Bleeding Disorders Association of Northeastern New York, Inc.

Annual Report 2016
A message from the Executive Director -

Dear Friends,

I hope this finds you well and I hope you had a great year!

The BDANENY has had an exceptional year. This year we held our second annual Hemophilia Walk and 5K which was a lot of fun and a huge success. We also had a successful golf fundraiser, which was held in September.

We are currently working on two new programs for 2017. We will be launching a New Family Program; we believe no one should feel alone after receiving a bleeding disorder diagnosis. The BDANENY is also working on a program for teen advocacy which will include teens from all chapters in NYS. We will continue with our other successful educational programs including a Night at the Joe Baseball game, a Mother/Daughter retreat, a night of hockey and many other events.

We have maintained our most successful membership support programs. Our Clinical Travel Assistance Program (CTAP) helps patients get to their annual appointment at the HTC by reimbursing some of the travel expenses. The BDANENY gave out educational scholarships to two very talented students and we continue to support the community by granting emergency requests.

We are happy to welcome Casey O’Brien as our new Administrative Assistant. She started June, 2016 and has become a very valuable addition to our association.

Our association moved to a new office at the end of May. This move has given us more space for our growing staff and has allowed us space to meet and greet the community. You are welcome to come into the office to look through our materials for research or if you have a child who is interested in learning more about his/her bleeding disorder we have children’s books as well. It is the mission of the BDANENY to provide services and referrals to members of the community. We encourage our community to advocate for their own health care. Your input and assistance is necessary in making this happen.

We are here to serve you. Please let us know what you need and how we can best serve you. We ask that you reach out when you need assistance, lend a hand when you can, and connect with us –because together we have a voice!

Laura Kinson-Curtin
Executive Director

BDANENY Programs and Events

The Bleeding Disorders Association of Northeastern New York provides several programs and activities throughout the year for all age levels and interests.

**Hemophilia Walk and 5K** – This fundraiser is a family-oriented event full of fun activities and exercise opportunities which allows community members to meet other families who deal with the challenges of bleeding disorders in a fun and engaging environment.

**Mother/Daughter Retreat** – Designed specifically for mothers and daughters (ages 10 and up) with von Willebrand Disease. This retreat includes programs about living with vWD, social programs, and free time to enjoy the serene setting of the conference in the company of other individuals affected by vWD.

**Snowflake Fest** – Join the BDANENY and the staff at the Albany Medical Center HTC for a celebration of the start of winter. This kid-friendly party is packed full of entertaining exhibits and provides a great chance to relax and get to know the HTC and BDANENY staff in a fun environment.

**BDANENY Annual Golf Classic** – Play a round of golf with friends, win prizes on or off the course, and enjoy a pig roast at the end of the day! Always one of our best events of the year, and it just keeps getting better!
Albany Days – Meet face-to-face with the lawmakers and staff who shape healthcare policy across the state, become more informed about critical issues affecting you and your access to quality health care, and learn effective grassroots advocacy techniques as you make your voice heard for matters that affect our community.

Carriers’ Retreat – Women from across the state gather to share their experiences and concerns about being a carrier of hemophilia. Too often this group is going without proper medical care, or told they don’t have hemophilia because they are women. We are here to advocate for you.

New Family Program – Hearing for the first time that your child has a bleeding disorder can be difficult and you may feel alone, You Are Not Alone. We will be offering a chance for new families to come together to share in their trials, tribulations, achievements and joy.

More? – The BDANENY is always looking for ways to better serve our community! If you have an idea for an event or program you’d like to see, or if you’d like to get involved with some of our programs, just let one of the staff or board members know or visit our website at BDANENY.org for contact information.

BDANENY Board of Directors and Staff

David Huskie–President
Bruce Weiner– Vice President
Cindi Keeler– Treasurer
Jeff Bostwick–Board Member
Don McKay–Board Member
Michael Deeb–Board Member
Laura Kinson-Curtin– Executive Director
Casey O’Brien– Administrative Assistant

Revenue

![Revenue Chart]

Revenue– $162,698
Expenses - $126,414
Total– 36,284

Financial Report

Each year the BDANENY makes decisions and sets goals for how our resources will be used to provide a range of services to individuals with bleeding disorders and their families. The Board of Directors establishes long range plans, approves the budget and programming to achieve those goals.

Expenses

![Expenses Chart]
Affiliation/Memberships
The BDANENY is proud to be affiliated with the National Hemophilia Foundation, and we are also a proud member of the Hemophilia Federation of America and the New York Council of Non-Profits, Inc.

Contact and Communication
BDA News – Our newsletter (available in electronic format or by mail) includes information about current activities, upcoming events, current events that may impact you or your family, advocacy information and updates, articles written by board members or other community members, and more. The newsletter is published quarterly, and the current issue (and previous issues) can be found at BDANENY.org/newsletter
Social Media – You can find our website at BDANENY.org, and follow us on Facebook, Twitter and Instagram.

Get Involved!

Donate your time! The BDANENY is always looking for passionate and excited volunteers to help with the many programs and events we put on throughout the year and with the day-to-day functioning of the Association. We also have opportunities for serving on our Board of Directors, or on a committee for any of the largest events and activities (the Golf Tournament or Advocacy, for example). If you are interested in helping, simply visit BDANENY.org/volunteer to see how you can make a difference! No matter what you’re interested in, there is something you can do to help the chapter!

Donate your expertise! We are always looking to partner with organizations or individuals who have expertise that may help us. If you or someone you know is experienced in the areas of healthcare planning, web development, financial planning, advocacy, etc. consider donating your expertise to help the community! If you think you can help, please reach out and contact the BDANENY!

Donate your funds! As a non-profit organization, the BDANENY relies on the generosity of individuals and organizations to support our mission. Every cent we receive goes directly to helping further support and enrich the bleeding disorders community we serve. Whether by direct donation, putting us in touch with an employer or potential sponsor or donor, helping us fundraise, or considering a memorial donation, every effort helps us continue to deliver the best support and assistance that we can, and every single donation is appreciated!

Thank You!
Thank you to the following people that volunteered throughout the year: Charity Borst, Michael Budka, Bob Curtin, Rachel Gray, Christina Mastrianni, Casey O’Brien, Velvet Gladd, Ellen Kahil, Cindi Keeler, April Kenyon, Martha Boria, Christine Song, Matthew Delaney, Linda Peacock, Lisa Schmitt, Greg Mastrianni, Christine Whipple, Maria Peart and Katherine Rosenblatt, and all who helped out at the walk! Without you this year would not have been possible!

More Thank Yous!
Thank you also to our sponsors throughout the year: Accredo, Shire, Bayer Healthcare, BDRN, Biogen Idec, Cottrill’s Pharmacy, Inc, CSL Behring, CVS Caremark, Emergent, Great Escape Lodge and Indoor Water Park, Grifols, Novo Nordisk, Octapharma, and Pfizer...Your generous donations have given the BDANENY the opportunity to present quality programming to the community.