



ANNUAL REPORT 2013

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The premier advocacy and support organization for New Yorkers
with brain injury and their families.

The mission of the Brain Injury Association of New York State is to improve the quality of life for individuals with brain injury and their families and friends, and to prevent brain injury.

Since its establishment in 1982, the Association has worked to meet the needs of individuals with brain injury and their families, and to educate the public and policy makers about living with a brain injury and prevention. As the chartered state affiliate of the Brain Injury Association of America, BIANYS fulfills this mission through a broad array of programs and activities.

Information and Outreach: The Association maintains an extensive information clearinghouse for consumers, advocates, providers, media, policy makers, educators, and the public about all aspects of brain injury, rehabilitation services, living in the community, and prevention. Many community-based programs are offered to educate the public and to support individuals with brain injury and their families

Community Outreach/Family Help Line: The Association's toll-free Family Help Line was an invaluable resource for thousands of callers seeking information and support in 2013. The BIANYS lending library, public education materials, speaker's bureau, newsletters, publications, events, seminars, and website proved integral to community outreach efforts. BIANYS also provided resources through email and hard copy to people seeking information. The Association's newsletter, *Brain Power*, was distributed quarterly to more than 1,000 individuals and organizations, plus thousands more through the website. Over a thousand individuals received vital updates in our monthly e-mail newsletter, *BIANYS e-Bits*. Materials were circulated at health fairs, schools, community safety days, conferences, and meetings state-wide. Volunteers offered peer support, encouragement, and friendship to others across the state, providing a vital link for individuals with brain injury and their families with others who have also been affected by brain injury. The Association's website at www.bianys.org provided essential information to more than 93,000 visitors, with annual page views totaling over 165,000. BIANYS also provides links to resources, events, awareness activities, and other services via posts to the BIANYS Facebook and Twitter pages, both listed under BIAofNYS. On Facebook, BIANYS is followed by over 1100 people. Our Twitter followers number over 900.

Chapters and Support Groups: The Association supports an active network of more than 30 chapters and support groups throughout the state. Chapters and support groups provide hope, information, personal growth opportunities, and advocacy to individuals with brain injury and their families and friends. Association staff provided the assistance necessary to enable these groups to strengthen their capabilities.

For the third year, a special state-wide project called "Connecting Our Lives," was enthusiastically embraced by chapters and support groups. To raise brain injury awareness while highlighting the individuality of New Yorkers with brain injury, the project this year involved the creation of collages expressing some aspect of brain injury. Final projects, completed by individuals or groups, showed the emotional impact of an injury through the use of magazine clippings, fabric items, text, and photographs.



Several support groups and chapters held special events at which members created collages, then sent them to Albany for display at the BIANYS Annual Conference. Confer-

In spite of how hard things were, you made our lives better. – MJ

Thank you from the bottom of my heart for another wonderful Conference... It is always the highlight of my year! I know it takes a lot of hard work and time but it is always amazing! – LW



ence participants expressed amazement at the creative abilities of the artists and at the effect of the assembled pieces.

Brain Injury Awareness Month: Throughout March, the Association focused on public education activities designed to raise awareness of brain injury and means of prevention. A comprehensive Brain Injury Awareness educational packet was distributed electronically through the BIANYS website for use in developing programs in local communities. Proclamations were received from the Governor and local government officials, including the Mayor of New York City and the Orange County Executive. Activities around the state included press conferences, community fairs, school programs, public service announcements, and fundraisers. This year, BIANYS debuted Virtual Awareness Day, an effort to get community members involved in brain injury awareness without the need for travel. Resources were posted to the BIANYS website regarding specific areas of need and advocacy, and individuals were encouraged to share the information or contact local officials to advocate for brain injury services. A large delegation of members and staff participated in Congressional Brain Injury Awareness Day In Washington DC, visiting with members of the New York Congressional Delegation to advocate for legislative changes that support Individuals with brain injury and their families.

Art Exhibit: For the twentieth consecutive year, the Association showcased art at the Empire State Plaza in Albany created by individuals with brain injury. The Art Exhibit took place April 8-12, 2013 and featured paintings, drawings, sculpture, poetry, and photography from dozens of artists state-wide. Additionally, the display included the winning helmet designs from the Greater Amsterdam BIANYS Chapter's Helmet Decorating contest. During this week-long event, visitors, state workers, and policy makers viewed the artistic efforts of New Yorkers with brain injury, while learning more about brain injury and the services provided by the Association.

Annual Conference: Each June, several hundred individuals with brain injury, family members, professionals, providers, and advocates come together to share information about services and programs, and to learn about the latest research in brain injury. More than 300 people convened in Albany for the Brain Injury Association of New York State's 31st Annual Conference, "Uniting as the Voice of Brain Injury," for two days of advocacy, education and networking. This Conference, the only one of its kind in New York State, brings together a broad array of professionals, volunteers and individuals and families impacted by injury.

BIANYS was honored to have PJ Long, author and advocate, present the 2013 Sandy Finklestein Memorial Address. Ms. Long's presentation, "Rediscovering Hope, Beauty and Joy" was a deeply moving and intensely personal account of her own fight to reclaim her life in the wake of tragic setbacks. The story of how Ms. Long, with the support of family and friends, found the light and the strength to rebuild a life is told in her critically acclaimed autobiographical book, *Gifts from the Broken Jar*. In all that she does today, PJ remains uniquely able and committed to passing on the insights that she has found to others facing terrible journeys of their own. In accordance with Ms. Long's tradition of selfless giving to others, she remained after her address to sign dozens of books and offer hope and gratitude to her listeners

Conference participants chose from 15 diverse workshops, providing depth, variety, and invaluable information for everyone attending. Topics included employment after brain injury, utilizing technology in rehabilitation, dealing with legal issues, explor-

ing creativity, coping with the challenges of emotional demands, concussion management, vision and behavioral problems, and understanding Medicaid redesign. Drs. Steve Flanagan and Mary Hibbard presented the annual research update.

The annual meeting featured a review of the Association's work over the past year, as well as areas of concern and attention for the future. BIANYS members provided insight into how the Association can further assist them. The morning's events continued with the annual awards ceremony and an "Advocacy Exchange," in which several Association supporters shared their experiences as advocates and suggestions for becoming stronger, more effective advocates, and ended with lunch and wonderful raffle baskets and prizes.

The Association was pleased to award more than 125 scholarships totaling more than \$27,000 to our members to support their participation in the conference. Sincere thanks to the BIANYS Syracuse Chapter; Kirk A. Johnston Foundation; NYS Department of Health; NYS Office for People with Developmental Disabilities; NYS Developmental Disabilities Planning Council; and NYU Rusk Institute of Rehabilitation Medicine; Belvedere Services; BIANYS Rochester Chapter; Hodgson Russ, LLP; and NYSARC Trust Services. We are grateful to all our advertisers, exhibitors, and volunteers for their assistance, as well as chapters and support groups that provided scholarship support.

Professional Conferences: Throughout the year, BIANYS provides training and educational opportunities for professionals.

Training is offered on a variety of topics including participant rights, brain injury basics, strategies for the classroom, and family dynamics. Association staff administer Certified Brain Injury Specialist (CBIS) and Certified Brain Injury Specialist Trainer (CBIST) training through the Academy of Certified Brain Injury Specialists. The Association partnered with Transitions of Long Island in March to present a training conference entitled "Living with Brain Injury: Fostering Post-traumatic Growth and Continued Progress." Among the highlights were a comprehensive keynote presentation from Dr. Raj Narayan, several excellent technical presentations, and recognition of alumni from the Transitions of Long Island program. In April, BIANYS partnered with AHRC-NYC to present the 6th Annual Brain Injury in the Community Symposium, Brain Injury Across the Lifespan featuring BIAA CEO Susan Connors.

Fundraising Activities: Many individuals and organizations found wonderful ways to bring recognition and funding to the Association. In July and again in September, almost 500 of the Association's baseball-loving members gathered for the Third Annual Brain Injury/Concussion Awareness Day at Citi Field in Queens. While the New York Mets played, BIANYS and its supporters provided information about concussion prevention, as well as resources available to those with brain injury in the state. Members were recognized on the field with a Spirit Award noting their work on concussion awareness.

The Syracuse Chapter of the Association held its Seventh Annual Golf Classic at the Turning Stone Resort and Casino in Verona. Proceeds from the event benefit the Syracuse Chapter, as well as provide scholarships to the Annual Conference. The Rochester-based Kirk A. Johnston Foundation held its Tenth Annual Golf Tournament at the Victor Hills Golf Club. Funds raised provide Annual Conference scholarship support.



During this incredibly complicated career-journey no matter how long it is taking, I again thank BIANYS very much for its ongoing support - JQ

“Despite my disability I continue to design and live my life prior to my injury. I’d like to serve as an example for people who have experienced these types of brain trauma, convinced that we remain vital members of the community. I love my work.” – CN



Noted neurologist Dr. Barry Jordan, former BIANYS President Dr. Marie Cavallo, journalist and brain injury survivor John Quinan, and community leader and brain injury survivor Marion Hedges were honored at the Sixth Annual Journey of Hope Gala in October. This spectacular fundraiser, held at SLATE in Manhattan, featured a cocktail reception, buffet dinner, silent and live auctions, music and awards. BIANYS supporters actresses Lorraine Bracco and Penny Marshall served as honorary co-chairs, and Ms. Bracco conducted the live auction. The musical performance of Jerry Gretzinger made the evening extra special, and pool champion Jennifer Baretta challenged guests to test their skills at the pool table. The Journey of Hope is a fun way to raise funds and honor individuals who have shown outstanding dedication to the mission of the Association and the field of brain injury.

Services: The Brain Injury Association of New York State provides direct support to individuals with brain injury and their families

Family Advocacy, Counseling, and Training Services Program (FACTS): This program, funded by the NYS Office for People With Developmental Disabilities, links individuals injured before age 22 and their families with community-based services and supports. The FACTS program is implemented state-wide by 15 FACTS Coordinators, who also educate the public about brain injury services and prevention, and assist in the activities of local Association chapters and support groups. Hundreds of families and individuals benefit from the Coordinators’ empathy and expertise. Their activities included facilitating support group meetings, exhibiting in local health fairs, conducting training about brain injury to schools and community organizations, conducting training about the Concussion Management and Awareness Law as well as REAP, maintaining on line support communities, participating in school meetings as they provide educational advocacy, referring and securing services for Individuals with brain injury, presenting training to service providers, and providing ongoing emotional support to individuals and their family so they are connected to a community that cares and understands their needs. In 2013, FACTS Coordinators provided nearly 13,000 hours of service and enrolled over 100 new people into the program.

LEARNet (Living Education and Resources Network): This program is designed to assist all those involved in the lives of students and children with brain injury. The LEARNet website, www.projectlearn.net.org, is a problem-solving system that assists in determining the most appropriate intervention strategies for a variety of challenges exhibited by students with a brain injury. Additional features of LEARNet include information about the brain and the effects of brain injury, a comprehensive glossary of terms, helpful resources for students, parents and teachers, and over 50 tutorials pertaining to issues that impact a student with brain injury. Throughout the year, LEARNet was demonstrated to a wide variety of audiences and received enthusiastic support for its design and effectiveness. The website continues to serve as a resource to parents, students, teachers, and professionals throughout the United States and internationally.

Brain Injury Training and Services (BITS) Project: This project is a collaboration between BIANYS and the NYS Department of Health, with funding from the US Department of Health and Human Services, Health Services and Resources Administration. The BITS project works to provide brain injury and prevention education as well as information and resources to TBI survivors and their families through outreach, training, and collaboration. Ongoing program efforts include the completion of “Head Smart Kids,” an educational book pack addressing brain injury for children; more than 100 were distributed to the School Nurses Association, chapters, and child care programs throughout the state. The Association hosted a series

of webinars focused on TBI in children and veterans and continued its participation in VA and NASW-NYS events geared towards aiding veterans and the professionals who work with them. With the growing success of the webinars, the Understanding Life with Brain Injury Training was formatted into a webinar series, reaching almost 300 participants during each of the two webinars held in 2013. The Association continued to conduct outreach and educational activities through in person trainings for a variety of children and veteran organizations and regularly disseminated an array of BIANYS printed material to several schools, hospitals, and offices, as well as at numerous fairs, symposiums, and conferences. The documentaries *Beyond the Invisible*, *Coming Home*, and *Keep Moving Forward* continue to be distributed in DVD form and viewed online. The Association has also worked to provide to further implementation of the Concussion Management and Awareness Law, and continues to distribute publications, including the specially-developed “REAP” (Reduce, Educate, Accommodate, Pace) and “Concussion in the Classroom” booklets to assist educators, families, and students with brain injury.

Family Fund: Established in 1992, the Family Fund provides financial resources of last resort to Association members with brain injury and their families. The Family Fund provides limited direct financial assistance for special needs that would not be available through other services. In 2013, the Association awarded over \$12,000, responding to 38 requests. Funded requests covered needs such as food, rent assistance, medical bills, a computer, furniture and household items, security deposits, travel to care for an injured relative, plumbing costs, and utility costs.

Prevention Activities: Because the best cure for brain injury is prevention, the Brain Injury Association of New York State has initiated a number of prevention programs

In cooperation with an array of concerned individuals and organizations, the Association engages in many prevention programs. We continue to distribute the “Get Into the Helmet Habit” booklet which is designed to help children learn that wearing helmets is their first line of defense in the prevention of brain injury. BIANYS staff have participated actively in a number of state and local injury prevention programs throughout 2013. Their activities included participating in bicycle rodeos, helmet give a ways, Safe Kid Coalition events, car seat safety checks, and local safety fairs. We continue to distribute prevention materials such as “REAP”, “Preventing Concussion in Sports”, “Violence Prevention” and helmet fitting information to parents, teachers and community organizations.

Advocacy: The Brain Injury Association of New York State provides valuable input into the development of programs and policy at the federal, state, and local levels

Policy Advocacy Activities: Association members, Board members, and staff consistently advocate for policies that protect and expand the rights of individuals with brain injury and their families, and promote prevention. In addition to individual advocacy, BIANYS is actively involved in policy advocacy that impacts all New Yorkers. Association representatives serve on the NYS Traumatic Brain Injury Services Coordinating Council (TBISCC) and other advisory groups. BIANYS participates in the annual NYS Assembly Disabilities Awareness Day and regularly provides information to state legislators and the Governor’s office, including securing a state resolution declaring March as Brain Injury Awareness Month. BIANYS continues to promote implementation of the state’s five-year plan for serving individuals with TBI. Staff has reached



Thank you for giving me this information!! It is SO appreciated!!

CB



out to state legislators and the media about proposals that ensure the safety of our children, strengthen the state's services for individuals with brain injury and the TBISCC, create funding mechanisms for brain injury services, ensure implementation of the state's new concussion law, and other Issues of concern. BIANYS members and staff met with Congressional representatives and staff on Congressional Brain Injury Awareness Day to advocate for policies and laws to expand services for civilian and military individuals with brain injury and their families. Association staff and board members continue to intervene when state agencies implement changes that negatively impact hundreds of program participants.

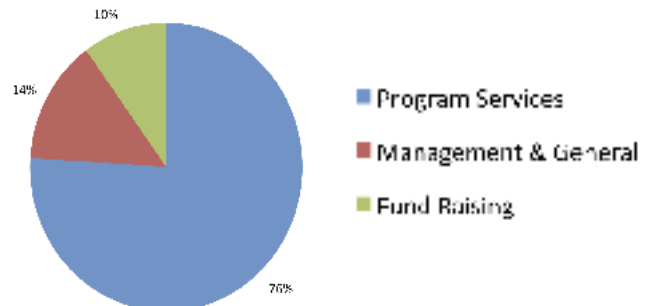
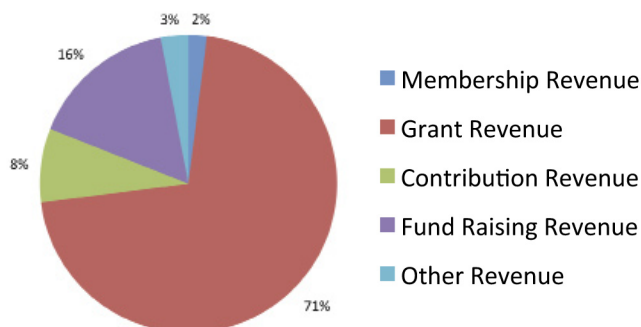
Organization and Finances

A volunteer Board of Directors from across New York State is responsible for establishing policy, financial goals, and organizational objectives. The Association staff implements policy and is responsible for day-to-day operations. The Board is comprised of individuals with brain injury, family members, professionals, advocates, and interested community members. The Independent audit for the fiscal year ending December 31, 2013 was conducted by Heveron and Heveron, CPAs, P.C. The auditors issued unqualified (clean) audit reports on the 2013 financial statements. They deemed the record-keeping system appropriate for the Association's record keeping and financial reporting needs. The Association finished the year with a decrease in net assets of \$39,872. Total revenues for 2013 were \$994,949, a decrease of \$114,084. Expenditures in 2013 were \$1,034,821 as compared with \$1,198,322 for 2012. The ratio between current assets and current liabilities is good at \$13.00 of current assets for each \$1.00 of current liabilities. Program services accounted for 76% of expenditures, management and general services accounted for 14%, and fund raising the remaining 10%.

ASSOCIATION 2013 REVENUE

ASSOCIATION 2013 EXPENSES

Based on Heveron & Heveron 2013 Audit



Board of Directors (as of December 31, 2013)

Officers

Lois Tannenbaum, Psy.D.....President
Timothy Pruce.....First Vice-President
Cindy Dott.....Second Vice-President
Amy Sigona.....Secretary
Robert Gundersen.....Treasurer

Members

Elizabeth Curtiss, Barry Dain, Peter Danziger, Esq.,
Rosemarie diSalvo, Cynthia Dott, Steven Flanagan, M.D., Mary Hibbard, Ph.D.,
Jennifer D. Kilpatrick, Kathryn Metzger, Joanne Miller, Kaitlyn Pierce, John Quinan,
Michael Ronemus, Esq., Rob Ryan, Mark Shaw, Christina Shorr,

Staff (as of December 31, 2013)

Judith I. Avner, Esq.....Executive Director
Debbie Chilandese.....Director of Finance & Administration
Victoria Clingan, MLIS, CBIS.....Director of Information Resources and Member Services
Rory Harte.....Program Assistant
Bridget Aliaga.....Brain Injury Training and Services Program Director
Karen Thomas, CBIST.....Director of Family Services

Family Support Field Staff

Jacquelyn Abreu.....Rockland County Recreation Program
Laleene Ali, CBIS.....Westchester
Victoria Monaco.....Orange, Rockland, Sullivan
Krista Brown, CBIS.....Monroe, Orleans
Ellie Bibawy, CBIS.....New York City
Sharon Johnson, CBIS.....Chemung, Livingston, Ontario, Seneca, Schuyler,
Steuben, Wayne, Yates
Toni Longshore, CBIS.....Clinton, Essex, Franklin, Hamilton, St. Lawrence, Warren
Vicky Myers, CBIS.....Allegany, Cattaraugus, Chautauqua, Erie, Genesee,
Niagara, Wyoming
Magdalena Ornstein-Sloan, MA, MPH.....New York City
Carmen Garcia.....Long Island
Josephine Roberts, CBIS.....Chenango, Delaware, Otsego, Schoharie
John Hathaway.....Broome, Cortland, Tioga, Tompkins
Mary Sheridan.....Cayuga, Jefferson, Madison, Onondaga, Oswego,
Herkimer, Lewis, Oneida
Linda Lauber.....Albany, Columbia, Fulton, Greene,
Montgomery, Rensselaer, Saratoga, Schenectady, Washington
Janyce Wollney, CBIS.....New York City

