

# HACA News

**December  
2005**  
Volume 21 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.

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CFC #6022

## HACA Is Moving!

Big news for the HACA Office! After 13 years in the same location, we are moving on December 1, 2005. We have simply outgrown our current office space. Our larger space is located in the Mosby Towers Building at 10560 Main Street in Fairfax, Suite 604. We ask that you bear with us for the first week or two as we get phone lines and internet re-established. Our phone and fax numbers will remain the same.

Our new mailing address:  
HACA  
10560 Main St., Suite 604  
Fairfax, VA 22030

Phone: 703-352-7641  
Fax: 703-352-2145

Email: [hacacares@aol.com](mailto:hacacares@aol.com) until further notice



## Holiday Party

Thanks to Terry and Michelle Stone, Kirstin Duggan, and our Gingerbread Girl, and Holiday Elf for helping with a terrific Holiday Party on December 4th. Over 70 people enjoyed seeing Washington DC like a group of tourists and then enjoyed gathering for dinner at the Country Buffet following the tour. What a great way to begin the Holiday Season!

## Annual Campaign

Thank you for your donations to our annual campaign. HACA has set important goals for the next few years. Whether we can accomplish them or not depends on your financial support. Many of you have been very generous in returning your donation forms. If you have not made a donation to HACA yet, please consider doing so. We are not asking for large donations, although we will certainly accept those. Instead, we're seeking a greater participation of our members. If everyone makes even a small contribution, it will go a long way to achieving our shared goals. Please help us continue the work for our families by stepping up and making a financial contribution. Your support is vital!

## Upcoming Art Auction

Don't be an April Fool and miss your chance to take part in our newest fundraiser! We will be working with Ross Galleries to present an Art Auction at the Old Town Hall in Fairfax City at 7 pm on Saturday, April 1, 2005. Tickets to the auction are \$10 each or \$15 a couple. Beautifully framed pieces of art will be offered that evening by a professional auctioneer. We will be serving tempting desserts during the preview prior to the sale.

We'll give each of you the opportunity to support this fundraiser by selling tickets, selling ads for the program, and or attending the auction and purchasing art to enhance your home. We also have the opportunity to auction off 6 pieces of donated art, so if you know of an artist or are an artist that would donate art for the auction, please let us know at 703-352-7641.

## Chapter News continued

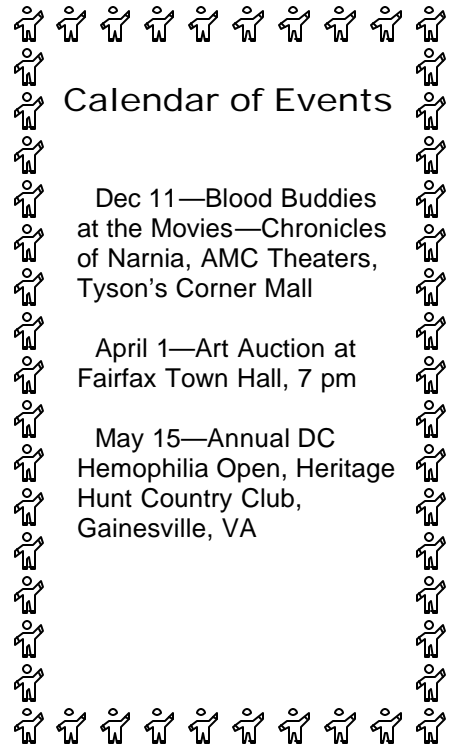
### Thanks to Departing Board Members

Several board members have rotated off the HACA Board of Directors. We would like to extend sincere thanks to those members for their time and dedication to the bleeding disorders community. Sandy Sanford has been on the board for the past two years. During that time, she was instrumental in putting together our Conflict of Interest policy. Sandy also often was the “voice of reason” at board meetings and her pertinent questions often helped the board think outside of the box. Lynda Mulhauser was on the board three years. During her tenure on the board, Lynda was very active in helping with the program for our Annual Educational Seminars and she also was a great help in developing the program that helped HACA win a grant from NHF for Outreach to Women with Bleeding Disorders. After departing from her position as Social Worker at CNMC, Lynda began working at NIH. There, the NIH Conflict of Interest Policy eventually required her resignation from HACA’s board.

### Welcome Newly Elected Board Members

Several people were elected (or re-elected) to the Board of Directors at our Annual Meeting on September 24, 2005. Ann O’Leary Amato, the social worker for the Hemophilia Treatment Center at Children’s National Medical Center, was elected to her first term on the Board. Mitch Ballweg was re-elected to the board. Mitch is a lawyer with the United States Department of Justice and is a person living with a bleeding disorder. Lou Baumgartner was re-elected to the Board and has agreed to another 2 year term as our treasurer. Kirstin Duggan, our summer intern and a woman living with a bleeding disorder; is currently employed by a marketing firm in the Tysons Corner Area. Meredith Holland is employed by Archstone-Smith in Arlington where she serves as Executive Assistant to Robert H. Smith. Meredith volunteers in the community through her membership in the Jr. League. She became interested in HACA through close friends who have a child with a bleeding disorder. Cliff Krug, Jr is a co-owner of Regency Moving and Storage in Woodbridge and the father of a child with a bleeding disorder. During his first tenure on the board, Cliff was the Chairperson for our very effective golf tournament. Cliff also was elected the position of Vice President of the Board. Eileen Prohett is a Marketing Manager for McNeill Nutrntionals and the parent of a child living with a bleeding disorder. During her first tenure on the board, Eileen served on the Scholarship Committee and the Nominations Committee. She has also been actively involved in the golf tournament and has helped with most of the policies that have been developed during the last two years.

We welcome each one of you to HACA’s Board of Directors and look forward to the great things we will do together. These newly elected



### Calendar of Events

Dec 11—Blood Buddies at the Movies—Chronicles of Narnia, AMC Theaters, Tyson’s Corner Mall

April 1—Art Auction at Fairfax Town Hall, 7 pm

May 15—Annual DC Hemophilia Open, Heritage Hunt Country Club, Gainesville, VA

members will join the following continuing members: Keith Bushey (President), Nina Duggan (Secretary), Becky Cohn, Martha Downing, Damaris Hagge Goss, Don Han, and Terry Stone.

We also extend thanks to the members of our nominating committee—Don Han (chair), Keith Bushey, Nina Duggan, and Eileen Prohett—for bringing forward such a fine group of new board members.

### Alternate HFA Representative Sought

HACA is currently seeking an alternate representative to the Hemophilia Federation of America Board. Your duties would include taking part in the board conference calls if our representative was unable to take part in the call. Please call the HACA office at 703-352-7641 if you would be willing to fulfill these duties.

## Congratulations to the Doar Sinkfield Family

We are happy to welcome a new member to the Doar Sinkfield family. Colette Simone Doar Sinkfield, weighing in at 9 lbs, 2 oz. and measuring 21", was born on August 1. Congratulations to Rick and Julie, and to new big brother, Hunter.

## To Go Bags

With all the natural catastrophes we've seen this year, there is an extra impetus for families to have a "To-Go Bag" ready at all times. Useful whether you're running out to visit friends, running errands, or for some more dire reason, the "To-Go Bag" helps speed you on your way. What is a "To-Go Bag"? Simply, a collection of anything you might need to treat an affected child when you're away from home. Moms with more than one affected child suggest color-coding the bags and the items in them so that you know which bag is for which child. Keep the bag packed so you can grab it quickly as you go out the door and don't forget to replenish supplies when you use them. Among the suggested items to put in the bag:

- Factor (added at last minute)
- Ice for the factor (added at last minute)
- Instant Ice packs
- Hand warmer
- Sharpie box
- Wet Ones
- Tourniquet
- 12 Syringes
- Band-aids/Butterfly bandages
- Amicar
- Extra gauze
- Ace bandage
- Flashlight
- Alcohol
- Shock blanket
- Treats (candy, games)
- Infusion Log
- Books—to entertain restless children
- Measuring tape – to monitor size of bleed sites
- Medical Release for Any Adult
- Emergency Contact List

## 2006 Board of Directors Meetings

January 9, 2006

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.

Letter from HTC (Treatment Plan)  
Empty bag for garbage

This 'n That

### **Bayer Receives FDA Approval for Room Temperature Storage of Kogenate(R) FS; Extended Storage Labeling Provides Greater Flexibility for Individuals Living with Hemophilia A**

The Biological Products Division of Bayer HealthCare, LLC., (Bayer BP) has announced that Kogenate(R) FS (Antihemophilic Factor (Recombinant), Formulated with Sucrose) received approval to be stored at room temperature (77 degrees F, 25 degrees C) for up to three months. The new storage guidelines for the treatment will provide users with greater flexibility and simplify storage options.

Starting in November 2005, each package of Kogenate(R) FS will include a special notification with details on the new labeling. While the new room temperature storage option may be used, Bayer recommends refrigerating (36 degrees - 46 degrees F, 2 degrees - 8 degrees C) Kogenate(R) FS whenever possible. It also is important to note that product stored at room temperature should not be returned to refrigeration. Kogenate(R) FS users who may have additional questions about storage requirements for their existing product inventory should call Bayer Clinical Communications at 800-288-8371.

### **ZLB Behring Announces Web Site for Hemophilia B Patients and Their Families**

(Continued from page 3)

ZLB Behring has developed a web site dedicated to Hemophilia B patients and their families. Located at [www.HemophiliaB.com](http://www.HemophiliaB.com), the web site is billed as your one-stop source for the latest information about hemophilia B.

### U.K. Woman Treats Symptoms of VWD with Over-the-Counter Medication

Rona Macdonald, a 41-year-old woman from the United Kingdom (U.K.), experienced regular nose bleeds since childhood. However, it was not until she reached her 20s that she was diagnosed with von Willebrand disease (VWD). She is one of 600,000 people in the U.K. estimated by the London-based Haemophilia Society, to have VWD. Nose bleeds, along with heavy and prolonged periods, and easy bruising are generally accepted as warning signs of a bleeding disorder, although only 5,000 women in the U.K. have been diagnosed.

Rona has inherited Type 1 VWD, a milder form of the disorder. "I had always been prone to regular nose bleeds, which often seemed to happen in the most embarrassing situations. When I was younger it wasn't uncommon for me to suffer several nose bleeds a week. Some could last for ten minutes before I managed to stop them," she said. Her symptoms, which are less severe than in other subtypes of VWD, are manageable with treatment. Rona is able to treat her chronic nose bleeds with a readily available product. Nasal plugs, manufactured by the biopharmaceutical research and development company SEAL-ON, may be used to treat this bleeding symptom. The plug acts as a sponge by filling the nasal cavity and absorbing blood, while also releasing a powder that expedites the clotting process. This over-the-counter product is available in the U.S. and the U.K.

Source: *Daily Mail (London)*, October 11, 2005

## QUESTIONS AND ANSWERS

### QUESTION # 1: MY DOCTOR TOLD ME I MUST KEEP MY AMICAR SYRUP REFRIGERATED. IS THIS TRUE?

A. No. Amicar (aminocaproic acid) is an antifibrinolytic that is used to prevent a blood clot from dissolving once it is formed. It doesn't make you clot,

but it helps to keep you clotted once you do clot. It is very useful following mucous membrane bleeding such as nosebleeds, mouth and throat bleeds, GI bleeds and for women with menorrhagia (heavy or prolonged menstrual bleeding). Amicar is available in pill, syrup and intravenous injection. The brand name Amicar is manufactured by Xanodyne. There is a generic form, aminocaproic acid, manufactured by Versapharm. Both companies produce a syrup formulation and both companies recommend that the syrup be stored at controlled room temperature from 59-86 degree F. Most refrigerators are around 43 degrees F; therefore, Amicar should never be refrigerated. For more information please visit the companies' websites: [www.xanodyne.com](http://www.xanodyne.com) or [www.versapharm.com](http://www.versapharm.com).

### QUESTION # 2: HOW COMMON IS IT TO HAVE HEMOPHILIA AND VON WILLEBRAND DISEASE?

A.

B. While there are no firm numbers it is probable that vWd would occur in 2% of the general population. Although vWd and hemophilia are both inherited bleeding disorders, they are entirely different bleeding disorders involving two different proteins and two entirely different modes of inheritance. Hemophilia involves a deficiency of either factor VIII (hemophilia A) or factor IX (hemophilia B) needed to form a blood clot. Hemophilia is known as an X-linked or sex-linked recessive disorder meaning it is carried on the X chromosome. A male is XY and a female is XX so every person has at least one X chromosome. If a male has the hemophilia gene on his only X chromosome then he will have hemophilia. If a female has the hemophilia gene on one of her two X chromosomes then she is called a carrier of hemophilia (although about 1 in 5 carriers will have a subnormal level of either factor VIII or IX which can cause them to have abnormal bleeding.) Hemophilia affects approximately one in every 5,000 males. The main symptoms of hemophilia are joint and muscle bleeding, in severe cases occurring spontaneously with no known trigger. VWD, on the other hand, involves a deficiency or defect of a protein known as von Willebrand factor needed to help platelets stick to each other and the blood vessel wall to form a platelet plug at the site of the injury. VWD is known as an autosomal disorder, meaning it is carried on one of the chromosomes not involved in the determination of the sex of the person. In the case of vWd, it is transmitted on chromosome 12. Each person has two #12 chromosomes, one from

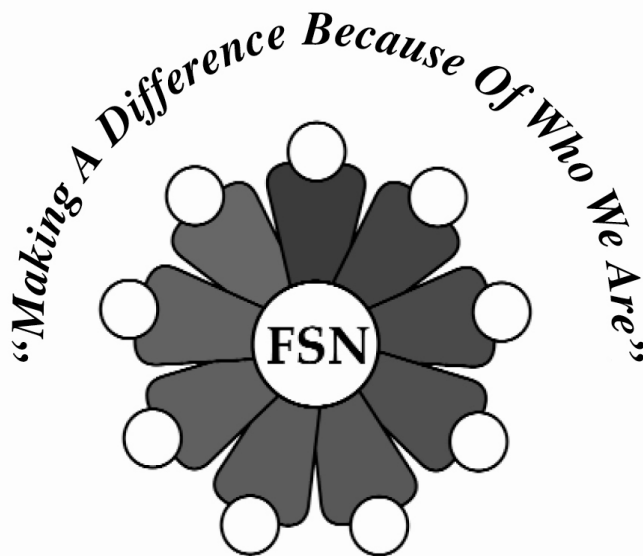
their mother and one from their father. vWD can be passed down by either parent to a child of either sex. It is generally inherited in a dominant fashion meaning the child needs to inherit only one vWd gene to have vWd and that gene can come from either parent. vWD affects both males and females with equal frequency and affects about 1 in every 50 people. The main symptoms of vWd are easy bruising, frequent or prolonged nosebleeds, heavy or prolonged menstrual bleeding and prolonged bleeding following injury, surgery, dental work or childbirth. So it is possible to inherit both the hemophilia gene on chromosome X and a vWd gene on one of your #12 chromosomes, just as it's possible for someone with hemophilia to also inherit other genetic disorders such as Cystic Fibrosis or Muscular Dystrophy.

*Views, published by the Hemophilia Foundation of Nevada, Volume 13, Number 1.*

*DISCLAIMER: The Hemophilia Association of the Capital Area does not endorse any provider, company or product. We do not provide direct medical care. The information contained within this newsletter is provided to you as an educational service and you should always consult with your physician or health care provider before pursuing or modifying any course of treatment.*

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# Giving Genetic Disease the Finger

By Sam Jaffe

Scientists are closing in on techniques that could let them safely repair almost any defective gene in a patient, opening the door for the first time to treatments for a range of genetic disorders that are now considered incurable.

The breakthrough, announced in the journal *Nature* in June, relies on so-called zinc fingers, named after wispy amino acid protuberances that emanate from a single zinc ion. When inserted into human cells, the fingers automatically bind to miscoded strands of DNA, spurring the body's innate repair mechanism to recode the problem area with the correct gene sequence.

A method for fixing miscoded DNA by injecting foreign genes into cells won headlines three years ago when doctors in France and Britain announced a handful of successful cures related to X-linked severe combined immunodeficiency disease, or SCID, also known as "bubble boy" disease. But that method was ultimately proven unsafe.

In a paper published earlier this month, scientists at California biotechnology company Sangamo BioSciences showed that zinc fingers can be used to erase targeted portions of DNA without risk of harmful side effects. "This doesn't just deliver a foreign gene into the cell," said Nobel Prize winner and CalTech President David Baltimore, who, with a Sangamo paper co-author Mathew Porteus, proposed this method to cure genetic diseases. "It actually deletes the miscoded portion and fixes the problem."

At the heart of the breakthrough is the concept of "if it's broke, break it some more." Cells have a method of DNA repair called homologous recombination, which fixes breaks in the double helix of our chromosomes. But the process only repairs places where the DNA has been cut, not where genes have been miscoded. Using a package of synthesized zinc fingers, cells can be tricked into doing nano-surgery on their own genes, Sangamo researchers found. The zinc fingers hone in like a guided missile on the exact spot in the genome doctors are trying to target and then bind to it. DNA-devouring enzymes then cut through the double helix of DNA at the exact beginning and end of the targeted gene, and a template of donor DNA helps rebuild the deleted strand.

While such a therapy has been theorized for years by Baltimore and others, Sangamo scientists are the first to show test-tube results with human cells. In a paper published June 2, Sangamo researchers showed how they were able to correct the defective gene in 18 percent of the T-cells extracted from the body of an Xlinked SCID patient. That should be enough to cure the disease, as it only takes one corrected T-cell to repopulate a person's

immune system with healthy cells, according to Sangamo.

If successful in trials, Sangamo's technology would be the first successful gene therapy, three decades after the concept of curing diseases by tinkering with the genome was first proposed. Most gene therapy trials have failed because the methods of inserting new genes into cells (usually with modified viruses as vectors) haven't proved to be effective enough.

One trial that did succeed, but then ended in tragedy, was a 2002 French Xlinked SCID trial that used retroviruses to deliver a new gene into the patients. The new gene cured the disease in 12 patients, but went on to cause leukemia in three of them. It turned out the foreign gene, in addition to producing the protein that vanquishes X-linked SCID, had the unexpected side effect of sometimes turning on a cancer-causing gene.

Sangamo's technology overcomes that problem. Whereas the French viruses inserted the foreign gene randomly into the host cell's genome, the zinc fingers are highly specific and can land only at the targeted gene.

"They've certainly raised the bar for gene-therapy safety," said Scott Wolfe, a zinc-finger researcher at the University of Massachusetts Medical School in Worcester, Massachusetts. He points out that the early proof-of-principle work was highly toxic to the cells. The zinc fingers weren't specific enough and they created so many double-stranded breaks in the DNA that a lot of the cells chose to commit suicide rather than try to repair all the breaks. "They really seem to have solved the toxicity problem altogether."

Although Xlinked SCID patients will probably be the first to try the therapy, the technology is extremely versatile for a host of human diseases. "Right now, its greatest weakness appears to be that it is optimized for very small patches of gene repair," said Baltimore. "If it's a long sequence of DNA that has to be fixed, this might not be the best way to do it."

Nevertheless, there are a lot of ways to attack diseases without replacing whole genes. Other potential targets for the therapy range from many types of cancer to cystic fibrosis and even AIDS. "If they can figure out how to optimize their zinc fingers for any spot on the genome, this could target any gene you want it to," said Wolfe.

-reprinted from *Wired News*, 02:00 AM July 5, 2005 PT

## An Attitude of Gratitude

It's that time of year. We're still recovering from our wonderful Thanksgiving feasts, and thinking fondly of the time we've spent with extended family. But even with Thanksgiving behind us, it's still an ideal time to reflect what we are grateful for in our lives, when we can appreciate what we have.

It's easy to pass through our busy daily lives and become swallowed up by problems. Problems, dilemmas and predicaments are inescapable. The attitude with which we face the problems is what is significant. Daily life supplies enough challenges, and to people living with a chronic disease, like a bleeding disorder, there are even more challenges. You can focus on how tiresome it is to live with hemophilia or you can choose to be grateful for everything that makes living with a bleeding disorder easier and less burdensome. Attitude is a choice.

A list of things for which to be truly thankful:

**Factor** – Be grateful for the relief and prevention of bleeds that factor provides.

**Joint Replacement Surgery** – Be thankful for the technology that allows the development of joint prosthesis. The pain relief from joint replacement can be tremendous.

**Excellent Doctors** – Be thankful for the skill, expertise and care given by doctors.

**Physical Strength**- Be thankful for the physical strength, stamina and endurance you have.

**Emotional Strength** – Be thankful for your ability to cope, and for courage and determination.

**Mutual understanding from friends** – Be thankful for the camaraderie of friendship and the effort made by friends to understand and to help.


**Love and support from family** – Be thankful for family and the unconditional love and support that is abiding.

The physical and emotional changes which come with having a chronic disorder need not destroy your zeal for life. Not all change must be negative. Make your life the best it can be. Be grateful for what you have. After all, part of gratitude is attitude.

-generously modified from the article, **An Attitude of Gratitude**, by Carol & Richard Eustice at: [http://arthritis.about.com/cs/inspiration/a/gratitude\\_p.htm](http://arthritis.about.com/cs/inspiration/a/gratitude_p.htm)

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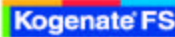
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Antihemophilic Factor (Recombinant)  
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# Medicare Drug Benefit Goes Into Effect January 1, 2006

Known as Medicare Part D, this program provides people enrolled in Medicare with the opportunity to voluntarily obtain, for a monthly premium of \$37 or less, a private drug insurance plan. **For people with both Medicaid and Medicare, this program will replace the Medicaid drug coverage they now have.** Medicaid drug coverage ends on December 31, 2005.

Everyone enrolled in Medicare will receive mass mailings explaining the program and how to choose a plan. **DO NOT THROW THEM AWAY.** Open them, read them and keep them. The handbook "Medicare and You 2006" should have arrived in October.

Part D coverage will be limited to drugs purchased in the United States which your plan agrees to pay for. In addition to the premiums there will be costs for the insured person: a deductible, co-payments, and limits to the amounts paid for claims.

## The "Extra Help" Program

People with low incomes are eligible for a program which

reduces their costs. The amount of "extra help" varies with income level. Social security has already mailed applications to Medicare beneficiaries on limited incomes who might be eligible. If you think you are eligible to apply, but have not received an application, call Social Security, 800-772-1213, right away. Those who receive Medicaid benefits, SSI or are on a state program that pays their Medicare premium should have been notified in June that they will automatically get "extra help" without having to apply. These people must choose a plan before November 15, 2005 or Medicare will assign them to one.

## **Q&A FOR MEDICARE PART D**

### What if I already have drug coverage?

You may add Part D to current drug coverage you have through your private insurance. If your plan is as good as Part D and you decide not to sign up for Part D coverage, you will not have to pay the higher premiums for later enrollment. Check with your existing plan: is it considered "creditable coverage" and will it be available in 2006?

### What if I have a Medigap insurance plan with drug coverage?

If your Medigap plan covers drugs, you can keep it. After 2005, drug coverage will not be offered with new Medigap plans. Your Medigap plan will tell you how your plan compares to Part D. You may change to a Medigap plan that does not cover drugs if you want to sign up for Part D; you cannot have drug coverage from both. If you stay with your Medigap drug coverage, you'll face a late enrollment penalty if you later join Part D.

### What if I have a Medicare Discount Drug Card?

Medicare Part D replaces the Medicare approved drug discount card program. Your discount card ends May 15, 2006, or sooner if your Part D plan takes effect sooner. You can keep non-Medicare-approved drug discount cards even if you enroll in Part D.

### What drugs will/will not be covered?

A prescription drug plan may establish a list of preferred drugs and may refuse to pay for other medicines. The law generally requires that all plans offer at least two different drugs (of the insurer's choice) for treatment of each condition or illness, and must provide "adequate coverage of the types of drugs most commonly needed" by Medicare beneficiaries. There are special rules for HIV drugs.

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If a doctor certifies a particular drug is medically necessary for a patient, the drug plan must cover it. The insurer is supposed to accept the judgment of the prescribing physician. Appeals for denials are complicated.

An insurer can remove a particular drug from its formulary (list of covered drugs) or increase co-payments after 60 days notification.

A few classes of drugs are entirely excluded and will have to be paid out of pocket. These include benzodiazepines (Xanax, Valium, etc.) and barbiturates (sleeping pills). For those on Medicaid, Medicaid will pay for any excluded drugs for which Medicaid currently pays.

**What is the “Doughnut Hole?”**

For those not on “Extra Help,” there will be a big gap, called the doughnut hole, in coverage. After Medicare Part D has provided \$1,500 toward payment of drugs, the plan holder will have to have spent \$3,600 out-of-pocket for covered drugs before being eligible for the “catastrophic coverage” part of the plan.

**What about the state drug assistance programs?**

EPIC for seniors and ADAP for HIV care will continue to exist and will interact with Part D. You must purchase a Part D plan to continue to participate in EPIC or ADAP.

**When can I sign up for Part D?**

You can enroll between November 15, 2005 and May 15, 2006. If you sign up after May 15, 2006, you will have to pay a late enrollment fee of 1% of the premium for every month you delay. You’ll pay it as long as you keep the Part D plan.

**How do I choose a plan?**

By October 13, you should be able to compare the coverage of available plans by going to [www.medicare.gov](http://www.medicare.gov) or calling (800)-633-4227. Look for the plan that best covers the drugs you need. If there is more than one, check which pharmacies accept the plan; you’ll want a convenient one.

**Can I change to a different Part D plan?**

If you have Medicaid, you can change plans at any time. Others can change plans once a year.

**Whom can I contact for help?**

- Medicare Rights Center (800)480-2060, ext. 82; [www.medicarerights.org](http://www.medicarerights.org); email: [lincs@medicarerights.org](mailto:lincs@medicarerights.org)
- Centers for Medicare and Medicaid Services (CMS) Hotline: 1-800-MEDICARE; web site: [www.medicare.gov](http://www.medicare.gov)
- National Council on Aging and the Access to Benefits Coalition, Phone: 202-479-6670; web site: [www.accesstobenefits.org](http://www.accesstobenefits.org)
- Social Security Administration (800) 772-1213, [www.ssa.gov](http://www.ssa.gov) (For questions about the “extra help” plan.)

Reprinted from *Hemophilia Outlook*, Fall 2005



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# SHARE OUR VISION

## A Whole New Outlook for People with Hemophilia and Their Families



Baxter's ongoing support of the hemophilia community will continue to make life better for patients and their families.

Take a look:

### EDUCATION

- Educational workshops for patients, caregivers and health-care professionals
- A variety of educational resources to help you improve your health and well being
- Hemophiliagalaxy.com

### REIMBURSEMENT ASSISTANCE

- Factor Assist and Factor Plus: compassionate care programs for eligible patients that help maintain access to therapy during insurance lapses or lack of insurance
- Support of national advocacy and reimbursement programs

- Healthcare Economics Department: an advocacy and insurance coverage resource for patients, providers, and medical professionals, 1-800-968-9937

- Reimbursement hotline 1-800-548-4448

### COMMUNITY SUPPORT

- Support for local hemophilia chapter and national foundation programs
- Hemophilia summer camp support
- Sponsorship of National Hemophilia Foundation's Clinical Fellowship Program

The  
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Factor

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# HACA Kids' Page

Vol. 2, Issue 6

November/December 2005

Hemophilia  
Association of the  
Capital Area

## Happy November/ December Birthday to:

Jack Downing	11/1
Kenzan Tanabe	11/1
Timothy Blanchett	11/5
Ian Cole	11/12
Alexander Harper	11/19
Victor Mircea	11/21
Patrick Kanu	11/28
Isis Oaks	11/28
Kairo Rivera	11/28
Subash Parachuru	12/1
James LeFevre	12/19
Jay Hurtt, Jr.	12/23
Matthew Spencer	12/26
Neil Collins	12/27
Gabriel "Jack-Jack" Shermer	12/29
Logan Hughes	12/30

## The Ultimate Gift

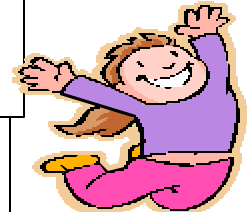
Faced by the challenge of hemophilia, you've had to learn many things other people never do. In the process, you are learning to take care of yourself the way an athlete would. You're more sensitive to your physical well-being than other people, and you have the tools to create the best possible environment for yourself.

There are three aspects to keeping your body in shape. One is to be physically fit. Physical activity is highly recommended for children with hemophilia, because it can strengthen joints and prevent injury. Exercise also helps control your weight which is important because excess weight is related to impairment of joint function. Be sure to consult with your

doctor to pick which exercise option is best for you.

The second aspect is to pick the right fuel for your body. Even minor bleeds produce stress for the body and stress adversely affects immune status. Good nutrition builds the immune system and helps protect against infection and disease. Wise choices for food include more vegetables and fruits, lean meats and small amounts of cheeses, rather than high-fat foods or sugary treats.

The third part of taking care of yourself is attitude. Look at each new day as opportunity. Surround yourself with positive people. Laugh often (see article below). Use your time and talents to reach out to others. Be a friend. And be grateful for the blessings



Give yourself the ultimate gift.

in your life.

Watching and balancing these three sides—physical fitness, diet and attitude—will go a long way towards taking care of yourself and creating the best environment for yourself. It is also the best way to give yourself the ultimate gift—a full and active life.

Happy Holidays!



## What's So Funny?

**Q: What do you call a reindeer wearing earmuffs?**

**A: Anything you want; he can't hear you!**

What makes something funny? Scientists who study laughter (now that's a funny job!) offer reasons why. Some claim that laughter is actually a release of tension. Some people think it has to do with whatever the reason, did you know that laughter is good medicine?

Believe it or not, laughter can help with pain relief. Mirthful laughter increases pain tolerance according to researchers.

The act of laughing reduces the production of certain hormones associated with stress that disrupt the balance of the immune

system. So next time you are going to get an infusion and find yourself scared, try watching a funny TV show to help ease some of the tension.

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