

CENTRAL VIRGINIA CENTER FOR COAGULATION DISORDERS NEWSLETTER



Virginia Commonwealth University Medical Center

VCU extends a big thanks to all of the patients and families as well as advocacy groups at the Virginia Hemophilia Foundation and Patient Services, Inc and the statewide Hemophilia Advisory Board! Through your advocacy work with the Virginia Department of Health has agreed to fund the Virginia Bleeding Disorders Program at the same levels for FY2012.

WAY TO GO!

Treatment Center News

CVCCD Involvement with ATHN Dataset

Through the use of technology, ATHN (the American Thrombosis and Hemostasis Network) helps providers improve clinical results, prevent care disruption, support research, expand collaboration and

protect confidentiality. ATHN is currently working in conjunction with the Central Virginia Center for Coagulation Disorders to establish and maintain the ATHNdataset; a safe, secure national database to improve the quality of care for patients with bleeding disorders.

Now, the CVCCD is extending the opportunity for you to participate in the ATHNdataset. This vitally important database is devoted to research for bleeding and clotting disorders that will advance clinical knowledge; support advocacy to ensure access to and funding for treatment; and improve the quality of your medical care.

Among the greatest benefits of the ATHNdataset, however, is its power to begin addressing questions about bleeding disorders and their treatment that haven't been answered simply because there hasn't been enough standardized data. The ATHNdataset opens the door to new possibilities for the bleeding disorder community, now and for generations to come. The value of the ATHNdataset lies

in your participation! The more patients contribute their information, the more certain we can be that the ATHNdataset represents community characteristics. That's a benefit to you- and to the entire community!

Chapter News

The Chapter has a variety of fun programs planned for this spring and summer. For more information about any of these events, please contact VHF at 1-800-266-8438 or visit them online at www.vahemophilia.org

Here are just a few of the upcoming events, activities, and programs you should know about:

UVC Lyman Fisher Scholarship

The Virginia Hemophilia Foundation (VHF) offers two scholarships of \$2000 each to members of the bleeding disorders community and their families who are residents of Virginia. The deadline for the Lyman Fisher scholarship is **May 6th, 2011**.

"Tastes Around the World": VHF Wine Tasting and Raffle Event

Support VHF as it continues its mission of serving and supporting the needs of those impacted by a bleeding disorder through education, advocacy, and community by attending their 7th annual wine tasting event **Sunday, April 17, 2011, 3-5 PM.**

Taste a selection of wines, hors d'oeuvres, and desserts and listen to live music. A raffle and silent auction will also be held.

Tickets are \$40 per person/\$75 per couple. Please contact VHF if you are interested in attending.

A portion of the proceeds will be donated to the World Federation of Hemophilia.

Chapter Annual Meeting

When: **Saturday - June 18, 2011, 8:30 a.m.**

* A dinner event will also be held **Friday, June 17th at 6:00 PM**

Where: Second Baptist Church,
9614 River Road,
Richmond, VA 23229

What:

- State Educational Meeting
- Chapter Business Meeting
- Presentations on genotyping and joint health
- Exhibits by Sponsors
- Special Program Just for Kids (5 and up)
- Childcare (4 and under)

Where to Stay:

Please call VHF so that they may reserve your hotel room at Fairfield Inn and Suites, 9937 Mayland Drive, Richmond, VA 23233, (804) 545-4200. Hotel rooms are \$72 per night. Assistance is available to qualified families or individuals.

Summer Camps

Camp Youngblood at Holiday Trails

The chapter will once again host Camp Youngblood at Camp Holiday Trails in Charlottesville, VA from **July 24th to July 29th**. Plan to join other youth from throughout the state for a great week of fun! The camp features:

- 75 acres of beautiful woodlands and hiking trails
- 5 youth cabins and 2 Blazer (teen) cabins
- Swimming, arts and crafts, drama, music, dances, talent show, campfires, etc.
- Sport Court
- Challenge Course with Climbing Wall Therapeutic Riding Program
- Waterfront with canoeing, kayaking and fishing
- MedKorner - fully equipped healthcare center

Applications are available online at www.campholidaytrails.org or www.vahemophilia.org or call 1-800-266-8438.

The cost of the camp is free. However, there is a \$25 refundable

application fee.

VHF Family Camp at Camp Holiday Trails

Do you want to engage in exciting family camp activities like horseback riding, canoeing, swimming and campfires? Do you like to have fun, play games, eat great food, meet new people and learn? Do you like to share stories, experiences and laughs with other families and kids that have things in common with you? Do you want a place that is special just for your family? If you answered 'yes' to the above questions, then VHF's Family Camp is the place for you!

VHF's Family Camp is a traditional camp for the whole family to attend. Activities include:

- A mixture of traditional camp activities, discussions and crafts
- Opportunities to meet other families and kids
- Music concert, flag ceremony and ice cream social
- Socializing and making healthy treats around the campfire

Guests will stay in private family cabins with 8 bunks, bath/shower and AC/heat in the cabins.

Space is limited so please apply ASAP if you are interested! The camp will be open from **May 27th – May 29th, 2011.**

For more information and an application for VHF Family Camp Weekend, call (800) 266-8438, vahemophiliad@verizon.net or

Camp Holiday Trails at (434) 977-3781, www.campholidaytrails.org.

Medical Research

Mechanisms of Race-Based Differences in Factor 8 Immunogenicity in Hemophilia

The VCU Coagulation Disorders Center is participating in a study sponsored by the National Institutes of Health (NIH), looking at why some people develop antibodies (inhibitors) to factor 8 that they give themselves to treat or prevent bleeds. When a person develops an inhibitor to factor 8, this prevents the factor from raising the level in the blood stream, making it ineffective in treating or preventing a bleed. Little is known about exactly why an inhibitor develops. What is known is that black hemophilia patients seem to get inhibitors more frequently than white hemophilia patients. This study is looking at immune responses and genetic differences in people, both black and white, with and without inhibitors. The goal of this study is to learn why inhibitors develop in some patients with factor 8 deficiency. People with factor 8 deficiency may be asked to participate in this study. If you participate, you will be asked to donate blood samples once, usually at an already scheduled clinic appointment. Please call the center if you have any interest in or questions about this study.

Resources

Understanding Patient Assistance

Experiencing a break in insurance coverage can happen to anyone. Just about any major event in life can cause a loss of benefits. No matter what the situation, manufacturers' patient assistance programs can help. There are two basic kinds of programs.

The first type provides emergency factor to customers who already use the manufacturer's product and experience a gap in insurance coverage. The other type provides a limited amount of factor to people who have low incomes and no insurance coverage at all. Typically, you must be a legal resident in the US to be eligible for the latter.

Within the customer-oriented programs, there are also two variations. One kind simply provides factor to customers who experience a gap in insurance coverage. The other kind works like a loyalty program. In these programs, customers earn credits or coupons to redeem later if they have a break in insurance coverage.

The factor doesn't come directly from the manufacturers. Instead, it comes from hemophilia treatment centers, homecare companies, pharmacies and the like. Some times companies will give you a credit or a voucher to use at any pharmacy.

Similar patient assistance programs are available from manufacturers of

drugs for hepatitis C and HIV. Typically these companies don't require that you be using the product beforehand.

Source:
www.hemaware.org/store/patient-assistance-programs

Government Eases Eligibility Requirement for Children in PCIP

On February 17th, the US government issued a policy guidance reaffirming that children under the age of 19 would be eligible for the government-sponsored Pre-existing Condition Insurance Plan (PCIP). The PCIP program is similar to high-risk pools available in many states, but is designed to cost the same as the average private insurance plan.

In the past, to be eligible for the PCIP, a person had to prove he or she was denied coverage by a private insurer, or was offered coverage at a price that was twice the standard market rate. Patients under 19 only need a signed statement from a healthcare provider affirming that they have been diagnosed with a pre-existing condition.

Source: Hemophilia.org Article Government Eases Eligibility Requirement for Children in PCIP

Transition

By Lauren Dunn, MSW

Adolescence is an exciting and sometimes challenging time for many families. Teens begin exploring new interests and start to gain independence from their parents. Along with the everyday challenges all teens face during this transition time, teens with a chronic illness have the additional task of learning to manage their condition on their own.

This transition is a time of change for parents too. Seeing your child become more independent can be incredibly rewarding, and at the same time, very scary. If you have intensively managed your child's treatment for many years, letting go of some of that control can be difficult. Through the transition, your role as a parent will change.

Here are a few tips to help empower your teen during this transition:

- 1) Model behavior for your teen. Encourage them to listen when you call to make a medical appointment, talk with the insurance company, or ask a question of the treatment team. This may seem like a simple task, but for a teen that's never had to do this it can be intimidating.
- 2) During clinic visits, encourage your teen to begin communicating directly with the treatment team members. As they become comfortable with this, allow them to spend some

time alone with the treatment team.

- 3) Allow your teen to have a voice in their treatment and acknowledge that their input in treatment decisions is important. Work together with your treatment team to develop a plan that both you and your teen feel is reasonable.
- 4) Encourage your teen to participate in social activities and camps hosted by the treatment center and local chapter. Meeting others that are coping with the same issues can be a good support during this time.
- 5) Be patient. Some teens may take on responsibility for all of their medical management at once, while others may need to begin with one thing at a time. It's important to set realistic goals that your teen will be able to accomplish. With each accomplishment, they will develop greater confidence in their ability to take on the next challenge.
- 6) Provide your teen with guidance and assure them that you are still there to help. Let them try to do things on their own, but be ready to step in when needed.

Remember, with your guidance and support, your child has lived with their bleeding disorder for many years. As a parent it will be difficult to see them face challenges and

possibly stumble along the way, but this step is important for them. Don't forget that you always have the support of your treatment center, the local chapter, and many members of the bleeding disorders community to help you through this transition.

For more information and online resources for transition, check out these website:

Healthy Transitions NY:
<http://healthytransitionsny.com/site/view/152>

University of Florida, Healthcare Transitions Initiative:
<http://hctransitions.ichp.ufl.edu/>

Adolescent Health Transition Project:
<http://depts.washington.edu/healthtr/>

Children's Memorial Hospital, Chronic Illness Transition Program:
<http://www.childrensmemorial.org/professionals/transition-resources.aspx>