

CENTRAL VIRGINIA CENTER FOR COAGULATION DISORDERS NEWSLETTER



Virginia Commonwealth University Medical Center

Programs/Activities for Patients and Families

Ladies Night Out: Cooking Class

The center is partnering with VHF to present an interactive program for women with bleeding disorders on **Wednesday, April 15, 2009**. Join Janet Willis, MPH, RD from VCU and other women with bleeding disorders to learn about nutrition and healthy eating through a cooking class at Sur La Table at Stony Point Fashion Park. Space is limited! For more info, or to RSVP, contact the chapter at (800) 266-8438. Special thanks to CSL Behring for sponsoring this event!

Health Insurance Dinner Program

On **March 24, 2009**, the center and VHF offered an educational program on health insurance for members of the bleeding disorders community. Lauren Dunn, CVCCD social worker, presented an overview of health insurance and discussed the impact of the new economic stimulus package on access to healthcare. Special thanks to the

chapter and AHF for sponsoring this program.

NHF YMCA Initiative: Fitness and Fun

The Virginia Hemophilia Foundation (VHF) is one of 6 sites in the country chosen to participate in an exciting new fitness initiative. The center is partnering with the VA Hemophilia Foundation, the National Hemophilia Foundation (NHF) and the YMCA to enable patients and their families with bleeding disorders to join the YMCA in the Greater Richmond area.

Currently 5 families have joined this new program, where participants get a no-cost monthly membership the YMCA in exchange for regular participation.

There are only a few openings left! To find out more about this exciting opportunity, please contact Kelly Waters at 1-800-266-8438 or vahemophiliaed@verizon.net

Treatment Center News

CAB Meeting

The VCU Consumer Advisory Board meeting is scheduled for **Wednesday, May 6, 2009** at 10am at VCU Medical Center. If you are interested in attending the meeting, please contact the center for information.

Ob/Gyn Provider Outreach

On May 5, 2009, Dr. Barrett will be presenting at an educational dinner targeting Ob/Gyn providers in the Richmond area. He will be discussing symptoms of vWD in women, diagnosis, and treatment options for managing bleeding disorders.

Region III Annual Meeting

The HTC clinicians recently attended the region III meeting in Alexandria, VA, an annual meeting for region III treatment centers and chapters. This year's agenda included a regional update and several clinical presentations.

Participants were also able to meet in breakout sessions with members from each discipline to share ideas.

Chapter News

Wine Tasting Fundraiser

Where: Agecroft Hall and Gardens
www.agecrofthall.com
4305 Sulgrave Road
Richmond, VA 23221

When: Sunday, April 26, 2009
3-5 p.m.

What: Taste a selection of specially selected "Spring Wines", hors d'oeuvres, raffle and silent auction, and live music.

Cost: \$40 per person/
\$75 per couple

RSVP: 1-800-266-8438 or
vahemophiliaed@verizon.net by
April 17.

Family Camp

Join VHF for Family Camp- an educational and supportive time for families – but best of all it will be a time of traditional camp fun for the whole family!

When: May 22-24, 2009

For more information and an application contact VHF at (800) 266-8438, vahemophiliaed@verizon.net or Camp Holiday Trails at (434) 977-3781, www.campholidaytrails.org or campisgood@campholidaytrails.org

Camp Youngblood for Adults!

This special camp is designed for adults 21 and over. Participants will have the opportunity to network with other adults, in a relaxed camp setting, that share common joys, worries, concerns, and questions.

Camp features:

- Cabins with AC/heat and remodeled bathrooms and showers
- Room for each individual/couple to have their own space
- Lots of fun through a lively mixture of traditional camp activities, discussions and crafts

When: Saturday, May 30-
Sunday, May 31, 2009

RSVP: Call or email Kelly Waters at 1-800-266-8438 or
vahemophiliaed@verizon.net

VHF Chapter Annual Meeting

Mark your calendars for the Virginia Hemophilia Foundation's (VHF) 2009 Annual State Meeting

When: Saturday, June 20, 2009

Where: YMCA – Shady Grove
11255 Nuckols Road
Glen Allen, VA 23059

What:

- Chapter Business Meeting
- Factor 8 – Medical Update
- Fit for Life - Health and Wellness for All
- The Importance of Grassroots Advocacy
- Kids program focusing on Health and Wellness (kids 5 and up)
- Childcare (kids 4 and under)

- Dinner Cruise along the James River (Space is limited)

Bonus: Drawing for Free Trip to the NHF National Meeting in San Francisco!

To learn more about additional programs to register for one of these programs please contact VHF at vahemophiliaed@verizon.net or (800) 266-8438.

Legislative News

American Recovery and Reinvestment Act of 2009: COBRA Assistance

The American Recovery and Reinvestment Act of 2009 (ARRA) provides for a 65% reduction in COBRA premiums for certain assistance eligible individuals for up to 9 months. An assistance eligible individual is a COBRA "qualified beneficiary" who meets all of the following requirements:

- Is eligible for COBRA continuation coverage at any time during the period beginning September 1, 2008 and ending December 31, 2009;
- Elects COBRA coverage (when first offered or during the additional election period), and
- Has a qualifying event for COBRA coverage that is the employee's involuntary termination during the period beginning September 1, 2008 and ending December 31, 2009.

Those who are eligible for other group health coverage (such as a spouse's plan) or Medicare are not

eligible for the premium reduction. Other limitations may also apply. There is no premium reduction for periods of coverage that began prior to February 17, 2009.

The Department of Labor is actively working to issue additional guidance regarding the COBRA premium reductions. You can also contact a Benefits Advisor by calling toll free 1.866.444.3272 for more information. More information is also available at: <http://www.dol.gov/ebsa/>

VA General Assembly Update

This session, both the house and the senate passed bills (HB 2024 and SB 1411) that allow health insurers to offer and sell group health insurance policies or contracts that do not include state mandated health insurance benefits to employers with 50 or fewer employees to provide coverage for employees who have been uninsured during the preceding six months. Such a group policy or contract may include any, or none, of the state-mandated health benefits as the health insurer and the qualified small employer agree. The VA Hemophilia Foundation was actively involved in advocating to protect the hemophilia mandates. To learn more or to get involved in advocacy, please contact the chapter.

Summer Camps

It's time to start thinking about summer camps! Check out these

options available to your children:

Camp Youngblood at Holiday Trails

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

When: **July 26- 31, 2009**

Where: Charlottesville, VA

Contact: 1-800-266-8438

vahemophiliaed@verizon.net

For more information about Camp Youngblood, read Jan Kuhn's article on page 4.

Camp Victory Junction

Camp Victory Junction is hosting its 4th year of hemophilia camp. This year's theme is "NASCAR" and it's sure to be an exciting week!

When: **June 21- 26, 2009**

Where: Randleman, North Carolina

Contact: (336) 498-9055

www.victoryjunction.org

Industry News

Baxter Acquires New FVIII Compound

In December 2008, Avigen, announced that it sold its rights to an early-stage blood coagulation compound (AV523), to Baxter Healthcare Corporation. An *orally* administered drug, AV513 is being developed for the treatment of hemophilia A and related bleeding disorders. The drug contains fucoidan, a type of polysaccharide (carbohydrate that contains sugar

molecules linked together chemically) extracted from sea algae, which has been shown to boost blood clotting. While early studies showed promising results, further development of the therapy will depend on additional clinical research.

Pfizer Acquires Wyeth

Pfizer has agreed to acquire Wyeth Pharmaceuticals for \$68 billion. Wyeth manufactures several products to treat bleeding disorders including Benefix, ReFacto, and Xyntha. Please note that **ReFacto will no longer be available after May 31, 2009**. Patients who are currently treating with ReFacto should talk with their HTC about the various options for factor VIII replacement therapy.

Patient Resources

Strap Wrap Medical ID

The "Rescue Facts" Emergency Medical ID Strap fits on your seat belt, and can communicate crucial information to EMS in the event that you are unable to speak or communicate. The Medical ID Strap is a nylon, embroidered strap. The medical symbol is either embroidered or silk screened onto the strap. The strap wraps around the item and is secured by Velcro. Inside the strap is a pocket designed to hold the paper medical information insert card. If you'd like to order a strap wrap, please visit the Rescue Facts website at www.rescuefacts.com

Camp Youngblood

by Jan Kuhn, RN, MPH and
Zach Morris

It may only be April, but it's time to think again about summer vacation!

The Virginia Hemophilia Foundation offers a great opportunity for patients with inherited bleeding disorders and their siblings to attend a weeklong camp at Camp Youngblood. What makes Camp Youngblood so special? The Campers!! What else is great about Camp Youngblood? The great facility at Camp Holiday Trails and the team of committed staff and experts! Here's a few highlights of the camp location:

- Med Korner - fully equipped, bright & cheery healthcare center
- 75 acres of beautiful woodlands and hiking trails
- 5 youth cabins with 2 sides joined by a porch (10 fully accessible bathrooms with roll-in showers completed with the Building Goodness Foundation Sep. '08!)
- 2 Blazer (teen) cabins
- Dining Hall (floors refinished Nov. '07!)
- Commercial Kitchen (remodeled in Jan. '07!)
- Activities Pavilion with campfire circle, BBQ

- Sport Court
- Swimming Pool
- TP Hill with campfire circle and outdoor sleeping platforms (100+person campfire circle completed with APO service fraternity, Spring '07!)
- Challenge Course with Climbing Wall (high and low ropes elements)
- Waterfront with canoeing, kayaking and fishing
- Activity areas for nature, drama, music, arts & crafts, sports, cooking and more.

The hemophilia treatment center nurses at University of Virginia and Virginia Commonwealth University participate in the camp. The nurses assist with the opening day clinic preparation, daily medical triage, training on home infusion and just having fun!

Here's an interview from one of our "seasoned" campers, Zach Morris:

"Hi my name is Zach Morris and I am 14 years old. I have a bleeding disorder called hemophilia. I have been going to Camp Youngblood at Camp Holiday Trails for two years. Some things I like best to do at camp are hanging out with my friends and playing games like Knockout and beating my friends like Trey, Hahahahahahahahahahaha! I have returned for the past two years just because it is a safe, fun way to meet new friends with hemophilia or other

blood disorders. There are not many things that could make my camp experience better because it's already such a great camp but one thing is that you could add like a snack machine, if you just wanted a snack. My favorite Camp Story is about the family who died who lived near the camp and the daughter was found in the lake but I won't go into too much detail because you will just have to go to the camp and find out the rest of the story. I hope that one of my camp buddies from the past can come for the whole time this year, Mr. Matt Gates. I hope I can see a bunch of you cool guys from the past and meet new people too. Peace!"

Come join us from July 26-31, 2009!
See page 3 of this newsletter for more information about enrollment.



Jan Kuhn, RN, MPH is the nurse coordinator for CVCCD and program director of the VA Bleeding Disorder Program.

Zach Morris is a 14 year old young man with severe factor VIII deficiency from Salem, VA.