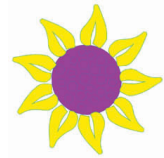


# Factor Nine News

The Coalition for Hemophilia B Summer 2010

## Topics in Hemophilia

- *90 year old man with Hemophilia B*
- *Updates on Treatment for Hepatitis C*
- *Managing Your Child's Inhibitor*
- *Are You Smarter than Your Hemophilia?*
- *Adirondack Spintacular Event*
- *Lawrence Madeiros Scholarship Winners*
- *Common Factors*
- *Grifols and Talecris Join*
- *Biogen Idec and Swedish Orphan Biovitrum Announcement*
- *Factor Nine Holiday Fund 2010!*
- *Save the Date Events*
- *2011 Scholarship Information*



**Leroy Carter** from Highland Park, Michigan turned 90! Leroy is the oldest hemophilic in Michigan and the second oldest in the country - by two months! Dozens of friends and family celebrated his 90th birthday Tuesday at Detroit's Henry Ford Hospital, where he received treatment for 60 years.

Carter sat behind his humongous birthday cake and large tub of ice cream, smiling as people stopped by to wish him happy birthday. "It's a pretty good day!" he said. "It's a surprise to still be here."

By Joshua Jamerson, Free Press Special Writer, Freep.com

## Adirondack "Spintacular" a Success!

Story on page 8.



# *Update on Treatments for Hepatitis C*

**By Dr. David Clark**

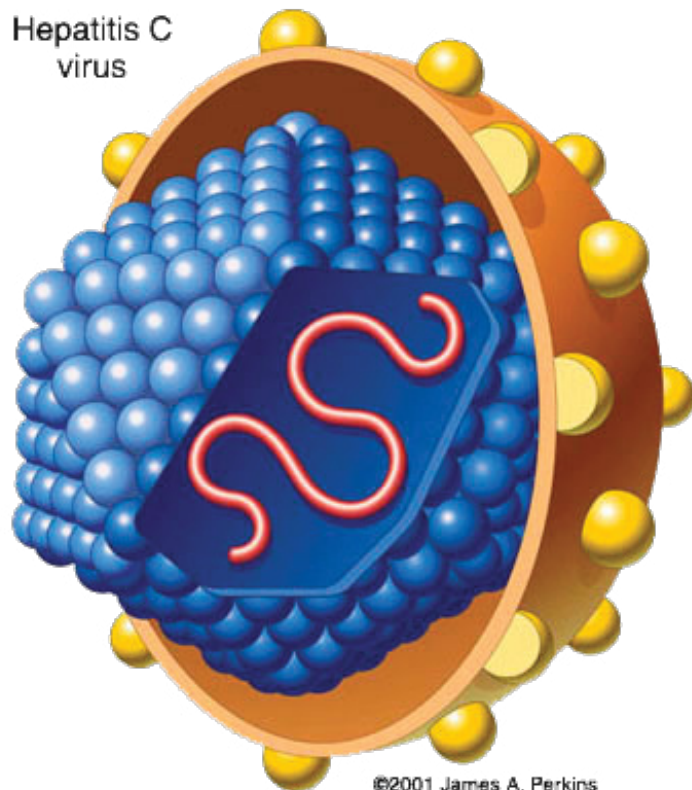
**M**any hemophilia patients are infected with hepatitis C virus (HCV), mostly older patients who received plasma-derived factor VIII and factor IX concentrates before the advent of viral inactivation methods. HCV is actually easily inactivated or removed from today's products, but it wasn't that long ago that even the cause of the disease was unknown. Until 1988, when HCV was finally identified, hepatitis C was known as non-A, non-B hepatitis. It was the most common form of hepatitis from blood transfusions and plasma-derived products, but doctors didn't know whether it was caused by an infectious agent, like a virus, whether all the patients had the same disease, or whether it was just a collection of symptoms that might have various causes. All people knew is that it was an inflammation of the liver that wasn't hepatitis A or hepatitis B.

Hepatitis C is a serious disease. Like hepatitis B, it can lead to cirrhosis, liver failure, liver cancer (hepatocarcinoma) and death. Identification of the hepatitis C virus quickly led to development of screening assays for blood, plasma and tissue donations. It also turned out to be inactivated by heat, solvent/detergent treatment and other methods that had been introduced into the processes for manufacturing plasma products, originally to inactivate HIV, the AIDS virus. Today all blood, plasma and tissue donations are screened for HCV and plasma-derived products are further treated to inactivate and/or remove the virus. HCV transmission today is mainly through sexual contact, intravenous drug use, and accidental contact with contaminated body fluids. Hemophilia patients are no more at risk than the general population.

Still, there remains a significant number of older hemophilia patients who were infected by blood and plasma products. Unfortunately, treatment for HCV infection is difficult and not always

effective. The current treatment, a combination of interferon and ribavirin, must be taken for a year and are only effective in about 50% of patients. In addition, there are often significant side effects to the treatment such as flu-like symptoms, nausea, anemia, headaches and depression. It is actually interferon, which our bodies produce in response to the infection, and not the flu virus itself that causes the symptoms associated with the flu. Imagine enduring that for a year, and then only having a 50% chance of the treatment working.

However, there are a number of new treatments on the horizon that will hopefully improve that situation. The two treatments farthest along, expected to be approved by FDA in 2011, are telaprevir from Vertex and boceprevir from Merck (the brand names are not known yet). Both are protease inhibitors that block an enzyme that is necessary for the virus



to reproduce. They would still be used in conjunction with interferon and ribavirin, but the course of treatment is expected to be six months rather than a year. Both seem to be equally effective in clinical trials to date with success rates in the 60 - 75% range.

A second generation of anti-HCV drugs is also under development and expected to be marketed in three to five years. These would also be used in conjunction with interferon and ribavirin, at least initially. Researchers hope that in five to ten years enough progress will be made that interferon and ribavirin with their miserable side effects can be eliminated. The second-generation drugs are expected to be used in a cocktail, a combination of drugs like that used to treat AIDS. One of the problems with the first generation protease inhibitor drugs like telaprevir and boceprevir is that the virus tends to become resistant to them. They are given with interferon and ribavirin to help knock down the virus rapidly and reduce the development of resistance. Hopefully, a cocktail of second generation drugs will do the same thing without the severe side effects.

Most of the second generation drugs under development are either protease inhibitors, like telaprevir and boceprevir, or polymerase inhibitors. HCV, like HIV, contains RNA as its genetic material and also contains an enzyme called RNA polymerase that converts the RNA in the virus into the DNA genes that it needs to make more viruses. Polymerase inhibitors block the RNA polymerase to prevent the virus from reproducing and infecting more cells. Another interesting second generation drug inhibits a viral protein called NS5A, which the virus also needs to reproduce. Bristol-Myers Squibb used a technique called High Throughput Screening to evaluate more than a million chemicals for activity against NS5A. The most promising compound, known as BMS-790052, shows strong activity against HCV. In a Phase II trial some patients were virus-free after only four weeks of treatment when BMS-790052 was used in conjunction with interferon and ribavirin. However, BMS-790052 still has several years to go before being approved, assuming that other problems don't crop up along the way.

Still other companies are working on cyclophilin inhibitors. Cyclophilins are enzymes that help

to fold up and package RNA into new virus particles. One of the cyclophilin inhibitors is interesting in that it also seems to reduce the formation of scar tissue on the liver that is caused by HCV. Cirrhosis is the result of severe scarring that interferes with proper liver function.



One of the biggest issues with hepatitis C, both for hemophilia patients and for the general population, is identifying people who are infected. HCV infection usually produces no symptoms until liver damage is advanced. Therefore, anyone who thinks they might have been exposed should be tested. This is especially true for older hemophilia patients who received plasma-derived products before the early 1990s. It is a simple blood test similar to that used to test donated blood and plasma.

Finally, after decades of relying on interferon and ribavirin as difficult and not-always-effective treatments for hepatitis C, there are a number of new treatments on the horizon. Although not all of them will succeed in becoming products, the competition for a market that is expected to reach \$ 7.4 billion by 2013 should produce a real benefit for the patient. 🇧🇪

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.

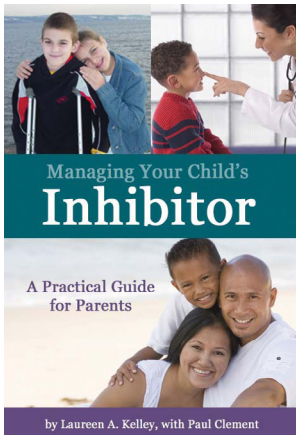
Mononine® is derived from human plasma. As with all plasma-derived products, the risk of transmission of infectious agents, including viruses and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent, cannot be completely eliminated.

**Please see brief summary of prescribing information on adjacent page.**

**Mononine®**  
MONOCLONAL ANTIBODY PURIFIED  
**Coagulation Factor IX (Human)**

# Managing Your Child's Inhibitor

By Lauren A. Kelley



I know a lot of people in the U.S. hemophilia community, and I count Dan Holibaugh of Matrix Health as one of my dearest friends. We met in the early 1990s at a hemophilia function and later had dinner with Glenn Pierce, then NHF president. We've all been friends ever since. It was natural that I one day also met his son Joe, a delightful young man with hemophilia who was blossoming into a career helping others in the hemophilia community.

Joe knew something about suffering as he had inhibitors. And though I knew about hemophilia suffering, I knew nothing about what pain was really like until I started meeting patients like Joe.

Up until about four years ago, like most of our community, I was ignorant of the plight of people with inhibitors. My eyes were opened to this silent community when I was invited to join a consumer advisory panel composed of twelve inhibitor patients and parents of children with inhibitors. The needs uncovered that day astounded me. I listened to some of the saddest stories I had ever heard. I learned how hard it was to find product that worked to stop bleeds and I cringed at stories of unrelenting bleeds that kept child and parent awake for hours at night, for nights on end. The unresolved bleeds confining children to wheelchairs. Days—weeks—lost from school or work. I listened to families who had burned through their insurance caps because of the high cost of treatment. Parents who hopped from job to job just to find new insurance policies.

The stories left me stunned. And there was so much medical information, it was almost overwhelming. My own son with hemophilia does not have an inhibitor, and I knew I was woefully equipped or prepared if I learned suddenly that he had developed one. And so the idea was born to capture the experiences and feelings of families with inhibitors and publish a book, the world's first on inhibitors. *Managing Your Child's Inhibitor*, which will be ready October 1, compiles the practical advice, heartache and struggles of 40 families with inhibitors. It also presents straightforward medical information on inhibitors in a way anyone can understand. When you are diagnosed with an inhibitor, you have little time to process things at your own pace; you must make immediate medical decisions. This book will help you to understand your hematologist's recommendations.

I learned a great deal while writing this book. Isolation is perhaps the biggest obstacle families face. And a lot has

changed since 2005. We now have excellent inhibitor summits that unite families with inhibitors. As not everyone can attend educational summits, this book will serve as a reference that is comprehensive, yet written in plain language families and patients can understand.



Joe and Dan Holibaugh with Laurie Kelley

Inhibitors are known to affect up to 30% of patients with severe hemophilia A. It is good to know there is now a parenting book to help guide you, in case you experience inhibitors. And there's a very special community of parents, medical staff and industry supporters who know what you're going through, and what you will face.

With all that I learned, it seemed right to dedicate the book to Joe Holibaugh, who passed away June 2006. He dedicated his brief life to helping those who suffer, as we hope this book will enlighten and educate, and alleviate suffering, too.

*Managing Your Child's Inhibitor*, by Lauren A. Kelley with Paul Clement, is available through [www.kelleycom.com](http://www.kelleycom.com). Laurie is president of LA Kelley Communications, and the mother of a 23-year-old son with hemophilia. She is also the author of 11 books on bleeding disorders and founder of the Parent Empowerment Newsletter (PEN). Paul is a high school science teacher and father of a son with hemophilia. He is a medical writer for LA Kelley Communications. *Managing Your Child's Inhibitor* was created with an unrestricted grant from Novo Nordisk.

Imagine caring for your child with hemophilia with no factor, refrigerator, running water, electricity, or transportation to a clinic.

This is the reality for thousands of families in developing countries.

For just \$20 a month, you can help an impoverished child with hemophilia. Become a sponsor today!



[www.saveonelife.net](http://www.saveonelife.net) | [contact@saveonelife.net](mailto:contact@saveonelife.net)  
Caring for people with hemophilia around the world—one at a time.



# ARE YOU SMARTER THAN YOUR HEMOPHILIA?

Credits: Wayne Cook, Kim Phelan, Dave Clark, Lisa Weideman, Chris Mraz

We hope you all have enjoyed the summer months and thought it would be fun to share with you our game, “*Are You Smarter Than Your Hemophilia*” that we have been playing at our Factor Nine Family Meetings and our New York Symposium over the past three years. It is an interactive family game combining the principals of “Jeopardy”, “Family Feud”, “Who Wants to Be a Millionaire” and “Are You Smarter than a 5th Grader.” It is educational and fun and a good way to end the summer!

**RULES OF THE GAME:** You must have FUN! Everyone is a winner!

“*Are You Smarter Than Your Hemophilia?*” is intended to be an educational, interactive exercise.

## Question #1

***Which name does not belong?***

- a) Hemophilia B
- b) Factor IX Deficiency
- c) Easter Disorder
- d) Christmas Disease

## Question #2

***Approximately how many people in the U.S. have hemophilia B?***

- a) 25,000
- b) 200
- c) 10,000
- d) 3,500

## Question #3

***Where was the first factor IX concentrate developed?***

- a) Frankfurt, Germany, 1925
- b) Paris, France, 1959
- c) New York, NY, 1973
- d) Atlanta, Georgia, 1936

## Question #4

***When was the first factor IX product licensed in the United States?***

- a) 1941
- b) 1930
- c) 1969
- d) 1990

## Question #5

***Hemophilia B is...?***

- a) Hereditary
- b) Caused by a spontaneous mutation
- c) Both a & b
- d) None of the above

## Question #6

***What is an inhibitor?***

- a) An antibody that blocks factor IX activity
- b) An antibody that stops bleeding
- c) A person who stops traffic
- d) All of the above

## Question #7

***What product is not used to treat hemophilia patients with inhibitors?***

- a) Activated factor VII
- b) Activated factor IX complex
- c) Large doses of factor IX
- d) Large doses of factor VIII

## Question #8

***What is prophylaxis?***

- a) Cleaning the infusion site with alcohol
- b) Infusing factor IX when you feel like it
- c) Physical therapy for a damaged joint
- d) Routine, periodic infusion of factor IX, often every 3 days

### Question #9

*What is a trough level?*

- a) When you feel depressed
- b) The maximum angle a hemophilia patient can bend his knees
- c) When you exceed your insurance cap
- d) The lowest level of factor IX in the blood, just before a prophylactic infusion

### Question #10

*A man with hemophilia B and a woman who is not a carrier, have a grandson with hemophilia B. Is the grandson their son's or their daughter's?*

- a) The son's
- b) The daughter's
- c) Must be adopted
- d) None of the above

### Question #11

*What common animal has a clotting system most like that of humans?*

- a) Sheep
- b) Cow
- c) Guinea pig
- d) Pig

### Question #12

*When you take your factor out of the refrigerator to get ready to infuse do you:*

- a) Decorate it
- b) Allow it to get to room temperature before mixing
- c) Play with it
- d) Boil it in hot water

### Question #13

*What or who is Gene Therapy?*

- a) The inventor of BeneFix
- b) A new singer on American Idol
- c) Exercise for your genes
- d) Introduction of a new gene into the body

### Question #14

*What chemical element is required for coagulation?*

- a) Oxygen
- b) Water
- c) Calcium
- d) Sodium

### Question #15

*After an infusion, how much of the factor IX ends up in the bloodstream?*

- a) About half
- b) All of it, of course
- c) 10 %
- d) None

### Question #16

*Where does most of the rest of the factor IX end up?*

- a) It sticks to the inside of the syringe
- b) It sticks to the walls of the blood vessels
- c) It accumulates inside the heart
- d) It leaks into the stomach

### Question #17

*What protein starts the clotting process?*

- a) Factor X
- b) Prothrombin
- c) Fibrinogen
- d) Tissue Factor

### Question #18

*Where does Tissue Factor come from?*

- a) The liver
- b) The walls of damaged cells
- c) A bottle of clotting factor
- d) A box of Kleenex

### Question #19

*The main focus of a Phase I clinical study is...?*

- a) Safety
- b) Cost
- c) Effectiveness
- d) Dosage

### Question #20

*How does an 18 gauge needle compare to a 22 gauge needle?*

- a) It is shorter
- b) It is longer
- c) It is wider
- d) It is narrower

*The answers can be found on page 9.*



Carla Kolbe / For the Recorder

**ABOVE: Runners and bikers participate in the Adirondack Spintacular Saturday in Mayfield. The event aims to raise awareness for chronic disorders and organ donation, as well as money for the Lawrence Madeiros Memorial Scholarship fund. BELOW: Adirondack Spintacular coordinator Carol Madeiros, right, with daughter Ashley, make an announcement at Saturday's event.**

## Annual 'Spintacular' a success

MAYFIELD — The ninth annual Adirondack Spintacular, a 5K, six or 12-mile cycle/run/walk event took place Saturday, beginning and ending at the Mayfield Fireman's Association Fairgrounds.

The event was co-sponsored by Positudes, Inc. and the Center for Donation and Transplant, with the purpose to raise awareness for chronic disorders and organ donation, as well as money for the Lawrence Madeiros Memorial Scholarship fund. Event coordinator was Carol Madeiros the scholarship fund.

The Lawrence Madeiros Scholarship is awarded annually to high school seniors living with a chronic disorder and continuing their education at an accredited college or university. Six \$1,000 scholarships were awarded this summer, and the recipients were to be honored at this year's event. Over \$42,000 in scholarships has been awarded since 2003.

The causes are dear to Carol Madeiros' because her husband, Larry, a hemophiliac who had hepatitis C as the result of blood transfusions, passed away in 2001 while waiting for a liver transplant.

Because Larry was such a well-loved, positive person, he has left a legacy of enjoying life to the fullest — the Adirondack Spintacular fulfills much of what Larry was about — having fun, staying fit, enjoying the lake and the Adirondacks, and incorporating people of all ages and situations into a quality family event. Entrants chose to ride bikes, run or walk at the



5K, 12 mile, six-mile, or one-mile level. Awards were presented to the top two finishers in each category, and by age.

Those who didn't want to race were still able to enjoy a barbecue picnic when the race participants returned to the Mayfield Fairgrounds, as well as participate in a silent auction, entertainment and family fun.

The Adirondack Spintacular travels along a scenic route along the Great Sacandaga Lake and its environs. For more information on the Adirondack Spintacular and to find out more on chronic disorders and organ donation, go to [www.adirondackspintacular.com](http://www.adirondackspintacular.com). Race results can be found at [www.fasttracktiming.com](http://www.fasttracktiming.com).



## **The Lawrence Madeiros Scholarship Committee** **Proudly Announces 2010 Scholarship Winners - \$1,000.00 each**

*The Lawrence Madeiros Scholarship was formed in 2001 in memory of Larry Madeiros. Through extensive fundraising with the Adirondack Spintacular, we are proud to announce the selection of six inspiring recipients of scholarship monies, in the amount of \$1,000.00 each.*

**Shameem S. Fakory** is from Saco, Maine and will be attending the University of New Hampshire and is pursuing a Biology degree. Shameem has a genetic blood disorder called Beta Thalassemia which has affected her life with frequent iron-chelating medication that is slowly injected over a 12 hour period. She recently was able to become liberated with an oral medication. *"...Thalassemia no longer controls how I live my life from day to day. It has given me strength when I thought I had none and has made me very appreciative and more determined than ever to reach my goals."*

**Chelsea L. Hadden** is from Poughkeepsie, New York and will be attending Fredonia to pursue a degree in Music. Chelsea was diagnosed with Ehlers-Danlos Syndrome, a genetic disorder that results in a collagen deficiency between the joints. This causes the joints in her hands to dislocate causing unbearable pain. *"...I believe you should grab every opportunity that comes your way. If someone opens a door, you need to walk through and embrace what's on the other side. Missed opportunities cause regret, a word I don't like."*

**Samantha L. Illenberg** is from Castleton, New York and will be attending Clarkson University to pursue an Engineering degree. Samantha has a degenerative nerve disease called Charcot-Marie-Tooth (CMT) which causes muscles and her reflexes to be slow and weak. This disease has prevented her from doing many activities however she has persevered in swimming as a positive role model. *"Although I will never be a Michael Phelps, everyone seems to associate my name with persistence and a positive attitude that influences the rest of the team."*

**Maureen B. Riegert** is from Greendale, Wisconsin and will be attending The University of Notre Dame to pursue a Biology degree. Maureen was diagnosed with severe Idiopathic, Immune Thrombocytopenia (ITP), a disorder with a risk of bleeding when platelet counts are low and requiring frequent IV therapy. *"...I feel I can be a good role model for young children with bleeding disorders to let them know they can dream and set high goals for themselves. I plan to encourage others to challenge themselves and pursue their goals to do what they want to achieve in life."*

**Mallory A. Rowley** is from Liverpool, New York and will be attending Colgate University with a Pre-Medicine/Biology major. Mallory was diagnosed at the age of 12 with Crohn's disease after losing 30 pounds and having symptoms not unlike those of the stomach flu. *"...I want to give back to those who need a hand, a friend. I would like to become a passionate person who can perhaps discover the cure for Crohn's that have robbed the childhoods and dreams of others. I know that nothing is impossible."*

**Alissa A. Urich** is from Maple Grove, Minnesota and will be attending the University of Kansas to pursue a Pre-Medicine/Biology degree. Alissa has a thrombotic disorder and had a life-threatening thrombosis which required surgery and removal of her left lower lobe of her lung. *"...My goal is to be a bilingual pediatric hematologist in a children's hospital. I am very passionate about wanting to help children and their families with blood disorders. I want to be a reason a child will be able to fight through their battle and continue on living a normal life."*

### **ARE YOU SMARTER THAN YOUR HEMOPHILIA?**

- |  |  |  |
|--|--|--|
| 1.) c - Easter Disorder is not a name for hemophilia B.  | 8.) d - Routine, periodic infusion of factor IX, often every 3 days.                     | 13.) d - Introduction of a new gene into the body.           |
| 2.) d - Approximately 3,500 people in the US have hemophilia B.                                  | 9.) d - The lowest level of factor IX in the blood, just before a prophylactic infusion. | 14.) c - Calcium.  |
| 3.) b - Paris, France, 1959.   | 10.) b - The daughter's (unless the son married a woman who is a carrier.)               | 15.) a - About half.   |
| 4.) c - 1969.  | 11.) d - The pig!  | 16.) b - It sticks to the walls of the blood vessels.        |
| 5.) c - Both a & b.  | 12.) b - Allow it to get to room temperature before mixing.                              | 17.) d - Tissue Factor.                                      |
| 6.) a - An antibody that blocks factor IX activity.  |  | 18.) b - The walls of damaged cells.                         |
| 7.) d - Large doses of factor VIII do not help prevent bleeding in factor IX-deficient patients. |  | 19.) a - Safety.   |
|  |  | 20.) c - An 18-gauge needle is wider than a 22-gauge needle. |



## Pfizer and Wyeth are now one.

For over 150 years, Pfizer has been working to make a difference for patients.

We are dedicated to developing innovative hemophilia products, offering consistent supply, and providing helpful support services.

For more information, contact us at:

Visit [HemophiliaVillage.com](http://HemophiliaVillage.com) to learn more.



**Common Factors** is a speakers bureau program for the bleeding disorders community. This program highlights the shared connections created by healthcare professionals, caregivers, and patients as they each seek to enhance the quality of life for those living with these conditions.

Common Factors was created in response to the insight that patients and caregivers continue to have a need with regard to the dissemination of timely and relevant information which will enable them to better deal with their bleeding disorder.

At Common Factors live events, patients and caregivers learn more about timely, relevant topics including:

- Staying on track with therapy - facilitated by Shannon Penica, MA, BCBA
- Inhibitors - facilitated by Sue Geraghty, RN, MBA
- Insurance and reimbursement - facilitated by Lynne Szott
- Pain and anxiety management - facilitated by Diane Dimon, DrRS
- Aging with Hemophilia – facilitated by Angela Lambing, RN

CSL will update the topics over time, adding new topics and new speakers with unique expertise in dealing with a bleeding disorder. If you need more information on the speakers please let me know.

For more information on this program, patients or chapter representatives can call **1-888-508-6978** or visit **[www.WeHaveCommonFactors.com](http://www.WeHaveCommonFactors.com)**

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## Coagulation Factor IX (Human)

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Potency	Diluent	Color Code
500 IU FIX Range	10 mL	Blue box
1000 IU FIX Range	10 mL	Red box
1500 IU FIX Range	10 mL	Black box



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](http://www.grifols.com)



## **GRIFOLS TO ACQUIRE TALECRIS BIOTHERAPEUTICS CREATING A WORLD LEADING PROVIDER OF LIFE-SAVING PLASMA PROTEIN THERAPIES**

- The combination of Grifols and Talecris will create a diversified, global provider of life-saving and life enhancing plasma protein therapeutics built on the strong global presence of Grifols and the established position of Talecris in United States and Canada.
- The merger accelerates key strategic initiatives for both Talecris and Grifols as it creates a more efficient platform for manufacturing, innovation and global sales and marketing.
- Combining the expertise of both companies will build upon their individual legacies of patient commitment, growth and innovation while increasing the availability of high quality plasma protein therapies for patients worldwide.

**Barcelona, Spain and Research Triangle Park, N.C., June 7, 2010** – Grifols (GRF.MC) a global healthcare company and leading producer of plasma protein therapies, and Talecris (NASDAQ: TLCR) a U.S.-based biotherapeutics products company, today announced that they have signed a definitive agreement through which Grifols will acquire Talecris for a combination of cash and newly issued Grifols non-voting shares having an aggregate value today of approximately \$3.4 billion (€2.8 billion), creating a global leader of life-saving and life enhancing plasma protein therapeutics.

The combination of Grifols and Talecris will create a vertically integrated and diversified international plasma protein therapies company, bringing together complementary geographic footprints and products, as well as increased manufacturing scale. Grifols' leading global footprint will benefit from Talecris' strong presence in the United States and Canada. Grifols' available manufacturing capacity will enable Talecris to increase production in the near term. As a result, the combined company will be better able to meet the needs of more patients with under-diagnosed disease states around the world.

In addition, upon completion of the transaction, the combined company will have:

- the ability to derive more protein therapies from every liter of plasma, enhancing access and availability for patients, and optimizing use of collected plasma;
- an established plasma collection operation capable of meeting the combined company's needs to address increasing patient demand and an accelerated path to improving the cost efficiency of the Talecris plasma platform;
- a broad range of key products addressing a variety of therapeutic areas such as neurology, immunology, pulmonology and hematology, among others;
- an enhanced R&D pipeline of complementary products and new recombinant projects that will drive sustainable growth;
- a well established clinical research program in the U.S.

Grifols Chairman and CEO Victor Grifols commented, "The acquisition of Talecris furthers our vision to better serve patients and health care professionals with innovative products, a strong clinical research capability and new research into recombinant therapies. We look forward to combining the strengths of both companies to improve the quality of the lives of patients around the world, while positioning the enlarged group for long term profitable growth."

Talecris Chairman and CEO Lawrence D. Stern commented, "We believe that Grifols' well-established reputation, know-how and expertise will enable the combined entity to meet the needs of more patients. Our employees will benefit from the opportunities available to them as part of a larger, global organization committed to the expansion of Talecris' existing business, the development of our pipeline products, and the maintenance of our culture of compliance and quality. Importantly, our stockholders will realize a compelling premium and benefit from the ability of the combined business to accelerate key gross margin improvement opportunities within Talecris."

## **BIOGEN IDEC AND SWEDISH ORPHAN BIOVITRUM PRESENT DATA ON LONG-LASTING HEMOPHILIA B THERAPY AT THE WORLD FEDERATION OF HEMOPHILIA CONGRESS**

**Weston, Mass. and Stockholm, Sweden – July 12, 2010** — Biogen Idec (NASDAQ: BIIB) and Swedish Orphan Biovitrum AB (STO: SOBI) today announced results from a Phase 1/2a open-label, dose-escalation, safety and pharmacokinetic study of the companies' long-lasting, fully-recombinant factor IX Fc fusion protein (rFIXFc) in hemophilia B patients. The data, which were presented at the World Federation of Hemophilia Congress in Buenos Aires, Argentina, on July 11, 2010, showed that rFIXFc was well tolerated and demonstrated an approximately three-fold increase in half-life compared to historical data for existing therapies.

“Current prophylactic regimens for hemophilia B require intravenous injections twice per week, so there is great desire among physicians and patients for a therapy that will provide prolonged protection from bleeding,” said Amy Shapiro, M.D., Medical Director of the Indiana Hemophilia and Thrombosis Center. “Results from the Phase 1/2a trial show that rFIXFc may be able to reduce the number of injections to once weekly or less, which would be an important advancement for the hemophilia community.”

“Our hemophilia B program demonstrates Biogen Idec’s commitment to utilizing pioneering science to create new standards of care for patients,” said Glenn Pierce, M.D., Ph.D., Vice President and Chief Medical Officer of Biogen Idec’s hemophilia therapeutic area. “Developed using our novel Fc-fusion technology, rFIXFc has the potential to improve the lives of individuals with hemophilia B by providing longer-lasting protection from bleeding.”

Based on positive results from the Phase 1/2a trial, rFIXFc was advanced into a global registrational trial called B-LONG in January. B-LONG is designed to assess the safety, pharmacokinetics and efficacy of rFIXFc in the prevention and treatment of bleeding in 75 previously-treated people with severe hemophilia B. rFIXFc’s ability to prevent bleeding using different dosing regimens is being measured by evaluating the number of breakthrough bleeding episodes.

**Biogen Idec and Swedish Orphan Biovitrum Present Data on Long-Lasting Hemophilia B Therapy at the World Federation of Hemophilia Congress**

“We look forward to results from the registrational trial and are excited about the potential of rFIXFc to significantly reduce the frequency of injections necessary for people with hemophilia B,” said Peter Edman, Ph.D., Chief Scientific Officer of Swedish Orphan Biovitrum.

Using the same proprietary technology as rFIXFc, Biogen Idec and Swedish Orphan Biovitrum are also developing a recombinant, long-lasting Factor VIII Fc fusion protein (rFVIII Fc) for the treatment of hemophilia A. The companies recently announced their decision to advance rFVIII Fc into a registrational trial based on positive results from a Phase 1/2a open-label, cross-over, dose-escalation study designed to evaluate the safety and pharmacokinetics of rFVIII Fc in people with severe hemophilia A. For more information on the rFIXFc and rFVIII Fc trials, please visit [www.biogenidechemophilia.com](http://www.biogenidechemophilia.com) or [www.clinicaltrials.gov](http://www.clinicaltrials.gov).



# *Factor Nine Holiday Fund 2010!*

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, 2010* 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, 2010.**

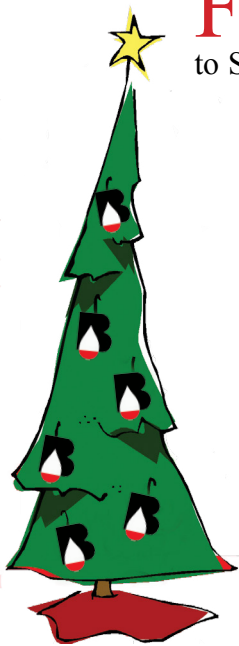
(Your name and information will be kept *strictly* confidential.)

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!

### INHIBITOR FAMILY CAMP

Comprehensive Health Education Services (CHES) presents a weekend long, first-ever, camp for children with inhibitors and their families which is being held at Victory Junction in Randleman, NC on October 15-17, 2010. Inhibitor Family Camp is available to children and teens living with an active inhibitor and their immediate families. There are no fees to attend the camp and travel assistance is available. The camp is designed to provide education and fun activities in a relaxing atmosphere enabling families to establish meaningful bonds with one another. For more information and registration visit the CHES website at <http://www.comphealthed.com/Inhibitor-Family-Camp-Main-Page.php> or call 877-749-2437. This camp is supported by an educational grant from Novo Nordisk.



## The Coalition for Hemophilia B *Autumn 2010 Factor Nine Family Meeting*



**Visit the Coalition for Hemophilia B Booth!**  
**New Orleans, Louisiana November 11-13, 2010**  
In conjunction with National Hemophilia Foundation Conference  
New Orleans Marriott, 555 Canal Street, 800-266-9432

**Factor Nine Family Breakfast Meeting**  
**Saturday, November 13, 2008**  
8:00 - 9:30 am  
Location TBA

### **Please join us in New Orleans for Breakfast on Saturday Morning!**

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!**

### *Scholarship Notice!*

The William N. Drohan Scholarship application form for 2011 is now available on our website [www.coalitionforhemophiliab.org](http://www.coalitionforhemophiliab.org) under scholarships. The deadline is February 15, 2011.

*Wishing all of you a Wonderful Autumn!*

### **Reminder**

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

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](mailto:hemob@ix.netcom.com) Website: [www.coalitionforhemophiliab.org](http://www.coalitionforhemophiliab.org)