



Factor Nine News

The Coalition for Hemophilia B Spring 2010

Topics in Hemophilia

- CHB Third Annual Fundraising Dinner
- CHB Fourth Annual Symposium
- Pfizer Lifelines Ambassador Program
- Gene Therapy Update
- In Memory of Jim Brown
- Inalex Communications
- Grifols
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3rd Annual Fundraising Dinner



*Dr. David Clark,
CHB Chairman*

The Coalition for Hemophilia B held its *Third Annual Fundraising Dinner* at the Millennium Broadway Hotel in New York on Friday, March 26th, 2010. Attendees included the families that won the Lottery Trip, which we flew in for the symposium, industry people and private donors. Funds raised will benefit our Educational Programs and the William N. Drohan Scholarship Fund.

Cocktail hour included entertainment by Jazz Saxophonist Stephen Dryefuss, a dazzling Magician, and leading us all into dinner, was Andy McEvoy playing the bagpipes.


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 winners of the William N. Drohan Scholarship.

During a truly heartwarming moment, Wayne Cook presented John Taylor with a \$2,000 check towards the

scholarship fund as it was one of Maureen Cook's wishes.

Wonderfully talented entertainment followed with David Schaefer on the piano and Tenor Vincent Ricciardi singing. Following their performance, the A Capella Singers from ISMILE in NY Productions took the stage. We also had a delightful surprise as John Taylor III gave us a special piano performance of his own composition, a "Nocturine."

After a delicious dinner, we continued the enjoyable evening at our Casino Night 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 Fourth Annual Fundraising Dinner! 



*Photos from the
Third Annual
Fundraising Dinner*



Kasie and Shannon Cook

Maya Petrova and Kevin McDonald



*Ron and Tyler Ricchiuto
and Deb Schachter*

Wayne Cook

Robau Family



*Dr. and Mrs. Glenn Pierce
and Scott Martin*

Magician and Deb Schachter

Nick and Matt Amrani ready to work



Wayne Cook and Amy MacBeth



Cleary Family



Linda and David Clark



*Laura Droha-Little,
Christina and Tommy Little*



*Craig Drohan, Christina,
Tommy and Laura Little*



Carl Wexler



Joanny Santana and Richard Rosado



McDowell Family



Joyce Hewitt and Lynne Capretto



Cannon Family



*Dr. & Mrs. Glenn Pierce, Scott and
Kim Martin with son, Scott Jr.*



*Pam Williams, Jill Twohig, Ted and
Rob Newland*



Mary Bauman and Michel Dahan



George and Bridget Fujioka



Scalfani Family



Magician with Children



Magician continues to WOW them



Kate McCoy, Wayne Cook, and Jess Swann



Bridget and George Fujioka, Eugenia Arnov, Billy Greene, Tony Sacco, Joanny Santana and Richard Rosado



Alexander and Alex Robau



Kirsten, Leslie and Amy Hunter



Elke Albrecht, Cristina Scherer, Eugenia Arnov and Billy Greene



Scott Martin, Alison Arter, Michel Dahan, and Mary Bauman



Lachandra Jones



Bert Horowitz and Marie Currim



Andy McEvoy on the bagpipes



Andy McEvoy entertains the guests





Colleen Ross, Rob and Ted Newland



Schimmels Family and friend, Brandon



Jean Ryan and Mark Cleary



Kevin McDonald



Jurg Sommer



Craig Drohan and Christina Little



*Dr. David Clark,
Chairman*



John R. Taylor, Jr.



Wayne Cook and John Taylor



Wayne presents check to John



*Wayne and John embrace in a
heartwarming moment*



Wayne Cook and John Taylor



David Schaefer



Patrick Torrey



Kirsten Rutherford



Shenikay Jones



Vincent Ricciardi



Vincent Ricciardi



Stephen Dreyfuss



Jessica Taylor and Joshua Williams



Amrani Family, Kim Phelan, Joyce and John Taylor III and Lisa Mittman



Amanda and Michael Amrani



Dr. Marie Mann and Dr. Christopher Walsh



John Taylor III



A Capella Singers



John Taylor III



Bernice Torrogrossa and Dan Bond



Kathleen, Maureen Drohan, Christina Little and Laura Drohan-Little



Stephen Dreyfuss



Bob Ginsberg



Jonathan Clark



Scott Martin, Jr. Picks 1st Raffle Winner



Zach Ross picks 2nd Raffle Winner



The game is on!



Casino Night!





Neubauers are ready to play



*Ray Liu, Mike Amrani,
and Dr. Chris Walsh*



Serious thinking going on

Kids having fun!



Scott Martin, Jr.



Caricature time





Mario the Magician at the Symposium



Amanda the Assistant



Scott helps next



Nat's on board



Mario shows his magic bird



Mario's Magic Bird



Mars 2112 Dinner Saturday night



Carl and the Alien



Carl Wexler

Fourth Annual Symposium

The Coalition for Hemophilia B's Fourth Annual Symposium was held on Saturday, March 27th, 2010 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. Christopher Walsh, head of the hemophilia treatment center program at Mt. Sinai Hospital in New York City. Dr. Walsh spoke about hemophilia updates for 2010. His speech followed with a multitude of questions from symposium participants.


Second on the Agenda was Michael Bradley of Baxter Bioscience in California where he is the Vice President of Healthcare Economics and Reimbursement. Mike's talk was about Insurance updates and transitions. After his talk, he welcomed lively discussion and debate from the audience. Our next speaker was Ben Shuldiner, founder and principal of the High School for Public Service in Brooklyn, New York. Ben also has severe hemophilia B. His speech was called "Living with Hemophilia." Ben is a true role model for everyone living with hemophilia.

Afterward everyone enjoyed a lunch and visited the industry

exhibit booths on display. Later in the afternoon, we heard from speaker Patrick Torrey from Physis Inc. in Oregon. His topic was "Perceiving the Possible: Tools to help us grow towards our boundless potential."

Patrick has been designing and delivering innovative education programs and training for over ten years. He challenges and inspires people to explore outside of their perceived limits in the course of striving for excellence in their lives. Well we do not want to give away Patrick's secrets so we will just say that Patrick truly does inspire us and this was truly an eye awakening experience. It was well received by all.

Following Patrick's talk we took a break, visited the exhibit booths and then held our Breakout sessions which included Living with Inhibitors run by Joyce Hewitt, Peer to Peer Groups for 13 and over moderated by Wayne Cook and Peer to Peer Groups 12 and under moderated by Jill Lathrop. Our Factor Nine Family meeting was held and we played the game "Are You Smarter Than Your Hemophilia?"

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

Symposium Attendee Comments

"The speakers were excellent as always! My favorite is Dr. Walsh, I love the job he does. He breaks everything down for us and makes it all so understandable. Ben was great, even having heard him once before, I still enjoyed it just as much the second time. I thought his message was great especially since you had such a big teenage turnout this year. Pat Torrey was excellent as well. Everyone was awesome – no kidding! I appreciate the fact that you have the babysitting for us so that we can really enjoy and get the most out of the day. Shannon and Kasie were awesome as usual." N. S. – Alabama

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"Thanks for everything that you and Wayne do for us. Kim you do an incredible job every year...you should be very proud of your accomplishment. You made a special weekend for all that attended. This is usually the only time I get to mix with individuals/families with hemophilia. I enjoy seeing the folks I met at earlier meetings and seeing how the kids have grown and how well adjusted they are with their situations. On the other hand it breaks my heart when I speak with families with complications and it makes you thankful for what you are dealing with as someone unfortunately always has it a little more difficult than you do. That is why these events are important on so many levels. So thank you Kim for being such a caring and thoughtful individual, it is you that makes this wonderful weekend such a success each year! I also want to mention what giving girls Shannon and Kasie are...each year they attend and do what they do for the kids and it might go unnoticed by some. I want to make sure we thank them too!" M. S. – New York

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"Kyle and I had a great time at the Symposium. I believe my son is at the age where he has to take an active part in dealing with his hemophilia. He came readily to the lectures and I questioned him on what he got out of them. He seems to understand that there will be breakthroughs (from Dr. Chris Walsh's talk) in the future regarding his factor and he was inspired by the presentation made by Ben Shuldiner and how important it is to give back to society. The vendors were pleasant and informative. They gave me information that is useful. Thank you so much for inviting us and all you have done for our family." B. G. – New York

Symposium Attendee Comments, continued...

“All of the speakers were informative and gave excellent presentations. Dr Walsh’s information was very useful to me. I don’t get that at my clinic. I knew Mike Bradley would be in trouble with questions about “healthcare reform” but he handled it well. I could have listened to Ben Shuldiner for more than his allotted time! Patrick Torrey was very energetic. I liked both his topic and presentation. Having worked with both the adventure tower and zip line at Victory Junction Gang Camp. I was right there with him. Babysitting activities were beyond excellent! My daughter had a great time. She is usually very shy but not with this group. They made her feel right at home.”

M. C. – North Carolina

“I just wanted to let you know what a tremendous job you did with the Coalition event. It went off without a hitch! Every detail was attended to and each person was so well taken care of. I know how much work goes into a large event like this and I just can’t believe you had a smile on your face the whole time! It is amazing to see how this event has grown from a smaller meeting, to the comprehensive well-attended and highly anticipated event that it is today. On behalf of my family, I sincerely thank you for having us.” **C. R. – Virginia**

“We enjoyed the speakers. The most fun was the “comfort zone” with Patrick Torrey. I also enjoyed the information on new products by Chris Walsh and the talk by Ben Shuldiner. He truly has lived through a lot. The “Are you Smarter Than Your Hemophilia” game was fun too. Thanks to everyone for making the weekend so wonderful!”

D. C. – Arkansas

“Excellent Speakers! The kids even enjoyed it and stated it was the first conference they attended where they were not bored with the topics and where the speakers were engaging and interactive. Loved your choices! You all did an awesome job and the weekend appeared to go without any problems. We all learned a lot in the sessions. The kids met new people too! Thanks, we are grateful.” **P. W. – Ohio**

“My boys and I had a great weekend. The speakers were excellent and provided a good variety of topics. The boys enjoyed playing Are You Smarter Than Your Hemophilia. It was fun and educational! Thank you so much for sending our family. It was truly a wonderful opportunity for my boys. We are very gracious.”

B. N. – North Dakota

“I enjoyed all the speakers that were present, especially Ben. My son had fun with the child activities. He said the magician was good. It was wonderful to see everyone. My son had a blast seeing old friends and making new ones and so did I.” **J. L. – Illinois**

“We had a wonderful time meeting new people and learning about new things happening in the Hemophilia B community. I felt the speakers at the symposium were very informative. My kids really like to hear Ben speak. I think it helps them to put their own situations in perspective. All in all, I want to thank the Coalition for the opportunity to attend the event. I truly appreciate the effort to bring us all together and learn more about hemophilia B and how to best manage the ‘big picture.’ Our family is very grateful for all that you do!” **L. C. – Massachusetts**

“Good Speakers! I thought all had some good topics and were interesting. It was great to see some old faces and meet some new ones.” **A. M. – California**

“I loved the speakers - they had important topics well covered. My kids enjoyed the babysitting and teen activities. Wonderful supervisors. The entire experience was fantastic for our entire family. Thank you Kim and Jean for all your planning effort and handling all the extra details.” **M. K. – Wisconsin**

“We want to thank you all and Kim personally for the invitation and for all the kind attention we received. We really appreciate the opportunity since we got to get together with some families and people that shared with us their own experience. The speakers were wonderful and enlightening. We look forward to seeing you all again next year!”

A. R. – New York

“Jerry, John and I so enjoyed being invited to attend the Hemophilia B Symposium in New York. It was really gratifying to meet new members of our community who experienced interest in the memorial and we were made to feel so welcome by everyone. Thank you for giving us this opportunity. We look forward to future meetings.”

M. Murphy, Historical Hemophilia HIV/AIDS Memorial Committee



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Share Your Story

The Lifelines™ Ambassadors Program sponsored by Pfizer, the maker of BeneFIX® Coagulation Factor IX (Recombinant), is inviting those impacted by hemophilia B to share their disease and treatment experiences. The Lifelines Ambassadors Program is a voluntary nationwide network of people impacted by hemophilia A or B, who are willing to talk about their experiences, challenges, and perspectives relating to their disease and treatment with Pfizer factor replacement products for hemophilia.

Ambassadors may be asked to participate in a variety of local and national activities based on their interest and availability. For example, Ambassadors could be invited to talk to reporters about living with hemophilia; share their story with Pfizer employees; be featured in marketing materials; or, provide feedback on educational materials with other families.

If you currently have hemophilia, or care for someone that does, and are using a Pfizer replacement product and would like to find out more about the Lifelines Ambassadors Program, please call 1-877-360-4366 or e-mail info@lifelinesambassador.com.



What Is BeneFIX?

BeneFIX is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease.

BeneFIX is NOT used to treat hemophilia A.

Important Safety Information for BeneFIX

- BeneFIX is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if your bleeding is not controlled after using BeneFIX.
- Allergic reactions may occur with BeneFIX. Call your health care provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash or hives.
- Your body can make antibodies, called “inhibitors,” which may interfere with the effectiveness of BeneFIX.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFIX is given by continuous infusion, BeneFIX may increase the risk of abnormal blood clots. The safety and efficacy of BeneFIX administration by continuous infusion have not been established.
- Some common side effects of BeneFIX are nausea, injection site reaction, injection site pain, headache, dizziness and rash.

Please see the full Prescribing Information included with this newsletter.

Update on Gene Therapy for Hemophilia B

By Dr. David Clark

Gene therapy has often been called a potential cure for hemophilia B and other genetic diseases. Hemophilia B is caused by a defective or missing gene for factor IX, one of the proteins in the blood's clotting system. Without functional factor IX protein molecules in the blood, the clotting process stops at the factor IX step, and can't go on to produce a clot. The aim of gene therapy is to replace or repair the defective gene.

The traditional approach to gene therapy for hemophilia B has been to introduce normal copies of the factor IX gene into specific cells in the body that can then produce normal factor IX molecules and excrete them into the bloodstream. The idea seemed so simple in the 1990s that NHF set a goal of "curing" hemophilia by the end of the century. As we know now, a decade into the next century, it didn't quite work out that easily. However, one thing about science is that you often learn more when things don't work than when they do. As we'll discuss below, new approaches have been developed to address some of the old problems, and a new gene therapy trial is currently underway.

The traditional approach is now called gene addition therapy, because other methods of gene therapy have been developed. Techniques are being developed to actually repair defective genes rather than replace them with new ones. This is called gene correction therapy or gene repair therapy. Later in this article we'll describe a possible new approach for gene repair using proteins called zinc fingers.

One of the most popular approaches for gene addition therapy is to use a virus to deliver a new gene to certain cells in the body. That's exactly what viruses do. A

virus is a small group of genes inside a coating made of proteins. The proteins in the coating allow a virus to attach to itself to specific kinds of cells and then inject its genes into the cells.

The cell then starts making the proteins encoded by the viral genes, usually including making more viruses. Using genetic engineering techniques, scientists can

include a gene like factor IX in a virus, and take out harmful genes, so that after the virus "infects" a cell, the cell will start making factor IX. Intentional infection of a cell with a new gene is called transfection, and the cells are transfected cells.

One of the most common viruses used for gene therapy is AAV - adeno-associated virus. AAV infects humans but does not cause disease. Factor IX gene therapy using AAV has been done successfully in animals, but transferring the technology to humans has been

problematic. There have been two major problems. First, some genes when introduced into a cell will become incorporated into the genome of the cell. The genome is the complete collection of all of the genes in an organism. Each cell has a complete copy of the genome in its nucleus.

Unfortunately, when a new gene is incorporated into the genome, it often is inserted randomly, and it may end up interfering with other genes. It can disrupt a necessary gene or activate a cancer gene, for instance. In two early gene therapy trials in Europe, several children developed leukemia, probably due to activation of cancer genes. All gene therapy trials were stopped for a period of time, and now there are much more stringent requirements for undertaking gene therapy trials. Scientists now generally use genes that are not incorporated into the genome.




The other problem, which has been seen in AAV gene therapy trials for hemophilia B, is that the cells with the new factor IX genes may be attacked by the body's immune system. There is also concern about whether the factor IX produced by the cells will be seen as a foreign protein and cause the body to produce inhibitors, antibodies directed against factor IX. These are difficult problems because the immune system is still not completely understood.

In the most recent hemophilia B trial using AAV, conducted by Children's Hospital of Philadelphia (CHOP), one patient's factor IX level increased to a maximum of 11.8 % of normal, a level that generally restores the blood's ability to clot. However, the patient's factor IX level continually decreased until it was back to less than 1 % after 10 weeks. The reason was that the transfected cells were attacked by the patient's immune system, but the actual reason that the cells were attacked is unclear. CHOP researchers are planning to resume the trials in the near future. They want to suppress the patient's immune system for several weeks after infusion until all traces of the AAV viral proteins are gone.

Amsterdam Molecular Therapeutics of The Netherlands in collaboration with St. Jude's Children's Research Hospital in Memphis is also currently beginning a gene therapy trial for hemophilia B. They have developed

an AAV type that they believe is less likely to cause immune rejection, and they also have a method to prevent immune responses against the newly-produced factor IX, which they hope will lead to elimination of inhibitor development.

Finally, a new technology that uses naturally-occurring enzymes called zinc fingers may eventually be able to "edit" and correct a defective factor IX gene. Zinc fingers recognize specific gene sequences and are used by cells to turn genes on or off. Researchers have recently been able to use zinc fingers in the laboratory to identify a certain spot on a gene and then cut and paste a modified gene segment into that spot. Right now there are only a few laboratories working on this, but if it turns out to actually work, it could have great potential for use in gene repair therapy.

Gene therapy still appears to be the best candidate for an actual cure for hemophilia B. While it has turned out to be much more difficult than originally hoped, researchers are still making great strides in understanding all of the difficulties, and have learned a great deal about how the human body works along the way. The history of medicine is full of stories in which long-term persistence eventually solved the problem. There's no reason to think that hemophilia won't eventually be another. 



*In Loving Memory of
Jim Brown*

On March 11, 2010, we lost a long time Coalition member. Jim Brown lost his battle with cancer.

Jim dedicated his life to helping others. He had a great way of lifting your spirits when you were down. Many in the bleeding disorders community knew him well and know what a wonderful, caring man he was.

Jim will be dearly missed by all.

CSL Behring is a proud supporter
of the Coalition for its many
years of service and dedication
to the community.



*CSL Behring, a company with more
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Inalex: A Vision of *Hope* *Information* *Inspiration*

Eight years after Joe Caronna's son was born with hemophilia in 1994, it became apparent to him that he had to do something to address the emotional and practical challenges families face when managing the issues surrounding a chronic disorder. As a husband, community advocate, and most importantly, a parent of a child with a bleeding disorder, Joe's passion soon led him create a series of nationally acclaimed programs that are innovative, effective, straightforward, and always inspiring.

With the assistance of world-renowned subject matter experts along with the family members living with the practical wisdom, Joe developed a series of innovative workshops, teleconferences, and weekend retreats, where all in the bleeding disorder community could gather to learn and share insight, support, and practical advice on families, relationships, and lives.

During the past seven years, Joe has been very fortunate to assemble a solid national presence that regard Inalex as a first class education and support organization, presenting to over five thousands participants throughout the United States and the Canadian bleeding disorder community.

To continue his vision, Joe collaborated with a multiple Emmy and Peabody award winning director and cinematographer in 2005 to create Inalex Productions. The result was the highly acclaimed "A Bright Future" DVD series, which has been embraced by the bleeding disorder community, not only because of the effective and practical information each segment in the series provides, but also for the hope, inspiration, and sense of

empowerment, each viewer realizes after viewing. The first two volumes in the series, address the issues surrounding the child's bleeding disorder diagnosis, from the perspective of the parent and extended family members. The third volume address issues pertaining to managing the bleeding disorder for the school educator, and the fourth volume address the issues surrounding aging with a bleeding disorder.

Inalex is now extremely excited to announce that their fifth volume, "Transitioning to Independence." This newest segment is currently in production and focuses on helping young adults, within the bleeding disorder community, transition into independence and adulthood.

The Inalex vision is a simple one, but one that is very powerful - to always ensure that the Inalex programs and tools provide Hope, Information, and Inspiration.

For additional information, please contact the Inalex office at 201 493-1399, or send an email to Joe_Caronna@inalex.com.



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GRIFOLS

GRIFOLS INTRODUCES MIX2VIAL™ FILTER TRANSFER SETS

A new needle-free transfer set will add to patient convenience and ease of use when reconstituting Grifols' coagulation therapies.

Los Angeles, California (April 23, 2010). Grifols USA, LLC (Grifols) today announced the availability of the Mix2Vial™ filter transfer set for the reconstitution and administration of Grifols' coagulation therapies. The Mix2Vial™ transfer set is a plastic, needle-free transfer device with a built-in 15 micron filter specifically designed to be used with the Sterile Water for Injection diluent packaged with Grifols coagulation products. The Mix2Vial™ is a simple to use transfer device designed exclusively for Grifols' coagulation therapies.

"As someone who has a bleeding disorder and has to treat regularly, I like the way the Mix2Vial™ is made to fit the solution because it makes the reconstitution process quicker and easier," said Lesa Kaercher, who serves as the HFA Board Representative for the Bleeding Disorders Association of the Southern Tier. "The Mix2Vial™ makes me more comfortable with the whole process because it is easy to use and doesn't require any needles to mix the medicine," she continued.

The Mix2Vial™ transfer set rapidly transfers water to the product vial making the reconstituted coagulation therapy immediately available for aspiration into any luer lock syringe for injection. "We continually strive to meet our customer's needs and enhance the convenience and ease of using our medicines," commented Bill Stopher, President of Grifols USA. "Introduction of the Mix2Vial™ transfer set represents just one more step we can take to address the challenges of living with hemophilia," Stopher said.

Availability of the Mix2Vial™ transfer set will be phased in over several months. Currently, DemoPacks are available for instructional purposes so that patients, parents and nurses can become familiar with the new system.

About Grifols

Grifols SA (Grifols) is a global healthcare company founded in 1940 in Barcelona, Spain. Today Grifols products and services are provided in more than 90 countries around the world. Grifols specializes in the production of plasma therapies to treat a variety of life-threatening diseases and conditions. Grifols operates 80 plasma donor centers throughout the US and has manufacturing facilities located in Barcelona, Spain and Los Angeles, California. For more information about Grifols, please visit www.grifols.com.

For more information on Grifols products, visit www.grifols.com or contact:

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Nation Hemophilia Foundation Washington Days 2010



By Jon Davis

On Thursday Feb. 25, 2010 participants of Washington Days, educated members of congress with personal stories and knowledge about bleeding disorders. The event included nearly 300 individuals living with a bleeding disorder, their families and members of their support networks.

Although health insurance reform had been vigorously debated all over the country at the time of this year's event, Washington Days participants energetically walk the halls of congress talking about the needs to eliminate pre-existing conditions exclusions, abolish lifetime health insurance caps, remove annual health insurance limits and maintain CDC funding for comprehensive, hemophilia treatment centers.

On March 23, 2010, President Obama signed H.R. 3590: Patient Protection and Affordable Care Act and it became Public Law No: 111-148. 🇺🇸



Bleeding disorder advocates from New York State visited with the members of Congress during Washington Days 2010.



THE HEMOPHILIA ALLIANCE FOUNDATION

Press Release: May 2010, Lansdale, PA

The Hemophilia Alliance has just completed the 2010 funding cycle, again this year they have donated in excess of \$300,000 to the hemophilia community.

“The Hemophilia Alliance Foundation serves as an excellent role model by investing in other nonprofit organizations serving the bleeding disorders community, and by making the application processes a simple one. The recipient organizations have many needs and few revenue streams. The Alliance Foundation grants make an important difference in the operations of these organizations.” *Joyce Strazzabosco, Hemophilia Alliance Foundation Grants Committee Chair*

Joe Kleiber, Vice President for Chapter Services, National Hemophilia Foundation, “The Hemophilia Alliance Foundation Grants are a much needed source of financial support for the NHF Chapters, other non-profit organizations, Hemophilia Treatment Centers (HTC) and the HTC Regions. Their dedication to these organizations shows an unprecedented commitment to crucial infrastructure support. The collaborative partnership that the Alliance has offered the community is vital to our growth and our ability to serve the bleeding disorders community.”

“Hemophilia of Indiana serves Indiana residents with bleeding disorders, their families, employers and others who are impacted by hemophilia, von Willebrand disease and other forms of bleeding disorders. We do this with a modest budget. Thanks to the Hemophilia Alliance Foundation, the Indiana Hemophilia and Thrombosis Center and other HTCs across the country, we were successful in securing a grant from the Foundation that will enable us to develop professionally produced public service announcements and longer form videos. The PSAs will be produced in a way that will allow them to be adapted for use by other NHF chapters, as well. The PSAs and videos will be important tools that help us tell our story in ways we were not able to do before. Hemophilia of Indiana and other NHF chapters are fortunate that the Hemophilia Alliance Foundation exists to provide critical funding for new programs that expand the advancement of our mission,” *says Michael Perigo, CFRE Development Director*.

“It is wonderful to see the momentum generated on behalf of the Hemophilia Community. Through a fantastic partnership and through forward-thinking by members of the Hemophilia Treatment Centers and Foundation Committee members, we continue to realize our vision of reinvesting resources into improving the lives of our patients. This is very gratifying given the challenges HTC’s and patients face each day.” *Mark Plencner, RPh Chair, Hemophilia Alliance*

The Foundation has again provided \$5,000 in funding to each of the 12 federal hemophilia regions in support of their annual meetings. These meetings provide a forum for hemophilia care providers to exchange information and share best practices.

We are planning another round of funding in 2011. Leaders of tax-exempt organizations that serve people with bleeding disorders who are interested in more information should contact Joe Pugliese at the Alliance offices, 1758 Allentown Road #183 Lansdale, PA 19446, joe@hemoalliance.org 215-439-7173, or visit our web site.

*The Alliance is a not-for-profit organization that is currently comprised of 80 Hemophilia Treatment Centers. The purpose of the Alliance is to assist its members in providing outstanding care for their patients. Our mission as The Hemophilia Alliance is to provide member Hemophilia Treatment Centers with resources and services to sustain the Comprehensive Care Model for individuals with bleeding and clotting disorders. For more information about the Alliance and how you can help further our mission visit us at www.hemoalliance.org or email us at info@hemoalliance.org

The Coalition for Hemophilia B at HFA in Kansas City, Missouri

The Coalition for Hemophilia B's Factor Nine Family Meeting was held in conjunction with the Hemophilia Federation of America Symposium in Kansas City, Missouri on April 24, 2010.

Thank you to all Coalition B members that attended our meeting! 



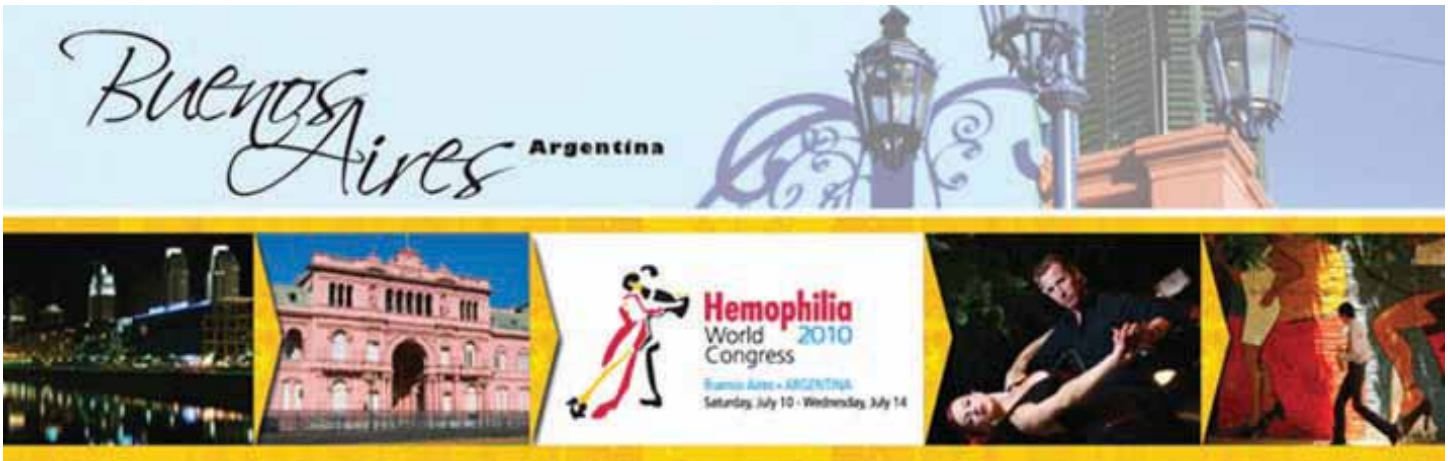
The Coalition for Hemophilia B in Kansas City. Members pose for a group shot.

Wishing all of you a Wonderful Summer!

Reminder

The Factor Nine Group moderated by Jill Lathrop is located on Yahoo.com Search "Factor 9" on Yahoo Groups

Upcoming Events!



Saturday - August 14, 2010

Adirondack Spintacular - Sacandaga Lake in Mayfield, New York



The 9th Annual Adirondack Spintacular, a 5K, six or twelve mile cycle/walk/run event is co-sponsored by Positudes Inc. and The Center for Donation and Organ Transplant. Our purpose is to raise Hemophilia and Organ Donation awareness, and to raise scholarship funds in memory of Larry Madeiros. The Lawrence Madeiros Scholarship will be awarded to graduating seniors living with a chronic disorder that are continuing their education at an accredited college or university. The course is a scenic 5K, 6 mile route amidst the Adirondack Mountains and along the Great Sacandaga lake in Mayfield, New York. Last year, over 450 people participated! Event Day check in begins at 8:30 a.m. to 9:30 a.m. Spintacular race begins at 10:00 a.m. followed by a barbecue lunch at noon. We hope that by contributing in some way by running, walking, biking, volunteering, and/or donating, you too will enjoy yourself and directly help someone fulfill their dreams.

For more information, contact: Carol Madeiros: 518-863-8998 carol@adirondackspintacular.com

THE 2010 INHIBITOR SUMMITS HAVE ARRIVED!!

August 5-8, 2010 - Houston, TX August 19-22, 2010 - Boston, MA

Come join other people with hemophilia A or B with inhibitors and their families for a weekend of education designed to improve your overall health and quality of life. Having an inhibitor can seem overwhelming at times that even day-to-day life can be a challenge. This can affect your well-being in ways that only other people with this condition can understand. The annual Inhibitor Education Summits connect people with inhibitors, their caregivers and members of their support network with expert healthcare professionals. They also connect you with others who have been where you are - people who can share their experiences or suggest a coping skill.

New this year:

- Multiple educational tracks
- Exciting Youth Camp activities planned for kids ages 4-12
- Coping mechanisms for improving the psychological well-being of patients and their caregivers

Call Toll-Free 877-560-5833 or Email inhibitorsummits@hemophilia.org

Atención: los representantes hablan español.



For back issues of **Factor Nine Newsletter** or for more information on research, please call or write to:
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