



Cerebral Palsy Associations
of New York State



2006 - 2007
ANNUAL REPORT

MISSION STATEMENT

The mission of Cerebral Palsy Associations of New York State is to advocate and provide direct services with and for individuals with cerebral palsy and other significant disabilities and their families, throughout New York State, in order to promote lifelong opportunities and choices for independence, inclusion, and enhanced quality of life.

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2006 - 2008

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Abstract cover photo courtesy of Michael Mullarkey.

Michael lives in Queens and is an avid photographer. He will have three pictures exhibited this year at the Progressive Visions 2 Art Show in New York City. He took the cover photo in December 2006 while participating in the CP of NYS Metro Services Photo Club.

“Coming together is a beginning . . . working together is success.” – Henry Ford

Henry Ford’s observation is a worthy challenge for all our organizations. Last year, we celebrated sixty years of Cerebral Palsy Associations of New York State (CP of NYS) working with Affiliates, families, and communities and fulfilling our mission of supporting people with cerebral palsy and other significant disabilities as they reach their individual goals. Over the years, we worked with many other social service and community agencies to ensure that we offered the best opportunities for people to succeed. Today, the need for us to work with others in our communities has never been greater.

We have seen increased threats to funding for programs for people with disabilities from both federal and state government. Working with our Affiliates, our colleagues from other provider associations, and with our national organization, ACCSES (formerly the ACCSES-DSPA Alliance), we have successfully thwarted these attempts. However, we know that in the year ahead, there will be additional attempts to cut funds to programs. And throughout New York State, our programs have been subject to increased oversight by the Office of the Medicaid Inspector General.

During this past year, CP of NYS worked with the new Administration in Albany to help them better understand the residential, health, education, and personal development needs of people with disabilities. We intensified our advocacy for access to health services, engaging in discussion and debate on the appropriate service delivery system and rate structure. Through our efforts, there were cost of living adjustments (COLAs) approved for Early Intervention and the Traumatic Brain Injury programs as well as other non-trended programs in the Office of Mental Retardation and Developmental Disabilities (OMRDD). In the past few years, there have been many problems in the approval of Durable Medical Equipment. This year, we worked with the NYS Department of Health (DOH) and a committee comprised of other interested groups, and have seen much improvement in the approval process.

In November, we bid farewell to OMRDD’s Commissioner Thomas Maul. Commissioner Maul was well respected for his efforts in community inclusion and funding systems. In January, Diana Jones Ritter was appointed the new Commissioner of OMRDD and the parents, advocates, providers, and people with disabilities were extremely delighted that such a dedicated, knowledgeable and caring individual was chosen. We met with Commissioner Ritter many times in the first 6 months of her appointment and know that she will continue to strengthen OMRDD’s partnership with providers.

The education programs our Affiliates provide continue to assist New York State in providing a continuum of services for children. Through the Task Force on Preschool Special Education we hope to have the positive recommendation for a new rate methodology for all our programs. We continue to work with individuals and their families in all parts of the state to help them find homes and services that meet their needs. All our Affiliates have strived to develop day programs and community activities that respect the desires of the people they serve while also helping them become part of their community. It is within this concept of integration that our challenge lies.

We must move forward, building upon our history of networking with others to provide assistance for people with disabilities. Our work must include educating schools and communities in the techniques that are most effective in supporting people with significant disabilities including, autism and traumatic brain injuries. Our Affiliates have great expertise in these areas and must share them with others in their communities.

The past year has seen many accomplishments. However, if we are to succeed on every level as suggested by Henry Ford, we must work together with our community members, other service providers, family members, and people with disabilities to develop a common goal of broader understanding, integration, and acceptance.



Idajeon Windell, Ed.D.
Chairwoman

A handwritten signature in black ink that reads "Idajeon Windell".



Susan Constantino
President & CEO

A handwritten signature in black ink that reads "Susan Constantino".

LEGISLATIVE ACTIVITIES

The 2007 New York State Legislative Session was the first for Governor Eliot Spitzer. The Governor and the Legislative Leaders were able to come to a budget agreement “on-time” for the third year after 20 years of late budgets. This budget was negotiated in a very compressed timeframe with the Governor, the Senate, and the Assembly beginning real budget negotiations less than a week before the April 1 deadline. Most of the CP of NYS priorities were included in the final budget including:

- **OMRDD Budget** – The Governor’s Office of Mental Retardation and Developmental Disabilities (OMRDD) budget proposal, including the trends, a COLA for non-trended programs and health insurance adjustment, was approved.
- **Article 28 Clinic Services** – The final budget included CP of NYS’s bill language requiring OMRDD and the NYS Department of Health (DOH) to reconvene the Provider Council and work out the myriad of issues regarding Article 28s and Article 16s.
- **Special Education Teacher Shortage** – The Governor’s proposals for \$2 million for teacher recruitment and retention and \$13 million in uncommitted IDEA funds for teacher certification initiatives were

approved, as well as a new \$2 million for 4410 and 853 special education teacher salaries.

- **Preschool Special Education Task Force** – The Governor’s Preschool Special Education Task Force was approved. This Task Force is studying the relationship between preschool special education and other early childhood programs, the current tuition rate methodology, and conducting a comparative study of preschool special education systems with other states. Susan Constantino, President & CEO of CP of NYS, was appointed to this Task Force by the Governor as one of the three provider representatives from across the state.



Alan Krafchin, President of the Centers for Disability Services (left) and Louis Tehan, Executive Director of Upstate Cerebral Palsy talk with Rebecca Cort, Deputy Commissioner of VESID/NYS Education Department (right) at the March 2007 CP of NYS Legislative Reception

LEGISLATIVE ACTIVITIES

The Legislature passed many bills of interest to CP of NYS. Governor Spitzer has acted on some of the bills, but there are a number that have not been sent to the Governor as of this writing. The following are some of the bills of interest.

BILLS SIGNED BY THE GOVERNOR

- **The Health Care Decisions Act** – This law authorizes involved family members of a person with mental retardation to withhold or withdraw life sustaining treatment when a guardian (Article 17A) has not been appointed. The legislation specifically requires that non-guardian family members qualified to act as surrogates have “a significant and ongoing involvement in a person’s life . . . so as to have knowledge of their needs and, to the extent ascertainable, their moral and religious beliefs” when making such decisions.
- **Jonathan’s Law** – Effective May 5, 2007, this new law provides full access to all records and documents pertaining to allegations and investigations of patient abuse and mistreatment, including complaints and reports for individuals in mental hygiene facilities. A subsequent law was signed that authorizes records access back to January 1, 2003.
- **Individuals with Disabilities Education Act (IDEA)** – This law extends the New York State statute which is required to be in compliance with the federal IDEA.
- **Prompt Contracting Law** – This new law strengthens the first Prompt Contracting Law that was passed 15 years ago to establish a framework for state contracting with not-for-profit agencies that would assure timely communications, negotiations, and decision making.
- **IEP Billing** – This law extends the authorization of Article 28 clinics which are also 4410 preschools, to bill Medicaid for Individualized Education Program (IEP) services provided to preschool children with disabilities until July 1, 2009.
- **PJ’s Law** – This new law requires school bus drivers and school bus attendants who ride with children with disabilities, to complete training in the needs of children with disabilities.
- **IDA Extender** – This law extends the authority of Industrial Development Agencies (IDAs) to finance not-for-profit projects for seven months.
- **Burden of Proof** – This proposal places the burden of proof back with the school district in all impartial due process special education hearings. The Supreme Court decision *Shaffer v Weast* ruled that, in the absence of a state statute, parents must bear the burden of proof in an impartial due process special education hearing. This proposal provides the statutory authority so that parents do not have to bear the burden of proof.

LEGISLATIVE ACTIVITIES

BILLS VEOTED BY THE GOVERNOR

- **SED Methodology** – This bill would have required the implementation of a three-year rate setting methodology and would have authorized private 853 and 4410 schools for children with disabilities, and special act school districts to maintain a 2% fund balance. The Governor's veto message indicated that they were looking at revising the rate methodology.
- **Cash and Counseling** – This legislation would have created the self-directed personal assistance services program and authorized the Health Commissioner to establish a Cash and Counseling program. The Governor's veto message stated that New York currently has a self-directed personal assistance program.

LOBBY DAY

Nearly 100 consumers, staff members, and volunteers from Affiliates across the state gathered in Albany March 5 and 6 for the 2007 CP of NYS Lobby Day. They met with legislators, agency staff, and members of Governor Eliot Spitzer's new administration over the two-day period. The event included a reception Monday evening and office visits on Tuesday. Representatives of Affiliates from across the state came to Albany to discuss issues including Article 28 and Article 16 Clinic Services, Medicaid, Early Intervention, and the shortage of Special Education Teachers. Government representatives were also given packets of information and publications

created by CP of NYS and its Affiliates to help them better understand how their actions impact people with disabilities and their families on a daily basis. Additionally, the March 5, 2007 edition of the "Legislative Gazette" weekly newspaper included the CP of NYS insert. This year's insert had stories and vignettes from various Affiliates highlighting the programs and services for people with disabilities and their families.



New York State Assemblymember Harvey Weisenberg (center) talks with Robert McGuire, Executive Director of UCPA of Nassau County, and Susan Constantino, President & CEO of CP of NYS, at the March 2007 CP of NYS Legislative Reception

GOVERNMENT NETWORKING

In order to ensure that the needs and desires of people with disabilities and the interests of our 24 Affiliates are represented before policies and regulations are changed or enacted, CP of NYS participates on statewide Advisory Councils and Task Forces. Staff members from CP of NYS and its Affiliates represent the organization and its constituents on various committees and advisory groups, as well as at public hearings, including the following:

OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES (OMRDD)

- Medicaid Service Coordination Task Force
- Provider Association Council
- New York State CARES Advisory Council
- Home & Community Based Services (HCBS) Waiver Units of Service Task Force
- Provider Council
- Provider Council Clinical Services Subcommittee
- OPTS Steering Committee and Work Groups
- Employment Training Internship Program Advisory Council
- Workforce Recruitment & Retention Work Group

STATE EDUCATION DEPARTMENT (SED)

- Preschool Special Education Longitudinal Study Advisory Group
- NYS Rehabilitation Council
- CRP Planning Group
- VESID Supported Employment
- Pre-School Special Education Task Force

DEVELOPMENTAL DISABILITIES PLANNING COUNCIL (DDPC)

- DDPC Assistive Technology Work Group

NYS COMMISSION OF QUALITY OF CARE AND ADVOCACY FOR PERSONS WITH DISABILITIES

- TRAIID Interagency Partnership for Assistive Technology Advisory Board

DEPARTMENT OF HEALTH (DOH)

- Early Intervention Coordinating Council (EICC)
- EICC Task Force on Provider Approval (Chairperson)
- Durable Medical Equipment (DME) Work Group
- Provided Testimony at the Legislative Hearings on Access to Medicaid Funded DME
- DOH/OMRDD Clinical Services Provider Council

OTHER STATEWIDE ACTIVITIES

Development of new statewide training curricula for the NYS Early Intervention Program via competitive grant funds from the NYS Department of Health. Two new training curricula were developed in 2006.

AFFILIATE ACTIVITIES

The State Association works collaboratively with Affiliates to promote life-long opportunities for people with disabilities and to deliver programs and services more efficiently to consumers and their families.

ANNUAL CONFERENCE

Nearly 900 people from across the state came to Albany October 23-25 to attend the 46th CP of NYS Annual Conference. Jan Moss, Director of Community Leadership and Advocacy for the Center for Learning and Leadership, University Center for Excellence on Developmental Disabilities, Oklahoma University HSC College of Medicine, delivered a high-energy and insightful Keynote Address to more than 300 attendees, setting the tone for the entire Conference.

The Conference, entitled **“Decades of Dedication,”** included nearly 50 sessions and meetings dealing with a wide range of issues and included a celebration of the organization’s 60th anniversary. Representatives from state agencies also addressed Conference participants on new initiatives. The CP of NYS Annual Banquet on Monday evening featured a live and recorded presentation of some of the highlights of the first 60 years of the organization. More than 450 people in attendance were treated to video presentations, slides, and live music. Natalie Rogers, Active Past Chair



Nancy Kong from Aspire of WNY (second from right), Janina Jensen (CP of NYS Metro Services) and Matthew Calautti from the Center for Disability Services (at microphone) say thank you to retiring OMRDD Commissioner Thomas Maul, who attended the 60th Anniversary Dinner

of the CP of NYS Board of Directors, created original songs for the evening and invested a great deal of time in coordinating the special anniversary celebration. The next night nearly 60 employees from 20 Affiliates and CP of NYS were honored for outstanding service at the Celebrate Staff Dinner. A display of artwork, submitted by consumers from across the state for the third annual **Visions of New York** Consumer Art Contest, was featured on Tuesday. Mary Whalen, of Staten Island and United Cerebral Palsy of New York City (UCP/ NYC), was chosen as the CP of NYS Artist of the Year in the 2006 contest.

CP OF NYS AND AFFILIATES DEVELOP IMAGE CAMPAIGN

CP of NYS has begun work on a statewide public relations and image campaign designed primarily to make people in state government more aware of who we are, what we do, and why it is important. The campaign will include a powerful and succinct statement of who we

AFFILIATE ACTIVITIES

are and what we do, and the message that we serve many people with significant disabilities. The campaign will also convey our commitment to providing quality services and advocacy for more than 60 years and highlight our innovative programs and services designed to meet the needs of those we serve.

The campaign will consist initially of print advertisements and articles that highlight consumers and their success stories. We will also produce a short overview video using the stories of consumers and their families to illustrate what we do, the value of our programs and services, and the collaborative nature of our work. Radio scripts and television public service announcements will also be part of the project. Materials will be produced so as to allow Affiliates to personalize them for use in their publications and local media outlets.



TECHNICAL ASSISTANCE

CP of NYS:

- Provided technical assistance to Affiliates regarding OMRDD program development and reimbursement issues. Staff offered technical assistance to Affiliates on OPTS proposal development, rate appeals, changes to day program, residential program oversight and development, respite programs, and implementation of special OMRDD initiatives, such as the health care enhancement.
- Provided information, technical support, and/or direct assistance to Affiliates regarding Early Intervention, Preschool and School Age Special Education, Assistive Technology, and Traumatic Brain Injury issues.
- Provided assistance with SED regarding approval of new special education program models.
- Provided technical assistance and advice to Affiliates regarding DOH fiscal and regulatory issues.
- Assisted Affiliates with matters related to tuition rates and fees for education programs.

AFFILIATE ACTIVITIES

NYS ELKS ASSOCIATION AND THE CP OF NYS HOME SERVICE PROGRAM

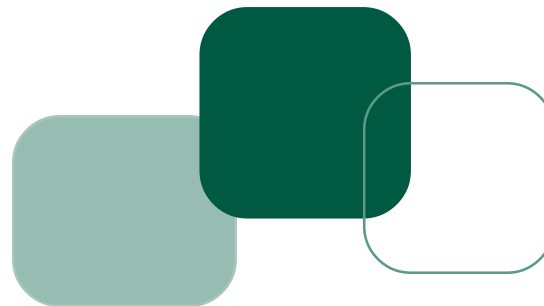
For more than 40 years the New York State Elks Association (NYSEA) has helped to fund a program that began as a way to provide services to individuals with disabilities in their homes. The Home Service Program was adopted as an Elks Major Project in 1964 and the NYSEA has contributed more than \$20 million and countless hours of volunteer commitment since.

As part of an effort by the NYSEA and CP of NYS, we have begun a program of regional meetings across the state involving members of the Elks at the state and local level, and staff from CP of NYS and its Affiliates. The meetings have created new relationships at the local level, generated ideas that

have benefited both the Elks and CP of NYS Affiliates, and provided opportunities for members of both organizations to learn more about how to continue to strengthen and improve this long-standing partnership.

This year, NYSEA agreed to significantly increase the amount of financial support for the vehicle grant program in the future, which will allow more vehicles to be replaced each year.

Richard De Silva, from Westchester County, has been named Chairman of the Major Project Committee of the NYSEA, which oversees fundraising in support of the CP of NYS Home Service Program. Gregory Santiago, of Mount Vernon, and his family have agreed to accept the position of Elks Ambassador and will work with Mr. De Silva to raise funds and public awareness.



STATEWIDE COMMITTEES

CP of NYS Statewide Committees

- Assistive Technology
- Development/Public Relations
- Education/Early Intervention
- Employment/Vocational
- Finance
- Guardianship
- Health and Clinical Services
- Human Resources
- Information Technology
- Medical Directors Council
- Quality Assurance
- Residential and Day Services
- Traumatic Brain Injury

Workgroups

- Corporate Compliance
- HIPAA
- Managing Multiple Sites
- Medicare Part D



METROPOLITAN SERVICES

CP of NYS's Metro Services offers a wide range of programs and services designed to support individuals with disabilities in leading more independent and productive lives. These include comprehensive health care services, community living services, adult day programs, vocational, and traumatic brain injury services, summer camp and vacations, service coordination, and family support services.

COMMUNITY LIVING SERVICES

- Three hundred and forty individuals live in 74 residences certified as Individual Residential Alternatives (IRAs) and 100 individuals live in 8 residences certified as Intermediate Care Facilities (ICFs). Included in these are four ICFs and one IRA, serving 64 consumers that provide around the clock, on-site nursing services.



Rosalinda Glasper-Gregg

DAY SERVICES

- Metro Services' Day Programs provide services to over 400 consumers. The programs feature inclusionary programs which are integrally involved in their immediate communities, providing volunteer opportunities at various community programs and participation in community restoration and gardening projects.

HEALTH CARE CENTERS (Diagnostic & Treatment Centers)

- Metropolitan Services specializes in a wide range of primary and specialty health, medical, and habilitative services for people with disabilities. Our physicians specialize in meeting the health care needs of people with developmental disabilities in a comfortable and caring atmosphere. The Health Care Centers continue to seek increased opportunities to provide services. This year nearly 50,000 visits were recorded.

CAMP JENED

- Camp Jened served 825 guests in residential camping sessions during the summer of 2006.
- Travel Camp vacations in Bermuda, Philadelphia, Atlantic City, Cape Cod, Saratoga Springs, Niagara Falls, Mystic Connecticut, the Pocono's (Claws & Paws Wild Animal Park), Hershey Pennsylvania, and Disney World in Florida, were conducted for 155 guests during the 2006-2007 fiscal year.

METROPOLITAN SERVICES

SERVICE COORDINATION

- Metro Services provided Medicaid Service Coordination (MSC) to 339 individuals over the past year. A total of 227 individuals live in IRAs operated by CP of NYS and 67 individuals live with their families, on their own, or with other agencies.

TRAUMATIC BRAIN INJURY SERVICES

- Forty-seven individuals with Traumatic Brain Injuries (TBI) receive service coordination. Nine individuals are currently enrolled in the Structured Day Program that operates three days per week, and Independent Living Skills Trainers are currently providing one-to-one assistance and training to 33 participants living in the community. Services are provided through the DOH Medicaid Waiver Program.

VOCATIONAL SERVICES

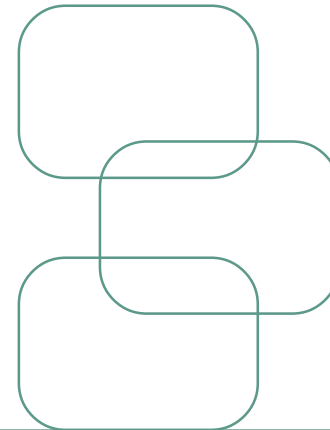
- Vocational services were provided exclusively in community-based settings. More than 100 individuals were enrolled in VESID-sponsored services; OMRDD extended services; OMRDD day habilitation; and OMRDD HCBS Residential Habilitation. Nine individuals met the VESID-mandated criteria for having been successfully “rehabilitated” and 18 individuals were employed under the VESID contract which also provides opportunities for individuals with TBI. A total of 48 individuals were gainfully employed by year-end.

STAFF DEVELOPMENT AND RECRUITMENT

- CUNY’s School of Professional Studies, in collaboration with the John F. Kennedy, Jr. Institute for Worker Education, continues to offer a Graduate Certificate in Disability Studies designed for direct support professionals who already have a bachelor’s degree. Professionals from Metro Services are presently enrolled in the program. Metro Services, as a collaborative partner, submitted a letter of support to assist in obtaining additional funding for this program.

COMMUNITY AFFAIRS

- Volunteers and interns continue to be an integral part of Metro Services programs. Volunteers provide clerical support, direct assistance with patient care in the Health Care Centers, and assistance for consumers in the Community Living Services program in fulfilling their community inclusion goals. Volunteers and interns also play an essential role in preparation for the annual art show.



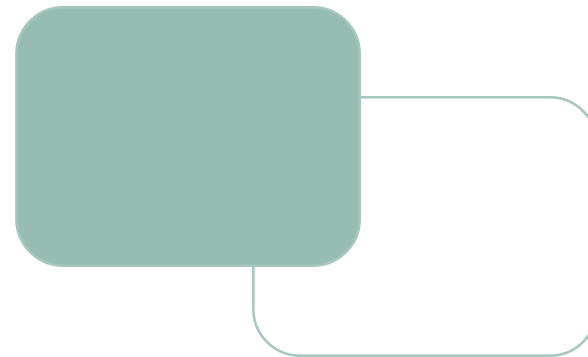
PROFILE

Emilliano Perez is a well-liked and respected member of the team at the Jerome Belson Center (JBC) in the Bronx. He has been attending the Metropolitan Services' Day Habilitation program at JBC for years. In that time, Mr. Perez has crafted and grown into a position of trust. He participates in the program, but much more than that, he has become a valuable Jack-of-all-trades for the staff and participants. Mr. Perez is adept at making repairs to electronic and mechanical devices. He can often be found working on a VCR or DVD player that refused to function properly. He also works with teachers' aides and other staff members during the day. He has gained skills and confidence in his abilities as he has taken on more duties and works to be as independent as possible and hopes to move into a supported employment environment in the future.

Emilliano is also an accomplished artist. Many of his works have been featured in the annual Metro Services Art Exhibition and he has also had his artwork appear in publications promoting the event. When he is not tinkering with uncooperative equipment or creating art, Mr. Perez enjoys basketball and other recreational activities with friends or the roommates who share his Manhattan apartment. He has been living in Metro Services facilities for more than 20 years and currently resides with four other individuals in a small Individual Residential Alternative (IRA) apartment. He enjoys working and earning money and being as independent and as involved in the community as possible. The programs at Metro Services help him accomplish those goals and, in return, he helps other participants as well.



*Emilliano Perez (right) with Joseph Pancari, Executive Vice President/
Chief Operating Officer of CP of NYS*



FINANCIAL REPORT

NEW #S EXPECTED 10/1/07

CEREBRAL PALSY ASSOCIATIONS OF NEW YORK STATE
 STATEMENTS OF SUPPORT, REVENUE AND EXPENSES
 FOR THE YEARS ENDED JUNE 30, 2007 AND 2006
 (In Thousands)

	<u>6/30/07</u>	<u>6/30/06</u>
SUPPORT AND REVENUE		
Support from public:		
Contributions		
NYS Elks Association Major Projects, Inc.	\$ 000	\$ 424
Total Support	<u>\$ 000</u>	<u>\$ 424</u>
Government Fees/Grants for Program Services:		
Medicaid Fees	\$ 00,000	\$ 91,239
Grants/Fees: Education, Training and Direct Consumer Services	<u>000</u>	<u>\$ 973</u>
Total Grants and Fees	<u>\$ 00,000</u>	<u>\$ 92,212</u>
Other:		
Camp Fees	\$ 0,000	\$ 1,471
Affiliate Support	000	532
Other Revenues	<u>0,000</u>	<u>1,065</u>
Total Other	<u>\$ 0,000</u>	<u>\$ 3,068</u>
TOTAL SUPPORT AND REVENUE	<u>\$ 00,000</u>	<u>\$ 95,704</u>
EXPENSES		
Program Services		
Day Services	\$ 00,000	\$ 10,497
Residential Services	00,000	67,470
Clinic	0,000	5,266
NYS Elks Association Major Projects, Inc.	000	424
Affiliate Clinics	000	715
Affiliate Services and Conference	000	926
Transportation	<u>\$ 000</u>	<u>\$ 315</u>
Total Program Services	<u>\$ 00,000</u>	<u>\$ 85,613</u>
Administrative/Supporting Services	<u>\$ 0,000</u>	<u>\$ 6,662</u>
TOTAL EXPENSES	<u>\$ 00,000</u>	<u>\$ 92,275</u>
EXCESS (DEFICIENCY) OF SUPPORT AND REVENUE OVER EXPENSES	<u>\$ 0,000</u>	<u>\$ 3,429</u>

* Copies of complete financial statements are available upon request from CP of NYS, 330 West 34th Street, New York, NY 10001.



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