



Factor Nine News

The Coalition for Hemophilia B Spring/Summer 2011

Topics in Hemophilia

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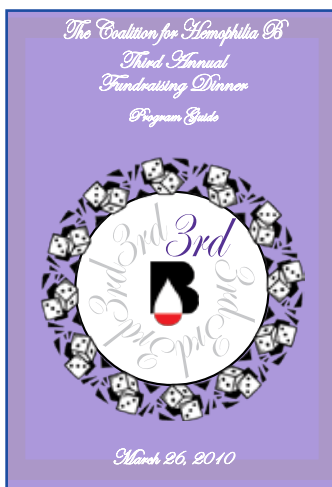
4th Annual Fundraising Dinner

By Kim Phelan

The Coalition for Hemophilia B held its Fourth Annual Fundraising Dinner at the Millennium Broadway hotel in New York on Friday March 4th, 2011. 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.

Cocktail hour included entertainment by the very talented Pianist and Saxophonists, Bill Gati's Jazz Trio, dazzling Magician Henry Hu and leading us into dinner was Bagpiper Joe O'Carroll from the New York Police Department

Dinner began with a warm welcome to our guests by Dr. David Clark, Chairman of The Coalition for Hemophilia B, followed by John Taylor who announced the William N. Drohan Scholarship winners. We were delighted to have Anthony Vetter, one of our scholarship winners, in attendance. Wayne Cook presented Paul Brayshaw with the Eternal Spirit Award for his many years of dedication



and devotion to improving the health and quality of life for many people with hemophilia and their families. Jill Lathrop gave a nice talk about what The Coalition for Hemophilia B means to her and her family. Wonderfully talented entertainment followed when the A Capella singers from ISMILE in NY Productions took the stage as well as Bill Gati's Jazz Trio.



After a delicious dinner, Dr. Dave Clark and his lovely little assistants announced the raffle prize winners. We continued the enjoyable evening at our *Night at the Races* event where everyone had a good time indeed!

The Coalition for Hemophilia B sends a sincere thank you to all of our generous contributors. We hope you will join us again next year at our *Fifth Annual Fundraising Dinner!*

*Photos from the
Forth Annual Fundraising Dinner*



Marie Currim and Mary Bauman



Mike Griffith and Ashley Griffith



McCarthy Family



Van Sant Family



Bagpiper Joe O'Carroll, NYPD



Ashley Griffith, Ewa Sobon, James Buglione and Susan Suliman



John Taylor, Tony Sacco and Leonard Weedman



Jennifer Marlatt and Celeste Schimmels



Michel Dahan, Dr. Glenn Pierce and Paul Brayshaw



Laura (Drohan) Little, John Taylor, Maureen Drohan and Tommy Little



Craig Drohan, Maureen Drohan, Laura Little and Kathleen Drohan



Francis Garcia and Frank Garcia



Tina Hurley and Alvin Luk



Laura Little, Maureen Drohan, Greg Patrick and Keith Arbuckle



Dave and Linda Clark



Baby Santiago Garcia



Nancy Wu and Jean Huie



Wayne Cook and Paul Brayshaw



A wonderful dinner!



*Anthony Vetter, Maria Vetter,
Peaches and Earl Johnson, Jr.*



Bobbie and Jack DeBolt



*Dr. Garrett Bergman, Bob Lefebvre and
Dr. Diane Dimon*



Fundraising Dinner



Acapella Singers



*Jill Lathrop speaks about what the
Coalition means to her and her family*



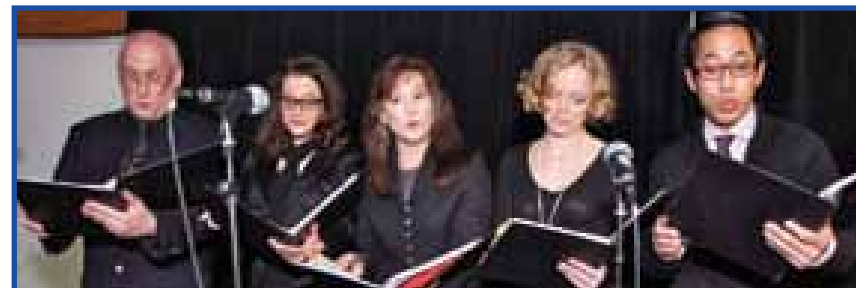
VanSants and Jill Lathrop



*John Taylor, Linda Mugford and
George Agnew*



Fundraising Dinner



Acapella Singers



Kelly and Wayne Cook



*Shannon Cook,
Yolanda and Felix Garcia*



*Hope Woodcock, Deborah Schachter
and Herb Jacobs*



Dr. David Clark



Celebratory Kiss by the Cooks



Mesrobian Family



*Nancy Wu, Liang Shi, Jean Huie, Veronica Zurita,
Kimberly Davis. (Sitting left to right) Tony Sacco,
Leonard Weedman, Funmi Ajao.*



John Taylor



John Taylor and Anthony Vetter



Paul Brayshaw and Wayne Cook



*Elke Albrecht, Billy Greene and
Cristina Scherer*



Caricatures by Steve Nyman



Artist at work



Ryan Tabacchi and Kathleen Drohan



William Gati and Ensemble



Christi Kroupa and Patrick Collins



Children patiently waiting



Amanda and Dave Clark



Emma and Dave Clark



Davis Family



George Agnew, Linda Mugford and Keith Arbuckle



Shannon Cook and Baby Garcia



Sweeney Family



Emma announces Winner!



Ryan Tabacchi, Kathleen Drohan, Craig Drohan, Laura and Tommy Little



Glen Pierce, Bea Pierce, Lee Hall, Larissa Busby, Stephen Gust and Alvin Luk



Carl Weixler, Kate McCoy, Kim Phelan and Amanda Bluebird



Mary Bauman and Amy McGrath



Dr. and Mrs. Garrett Bergman



Gina Monroe and Justin Jackson



We have a winner!



Another Winner!



Amanda announce winner



Diane Pomarzynski and Katelyn Marlatt



The DeBolts and Kim Phelan



Garcia Family



Rachael announces winner



Happy Winners!



What a prize indeed!

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Our
Hemophilia Community 



Find us on [Facebook.com/OurHemophiliaCommunity](https://www.facebook.com/OurHemophiliaCommunity)



Wayne and Kelly Cook



Jared and Neal Schimmels



Maureen Drohan and Greg Patrick



*Leonard Weedman, Timberly Davis,
Nancy Wu and Liang Shiu*



Seriously, how did you do that?



WOW!



*Michael Amrani, Kimberly and Rob
Newland, and Kelly Amrani*



Neal and Celeste Schimmels



Mr. and Mrs. Dan McKinley



Luckey Family



Amrani Family with Rachael Sweeney



Jeffrey Offutt and Angela Bennett



Dr. David Clark and Paul Brayshaw



*Dr. David Clark, Paul Brayshaw and
Wayne Cook*



Paul Brayshaw and Wayne Cook

New Treatments for Hepatitis C

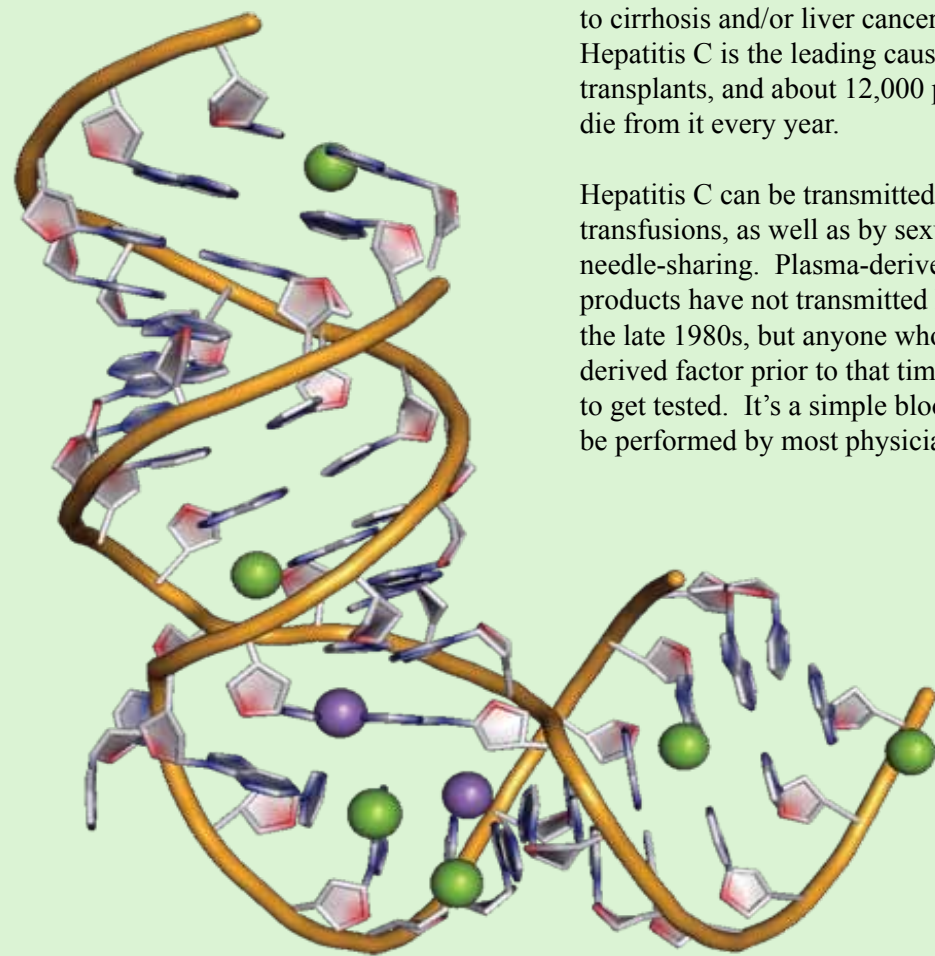
An article in the Summer 2010 issue of Factor IX News described several new treatments that are being developed for hepatitis C. Two of those treatments have been approved by FDA and are now on the market. Both Victrelis (generic name: boceprevir) from Merck and Incivek (generic name: telaprevir) from Vertex are protease inhibitors that block an enzyme that the hepatitis C virus needs to reproduce.

The current treatment for hepatitis C is a 48-week course of interferon and ribavirin that only works in about 50 % of patients.

It also has significant side effects that discourage many patients from completing the treatment. Both new products are still taken with interferon and ribavirin, but the length of treatment is shorter and hopefully more tolerable. The new products are expected to increase the success rate above the current 50 % level.

Many people infected with hepatitis C don't even know they have it because the symptoms can be very mild. The Centers for Disease Control (CDC) estimates that only about one out of four people with hepatitis C are aware that they are infected. However, treatment is important because hepatitis C can lead to cirrhosis and/or liver cancer later in life. Hepatitis C is the leading cause of liver transplants, and about 12,000 people in the U.S. die from it every year.

Hepatitis C can be transmitted by blood transfusions, as well as by sexual contact and needle-sharing. Plasma-derived clotting factor products have not transmitted hepatitis C since the late 1980s, but anyone who used plasma-derived factor prior to that time is encouraged to get tested. It's a simple blood test that can be performed by most physicians. 🇺🇸



Race Gear



A Night at the Races!



Jon Davis "Place your bets!"



Race Night Begins



Earl and Peaches Johnson Jr.



Race Night Betting



Brabon Family



Place your Bets!



Getting Ready



Future Race EmCees



Heading to the Gate



And they're off!!



Dr. Garrett Bergman, James and Patrick Collins



Jill and Ric Lathrop



Smile for the Camera!

FACTOR FORWARD

We are Biogen Idec Hemophilia,

and we're exploring ways to make factor last longer. Backed by 30 years of biotechnology leadership, our goal is to make progress for the hemophilia community. As we blaze a new trail of scientific discovery toward long-lasting factor, we're also creating programs and resources with the potential to change lives. **Join us as we move hemophilia treatment forward.**

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We are currently enrolling patients in our clinical trials.



Jill Twohig, George Agnew, Linda Mugford and Deborah Schachter



Dr. Garrett Bergman and Dr. Glenn Pierce



A Winner!



Serious Betters



Anticipation



Racing Good Times!



Some Winners!



Looks Like James Won!



George Agnew and Linda Mugford



Felix and Yolanda Garcia



Ashley and James... Hardworking!



Full of Pep!



Good Fun!



Phyllis Thompson and Pamela Wilson



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COL14-13-US-11



...and Yolanda WINS!



Henry "The Magician" and Luckey Family



How did he do that?



Kimberly and Rob Newland



Lee Hall and Larissa Busby



Lathrop Family



Do that Again!



Thank you gift bags

5th Annual Symposium

The Coalition for Hemophilia B's **Fifth Annual Symposium** was held on Saturday, March 5th, 2011 at the Millennium Broadway Hotel in New York City. Pfizer Inc. generously funded the educational symposium.

The Symposium began with a warm welcome and opening comment by Wayne Cook, President of the Coalition. Our first speaker was Dr. Anne Hurllett, Pediatric Hematologists at Mt. Sinai School of Medicine in New York City. She spoke about a Review of Hemophilia and where we are now. Dr. Hurllett's speech was very well received and followed with a multitude of questions from symposium participants.

Second on the Agenda was Felix Garcia who has hemophilia B and has been an active advocate for over nine years. His presentation *Hemophilia: A Family Affair* addressed the day-to-day emotional and social challenges faced by families dealing with hemophilia. The talk took you through a holistic view of the role, responsibilities and needs of each member of the family and addressed the topics of why it is important to be a proud member of the hemophilia community; how to feel good about the hemophilia in your family; the father-son relationship and how to play an active role in managing hemophilia in your family.

Following Felix was Dr. Diane Dimon, Founder of the Matters of the Mind, a California based company that teaches a full range of mind/body techniques for stress management, self-awareness and health. Her topic was on *Meditation for Stress and Anxiety*. Her presentation covered the following topics such as self transformation through self-care skills to enhance well-being and peace of mind. The mechanics of stress and the role the mind plays in stress response, the Gate Control Theory of Pain, reframing the context in which acute and chronic pain are experiences and the preference process: Identifying skillful different way to respond rather than react to pain. She guided us through a meditation process to teach us how to quiet our mind. This practice can be used as a tool for people with hemophilia and their family members.

Afterward, everyone enjoyed a lunch and visited the industry exhibit booths on display. Later in the afternoon, we hear from speaker Patrick Collins, Director of Public Affairs for CSL Behring. Patrick is responsible for managing their state government affairs program and has testified before Congress, State legislative committees, state agencies and municipal bodies. He has over sixteen years

experience in public and health policy. Prior to joining CSL, Patrick served as Director of Government Relations for the NHF and played a principal role in the congressional passage and funding of the \$750 million Ricky Ray Hemophilia Relief Trust Fund for those who contracted HIV. He was also a central figure in the creation of the Patient Notification System. Patrick gave a very timely talk on *Insurance Updates* - very much needed in this time of turmoil.

Next up was Howard Unger, Pharmacists for BDRN in New York. Howard's talk was on *Over the Counter Medications: What You Should Know*. Following was Kevin Harris, a nineteen year old student at Sam Houston State University with hemophilia B. He shared his story of growing up with hemophilia. Following Kevin was Hope Woodcock, RN. Hope has been involved with the bleeding disorder community for a number of years and is active in all local chapter and hemophilia camps. She is also the founder of Camp Little Oak for girls with bleeding disorders, carriers and siblings. Her talk was on *Healthy Lifestyle Choices: The Role of Medication Adherence*.

We had breakout session *Peer Groups 12 and under* moderated by Jill Lathrop, *Peer Groups 13 and over* moderated by Wayne Cook and *Woman with Bleeding Disorders* group moderated by Becky VanSant. Following the sessions, we held our Factor Nine Family Meeting. At the meeting we took a moment to congratulate Wayne Cook and his new bride Kelly who were married in December 2010. We toasted with sparkling apple cider, and gave the newlyweds some nice presents and some fun presents as well!

Babysitting was available on the premises for children under age five. The older children were escorted by several adult volunteers to attend Madame Tussauds Wax Museum followed by lunch at the famous John's Pizzeria.

We had one child from out of state with an ear infection that was taken care of immediately by a wonderful doctor in New York and another adult out of state who had a bleed and did not bring enough factor had to go to the hospital. A write-up on his story will follow. It is still amazing after all these years how difficult it is to get treated properly. We do plan to follow up with this hospital to find ways to make things run more smoothly and will let you know the outcome.

A big thank you to our sponsors, exhibitors and speakers for making our Annual Symposium a huge success! 🎉



Susan and Ashley



Kim Phelan and Kelly Amrani



Deborah Schachter



Ron Ricchiuto and Frank Garcia



Kim Phelan and Kasie Cook



Mary Bauman, Regina Monroe, and Amy McGrath



Kirsten Ray, Kim Phelan and Jared Schimmels



Wayne, Kim and Dave



Carl Weixler



Jennifer Marlatt, Carl Weixler and Jill Lathrop



Holly Haskell and Jane Fahgan



Symposium



Anthony Vetter with his mom Maria Vetter



Pete Vento and Nelson Escoto



Wedding gag gifts presented to the cooks by Jill Lathrop

Symposium Attendee Comments

“Our family wants to sincerely thank you and the Coalition for the opportunity to attend the symposium in New York. The conference was very unique, informative and helpful. The genuine outpouring of acceptance, love and mutual bonding was surreal to me. This was truly a very heartfelt rewarding experience that our family will never forget. This has made a positive impact in our lives forever. Thank you again.”

JM - Wisconsin

“We had a blast on our trip to NYC. We are so grateful to you for all your help while we were there too. I sooo appreciate your help with getting our son into the doctor for the ear infection. We really enjoyed meeting Felix and his family and look forward to keeping in touch with them through the Texas group. We were grateful to network with other families and to start networking with them on a regular basis through Facebook. Not sure how we can ever thank you enough for the opportunity to attend the symposium. We would love to attend again in the future! Thank you so much!”

AB - Texas

“I want to thank you for the wonderful trip to New York City. The Symposium was great. It was so awesome to be surrounded by others with hemophilia B. We are usually the odd family out when we attend hemophilia functions. It was also great to meet another family affected by hemophilia B, inhibitors and allergy. We are an even smaller group and need all the support we can get. We enjoyed the educational session and my son enjoyed hanging out with some new teen friends. The food all weekend was fabulous! We cannot thank you enough for such an awesome experience. We are glad to be a part of the Coalition for Hemophilia B family.”

SL - Michigan

“I just want to continue thanking you for giving us the opportunity to participate in the New York Event. We are extremely thankful and blessed to meet you and the Hemophilia B community. It was both rewarding and most memorable experience to share with my family. We liked all the guest speakers. The one that we liked most was Felix Garcia, he sure knew how to tell what it’s like to be a father, son and mentor with hemophilia. The hotel was great. We loved the location. It helped my son with his legs that tend to get tired very easily. The activities for the kids were awesome, that’s how my son describes it. Both my husband and I loved everything. We had a great time and met a lot of new people, who we will continue to be in contact with. My son made a lot of new friends too. He did not want to leave. There wasn’t anything that we did not enjoy. We

always learn something new attending our hemophilia events from the speakers or learning materials, or from the other families we meet. Thank you so very much.”

MB - Arizona

“Thank you so much for giving us the opportunity to attend the symposium. It was my first time really networking with people and I look forward to keeping in touch with them. The support was just wonderful and the speakers were great. I really enjoyed Dr. Hurlett’s talk as the information was so timely as well as Patrick Collins. Such great information and support. We look forward to attending again in the future. Thank you for all you do for our community.”

JS - California

“We had a wonderful time at the conference. I really liked Felix Garcia’s talk and Dr. Dimon’s meditation talk. I thought they were both wonderful and just what I needed. Felix’s talk was very motivational and left behind a good feeling. I liked the idea of seeing each other as a family and his phrase, “Don’t do anything stupid and don’t let anyone else do anything stupid!” It rang true for me regarding hemophilia in all aspects of life! The meditation talk was also quite helpful. Hemophilia certainly adds an extra stress to life which already has plenty, especially since it’s been in our family for a few generations. I loved some of her tips – the breathing techniques and her suggestion to look at life a bit more from afar – i.e., most things in life are not an emergency. Her parables and the idea of how you think about things can cause or reduce stress made sense. I liked her phrase, “Oh well, now where is my breath.” I’ve started to use some of her techniques when giving my son factor and when it comes to sleep. More of these talks would continue to be helpful for us in the future. I was able to speak with a few families and it would be wonderful if somehow there was a way to have an icebreaker or “meet the other families” thing in the morning. The folks at the table were all very friendly as usual and it was great to pick up some great booklets on how to talk to schools. The breakfast and lunch were wonderful. The playroom just fine for my son. Thanks to the teenage volunteers. Thanks for all your hard work and everyone else’s!”

HH - New York

“We cannot thank you all enough. We marvel at how you are able to accomplish everything you do. We find it so beneficial to be able to interact with the other families who are facing similar issues and concerns. Felix gave a very informative, uplifting, as well as entertaining presentation. All the speakers were wonderful as well. Thank you so much for giving us the opportunity to attend.”

JM - Maryland



Wayne with Rachel Sweeney



Wayne and Kelly Cook



Kim Phelan and Anthony Vetter



Cook Family an emotional “Thank you”



Rocky Williams



Dinner Attendees



Sweeney Family



Wayne and Rachael

Thursday Night March 3 2011 New York Dinner

A small gathering was held on Thursday night for some attendees who came in early

A good time was had by all!



Carl Weixler



The boys are back in town!
Carl Weixler, Jared Schimmels, Wayne Cook, Neal Schimmels and Chad Stevens

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“Once again, a great job! The speakers were just wonderful. I enjoyed Hope’s talk on *Adherence* as it is extremely important especially as our children become teens and young adults. Patrick Collins always gives us the most up to date information and for that we are truly grateful. Dr. Hurllett did a wonderful job and we liked the talk by Howard Unger on over the counter medications, which empower. It was nice to hear Kevin share his experiences as well. Your programming for the weekend was superb and so very valuable. I cannot thank you for all you do for our community. Thank you again we look forward to next year!”
CS - Kentucky

“I feel so blessed by the Coalition and we all want to be able to give back as much as possible. My daughter said as we left, ‘it’s like our extended family was all here!’ I love that the kids ‘get’ it!”
BV - Missouri

“Congratulations on your New York Symposium. I thought the event was wonderful, friendly, informal, upbeat, something for everyone, a great location. Nice Job!”
DD - California

“We had a blast and are forever grateful and will try our best not to miss another Coalition symposium!”
EJ - Louisiana

“We had a great time. It looked like it was the most attended conference that I have seen in the five years we’ve been

going. It’s a shame that Dr. Walsh could not be there, but I did really enjoy Dr. Hurllett. I think she did a great job! She really kept the audience involved throughout the entire presentation. Thanks again for all you do for us!”
CD - Maryland

“Thank you Kim, your kindness is the kind of gift the human heart needs...Dear Kim, how can we say thank you? There is no one word that can describe how you and your dedicated staff made us feel welcome. Your Kindness and Love flows with extended arms to welcome us as family and friends. We can see that everything you do comes from a HEART that really have a tender place for others. The kind of work that you do will live on forever. Kim, you are blessed with a gift, a gift that you use to touch people with kindness. We pray that you will have continuous strength to do your good work. We love you!”
T & PT - Michigan

“The NY Symposium is an amazing experience. We live in a small community that is very close. I like to think of this community as my family. Each person that I meet with a bleeding disorder is my brother or sister. We share a connection like no other. We know and understand each other in a way that allows us to connect instantly on a very personal level. It is important that we continue to learn and support each other, and the NY Symposium gives us this opportunity. The symposium brings our family together. Thank you Kim and all of the other people who made this possible.”
RW - Illinois

Wax Museum Visit

During the symposium, children ages six and older were chaperoned to Madame Tussauds wax museum. Afterward they enjoyed lunch at the famous John’s Pizzeria. A fun time was had by all!



Importance of Pharmacokinetics in Prophylactic Treatment of Hemophilia B

By Dr. David Clark

As prophylactic treatment of hemophilia B becomes more common in the U.S., determination of an individual patient's pharmacokinetic responses has become more valuable and more common. Pharmacokinetics (PK) is the study of the movement (kinetics) of pharmaceuticals (pharmaco) in the body. For hemophilia B, it mainly pertains to the changes in factor IX (FIX) levels in the bloodstream after an infusion. A recent article (Haemophilia, 17, 2-10, 2011) by the Pharmacokinetics Expert Working Group of the International Prophylaxis Study Group explored the importance of considering an individual patient's PK for prophylactic treatment.

There are many studies in the medical literature that have looked at the PK of FIX in the "average" person, and the general characteristics are fairly well understood. However, there is a large patient-to-patient variation, so it is valuable to determine a patient's individual PK parameters - few people are actually average. This can help a physician tailor treatment to the individual patient, which can lead to more efficient use of expensive clotting factor, as well as make sure the individual patient is maintaining the necessary factor levels for adequate protection against joint damage.

One of the primary aims of prophylactic treatment is to minimize the low-level bleeding into the joints that leads to joint damage over time. Evidence is accumulating that the amount of time a hemophilia patient on prophylaxis spends with their factor level below the trough level corresponds to increased bleeding risk, and thus potential joint damage. The trough level, the lowest FIX level reached before the next dose of FIX, may be arbitrarily set at 1 %, or preferably, it might be determined for the individual patient. The 1 % level was originally chosen because it is the traditional dividing line between moderate and severe hemophilia, and it is known that people with moderate hemophilia have fewer bleeding issues and often minimal joint damage. However, again this is an average. Some patients may not require that much factor, and some will need even more.

It is fairly well known that recombinant FIX (BeneFIX) has a lower recovery than does plasma-derived FIX. Therefore, patients on BeneFIX need to infuse a larger number of units of FIX to get the same effect. What

has not been appreciated as much is that BeneFIX also generally has a higher clearance rate than plasma-derived FIX. A recent article (Haemophilia, 17, 179-184, 2011) showed that the clearance (CL) for BeneFIX ranges between 7.5 and 9.1 ml/kg-h, while that for plasma-derived FIX ranges between 3.8 and 5.4 ml/kg-h. Clearance is a measure of how fast FIX is removed from the bloodstream, so a larger clearance indicates that the FIX level in the bloodstream drops more quickly. Therefore, patients on prophylaxis with BeneFIX either need to infuse more frequently or infuse larger amounts. Otherwise, they risk dropping below their trough level before their next infusion, and thus risk bleeding or joint damage.

The longer-acting recombinant FIX products coming out in the next few years are potentially beneficial because they have a much longer half-life, which is the same as a much lower clearance. Instead of dosing every two or three days, it may be possible to dose once a week for some patients. However, with longer-acting products it is even more important to measure a patient's individual PK parameters, rather than just assuming the average. With a longer period between infusions, there is the danger of spending more time at risk of joint damage if the FIX level drops below the trough level.

Unfortunately, a PK study is somewhat demanding, requiring a significant commitment by the patient and family and, in some cases an overnight hospital stay. As such, it may also be expensive, and some payers may not recognize that there is a potential to reduce the amount of factor needed or recognize the possible benefit of an improvement in the patient's long term health. Of course, the PK study might also show that the patient actually needs a larger amount of factor, but such patients may already be under-dosing in their regular prophylaxis treatment. That can have an even more detrimental effect on long-term health as well as wasting the patient's efforts in going through frequent infusions that might not be doing as much good as they could.

For hemophilia B, a PK study involves infusing of a dose of factor IX (FIX), and then taking blood samples periodically over a period of about three days. Sometimes it is easiest to do this in a hospital setting, at least for the first few samples. Others might return to the doctor's

office or clinic periodically over the three days for the remaining samples. That might actually be a better way of doing the study since going through everyday life could present a more accurate picture of how much FIX a patient normally uses.

The blood samples show how much of the infused FIX stays up in the bloodstream (recovery) and then how rapidly the FIX blood level decreases with time (clearance or half-life). A study usually starts with a washout period, often five days, during which the patient receives no FIX. This is to get the patient down to a baseline level where the only FIX in the bloodstream is what's made by his or her own body, if any. After the washout, the patient is given an infusion of FIX, with blood samples taken immediately before and immediately after the infusion. Then additional blood samples are taken over time. The FIX levels in the samples are analyzed and used to calculate the patient's PK parameters.


Because of the differences in recovery and clearance between recombinant and plasma-derived products, it is important to do the study with the product that the patient is planning to use. Most plasma-derived products will behave similarly, but different recombinant products could vary greatly—we don't know that yet since there is only one product available. It is also important to take enough samples over a long enough period of time to get accurate results. FIX is different from factor VIII in having a two-phase PK curve. Physicians more familiar with treating hemophilia A might not appreciate that. It is usually recommended that at least seven samples be taken (sometimes five for young children because of the

difficulty of venous access), and that the study extend for at least 72 hours. There are some possible shortcuts using complex statistics that have been developed to study factor VIII in hemophilia A patients, but unfortunately these have not been adequately studied in hemophilia B.

Knowing one's PK parameters is the first step, and using them to set up a prophylactic treatment regimen is the second, but neither of those is useful without adherence to the regimen. Since the amount of time that a patient spends below their trough level corresponds to the extent

of joint damage, skipping or postponing a prophylactic infusion can immediately increase the risk. Although a few patients have shown improved joint scores after being on prophylaxis, in most cases the damage seems to be permanent. Being a few hours late shouldn't cause great anxiety, as long as that doesn't happen too regularly—there should be enough leeway built into the prophylaxis regimen to take care of that. However, delaying a day or more, or regularly skipping infusions is a bad idea. The effectiveness of the next infusion depends on having enough FIX left in the bloodstream from the previous infusion. It's a complex system that depends on precise inputs of factor. Adherence is key!

The appearance of recombinant FIX with

its different PK behaviors has placed more importance than ever on measuring an individual's personal PK parameters and using that information to tailor a prophylactic treatment regimen. As more recombinant products come to market this need will only increase. PK studies will likely become a routine part of hemophilia treatment, and that should even further improve the long term health of patients with hemophilia. 





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A Mom's Perspective

By Lisa Schoenfeld

As if sending your child to preschool for the first time isn't intimidating enough, does adding hemophilia to the mix need to make it scarier? This story is the recent experience of one family who found their answer.


If you're a family with toddlers, perhaps you've done some early childhood separation classes, if only for a few hours. Pondering preschool, as early as the age of 3, the road ahead now looks to be filled with longer, or in some instances, full school days. Combine this with the prospect of meeting new teachers/caretakers, and perhaps being in an entirely new classroom setting. And, did I mention, hemophilia?

Just thinking of corners without safety cushions, hardwood floors, not to mention a dozen of other toddlers, all under questionable supervision... These were all of the thoughts that raced through my mind in contemplating whether or not to send my twin sons, both of whom have severe hemophilia B, to preschool for the first time.



From day one, our motto became "educate, don't alarm". We researched various websites, gathered handouts we received from our HTC and conferences, and looked for what seemed to be the most concise and clear (and not scary!) in terms of defining hemophilia. We filled out the school's emergency contact card, along with a customized one related to hemophilia. We set up an

appointment with the director and the classroom teacher prior to the start of the school year, knowing that being proactive is more beneficial than reactive. While the school staff may have seemed taken aback during our initial conversation, it was more because they hadn't heard the term hemophilia in quite some time. Once we spoke and covered the facts (a paper cut cannot kill anybody!), no one seemed uneasy. Most importantly, we went over the steps to take if one of our children got hurt. Secondly, we described what to look for in a bleed. After that, we put the responsibility on us, left them with paperwork to read at their leisure, and let them know we were available to talk and answer questions at any point. We did advise them to share the literature with appropriate faculty, and only to utilize the resources that we provide.


It's now the end of the school year, and the boys are indeed little school children. So much, that when I come home from my school, ready to finally take my teacher hat off, all they want to do is "play school". I'm bossed from music class to the gym, forced to wait in line, and raise my hand. It's obvious they were ready for this next step. I'm thankful we never let hemophilia hold us back. 

Obviously, the kind of treatment regimen your child is on does play an important role. Much of my confidence comes from the fact that my boys, now three and a half, are treated preventively two times a week. That being said, we feel

pretty secure about their factor levels throughout the week in regards to their level of activity, which by the way, never stops.

When the boys started preschool right before they turned three, we had a hard time picturing these little beings becoming school children. We had an even harder time imagining that they would last for several hours, five days a week. These were the initial thoughts we contemplated about preschool, much like everyone else in our neighborhood with children of this age. Also for consideration, there's the elephant in the room, hemophilia.

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Wayne and Kelly were married in their home on December 12, 2010

We wish them the best of happiness!

Congratulations!



It Takes a Village

Dr. Bartholomew Tortella,
MTS, MD, MBA, FACS, FCCM

Growing up our parents took responsibility for helping us do the things we needed to do, all in an effort to make us better and to keep us safe. *“Don’t forget to brush your teeth,” “Look both ways before crossing,”* I can still hear Momma Tortella’s voice. This is one way to consider adherence. The World Health Organization defines adherence as *“The extent to which a person’s behavior – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider.”*

responsibility ourselves.

Adherence to a medical treatment program can be challenging. Life presents us with many demands, often several at a time. You are not alone though, and family members, friends and the medical team at your HTC are all there to help. Each of us has the ability and the responsibility to take control of our lives. This is especially important for those with hemophilia where adherence may pay true dividends by better controlling your disease and allowing you to do more of the things that are important to you.

This statement gives the perspective that adherence touches many parts of life outside of simply taking medicine (Factor) such as diet, exercise, and lifestyle. All of these may, combined together, place each of us in a better position for success which is, after all, what every parent wants for their child. At some point, however, we must take on that

Improving adherence to your prescribed treatment plan begins with focusing on your wellness, setting meaningful goals for your treatment along with your care team, and finding ways to overcome day-to-day challenges. Whatever it takes, it is well worth the effort so work with those around you and get to it! 🍀

The Coalition for Hemophilia B Survey will be coming soon!



Your participation is so important as it helps us meet your needs and helps our community see trends which will inform and empower you all. Please be on the lookout for the survey and make time to fill it out.

We’re “counting” on you!

The Coalition for Hemophilia B Lotto forms will be available soon!



A drawing will be held to attend the Coalition’s New York Symposium in March 2012. Winners will receive airfare and hotel for their family to attend our Friday night fundraising dinner, Saturday Symposium and dinner. Lotto forms will be sent to our members in October. Winners will be notified December 19, 2011.

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During our March 5th 2011 New York Symposium, we had a member attend from out-of-state. He had a bleed and did not bring enough factor with him. We thought we would share with you what he endured when he had to go to a New York Hospital. It is still amazing today that Emergency Rooms have only slightly improved over the past several years. The Coalition for Hemophilia B does plan to visit this hospital to find out how we can make things move more quickly and we will let you know the results in our next newsletter.

My New York Emergency Room Experience

Time 11:06 AM

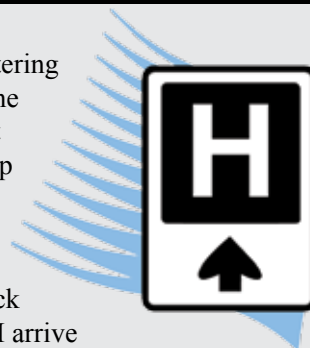
I just passed the N Sync figures and was entering the Wizard of Oz exhibit when my cell phone rang. The call was about someone from out of town that had hemophilia and had used up all their factor treating an ankle bleed. The question for me was if I could breakaway from the group and help with taking the patient to an ER. I said sure and headed back to the hotel to find out what was going on. I arrive and meet up with two advocates and two HTC nurses. One of the two nurses was trying to contact the ER to forewarn that a person with hemophilia with an ankle bleed was on the way (I later found out that she never reached anyone because the hospital never picked up). The other nurse was explaining some of the related details to me. After a few minutes, I was introduced to the patient. After a quick verification that the patient had his Medic Alert card and insurance card, we were off in a cab to the ER.

Time 11:42 AM

Upon arrival, we were directed to the ER. We walked up to the receptionist and I explained that the patient had hemophilia with an active ankle bleed and that this particular hospital had an HTC and that he needed to be treated with replacement clotting factor ASAP. She handed the patient a form on a clipboard to be filled out. On the triage form, the patient explained the current medical situation and that the hospital's hemophilia treatment center should be contacted. After the completed form was handed to the receptionist, she told the patient to wait for the triage nurse.

Time: 12:12 PM

The triage nurse called the patient in for an assessment. "Not bad," I thought after checking my watch. It had only been 30 minutes. The patient proceeded into the triage office and I stayed back for privacy reasons since I had just met the patient only an hour



ago. The patient made it out of triage back to the waiting area and said that he was told because of the hemophilia and the active ankle, bleed everything would be "fast-tracked".

Time 1:22 PM

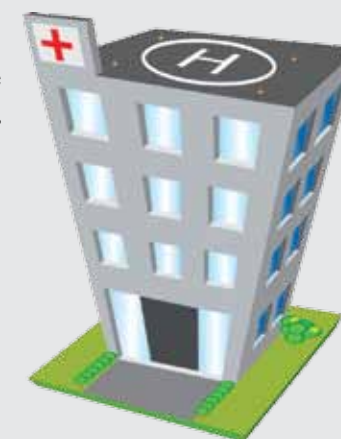
I received a text from the advocates back at the hotel asking how it was going and I replied that the patient was waiting to be seen but was being "fast-tracked" because of the hemophilia and the active ankle bleed.

Time approx 1:30 PM

The patient was called and then disappeared into the ER. I stayed back so the patient would have privacy. I looked at my watch and thought "not too bad, approx two hours and the patient is being seen in the ER. Factor will be infused in an hour or so and we'll be back to the hotel to catch the last presentation." So I just waited, answered some text messages, people watched and pondered what might be happening behind that combination-locked ER door. After several trips to the coffee machine and a few hours later, I received another text message at 4:10 PM.

Time 4:10 PM

The text message read: "How are you two doing?" I sent a text message back: "I'll go find out."



Time 4:12 PM

I said to the ER receptionist, "I came here with someone and they went into the ER at 1:30 PM and I need to know their status." She checked the name and told me the patient was in ER Section A, in the hallway on a bed. Ok, I thought, then she hit some keys on the combination lock and I too entered the ER abyss. When I made it into the ER, I walked down the first hall looking around, peeking in a few exam rooms hoping to recognize the patient. I turned the corner and walked down

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the hall on the other side of the nursing stations to no avail. So I went to one of nursing stations and asked for assistance. I was told the same location... "one of the hallways in Section A, on a bed." I took another stroll down the same route, but this time I noticed an empty bed with a sneaker on it. I immediately looked around for the patient, rest rooms and possible exits hoping nothing bad had happened to the patient. I decided to just stay put with the sneaker and hope for a safe return. The nurse from earlier walked by and asked if I had found the patient. I replied, "Well all I found was this sneaker on an empty bed and I think it's the patient's sneaker."

She said that she would go find out the patient's whereabouts. She came back and said the that patient had gone for a test. So I just waited and after awhile the patient showed up. I asked if there had been an infusion yet. The patient advised that a CT scan was just done. I said, "For your ankle?"

"No, for my head." The patient went on to explain that they wanted to make sure that there wasn't any internal head bleeding happening.

"Ok did you get infused yet?" I asked again. The patient said "no" but that an attendee and a hematologist had stopped by to discuss what was going on with the hemophilia and ankle bleed.

Time 4:41 PM

My phone died and soon after a nurse came by to insert a saline-lock in the patient's forearm so a blood sample could be drawn for a factor level test. Not long after, the blood was drawn and the patient reminded the nurse that we had been there since noon and only needed factor infused for an ankle bleed. It fell on deaf ears. At this point, I thought, "What good did it do for the patient to carry a Medic Alert Card if it was just going to be ignored?" Shortly after, the patient was wheeled away for an ankle x-ray.

Time 6:00 PM

While waiting for the patient to return, I watched a young lady with a video camera follow the ER doctors around taping all the chaos that was unfolding as the ER started to quickly fill up.

Time 7:00 PM

The patient finally returned from x-ray looking very tired. Then a nurse came by and said that the hematologist would be talking with us soon. Meanwhile, a shift change occurred and a new gaggle of staff appeared.



Time 7:30 PM

The new ER nurse introduced herself and said that she was taking over. She said the hematologist would be by to speak with us and depending on what she said, clotting factor would be ordered. Meanwhile, an attendee stopped by with the camera woman and a group of medical students. The camera woman interviewed the patient while the doctor explains that the patient has hemophilia and was being treated for an ankle bleed. After the patient had finished being interviewed, I told the attending doc that this hospital had a world class HTC. He paused and asked me what an HTC was. "I replied "Hemophilia Treatment Center." He looked at me and didn't say anything like I had just shared some useless

trivia with him. Soon after, another doctor stopped by and suggested that the patient should be admitted for overnight observation. That is when we both said, "No way, just get some factor and do an infusion. That is the only reason that we are here. If we hadn't run out of factor, we would have done an infusion at the hotel and would have never gone to an ER." The doctor seemed to understand and walked away.

Time 8:00 PM

When the camera woman finished filming another ER soul in a room across from the patient's bed, I asked her if we were going to be on TV or in a documentary. She explained that she worked for ABC TV and if we had heard of a show called "Boston Med." The patient said he flipped past it on TV once. I said it sounded familiar. She said that they were doing something similar in this ER. I thought to myself, "Great, there was time for a patient to be interviewed for a television show, but it has been eight hours since arriving at the ER and the patient still hasn't received any factor."

Time 8:30 PM

Finally, the hematologist advises the nurse to call the blood bank and order factor. That is when the patient says loudly, "Well, I have only been here since noon and now its 8:30 PM." The nurse replied that patient's hematologist from home should have been asked to fax an order to the ER when we first arrived. All I thought was, "Really?"

Time approx. 9:50 PM

The factor arrived and the nurse had the patient mix the factor after another nurse checked the order for accuracy. She infuses the patient and removes the saline-lock.

Time 10:20 PM

The patient is discharged and we are in a cab headed back to the hotel.

Time 10:45 PM

Finally, we arrive back at the hotel. 🍷

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The First Written Account of Hemophilia in America

In the January 2011 issue of the journal *Haemophilia* the following obituary was identified as the first known written account of hemophilia in America. It was from the February 16, 1791 edition of the *Virginia Gazette* and the *Winchester Advertiser* in Winchester, Virginia. Note the indication that the mother (the father's first wife) was probably a carrier. The condition was not identified as hemophilia at the time.

Remarkable Instances of Persons Bleeding to Death.

On Tuesday the first, died, near the North-Mountain, Frederick County, Isaac Zoll, aged 19 years. His death was occasioned by a slight cut in one of his feet with an axe. From the time of his receiving the wound, until he expired, no method could be devised to stop the bleeding—if the wound was bound up, the blood gushed out at his mouth or nostrils. Five brothers to the above person have bled to death at different periods, from the following simple accidents—one received a prick with a thorn—another, a scratch with a comb—a third, a prick with a needle—a fourth, bruised his cheek against a stove—and the fifth received a cut in one of his thumbs. The father of the above persons has had two wives, and, by each of them several children; those who died in this singular manner were all by the first wife. It should be noted, that when they arrived at a certain age, several black spots were discernable upon their bodies. However marvelous this account may appear, our readers may rely upon its authenticity.

Dealing with an Inhibitor... One Mom's Story

By Shari Luckey

Having had an older brother with hemophilia B, who passed away, shortly before Jay was born, we were prepared when our infant son was diagnosed with severe hemophilia B, just hours after he was born. We anticipated that life would be fairly "normal" for our son.

The first eleven months of Jay's life, we were on track and had no unusual incidents. Then Jay had his first bleed, and to our horror, it was a head bleed. He ended up having emergency surgery, large doses of factor IX and was hospitalized for over two weeks. Because of the head bleed, our physician had us continue to dose him daily for about a month.

Jay began to show signs of having an allergic reaction to factor IX and shortly after he was diagnosed with an Inhibitor. Our life, as we knew it, immediately changed. We could no longer use medication that could replace his missing clotting factor, if he had a bleed. Fortunately, there was a new bypassing product in trials that we were given special permission to use, when Jay had a life or limb threatening bleed.


Since then, it has been a rollercoaster of highs and lows, challenges and successes, disappointments and accomplishments. Before our bypassing product was FDA approved in 2000, we spent a lot of time with Jay being admitted to the hospital. For 5 years, anytime he had a bleed, he was admitted, and we were not allowed to have or administer the product at home. We were unable to travel outside of our hometown, because we could only get his medication at a few local treatment centers, and it was too risky to be away from them.

We are grateful for having access to medication now, but because of the short half life, we are unable to treat on a prophylactic basis. Due to this, Jay has extensive joint damage and has had to have several surgeries on his left knee and several radiosynovectomies on his elbows and ankles.

The cost of the medication is many times per unit more expensive than typical factor replacement therapy. This has resulted in series health insurance issues for our family. We have gone through five million dollar life time caps in as short as nine months. When our son had surgery several years ago, we had to change jobs to secure new health insurance and currently have a costly private plan, as we have capped out on every insurance plan available in our area.



Other than his hemophilia, Jay is a typical and exceptional teenager. At 17, he is getting ready to start a full college class load this fall at Eastern Michigan University, while finishing his senior year in high school. He loves reading, video games, and hanging out with friends. Jay has been a camper at Camp Bold Eagle in Michigan, for 10 years, and just completed his first year as a CIT (counselor in training). This past May, Jay enjoyed a trip to New York with our church to participate in a mission trip at the Bowery Mission. He loved the experience and hopes to go back again next year.

Even though Jay is such a great kid, there are still challenges and fears raising a son with an inhibitor, include the constant worry about his joint health. At 17 years old, he already needs a knee replacement. We are trying to wait until he is done growing, so that it doesn't affect the length of his legs. We worry about the high costs associated with his condition. Will he be able to get a job with decent insurance? Will he be able to keep his job, or will he be fired for missing work due to bleeds? We hope and pray that as time moves forward, these issues will be resolved, where Jay doesn't have the constant worry about health insurance, that we have had for the past 17 years. 

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Factor Nine Holiday Fund 2011!

The Coalition for Hemophilia B understands that there are families within our bleeding disorder community who are feeling the effects of the current economic situation. We thought it would be a nice idea to ask our more fortunate Factor Nine Families to make a financial donation to the **Factor Nine Holiday Fund** to help buy gifts for children with hemophilia this holiday season.

(The Coalition for Hemophilia B will also contribute to this fund.)

If you wish to make a donation, please send a check payable to:

The Coalition for Hemophilia B "Holiday Fund"
825 Third Avenue, Suite 226; New York, New York 10022

Please respond by *December 3, 2011* so that the Factor Nine Santa can load his sleigh with holiday gifts for all good boys and girls! 100% of your donation will be used to put a smile on a child's face.

We wish everyone a wonderful holiday season filled with love, happiness and good health!



For those families in our community in need of a little *Holiday Cheer*, we would like to help put something under the tree for your children! Just fill out this form and send it to Santa's special elf, Kim at the "East" Pole. Since the Factor Nine Santa has such a busy schedule, please send it to us **no later than December 3, 2011.**

(Your name and information will be kept *strictly* confidential.)

Send this form to: The Coalition for Hemophilia B Holiday Cheer
Attention: Special Elf Kim
825 Third Avenue, Suite 226
New York, New York 10022

Name: _____ Phone: _____

Address: _____

Please give us an exact description of the item your child is wishing for.
If we have any questions, we will contact you directly.
Holiday gifts will be purchased by The Coalition and sent to your home.

Child's Name and Age:

Child's Name and Age:

Child's Name and Age:

Wish List:

Wish List:

Wish List:

Save the Date!

National Hemophilia Foundation 63rd Annual Meeting

November 10-12, 2011 Chicago, Illinois

The Coalition for Hemophilia B Fall Family Meeting

Visit the Coalition for Hemophilia B Booth
for information regarding the Factor Nine Family Meeting.

In conjunction with the NHF Annual Meeting
Hyatt Regency Chicago - 151 East Wacker Drive; Chicago, Illinois

We look forward to seeing you!



Northern Ohio Hemophilia Foundation Conference

October 21-22, 2011 Independence Ohio

The Coalition for Hemophilia B Family Meeting

Visit the Coalition for Hemophilia B Booth for time and location information.

In conjunction with the Northern Ohio Hemophilia Foundation Conference
Embassy Suites - 5800 Rockside Woods Boulevard, Independence, Ohio

Please join us!



Factor Nine Family meeting held in conjunction with HFA's conference in
Louisville Kentucky in April 2011.

Our sincere thanks to Carl Weixler and the Schimmels Family for helping us this year!

Reminder

The Factor Nine Group moderated by Jill Lathrop is now located on Facebook search Hemophilia B Group

For back issues of **Factor Nine Newsletter** or for more information on research, please call or write to:
Kim Phelan; 825 Third Avenue, Suite 226; New York, New York 10022; Telephone (212) 520-8272
Telefax (212)520-8501; E-mail: hemob@ix.netcom.com Website: www.coalitionforhemophiliab.org