



Factor Nine News

The Coalition for Hemophilia B Summer 2009

Topics in Hemophilia

- P.E.P. Talk!
- 2008 Survey Results
- B2B Preteen Guide Amendment
- Factor Nine Christmas Fund
- Upcoming Events



INTRODUCING...



P.E.P. TALK!

Peers Empowering Peers:

What do you KNOW?

What do you THINK?

FACTS:

*According to The National Coalition on Healthcare, 46 million Americans are without healthcare. An estimated 7 million more people will be without healthcare between 2008-2010.

*In February 2009, a 10 Million Lifetime Caps Bill was introduced by Anna G. Eshoo (D-GA), Jim Langerin (D-RI), along with Senators Byron Dorgan (N-ND) and Olympia Showe (R-ME), Health Insurance Coverage Protection Act (H.R. 1085'S442). The legislation introduced in both Houses in 2008 will set a 10 million lifetime cap on health insurance with future increases based on inflation. (Information from The National Hemophilia Foundation's website).

*The cost of Health Insurance has skyrocketed nearly 80 percent since 2001 (Democratic Policy Committee DPC.Senate.gov). Earnings of insurance companies range anywhere from 18 million to 994 million (Factcheck.org).

We are happy to introduce a new section in our newsletter called,

P.E.P. TALK!

Peers Empowering Peers:

What do you KNOW? What do you THINK?

P.E.P. Talk! has been formed for two reasons:

- 1.) Help alleviate fears
- 2.) To empower each other.



We begin with some questions to think about. Please send in your responses by October 5, 2009 to be posted in our Fall Newsletter. Email: hemob@ix.netcom.com

or by mail to:
The Coalition for Hemophilia B
825 Third Avenue, Suite 226
New York, New York 10022.

Your names will be held strictly confidential. We ask that you send in questions of your own as well.

-
1. How active are you with advocacy to help pass the Lifetime Cap Bill?
 - a.) You find a better price for factor?
 - b.) Your insurance carrier has forced you to use a distributor that keeps making mistakes and clearly knows nothing about hemophilia?
 2. Do you plan to attend to NHF's Washington Day - February 24-27, 2010?
 3. What are your thoughts on having a government non-profit insurance company compete with current insurance companies?
 4. How could Whole foods Market's Consumer Driven Health Plan (http://www.worldcongress.com/news/Mackey_Transcript.pdf or the Wall Street Journal at <http://online.wsj.com/article/SB10001424052970204251404574342170072865070.html>.) benefit people with hemophilia What do you think of their program overall?
 5. Do you know how much you are paying for your factor? Do you compare pricing?
 6. How do you advocate for yourself with your insurance company if:
 - a.) You find a better price for factor?
 - b.) Your insurance carrier has forced you to use a distributor that keeps making mistakes and clearly knows nothing about hemophilia?
 7. What advice do you have for a person with Hemophilia graduating from College and looking for a job? How would you handle the concern of not being hired due to having hemophilia?
 8. Your son/daughter with hemophilia has reached the age where he/she is no longer covered under your insurance. How have you handled this transition? What mistakes would you offer your peers to help them avoid?
 9. What are the best states to reside in right now for people with hemophilia insurance wise? And why? What do you think about the Massachusetts health reform (www.masshealthreform.org)?

For Hemophilia B patients who
need an alternative to their
recombinant factor IX therapy



Mononine® Is The One to Choose

- Established Recovery Rates
- Proven Protection
- Demonstrated Safety
- A WHO Standard for Purity and Potency

Important Safety Information

Mononine® is contraindicated in patients with known hypersensitivity to mouse protein.

The following adverse reactions may be observed after administration: headache, fever, chills, flushing, nausea, vomiting, tingling, lethargy, hives, stinging or burning at the infusion site, or other manifestations of allergic reactions, including anaphylaxis.

Mononine® is derived from human plasma. As with all plasma-derived products, the risk of transmission of infectious agents, including viruses and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent, cannot be completely eliminated.

Please see brief summary of prescribing information on adjacent page.

Mononine®
MONOCLONAL ANTIBODY PURIFIED
Coagulation Factor IX (Human)

AlphaNine[®] SD

Coagulation Factor IX (Human)

Sample Program

Provided in the following range of sizes

Potency	Diluent	NDC Number	Color Code
500 FIX IU/Vial	10 mL	68516-3600-4	MID in blue box
1000 FIX IU/Vial	10 mL	68516-3600-5	HIGH in red box
1500 FIX IU/Vial	10 mL	68516-3600-6	SUPER HIGH in black box

The Grifols AlphaNine[®] SD Sample Program offers your patients, not currently using AlphaNine[®] SD and/or who have not sampled AlphaNine[®] SD in the past, an opportunity to try this product.

Healthcare providers and/or Treatment Centers, please contact Grifols at 888.325.8579 (Customer Service) to determine eligibility for this program. Samples are subject to availability.



For further information call: Grifols USA, LLC Professional Service: 888-GRIFOLS (888 474 3657)
Customer Service: 888 325 8579; Fax: 323 441 7968 www.grifols.com

2008 Survey Results

Product

BeneFIX	80%
Mononine	12%
Alphanine	7%
NovoSeven	1%

Age

1-12	40%
13-19	30%
25-49	25%
50+	5%

History

Family History	70%
No Family History	30%

Severity

Severe	70%
Moderate	20%
Mild	10%

Factor Obtained From

Home Healthcare	69%
Hemophilia Treatment Center	28%
Retail/Specialty Pharmacy	2%
Other	1%

Treatment

On Demand	55%
Routine Prophy (2 or more times a week)	40%
Prevention Prophy (before a sporting event)	5%

Gender

Boys with Hemophilia	98%
Girls with Hemophilia	2%

Would you change product for a surgery?

NO	90%
YES	10%

Reasons to consider a change

- If my doctor recommends it.
- Another product might work better.
- If my product was not available.

Recovery/Half-Life

The majority of respondents do not know their half-life or recovery

levels and/or have never been tested.

Respondents Activities

Archery, Art, Baseball, Boating, Ballet, Bicycle Riding, Basketball, Boating, Boogie-boarding, Boy Scouts, Bowling, Building Street Rods, Camping, Canoeing, Choir, Croquet, Cub Scouts, Dodge ball, Dancing, Drums, Football, Fishing, Fencing, Golf, Guitar, Gymnastics, Gardening, Hiking, Horseback Riding, Hunting, Jogging, Jump Rope, King Fu, Kickball, Karate, Kayaking, Life Guard, Marching Band, Mountain Climbing, Piano, Photography, Push-ups, Racquetball, Rafting, Rock Climbing, Rollerblading, Running, Sailing, Soccer, Skateboarding, Snow Skiing, Softball, Singing, Soccer, Skiing, Ski Surfing, Racing, T-Ball, Tae Kwon Do, Tennis, Track and Field, Track Cross Country, Ultimate Frisbee, Volleyball, Walking, Water Polo, Water Skiing, Weight Lifting, Wiffle Ball, Yoga.

Reasons for switching product?

•Product Purity	83%
•Safe, Effective	
•Doctor Recommendation	15%
•Works better for me	
•Recovery good	1%
•Allergy/Inhibitor	
•Availability, Costs	1%

Emergency Room Experience

“Poor, I can tell them why I am there, carry in my factor and still have to wait and be seen by a doctor who knows nothing about hemophilia.”

“They did not know how to spell it! They treat us as if we are stupid and don’t know what we are talking about. We need a basic hemophilia info and emergency treatment guide.”

“Hematology fellow on call

consulted textbook in our room – During hospital stay we saw 4 different hematologists of varying educational levels.”

“Doctors/Nurses assume I do not know what I am talking about when I tell them my boys have Factor 9. They would insist the boys were factor 8.”

“We were turned away because our factor was not on their formulary list. We learned home infusion after that experience.”

“We had two nurses arguing in the hall – neither felt comfortable giving factor to a baby – I was not yet trained. They finally asked us to leave and take him to the HTC ER which added another hour of bleeding.”

“Don’t get me started – some good – others not so. You just have to be vocal and persistent and get your doctor to call ahead.”

“It was a painful long process with staff that were clueless to our needs and they wanted to draw blood to run tests that were not pertinent to hemophilia and why we were there.”

“A nightmare. Very long and complicated. Most ER’s do not have a lot of knowledge about hemophilia and don’t believe me because I am a female with hemophilia.”

Emergency Room Funniest Comment for 2008

“Yeah, right. Are you kidding? – I’d rather they leave me in a field somewhere!”

Note: We have seen some improvement in Emergency Room experiences about 15% have had good or adequate services now.



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possibilities in
hemophilia™

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Science
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Novo Nordisk is helping people with inhibitors realize their dreams.

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Information for ERs

- Have as much information about Hemophilia and different types, also severity.
- ASK about Allergic Reactions
- Have factor on hand ASAP.
- Believe that females can have hemophilia.
- Know that people with hemophilia also carry factor with them.
- LISTEN to the parent or patient.
- Know bleeds need to be treated IMMEDIATELY - Then examine.
- LET parent or patient mix factor if you do not know how.
- TRUST parent or patient's knowledge.
- KNOW bruising is not child abuse.
- Know each case is different based on type, severity, inhibitors, etc.
- Teach them how to reconstitute factor.
- Have classes on hemophilia.
- Know that a hemophilia patient may look normal but their internal bleeding is life-threatening.
- Have fast reference charts.
- Have immediate ice and pressure beneficial.
- Posters on wall - TREAT FIRST - DO NOT MAKE A PERSON WITH HEMOPHILIA WAIT.

ER Patients should

- Call ahead if possible.
- Have a Medic Alert or card with information with hemophilia type.
- Know severity, factor product used, allergies, medications, doctor info.
- Have contact numbers, i.e., hematologist, etc.
- Have your hematologists call the ER before you arrive.
- Make an appointment for an inservice with the ER before you need them, but may need to be done frequently due to high turnover at the ER.

Type of information helpful to you and/or your child

(Rated by most popular responses)

- 1) Current Research in Hemophilia
- 2) Gene Therapy
- 3) Hemophilia Information Sources

- 4) Manufacturing Process
 - 5) Support Groups
 - 6) Prophylaxis
 - 7) Product Information
 - 8) Inhibitors*
- * Note: Inhibitors low on the list due to small percentage of people with inhibitors

People interested in having seminars in their area

YES	99%
NO	1%

Topics for seminars

(Rated by most popular response)
Same as above

Other Topics of Interest

- Insurance
 - Options
 - Switching at Adulthood
 - Government & Insurance Issues
 - CAPS
 - Making medical payments
- Scholarships
- Woman's Bleeding Disorder
- Transition from Port to Peripheral
- Going to College with Hemophilia
- Orthopedic Information
- Leaving College and beginning a career (how not to get turned away due to pre-existing condition)

Current problems & Future concerns regarding Factor:

(same as 2006 Survey with some new additions below)

- Price of Factor
- Insurance Costs
- Lifetime Caps
- Co-Pay Burden

There are many concerns within the Hemophilia B community regarding Insurance problems. There is also a great fear of dictatorship of sole source providers, being forced to switch suppliers, losing their choice of factor, and losing insurance because rates go up so high each year. Co-pay issues, Mother's have great concern whether or not their child will be able to get a good job (and keep it) and have insurance

coverage once out of college. People are reaching their lifetime caps and worry about insurance. Those on Medicare cannot afford the 20% co-pay. These problems are very real and most people are starting to feel the effects.

Comments (from 2008 survey)

"We cap out on insurance every 12 – 18 months." - Mother of 15 year old with FIX & Inhibitors

"We have had issues with a bunch of things; the more bothersome are 1) how to choose which insurance is better for my son. My company had 4 choices of insurance and it wasn't until we started asking informed questions that we had to change our choice. We realized that with one option our co-pay was going to be 33% of the total amount! And the other option (which costs more per paycheck) was going to cost us a co-pay of \$80.00 for factor per month, but we would pay more for all other services (doctor visit, ER visit, checkups...) Parents have to make informed choices about which insurance they want and it took me about 7 days to be able to understand all the different aspects of the Health insurance choices. Not everyone can spend 7 days looking at all the options and calling human resources, choice providers, etc. It took several conference calls with a rep from each party along with a rep from my current home care to fully understand our options. 2) in the future, lifetime caps will be an issue, but hopefully the Health Insurance Coverage Protection Act will pass. Let's talk about being switched...my son was born in 2006, a homecare company called me on my cell while my son was still at the hospital to let me know that they will be providing us with factor. At no time did she tell me I had a choice and that they were not the only provider in the area. We urge you to get the facts and educate yourself." - Mother of a 3 year old with Severe Hemophilia B

Wyeth

Lifelines™

FORM A LASTING CONNECTION WITH YOUR COMMUNITY!

.....

Designed to deliver information to people with hemophilia and those who care for them, *Lifelines* brings you news about Wyeth products, programs, and services; happenings in the hemophilia community; and more.

You'll receive customized information such as:

- Seasonal newsletters
- Relevant communications designed with your needs in mind
- Personalized e-mail updates
- Information about Wyeth-sponsored events and offerings



Get connected and get a **FREE** hemophilia-related item, including educational materials regarding traveling with your factor.*

Joining is easy—visit www.WyethLifelines.com to register today!



Contents pictured inside the bag are not included.

Due to limited quantities, the free gift pictured above may be substituted. Allow 4 to 6 weeks for delivery.

*Health care professionals are not eligible for the free gift.

“They made us switch. No, I am not happy. It is a different type of service that does not fit our schedule. I have to make 10 phone calls to get a shipment!” - Mother of 13 year old with Moderate FIX

“We have no choice, we have a lot of problems with our current supplier of factor. We are trying to work them out.” - Mother of 19 and 17 year olds with Moderate FIX

“We had a bad experience with our current supplier of factor. They sent us the wrong Heparin for 3 months and when asked they said it was the correct dose. They gave us 10 units and not the 100 units we needed. Many other small Issues – sent no saline but sterile water and said we could use it. Sent bed pads Instead of drapes for counter tops.” - - Mother of 8 year old with Severe FIX

“We have had to stay at a certain income to continue receiving help with insurance through the state.” - Mother of 8 year old with Severe FIX

“Initially our insurance made us switch but we switched back after complaining and working with the home health company.” - Mother of 19 year old with Moderate FIX

“Yes, they just sent me notice that they will not cover it unless I order from their approved supplier.” - Father and 19 year old daughter with Mild Hemophilia B

Comments from 2006 (Still apply)

“Insurance problems are happening to us now. Every dose is questioned and watched. Very scary” - Mother

of 18 year old with Severe FIX

“I am a teacher, I may have to leave my district and start at the bottom to be eligible for new insurance.” - Mother 10 year old with Severe FIX

“When my husband was employed by small companies they had no trouble figuring out who was driving up health care costs for them; needless to say it was difficult to maintain a job” -Mother of 12 year old with Severe FIX

“The insurance companies are limiting the amount of factor I can keep on hand - what if I have an emergency?” - 47-year-old Man with Severe FIX

“How do we prevent our freedom of choice from disappearing?” - Mother 7 year old with Severe FIX

“I have great worries about my son leaving college and having to get a job and insurance” -Mother of 20 year old with Severe FIX

“I live in panic of my son being uninsurable, we live in a place where there is high risk insurance, which he has, but he wishes to move out of state where there is no high risk pool!” - Mother of 25 year old with Severe FIX

“I foresee co-pay burdens, insurance companies telling us what brand of factor to use, whether or not we can have a bleed treated and how much factor we can have in our home.” -Mother of 5 year old with Severe FIX

Strong Statement and Hard Questions

Insurance companies should give us

a choice of factor suppliers, not just one. Some of these Suppliers have very little knowledge of hemophilia.

If WE find a company that sells factor at a lower cost, WE should be able to use that company and not have the insurance companies dictate to us, after all, WE have to lookout for our lifetime caps!”

Why can't WE bring factor to the hospital? It would probably be cheaper. If WE carry a prescription would WE then be able to bring it to the hospital?

How can insurance companies tell us how much factor WE can have on hand? When did they become experts? What if there is a mail strike or some type of natural disaster and they cannot deliver the factor on a timely basis?

NO one can afford to pay the 20% Medicare Co-pay - That's totally unrealistic.

Recommendations for the Factor Nine Newsletter

No Changes 98%

- Great Job
- Very Informative
- Interesting Articles
- Keep up the Good Work

Success Stories 2%

- Personal Profile Stories (Teens and Adults)
- More Often
- Insurance Advocacy
- Online way to submit articles for the newsletter
- Factor IXs with Inhibitors
- Stories on woman with hemophilia B

Thank you all for your time and valuable input!

- The Coalition for Hemophilia B

B2B Pre-Teen Guide - Amendment to MASAC Statement

Dear Members, we recently send you the new B2B Pre-Teen Guide Publication released in June 2009. Please note the following amendment for the MASAC information stated on page 11 of the B2B Pre-Teen Guide.

In MASAC Document #177, the following statement exists:

Reduction of Thromboembolic Risk During Surgery

The use of recombinant factor IX or pd-coagulation FIX concentrates (PCCs) is recommended in certain situations associated with a higher risk of thromboembolic complications, such as surgery or severe hemorrhage requiring treatment 1 to 2 times per day.

In MASAC Document #190, the statement has been omitted.

The MASAC Representative explains the reason for the removal of this statement from the recommendation,

“It is no longer necessary to say use of recombinant or coagulant factor IX products because no one should be using Bebulin or Profilnine to treat hemophilia B.”

The Coalition for Hemophilia B recommends the use of the highly purified products Coagulation Factor IX (Human) or Coagulation Factor IX (Recombinant) in situations associated with higher risk of thrombosis, such as surgery or severe hemorrhage requiring treatment 1 to 2 times a day. Factor IX Complex (Human) should not be used since it is associated with a higher risk of thromboembolic complications, which can be very serious or even fatal.



YOU ASKED FOR IT!

“Share your Story”

is now available on our website www.coalitionforhemophiliab.org

We encourage you to submit your articles that will appear in upcoming issues of our newsletter

Factor Nine News



My grandmother on my mom’s side always said that because I went so far away (to the U.S.) from France that there was no limit to how far Tristan would go.

When he was born, she said that he would probably go to the moon!!!!

So when our daycare gave us the opportunity to have a “career” day picture, we took it! :)

I present to you,

Commander Tristan Martin!

- from the Martin-Dubois Family

Photo by Project V.I.S.I.O.N.S.
(www.projectvisions.com)



Factor Nine Holiday Fund 2009!

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 1, 2009* 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 5, 2009.**
(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:
_____	_____	_____
_____	_____	_____
_____	_____	_____

The Coalition for Hemophilia B

Autumn 2009 Factor Nine Family Meeting

NHF's **61ST** ANNUAL MEETING

BUILDING BRIDGES



OCTOBER 29-31, 2009
SAN FRANCISCO, CALIFORNIA

Visit The Coalition for Hemophilia B Booth!

San Francisco, California October 29-31, 2009

In conjunction with

National Hemophilia Foundation Conference

San Francisco Marriott 800-266-9432

55 Fourth Street; San Francisco, California

Factor Nine Family Breakfast Meeting

Saturday, October 31, 2009

8:00 to 9:30 a.m.

Room: Foothill E

Atrium Level of the San Francisco Marriott

NHF has graciously waived the fee for our meeting space

Please join us in San Francisco for Breakfast on Saturday Morning!

We are pleased to present our fun educational game called "Are you Smarter than Your Hemophilia."

Join our relaxed, open forum created to help people with Hemophilia B and their families gain support, share concerns, stories, and information. Take this opportunity to see your friends and meet new ones!

We look forward to seeing you!

A Word of Thanks from Wayne Cook

"I would like to thank everyone for all your kind loving support these past months. All of your cards, letters and flowers have lifted Maureen's spirits and warmed our hearts. The posts on Carepages.com website under Maureenslife have been uplifting and supportive...we are grateful. Thank you." - Wayne Cook

As many of you know, Maureen Cook, wife of the Coalition's president, Wayne Cook, was diagnosed with cancer. Wayne has created a page called Maureenslife on carepages.com to keep everyone updated on Maureen's progress.

If you would like to send cards or letters please mail to:

Maureen Cook, 8 Aspen Road; Latham, New York 12110

Scholarship Notice

The William N. Drohan Scholarship application form for 2010 is now available on our website. www.coalitionforhemophiliab.org under scholarships. The deadline is February 15, 2010.

Notice

There are several medical trials that members of our community have the opportunity to participate in. The Coalition for Hemophilia B encourages you to look into getting involved by going to: <http://clinicaltrials.gov> (search under Hemophilia B.)

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