

HACA News

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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

Educational Seminar and Annual Meeting

Our annual educational seminar will be held on Saturday, October 28, 2006 and will begin at 9 am. The seminar will be held at the Courtyard Marriott in Tysons Corner. Registration will begin at 8:30 a.m. Topics this year will include:

- "Infusion Techniques; Tips to Make Your Infusions Easier". This session will feature two chapter members who will share their tips for getting organized. It will also feature representatives from Baxter, Bayer, Wyeth, and ZLB Behring who will demonstrate their company's infusion kit.
- "Which Insurance Will Best Meet My Needs?" This session will feature a panel including Ann O'Leary Amato, social worker from CNMC, Mary Jane Berry, social worker from Georgetown, and Jan Kuhn, coordinator of the Virginia Bleeding Disorders Program. The panel will also include at least one other person. The panel members will discuss the recent changes to insurances, which insurances are accepted at the local treatment centers, and what options are available and viable for people living in this geographical area.
- "Prepared for Disaster". Our guest speaker for this session will be Kevin O'Connor, president of the United Virginia Chapter of NHF. Kevin will share some of the lessons learned from Katrina and what steps you can take today to be prepared for any emergency
- "Create with Kirstin" Kirstin Duggan and others will be leading sessions for young people ages 6-15 in which the young people will be preparing skits, songs, and art work to share with the attendees during a special session just prior to our keynote presentation.
- Annual Meeting. Attendees will be presented with HACA's Annual Report and will elect members to and officers of the Board of Directors. We will also be recognizing outgoing members of the Board of Directors and thanking them for their years of service.

You will also have the opportunity to visit the informational booths of pharmaceutical and homecare companies that provide factor and other services to people with bleeding disorders.

Combined Federal Campaign

Those of our readers who are Federal Workers know that the Combined Federal Campaign (CFC) kicked off in September. To support our local chapter, please direct your donations to #6022. Donations made to the National Hemophilia Foundation will not benefit our local chapter. Please ask your family, friends, and co-workers to support our local chapter. Thanks to all you have so generously supported our chapter in the past through the CFC. You provide a generous portion of our budget.

United Way Contributions

Although HACA is not listed in the "Agency Services and Contributions Guide", you can direct your donation to HACA by requesting and filling out a "Donor Choice Form". Follow the easy steps listed:

1. Check the box for specific agency serving people in your community.
2. Fill in Hemophilia Association of the Capital Area as the agency name. The address is: 10560 Main Street #604, Fairfax, VA 22030-7182.
3. Leave the agency ID number blank.
4. Specify the amount of the donation.
5. Fill in your name, address and employer
6. Check the box indicating that you would appreciate an acknowledgement.

Thanks to all who have so generously supported us in the past through the United Way. Your generosity helps us to make a difference.

Chapter News continued

Combined Virginia Campaign

The Hemophilia Association of the Capital Area is listed as #3788 in the Combined Virginia Campaign. This campaign is for Virginia State employees. CVC rules state that we must receive at least \$300 in donations from this campaign on a yearly basis or we will not be allowed to participate in the CVC. We thank everyone who has generously support the chapter through CVC in the past and urge you and other state employees to step forward and contribute this year.

Other Campaigns

HACA also participates in the Montgomery County Combined Campaign and the Prince George's County Campaign. This means employees of Montgomery and Prince George's counties have an opportunity to support HACA. Please ask your friends, family members and co-workers to remember HACA when making their pledges.

If you wish to make a donation to HACA through the Fairfax County Combined Charitable Campaign, you will need to request a "Donor Choice" form and follow the procedures outlined in the paragraph about the United Way contributions.

Women's Day Out

The Hemophilia Association of the Capital Area and NuFactor invite all wives, mothers, and women living with bleeding disorders to our annual Women's Day Out. This year we will be meeting on **November 18th** at a home in Manassas, VA from 2 pm until about 7 pm. We will be creating cards, with the help of representatives from Stampin' Up, for kids' birthdays, adult birthdays, the Holidays, and Thank You cards. We will share a delicious dinner, yummy desserts, and have lots of time together to share tips, trade war stories, and to make new friendships and renew old friendships. Call the HACA office at 703-352-7641 today to reserve your place at the table.

Gene Transfer to Treat von Willebrands Disease

A group of scientists representing the departments of genetic medicine and pediatrics of the Weill Medical College of Cornell University in New York City have developed a gene transfer technique that reportedly corrected the symptoms of severe von Willebrand disease (VWD).* The cure for a disease of this magni-



Calendar of Events

October 12-14 NHF Annual Meeting in Philadelphia, PA

October 28 HACA Educational Seminar and Annual Meeting—Courtyard Marriott, Tysons Corner—8:30 am-1:30 pm

November 18 Women's Day Out, 2 pm—7pm.

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tude has particular significance because millions of people are affected by it.

Gene transfer is a technique that delivers genetic material into cells that lack genetic information, or in this case von Willebrand Factor (VWF) in VWD. Individuals living with VWD either lack or have a defect in the genes needed to express VWF. VWF is important in forming blood clots because it shields factor VIII (FVIII), another important protein in blood coagulation, from becoming deactivated in the bloodstream if left exposed. Without either VWF or FVIII, a clot cannot properly develop, resulting in a bleeding disorder.

The gene transfer technique developed by Dr. Robert G. Pergolizzi and colleagues successfully restored mice with severe VWD with the genetic material required to make VWF. Gene transfer was accomplished by injecting a solution of mouse VWF-DNA into mice affected by severe VWD.

To track the success of the gene transfer, the researchers collected data on the concentration of VWF in the bloodstream of mice after the transfer. They reported that the concentration of VWF never rose to the same level as that of mice with normal VWF. Likewise, the levels of VWF in mice receiving gene transfer were inconsistent over time. Nevertheless, the rates at which blood clots were formed in mice receiving gene transfer were comparable to those in mice without VWD. In other words, the gene transfer approach restored the ability to form blood clots in mice with severe VWD, which was comparable to the process in healthy mice without VWD.

Liver analysis of the mice receiving gene transfer revealed that the genes for VWF were expressed differently than in healthy mice. They manufactured, processed and packaged VWF differently than mice without VWD.

Nevertheless, this study reveals the strong clinical applications that gene transfer has in treating VWD. The research team anticipates discovering

different methods of gene transfer that prolong the expression of VWF in subjects receiving it. It recommends further research into different viral vectors for use in gene transfer.

*Pergolizzi, Robert G., et al. "Correction of a Murine Model of von Willebrand Disease by Gene Transfer." *Blood*, 2006; 108(3): 862-9.

Revelations on Carrier Status

A group of scientists in the Netherlands recently published data suggesting that women who are carriers of hemophilia, regardless of type, may be at greater risk of joint bleeds and prolonged bleeding from small wounds than women who are non-carriers of hemophilia. Moreover, the scientists found that carriers of hemophilia produce less factor than non-carriers when comparing the lowest factor values among the two groups.

This study is significant for two reasons. First, it is one of the only longitudinal studies – scientific investigations that track subjects over a given time period – examining carriers of hemophilia. Second, it provides valuable insight into and data on the various symptoms and hematological profiles of hemophilia carriers.

The investigators propose the need for further investigations into the bleeding experience of carriers of hemophilia, since they would seem to be at greater risk of morbidity related to spontaneous bleeds than non-carriers.

Source: Plug I, Mauser-Bunschoten E, Brocker-Vriends A, et al. Bleeding in Carriers of Hemophilia. *Blood*, July 1, 2006; 108: 52-56.

Bayer Offers Free Product Trial

Bayer has introduced a free product trial. You may obtain 6 infusions of Kogenate® FS with BIO-SET®, not to exceed the program maximum of 20,000 IU. You can also receive the Kogenate® FS E-Z Log electronic patient diary (optional) for simplified record keeping. Visit www.kogenatefs.com for full program details.

Please note that patients previously enrolled in the Kogenate® FS Free Trial program and patients currently receiving Kogenate® FS therapy are not eligible to participate in the program. In accordance with government statutes, patients covered in whole or in part by federal or state healthcare programs, such as Medicare and Medicaid, cannot participate.

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2006 Board of Directors Meetings

General Board Meeting
November 13, 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.

(Continued from page 3)

Coram Offers Educational Conference Call Series for Consumers

Coram Homecare Company offers a series of Educational Conference Calls for Consumers. On October 25, 2006, the topic will be: "How to Avoid Obesity in Children—Good Eating Habits for Children with Bleeding Disorders." On November 29, 2006, the topic will be: "Physical Therapy for Individuals with Bleeding Disorders."

The calls begin at 7 pm. There is no charge for participation. If you are interested in signing up for the call, just call or email Art Stinger at 866-407-3154 or stingera@coramhc.com a few days prior to that call. He will give you the call in information and access code. Access codes will differ for each call and you should not share the access numbers as ports are limited to those who have signed up.

Novo Nordisk Offer Scholarship

If you're a high school senior—or if you're a college or vocational student under the age of 23—and interested in getting the education or training you need for a good career, you'll want to apply for an Ulla Hedner Scholarship!

Once a year, SevenSECURE, the first and only patient assistance program created just for people with hemophilia with inhibitors or FVII deficiency, awards scholarships valued between \$2,000 and \$7,000 per person in honor of Professor Ulla Hedner.

SMI, an independent organization, will accept and evaluate completed applications. All applicants in 2006 received a scholarship!

Scholarship applications are due by April 30, 2007, and award winners will be announced that summer.

Call 1.877.NOVO.777 (1.877.668.6777) toll-free or e-mail SevenSecure@rxcrossroads.com today to enroll in SevenSECURE and receive a scholarship application.

What's New With the Virginia Bleeding Disorder Program? (continued from page 12)

insurance. In the past ten years of the contract with PSI, 113 patients received insurance assistance.

VBDP also staffs the Virginia Hemophilia Advisory Board (HAB). This board is appointed by the governor to advise the Virginia Bleeding Disorders Program. The board includes representatives from voluntary agencies interested in hemophilia, hematologists, blood banks/pharmacies, medical schools, hospitals, local public health agencies and the general public. Current issues before the board include: A Study of Adults with Hemophilia in Virginia; Transitioning from a pediatric to an adult Hemophilia Treatment Center and the implications of changes in Medicaid and Medicare to persons with bleeding disorders.

For more information about the VBDP or the HAB, please contact Jan Kuhn, RN, MPH, or Tamara Quarles at 1-866-228-2516 (toll-free in Virginia) or check out our website at www.vahealth.org/bleedingdisorders/CSHCNHemophilia.htm.

¹ Soucie et al, "Mortality among males with hemophilia relations with source of medical care", *Blood*, 15 July 2000, Volume 96, Number 2.

² Center on Budget and Policy Priorities, August 30, 2005

³ "Instability in Public Health Insurance Coverage for Children and Their Families: Causes, Consequences, and Remedies" The Commonwealth Fund, 2006.

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Changes in the Market Place: More Consumers Will Have to Get Factor Product From Specialty Pharmacies in 2007

By David Linney

The following information pertains primarily to individuals with employer-sponsored insurance plans. Medicaid specialty pharmacy programs are not addressed in this article.

In 2007, insurance companies will require more consumers with bleeding disorders to obtain their factor products from specialty pharmacies. In 2008, those numbers will be even greater.

Specialty pharmacies provide biotechnology drugs that are very expensive. Most biotech drugs are either infused (intravenous) or injected (intramuscular). As a category, these drugs are commonly referred to as "specialty pharmacy drugs." Factor products are specialty pharmacy drugs.

Specialty pharmacies sometimes are associated with drug plans known as pharmacy benefit managers (PBMs) and a limited number of health plans. Specialty pharmacy services, which focus on the effective cost management of high-cost specialty pharmacy drugs (through efficient purchase, supply and programming), are marketed to payers.

Payers, including employers and insurers who pay for pharmacy bills, have become very interested in using specialty pharmacies to try to reduce their overall drug costs. Interest has risen in direct response to the large number of specialty pharmacy drugs expected to enter the marketplace over the next few years. Payers are concerned that their drug costs will increase dramatically as these new therapies become available

Until a few years ago, factor products were covered almost exclusively as a health plan benefit. While this is still common today, there is a strong, growing trend to change factor products coverage to a separate drug-plan benefit. Many payers have determined that it is easier to manage drug costs through a drug plan than through a health plan because it is quite difficult to track and manage specialty pharmacy costs through the medical claims review process of a health plan.

TYPES OF SPECIALTY PHARMACIES

PBM Specialty Pharmacies

A PBM is a pharmacy benefits manager. For consumers, a PBM is a drug plan that provides pharmacy benefits separate from the health plan.

PBMs contract with employers and insurers to be the fiscal managers of drug benefits for the group's members. They develop and manage formularies (listings of approved drugs). PBMs typically have a network of retail pharmacies to supply prescription drugs and a mail order pharmacy that may supply up to several months' worth of regularly prescribed drugs.

As more PBMs pop up in the marketplace, a number of them either have or are developing a specialty pharmacy to supply drugs like factor products. The three largest PBMs, in order of size based on covered lives, are Caremark, Medco and Express Scripts. Together, they serve more than 200 million policy holders, or approximately two-thirds of the marketplace. Each has its own specialty pharmacy.

Caremark's self-named specialty pharmacy became an even more significant force after it acquired AdvancePCS in 2004. Medco acquired Accredo Health, Inc., in 2005 to create its current specialty pharmacy services, including Hemophilia Health Services, which is dedicated exclusively to hemophilia care. Express Scripts acquired CuraScript Pharmacy and CuraScript PBM Services in 2004 and Priority Healthcare in 2005, creating CuraScript, its specialty pharmacy.

Having a drug plan, though, does not mean it will automatically cover your factor products. Currently, factor products remain more commonly covered under health insurance plans.

The sponsor of the health insurance plan – commonly, the employer or an insurer – decides if it will include specialty pharmacy drugs, including factor products, as a benefit of the drug plan. (If the

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sponsor does *not* include specialty pharmacy as a drug-plan benefit, then the factor products usually will be covered under the health plan.) The outlook for 2007 is that more employers and insurers will contract with PBMs to supply specialty pharmacy drugs, including factor products.

So, if you have a drug plan in 2007, it's very important to verify coverage and supply of factor products for the coming year. Look at your insurance card(s) and call the drug plan number on it. (Most of us have either a health insurance card with a drug plan listed *or* a separate drug plan card.) For further assistance, contact your hemophilia treatment center (HTC), physician or factor product vendor.

Health Insurance Plan Specialty Pharmacies

Some health insurance plans that provide pharmacy benefits in addition to health benefits have

established their own specialty pharmacies. Three of these are Aetna, Cigna and WellPoint. Aetna requires the use of its own specialty pharmacy or an Aetna-approved HTC factor product program. Cigna urges – but does not exclusively require – the use of its specialty pharmacy, Tel-Drug. Well-Point's specialty pharmacy, PrecisionRX, is its exclusive option.

If you have Aetna, Cigna or WellPoint, be sure to check out the company's required use of specialty pharmacies associated with the health plans in 2007. Call the plan number on your health insurance card. For further assistance, contact your HTC, physician or factor product vendor.

-reprinted from Hemaware, September/October 2006

Impact for Consumers

The trend toward coverage of factor products as a drug benefit brings both positive and negative changes for consumers.

Pros often include:

- No lifetime limit.
- Low out-of-pocket expenses (many drug plans only have a co-payment).
- Potential use of a PBM that provides a high-quality service supplying factor products to consumers.

Cons may include:

- Decreased ability to select a factor product vendor (i.e., a home care company), as payers likely will increasingly require the use of specialty pharmacies.
- Little of no recourse in having to use a specialty pharmacy (unless, perhaps, quality of service is below accepted standards).
- Decreased ability to use current factor product vendor if that vendor is an HTC factor product program or another factor product vendor that is not a PBM.
- Newer specialty pharmacies with little experience supplying factor products. Follow up with your HTC or physician to advocate for a reputable, high-quality service *and* contact both your local chapter and the National Hemophilia Foundation.
- HTC factor product programs likely will lose some of their customer base, which will decrease critical revenue used to support essential HTC services.

Gene Therapy Update

Highlights from the Eighth Workshop on Novel Technologies and Gene Transfer for Hemophilia
By Bruce Goldfarb

In the 15 or so years since gene therapy has been tested in humans, progress seems to come in fits and starts. Since there have been no new gene therapy clinical trials for hemophilia in several years, some in the bleeding disorders community fear that research is at a standstill. Katherine High, MD, a gene therapy researcher at The Children's Hospital of Philadelphia and co-chair of the Eighth Workshop on Novel Technologies and Gene Transfer for Hemophilia, denies that this is the case.

"The field remains very active," High says. "There's a natural tendency to view clinical trials as the evidence of progress. That's easy to understand. The nature of gene transfer for genetic disease is that it has tended to proceed by small-scale clinical studies that then define a problem that requires more work in the laboratory. You see a lot of activity in clinical trials, and then things fall silent. People sometimes draw the conclusion that things aren't happening, but I just means we're back in the laboratory. We're in that kind of phase now."

The workshop, sponsored by the National Hemophilia Foundation (NHF) and co-chaired by Glenn Pierce MD, PhD, of Bayer HealthCare-Pharma, was held March 31 – April 1 at The Children's Hospital of Philadelphia and offered an opportunity for researchers and clinicians to touch base and compare notes about progress in the treatment of bleeding disorders.

"It was a wonderful conference," says Margaret Ragni, MD, MPH, director of the Hemophilia Center of Western Pennsylvania, in Pittsburgh. "Aside from informing us what's going on, it brings together people from basic research and couples them with clinicians."

Clinical Trial Update

Two clinical trials of potential gene therapies for hemophilia are expected to begin within a year, according to presentations at the NHF workshop. A group of researchers at St. Jude's Children's Research Hospital in Memphis, Tennessee and the University College of London plan to give human volunteers factor IX (FIX) gene therapy using an adeno-associated virus (AAV) called AAV-8. Tests in

macaque monkeys have resulted in production of human FIX levels of 22% without toxic efforts.

High and Pierce investigated why the trial using a related virus, AAV-2, sponsored by Avigen (Alameda, CA) gave only a transient increase in FIX levels in a patient to 12% and found a novel immune response to the delivery vehicle was responsible. Based on those findings, High is working toward a clinical trial delivering a therapeutic FIX gene with AAV-2 while the recipient temporarily receives immune-suppressing treatment to minimize a harmful response. She believes this may be the way to achieve a long-lasting cure for hemophilia B.

Experiments with gene therapies for other diseases may spin off into applications for hemophilia. Janneke Meulenberg, PhD, of Amsterdam Molecular Therapeutics, the Netherlands, gave a presentation on gene therapy delivered by AAV-1 to treat a metabolic disorder known as lipoprotein lipase deficiency, which causes large amount of fats to accumulate in the blood. Another presentation described a clinical trial at the University of Florida in Gainesville to treat alpha-1 antitrypsin deficiency, an inherited disorder that can cause serious disease of the lung and liver. Successful results from these trials may lead to experiments with therapeutic genes for hemophilia.

Vector Search

Research continues to actively evaluate a number of viral vectors for the delivery of therapeutic genes without triggering an immune response in the recipient. Aside from the varieties of AAV being studied, researchers at the NHF workshop discussed work with lentiviruses, retroviruses and feline immunodeficiency virus to deliver therapeutic genes.

Robert Montgomery, MD, and colleagues at the Blood Research Institute at the Medical College of Wisconsin and Blood Center of Wisconsin in Milwaukee are taking a different tack, applying gene therapy to platelets for treatment of hemophilia A.

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A similar tactic to target platelets is being investigated by Mortimer Poncz, MD, and colleagues at The Children's Hospital of Philadelphia.

Other groups of researchers targeting stem cells include Robert Hawley, PhD, and colleagues at George Washington University Medical Center in Washington, DC. Hawley described the team's work using retroviruses to deliver therapeutic FVIII genes to blood-producing cells of mice. Simon Waddington, PhD., of Imperial College London, reported on similar stem cell research, but delivering FVIII DNA to mouse fetuses.

Another novel approach eliminates the viral vector altogether, instead employing only the enzyme integrase, which is used by a virus that normally infects bacteria to inject its payload into a host cell. Michele Calos, PhD, and colleagues at the Stanford University School of Medicine in Palo Alto, CA, are testing this approach. Ultimately, this may permit long-lasting cures for the hemophiliac and avoid the use of viruses to deliver the genes.

Hemophilic Dogs

David Lillicrap, MD, of Queens University in Kingston, Ontario, provided an update on research with a colony of dogs with hemophilia raised at his institution. The study, in collaboration with Avigen, tested three different types of AAV vector to deliver a therapeutic FVIII gene into the livers of eight dogs with hemophilia A.

"All of the dogs showed evidence of long-term benefit and expression of therapeutic levels of factor VIII," Lillicrap says. "This is the first demonstration for hemophilia A that you could use an AAV vector system to deliver the factor VIII and express it long term."

The treated dogs, which ordinarily suffer about five bleeds a year, have remained bleed-free since receiving the gene therapy—in one case for four years. The dogs produce FVIII levels about 3% to 7% of normal. "There's no reason to believe the levels won't stay the same for the rest of their lives," Lillicrap says. "They're probably cured."

Novel Proteins

Until a safe and effective gene therapy is available, researchers are focusing on improving the fac-

tor proteins currently use to treat hemophilia. "The technologies are available to modify those proteins and make them better," Pierce says. "That's where the field is going over the next decade."

Efforts are under way to make factor proteins that are less likely to trigger the production of inhibitory antibodies. Other research is investigating how to formulate factor so it is more active or released more slowly into the bloodstream, which may reduce the number of infusions needed by people with hemophilia.

Steven Pipe, MD, of the University of Michigan in Ann Arbor, offered the presentation describing the promise and challenges of bio-engineered recombinant clotting factors. Andrew Gale, PhD, of the Scripps Research Institute in La Jolla, CA, presented data on his lab's work in characterizing new variations on the FVIII protein.

Phillip Fay, PhD, of the University of Rochester (New York) School of Medicine, discussed work in his lab to develop FVIII proteins with higher specific activity, while Pierce gave an update on Bayer's development of FVIII made with liposomes and polyethylene glycol (PEG).

"There are a variety of new protein therapies being developed now that will nicely bridge the time to an ultimate genetic cure," says Paul Monaha, MD, of the University of North Carolina, Chapel Hill.

Novel Gene Therapy Does End Run Around Antibodies

A group of researchers has reported success in sneaking therapeutic factor VIII (FVIII) genes past the immune system by treating stem cells with gene therapy outside the body.

Animal studies on genetically altered mice with hemophilia recently reported in the July 3 *Journal of Clinical Investigation* suggest that the approach has the potential to correct hemophilia A even if a person has inhibitory antibodies, according to Robert Montgomery, MD, and colleagues at the Blood Research Institute at the Medical College of Wisconsin and BloodCenter of Wisconsin in Milwaukee.

Rather than treat all of the body's blood-producing cells, the group developed a therapeutic

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Trojan horse by hiding FVIII within platelets, where it remained undetected by the immune system until needed at the site of bleeding.

“The place where you need factor VIII is locally.” Montgomery explains. “The factor VIII is kept in the platelet, where inhibitors can’t get to it. When a platelet sticks to a damaged blood vessel, the stored proteins are released, which now include factor VIII.”

The team’s research, funded by the National Institutes of Health, has received a lot of press attention since being published in July.

The new approach begins by harvesting stem cells from peripheral blood, much like a blood donation. Stem cells are immature cells that can grow into different types of cells, such a platelets or red blood cells. In the laboratory, the stem cells are exposed to a harmless, non-replicating virus that carries a copy of the FVIII gene.

The new FVIII gene has been engineered to pro-

duce protein only in platelets. Treated stem cells would then be put back into the patient, where they would reside in the bone marrow and continue to make blood cells normally. The treated cells would remain in the recipient’s body of the rest of his or her life, resulting in a permanent correction of hemophilia.

The approach has been found effective even in mice treated with five to ten thousand times the amount of antibody that normally would inhibit the activity of FVIII treatment.

The method will be tested in dogs and other large mammals before clinical trials can begin in patients. More research is needed to determine how much treatment is needed to produce effective levels of FVIII in humans.

Source: *Hemaware*, September/October 2006

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The Game of Life Financial Planning

By Jean Duncan Foster

What is financial planning and how will it benefit me and my family?

Certified Financial Planner Board of Standards (www.dfp.net) defines financial planning as, "...the process of meeting your life goals through the proper management of your finances. Life goals can include buying a home, saving for your child's education, or planning for retirement... This process involves gathering relevant financial information, setting life goals, examining your current financial status, and coming up with a strategy or plan for how you can meet your goals given your current situation and future plans."

Financial planning helps guide your financial decisions, allowing you to see how each individual decision affects other areas in your financial life. The aforementioned website further explains: "By viewing each financial decision as part of a whole, you can consider its short and long-term effects on your life goals. You can also adapt more easily to life changes and feel more secure that your goals are on track."

What are the basics of financial planning?

The first step is to determine where you are right now. Until you know your current spending habits and finances, you will not be able to develop a realistic financial plan. What is your income? What are your expenses? Do you have any debt? Many banking, credit union and other web sites feature budgeting calculators. Just write/type it all in, add everything up, and they will do the calculations.

Here are a few calculator sources:

- A template for Excel users: <http://office.microsoft.com/en-us/templates/TC010233421033.aspx?CategoryID=CT011815531033>.
- A sample calculator from a well-known national bank: <http://www.bankofamerica.com/financialtools/index.cfm?view=planning&calcid=budget03>
- Budgeting forms from a well-known radio personality: <http://www.daveramsey.com/fpu/home/index.cfm?FuseAction=dspContent&intContentID=135>

Now that you know where you are, what's next? You need to set your goal(s). Your goal(s) should be tangible so you can track your progress. Examples of goals include:

- Establishing an emergency fund
- Investing for long-term goals such as education or a new home

To achieve your goal, you should set a time frame and design a savings strategy.

Dealing with debt

Medical bills aside, dealing with debt is a tricky subject, as everyone's case is unique. So what's the best way to deal with debt? There are many schools of thought floating around these days on how to wipe out debt. According to popular radio show host Dave Ramsey, a basic concept is to "spend less than what you earn." His website (www.daveramsey.com) offers tons of articles covering just about every debt-related situation. Many are real-life stories! It's a great reference tool.

Estate Planning

You may wonder why you should even do estate planning. You may say to yourself, "I don't plan on dying anytime soon and besides, I don't have enough assets to worry about." The truth is we don't live forever. Accidents happen. We get sick, or even worse, we become incapacitated and need someone to make life-altering decisions for us. This is a fact of life. Wills are not just for the rich and famous!

Suze Orman (www.suzeorman.com) offers basic information on her website regarding wills and trusts. Simply put, a will designates where your assets go upon death. But sometimes you need someone to make these decisions when you get sick. In this case, you may need a living revocable trust. Each state's laws regarding wills and trusts vary. It is best to consult with an attorney experienced with your situation and familiar with your state laws before signing any documents.

At any life stage

Financial planning is a must at all stages of life. You can chart your course to achieving your financial goals, maintaining security for you and your family, and ensuring a bright future for your loved ones. All it takes is a little bit of planning.

If you have tax questions about medical expense deductions, consult your tax preparer, visit www.irs.gov or call 1.800.829.1040 to obtain answers.

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*(Continued from page 11)***IRS regulations and medical expenses**

Did you know that certain medical expenses can be deducted from your adjusted gross income? IRS Publication 502 outlines what can/cannot be considered deductible medical expenses in your tax return.

“Medical expenses are the costs of diagnosis, cure, mitigation, treatment or prevention of disease, and the costs for treatments affecting any part or function of the body. They include the costs of equipment, supplies, and diagnostic devices needed for these purposes...Medical care expenses must be primarily to alleviate or prevent a physical or mental defect or illness. They do not include expenses that are merely beneficial to the general health, such as vitamins or a vacation...”

Basic definitions for estate planning

- Durable Power of Attorney: A document by which a person appoints a legal representative to manage financial affairs if he or she is unable to do so.
- Healthcare Power of Attorney: A durable power of attorney that appoints an agent to

make a person's healthcare decisions in case he or she is incapacitated.

- Living Will: A legal document that expresses a person's wishes regarding prolonging his or her life by artificial, extraordinary or heroic measures when death is inevitable.
- Will: A written document representing the instructions from the deceased for distribution of his/her estate.

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This article does not constitute legal or financial advice. Always consult a suitably qualified lawyer or financial professional on a specific issue, problem, or matter. Hemophilia Health Services and the Hemophilia Association of the Capital Area assume no responsibility for information contained in this article and disclaims all liability in respect of such information. If your current financial situation is complex, it is recommended that you seek a professional.

This article links to other websites, resources and to material contained on other websites. Hemophilia Health Services and the Hemophilia Association of the Capital Area are not responsible for the content of such other websites or content which you may be able to access from such websites. Source: Bloodstone Magazine, Summer 2006

What's new with the Virginia Bleeding Disorder Program?

(Formerly Children's Specialty Services Hemophilia Program)

by Jan Kuhn, RN, MPH

Persons with inherited bleeding disorders live longer and healthier lives if they seek care through comprehensive hemophilia treatment centers (HTCs).¹ However, if they do not have health insurance coverage or if HTCs cannot maintain their programs due to fiscal constraints, the benefits from these programs are not realized. Key findings from the new census data show that:

- The number of people without health insurance was 45.8 million in 2004, compared to 39.8 million in 2000.
- The increase in number of those without insurance focused among the working age adults (18-64 years).
- For the fifth consecutive year, private employment-based health insurance fell (59.8 % in 2004 from 63.9% in 2000.)¹
- One study shows that nearly four in 10 Americans under age 65 lose health insurance within a four-year period.²

The Virginia Bleeding Disorders Program (VBDP) is a legislatively enacted program through the Virginia Department of Health for the care and treatment of persons with hemophilia and other inherited bleeding disorders. Funding from the VBDP supports several HTCs in Virginia, provides insurance case management services through Patient Services, Incorporated (PSI) and acts as a "safety net" for patients who have no other health insurance. Almost half of the budget directly supports clinical care and medications for these patients. Also, VBDP also works with Virginia HTCs to assist with coinsurance costs for comprehensive clinic visits. Staff from the VBDP work closely with HTC social workers and nurses to address the needs of families regarding coverage for health costs. In 2005, 251 patients were served through the program, 28 of those had no

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