From the Dallas Cowboys to the New England Patriots, NEHA’s new Executive Director Kevin Sorge has seen lots of change this year. Starting on March 3rd, Kevin assumed both a new position and a new home. For the past 22 years, Kevin has worked for the American Heart Association, most recently in Dallas, TX, where he served as the National Director of Operations for their Emergency Cardiovascular Care Division. In this role, he managed the education and fundraising efforts of a large nonprofit division of 103 staff generating over $50M of revenue. This experience gives him strong insight into the workings of a nonprofit like NEHA, and his program planning and fundraising skills will be put to great use. But according to Kevin, the best part of the NEHA job is “working with volunteers, the real heroes of a non-profit health agency.”

Having worked with volunteers most of his professional life, Kevin has led numerous boards and committees and feels that the true indicator of an organization’s success is the quality of its volunteers. So, he feels confident in saying that “NEHA’s volunteers are second to none. They have done a tremendous job of not only welcoming me, but aiding in my transition to the bleeding disorders community. I had a very well organized orientation program, and tons of support from the NEHA Board of Directors.” While he does not have a bleeding disorder, Kevin has a great deal of experience working with a health-oriented organization at the American Heart Association. He brings this wealth of knowledge and experience to NEHA at a time when our organization is seeking to expand.

In the past two months, Kevin jumped right in with attendance at the annual Washington Days advocacy event, received a warm welcome at SpringFest, and even attended dinner at Palmers. When asked about the event, Kevin said, “It was evident early on that SpringFest is a premier event in the lives of our consumers, and targeting it to families enabled everyone to learn and have fun! The support of our (Continued on page 9)
From The President

Dear NEHA Member,

Spring is finally here, and with it we have the start of some new beginnings, much like the awakening during the season itself.

In the Winter edition we talked about the arrival of Kevin Sorge as our new Executive Director, and some of you had the mutual pleasure of meeting one another at SpringFest in early April. I am delighted to report that Kevin has been very busy meeting with volunteers, community members, industry representatives, staff, and hematologists from our Hemophilia Treatment Centers, and many people from the National Hemophilia Foundation, getting to know each other and continuing to build and strengthen our important relationships within the NEHA family.

Our SpringFest 2008 was fantastic – I am excited and pleased to report that the programming and venue received overwhelmingly positive feedback. The waterslides were cool, but the overall event was truly HOT! Thank you to Jane and all of our fantastic staff, volunteers and industry representatives for making this the incredible day that it was.

Only a few days after SpringFest, our volunteers were springing right back into action with the third annual Palmers Fundraising Dinner event held at Palmers Restaurant, led by Chris Smith. This year the live and silent auctions raised a staggering $19,000 to benefit NEHA. This is another fine example that showcases the tremendous results that can be achieved by volunteer efforts. Special thanks to our auction winners for your generosity in helping Chris achieve this impressive result!

It is with tremendous regret, yet great envy, that we announce the departure of Jackie Fagone. Jackie will be leaving NEHA at the end of May to spend more time with family. This is truly a great loss for NEHA but a wonderful opportunity for Jackie. Decisions of this nature are never easy, so please join me in wishing Jackie all the best moving forward. Thank you Jackie, for your amazing contributions to our organization on a multitude of levels, we will all sincerely miss you.

Best wishes to all, for a healthy and happy spring season

Warmest Regards,

Patrick Mancini
NEHA President
My Story . . .
by Mike Reutershan

I vividly remember the days when my dependence on my parents was extensive—back when they ordered my factor and supplies, when they scheduled and paid for my doctor appointments, and when they prepared and administered my factor. Fortunately, I had adequate practice infusing and ordering supplies well before I started living on my own, and I knew that moving and working after college could also require changes in insurance and doctors. But even with all that practice and foresight, I wasn’t as prepared for my transition from college to that so-called real world as I thought.

Last May I graduated from Bowdoin College in Maine. That same month, I received a job offer from Merck Research Labs in Boston, Massachusetts, to work as a chemist. Although I was excited to spend my days in the laboratory synthesizing potential drug molecules, before accepting their offer, I wanted to learn about their health insurance policy. Would it cover factor? Did it have a lifetime cap? Would they make me change home health care providers? Would they make me change medication? Would there be a gap in coverage? Merck’s HR staff was very supportive, as they provided me with the name, phone number, and policy number of their provider so that I could get answers to my questions. Even more helpful was the staff at my home care company, who contacted the insurance provider for me, saving me hours of frustration and confusion.

I was comforted, knowing that my factor would be covered by Merck’s insurance provider, that my insurance coverage was active on the first day of work, and that I would not have to change home health care providers. I accepted the job offer and moved to Boston. Like most moves, it wasn’t easy. I signed a lease on an apartment in Boston’s North End. I was excited to live in the Italian district amongst the historic landmarks and world-renowned restaurants and bakeries. But there was no elevator access to my fifth floor apartment, and the move in was like walking up a lighthouse tower with a recliner in tow. I don’t look forward to moving out. Luckily the North End was worth it. And with my health care needs settled, I could afford to worry about getting my furniture up the stairs and not getting lost on the way to work.

The final major hurdle to complete my transition was to be certain that the hematologist suggested by the Maine Hemophilia Treatment Center was covered by my insurance. This time I did the research, and I was relieved to see her name on a list of accepted physicians. At work, I found the transition to be just as easy when I approached my manager and told him about my blood disorder. I found that, thanks to my manager’s background in science, for the first time, I didn’t have to explain what a bleeding disorder was. The conversation was surprisingly short, but he made a good point. He told me that I made the right choice to work at Merck.

In our previous issue, the NEHA Newsletter team introduced a new column, 'My Story,' a space for NEHA members to tell the stories of life with a bleeding disorder. As inaugural writer, Allie Boutin laughingly described her two sons squabbling over getting factor. Her husband, Jim Boutin, offers this cartoon as a companion piece, showing what sibling rivalry can look like...when you add a dash of hemophilia.

"Who wants Factor First?"
Art, Sonja & Evan Mingo  
Mingo’s Evergreen Products, Inc.  
Calais, Maine

For the past two years the Mingo family has generously donated $7 of each decorated wreath and table centerpiece ordered to benefit NEHA’s programs and services in Maine. Ordering on-line or by phone is quick and easy. Watch your mail for a flyer in the fall!

Sean LaMontagne  
New Castle, NH

In honor of Sean LaMontagne, students in the Fifth and Sixth grade classes at the Maude H. Trefethen School in New Castle, NH raised $230 by running a book fair. Sean has requested that this money go directly toward the support of Family Camp.

Also in honor of Sean LaMontagne, the New Castle Fire Dept. firefighters and EMT’s have donated $500 from their holiday funds to go towards research for a cure for hemophilia.

“Casual Friday” Fundraiser  
MMG Insurance Company  
Presque Isle, ME

Kingpin Charity Bowling Tournament
$ 2,800 raised for NEHA programs!

The Harty Family – “Those In Need” Golf Tournament

“We, at Those In Need, for the sixth consecutive year, are proud to donate the proceeds of our annual fund raising golf tournament to NEHA… Please accept, with our profound gratitude the enclosed small token ($6,400) of our appreciation. As we prepare for our 2008 tournament, it is our hope and prayer that the work we do is helpful, in some small way, to your continued efforts in bringing education and support to all the families afflicted with hemophilia.” ~Herb Harty, Executive Director

(Continued on page 5)
Chris Smith - Palmer’s Dinner & Auction

This event began as a way for Chris use his connections in the food service industry to give back to NEHA, in appreciation of the education, support and strong sense of community that NEHA has provided Chris and his family. Over the last three years, this dinner and auction has raised $52,000 for NEHA programs and services. Special thanks goes to host John Ingalls, Owner and Chef of Palmer’s Restaurant & Tavern in Andover, MA; Phil Harty, event co-organizer in 2006 and guest chef in 2007; and Ron Ricchiuto, guest chef in 2008.

Nyhan Family Golf Outing In the Memory of J. Paul Nyhan

The J. Paul Nyhan Golf fundraiser has been an annual event, concluding this year. NEHA was delighted to receive this letter:

“Enclosed are checks collected in memory of J. Paul Nyhan totaling $1,320. This year was our final golf outing in Paul’s memory. Thank you for all that you are doing for the hemophilia community.” - Helen Nyhan

4th Annual Katzman Family Snow Shoe Walk To benefit NEHA
February 29 – March 2, 2008

On the weekend of February 29 – March 2, 2008 families from all over New England and New York gathered to take part in the 4th Annual Katzman Family Snow Shoe Walk to benefit NEHA. The weather did not disappoint by dumping 15” of fresh powder on the Stratton Mt. trails. Participation increased by 35% with over 75 walkers and gross profits doubled from last year to $40,000!!!

Thank you to our NEHA families and the Katzman family and friends for generously donating so NEHA can continue improving the quality of lives of people with bleeding disorders through education, support and advocacy. Sponsors treated our families to dinners on Friday and Saturday evening and provided snacks for the 3K walk Saturday afternoon.

We owe a tremendous amount of thanks to Ina Katzman who spent countless hours gathering contributions and donated auction items. It is Ina’s creativity, energy, and compassion that has made this annual event such a great success. Thank you to all who participated!!
FDA Approves New HIV Drug for Hard-to-Treat Patients

The U.S. Food and Drug Administration (FDA) has approved etravirine (brand name INTELENCE) tablets to treat HIV infection in adults who have been treated unsuccessfully with other antiretroviral therapies. Etravirine, which is distributed by Tibotec Therapeutics, is approved for use in combination with other anti-HIV medications. It belongs to the class of drugs called non-nucleoside reverse transcriptase inhibitors (NNRTIs).

When used with other therapies, NNRTIs can inhibit the replication of HIV in the blood by blocking an enzyme the virus needs to multiply. According to the FDA, approval was based largely on two randomized, double-blind, placebo-controlled trials involving 599 adult patients undergoing 24 weeks of anti-HIV therapy. Both studies showed that a greater number of patients on the etravirine/combination regimen had decreased HIV levels in their blood than those receiving a placebo/combination therapy.

"This is another significant new product for many HIV-infected patients who are NNRTI-resistant and whose infections are not responding to currently available medications," said Debra B. Birnkrant, MD, director of the FDA’s Division of Antiviral Products.

The most common side effects of the drug were nausea and skin rashes. Patients who develop a rash while taking INTELENCE should call their physician.

Tibotec Therapeutics, which is based in Bridgewater, NJ, is a division of Ortho Biotech Products, L.P.

Source: FDA news release dated January 18, 2008

When Only the Best Homecare Will Do!

Since 1989, AHF has set the standard for quality bleeding disorders home care. The AHF pharmacy works exclusively with bleeding disorders... you are our only business. Our specialists will design a care program that is personalized for you. As a result, AHF receives a rating of nearly 100% satisfaction from our clients. Remember, it is your right to choose the very best home care company to meet your family’s needs.

- Delivering overnight with 24 hour-a-day client services support
- Providing the full range of clotting medications and ancillaries
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For further information contact:

Mandy McCullough 800-652-5242
Meryl Brown 888-350-0486

Returning a large percentage of all proceeds back to the bleeding disorders community.

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The Bleeding Disorders Homecare Company
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www.AHFinfo.com

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Tibotec Therapeutics, which is based in Bridgewater, NJ, is a division of Ortho Biotech Products, L.P.

Source: FDA news release dated January 18, 2008
Although the NEHA contingency was smaller this year than in '07, the messages brought to the U.S. Congress were strong as ever. Members of the bleeding disorders community discussed the need for uniform access to Medigap policies for individuals who qualify for disability and are under the age of 65, regardless of the state they live in. Increased funding for treatment centers continues to be an essential position for our community to maintain in the national debate on health care reform, along with the elimination of lifetime caps in insurance policies. GINA, the genetic information non-discrimination act, passed in the House of Representatives during our visit after years of effort. It has since passed in the U.S. Senate and awaits the President’s anticipated signature. NEHA members were thanked by legislators and staff alike for taking the time and energy to travel to our nation’s capital, being told several times how our stories and presence do matter.

The energy and focus of NHF Washington Days carried over effectively to NEHA’s first legislative briefing at the Massachusetts State House one week later. Twenty NEHA members were able to attend, requesting a total of eleven individual visits with their local legislators. There were three legislators who attended the event and over 16 staff and aides. Two active pieces of legislation impacting the bleeding disorders community were discussed in more detail; (H2155/S681) the elimination of prior authorization requirements for the regular purchase of factor, and (H4574) the revitalization of a Hemophilia Advisory Committee within the state Department of Public Health.

Once again, NEHA members were applauded for sharing their stories and concerns. The partnering of information and data helps to keep the democratic process in motion, while maximizing the opportunity for everyone to work effectively together and make a difference.
Scholarships Available To NHF Annual Meeting

NEHA is pleased to announce that we will provide two scholarships to NHF’s 60th Annual Meeting to be held November 13 – 15, 2008 in Denver, Colorado. One scholarship will be awarded to a family living with hemophilia, the second will be awarded to a family living with vonWillebrand’s disease.

Each scholarship will pay travel expenses (airfare and transportation to and from the airport), as well as one hotel room and meeting registration fees for two family members. Families are responsible for all additional expenses, however, most meals during the meeting are available free of charge.

ELIGIBILITY: this opportunity is available to families currently living in New England. Families whom NEHA has previously sponsored will not be eligible.

EXPECTATIONS: NEHA sponsored attendees are expected to attend educational and support sessions throughout the two day meeting and will be asked to write about their experience for our chapter newsletter, NEHA News.

If you have questions or would like to apply for one of these scholarships, please call the office at 781-326-7645 or email info@newenglandhemophilia.org. Please indicate if your family member has hemophilia or vonWillebrand’s disease. The deadline to submit your name is Monday, August 11, 2008. Winners will be drawn by lottery on August 12th and notified that day.

For more information on NHF’s 60th Annual Meeting, please visit their website at www.hemophilia.org. NHF also offers a limited number of travel grants for first-time annual meeting attendees. For more information, check out their website or call NEHA. The deadline for NHF travel grants is June 27th.
New Director  (Continued from page 1)

industry and home care partners was so strong, and our staff, led by Director of Programs Jane Smith, did
an outstanding job of organizing all the hundreds of details that made this event a huge success.” Kevin has
made a commitment to attend all of NEHA’s events to support our staff as well as our volunteers and con-
sumers. He says that he can’t wait for Family Camp (he was a camp counselor for many years) and looks
forward to meeting more NEHA friends and families.

Part of Kevin’s responsibilities will be to grow the programs and services offered by NEHA. To do so,
he agrees that a new approach to working with our many partners will be needed. The size of the bleeding
disorders community in New England presents many challenges to identifying new sources of income, but
doesn’t lessen the need. Kevin shared that expanding NEHA’s current revenue sources will be a high prior-
ity. He’s also exploring ways to increase efficiency in the office and expand our membership program. But
it all comes down to having the right people in the right spots. The need for additional volunteers to help
NEHA grow will play an important role in the next year. Later this summer, Kevin will work with the
Board of Directors to conduct a Strategic Planning Retreat to set our goals and directions for the next 3-5
years. Coupled with this new plan, Kevin looks optimistically to the future where NEHA is able to expand
programming into all 6 New England states. “Right now, our reach throughout New England is limited by
our staff and volunteer resources, but with increases in revenue sources and industry support, I believe we
can improve the quality and quantity of our community programs. I look forward to having NEHA activi-
ties through our territory.”

On the personal side, Kevin is single, living in Walpole, MA, and is seeking opportunities to pursue his
favorite sports of tennis and golf. Also an avid reader and internet buff, these hobbies are overshadowed by
his true love, international motorcycle travel. Kevin travels throughout the world each year by motorcycle
(19 countries to date), and loves the opportunities to meet new people and learn about new cultures. This
summer, he’s heading for the Swiss Alps! Born on the east coast, Kevin went to college in MA and was ex-
cited about the opportunity to return to New England, “I’ve been searching for an opportunity to return to
the east coast, especially to New England, and am now so proud to be part of the NEHA family.” Please
feel free to welcome Kevin by calling him at the NEHA office. He’s always willing to talk and looks for-
toward to hearing your thoughts on NEHA’s future.

My Story  (Continued from page 3)

as Merck’s research facility is located in the Longwood Medical Area, which was convenient for appointments with
my new hematologist. He was right.

With health insurance and a new hematologist, my medical life was beginning to look normal again, though my
personal life was still a bit hazy. Let’s face it; I had no idea how to navigate Boston! Although I hadn’t yet worked
out some details, like where the shipping carrier would leave my factor shipment upon delivery to my apartment, the
major transition points were complete and I had triumphed relatively unscathed. While the tasks leading up to the
transition seemed very daunting, I was not alone in completing them, and that made their execution much less stress-
ful than it could’ve been. And I have my friends at my home care company and the Maine HTC to thank for my suc-
cessful transition.
I recently had the pleasure of escorting a beautiful 5-year-old child to the fun and excitement of SpringFest. It was his first exposure to the compassion and kindness of such a wonderful group of people. He also had never socialized with other children with hemophilia. Everyone couldn't do enough to make this weekend happen for this child. Several friends from NEHA and their industry partners made sure he not only learned more about his bleeding disorder, but also connected with other kids at meals and a water park outing the next day. The generosity continued with teens like Haley (13), Taylor (12), Matt (13), and Zack (11) jumping right in without being asked, making certain he was safely having fun.

There were impromptu sleepover invitations from many families, with a final crib-crashing with the Willis family on Saturday night, ending in a chorus of "99 monkeys jumping on the bed" at 11:30 PM.

For the first time, my little guest observed other children receiving factor. Watching one of his new buddies get ready for an infusion, just as the butterfly needle entered the vein, he commented, "I feel bad for him." His new friend, Jack, started to smile and told him it would be OK. He then wanted to help his new friend by holding the gauze and applying the Band-Aid.

The magic continued Monday morning during a routine visit at the child's school by one of my nurses, Donna. Donna couldn't wait to share the change in the way this child participated in his infusion. He greeted her with a smile and asked if he could mix and "do everything." He proudly stated he could "do it better than her" and that he "knows everything."

Later that day he needed to be seen at home with his Dad. Dad was attempting to mix the factor while I was on the phone with the doctor and, from the corner of my eye, I watched this child correctly instructing his Dad on how to mix the factor. "Poppy, take the blue cap off and wipe with the alcohol, then put the water on the table and push in the blue cap.... then put the other bottle on the table, and push the white cap into that bottle, and when all the water is gone then take off the blue part." He explained all this to his Dad in between tears from the pain of a new injury. Dad gave him a hug and then promised he will most certainly be at the next NEHA family event!

Through my years of working with such a compassionate group of people, I have collected a number of heartwarming stories that I have kept close to my heart. However, when some of these stories (like this one) contain such a wonderful show of the communal support, they need to be shared. My thanks to all for these magical moments!
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Through Participation
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For more information on Baxter programs and services, visit www.thereforyou.com.

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Maine SummerFest: June 28, 2008. Educational Symposium and Sea Dogs Ballgame / Portland, ME

Family Camp '08: July 23-26, 2008. Geneva Point Center / Moultonborough, NH. 
*Please note that camp is full; call NEHA if you would like to be added to the waiting list.*

NEHA Annual Golf Tourney & Auction: September 8, 2008. Cyprian Keyes Golf Club / Boylston, MA

Family Weekend at The Hole in the Wall Gang Camp: October 2008. Ashford, CT. Date will be announced in June.

Father/Son Weekend for Middle School and High School Students: October 2008. Watch for more info.


Maine Consumer Advisory Board: Meets the 2nd Thursday of every month. 
For more info, call Vicki Jacobs-Pratt at 207-786-5924