



# BDA NEWS



Newsletter of the Bleeding Disorders Association of NENY, Inc.

## **New Bill to Hit the State Senate Floor**

by Wayne Cook

Again, the Hemophilia community has been struck with another blow in the area of politics. On June 12, 2002, people from various parts of the hemophilia community were invited to a meeting at our state's capital, within the governor's office with the Assistant Director of the Department of Health and with the state Senator that introduced bill S4466-A. Our discussion concerned the treatment of hemophilia patients within the Medicaid program in need of factor who have been admitted into a health care facility. In the State of New York under current Medicaid provisions, hospitals are not reimbursed for factor used on an inpatient basis. This is a big concern, not only to treatment centers throughout the state, but also to the consumers. Each year hospitals and treatment centers lose millions of dollars due to this issue. With the loss of these dollars the possibility of cutbacks in hospital treatment, and the costs of factor filters down to the consumer.

S4466-A which has passed the state assembly and is now in the state senate, allows the Commissioner of Health, upon approval from the operator of a health care facility to designate certain necessary drugs as billable and reimbursable by Medicaid, separate and apart from the established rate to the facility.

As a consumer I am very alarmed by this issue and after meeting with these people they too were also alarmed by this. We were assured that the matter of this bill would have great consideration in the state senate now that they have heard all concerned sides.

Once again the tight-banded hemophilia community has stuck together in another fight for our rights as consumers.

If you would like a copy of this bill please contact us here at BDANENY and we will be glad to forward you a copy, or go on-line to <http://www.senate.state.ny.us> and find it under Bills/Laws.

## **A Message for The Class of 2002**

Congratulations on your graduation whether it be from kindergarten, elementary school, high school or college. We wish you the best in your future endeavors. Reach for your goals, work hard, have fun, stay healthy and safe.

## **Membership Reminder**

### **ATTENTION!!!!!!!**

Unless you are a dues paying member, as of September 1, 2002 you will no longer be receiving important information from the Bleeding Disorders Association of NENY. Information regarding special events such as the various trips, annual picnic, or upcoming activities for our children will only be mailed to dues paying members. Membership cards will be mailed out in the next month

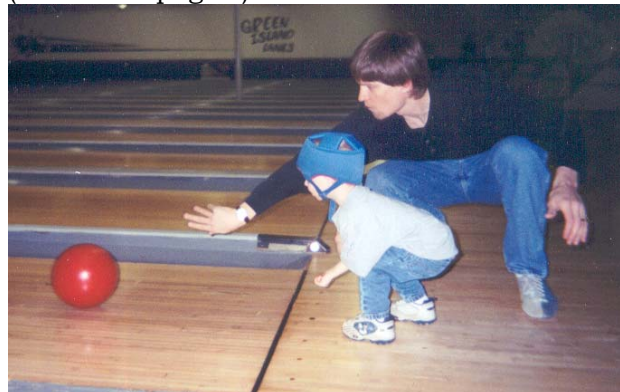
### **DON'T DELAY!!!!!!!**

Fill out the membership form on the back of the newsletter and mail today, or call Kevin Pelletier at: (518) 782-9787 or Debbie Huskie at: (518) 658-2878.

No one will be denied membership due to financial reasons.

## **Bowl-a-thon**

The annual Bowl-a-thon was once again held at the Green Island Bowl located in Green Island on April 6<sup>th</sup>. We had a great time bowling, eating, talking with each other, and (continued page 2)



most importantly sharing a common thread of supporting the bleeding disorders community.

We would like to thank those that came out to bowl on a busy Saturday afternoon and those that sponsored a friend or relative with such an important cause. The monies we raise are used to support the bleeding disorders community with emergency funding, camper ships for our youngsters of the bleeding

disorders community, education and yearly social gatherings.

The lucky winners this year were: Morgan Ryan, Jessica Smith, Katie Hatch, Don Abbot, Josh Strain, Jessica Molesky, Doug Jordan, Chris Bub and Colby Jordan. Congratulations to all of you!

If you were unable to participate this year we hope to see you next year!

## **LETTER FROM THE VICE-PRESIDENT**

I would like to take this opportunity to share a thought with all of you. Eighteen years ago my life was changed forever with the birth of my son, Christopher. His first few months were very eventful, centered on bouts of bruising, bleeds and visits to the emergency room. We all, as a bleeding disorders community, have experienced this story or one very similar.

However, I also learned something else that has also proven to change my life. It was the concept of service. We all have given of ourselves, throughout our life, to our families, church or country but for all of us who are touched by a bleeding disorder, it goes a lot further. We have and must give more.

I had to learn how to care for my family, who within a moment's time had a son and a brother with a bleeding disorder. My wife and I knew we had to stay healthy and strong in order to be able to meet the needs of our children. We felt that it was imperative that we stay informed, keeping up with the latest information regarding bleeding disorders. In order to help our family, we had to maintain and expand our knowledge through literature, workshops, talking with others at clinic appointments and through the chapter. Clinic appointments were, at times, difficult to keep while working two jobs and going to school, but we knew they were important for our family and our son's health for the present and in the future.

We quickly learned that any decision or plan, no matter how minor had a direct impact on the responsibility of caring for a child with a bleeding disorder. We had so many questions, concerns and fears without really knowing where or who to turn to. We became frustrated, as all of you have, with situations we could not change and the people we had to deal with that did not know or understand our challenges. At those times we fell back on the strength that is family and friends.

Lastly, I would like to talk about service to our community as a whole. The more individuals we met with similar problems the less we felt alone. How they coped with a situation got us through the same problems. Sharing a painful joint bleed or a chair in the emergency room gave my family and I the strength to endure. Service to each other helped us all through the roughest of times.

I tell you all this to remind you that we, the members of the board of directors are here to serve you. To help you through your tough times, to share with you how we coped with our challenges. To whoever much is given, much is expected and in our lives we have received much from others. Let us help you help each other through the difficulties that are life. Become involved if you can, however if you are unable, rest assured that we will be there for you. Drop us a line, e-mail us, or call us with any concern, idea or frustration that we can help you with. Let us help you make your life living with a bleeding disorder that much less challenging. We are in this together! Let us help each other!

Today, the child that we stayed up nights with because of joint bleeds and muscle pain is an adult. He is working this summer as a counselor with children who have life threatening illnesses, serving those he sees as less fortunate than he.

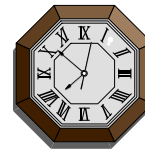
With Deepest Regards,  
David Huskie  
Vice-President BDANENY



**WE'RE ALL A-BUZZ**

**ABOUT THE SUMMER PICNIC, ANNUAL MEETING and  
ELECTION OF OFFICERS  
OF THE BLEEDING DISORDERS ASSOCIATION OF  
NORTHEASTERN NEW YORK**

**When:** *Saturday August 17, 2002*



**Time:** *11:00 AM – 5:00 PM*

**Where:** *Grafton Lakes State Park*

**Come!!** *Enjoy great food, games, prizes!!!  
And lots of fun in the SUN!!*



**RSVP:** *Debbie Huskie (518) 658-2878*  
**no later than August 14, 2002 to reserve your spot!**

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Present this tear-off to the Park attendant when entering the State Park and your parking will be free!



To Grafton Lakes State Park, Grafton NY

From the South:

Take Northbound Thruway to Exit 23 (Albany 787)  
Take Route 787 North to Route 7 East Exit  
Go over the Hudson River to Troy  
Stay on Route 7 East for 5 miles to Rt. 278 South  
This connects with Route 2; take Route 2 East for 7 miles  
The State Park is on Route 2

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From Massachusetts:

Get over to Route 22 North  
Continue to Route 2 in Petersburg NY  
Travel West on Route 2 (about 6 miles from Petersburg)  
State Park is on Route 2

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From the North:

Take the Northway Southbound to Route 7 exit (Troy-Bennington)  
Travel East to Troy, crossing the Hudson River  
From Troy Bridge, go 5 miles East to Route 278 South  
This leads to Route 2, Take Route 2 East for about 5 miles  
State Park is on Route 2



From the West:

Take the Thruway East to Exit 24  
Take the Northway North (87) to Route 7 Exit (Troy-Bennington).  
Take Route 7 East  
Cross the Hudson River into Troy  
Stay on Route 7 for 5 miles to Route 278 South  
Travel about 2 miles to Route 2  
Take Route 2 East for 7 miles  
The State Park is on Route 2



Bleeding Disorders Association of Northeastern New York, Inc.  
MEMBERSHIP/SUPPORT

Name: \_\_\_\_\_ E-mail: \_\_\_\_\_

Address: \_\_\_\_\_ Home Phone: \_\_\_\_\_

\_\_\_\_\_ County: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip Code: \_\_\_\_\_

- |                          |            |        |                          |                  |        |
|--------------------------|------------|--------|--------------------------|------------------|--------|
| <input type="checkbox"/> | INDIVIDUAL | \$2.   | <input type="checkbox"/> | FAMILY           | \$5.   |
| <input type="checkbox"/> | BENEFACTOR | \$50.  | <input type="checkbox"/> | SPONSOR          | \$150. |
| <input type="checkbox"/> | PATRON     | \$250. | <input type="checkbox"/> | PRESIDENT'S CLUB | \$500. |

Please return this form to:  
BDANENY  
P.O. Box 3707  
Albany, NY 12203-0707



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of Northeastern New York, Inc.

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**Albany, NY 12203-0707**

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