



**2003-2004**

# **Annual Report**

Cerebral Palsy Associations  
of New York State



# 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.*

*Cerebral Palsy Associations of New York State*

## *Board of Directors and Officers*

*2002-2004*

<b>President .....</b>	<b>James E. Johansen</b>
<b>Executive Vice President .....</b>	<b>Idajeen Windell, Ed.D.</b>
<b>Vice President for Finance .....</b>	<b>Robert C. Miller, Esq.</b>
<b>Vice President for Legislation .....</b>	<b>Jack M. Weinstein, Esq.</b>
<b>Vice President for Program Services .....</b>	<b>Ann B. LeMark</b>
<b>Vice President for Volunteer Services .....</b>	<b>Barbara N. Scherr</b>
<b>Secretary .....</b>	<b>Cora Baliff</b>
<b>Directors at Large .....</b>	<b>Ellis I. Barowsky, Ph.D.</b>
	<b>Thomas J. Caserta, Jr., Esq.</b>
	<b>Nancy Corelli</b>
	<b>John R. Horvath</b>
	<b>Marvin S. Reed</b>
	<b>Ernest Southworth</b>
	<b>Beatrice S. Wellens</b>
<b>Active Past Presidents .....</b>	<b>Robert M. DiFrancesco</b>
	<b>Anthony J. Koenig</b>
	<b>Natalie K. Rogers</b>

## *Executive Staff*

<b>Executive Director .....</b>	<b>Susan Constantino</b>
<b>Associate Executive Director .....</b>	<b>Duane Schielke</b>
<b>Associate Executive Director .....</b>	<b>Michael Alvaro</b>
<b>Vice President of Finance .....</b>	<b>Thomas Mandelkow</b>
<b>General Counsel .....</b>	<b>Steven Mosenson, Esq.</b>
<b>Assistant to the Executive Director .....</b>	<b>Heidi McManus</b>

## *Message from the President and Executive Director*

Cerebral Palsy Associations of New York State is a leading advocacy organization representing 22 Affiliates and one service division, which provides services to over 65,000 individuals with disabilities and their families. Each of our Affiliates has a separate mission and provides services important to their consumers, yet we all have a common goal, to provide the highest quality programs and services possible.



CP of NYS went through a transition this year due to the retirement of Michael Parker, our former Executive Director. The Board of Directors, through a well-executed succession plan, provided for an orderly and positive change in leadership. At last year's Annual Meeting, the three-year Operational Plan was approved and the implementation of that Plan began soon after. In the first year of the Plan, the goals and objectives targeted for Year One have been completed and reported.

This year, legislation was passed which solidifies New York State's commitment to the New York State CARES II program and to community-based programs needed for people with developmental disabilities. Through the Office of Mental Retardation and Developmental Disabilities (OMRDD) New York State OPTS program, our Affiliates will have the opportunity to collaborate with consumers and families on innovative program options.

The New York State budget continues to present problems, as some of the cuts proposed would affect the programs of our Affiliates. Through diligent lobbying efforts, we were able to have the cuts reinstated in the final budget, but were unable to get legislation, which we advocated for, passed by the Legislature.

In traveling through the State, we have had the opportunity to see first-hand the progress and services of the CP Affiliates. Our Affiliates are a great source of pride and encouragement. We are proud of the creativity and quality of their programs, and we are encouraged by their ability, each year, to continue fulfilling their mission.

We look forward to the continued success of Cerebral Palsy Associations of New York State.

  
*James E. Johansen*  
President

  
*Susan Constantino*  
Executive Director

**CP of NYS**

In June 2004, Dr. Michael Parker retired after 15 years as Executive Director of Cerebral Palsy Associations of New York State and was succeeded by Susan Constantino. Dr. Parker's leadership helped build a strong and influential organization. He worked tirelessly with and for people with disabilities and their families to make available critical services and to promote and create opportunities for inclusion and

enhanced quality of life. He also oversaw the establishment of an Affiliate Services Office which offers technical assistance and works to ensure that state public policy positively impacts the lives of children and adults with disabilities and their families. His presence will be missed, but his dedication and vision will have a positive and lasting effect.

The Affiliate Services Office, located in Albany, provides support to the organization's 22 Affiliates and the Metropolitan Division through representation, advocacy, legislation and public policy development, training and education, and government networking and technical assistance. Affiliate Services staff are a primary source of information about, and assistance with, state government.

The Affiliate Services Office works to advance statewide policy objectives and program development initiatives and provide individual technical assistance to Affiliates in the areas of special education, services and supports to individuals with mental retardation and developmental disabilities, and health services. The Affiliate Services staff of CP of NYS works with the Legislature and governmental agencies to ensure that public policy has a positive impact on the lives of children and adults with disabilities and their families.

Technical assistance is provided to individual Affiliates in the areas of regulatory compliance, program development, reimbursement analysis and management planning.

The Affiliate Services Office develops and advances these organizational objectives in conjunction with the Affiliates through a committee structure, development of an annual legislative and public policy agenda, and the Annual Conference.



# The State

## LEGISLATIVE ACTIVITIES

The 2004 New York State Legislative Session produced the latest state budget ever, with its adoption on August 12, 2004, almost four and a half months past the April 1 due date. The budget that passed was again only agreed to by the Senate and the Assembly and as a result, the Governor vetoed many of the Legislature's additions. Most of the Budget and Legislative Priorities of CP of NYS were included in the budget and were not vetoed by the Governor. These priorities included:

- ◆ Adoption of legislation establishing NYS CARES II in statute (A.10237/S.4586).
- ◆ Adoption of a revised fingerprinting bill that has the Office of Mental Retardation and Developmental Disabilities (OMRDD) receiving the fingerprints and notifying the employer if they can or cannot hire the individual.
- ◆ Rejection of the Governor's proposals for Early Intervention including: negotiated rates; two-tier approval process; provider registration fees; parent payment; and the elimination of the extended rate.
- ◆ Rejection of the Governor's proposal to eliminate Medicaid coverage of podiatry, enteral nutrition, and private practicing psychologists, dentists, nurses, and audiologists.
- ◆ Adoption of the Governor's proposal for \$2 million for 853 teacher recruitment and retention.
- ◆ Adoption of the Governor's proposed OMRDD funding.

CP of NYS once again held both an Albany Lobby Day and Reverse Lobby Days in each Affiliate's district. These Lobby Days were extremely successful. Almost all of the CP of NYS Priorities were included in the final budget or passed both houses of the State Legislature.

CP of NYS again produced a Special Report insert for *The Legislative Gazette*, the newspaper of New York State Government, read by thousands of people across the state each week. This year's Special Report was part of the February 23, 2004 edition and featured vignettes about CP of NYS Affiliate staff throughout New York State.



# Association

Cerebral Palsy Associations of New York State continues to increase staff participation on statewide Advisory Councils and Task Forces in an effort to ensure that the needs and desires of people with disabilities and their families are represented before changes in policy and service designs are made. Staff members from CP of NYS and Affiliates across the state represent the organization and its constituents on an increasing number of committees and advisory groups including:

**Department of Health (DOH):**

- ◆ Early Intervention Coordinating Council (EICC)
- ◆ EICC Task Force on Evaluation and Eligibility Determinations
- ◆ Early Intervention Clinical Guidelines Steering Committee
- ◆ Early Intervention Data Committee

**Office of Mental Retardation and Developmental Disabilities (OMRDD):**

- ◆ Supported Employment Work Group
- ◆ Medicaid Service Coordination Task Force
- ◆ Commissioner's Advisory 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
- ◆ Voluntary Agency HIPAA Work Group

**State Education Department (SED):**

- ◆ Preschool Special Education Longitudinal Study Advisory Group
- ◆ Vocational and Educational Services for Individuals with Disabilities (VESID) Supported Employment Stakeholders Group
- ◆ NYS Rehabilitation Council

**Office of the Advocate:**

- ◆ TRAIID Interagency Partnership for Assistive Technology Advisory Board

**Other Statewide Activities:**

- ◆ Completion of DOH contract to provide outreach, information and training for the Medicaid Buy-In Program for Working People with Disabilities
- ◆ Coordinated with SED to gain approval of Model Waivers for Preschool Programs
- ◆ Completed Supervisory Manual for Developmental Disabilities Planning Council (DDPC) Training Project

# GOVERNMENT NETWORKING

# AFFILIATE ACTIVITIES

The State Association works collaboratively with Affiliates in many ways to create, or enhance, opportunities for people with disabilities to reach their full potential and to deliver services more efficiently to consumers and their families.

- ◆ In collaboration with Affiliate representatives, CP of NYS developed Principles of Best Practice for Augmentative and Alternative Communication.
- ◆ Affiliate Services staff visited all Affiliates, updating data and gathering input.
- ◆ Five Affiliates conducted a cooperative hole-in-one golf event that attracted almost 400 participants.
- ◆ The 43<sup>rd</sup> Annual CP of NYS Conference in October – *“Creating Positive Approaches to Everyday Challenges”* – saw nearly 800 people attend over 50 workshop sessions and meetings. Steve Allen, Jr., MD, set a positive tone for the three-day event with an interactive, energizing and lighthearted Keynote Address entitled, *“Coping in a Changing World.”*
- ◆ Personal Outcomes Project (POP) was completed.
- ◆ Affiliate Services Staff was instrumental in assisting Affiliates with several million dollars in appeals, waiver, and other funds from SED, DOH, and OMRDD.

The committees formed in 2002 to deal with the effects of the Health Insurance Portability and Accountability Act (HIPAA) regulations (Steering Committee, and Transaction, Code Sets and Identifiers Committee) conducted several meetings via conference calls.

- ◆ The Steering Committee continues to oversee the other committees and distribute to Affiliates the HIPAA Update newsletter with new information on compliance.
- ◆ The Transaction, Code Sets, and Identifiers Committee (TCI) met several times to update Affiliates on the various aspects of electronic billing and to determine the progress made by Affiliates to become HIPAA compliant.
- ◆ A meeting of the HIPAA Security Committee was held in June 2004 to discuss security regulations and develop policies to help Affiliates reach compliance.





## ACTIVE CP OF NYS COMMITTEES

- ◆ Assistive Technology
- ◆ Clinical Services
- ◆ Development/Public Relations
- ◆ Education
- ◆ Employment/Vocational
- ◆ Finance
- ◆ Medical Directors Council
- ◆ Residential and Day Services
- ◆ Traumatic Brain Injury

## TECHNICAL ASSISTANCE TO AFFILIATES

- ◆ Served as liaison with SED for approval of new or modified school programs.
- ◆ Provided technical assistance to Affiliates regarding Early Intervention, Preschool & School-Age Special Education, Supported Employment, Assistive Technology, and Traumatic Brain Injury issues.
- ◆ Provided technical assistance to Affiliates regarding OMRDD program development and reimbursement issues.
- ◆ 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.

## NYS ELKS ASSOCIATION & THE HOME SERVICE PROGRAM

The CP of NYS Home Service Program is a collaborative effort of the New York State Elks Association and Cerebral Palsy Associations of New York State. CP of NYS provides direct services to adults and children with disabilities and their families in their home communities through a network of 27 Home Service Directors, serving all 62 counties in the state. Through its Major Projects Campaign, the Elks Association raised more than \$500,000 last year to support the Home Service Program across the state. In the past 38 years, this extraordinary organization has raised nearly \$19 million to support the Home Service Program. The Elks Association also helped fund new Home Service vehicles for four Affiliates this past year.

**Collaborative Efforts**

# Metropolitan – New York City Service Division

The Metropolitan New York Division of CP of NYS is one of the largest and most respected service organizations of its kind in New York City and a leader in creating innovative services and opportunities for people with disabilities and their families. The goal of the organization is to provide people with disabilities opportunities to live as independently as possible. Our dedicated staff provides a wide range of direct services that address the individual needs of our consumers.

## **Community Living Services**

- ◆ Three hundred and five individuals live in sixty-nine residences certified as Individual Residential Alternatives (IRAs) and sixty-eight individuals live in six residences certified as Intermediate Care Facilities (ICFs). In addition, there are four ICFs and one IRA, serving sixty-four consumers that provide around the clock, on-site nursing service.

## **Day and Vocational Services**

- ◆ The Division's Day Programs provide services to 349 consumers. There are inclusionary programs that are integrally involved in their immediate communities with consumers volunteering at community programs and participating in community restoration and gardening projects.
- ◆ Vocational services were provided exclusively in community-based settings to 76 consumers. Eight individuals were successfully "rehabilitated" under the VESID contract that also provides opportunities for individuals with Traumatic Brain Injury (TBI). By year-end, 32 individuals were gainfully employed.

## **Health Care Centers (Diagnostic and Treatment Clinics)**

- ◆ The Health Care Centers' services continued to steadily increase. This year, 49,019 visits were provided, an increase of 2.2% compared to last year. The clinics are running more efficiently and are responsive to consumers' needs.

## **Jened Recreational Village**

- ◆ Camp Jened served 1,033 guests in ten sessions during the summer of 2003.
- ◆ One hundred twenty-one guests enjoyed Travel Camp vacations throughout the year.

## **Service Coordination**

- ◆ Medicaid Service Coordination (MSC) was provided to 320 individuals this year. Two hundred seventy individuals live in IRA's operated by CP of NYS and 50 individuals live with their families or on their own.

## **Traumatic Brain Injury Services**

- ◆ Services provided through the DOH Medicaid Waiver program include: 33 individuals receiving service coordination; 13 individuals enrolled in the Structured Day Program; and 29 individuals living in “Supported Community Living” arrangements currently receiving one-to-one assistance and training from Independent Living Skills Trainers.



## **Staff Development and Recruitment**

- ◆ Twelve direct care staff are enrolled in a 12 college-credit program sponsored by the Kennedy Foundation and CUNY. The curriculum is designed specifically for staff working with people with developmental disabilities.
- ◆ Staff recruiting remains a challenge, particularly for nurses. International recruiting has been necessary to maintain adequate staff. These efforts have faced increasingly restrictive visa application processing.

## **Community Affairs**

- ◆ The Volunteer Services Program has recruited 100 volunteers for day programs, residences, health care centers and Metro Division offices. Affiliations have been established with many schools and job training programs in the region.

## **New Program Development**

- ◆ A site has been identified in the Westchester Square area of the Bronx to relocate the Jerome Belson Center, which houses Day Programs, the Health Care Center and the Bronx Community Living Program offices. The new location will provide state of the art, accessible facilities, convenient to public transportation.
- ◆ Two apartments in a large building complex on 3<sup>rd</sup> Avenue in Manhattan are being prepared for occupancy to relocate the consumers currently living elsewhere. The residence serves “aged out” young adult males referred by the NYC Agency for Children’s Services.
- ◆ A new first-floor and barrier-free residence is being developed in Brooklyn.

**CEREBRAL PALSY ASSOCIATIONS OF NYS**

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