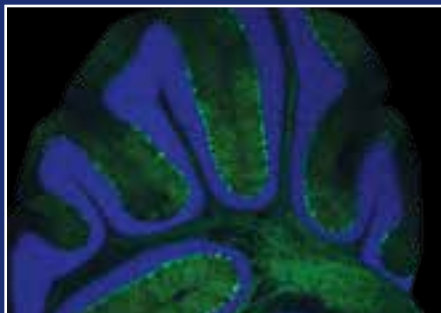
In 2015, Dr. Pablo Castillo's group reports that a mouse model of autism reveals altered excitatory inhibition in the hippocampus. This evidence suggests that synaptic dysfunction is a common mechanism underlying autism spectrum disorders.



That same year, Dr. Bryen Jordan's group finds that the AIDA-1 gene has a role in synaptic transmission in the hippocampus. The first individuals with mutations in this gene are discovered and are found to exhibit autism, Tourette syndrome and developmental delays.

Detailed analyses of mouse models allow Dr. Suzanne Zukin and colleagues to accelerate understanding of the molecular origin of autism and another IDD, fragile X syndrome.

Dr. Kamran Khodakhah and colleagues use their in-depth knowledge of cerebellar function, and its interactions with other brain regions, to explore its role in motor coordination, and in modulation of social and addictive behaviors.



# LOOKING TO THE FUTURE

“ We stand today on the shoulders of giants who have come before us in the Rose F. Kennedy Center—pioneers who have advanced our understanding of normal and abnormal brain function. From this privileged vantage point, armed with modern tools of neuroscience and genetics, we carry on in the ever-present hope that through rigorous scientific pursuit we can truly improve the lives of individuals with intellectual disabilities. ”

—Steven U. Walkley, D.V.M., Ph.D.



“ We are on the threshold of monumental advances in developmental brain research. We will leverage our institutional strengths to fashion dynamic interdisciplinary programs in modern genetics, imaging, stem cell biology, cellular reprogramming and tissue regeneration to create innovative therapeutic opportunities and cures for disease. ”

—Mark F. Mehler, M.D.



“ This is a time of great promise. Newly launched transdisciplinary clinical and research programs for children with IDD at Einstein and Montefiore capitalize on the expertise, partnerships and energy of IDDRC and pediatric faculty members to make positive differences for people with developmental disabilities and their families. ”

—Judy Aschner, M.D.



“ The past few years have brought significant improvements in the tools that allow us to interrogate the brain. On the foundation laid by generations of neuroscientists, and bolstered by the Einstein-Montefiore Brain Science Initiative, we are poised to better understand the brain and help identify therapies for intellectual disabilities. ”

—Kamran Khodakhah, Ph.D.



# THANK YOU!

We are deeply indebted to the countless individuals who have contributed so significantly to the successes of the Rose F. Kennedy Center over the past half-century.

For our 50th anniversary symposium and celebration, we also want to express our thanks to all of those who volunteered their own views on the most significant and innovative research discoveries and clinical advances made by Kennedy Center investigators since its founding. All such advances are achieved only through the dedicated and collaborative efforts of bench scientists and clinical investigators driven by curiosity and a desire to better understand brain function and dysfunction, and to continuously work toward promising new therapies for these conditions.

Such progress could never be achieved without the funding support of the National Institutes of Health and of private foundations and industry, and the generosity of philanthropists.

We are especially grateful to those who have provided their leadership and guidance throughout the center's 50-year history. In addition to those noted within the brochure, we thank Dr. Allen M. Spiegel, Einstein's Marilyn and Stanley M. Katz Dean, whose vision and recruitment efforts supported grant renewal of our IDDRC. And we thank Dr. Steven M. Safyer, president and CEO of Montefiore, whose commitment to Einstein and overarching leadership of Montefiore-Einstein have established an enduring partnership that will guide our center through the next half-century.

Above all, we thank the many children with intellectual and developmental disabilities and their families who, by their inspiration and activism, have steadfastly driven us toward this goal of promoting scientific research to advance expert clinical care.



Visit the Rose F. Kennedy IDDRC  
[www.einstein.yu.edu/centers/iddrc](http://www.einstein.yu.edu/centers/iddrc)  
to learn more about our exciting work  
in progress



Montefiore