The New England bleeding disorders community was saddened to learn that former NEHA Executive Director Janice Wilson died unexpectedly on March 6th. She suffered a heart attack at 68 years old. Jan, determined to find education and support, had come upon NEHA in its early stages as a growing chapter. She volunteered, fundraised, organized holiday parties, became a Board Member and, eventually, Executive Director. NEHA meant a great deal to Jan and she showed her appreciation with her tireless efforts to further our mission. She loved helping others, especially new parents who were looking for answers and help.

Jan had many challenges in her life, which she handled with strength and dignity. When Jan was 18 years old, married and the proud mother of her first child, she was diagnosed with von Willebrand Disease (vWD). In many ways, the diagnosis was a relief, as it explained all the bleeding episodes she had experienced as a child and young adult. Jan went on to have two more children, both of whom were also diagnosed with vWD.

In recent years, Jan had begun treatment for hepatitis C, but could not continue due to the difficult side effects. She never seemed to regain her strength after that experience, but refused to give up. She continued making strides towards better health. She was determined to live her life as fully as possible and not let her medical challenges get the better of her.

Jan was a special woman with many outstanding qualities. She had a huge heart and a vibrant personality that made everyone around her feel comforted and cared for. Jan was always available with a helping hand and gave 100% to everyone and everything she was involved with. When Jan was your friend, she loved you with her whole heart.

Jan was a devoted mother to Robert E. Wilson, Gregg A. Wilson and daughter-in-law Stephany, Heather Hoiseth and son-in-law Wayne. Jan was a loving Nana to Kyle Wilson, Stephanie, Alyssa, Gage and Jane Wilson, and Erik Hoiseth.

After many years as office administrator and executive assistant at Coldwell Banker in Concord/Carlisle, Jan had just settled into retirement and a new home with Heather and her family. She had planned to split her time between Heather’s home and her beloved lake house on Bear Island, NH. This retreat was Jan’s favorite place in the world.

Jan was one-of-a-kind. The bleeding disorders community gained much from her insight, strength, and devotion to others. She will be dearly missed.
Dear NEHA Member,

In recent months, we have witnessed the demise of some of the most highly regarded financial institutions in our country and across the globe. The typical dynamics of world markets as we have come to understand, and perhaps more importantly, expect them to be – have changed. Those changes have created a profound effect on businesses of all shapes and sizes, in particular the not-for-profit segment.

The great news for us is that in this period of financial uncertainty, fundamentally, NEHA remains viable and strong. This is due to many factors, but primarily because our mission continues to provide real value to our community members. That value, together with our vision for the future, allows us to remain steadfast and committed to supporting our organization through this difficult time.

Recently, our industry partners and NEHA families joined chapters across the United States for the National Hemophilia Foundation’s “Washington Days.” Together, we spent a full day marching “on the hill,” and meeting with local representatives on a state-by-state basis to discuss critical issues that affect the bleeding disorders community. This year, our focus was to (1) ensure that our HTC’s continue to receive funding at the federal level, and (2) remove lifetime caps for insurance carriers. This was a record-breaking year in attendance, and on behalf of NEHA we would like to extend our sincere appreciation to all participants and supporters who helped bring our message to Washington with a great sense of style and determination.

Giving comes in many different forms. At NEHA we benefit greatly from our financial contributors, advocacy participants, and those who willingly give us time – perhaps the most important gift of all. We expect to remain strong in 2009 as we continue to execute on the mission of education and advocacy for all.

Wishing you all a very pleasant spring season,

Patrick Mancini
NEHA President

Correction
The 2008 golf winners were incorrectly listed in the last issue of our newsletter. The winning foursome included: Mike Boggio, Rick Chagnon, Lee Freidrich, and Robert Linn. Congratulations!
Paul Newman was a man of many talents. He starred in 60 movies from 1955-2006. One of his most well-known roles was Butch Cassidy, in *Butch Cassidy and the Sundance Kid* (1969), a western-themed movie about a bank robber and his partner. Paul Newman won many awards for his acting, including an Academy Award for his performance in *The Color of Money* (1986), three Golden Globe Awards, a BAFTA Award, a Screen Actors Guild Award, a Cannes Film Festival Award, and an Emmy award. Newman was also very active auto racer, and a member of the Sports Car Club of America. Some of the races he was in include the 1979 24 Hours of Le Mans (2nd place), the 2000 Petit Le Mans, the 1995 24 Hours of Daytona, the 2005 24 Hours of Daytona, and the 2004 Baja 1000.

Paul Newman was also well known from his impressive business, ‘Newman’s Own.’ Newman’s Own makes everything from salad dressing to popcorn, and generated over $250 million dollars for thousands of charities. In 1998, Paul Newman wrote *Newman’s Own Cookbook*, and *Shameless Exploitation in Pursuit of the Common Good* in 2003.

Paul Newman was a very wealthy man, but it was not money that made him wealthy, it was love. Paul Newman donated $250,000 to Catholic Relief Services in aid refugees in Kosovo and $10 million to the Kenyon College. One of his biggest investments was his chain of camps. He started the Hole in the Wall Gang Camps in Ashford, Connecticut in 1988. Now there are Barretstown in Ireland, Camp Boggy Creek in Florida, Double H Ranch in New York, L’Envol pour les enfants européens in France, the original Hole in the Wall Gang Camp in Connecticut, Jordan River Village in Israel, The Painted Turtle in California, The Victory Junction Gang in North Carolina, Over the Wall in the UK, Dy-
Friends and Fun at NEHA Events!

Family Weekend at The Hole in the Wall Gang Camp!
Many thanks to the amazing folks at The Hole in the Wall Gang Camp for hosting our 10th annual Fall Family Weekend!

Holiday Parties
Over 200 people joined us at one of three NEHA holiday parties this year. Entertainment, crafts, food and a visit from Santa made the day fun for all. Many thanks to the volunteers whose hard work brings our community together to share the holiday season.

Want to read more about NEHA’s events in 2008? See our website www.newenglandhemophilia.org for NEHA Executive Director, Kevin Sorge’s Year In Review.
So Much to Be Thankful For
By Shannon Fawaz and Alex Talbot

My adventure as parent of a child with hemophilia began 14 years ago, with the birth of my son Alex. For the first six years of Alex’s life I raised him as a young single mother, but I was not alone. We were blessed with supportive family and friends, especially my parents and siblings. We received very personalized quality care at our HTC and were blessed with a hemophilia nurse who is nothing short of an angel in a lab coat. And last but certainly not least we were blessed with the gift of community when we joined NEHA.

My family of two is now a family of four: Alex, my husband Chris, and seven-year-old Jordan. As a parent of two boys with severe hemophilia I could not even put into words how NEHA’s programs have affected my family. However, I have something better than words… I have living proof. At age six Alex did his first self infusion at family camp and realized that he liked the sense of control that came with self infusing. When his brother was born, Chris and I were amazed by Alex’s dedication to helping his brother develop a healthy attitude about living with hemophilia. Alex has been a wonderful role model and coach for Jordan, cheering his brother on. So when we heard that the NEHA scholarship could send two of us to the NHF 60th Annual Meeting, we couldn’t think of anyone in our family more deserving than Alex. Don’t get me wrong, sibling rivalry is alive and well in our household, but they come together when it really counts.

On November 13th, Alex and I flew out of Manchester, NH, arriving in Denver late that morning. It was so nice to have this time away just the two of us, but Alex couldn’t wait to meet up with his friends Leland and Max. They chose to attend the teen program and go on a... (Continued on page 11)

The 5th Annual Alpine Snowshoe Walk

The 5th Annual Alpine Snowshoe Walk was held the weekend of March 13th at beautiful Stratton Mountain Resort in Vermont. Families from New England and New York joined us for a wonderful, fun-filled family event. It was perfect spring weekend with sparkling blue skies and warm sunshine. Over 80 people participated in the snowshoe walk.

Ina Katzman has been the driving force who ensured this event is a tremendous success. She spent countless hours gathering auction items and donations from local business and numerous friends to ensure another successful event for NEHA. Over $30,000 was raised for New England Hemophilia Association! NEHA families were treated to breakfast by CSL Behring and Bayer Healthcare sponsored dinner for over 100 people at the Saturday night dinner and auction.

Thank you to all the NEHA families, the Katzman Family and friends who continue to support this great event every year! We look forward to seeing you next year at Stratton Mountain Resort...
NEHA WISHES TO EXPRESS OUR GRATEFUL APPRECIATION TO ALL OUR DONORS!
October 1, 2008 to March 15, 2009

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**Academic Scholarships**

There are a variety of academic scholarships available for students with bleeding disorders and their families. Scholarships are available for a wide range of ages, from K-12 and beyond. Please note that most of these scholarship applications are due in the spring *before* enrollment in a program.

A list of scholarships can be found on the National Hemophilia Foundation website, using these steps:

- Go to www.hemophilia.org
- Click on the “About Us” tab on the left and scroll down to the bottom
- Click on “Scholarship”
- The page that opens lists all available scholarships, and is updated as new ones become available.

Lists of scholarships are also available at:

- LA Kelley Communications: [http://www.kelleycom.com/scholarships.html](http://www.kelleycom.com/scholarships.html)
- Hemophilia Federation of America: [http://www.hemophiliafed.org/site54.php](http://www.hemophiliafed.org/site54.php)
- COTT: [http://www.cott1.org/fullstory.html?id=50](http://www.cott1.org/fullstory.html?id=50)
A researcher can spend years developing an idea, drug or device, but at some point science has got to leave the lab, and walk into the real world. There are several steps and stages of approval in the clinical trials process before a drug or device can be sold in the consumer market, if ever. Drug and device testing begins with extensive laboratory research which can involve years of experiments in animals and human cells. If the initial laboratory research is successful, researchers send the data to the Food and Drug Administration (FDA) for approval to continue research and testing in volunteers. Once approved, researchers can begin their clinical trials, which are usually conducted in four phases. (see sidebar)

The small size of the bleeding disorder community can be a challenge for researchers, who need a lot of data to be certain of a drug or device’s safety. A lot of data requires a lot of volunteers, but even so, think before you sign up for a trial. Think carefully about any short or long term risks, as well as the financial or practical impact that a trial may have. Read the trial’s description carefully and ask lots of questions. Get a second opinion, and sleep on it. As always, be a savvy consumer!

NEHA News asked Judith C. Lin, MD, Associate Director, Boston Hemophilia Center, Brigham and Women’s Hospital in Boston to describe the center’s clinical trials program, the largest in New England. Dr. Lin said, “We have over 22 studies for persons with congenital bleeding and thrombotic disorders in the Boston Hemophilia Center. These studies include adults, children, women, persons with inhibitors to factors, as well as new treatments. We participate in studies both on the national and international level.”

This scientific activity hasn’t really been noticed by the bleeding disorder community. “Patients and families may not think of research in bleeding disorders beyond the UDC study or waiting for the promise of gene therapy,” Dr. Lin theorized. “This could be explained by the fact that there haven’t been any new major treatment advances in factor concentrates since recombinant factor VIIa. This year, however, we are participating in three special new treatment studies for hemophilia A, hemophilia B, and von Willebrand disease. Several of these are international studies. We are also currently considering participating in a gene therapy study for hemophilia B.” According to Dr. Lin, a women’s pilot study is now available through the Boston Hemophilia Center and they are recruiting for participants.

A quick look at online resources shows that the Boston Hemophilia Center is currently participating in these trials:

- “Rituximab to Treat Severe Hemophilia A (RICH),” sponsor/collaborator: National Heart, Lung, and Blood

(Continued on page 15)
NEHA Hosts Legislative Days in MA, CT and ME
By Mark Borreliz

When should you ask your local legislators for their help? Perhaps the best answer is before you need it. If you are asking for your representative’s and senator’s vote on a critical piece of legislation, you already want them to know who you are, and to understand and care about your interests. Which means that the time to acquaint your legislators with your concerns is now, if not yesterday.

That’s the reason to participate in a legislative briefing day, when legislators are invited to educational sessions put on by their constituents. NEHA conducted its first legislative briefing day in March 2008 at the Massachusetts State House. The session brought together twenty NEHA members and almost as many legislators and their staffers. Members of NEHA’s Advocacy Committee gave short talks about the basics of bleeding disorders, and two key legislators in the health care arena offered their own remarks. Then, before the NEHA attendees dispersed to visit the offices of their respective legislators, everyone had the opportunity to participate in an informal question and comment period. “That was probably the most valuable part of the program,” recalls Advocacy Committee chairperson Kate Muir. “Legislative aides felt free to ask whatever they didn’t understand about living with bleeding disorders, and the families and individuals in the audience had the chance to respond in the most vivid way – by simply telling their stories.”

Last year’s legislative briefing day was a definite success, which meant that another one wasn’t needed until . . . this year. In fact, this year NEHA made plans to host legislative days in three states. On March 24th, NEHA returned to Beacon Hill with the goal of garnering support for two pieces of legislation, the Hemophilia Advisory Committee bill (see “NEHA News,” Fall 2008) and the recently-introduced Bleeding Disorders Treatment Standards Act. NEHA members in Connecticut had the chance to interact with their legislators in the second legislative briefing day, held April 7th in Hartford. And on April 18th, NEHA offered a northern New England legislative training session at the Maine Hemophilia and Thrombosis Center in Scarborough, ME.

“The prospect of carrying NEHA’s message to lawmakers in three states is a challenging but exciting one,”

(Continued on page 13)

The Gift of Experience: Conversations About Hemophilia
Review by Ziva Mann

When Laura Gray joined the Boston Hemophilia Center as a social worker, she was asked to be a resource for a foreign world. “I knew nothing about hemophilia,” she admits, “I had never heard of factor or cryoprecipitate. I had never met a person with HIV and I knew very little about hepatitis C. To be effective in my job, I needed to listen and learn.” And she did. “I learned about courage, perseverance, pride and resilience. I witnessed how love, humor and faith were essential ingredients to handling the pain, disappointment and devastating loss. I want their stories to be told.”

The experience of that generation was crucial in the history of bleeding disorders. This was the first generation to have clotting proteins available, and this was also the generation of the HIV/AIDS crisis. Their experience with the tainted blood supply was heartbreaking, and the descriptions of bleeding are almost unfamiliar. A child on prophylaxis can move through a childhood unlike any described in The Gift of Experience. And while a parent of a young child might be tempted – as I was – to set this book aside, protecting against the weight of pain and honesty that these narratives carry, don’t. These are not stories of the past, and these are not stories to hide from. As Christine Chamberlain explains, though told in a range of voices, “the journal is universal.”

The book is an oral history, a collection of individuals’ stories. All too often, a history book will smooth out the single voice when telling a community’s story. The Gift of Experience refuses to do that, choosing fragments of narrative over a tidy whole, preferring to keep the voice of each individual. As Theodore Frost says in Gift, “There’s so much that you want to forget and there’s so much that you want to remember, so what do you cast to one side?” We can be grateful that the creators, contributors and supporters of The Gift of Experience chose not to put these stories to one side, choosing instead to preserve them, quirks, griefs, grins, and all.

The Gift of Experience: Conversations About Hemophilia, is available through the Boston Hemophilia Center and amazon.com

For a sneak peek inside the book, see our website: www.newenglandhemophilia.org
community walk away with after seeing the work? What would it mean to that person? I had to stop and think about what I was really trying to do. Ultimately, I realized that my goal for the senior project was to describe in my own way issues such as physical and emotional pain, coping with that pain and how it pertains to the human experience through a hemophiliac framework. This last was a third approach, and a third piece of the project.

I decided to make hemophiliac trading cards: a set of 5 different color cards, each with a different close-up picture from my childhood where bruising was evident. For each color card, there is another corresponding card asking the viewer to “Describe or draw where it hurts in exchange for a hemophiliac trading card” and allowing space for that response. By inviting the viewer to respond, I invited them to relate their pain to mine, and to life with a bleeding disorder.

To display the project, a unit was constructed with three shelves and glass sundry jars that held the cards to facilitate that exchange. Viewers were able to touch, and to physically interact with the ideas of pain, exchanging pain for pain. They were more able to contemplate the importance of the human experience, and join me in talking – and thinking - about it.

All three bodies of work were exhibited at the USM BFA Senior Thesis Exhibition in Gorham, Maine (April 2008). Shown together in a room painted like a doctor’s office, the work as a whole was titled, “The Waiting Room”, a place I’m confident we bleeders and our families are very familiar with. Thank you to everyone who helped and let me take their picture.
Thankful  
(Continued from page 5)

fieldtrip to Amazing Jakes for a day of video games and laser tag. I too was looking forward to catching up with my good friends and annual meeting veterans Jane Smith and Maryann May. Jane had helped me coordinate all our travel arrangements, and went out of her way to include us in all the wonderful events.

Over the next few days I ran into many old friends and made many new friends. I enjoyed good food and good company each evening over dinner. I really enjoyed the educational and interactive seminars such as anti-helicopter parenting, a rap session for parents of teens, and living life to the fullest. However, my personal favorite was called “It takes a Village,” which featured a panel of two NEHA families. As I sat in the audience and listened to the Mackey and Hebert families talk about the ways they have supported each other and the bond they have developed; I was so touched. It didn’t take long before their inspiring story had everyone teary-eyed.

Alex and I selected a few sessions that interested both of us. He is four short years away from leaving for college and knows he will be expected to manage his own care. I hoped that attending some of these seminars would help him better understand issues that the adult men in the hemophilia community are facing and what could be on the horizon for his generation. Based on the conversations we had during our flight home from Denver I was very pleased with how much he took away from those sessions and all he learned while networking with his peers.

I am so very grateful to The New England Hemophilia Association for its commitment to empowering its members through education and community support. The gift of our trip to attend the NHF 60th annual meeting is yet another example of how NEHA has enriched the life of my family as members of the bleeding disorders community.

I hope NEHA continues to offer this scholarship for first time families each year, and I encourage all those who have never attended to do so if you have the opportunity.
Briefly Noted

The following news stories can be read in their entirety at www.hemophilia.org. Recommendations from the NHF’s Medical and Scientific Advisory Council (MASAC) can be found under the header “Learn About Coagulation Disorders.” Medical Advisories and NHF eNotes can be found under the “News” header.

MASAC released Recommendation #188 Standards of Service for Pharmacy Providers. The purpose of this document is to establish minimum standards of service for pharmacy providers to meet the specific needs of individuals with bleeding disorders. For more information: MASAC Document #188

Post-mortem examination of a U.K. man with hemophilia showed him to have Creutzfeld Jakob disease (vCJD). From 1980-2001, a batch of UK-sourced plasma derived clotting factor was derived from a donor with vCJD. UK-sourced plasma is not used in products licensed for use in the US. For more information: Medical Advisory #409 (source: MASAC)

State Children’s Health Insurance Program (CHIP) expanded to cover an additional 4.1 million uninsured or underinsured children from low-income families. For more information: Obama Administration Demonstrates Commitment to Healthcare (source: NHF eNotes – March 2009)

Lentigen Corporation and Expression Therapeutics will work together to develop new therapies for the treatment of patients with hemophilia A (factor VIII deficiency). The partnership will research stem cell therapies for hemophilia A. For more information: Lentigen and Expression press release

Researchers at the Baylor College of Medicine made progress in gene therapy to treat hemophilia B. For more information: Hemophilia B Gene Therapy Vector Shows Promise

Promising early-stage research into the use of stem cell transplants to fend off attacks by the human immunodeficiency virus (HIV) was presented at the Stem Cells & Regenerative Medicine World Congress in Palm Springs, CA. For more information: Study Indicates Stem Cells Can Fight AIDS (source: NHF eNotes – February 2009)

(Continued on page 14)
Legislative Days  
(Continued from page 9)

says NEHA Advocacy Coordinator Steve May. “Things are happening in each of those states that have the potential to affect our community, some for better and some for worse. We want to make sure that the legislatures there know who we are and how they can help us.”

For a legislative briefing session to be effective, the most important ingredient is constituent turnout. If a briefing room is empty, legislators are not going to hang around. But if they know that even one person from their district will be present, most legislators will stop by or send a staff representative. Ms. Muir observes, “People have no idea of the impact they can have by showing up, shaking hands with their senator or representative, and sharing what they might think is an unremarkable anecdote about how they deal with hemophilia or von Willebrand disease. For legislators, it’s all about those moments of contact.”

For more information on advocacy, please contact NEHA at newenglandhemophilia.org or call (781) 326-7645.

Want to learn more about NEHA’s advocacy work? Go to the NEHA website (www.newenglandhemophilia.org) and read Kate Muir’s Advocacy Update.
**Briefly Noted**  
(Continued from page 12)

In a merger agreement, Pfizer has agreed to acquire Wyeth Pharmaceuticals for $68 billion. For more information: Pfizer To Acquire Wyeth

A team of researchers from Saint Louis University (SLU) in Missouri recently published a study advancing a new technique to predict if a patient infected with the hepatitis C virus (HCV) will respond to treatment. Such a test is needed because current therapies are costly, cause severe side effects and have a high failure rate. For more information: New Test Developed by SLU Researchers May Predict HCV Therapy Success (source: NHF eNotes – January 2009)

Baxter Healthcare Corporation announced the start of a Phase I, multicenter clinical trial for its investigational, recombinant von Willebrand factor (rVWF). For more information: Baxter Announces Recombinant VWD Trial

February 13, 2009: The Health Insurance Coverage Protection Act was introduced (S. 442 and H.R. 1085). If passed, the minimum level of lifetime caps will increase to $5 million for the first two years and $10 million in years three and four. For more information: Legislation Introduced for Lifetime Caps Increase (source: Hemophilia Federation of America)

CSL Behring’s RiaSTAP™ was licensed for the treatment of patients with congenital fibrinogen deficiency (factor I deficiency). There are approximately 300 patients with factor I deficiency in the U.S. For more information: FDA Licenses First Concentrate for Factor I Deficiency

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**Paul Newman**  
(Continued from page 3)

namo Camp in Italy and Bátor Tábor in Hungary.

Thanks to all that Paul Newman has done for our community I know that he will not be forgotten. Paul Newman led a full and fulfilling life. He gave all of his money to helping others and in turn he got much love back. The passing of our friend was a shock for most. I myself was lucky enough to meet him not once but twice! In just the minute that I talked to him I really got a picture of who this man was and what his life was about: helping others. Thank you, Paul Newman.

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Through Progress
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For more information on Baxter programs and services, visit [www.thereforyou.com](http://www.thereforyou.com).
Clinical Trials  (Continued from page 8)

Institute (clinicaltrials.gov)

- “International Immune Tolerance Study,” sponsor/collaborator: New York Presbyterian Hospital, Central Manchester and Manchester Children's University hospitals NHS Trust

- “Phase I/IIa Study of FIXFc in Hemophilia B Patients,” sponsor/collaborator: Syntonix Pharmaceuticals, Inc., Biovitrum, Biogen Idec (clinicaltrials.gov)

- “Bleeding and Clotting Disorders Surveillance” (UDC), sponsor/collaborator: Centers for Disease Control and Prevention. (www2a.cdc.gov)

Sources for this article include: hemophilia.org (NHF), clinicaltrials.gov, centerwatch.com, cdc.gov and more. Want to learn more about clinical trials? Check out clinicaltrials.gov for trials. The site can be searched by topic, condition or location. Or look at the NHF’s Clinical Trials Resource Center at www.centerwatch.com/ctrc/NHF.

NEHA News urges you to always talk to your doctor before signing up for a trial or new therapy, and remember: be savvy!

Want to see what research is happening at your HTC? NEHA News asked - see the answers on our website (www.newenglandhemophilia.org)
Northern NE Legislative Training: April 19, 2009. Maine HTC / Scarborough, ME

SpringFest ’09: April 25, 2009. Marriott Providence Downtown / Providence, RI

Leading Edge Program for Teens: May 31, 2009. Project Adventure / Beverly, MA

Dads in Action PawSox Game & Tailgate: June 7, 2009. McCoy Stadium / Pawtucket, RI

Maine SummerFest: June 20, 2009. Educational Program and Sea Dogs Ballgame / Portland, ME

17th Annual Family Camp: July 22 –25, 2009. Geneva Point Center / Moultonborough, NH

19th Annual Golf Tournament & Auction: September 14, 2009. Cyprian Keyes / Boylston, MA


Electronic (.pdf) versions of this newsletter are available on request. Contact the NEHA office for information!

www.newenglandhemophilia.org