ROSE F. KENNEDY UNIVERSITY CENTER FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES
Exemplary Services, Clinical Training, Research, Community Education
To Our Community

For 64 years the Rose F Kennedy University Center of Excellence in Developmental Disabilities (RFK UCEDD) has been a beacon of service, education and research. Our home base for this work is the RFK Children’s Rehabilitation and Evaluation Center (RFK CERC) in the Bronx, New York. As one of the nation’s 67 UCEDDs, we partner with people with developmental disabilities (DD), their families, advocates, professionals, and organizations. These connections elevate and give meaning to the interdisciplinary training, exemplary services, technical assistance, and information dissemination that we provide. As a UCEDD, the overarching goal for all of this work is to increase the independence, empowerment, and integration of persons with DD in their community.

Among this year’s interdisciplinary training successes, we note our pioneering of didactic and clinical training about DD into the Einstein medical school curriculum in Fall 2019. In March 2020 our UCEDD underwent major changes with the advent of Covid-19; our Bronx locale was among the nation’s first and hardest hit communities. In response, our UCEDD responded by shifting remote services and programs. Regarding services, for example, our long-time weekly Bronx Community Self-Advocacy Group was able to adapt to Zoom with the help of iPads secured through foundation funding. Our New York State Department of Health funded projects completed virtual video production, regional focus groups, and technical assistance to local health departments. The breadth of our poster and conference presentations, publications and grants this fiscal year attest to the productivity of our clinicians and researchers.

As we look ahead, we will continue to seek new opportunities to improve the lives of persons with DD in the Bronx, New York City and State, and in the nation. We hope you enjoy this report.

Dr. Karen Bonuck

Joanne Siegel, LCSW
GIANT STEPS

A HISTORY OF EXCELLENCE

In 1961, President John F. Kennedy challenged the nation to address the issue of intellectual disability through research and quality clinical care. In 1963 a network of Intellectual and Developmental Disabilities Research Centers (IDDRCs) was established under Public Law (P.L. 88-164).

"I hope my name...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

Our own Rose F. Kennedy Center was one of the first. We reflect on some of our most significant accomplishments. We also look toward the future as we continue our work to advance education, treatments and research that will promote the well-being of people with intellectual and developmental disabilities (IDDs).

"LADIES IN RED"

During the 60’s and 70’s a fiery group of mothers from The Bronx, who were passionate about improving the quality of life for children and adults with intellectual and developmental disabilities, they pushed the boundaries of advocacy, shaping the attention given to support and funding or the disabled.
Our UCEDD’s location in the Bronx, New York was the site of the COVID 19 epidemic’s earliest and worst devastation in the first months of the epidemic. On March 22, 2020 Governor Cuomo issued a shutdown of all but essential services throughout the 5 boroughs of New York City. It is difficult to over-state the impact of the epidemic upon the community served by our UCEDD.

This challenging time resulted in significant disruptions, as well as new ways of providing clinical services under the leadership of Lisa H. Shulman, MD Interim Director of RFK CERC and LEND. Leadership in Neurodevelopmental and Related Disorders. “CERC Adaptation in the Time of COVID” was the subject of the April 20 Grand Rounds. This Zoom event highlighted the creativity of our multiple disciplines - such as occupational, speech-language, and physical therapy -- in adapting to telemedicine.
2020 Vision - A Year of Redesign and Adaption

**collaborative change as result of activity:**

"Awareness & collaboration with more clinicians and services that I wasn’t aware of. I feel more comfortable reaching out to other disciplines."

**covid-19 impact on service delivery:**

"Very impressed with the imaginative adaptations that the various presenters made to their routines. How proud I am of my CERC colleagues. I plan to use the website storyline.net provided by the speech pathologists."

**CERC CLINICAL SERVICES**

All clinical activities were moved to telemedicine within several weeks of the New York City Pause on March 22, 2020

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**digital training workshop**

As part of our initiative to expand youth/transition activities, we had planned to sponsor a Spring 4-session training by TechKids Unlimited. The "TKU" programs are geared to children and youth with learning issues, autism, and AHDD and are generally held on-site in Bronx, with a computer scientist and social worker in the room. **Adapted** - As TKU went virtual due to COVID 19, we instead provided scholarships to those students who had signed up.

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**bronx legislative breakfast**

This annual gathering brings together RFK CERC staff, families and individuals we serve, with Bronx borough, city, state, and federal legislators, to discuss the most significant disabilities related issues for our community. It had to be reconceived with materials being distributed be internet rather that in an in person event on March 13, 2020.

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**college & transition fair**

We had engaged a range of vocational, college, and benefit programs to host tables at this event, planned for June. In addition, several young adults were going to hold a panel discussion. **Adapted** - we held a 3-session virtual series of College & Transition webinars on July 14th July 21st, and July 28th.
NEW ACTIVITIES DEVELOPED FOR EMERGENT NEEDS

Project Bravo

A food distribution program was also incorporated into the Bronx Self-Advocacy Group since food shortages and distribution points were major problems. Our Bronx self advocacy group benefit from Montefiore Project Bravo food distribution program.

Bronx Community Self Advocacy Group

Advocacy Group meetings were switched to a Zoom format and iPads were given to 5 self-advocates so they could remain active with their peers.

Remote Telehealth Services

This required development of IT program expansion that would be HIPPA compliant, and include electronic note taking and billing adaptations in order for staff to work remotely and still carry on therapeutic and medical services.
INFUSION OF IDD CURRICULUM INTO MEDICAL EDUCATION

A hallmark accomplishment for the RFK UCEDD was a grant from the American Academy of Development Medicine and Dentistry (AADMD) to Ms. Siegel, as part of AADMD’s National Curriculum Initiative in Developmental Medicine. Work for this grant began in FY 2019, continued in FY 2020 (details below), and is planned to continue in FY 2021 and beyond. The RFK UCEDD also collaborated with AADMD and the Universities of Louisville and Illinois on a grant application to develop nationwide curriculum efforts in IDD.

Our competitively funded grant supported pilot implementation of IDD into the second year Einstein medical school curriculum with n=180 students. From April of 2019 through September 30, 2020, UCEDD faculty piloted both didactic and experiential IDD course material thru the following venues:

- **MS 2Neurology - Nervous System and Human Behavior** - 100 minutes of didactic lecture and 30 minutes of a panel presentation by a parent/caregiver, 2 adult self-advocates representing different developmental disabilities, autism, cerebral palsy and intellectual disability.

- **MS2 Introduction to Clinical Medicine (ICM) II Communication Skills** - consisted of recruitment of 18 self-advocates and 10 caretakers to work within 15 groups of medical school students led by two faculty members who would lead in training of medical school students on best practices interviewing techniques.

TRANSITION PROGRAMS

In October 2019, our Grand Rounds focused on our successful NCDIM curriculum focusing on adults with IDD, FY 2020 saw expansion of our focus to transition age youth.

Regarding transition age youth, we worked with Karen Brown, MS, a former Transitions Specialist with the New York City Department of Education for the Bronx NY. She presented the October 2019 Grand Rounds. From November 2019 onward, Ms. Brown joined a multi-disciplinary team to plan for a June 2020 post-secondary Transition Fair.

To plan the Fair, the team met monthly to coordinate and engage 15 panelists to present on topics such as social security, benefits, job training, and college options. Due to Covid, the team pivoted to presenting a series of 3 webinars covering the topic in July 2020.
MULTI-MEDIA

Early Intervention Films

Our RFK UCEDD entered its third and final year of the Early Intervention: State Systemic Improvement Program (Family Centered) in collaboration with the New York State Department of Health (DOH) and two other New York UCEDDs.

This year, the project worked to fulfilling its deliverables of producing 10 webinars. Supervised by Joanne F. Siegel LCSW and Karen Bonuck, PhD. Emma Brezel, MBE and Marcelle Pachter, DDS[Spain] worked with a professional film-maker Jamon Lewis (TheWorksFilms) to produce videos for parents and professionals.

We are especially excited about the ‘Family Perspectives’ series that will feature English, Mandarin, Bengali and Spanish families. In addition to parents, the videos feature disability rights and special education attorneys, early childhood specialists, and a pediatrician.

THE HIGHLIGHTS

HEALTH SYMPOSIUM

Bronx Developmental Disabilities Council

This full-day conference attended by n= 223 family members, self-advocates and agency staff was co-sponsored by a coalition of city, state, and community organizations. It provided information on lead poisoning, the importance of vaccinations, good nutrition, educational transition and aging.

Community Advisory Committee (CAC)

Meets 4 times per year and includes: Self-Advocates, siblings, CERC clinicians, outside groups (e.g., Bronx Defenders, Parents as Partners and Bronx DD Council), and the New York State Developmental Disabilities Planning Council, among others.

Finally, senior UCEDD staff members attend regular meetings at the borough, city, and state level to discuss needs and gaps in services: Ms. Siegel co-chairs the IDD Subcommittee of the NYC Consumer Service Board, NYS DOH Disability Advisory Committee and President of the Bronx DD Council.
This 2-year $725,000 grant from the New York State Department of Health, is in collaboration with the 2 other New York State UCEDDs. The RFK UCEDD conducted focus groups (n=18) and interviews to ascertain needs and barriers to services.

Our groups and interviews are held in English, Spanish and Mandarin; due to Covid-19 all are successfully being held via Zoom. Qualitative data will be analyzed and prepared as part of an Evaluation report.

In addition, the project produced a Covid-19 Resource Directory, is compiling a CYSHCN Resource Guide, and is conducting a Needs Assessment with local health departments. The project is led by UCEDD Co-Directors Bonuck and Siegel and Director Rachel Passmore, MPH.
Continued Collaboration with Fordham Law

**Psychology Presentation** - Dr. Alvarez, an RFK CERC clinician provided an overview of neuro-psychological evaluations to the Law Schools’ Family Advocacy seminar.

**School-Age Case Conference** - the Law Schools’ Family Advocacy seminar students attended a February 2020 session, and stayed for a debrief afterwards.

This past year we implemented a pilot ‘lawyer-in-residence’ model. We engaged with a special education legal consultant in July 2019 who maintained office hours 2 days per week on RFK CERC’s main floor, alongside multidisciplinary clinical staff.

**Publication** - We documented the first years of our collaboration in Special Education Disparities Are Social Determinants of Health: A Role For Medical-Legal Partnerships. *Progress in Community Health Partnerships: Research, Education, and Action.* 2020; 14 (2) Summer.
THE HIGHLIGHTS

NATIONAL PARENT SURVEY
Research

This research was impelled by RFK CERC clinicians’ concerns for the families they serve, due to the changed socio-political environment in 2017. Our findings from more than 1,000 parents across the US are reported in: National Parent Survey 2017: Worries, Hopes, and Child Well-Being. Journal of Community Psychology. 2020; Aug 25: PMID: 32840885. (See related Einstein blog: [hyperlink] Doctor’s Tablet, 9.10.2020).

CULTURAL COMPETENCY

Diana Rodriguez, MSW has participated in the Georgetown National Center for Cultural Competence’s (NCCC) Communities of Practice (CoP). The goal of the CoP is to increase the number, diversity, and capacity of formal and informal leaders to transform their state/territorial DD systems. Through Georgetown University, Ms. Rodriguez is involved in the CoP peer exchange - an array of opportunities for shared learning, consultation, technical assistance, training and information exchange to state/territorial consortia. With her guidance, staff have met via zoom to discuss racism and how we can make our diverse patient population feel welcomed at CERC. These discussions, “Let’s Talk,” provided a safe space for all CERC staff to share their personal thoughts on issues of racism.

LEGISLATIVE ADVOCACY

The RFK UCEDD conducted heard from legislators and made Hill visits at the AUCD’s November 2019 conference. (See photo below with Senator Kirsten Gillibrand of New York, at AUCD.) We also continue to enter comments into the record on proposed legislation.
THE NUMBERS

PRE-SERVICE TRAINING PARTNERSHIP THROUGHOUT LEND PROGRAM

24 COLLEGES & UNIVERSITIES LEND Training Partnerships

29 PROGRAMS Report against the targets you set the previous year and set new ones for the coming year.

Audiology
Communication Disorders
Communication Sciences
Counseling Psychology
Dentistry
Developmental Pediatrics
Genetic Counseling
Family Medicine
Mental Health Counseling
Occupational Therapy
Physical Therapy
Psychiatry
Psychology
Psychology - Clinical
Social Work
Speech Language Pathology

Adelphi University, Arizona State University, Boston University, Brooklyn College, Clarkson, College of New Rochelle College of Staten Island, Columbia University, CUNY, Fairleigh Dickinson, Fordham University, Hofstra University, Hunter College, Ithaca College, Lehman College, Long Island University, Manhattan College, Mercy College, Montclair University, New York Medical College, New York University, Nova Southeastern University, Pace University, Queens College, Quinnipiac University, Rutgers University, Sarah Lawrence, St. John University, SUNY, The New School, Thomas Jefferson, Touro College, Townson University, University of Connecticut, University of Scranton, Utica College, Vanderbuilt University, Western Kentucky, Yeshiva
GRANTS & CONTRACTS
FY2020

TOTAL FUNDING FROM ALL SOURCES
$11,664,203*

* Includes FY 2020 grant awards to Einstein/Montefiore with Rose F. Kennedy UCEDD or affiliated staff on the grant

$5,701,050
FEDERAL

$4,301,029
STATE

$603,124
LOCAL

$1,059,000
FOUNDATION
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ROSE F. KENNEDY

UNIVERSITY CENTER FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

SCHOLARLY ACTIVITY | ENGAGEMENT

FEDERAL FUNDING
STATE FUNDING
LOCAL FUNDING
FOUNDATION FUNDING

CONFERENCE AND POSTER PRESENTATIONS
DISTANCE LEARNING MODULES
ELECTRONIC PRODUCTS
NEWSLETTERS
REPORTS AND MONOGRAPHS
PAMPHLETS, BROCHURES, OR FACT SHEETS
PEER-REVIEWED PUBLICATION IN SCHOLARLY JOURNALS
PRESS COMMUNICATIONS
WEB-BASED PRODUCTS
Federal Funding

**Act Early Ambassador**
Contact: Romina Barros MD  
Funder - Center for Disease Control and Prevention  
$2,000

**Autism Genetics Network, Phase III: Increasing Representation of Human Diversity** / Contact: Sophie Molholm, PhD / Funder-National Institute of Mental Health (Primary grantee: UCLA)  
$199,891

**Developmental Behavioral Pediatrics Training**  
Contact: Elisa Muniz MD / Funder - Health Resources and Services Administration (HRSA)  
$187,115

**Effectiveness Evaluation of ‘Learn the Signs - Act Early’ Books** / Contact: Karen Bonuck, PhD  
Funder-Centers for Disease Control and Prevention (Association of University Centers on Disability)  
$135,567

**Family Interaction Training (FIT) Program**  
Contact: Anne Murphy PhD  
Funder - Centers for Disease Control and Prevention/Association of University Centers on Disabilities  
$98,000

**Harnessing Clinical Genomic Characterization to Accelerate Translational Advances for Patients with IDD** / Contact: Sophie Molholm, PhD  
Funder - National Center for Advancing Translational Sciences (Primary Grantee: Washington University)  
$50,000

**Increasing Sleep Health Literacy: A Social-Ecological Approach** / Contact: Karen Bonuck, PhD  
Funder - National Institute for Child Health and Human Development NIH  
$450,812

**LEND Grant - Interdisciplinary Leadership Training in Neurodevelopment and Related Disabilities** / Contact: Lisa Shulman, MD / Funder - Health Resources and Services Administration (HRSA)/Maternal and Child Health Bureau (MCHB)  
$836,493

**Molecular Basis of Early Childhood Obesity Programming by Intrauterine Growth Restriction**  
Contact: Karen Bonuck, PhD (PI= M Charron)  
Funder - National Institute for Child Health and Human Development NICHD  
$692,521

**National Curriculum Initiative in Developmental Medicine** / Contact: Joanne Siegel, LCSW  
Rose F. Kennedy Center, UCEDD/LEND  
Funder - Centers for Disease Control and Prevention/American Academy of Developmental Medicine and Dentistry  
$25,000

**Obesity and Caries in Young South Asian Children- A Common Risk Factor Approach**  
Contact: Karen Bonuck, PhD (PI= A Karasz)  
Funder - National Institute on Minority Health and Health Disparities (NIH)  
$768,134

**Sensory Integration Therapy in Autism: Mechanisms and Effectiveness**  
Contact: Sophie Molholm, PhD / Funder - National Institute for Child Health and Human Development NICHD  
$619,431

**Support for the Rose F. Kennedy IDD Research Center** / Contact: Sophie Molholm, PhD  
Funder - National Institute for Child Health and Human Development NICHD  
$862,238

**Training in Intellectual and Developmental Disabilities (IDD) Research** / Contact: Sophie Molholm, PhD / Funder - National Institute for Child Health and Human Development  
$203,838

**UCEDD Grant**  
Contact: Karen Bonuck, PhD & Joanne Siegel LMSW  
Funder - Administration on Community Living AUCD  
$570,000
State Funding

Early Intervention: State Systematic Improvement Grant (Family Centered) / Contact: Karen Bonuck PhD & Joanne Siegel, LCSW
Funder: State Health Dept: New York State Department of Health
$240,624

Regional Support Centers for Children and Youth with Special Health Care Needs
Contact: Karen Bonuck, Ph.D. & Joanne Siegel, LCSW
Funder: New York State Department of Health
$362,500

Local Funding

Autism Recreational & Socialization
Contact: Tammy Fried, LCSW
Funder: New York City Department of Health and Mental Hygiene (DOHMH).
$120,000

Developmental Disability Clinic Deficit-Based Reimbursement / Contact: Joanne Siegel, LCSW
Funder: New York City Department of Health and Mental Hygiene (DOHMH)
$70,429

Developmental Disabilities Clinic (Adult Services)
Contact: Gail Bergin, NP
Funder: New York City Department of Health and Mental Hygiene (DOHMH)
$185,000

Group Attachment Based Intervention (GABI) Expansion (5 Boroughs) / Contact: Anne Murphy, Ph.D.
Funder: New York City Admin for Children’s Services
$3,500,600

Foundation Funding

Group Attachment Based Intervention (GABI) Trauma Services
Contact: Anne Murphy, Ph.D.
Funder: Catholic Charities
$384,000

Robin Hood Main Grant
Contact: Anne Murphy, PhD
Funder: Robin Hood Foundation
$475,000

Simons Foundation Powering Autism Research for Knowledge (SPARK)
Contact: Lisa Shulman, MD
Funder: Simon’s Foundation
$200,000
Conference and Poster Presentations (43)


Distance Learning Modules (2)


Electronic Products (2)


Bonuck K. Brezel E. Pachter M. Ramos M E. Siegel J. (2019). Family Perspectives (English) Training Module. Produced for (New State Department of Health Bureau of Early Intervention). To obtain a copy email: karen.bonuck@einsteinmed.org

Other (3)

Cardin Marie J. (2020, May). Kid &Teen Scene. Patient generated booklet of original work. To obtain a copy email: mcardin@montefiore.org


Newsletters (3)

Mckenzie S. Passmore R. (2019). RFK CERCulation Newsletter. Audience (Staff and faculty). To obtain a copy email: rachel.passmore@einsteinmed.org


Pamphlets, Brochures, or Fact sheets (3)


Passmore R. Bonuck K. Siegel J. (2019). RFK UCEDD Brochure. Brochure about the RFK UCEDD at Einstein/Montefiore. To obtain a copy email: rachel.passmore@einsteinmed.org

Reports and Monographs (1)

Peer-Reviewed Publications in Scholarly Journals Published/In Press (14)


Press Communications (7)


Web-Based Products (19)


Web-Based Products (19)

Ayoob Keith T. (2019, November). Biltong: The High-Protein, Zero-Sugar Alternative to Beef Jerky Your Snack Stash Needs. Quoted discussing biltong, a beef jerky-like dried snack that has no sugar added and is high in protein and low in fat, and its usefulness as a snack. https://www.livestrong.com/article/13722794-biltong/


Ayoob Keith T. (2020, January). 7 Nutrition Myths These Dietitians Are Busting. Registered dietitians bust popular food myths and misperceptions with sound science. https://cuttothecasenutrition.com/7-nutrition-myths-these-dietitians-are-busting/


Ayoob Keith T. (2020, June). Serving Science About MSG. Traced the origin of the misperceptions about monosodium glutamate or MSG, and how 50 years of rigorous scientific studies have disproved the fears, yet they persist. https://msgodish.com/serving-science-about-msg/


FACULTY & STAFF

The UCEDD continues to be co-led by Karen Bonuck, PhD (Co-Director), and Joanne Siegel, LCSW (Co-Director).

Karen Bonuck, PhD - is a Professor in the Departments of Family and Social Medicine, and Pediatrics. She brings nearly three decades of research experience in pediatric feeding, sleep, and child maltreatment, among other areas. She is currently the Principal Investigator (PI), Co-Investigator on three NIH research grants that intersect with our UCEDD. Since joining the UCEDD in 2016, Dr. Bonuck has collaborated the RFK CERC faculty and staff on a wide range of research activities, and promoted novel programming in fulfillment of the UCEDD mission.

LEAD STAFF

Phyllis Angelico - is the Administrative Secretary for the UCEDD (and LEND) programs. Ms. Angelico supports the UCEDD as the lead administrator.

Nicole Furnari, LMHC - is the Health Homes Service Project Director LMHC and continues as our Children’s Health Home Service Director. As the Waiver Service Director, she leads a team of 8 care managers that serve 200 children and their families who have serious health care needs.

Qi Gao, PhD - at Einstein’s Division of Biostatistics, continues to provide analytic support to our UCEDD research projects.

Kathleen McGrath, LSW - is the Research Coordinator for the RFKUCEDD/LEND programs and a Doctor of Social Welfare student.

Marcelle Pachter, DDS [Spain] - LEND Family Faculty is the Family Liaison bilingual (English/Spanish) for the CYSHCN Project and Family Faculty Discipline Coordinator at LEND (Leadership Education in Neurodevelopmental and Related Disabilities)

Joanne F. Siegel, LCSW - is Principle Associate in the Department of Pediatrics and also the UCEDD’s Director of Community, Legislative, and Advocacy Affairs. She is known for her pioneering work in self-advocacy (SA), including guidance and technical assistance to the Bronx Community Self-Advocacy Group (the longest running SA group in NYS). This year Ms. Siegel piloted the introduction of IDD within the Einstein Medical School Curriculum and included self-advocates as partners in this venture, with support as part of the National Curriculum Initiative in Developmental Medicine funded through AADMD, Special Olympics and ACL.

Jeannie Ramos, BSHM - is the RFK UCEDD/LEND NIRS Database Coordinator and Administrator for Training Operations.

Diana Rodriguez, LMSW - is Diversity Coordinator for the RFK UCEDD/LEND activities. She participates in Georgetown University’s Community of Practice Training through the NYS Developmental Disabilities Planning Council, as such, she leads an organizational self-assessment at RFK CERC.

Kay Binns-Simpson, MBA - came onboard as a Grants Administrator for CERC in July 2019. She has over 12 years of diversified grants management experience spanning pre-award, post award, audit & grant close-out duties for an annual grant portfolio of over $22 million in federal, state and city government funding.
FACULTY & STAFF

In-Kind

Mayra Alvarez, PhD - Director of Allied Health Training - Assistant Professor Pediatrics

Ailen Aponte, LMSW - LEND Self-Advocate Faculty

Monica McQuaid, PhD - Director of the Adult Literacy Program - Assistant Prof. Pediatrics

Sophie Molholm, PhD - Associate Director of IDDRC - Professor Neuroscience

Anne Murphy, PhD - Director of Early Childhood Mental Health - Associate Prof. Pediatrics

Elizabeth Ridgway, DOTR - Supervising Occupational Therapist - Assistant Professor Pediatrics

Erin Rivelis, PhD - Child and Adolescent Unit Director - Assistant Professor Pediatrics

Lisa Shulman, MD - RFK CERC Interim Director, Director of the Division Developmental Medicine, LEND Director - Professor Pediatrics

We would like to thank the Association of University Centers on Disabilities for its support and technical assistance in our RFK UCEDD activities.
The Children's Evaluation and Rehabilitation Center provides services at the Van Etten Building #5 in the Jacobi Medical Center complex.

The Van Etten Building
1225 Morris Park Avenue
Bronx, New York 10461
718.430.8500

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