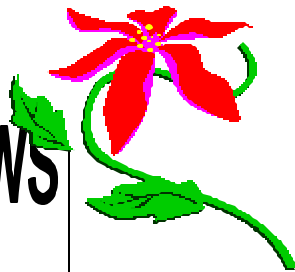


# HACA News



**December  
2002**

**Volume 18 Issue 6**

*The material provided in HACA News is for your general information only.*

*HACA does not give medical advice or engage in the practice of medicine.*

*HACA under no circumstances recommends particular treatment for specific individuals, and in all cases recommends that you consult your physician or treatment center before pursuing any course of treatment.*

## Mission Statement

*HACA's Vision is to improve the quality of life for persons and their families affected by bleeding disorders.*

*HACA's mission is to:*

- ◆ Educate, support and advocate for persons with bleeding disorders and their families.
- ◆ Network with healthcare professionals.
- ◆ Increase public awareness.

Hemophilia Association of the Capital Area  
3251 Old Lee Highway  
Suite 3

Fairfax, Virginia  
22030-1504  
(703) 352-7641

Fax (703) 352-2145

E-mail: [hacacares@aol.com](mailto:hacacares@aol.com)  
[www.hacacares.org](http://www.hacacares.org)

CFC #6022

## Poinsettia Sale

Our annual poinsettia sale will be taking place during the month of November. Once again, we will be offering poinsettias in two sizes: 6" with 4-5 blossoms and 8" with 12-15 blossoms. The plants will be offered in two colors: red and pink. The price of the 6" plant is \$8 and the price of the 8" plant is \$20. Half of the purchase price is a tax deductible donation to HACA. The deadline for ordering plants is **November 21**. Plants can be picked up on Saturday, December 7<sup>th</sup> at Lord of Life Lutheran Church, 5114 Twinbrook Road, Fairfax, VA between 8:30 and 10:30 am or at the home of Jim and Deb DeArmon in Maryland between the hours of 9 –11 am. Please call the HACA office at 703-352-7641 to place your order.

## Advocacy Workshop

HACA's Public Relations Committee is planning an advocacy workshop for January 25<sup>th</sup> from 9am to 1pm. The purpose of the workshop is to help us understand the organization of Capitol Hill and the various other groups such as Maternal and Child Health Bureau (MCHB), Centers for Medicare/Medicaid Services (CMS), etc. We will be looking at how to have an effective legislative visit and how to write an effective letter. Finally, we will be reviewing the issues that are currently being pursued on behalf of hemophilia on Capitol Hill. Please make plans to attend this very important workshop.



## NHF Washington Day

This year NHF is enlarging the scope of Washington Day. The event is becoming a two day event and will be held March 6-7. On the evening of March 5<sup>th</sup>, HACA is hosting a reception for attendees from 7-9 pm. A light dinner will be served at that reception and then there will be training on the talking points for the legislative visits that will be made the next day. Visits to Senators and Representatives will take place on Thursday, March 6<sup>th</sup>. On Friday, March 7<sup>th</sup>, NHF will be sponsoring a training session for effective lobbying at the state level. Please make plans now to take part in as much of this advocacy as you are able. HACA will be looking for a good representation of people at the reception on March 5<sup>th</sup> since we are serving as the host chapter for this event.

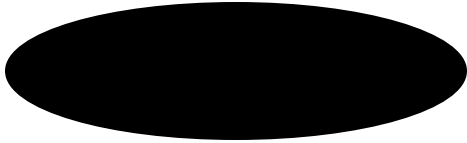
## Bleeding Disorders Directory

The National Hemophilia Foundation (NHF) is in the process of revising their Directory of Women and Parents/Guardians of Female Children with Bleeding Disorders. Since many of the issues that affect women and girls with bleeding disorders differ from those affecting men, NHF hopes that this directory will stimulate networking and information exchange among its participants.

The directory is distributed only once a year. To preserve the confidentiality of the participants, distribution will be only to those individuals who are listed and have signed a confidentiality agreement form. You can obtain the information and confidentiality forms by calling the HACA office at 703-352-7641 or by downloading the forms from NHF's website at [www.hemophilia.org](http://www.hemophilia.org).

Interested individuals should return their completed forms to NHF by **Friday, December 7, 2002**. The directory will be distributed in January 2003.

Update on West Nile Virus and Blood and



## Organ Donations

NHF Medical Advisory #394  
October 10, 2002

It now appears that it can be stated with confidence that West Nile Virus (WNV) is transmitted via transfusion of blood and blood components as well as by organ transplantation. Transfusion through breast milk is also being studied.

NHF has asked the manufacturers of all clotting factor products to demonstrate that WNV is destroyed or removed from their specific products. In addition, plasmapheresis centers have been instructed to develop protocols for deferring donors exhibiting possible symptoms of WNV as well as protocols for quarantining and retrieving plasma from donors that report post-donation illness.

## New Website Puts Critical Information for Emergency Care of Patients with Hemophilia At Caregiver's Fingertips

## Baxter Announces Larger Sizing for Hemofil M AHF September 2002

Baxter BioScience announced that Hemofil M AHF is now available in a vial that provides 1701 and 2000 I.U.s per vial.

## Wyeth Pharmaceuticals Introduces Larger Sizing for ReFacto® October 2002

Wyeth announced that ReFacto® is now available in a 2000 IU vial. The new vial contains more Refacto with the same small volume (4mL) of reconstitution.

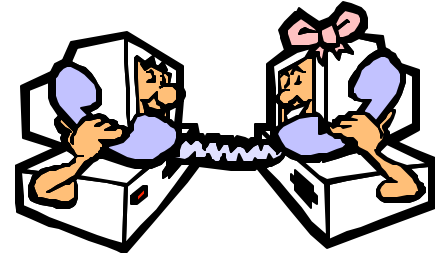
## Internet Wire October 15, 2002

## 2003 Board of Directors Meetings

General Board Meeting  
January 13, 2003  
Executive Board Meeting  
TBA

General Board meetings begin at 7:00 p.m. and are open to all interested HACA members. Because of security regulations at our meeting place, please notify the HACA office that you will be attending. Directions and site will be shared with you at that time.

A new, unique and potentially lifesaving online manual, "Emergency Care for Patients with Hemophilia" has been launched.



With even the best trained medical personnel having limited or no experience treating a person with hemophilia, immediate access by emergency room workers to vital treatment information and guidelines can mean the difference between life and death for such a patient. Now, for the first time, treatment information for a critically ill hemophilia patient with excessive bleeding is just a click away for hospital emergency rooms everywhere.

The website, located at [www.hemophiliaemergencycare.com](http://www.hemophiliaemergencycare.com) is made possible by an unrestricted education grant from Novo Nordisk to the Nursing Group of Hemophilia Region VI, which includes nurses in Texas, Arkansas, Louisiana and Oklahoma. The website contains information on treating specific bleeding issues including joint hemorrhages, head injuries, muscle bleeds, trauma and other bleeding situations.

**Calendar of Events**

December 7th	Poinsettia Pick-Up
January 25th	HACA Advocacy Workshop
March 5-7th	NHF Washington Day

# Germ-Killer May Let Body Ignore Some DNA Defects And Ease Genetic Diseases

By Malcolm Ritter, AP Science Writer

Can an old germ-killer provide a new weapon against genetic disease?

Some researchers battling such diseases as cystic fibrosis, muscular dystrophy and hemophilia hope so.

Intrigued by a handful of preliminary studies, they are giving the antibiotic gentamicin to carefully selected patients suffering from those conditions.

The weird thing is that nobody is asking gentamicin to kill germs. Rather, scientists hope to show that the drug can counteract the genetic defects that made those patients sick. And if that's true, scientists say, it could signal a new treatment strategy that goes far beyond those three diseases. "I'm most excited when I think about the general potential," said Dr. Steve Sommer of the City of Hope National Medical Center in Duarte, Calif., who has begun the hemophilia study.

"In theory, it can work for any (genetic) disease."

Gentamicin has been used for more than 30 years in the United States. It's generally given to treat a variety of infections, including those of the urinary tract or dangerous blood infections called sepsis in newborns.

When it comes to genetic disease, scientists already know that gentamicin and other drugs that act like it can't be a cure-all. That's because the kind of defect gentamicin targets shows up in only a fraction of people with a given genetic disease.

It's too soon to tell if the approach will really help anybody, and experts caution that patients should not try it on their own. For one thing, gentamicin use runs the risk of side effects like hearing loss and kidney damage.

But scientists hope the medicine will lead them to more benign drugs that have the same effect. It might inspire research that finds drugs that work against other kinds of mutations. And in the meantime, some say, the old antibiotic itself might help the right patients.

## In the new studies:

- Cystic fibrosis patients at several medical centers around the country will use a gentamicin nose spray to see if it spurs production of a crucial protein in the nose. It's the lack of this protein in the lungs and elsewhere that

causes the disease. The nose is simply a convenient place to look for an effect.

People with cystic fibrosis suffer from persistent coughing and potentially fatal lung infections. Scientists hope that eventually, drugs like gentamicin will aid lung functioning in patients, helping them lead healthier, longer lives. Some 5 percent to 10 percent of cystic fibrosis patients in general – but the majority of patients of Ashkenazi Jewish descent – have the kind of defect gentamicin targets.

- Three dozen Duchenne muscular dystrophy patients, ages 5 to 15, will enter a six-month study at Ohio State University. Scientists will see whether gentamicin makes their muscles stronger.

Duchenne sufferers also lack a key protein, and the result is muscles that waste and weaken. A preschooler may have trouble climbing stairs or running; most patients lose their ability to walk by age 12. Gentamicin probably couldn't restore walking ability because so much muscle would have been lost already. So doctors would want to use it early in the disease.

Up to 15 percent of Duchenne patients have the kind of mutation that might yield to gentamicin.

- Thirty hemophilia patients in Sommer's study will take gentamicin injections over three days to see whether their livers will start making a fully functional clotting protein. It's the lack of such a protein that causes their disease.

Patients with the bleeding disorder can lead relatively normal lives now by injecting a genetically engineered replacement protein, but Sommer hopes the gentamicin work could lead to a pill instead. And for developing countries, where the replacement protein is prohibitively expensive, Sommer said, even injected gentamicin offers the hope of an affordable drug that could save children who now die.

The class of mutation targeted by gentamicin appears in about 10 percent of patients with the most common kind of hemophilia, and about 30 percent of severe cases of the less common kind. Sommer's work is supported by grants from the National Hemophilia Foundation and the federal government.

*(Continued on page 5)*

# The Factor IX Property

By Dr. David Clark

Factor IX has a peculiar property. When it is infused into the bloodstream about half of it immediately disappears. Therefore, patients use twice the amount of clotting factor that would normally be calculated as needed. This is one of many facts that are well known to hemophilia treaters, but which may not be as well known to patients and their families. In this issue we are going to describe some of these routine aspects of treatment. (Please do not double your Factor IX dosage. The missing Factor IX has already been taken into account in your current dosage.)

The amount of Factor IX needed to treat a bleeding episode varies depending on the particular event being treated. For early hemorrhages occurring in sites that pose a low risk, the Factor IX level might be raised to 15 – 20% of normal, while for hemorrhages in particularly dangerous sites such as the brain, the level might be raised to 50 – 100% of normal. Note that the “normal” level is just an average over the whole population of people without hemophilia. People without hemophilia can actually have factor levels ranging from as low as 40% to as high as 200% of what is defined as “normal”.

The rule of thumb is that one unit of Factor IX infused per kilogram of body weight raises the level by one percentage point (One kilogram is 2.2 pounds; a 150-pound person weighs about 68 kilograms.) The amount needed is calculated in relation to body weight because larger people have a larger volume of blood and thus need more factor. However, these are just typical or average values. The actual amount of clotting factor needed can vary significantly from patient to patient.

In fact, through experience a patient and his family usually become the best experts on what works for them.

The amount of Factor IX in a patient's blood can be measured in several ways. The most common method used in the U.S. is a clotting assay. In this method the time that it takes a blood or plasma sample to clot is measured. That clotting time is then compared to the clotting time for a reference standard that has a known concentration of Factor IX to determine the amount of Factor IX in the sample being tested. The Factor IX concentration in a sample is often called its Factor IX potency. Because the clotting time is very sensitive to small changes in temperature and other conditions, the instruments used to perform clotting assays maintain these conditions at precise levels to ensure that the clotting times are reproducible from one test to the next.

The amount of Factor IX and of most other clotting factors is measured in units. A unit is the average amount in one

milliliter of plasma from donors without hemophilia. (One thousand milliliters equals one liter, which is about the size of a quart.) However, because the concentration of Factor IX varies from person to person, a pool of plasma from a number of donors is used to establish the average value for a unit. Test laboratories may use a reference standard made from such a pool of donated plasma, or they may use a reference material obtained from an outside source.

Several national and international health organizations have developed reference standards. The amount of Factor IX in these standards is typically established by being tested by 25 laboratories around the world using various test methods. Each laboratory uses a local reference standard plasma pooled from at least 15 donors. The average of the values obtained by all these laboratories then becomes the potency of the standard. When a laboratory uses an international standard in their assays, their results can be expressed in International Units (IUs). Most factor IX concentrates have a potency expressed in IUs.

Factor IX has a half-life of about 24 hours. This means that half of the Factor IX in the bloodstream disappears every 24 hours. For instance, if a patient is infused with Factor IX to give a level of 50% of normal, 24 hours later his Factor IX level will have dropped to about 25% of normal, and 24 hours after that it will have dropped to about 12.5% of normal. Proteins and other molecules in the blood stream disappear by a normal process known as clearance. Proteins gradually wear out and are normally cleared and replaced at fairly constant rates. This continual production and clearance maintains a fresh supply of the protein in the body and keeps the level of the protein approximately constant. However, hemophilia patients do not replace their cleared Factor IX, so the level of factor injected into their bloodstream gradually decreases. In cases where factor infusions are given repeatedly over a period of time, for instance in patients undergoing prophylactic treatment or in patients being prepared for surgery, the Factor IX level in the bloodstream will rise and fall in a fairly regular fashion. The Factor IX level will reach a peak value immediately after infusion and then decline as the Factor IX is gradually cleared. The lowest level, known as the trough level, is reached just before infusion of the next dose. The goal is generally to keep the trough level above a certain point at which the patient has minimal bleeding problems, for instance above 1% or 5% of normal.

*(Continued on page 5)*

(Continued from page 4)

### The Factor IX Property (continued)

The amount of Factor IX that can be measured in the bloodstream after an infusion compared to the amount infused gives the recovery. As mentioned above, Factor IX has a recovery of about 50%, that is, only about half of the Factor IX infused can be found in the blood.

Recovery can also vary significantly from patient to patient over a range of 30 to 70% or more. It can also vary among Factor IX products. For instance, it is known that recombinant Factor IX, BeneFIX, gives a slightly lower recovery in most patients, so slightly higher doses are normally used. Although historically recovery has been expressed as a percentage, today it is often

expressed as the increase in units of Factor IX per deciliter of plasma divided by the units of Factor IX infused per kilogram of body weight or "U/dl / U/kg". (A deciliter is one-tenth of a liter and is equal to 100 milliliters.) A recovery of 1.0 U/dl / U/kg is equivalent to a 50% recovery.

So where does the missing half of the infused Factor IX go? Researchers are still trying to answer this question. None of the other clotting factors exhibit this behavior. Although it is not completely understood, it appears that a significant amount of Factor IX binds to the surface of endothelial cells, the cells that line the inside of blood vessels. The bound Factor IX may represent a natural reservoir of extra clotting factor that can be released back into the bloodstream when needed.

(Continued from page 3)

### Germ-Killer (continued)

With the new studies, scientists hope to strengthen the case that gentamicin and other "aminoglycoside" antibiotics can treat genetic disease by helping patients produce key proteins. Normally, patients with a particular kind of genetic defect make only incomplete proteins, and the drugs are expected to encourage their bodies to finish the job. Such drugs wouldn't lead to normal levels of protein, but for many diseases, even a limited amount can help.

Scientists have known for decades that antibiotics like gentamicin can counter this kind of genetic defect in yeast cells. But it wasn't until 1996 that David Bedwell, a microbiologist at the University of Alabama at Birmingham, and his colleagues demonstrated the effect in human cells with a mutated cystic fibrosis gene.

And in 1999, H. Lee Sweeney at the University of Pennsylvania School of Medicine showed the same result in mice that couldn't ordinarily make dystrophin, the protein lacking in Duchenne muscular dystrophy. With treatment, the mice made enough dystrophin to protect their muscles.

Sweeney's paper galvanized efforts to look at antibiotics for genetic diseases, says one researcher in the field, Michael Howard of the University of Utah.

"I think seeing it in a living organism like a mouse made it much more dramatic and much more believable that it might work", he said.

Already, the search for better drugs has shown some promise, said Sweeney, who's working with PTC Therapeutics in South Plainfield, N.J.

"We actually have a few that look more promising than gentamicin at this point," he said. In the next year or two, one might be ready for studies in people, he said.

So far, previous research with gentamicin in patients has been very limited and preliminary.

In muscular dystrophy, two small studies found no direct sign of dystrophin production but did find evidence suggesting that muscle damage from the disease was reduced.

Dr. Jerry Mendell, a neurologist at Ohio State who led one of the studies, is launching the new follow-up with support from the Muscular Dystrophy Association and the federal government. He suspects both prior studies may have overlooked a real increase in dystrophin production.

In cystic fibrosis, two researchers who found encouraging signs in preliminary studies of the nose are following up. Dr. J.P. Clancy, a colleague of Bedwell's at Birmingham, is leading a bigger study with support from the Cystic Fibrosis Foundation. And Dr. Michael Wilchanski of the Shaare Zedek Medical Center in Jerusalem, is continuing work as well.

"I see great promise in this avenue of research," Wilschanski said.

He said he gets e-mails regularly from around the world, from parents of cystic fibrosis patients, asking how the research is going.

That "tells me I have to keep going," Wilschanski said.

- September 16, 2002 *The Associated Press*

# Stanford Researchers Develop Gene Therapy Technique That Sharply Cuts Risks

STANFORD, Calif.--(BUSINESS WIRE)--Oct. 13, 2002-- Researchers at Stanford University Medical Center have devised a new gene therapy technique that appears to eliminate one of the major health risks linked to gene therapy. The technique, published in the Oct. 15 advanced online edition of the journal *Nature Biotechnology*, overcomes the need for viral vectors that have plagued gene therapy trials, while retaining the ability to insert therapeutic DNA into specific sites in the chromosomes.

"Our approach provides an alternative that didn't exist before," said Michele Calos, Ph.D., associate professor of genetics at the School of Medicine and lead author on the study.

The goal of gene therapy is to insert a healthy copy of a gene into a cell where it can take over for a faulty version. If the therapeutic DNA does not integrate into the human chromosome, it produces its protein for a short time before being turned off or broken down within the cell. For a long-term cure, the gene has to wedge itself into a chromosome where it remains indefinitely integrated, getting passed on when the cell divides.

Current gene therapy approaches that cause genes to integrate use a viral vector to sneak the therapeutic DNA into the host cell, Calos said. However, the DNA inserts itself into the chromosome at random positions. In one recent French gene therapy trial, the randomly inserted DNA apparently activated a neighboring oncogene, causing a patient to develop leukemia. "That sort of puts another cloud over the existing gene therapy trials," Calos said.

Calos' technique avoids the pitfalls of other gene therapy approaches by integrating DNA without using viral vectors, inserting the DNA at known locations. This new technique can also handle genes that are too large to fit into a viral package, such as the gene for Duchenne's muscular dystrophy, Calos said.

In developing this new approach, Calos hijacked a mechanism used by a bacteria-infecting virus (called a bacteriophage) to integrate its genes into bacteria. The bacteriophage makes a protein called integrase that inserts the viral genes into a specific DNA sequence on the bacteria chromosome. It turns out that humans also have a version of that DNA sequence. When the researchers insert a copy of the therapeutic gene and a gene coding for integrase into a human cell, the integrase inserts the gene within the human sequence.

Calos and members of her lab, in collaboration with Mark Kay, M.D., Ph.D., professor of pediatrics and genetics, tested the technique using a gene that makes Factor IX-- a protein that is missing in the blood of people with one form of hemophilia. They injected mice with a piece of DNA containing the Factor IX gene plus a stretch of DNA that acts as an "insert me" signal to integrase. At the same time they injected a gene for integrase.

Within a week, mice that received this injection made 12 times more Factor IX than their littermates that received the injection without the integrase. Further experiments confirmed that the Factor IX gene had successfully integrated into the mouse DNA.

Although the mouse genome contains at least 53 potential integration sites, Calos and her team found the Factor IX gene in only two locations, with one location by far the more common. She said that for each tissue there may be a particular site that is the most likely insertion point. Her group is testing the technique in different tissue types to ensure that no human integration site is near a potential oncogene. "We need to look in different tissues to see where the hot spot is," Calos said.

Calos is also modifying the integrase so it targets specific integration sites that her team knows are safe. "We mutated the enzyme and evolved it so it will prefer one place over another," she said.

Calos said this approach should be effective for treating diseases in several different human organs including skin, retina, blood, muscle and lung. She hopes to start human trials for the technique in a fatal childhood skin disease called recessive dystrophic epidermolysis bullosa, which she has already treated in mice. "If that trial shows that it is safe then that will open the door for trials in other diseases," Calos said. She has collaborations underway testing the technique for use in Duchenne's muscular dystrophy and cystic fibrosis, among others.

Contributing researchers to the study include Stanford graduate students Eric Olivares and Thomas Chalberg, and post-doctoral scholar Roger Hollis, Ph.D.

Stanford University Medical Center integrates research, medical education and patient care at its three institutions--Stanford University School of Medicine, Stanford Hospital & Clinics and Lucile Packard Children's Hospital at Stanford.

*(Continued on page 7)*

# Trough, Nadir, One Hour Post?

## *What does it mean for my child?*

Both of my children have severe hemophilia B. As a result, they've had more than their share of blood tests done. It's easy to get frustrated with all the lab work that's ordered, but we have learned how important the results are in calculating factor doses and evaluating our prophylaxis regime. When the boys need routine blood tests ordered by our pediatrician, they are done at a lab or clinic in our hometown. However, when we need specific information about how their bodies are responding to the factor we are infusing, the tests are done through the laboratory associated with our hemophilia treatment center. Factor levels, or assay studies, are very specific, sensitive tests that are not routinely run in clinic or hospital laboratories. In order to get results that are reliable and valid, it's important to make sure the facility running the tests has extensive experience performing tests ordered by a hematologist.

Before our boys started on a regime of primary prophylaxis, we had never heard of a "one hour post" factor level or trough study. By the time we had settled in to our twice-weekly infusion routine, we felt like we were experts on the subject. We learned that trough studies are done to measure the amount of factor in their systems on their "lowest" day or just before their next infusion. Some medical professionals may also refer to this as a nadir level. Knowing and understanding the results of the myriad factor assays is key in determining if an infusion regime is effective.

When Sam was started on BeneFIX for prophylaxis, there weren't many other kids, if any, at our HTC who were using this product. Our physician was adamant that we analyze the way his body uses factor and what his levels were not only right after he was infused, but also right before we infused him. When we would have a clinic visit, blood would be drawn before we infused his factor to see how much, if any, was left in his system from his last infusion which had been anywhere from 48 to 72 hours before our visit; these are trough or nadir levels. Blood

was also drawn one hour after his infusion to see how much factor was circulating in his system at that time; these are called one-hour post levels. Additional levels are sometimes drawn 24 hours after an infusion to further show how well a patient's body is responding.

What we learned surprised us. We had been infusing enough factor to raise their levels to between 36 – 40% of correction twice a week. We expected that the one-hour post infusion levels would be right around that same percentage. Unfortunately, the levels were always much lower than that...in the low to mid twenties. By using this information, we established their half-life, or how quickly their bodies used up half of their factor. We thought that we may have to increase Sam's dose to keep him at about 1% correction at all times. You can imagine our surprise when we received the results of their trough levels; those results indicated that Sam's levels were staying between 3 – 7%; not less than 1% as we had surmised.

Had we only relied on the one-hour post infusion studies that were done, we probably would have significantly increased the amount of recombinant factor 9 that we had started out using. Instead, we were able to breath easy knowing that we were maintaining factor levels about 1%. Furthermore, our day-to-day lives showed us that we were doing the right thing. Our boys have stayed on primary prophylaxis infusing twice a week to a level of correction between 35 – 40% with no break-through bleed. We aren't using more factor than we need either. For some, this may be vital as they near lifetime insurance caps. Our experience with the current recombinant product on the market has been positive. Because of thorough testing on the part of our HTC, especially in regards to the trough/nadir level studies, we know that we're infusing the amounts that the boys need and at the same time not using more product than we have to.

*(Continued from page 6)*

### **Stanford (continued)**

For more information, please visit the Web site of the medical center's Office of Communication & Public Affairs at <http://mednews.stanford.edu>.

CONTACT:

Stanford University Medical Center  
Amy Adams, 650/723-3900 (Media)

amyadams@stanford.edu  
Neale Mulligan, 650/724-2454 (Broadcast Media)  
nealem@stanford.edu

*SOURCE: Stanford University Medical Center*

Today's News On The Net - Business Wire's full file on the Internet with hyperlinks to your home page. URL: <http://www.businesswire.com>

## Product Manufacture Companies

The following is a list of Product Manufacture Companies and the Factor VIII, Factor IX, anti-inhibitor, and von Willebrand's Disease products that they produce. The majority of products are derived from human sources, the recombinants, Stimate (high concentrate DDAVP), and Hyate:C being the exceptions (recombinant products are genetically engineered, Stimate is synthetically derived and Hyate:C is made from porcine factor). All human derived products are virally attenuated, using a variety of methods. Your HTC physician can explain these methods.

Many of the product manufacturers offer financial and other auxiliary services for consumers using their products. The names and phone numbers of the local representatives are listed for anyone interested in finding out more about the individual companies.

Company	Products			
	Factor VIII	Factor IX	Anti-Inhibitor	Von Willebrand's
Alpha Therapeutic Corporation	Alphanate	AlphaNine-SD		Alphanate (Off label usage. Clinical trials
American Red Cross	Monarc-M (Mfg.by Baxter			
Aventis Behring LLC	Humate-P Monoclote-P Helixate FS*	Mononine		Stimate (for Type I) Humate-P
Bayer Corporation	Koate-DVI			Koate-DVI
Baxter BioScience	Hemofil-M	Proplex-T	Feiba VH	
Porton Products			Hyate:C	
Genetics Institute	ReFacto*	Benefix*		
Novo Nordisk			NovoSeven* (also used for factor 7	
Nabi			AutoPlex-T	

\*Recombinant Product

## LOCAL MANUFACTURER'S REPRESENTATIVES

### **AMERICAN RED CROSS**

Veronica Foster (800) 256-6377x3122245

### **BAYER, INC**

Jack Shoff 1-800-246-5551X84807

### **AVENTIS BEHRING LLC**

Gina Raymond-Duncan (800) 394-1290x6384

### **BAXTER BIOSCIENCE**

Kevin O'Conner (800) 777-5513x7204

### **WYETH**

Kelly Wren (703) 837-0894

### **NOVO NORDISK**

Elizabeth Tawil (410) 349-8962

## HOME CARE COMPANIES

Home Care Companies provide numerous services for persons with bleeding disorders. Though all Home Care Companies can provide the major brands of products, there are individual differences between the companies and the services they provide. As with any purchase, it is wise to compare the companies to find the one that best suits your needs. It is also recommended that you consult with your physician before making your final choice.

### **AHF, INC.**

Shirley Moorhead (866) 243-4621

### **CAREMARK THERAPEUTIC SERVICES**

Vickie Strange (800) 670-6782x3305

### **HEMOPHILIA HEALTH SERVICES**

VA-Becky Cohn (703) 550-1824

MD-Sharon Walker (410) 296-7463

### **FACTOR SUPPORT NETWORK**

Randy DeSantis (877) 376-4968

### **HEMOPHILIA RESOURCES OF AMERICA**

Ana Spielberg (800) 549-2654

### **OPT CARE PLUS**

Renee West (703) 499-9440

### **APEX THERAPEUTIC SERVICES**

John Butram (410) 552-1150

### **CORAM HEMOPHILIA SERVICES**

Amy Judge (804) 375-3400

### **E BIO CARE**

Carletha Gates (301) 249-8163

### **NuFACTOR**

(800) 232-6832

## ADDITIONAL FACTOR SUPPLIERS

### **GEORGETOWN FACTOR CONSORTIUM**

Lisa Jacobs (202) 687-4861

Profit from the Georgetown Factor Consortium helps to support the Hemophilia Treatment Center at Georgetown

### **POSITUDES**

John Degiorgio (804) 789-1368

Positudes is a non-profit pharmacy. Profits from factor sales are directed back to the Hemophilia community in the form of grants to various hemophilia organizations.

Do not follow where the  
path may lead.



Go instead where there is no path and  
leave a trail.

Muriel Strode

# HACA News

3251 Old Lee Highway, Suite 3  
Fairfax, Virginia 22030-1504

---

Non-Profit Org.  
U.S. Postage  
PAID  
Fairfax, VA  
Permit No. 715

---