

HACA News

FEBRUARY 2005

VOLUME 21 ISSUE 1

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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Summer Camps

Applications are now available for summer camp. Young people between the ages of 7 and 15 are eligible to attend either the Hole in the Wall Gang Camp in Ashford, Ct, June 10-16 or Victory Junction Camp in Randleman, NC, July 24-29. Both of these camps are members of the Hole in the Wall Gang Camp Association and are Paul Newman camps. The Hole in the Wall Gang Camp has an old west theme while the Victory Junction camp was founded by the Kyle Petty family and has a race car theme. Applications for each camp are currently available online at www.holeinthewallgang.org or www.victoryjunction.org. If you do not have access to a computer, you can call the HACA office at 703-352-7641 and request an application form. The camps that belong to the Hole in the Wall Gang Association have a policy that you may attend only one of their member camps during the summer. This means that we will accept an application for only one of the camps from eligible families. The application forms must be returned to the HACA office by March 15, 2005.



We will also be looking for adults to travel to and from the camps with our campers. We would arrange for you to fly to Ashford, CT or Greensboro, NC and return later that day. You would also be asked to accompany the campers on the bus to both camps and help keep the atmosphere on the bus calm so the driver can attend to the driving. If we have 10 or more campers for either camp, we will also be required to provide a chaperone for the week. Please call the HACA office and let us know if you would be willing to fulfill either of those needs.



Bruise Brothers

If you are between the ages of 7 and 12, we have a fun day planned for you and your parent. We will gather at the Tyson's Corner Build-a-Bear on April 10th at 3 pm to build an animal. After that, we will go down to the Rainforest Café for a meal. Unfortunately, because of the limited space at Build-a-Bear, people with bleeding disorders will have priority for this event. We will wait-list siblings.

Please call the HACA office at 703-352-7641 by March 17, 2005 to let us know that you will be joining us.

DC Hemophilia Open

Our annual golf tournament will take place on Monday, May 16, 2005 at Heritage Hunt Golf and Country Club, 6901 Arthur Hills Road, Gainesville, Virginia. Cliff Krug, Jr. is chairing this event and could really use your help in the following ways:

1. Securing Sponsors for the event.
2. Securing Hole Sponsors
3. Obtaining items for the Silent Auction and the Live Auction
4. Recruiting Golfers
5. Volunteering to help on event day



Cliff will try really hard, but he can't make this event a success all by himself. Please call the HACA office at 703-352-7641 today and volunteer your help.

Chapter News continued

Annual Campaign

You should have received letters in the mail inviting you to participate in our annual campaign and giving you a chance to make a donation to NHF's Time for a Cure Campaign. HACA has set important goals for the next few years. Whether we can accomplish them or not depends on your financial support. If you have not made a donation to HACA in the last few years, please consider doing so this year. If you have made a donation in the recent past, thanks for your support and we hope you can find the means to again provide a monetary contribution. We are not asking for large donations, although we will certainly accept those. Instead, we're seeking a great 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!

PEN Included With This Mailing

We have included a copy of the November 2004 issue of Parent Empowerment Newsletter that is published by LA Kelley Communications, Inc. We have done so because there are many changes taking place in the world of factor distribution and reimbursement (insurance). We highly recommend that you read the article in the November issue entitled *Hemophilia, Incorporated—How the Hemophilia Business Works in America, and What Threatens to Change It* and also recommend that you subscribe to PEN so you can receive the February issue that will contain part 2 of the series and the article entitled: *The Coming Storm*. Many elements are coming together—Medicaid reimbursement changes, states having difficulty meeting their budgets, etc.—to portend huge changes in the way we might be able to obtain reimbursement for factor (i.e.: every family may be responsible for the 20% co-pay that homecare companies are now able to waive). Now, as never before, it behooves you to learn all you can about how the hemophilia business works so you can advocate to preserve the product choice you now enjoy.

Advertisements

The Hemophilia Association of the Capital Area accepts advertisements to help defray the costs associated with producing our newsletter. Sometimes the space purchased also allows for the inclusion of a company's "slick". The inclusion of an ad or a "slick" in *HACA News* does not imply an endorsement for that company or their product. As always, your treatment is between you and your doctor. Your treatment choice should be made only in conjunction with your doctor.

NHF Board Names New CEO

NHF's Board of Directors has announced the selection of Alan Kinniburgh, PhD, as the foundation's new CEO. Current plans are for the appointment to take effect on January 17, 2005. Kinniburgh comes to NHF after several years of service at the Leukemia and Lymphoma Society, where he was the senior vice president of research.

2005 Board of Directors Meetings

General Board Meeting
March 7, 2005

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.

Calendar of Events

February 19—Karing for Kids, Holiday Inn, Chantilly, VA followed by time at the Air & Space Museum at Dulles

March 10—NHF Washington Day on Capitol Hill

April 10—Bruise Brothers at Tyson's Corner Build-a-Bear and Rainforest Café

May 16—DC Hemophilia Open at Heritage Hunt Golf Club, Gainesville, VA

June 10-16—Summer Camp at Hole in the Wall Gang Camp, Ashford, CT

July 24-29—Summer Camp at Victory Junction Camp, Randleman, NC

September 24—HACA Educational Seminar and Annual Meeting

October 8—"Blood, Sweat, & Gears" Bike-a-thon



Scholarships Announced

Wyeth

Wyeth has announced that applications for the 2005 Soozie Courter Sharing a Brighter Tomorrow Hemophilia Scholarship Program are now available. This program awards scholarships to students with hemophilia A or B who present the best combination of academic achievement, letters of recommendation, and a personal essay. The program is open to high school seniors and students enrolled in junior college, college (undergraduate or graduate), or vocational school.

Applications can be downloaded from the Wyeth web site, Hemophiliavillage.com, under "Programs and Services." You may also obtain applications by calling the Wyeth Hemophilia Hotline at 1-888-999-2349, the Hemophilia Scholarship Line at 1-888-322-6010 (between 9 AM and 5 PM EST), or by calling the HACA office at 703-352-7641.

The application and accompanying materials must be postmarked by **April 15, 2005**.

Hemophilia Health Services


HHS Memorial Scholarship—this program awards scholarships to students with hemophilia A or B, von Willebrand disease, factor I, II VII, X, XI, or XIII deficiency. The program is open to high school seniors and students enrolled in junior college or college (undergraduate or graduate).

Scott Tarbell Scholarship—this program awards scholarships to students with severe hemophilia A or B. Students must be majoring in or seeking a degree or certification in Computer Science and/or Math. This program is open to high school seniors, high school graduates (or the equivalent/GED), college freshmen, sophomores or juniors.

Applications can be downloaded from the HHS web site at www.hemophiliahealth.com/consumers/products_services/scholarship.htm. You may also obtain an application by calling 1-800-800-6606, extension 5175 or by calling the HACA office at 703-352-7641.

The application for each scholarship and its accompanying materials must be postmarked by **May 1, 2005**.

Paid Advertisement



Please Call Toll Free:
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www.FactorSupport.com

Factor Support Network was founded by families with hemophilia over 10 years ago to help the community and empower consumers to make the best choices possible.

We are a full service pharmacy that specializes in dispensing clotting factor and medications for hemophilia and von Willebrand disease.

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Baxter

If Your Insurance Is Interrupted

By Bob Jarrett of the New England Hemophilia Association

Anne and David are local NEHA members, and their sons, John and David, have hemophilia. They had insurance through their work with a well known insurance carrier which had always covered their sons' medical needs. One day they received a notice that their insurance cap had been reached. Anne thought this strange, and after some checking, found that the insurance company had made a mistake. They were indeed still covered and were told that they were safely below their cap. Unfortunately, the insurance company had not taken into account all of their boys' hospital expenses. The next notice came several month later telling them that their cap had been reached a month before and not only did they have no coverage, but they owed for factor that they thought was covered.

Through their home care provider, they applied for assistance from the factor manufacturer. Even though their annual income was lower than their son's factor expenses for two months, they were told they made too much money to qualify. Fortunately, through persistence by Anne and David, help from the home care company's reimbursement service, and intervention by NEHA, they were able to get additional insurance and the situation was made manageable.

What can we learn from this? Anne and David's advice is make sure you know where you stand with your insurance cap and, while you still have insurance, determine what programs are available that meet your qualifications. Most of the factor manufacturers provide some kind of assistance program to help those using their products in the event of a lapse in health insurance. Many include a plan for eligible patients that provides a coupon or certificate every three months redeemable for one month's supply of product. Each plan has its unique benefits and requirements. It is therefore advisable to become familiar with the one most applicable to your situation. Some of these plans are outlined below.

Bayer has a multi-faceted patient assistance program called BKAP (Bayer Kogenate Assistance Program) for its patients using Kogenate® FS. Their Kogenate FS Reliance Program provides coupons as indicated above that are redeemable for factor

during a lapse of private insurance. This plan also accepts coupons from other manufacturers of similar products provided the patient is enrolled in Bayer's program before Dec. 31, 2004. Other aspects of Bayer's over-all plan include assistance for those lacking private health insurance. A help line (800-288-8374) and website www.bayerbiologicals.com/New_Center/Press/20040804.asp is available for information and assistance on the BKAP program.

Baxter's Factor Assist program provides a certificate every three months that a patient uses their product. Every four consecutive certificates may be redeemed for 15% of the patient's annual factor usage if a lapse in insurance occurs. If insurance coverage is not restored before running out of certificates, Baxter's Factor Plus program may provide assistance. Details are available through the Medical Technologies Hotline (800-548-4448) and information is available at Baxter's website: www.hemophiliagalaxy.com/therapies/reimbursement/factor_assist.html.

ZLB Behring provides a "Choice Assurance Award Certificate" for every quarter of continuous use of one of their factor products. Each certificate may be redeemed for a one month supply of factor if a lapse of their private insurance or Medicaid managed care plan occurs. Information is available on their website: www.ChoiceAssurance.com, or on their hotline (866-415-2164).

Wyeth does not have a certificate or coupon program, but they do provide their factor products to eligible hemophilia patients who have a need and register with them. An interesting aspect of Wyeth's Patient Assistance Program is that the plan is open to patients on other manufacturer's factor products. Information is available at their website: www.hemophiliavillage.com or from their hotline (888-999-2349).

Novo Nordisk's plan, called SevenSECURE™ has as its goal to ensure that no patient is denied access to therapy with NovoSeven® because of a lapse in insurance coverage or inability to pay. There are no coupons or certificates, but up to six months of

(Continued on page 10)

Should I Switch?

Factors to consider when considering factor choices

By Kevin Kelley

When Baxter Healthcare introduced their new recombinant factor VIII concentrate, Advate, last summer (July 2003), consumers and their medical providers were once again faced with the challenge of deciding whether to switch to a new product or stick with their current brand of factor. Such decisions can be difficult and confusing; the available scientific data may be beyond the grasp of many consumers, and frequently even the experts disagree on whether a new product is actually “better” than existing ones. What helps make the decision a bit easier is that whenever patients or providers face choices about factor brands or other treatment issues, the questions and concerns can usually be sorted into four basic categories: efficacy, reliability, safety and cost.

Today, the hemophilia communities in the U.S. and other developed countries are fortunate to have a variety of excellent factor products available from a number of manufacturers. All the current products are highly effective in controlling bleeding, and all have outstanding safety records – since 1986 there have been no documented cases of either HIV, hepatitis B or hepatitis C transmission by any of the ultrapure concentrates sold in the US, including both recombinant and plasma-derived products. And no factor products have ever been shown to transmit CJD or the prions that have been proposed to cause CJD. But past history has made the hemophilia community extremely sensitive to even potential dangers and, to a large degree, it is in response to consumer concerns over theoretical risks that some of the newer, so-called second and third generation products have been developed. The dilemma for consumers is deciding whether a new product is in fact safer, more effective, more reliable or more economical than the product they are currently using.

These decisions are difficult because the differences between brands are subtle, and are often

hard to evaluate with confidence until a product has established a long enough history to make a meaningful comparison. In addition, many consumers base their decisions less on scientific analysis than on their own feelings about a manufacturer (brand loyalty), or on the advice of their medical provider or the recommendations of their home care representative or insurance carrier. But each consumer should be aware of the characteristics of each of their product options, and at least consider the potential impact of each new product in terms of its efficacy, reliability, safety and cost. In discussing these four categories, below, examples from recent

new products are used to illustrate each point. ***These examples are not intended to either promote or discourage the use of any product, nor is there any intent to recommend any one particular brand over another. The chapter does not offer medical advice, and strongly encourages you to make any decisions about factor usage in consultation with your HTC or other medical providers.***

Efficacy

As mentioned previously, all current products are considered very effective in controlling bleeding. But precise measurement of efficacy is difficult, and the assays used to calculate the unit activity of factor can show considerable variation from laboratory to laboratory. In addition, recovery of factor, i.e., the amount circulating in the blood after an infusion, can vary from patient to patient. Still, in general, a given amount of factor, for example, 1,000 units, should be equally effective no matter which brand is used. But some issues have arisen in this regard. For example, Wyeth's ReFacto brand was introduced in early 2001, and approximately two and a half years later, in the summer of 2003, Wyeth announced that they were revising their assay procedures to compensate for discrepancies that had been seen between their stated activity levels and those calculated on the same



product in some other laboratories. The end result was that Wyeth increased the amount of factor protein in each vial of ReFacto by approximately 20% to ensure that the stated unit activity was met. The point is not that ReFacto was ever ineffective, but rather that determination of activity level can be difficult to determine precisely, especially with new products using new formulations or new assays.

Reliability

A product's reliability depends primarily on the consistency and rigor of that product's manufacturing process. Strict quality control (QC) procedures are used by all manufacturers to ensure product consistency, but recent history has shown that even with these procedures in place it may be impossible for manufacturers to anticipate product demand and/or provide a fully adequate supply. When Bayer introduced their Kogenate FS, they could not supply it at the same level as they had with their prior version of Kogenate. Also, at around the same time, other manufacturers were limited in their scale of production as they transitioned to new manufacturing sites. In addition, FDA imposed restrictions on one manufacturer which limited that company's ability to provide a steady supply of factor. As a result of all these issues, there was widespread fear throughout 2001 and into 2002 that factor supplies would fail to meet demands, and patients were advised to consider steps such as postponing elective surgeries and holding off on beginning new prophylaxis regimens. In hindsight, it appears that the shortages were not as severe as they were perceived to be at the time, but the important lesson is that all products are susceptible to unanticipated problems in maintaining their supply, and newer products with less established manufacturing methods could be at particular risk. Fortunately, at the current time, there do not appear to be significant supply issues with any of the factor product lines.

Safety

In the early-to-mid 1980's, safety issues dominated all discussions of factor products, as the devastation caused by the widespread transmission of HIV and hepatitis became more and more apparent. Having seen what can happen when safety is not the foremost consideration, the hemophilia community has pledged to never again allow safety to become a secondary issue. However, the introduction of ultra-pure technologies such as monoclonal antibody

chromatography, the development of viral inactivation and removal systems, extensive donor screening for plasma-derived products and the development via genetic engineering of recombinant factor concentrates have all contributed to a situation where product safety is at an all-time high. Never in the history of hemophilia treatment have patients had access to products as safe and effective as those available to us today.

Ironically, it is partly due to the extraordinary level of safety of current products that so much confusion exists over the relative safety of different concentrates. The recent publicity over Advate typifies the issue. Advate, as a "third-generation" factor product, contains no animal or human proteins in any step of the manufacturing process. In response to the overwhelming threat of HIV and hepatitis in the recent past, as well as the perceived potential threat of CJD, nvCJD or other unknown, emerging infective agents, many consumer advocates have long argued for the development of such products. When Baxter introduced Advate, they naturally highlighted the absence of all animal and human proteins, since it was clear that many consumers and medical professionals considered this advance a significant step forward in terms of product safety.

However, in June 2004 the FDA sent a warning letter to Baxter demanding that they alter their marketing materials for Advate to remove statements implying that Advate was "safer" than other products. FDA regulations require companies to base any statements implying superior safety or efficacy on verifiable scientific data, and their stance seems to be that if none of the current products have any demonstrated safety problems, how can Baxter promote their product as having "unsurpassed safety?" The FDA was certainly not saying that Advate was any *less* safe than other products, but rather that Baxter did not have sufficient data to scientifically justify promoting their product as having superior safety. With such excellent safety records for all products, comparisons of relative safety today are often based on projections of potential, theoretical risks. While such theoretical risks can, and should, be weighed into the decision process when choosing a factor brand, it is also important to keep discussions of relative safety based as much as possible on actual scientific data, to lessen the chance of "safety" being reduced to a marketing buzzword.

(Continued on page 8)

*(Continued from page 7)***Should I Switch? (continued)****Cost**

One undeniable trend among new recombinant products is that each one has been more expensive than those already on the market. When the first two recombinant products, Baxter's Recombinate and Bayer's Kogenate, were initially made available a decade ago, both products were priced the same, at a price significantly higher than the monoclonally purified products that were then considered state-of-the-art. Since then, each new product (Kogenate FS, ReFacto and Advate) has been priced higher than previous products. Baxter has recently announced a price reduction for Advate in an attempt to bring the cost down closer to their competitors' products.

For patients with comprehensive insurance coverage and no lifetime caps, cost can often be a minor consideration. But for patients with lifetime caps, cost is critical, as today's patients can often reach a million dollar cap level within ten years. For these patients, even relatively small differences in price can translate to a year of more of coverage before a cap is reached. And even for patients without lifetime caps, the issue of cost containment can be an important factor, as awareness of the overall effect of high medical cost on the country's health care system becomes a major political and social issue.

Unfortunately, direct comparison of product prices is often impossible. Manufacturers do not directly set the price consumers pay, and neither homecare companies nor insurance carriers are as straightforward in disclosing prices as one might think. As a personal example, I was recently unable to obtain a direct price figure (unit cost) for the factor my son uses from either my homecare company or my insurance carrier, even though my employer uses a self-funding insurance plan. The best I could get after numerous calls was a figure from my homecare company stating how much factor had been shipped to us during a set period and a corresponding figure from my insurance provider stating how much they had paid over that same period; after correlating the two lists I was able to decipher the unit cost, but I also discovered that if the price changed over time I would not necessarily be notified by either the homecare company or the insurance carrier.

Whatever product you use, the cost is, and will likely remain, high. Perhaps competitive forces will someday lead to lower prices, although this does not seem likely at present. Neither does it seem as if improvements in manufacturing processes will necessarily lead to lower prices. The "B-domain deleted" version of factor VIII that is used in ReFacto is reportedly produced at yields that are many times higher than unmodified factor VIII, yet this increased yield seems to have made no significant difference in the pricing of ReFacto, which is at least as expensive as the first generation recombinant products. As with efficacy, reliability and safety, the differences in cost between products, and the relative importance of these those differences, need to be evaluated by each consumer according to his own individual situation and circumstances.

In summary, we can be grateful that all current factor products are very safe, effective, and reliable, and acknowledge the fact that they are all expensive. For now, a major influence on consumers' choice of product will likely remain subjective factors, such as their own personal history and comfort level with the manufacturer and their trust in the recommendations of medical professionals. But in determining which product to use, consumers should also ask questions, weigh the particular advantages and disadvantages of each product, discuss their options with their medical providers, and, in the end, choose the product that best fits their particular combination of medical, financial and personal needs.

-from NEHA News, Summer 2004

The Days Ahead

By Elena Bostick and Julie Frenkel

The following article was excerpted from the HAN-Journal, Volume VII, Issue 2, August 2004 with the permission of the authors. For a copy of the entire article written by Elena and Julie, contact the HACA office at 703-352-7641.

The state of the nation's healthcare and reimbursement system has reached a very dangerous point, with no solution in sight.

Triple digit federal deficits; federal cuts to state programs; budget deficits in virtually every state;—and everyone is looking to make it up on the healthcare dollar. As a result, everyone is scrambling.

In December 2003, the federal government enacted the Medicare Prescription Drug Improvement and Modernization Act. If this is Congress's view of improvement – we are in big trouble. Among other provisions, the law calls for the following changes:

Beginning January 2005, hemophilia therapies will be reimbursed at cost, +6% + a dispensing fee yet to be determined. (*Ed note: In November of 2004, CMS announced a dispensing rate of \$.14 per unit*) The 20% co-pay that most families cannot afford – remains intact. Homecare companies that had been absorbing the co-pay will no longer be able to do so. The likelihood is that those individuals on Medicare, usually the most vulnerable of our community, will be forced back to the emergency room for treatment.

Beginning January 2006, Medicare Supplemental Insurance policies, also known as Medigap policies will no longer provide prescription drug benefits. It will be against the law. The federal government's rationale for this is that senior citizens take too much medication. Instead, a prescription drug plan will become available – for a cost – through Medicare – and only through Medicare. Which drugs will

be available on Medicare's formulary is anybody's guess.

Keep in mind, Medicare sets the standard for reimbursement. State medicaid and private payers usually follow suit.

Government is reducing payments or otherwise restricting access for many healthcare products and services in an effort to balance budgets. Private insurers are doing the same to increase what, in many cases, is an already sizeable bottom line. – For the medical insurance industry, the individual policy market is the least profitable of all their products. Generally, people with chronic illnesses or other health issues, will purchase policies in this market. Some in the insurance industry have reasoned that if they could rid themselves of the individual market, they could maximize profits even further.

We know that one day a cure will be found for hemophilia. We know that until then, hemophilia therapies will continue to improve to a point that perhaps one day a pill or patch may be all that is required. However, we also know that our families must get from here to there with patient choice, access to care, and reimbursement intact. To do this, we will need your help. As a community, as a state, and as a nation, we must take healthcare back.



(Continued from page 5)

If Your Insurance is Interrupted (continued)

factor may be provided free to patients who qualify. Their plan is quite broad and information is available at 877-668-6777 and on their website: www.us.novoseven.com/content/us.verus.seven.secure.asp.

Note that some, but not all, of these plans require that you have insurance to register. It is important that you not let your insurance coverage voluntarily lapse. For example, if a change in employment has forced you to a COBRA plan and the insurance premiums are too costly to maintain on your own, the non-profit organization Patient Services Incorporated may be able to help you with your premiums. Many of the factor manufacturers work directly with this agency. You may contact them at 800-366-7741.

All of these programs are relatively new and may change in their benefits and requirements. The factor manufacturers are making an effort to inform their patients in a variety of ways. Bayer, for example, is working with the home care providers to put notices about their plan in each shipment of factor. The home care companies and treatment centers are often the direct link to individual patients. They, therefore, may be the most convenient source of information on these various plans. The manufacturers do make an effort to keep these providers informed.

Adapted from NEHA News, Fall 2004

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Hemophilia Association of the Capital Area

Volume 2, Issue 1

February, 2005

YOUNG PEOPLE'S PAGE

Is Skiing Safe?

By Lauren A. Kelly

Skiing is an exciting sport. It involves braving the cold winter weather, strapping on a pair of long skis and riding up a hill or mountain to slide down quickly. For some people it is terrifying, for others exhilarating. How dangerous is it?

Some hemophilia doctors and organizations discourage kids with hemophilia from certain sports, like boxing. Some may tell you that downhill skiing is too dangerous, too. But unlike sports like boxing, skiing can be recreational, relaxing yet vigorous. It can provide you with much needed exercise. Children as young as three can start skiing, when enrolled in age-appropriate classes. People with many disabilities including those who only have one leg or those who have hemophilia, can ski. It is an excellent way to build confidence and self-esteem.

Legomania!



Congratulations to our own Ben Hubbert! He and his team, named "Insert Name Here" at HB Woodlawn Secondary School in Arlington, VA finished in the top three in the Northern Virginia regional Lego Robotics competition held November 21, 2004. In this competition, young participants build a robot and compete using LEGO Mindstorm kits, gaining hands-on experience in engineering and computer program-

When you learn how to ski—properly— you feel great!

While skiing can be fun and good for your physique, skiing takes responsibility and skill. Skill is essential in skiing. To become skilled, you can take ski lessons at any ski location. And ski slopes are always marked to tell you the level required to manage a safe trip down the hill. Most ski slopes are marked, "Beginner", "Intermediate", and "Expert".

Beyond skill, you also need a few more things, like proper equipment and good judgment. Proper equipment includes good skis, ski poles and warm winter clothing. Your skis should be appropriate for your age.

If you are thinking of learning to ski, and have hemophilia, think of ways you can protect yourself:

- You should definitely wear a helmet. Even if you become an expert skier someday, there will be others on the slopes who may not be.

ming. This year the theme of the challenge was to build and program a robot that addressed the specific needs of people who face physical challenges in today's society. The HB Woodlawn team also won first place in Robot Design and Robot Performance. They qualified for the State championships that were held on December 5, 2004 at Virginia Tech. Way to go, Ben and team!!

They can always crash into you. Your brain is too important to be left unprotected.

- Infuse factor before you ski. This may prevent a bleed from starting in case you are injured, or even just fall without apparent injury.



- Wear knee and elbow pads under your ski suit. These will protect your joints.

- Exercise before you begin a ski program to get in shape. You will need flexibility, so you don't stretch and tear your muscles, and strength to control your turns. Do stretching exercises before each ski session.

- Start slowly and carefully. Don't expect to learn how to ski in one season. It may take a few years before you are able to ski on your own, without instruction.

- Discuss whether skiing is right for you with your parents and doctor. Your doctor can tell you whether the risks outweigh the benefits. No two kids with hemophilia are the same. Some will be ideal candidates for skiing;

others will not. Ask yourself: how are my joints? Do I have a target joint? Do I have a lot of bleeds into my ankles and knees? Am I strong enough? Am I coordinated?

Remember, there are lots of ways to enjoy cold weather sports. If you can't ski, you can always try other recreational activities.

- excerpted from *Factor Friends*, January 1998 (Vol.7, No. 1)

Happy January/ February Birthday to:



- Aidan Cassidy Jan. 1
- Sam Doughty Jan. 1
- Adam Joson Jan. 1
- Eric Martinez Jan. 1
- Rachael Pascale Jan.1
- Brandon Barrett Jan. 9
- Kayleigh Spears Jan. 15
- Dennis Scott Jan. 18
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- Mary Elise Handermann Jan.30
- Andrew Knott Jan. 30
- Jacob Birkholz Feb. 6
- Kaison Tanabe Feb. 9
- Spencer Duggan Feb.16
- Hunter Plaines Feb. 17
- Andrew Portare Feb. 24
- Harvey Gates, Jr. Feb 28
- James Morris Feb. 28

WHO SAID IT?

- (1) "If you can dream it, You can do it."
- (2) "To achieve greatness: start where you are, use what you have, do what you can."

(2) Arthur Ashe
(1) Walt Disney

HACA News

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