

Factor Nine News

The Coalition for Hemophilia B

Spring 2008

Topics in Hemophilia

- First Annual Fund Raising Dinner
- Second Annual New York Symposium
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- Eshton Hewitt Quality of Life Project Update
- Hemophilia Alliance Group Purchasing Org.
- NHF Walkathon - NYC Hemophilia Chapter Event
- Factor Nine Family Meeting - Inalex



The Coalition for Hemophilia B First Annual Fundraising Dinner



Dr. David Clark, Chairman

The Coalition for Hemophilia B held its first annual fundraising dinner at the Millennium Broadway hotel in New York on Friday, March 7th, 2008. Attendees included the lotto families we flew in for the symposium, industry people and private donors. Monies raised will benefit our Educational Programs and the William N. Drohan Scholarship fund.

Dinner began with a warm welcome to our guests by Dr. David Clark, Chairman of the Coalition for Hemophilia B, followed by the acappella singers from ISMILE Productions.

Their first song was Sunrise-Sunset dedicated in memory of Dr. William N. Drohan (it was Bill's favorite song). Renae Baker from ISMILE presented the Drohan family with a beautiful framed song sheet of Sunrise-Sunset personally addressed to each member of the Drohan Family and signed by Sheldon Harnick (he wrote Sunrise-Sunset). The Drohan family was very surprised and gave us a heartfelt thanks.

"When I wrote the lyrics for 'Sunrise, Sunset', I was thinking of my own children. It's always gratifying to learn that one's work has moved another person. In this case, I'm deeply touched to find that the song affected someone who was engaged in such admirable humanitarian work as 'The Coalition for Hemophilia B'. That's the best reward a songwriter could have!"
Best, Sheldon

Afterward the singers went around to each table singing Broadway's greatest tunes. Following dinner was our Casino night where everyone had a fun time, indeed.

We thank all our contributors and hope to see you all next year!



*The Droham Family
Maureen, Craig, Laura, Kathleen,
and Tommy Little*

The Coalition for Hemophilia B

Second Annual Symposium

Generously Funded by Wyeth Pharmaceuticals

The Coalition for Hemophilia B's second annual symposium was held on Saturday, March 8, 2007 at the Millennium Broadway Hotel in New York. The symposium began with opening comments and welcome. Our first speaker was Dr. Christopher Walsh, head of the HTC program at Mt. Sinai hospital in New York City. Dr. Walsh spoke about current gene therapy research and advances being made for the treatment of hemophilia. His talk was followed by a multitude of questions from symposium participants.

Second on the agenda, Mike Herbert and Dawn Feraci from Patient Services, Inc. (PSI). They spoke about the ongoing and current issues with insurance and how PSI can work with individuals in need of insurance assistance.

Our next speaker was not only energetic and inspiring but he was also quite colorful. Michael O'Connor, a 17-year-old high school senior, and a person with severe hemophilia B, spoke to the audience about how swimming helped him both physically and mentally. Swimming helped strengthen his joints so he had fewer bleeding episodes, and how he felt like "just one of the guys" on the swim team. He spoke about swimming competition and also told a funny story about one of his coaches, which drew a good laugh from the audience. Michael was a true inspiration to parents and children alike, as he made them feel more comfortable about how a child can grow up living healthy productive lives with hemophilia.

Our next speaker was another true inspiration to all as well. Ben Shuldiner, is the Founder and principal of the High School for Public Service in Brooklyn, NY. Ben also has severe hemophilia B. His speech was called the "Blood of Others." It was a story about growing up and living with hemophilia. Ben's talk touched everyone's hearts. He is a true role model for everyone living with hemophilia.

After a wonderful lunch we continued the afternoon with a slide show presentation by Wayne Cook, about

Joint Replacement and Continuous Infusion. The presentation was well received and the audience had plenty of questions afterward.

Following was a wonderful new game we introduced called "Are You Smarter than your Hemophilia?" hosted by Lisa Weiderman. Each table was a team, and they had 30 seconds to answer the correct question by raising their cardboard letters A,B,C, or D. The team with the most points won. But everyone received a trophy, as you are all winners to us! The game was fun and educational.

Finally the sessions ended with our traditional family gathering. The Coalition's forum where everyone has a chance to talk about themselves, their families and just about any issues they may have or any insight they might want to share with the group.

A big thank you to our sponsor, exhibitors and speakers for making our symposium a success!



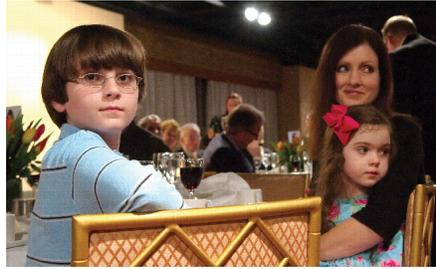
Ben Shuldiner speaks about "The Blood of Others."

The Coalition for Hemophilia B Photo Gallery

Fundraising Dinner



Acappella Singers



The Blair Family



Chris Blair



Fundraising Dinner Millennium Hotel



Deb Schacter, Meghan O'Brien, and Dr. Richie Neuman



The Drohan Family and John Taylor



Katherine Parsons, Mr. & Mrs. Prior and Chris Libertino



Dr. Christopher Walsh and Dr. Marie Mann



Shannon and Maureen Cook and Lisa Weiderman



Dan Bond and Bernice Torrogrossa



The Putbresi Family



Jack and Genie Arnov, Tony Sacco, Christina Scherer, George Fujioka, Marie Currim, Bert Horowitz



Rob and Kimberly Newland



Marie Currim and Bert Horowitz



Kathleen Didier and Rob San Fillippo

The Coalition for Hemophilia B Photo Gallery

Casino Night



Dr. Richie Neuman, Bernice Torrogrossa, Dan Bond and Wayne Cook



John Taylor and Maureen Drohan



A Capella Singers at Table #8



Dr. Walsh, Dr. Mann, and John Taylor



Matt Ottmer, David and Linda Clark



Casino Night



Casino Night



Casino Night



Casino Night



Casino Night



Casino Night



Casino Night

The Coalition for Hemophilia B Photo Gallery



Dorothy and John Prior



Kasie Cook



*Kate McCoy, Brian Murdy and
Meghan O'Brien*



*Elizabeth Adams, Laurie Pisano,
Lauren Orlouski, Veronica Zurita*



Kristin and Tyler Blair



Kristin Blair



Royal and Linda Hunter - Smith



The Putbrese Boys



Max and Nathaniel Putbrese



*Claire DuBois, Delphine and Tristan
Martin*



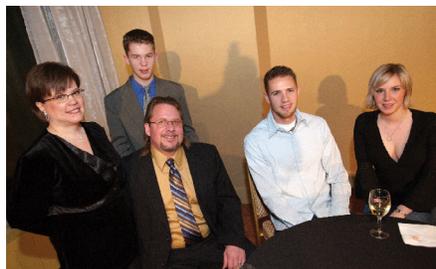
Tristan Martin



The Martin Family



*Katherine Parsons, Ron San Fillippo,
and Matt Ottmer*



*The Littig Family, Clay and
Emily Gorham*



The Ussery Family

The Coalition for Hemophilia B Photo Gallery Symposium



Critical Care Systems



Hemophilia Health Services



Factor Health



AHF



Mario the Magician and Kristin Blair



Symposium Attendees



Mike Hebert, PSI



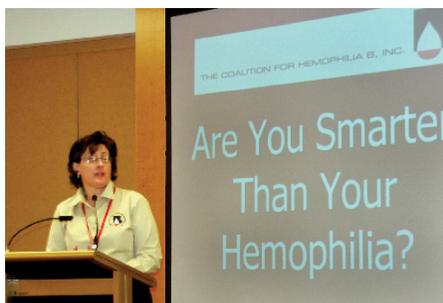
Dr. Walsh



Michael O'Connor



Wayne Cook



Lisa Weiderman



Critical Care Raffle Drawing

Symposium Attendee Comments

“Just wanted to let you know how much I enjoyed the symposium. From a consumer viewpoint I thought you really gave the families what they want to know about: 1.) ongoing research/where we are/where we are going. I can't tell you how many people have said they would like to see more of these sessions at other meetings. 2.) inspiration-wow two fantastic individuals and speakers. 3.) funding/financial support 4. vendors - what is out there/more education on what is available. Overall I honestly thought it was one of the best symposiums I have been to and I look forward to attending next year.” **M.M., Massachusetts**

“The symposium weekend was a great experience for me. I very much enjoyed the sessions; the speakers were great as well as the topics. Of course it was great to attend the Fundraiser Dinner and meet people all weekend; some new and some old. I especially enjoyed meeting the Drohan family. They are good people just like everyone else there. Thank you so much to you and the coalition for the weekend!” **T.A., Arkansas**

“The Symposium was really good! The speakers were all great. We really enjoyed the interaction of the game. It was really funny, but educational and the trophies were awesome. Having the vendors there was good too, and being smaller, was more personal and not so overwhelming. We picked up some info/vendor giveaways for a newly diagnosed family in Alabama. The Factor Nine Family meeting was great as usual, and thanks so much for the special book given to all the families. The kids had a great time with Kasie and Shannon. They did a great job! The kids had lots of fun with the games, activities, and the Magician. We cannot thank you enough for bringing us to New York. We had such a wonderful time. These are such memorable experiences for our family. The Coalition is such a blessing to us and all the Factor Nine families.” **R.B.,Alabama**

“It was excellent!! Will you please forward any pictures if possible? We were so busy enjoying the time we didn't take many. I really liked the game. And Dr. Walsh was incredible! My son got the most out of listening to Michael O'Connor. We really got something out of every speaker. Wayne talked about continuous infusion... Nathanael has to have oral surgery before getting braces so I'd like to check into that for him!! We had the best time, although it went so quickly!” **K.R.P., Florida**

“I had a really great time meeting everyone and I learned a lot from the symposium on Saturday. I thought Michael O'Connor's presentation was very informative and helpful. I had heard that swimming was good for people with Hemophilia but I never knew how helpful until I heard what he had to say. I also liked Wayne's presentation on continuous infusion, it was very enlightening and I will keep it in mind as we continue on our journey with Hemophilia. The “Are You Smarter Than Your Hemophilia?” was so much fun. I really felt connected to everyone after the family meeting where I was able to share my experience with hemophilia.” **C.L., Maryland**

“It was a privilege for us to travel across the country to participate in such an event. We had a wonderful time socializing with other families, meeting representatives, and listening to the presentations. After talking and listening to other people, I think we both realized how little we know about Hemophilia B. We want you to know how grateful we are for the motivating experience. Because of this, we intend on being more involved and up-to-date on current issues and information regarding our bleeding disorder. Overall, our experience was fun, informative, and invaluable. Thank you for making it possible.” **E.G. and C.G, Alaska**

“Again we had a wonderful time. We cannot thank you enough for providing this valuable educational experience. We got a lot out of all the speakers. Ben Shuldiner's talk was truly an inspiration. PSI did a wonderful job educating us about insurance issues, something we all need to be up to date on. We enjoyed the game, as you made it fun, but we also learned a lot. We enjoyed the opportunity to visit the exhibit booths to obtain more information as well. We can't wait to come back next year!” **A.H., New York**

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with important topics such as reimbursement issues, product updates, and tips on staying healthy

educational materials

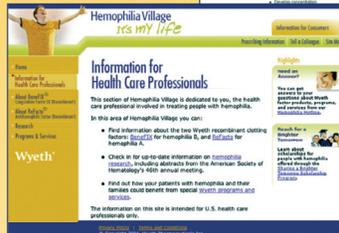
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For more information about products, services, and programs we offer to the hemophilia community, visit our Web site at www.hemophiliavillage.com or call 1.888.999.2349.



Wyeth

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Treble, Concert & Master Singers of the Fairfax Choral Society

Spencer Duggan will be performing at Carnegie Hall in New York City on April 20, 2008. Spencer is a member of the Chamber Singers, an advanced chorus of his high school Choral Department. Last year he sang with his school chorus at the Kennedy Center and Strathmore Hall for their Christmas concert with the Washington Chorus and won the *Outstanding Musician of the Year* award. He has lettered in music and been chosen to be a member of the District XI Chorus three years in a row. He is also a member of the Westfield High School Guitar Ensemble and the Jazz Ensemble. He was inducted into Tri-M, the Music Honor Society, this year.

Outside of school, he is a member of the Fairfax Choral Society. He will be traveling with this group to New York City to perform John Rutter's Mass of the Children at Carnegie Hall. Spencer will be majoring in Music in college. He has auditioned at several universities and is awaiting their decisions. His plans include vocal performance, composition, and perhaps music education. We wish him good luck and hope some of you will be able to see him perform. If you would like to purchase tickets for his Carnegie Hall performance, please call (212) 239-4669.



Spencer Duggan



Michael O'Connor Speaks at Symposium

Michael O'Connor, 17, spoke at the Coalition for Hemophilia B meeting on March 8, 2008, to Hemophilia B patients and their families. Michael is currently the three-time Nassau County Champion in the 100 Breaststroke, and is ranked Eighth in New York State Public High Schools in that event. He has qualified for NCSA Junior Nationals, and will be competing in Orlando, Florida, March 19 -24, 2008 in that elite meet.

At the family meeting, Michael spoke to patients and their parents about how he is able to compete on a "level field" as a swimmer despite having Hemophilia B, and how the sport of Competitive Swimming has actually protected him from joint problems for the last 6 years. He pointed out the many positive aspects of serious competitive swimming as a sport, as well as how rigorous it is, and what it takes to reach National competition.

Michael has been recruited to a prestigious college in New England, and he hopes to help lead the Men's Swim Team to an NCAA title during his next four years there.

We wish Michael much success at Junior Nationals!

Eshton Hewitt Quality of Life Update

In 2003, The Coalition for Hemophilia B formed an Umbrella project called “The Eshton Hewitt Quality of Life Project” (see winter 2004 newsletter and also under Programs on our website). It began to help Eshton Hewitt who has hemophilia B with inhibitors and also Ehlers Danlos Syndrome (EDS), a connective tissue disorder that wreaked havoc on Eshton’s body causing severe joint damage and making it difficult to control the bleeding episodes that inevitably follow a subluxation, or dislocation.

After a great deal of research and struggle to find adequate long-term care for Eshton, his parents decided that his best opportunity to slow the progression of disease in the joints was to strengthen the muscles supporting them through aquatic exercise, which has basically no impact on the joints. Eshton was not able to swim in a public swimming pool due to the combination of his fragile skin and having a port, which makes him susceptible to infection. There is no way to regularly test a public pool for bacteria and the Health Department does not require that logs be kept showing their testing. This puts him at a very high risk.

The Hewitt’s started out with an outdoor above ground pool. When Eshton was swimming, his bleeding episodes decreased and they had to infuse him less. When Eshton has a bleed, he has to be infused every 3-6 hours (depending on the dosage) for 1-4 days until he has full range of motion due to the EDS. As published in the Michigan Flint Journal (Title: ***Pool to Help Boy Be Like Any Other Kid; Businesses come through for mom; July 26, 2003***) “When Eshton is in water, everything is normal for him.” Joyce Hewitt explained. “One time he was swimming and said he was so happy we had the pool and that when I’m in here, it’s like I’m like any other kid!”

The difference was enough that Joyce and Jay wanted to give him a better quality of life year-round and that meant building an indoor swimming pool. Joyce and Jay Hewitt mailed out many letters and made numerous phone calls to prospective donors for this project. Soon after, donations for building supplies, pools, roofing material, windows and doors, a boiler and plumbing supplies came in. Individuals,

companies and The Coalition for Hemophilia B donated monetarily as well. The Hewitt’s were completely overwhelmed and never expected an out-pouring of such magnitude. Joyce Hewitt said “Without the support we would never have been able to make this dream a reality for our son.”

As of 2008, The Coalition for Hemophilia B “Eshton Hewitt Quality of Life Project” is still going strong and continues to help fund the Hewitts on a yearly basis. The fund has also helped many families who have hemophilia, inhibitors, and also dual diagnosis to have a better quality of life. Following is an update on the Hewitts from Joyce Hewitt:

“First and foremost my family and I want to thank everyone who has contributed to the Eshton Hewitt fund. Thank you for your support both financially and in your hearts and prayers. We are keenly aware that without all of you we would not be able to provide these things that my son has desperately needed. And for that I will never be able to find enough words to adequately convey my gratitude to you all.”

It’s now been almost five years since my husband and I first started working on the handicapped bathroom and pool. We’ve come a long way: Eshton’s able to use the pool and the bathroom unassisted and the boys are in their expanded room, but there is still a great deal that needs to be done.

We have at this point gotten the pool placed and enclosed; the boiler to heat the building, pool and handicap bathroom is placed and working. The handicapped bathroom is finished, new back doors have been installed and their bedroom has been enlarged for handicap accessibility. (And promptly turned into the Great Divide-MSU on Tekoa’s side and U of M on Eshton’s!)

Eshton has had few ankle bleeds since he has been able to use the pool, but continues to suffer from easily dislocating joints in his extremities. The muscle strengthening, joint stability, and conditioning he’s been able to gain has come only as a result of aquatic therapy. Before the pool, Eshton was bleeding into each ankle 6-9 times a year. He’s had less than 6



in the past 4 years! Although Esh bleeds less in his ankles, he still continues to bleed in his lower extremities on a very regular basis. He is using his wheelchair more and more. He was also just diagnosed with scoliosis.

There is still so much more that needs to be done. We are doing all the labor in our home with further renovations to create a home that will be handicap accessible for Eshton. A home that will serve him, throughout his lifetime.

We have replaced doors, put in a medical closet, removed obstructions, and created new entry ways for wheelchair accessibility. Our next step is to remodel the kitchen for handicap accessibility. Our twin boys are now 13 and at an age where independence and dependence are often at war. They want to make their own decisions, learn who they are, and challenge what we know as elders. It's the way it's supposed to be, for young people as well as old alike, to make the break from each other. There's no difference here except that in order for Eshton, and to a smaller extent, Tekoa, to learn and grow from those "learning" experiences, they need some adaptations that most of us don't. Their ability to become independent, self-

sufficient people that we all want for our children simply requires from us a little bit more than most. We consider it a privilege and an honor to be blessed with such amazing children. Currently, we need about \$50,000 to complete the project. Donations of appliances, flooring, light fixtures, kitchen cabinets, counter tops, windows, dry wall, lumber. I've taken some pictures of where we are now. Just remember: we've been living in the construction phase for almost five years now! Joyce Hewitt.

If you would like to make a donation to the Eshton Hewitt Quality of Life Project please send your donation to:

The Eshton Hewitt Quality of Life Project
The Coalition for Hemophilia B
825 Third Avenue, Suite 226
New York, NY 10022

All donations and materials will go directly to the Hewitt family.

The Eshton Hewitt Quality of Life Project is funded by Novo Nordisk

Hemophilia Alliance Group Purchasing Organization

(HAGPO)

Two years ago, a group of Hemophilia Treatment Centers, formed a group purchasing organization called Hemophilia Alliance Group Purchasing Organization (HAGPO). The group is headed by Mark Plencner, RPH, President. Mark is the managing pharmacist of the hemophilia program at Roger Maris, Cancer Center in Fargo, North Dakota. Joe Pugliese is the Executive Vice President. Joe has been involved in the hemophilia community for the last 30 years. Currently there are 26 participating treatment centers enrolled. It is a federal requirement that each member of HAGPO sign a participation agreement.

The objectives of this organization are to:

1. Secure a “guaranteed” supply of product in the event of shortage to help care for the needs of their patients.
2. Negotiate better prices and terms to effectively manage their business, which in turn will help patients in managing a very expensive disease, in the most economical manner possible.
3. Create a pool of unencumbered dollars that would be reinvested in the hemophilia community.

In January, 2008, HAGPO made its first reinvestment to the community by giving a restricted grant in the amount of \$25,000 to the National Hemophilia Foundation to fund nurses, social workers, and physical therapists from each region across the country to attend MASAC working group and educational programs. Any remaining support will be used toward chapter educational activities.

HAGPO is currently in the process of developing a foundation, headed by Joe Pugliese, which will be independent of HAGPO. The foundation board will make the decision as to the distribution of funds that HAGPO gives to the foundation to reinvest in the community’s national and local advocacy organizations and HTC’s. Joe Pugliese stated, “The goal is to support operational excellence, helping provide the resources necessary to fulfill the recipient’s mission.” The plan is to utilize staff members from other member organizations for administrative positions, thereby lowering overhead cost. Guidelines will be available soon.

We will keep you posted as to further developments with this organization. For more information please contact Joe Pugliese at (215) 439-7173 or email joe_Pugliese@hotmail.com

National Hemophilia Foundation Walk

Please join the **Factor IX Team** as we walk on Sunday, June 1, 2008 with the National Hemophilia Foundation to raise monies for research. We will meet at Pier 1 at 70th Street, 8:30 am. It is a casual fun walk; you can walk 1 mile or 5 miles. Bring your dog, your friends, neighbors, and grandparents, and have a great time walking!



Each person should get sponsors for the walk and checks should be made payable to:
Hemophilia Walk, The National Hemophilia Foundation
116 West 32nd Street, 11th Floor
New York, New York 10001

When sending checks to the National Hemophilia Foundation, please make a note that funds should go under the Factor IX Team and person's name you are sponsoring.

You can also register and donate online at www.hemophilia.org/walk (our team is listed under Factor IX). Or go directly to website address:
www.active.com/donate/hemophiliaWalkNY/FactorIXTeam.

For more information please contact Kim Phelan at hemob@ix.netcom.com.



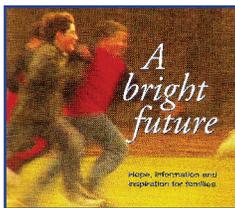
New York City Hemophilia Chapter Event

New York City Hemophilia Chapter, headed by Melissa Penn, mother of a son with Factor VIII, is launching its first event on Sunday, April 13, 2008 at the American Museum of Natural History. The event is for all people with bleeding disorders and their families. It is free of charge and includes museum admission, private tour and lunch. Meet at 10 am, private tour of the dinosaurs, whale room, and dioramas at 11 am, lunch is at noon.

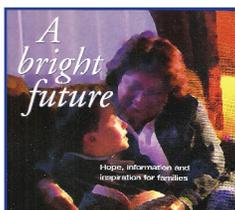
Pre-registration is required. You can also register online at www.nyhemophilia.org. Please call Melissa at 212-877-0280 if you have any questions.

New Inalex DVD in the “A Bright Future” Series Now Available

In 2005, Inalex Communications founder and president, Joe Caronna, conceptualized a series of topic specific DVD's that would offer the bleeding disorder community *“Hope, Information and Inspiration”*. To realize his vision, Joe partnered with a multiple Emmy and Peabody award winning film crew to create Inalex Productions. The result was the first DVD of the *“A Bright Future”* series, titled *“The Hemophilia Diagnosis for the Parent”*. This DVD made its premiere at the 2006 National Hemophilia Foundation's annual meeting in Philadelphia, and was extremely well received and touted as *“A must see for all new parents!”* and *“Will give others hope that they too can master their new life.”*



Inalex Productions is now excited to announce the release of the second DVD in the series titled, *“The Hemophilia Diagnosis for the Extended Family”*. The DVD was premiered at the 2007 National Hemophilia Foundation's annual meeting in Orlando, and once again, was extremely well received by the bleeding disorder community. Some of the comments were, *“This DVD is a professional, sensitive, intelligent, and needed education tool for all family members”*, and *“Inalex has done it again! This DVD points out the importance and the benefits of the extended family involvement...well done !”*



Inalex Productions is currently in pre-production on their third volume in the series, which offers education and support to educators of school aged children with hemophilia. If you would like to receive a complimentary copy of either *“The Hemophilia Diagnosis for the Parents”* and/or *“The Hemophilia Diagnosis for the Extended Family”*, please go to www.inalex.com, click on the “Inalex Productions” button, fill out the form, and submit for immediate delivery. *This DVD series is sponsored by Baxter BioScience.*

Inalex Communications
38 East Ridgewood Avenue, #244
Ridgewood, NJ 07450
201 493-1399
www.inalex.com

FYI: Hemophilia B Online Group

Website address for the Hemophilia B online group:

<http://health.groups.yahoo.com/group/Factor9/>



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Telefax (212)520-8501; E-mail: hemob@ix.netcom.com Website: www.coalitionforhemophiliab.org

Funding for this newsletter is provided by a grant from Wyeth Pharmaceuticals

Factor Nine Family Meeting in May

The Coalition for
Hemophilia B

Factor Nine Family Meeting

Friday, May 2, 2008
5:45 pm - Manning Room
in the Peabody Hotel

Come and eat dinner, meet
your peers, share stories
and information.

New - fun educational game
show!

We look forward to seeing you!

Sponsored by CSL Behring



Held in conjunction with the

Hemophilia Federation of America Annual Symposium

May 1-4, 2008
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