

CENTRAL VIRGINIA CENTER FOR COAGULATION DISORDERS NEWSLETTER

Virginia Commonwealth University Medical Center



Way to Go, Damon!

The CVCCD would like to recognize Damon Reynolds for his community volunteer work. He has volunteered his time to the Covington animal shelter, helped with the local bloodmobile services, and worked during Presbyterian mission week to build a porch for a family in his community.

Thanks for your hard work,
Damon!

2010 Hemophilia Advisory Board Meeting

The Governor's Hemophilia Advisory Board (HAB) met on December 10, 2010 in Richmond.

The agenda included an update on the work of the Obesity Subcommittee. This group reviewed the concerns about obesity in the hemophilia

population and is working on strategies for the HTC's and chapters to address these concerns. The HAB supported the hosting of the second Transition Summit. HTC representatives met in 2008 to discuss current issues regarding the unmet needs of young adults transitioning from pediatric to adult care and developed a strategic plan to address some of the barriers identified. The next summit will continue this work, especially in light of changes in health care. The HAB also reviewed the work of the Virginia Bleeding Disorders Program (VBDP) in the areas of von Willebrand outreach, and Lauren Dunn presented an overview of the impact to-date of new health care reform issues. Finally, the proposed 48% cut to the VBDP was discussed by the HAB. The HAB expressed discussed at length the proposed funding cuts and agreed to write a letter to the Commissioner of Health sharing their concerns.

Programs/Activities for Patients and Families

Holiday Breakfast

VCU and the VA Hemophilia Foundation hosted the annual holiday breakfast on December 11, 2010. This year's event was once again a great success! Special thanks to the women's circle at Ramsey United Methodist Church for preparing a delicious breakfast and also to the chapter and all the volunteers who continue to make this event a success!

Treatment Center News

HTC Pharmacy Now Enrolling Patients

The CVCCD homecare program is now operational and enrolling patients. As a federally designated Comprehensive Hemophilia Treatment Center, the CVCCD is eligible to participate in the 340B Drug Pricing Program, a federal discount program that allows

HTCs to purchase clotting factor at a discount for their patients. Congress established the 340B Program as part of the Veterans Health Care Act of 1992 to enable HTCs and other covered entities to stretch their resources and provide services to patients.

Patient participation in the pharmacy program is optional. If you are interested in learning more about the CVCCD homecare program, please call the center at (804) 827-3306.

For a listing of additional homecare pharmacy options, please visit the center website at <http://www.vcuhealth.org/cvccd/resources/companies.html>

NHF Social Work Working Group Update

By Lauren Dunn, MSW

NHF's 62nd annual meeting recently wrapped up in New Orleans, LA. As you may remember from the last newsletter, the social work working group initiated a service project this year to collect supplies and donations for the lower 9th ward community health clinic. I'm please to announce that this project raised \$670 in financial support and numerous supplies for the clinic. Thanks to all of you who helped contribute at making this program a success!

Through my position on the social work working group, I have had the opportunity to work on a research subcommittee that has been assessing to role of the

HTC social worker. This subcommittee had two poster abstracts accepted at the meeting, and also presented an educational session to share results with social workers as part of the annual meeting.

It's hard to believe, but this month the working group will begin planning for NHF 2011 in Chicago, IL! As I enter my final year as the region III representative for the social work working group, I'd like to thank the VCU HTC for all of the time and support provided to me so that I could be part of this working group.

Chapter News

Chapter Advocacy Day

Walk the halls of the Virginia General Assembly with other community members as a part of the VA Hemophila Foundation's 5th Annual Advocacy Training and Lobbying Day. Here you will get a unique opportunity to discuss Virginia's advocacy agenda with your legislators.

The event will be broken into two parts: Advocacy Training and 'Richmond Days' Advocacy Day.

Advocacy Training will take place on **January 16th** at the Omni Richmond Hotel. The time is yet to be decided, and dinner will be provided.

Advocacy Day will take place **Monday, January 17, 2011**

(Martin Luther King Day) The General Assembly - Room 5 West

For more information call 1-800-266-8438 or email vahemophilaed@verizon.net

Youngblood 5K

Join the chapter **Saturday February 19th** for a fundraising run to support treatment, education and advocacy for children and adults with bleeding disorders.

The run features a flat course, virtually all trails, in expanded Robious Landing Park in Midlothian. Only 5 minutes from the new Route 288 Bridge for easy West End Access. (Park is located off Robious Rd next to James River H.S.)

Contact the chapter to register.

Chapter Mailing List

Don't miss out on any of the great programs offered by the chapter for 2011! If you're not already on the chapter mailing list, please take a few minutes to complete the membership application at the end of this news letter and return it to the chapter as soon as possible.

Scholarships



It's time to start thinking about those college applications! Here are a few of the scholarships available to members of the bleeding disorders community:

UVC Lyman Fisher Scholarship

The VA Hemophilia Foundation offers two scholarships of \$2000 each to members of the bleeding disorders community and their families. This scholarship is available only to residents of Virginia and applications. Contact the Chapter at 1-800-266-8438 or get an application online at www.vahemophilia.org to apply.

National Scholarships

The National Hemophilia Foundation provides a listing of over 20 different scholarships opportunities for those affected by bleeding disorders. Please visit the "About Us" tab on the NHF Website at: www.hemophilia.org or call the center for a listing of the various national scholarship offers.

Internet Resources



Do you use Facebook or Twitter? Social networking sites are great tools for linking people with common interests and allowing them to interact with different organizations.

Many groups dedicated to helping individuals with hemophilia and their families also have social networking links to better keep their users up to date. Here are just a few:

National Hemophilia Foundation:

- Facebook:
<http://www.facebook.com/NationalHemophiliaFoundation>
- Twitter:
http://twitter.com/NHF_hemophilia

Hemophilia Federation of America:

- Facebook:
<http://www.facebook.com/hemophiliafed>
- Twitter:
<http://twitter.com/hemophiliafed>

VA Hemophilia Foundation:

Please visit their website: <http://www.vahemophilia.org/> for a link to their Facebook page (click the 'Facebook' icon located in the upper right hand corner of your screen)

Advoy.com Online Infusion Logging Software



'Advoy' is an online infusion logging software that is a great alternative to using paper logs or keeping track of individual box tops. Advoy is very user friendly and is as simple to access as your e-mail. All you need is access to internet and you can use Advoy.com for your infusion logging.

If you are interested in trying Advoy.com please call Jamie Leonard at 804-827-3306. Your center's Data Coordinator will create a free account for you so that you can start logging your infusions right away.

The Alliance for a Healthier Generation

By Candice Robinson



In Virginia the prevalence of childhood obesity is on a steady rise with 31% of Virginia children aged 10 to 17 years old being overweight or obese. To address the problem of obesity, the Alliance for a Healthier Generation was founded by the American Heart Association and William J. Clinton Foundation in 2005. In February, 2009 the Alliance for a Healthier Generation launched an Alliance Healthcare Initiative with a mission to reduce the nationwide prevalence of childhood obesity by 2015. Currently the Alliance Healthcare Initiative has its spotlight on Virginia and is addressing factors that affect childhood obesity to promote healthier lifestyles and motivate children to develop healthy lifelong habits.

One approach the Alliance for a Healthier Generation took in addressing the issue was to build a coalition of leading medical health insurers, employers and national medical associations. The intent of these collaborations was to offer comprehensive

health benefits for the prevention and treatment of childhood obesity. In result of their efforts more than one million children received access to a minimum of four follow up visits with a registered dietitian and four follow up visits with their primary care provider. Listed at the end of this article are the medical health insurers, employers and national medical association that participate in the Alliance Healthcare Initiative.

The Alliance Healthcare Initiative has taken steps to fight childhood obesity that have never been taken before. For the first time insurers and employers have agreed to offer benefits that prevent childhood obesity and utilize benchmarks to guarantee that the child benefits. The children who participate in the initiative will have individual evaluations that determine their overall health outcomes. To add, the Alliance Healthcare Initiative has an online website called empowerme2b.org that children can join that offers support, informational tools, and encouragement.

In Virginia the Alliance Healthcare Initiative is currently being piloted as a program called the Virginia Roll Out through Anthem Blue Cross and Blue Shield of Virginia. To be eligible for the Virginia Roll Out children must be between 3-18 years of age and be at or above the 85th percentile body mass index for their age.

Participants include:

- Accenture
- Aetna
- the American Academy of Pediatrics
- the American Dietetics Association
- Blue Cross of MA
- Blue Cross of NC
- Humana
- Nationwide Children's Hospital
- PepsiCo
- WellPoint.

Aetna has also recruited several employers including:

- Houston Independent School District
- Owens Corning
- Paychex.

The AHA and the Clinton Foundation are offering the benefit as well.

If you are interested in obesity and hemophilia, follow the work of the HAB subcommittee or volunteer to participate as a consumer representative by calling Jan Kuhn or Candice Robinson at 804-827-3306.



2011 Calendar

*Changes to the event calendar are possible. Please call the VHF office to confirm event details.

January

- January 16 and 17 - Advocacy and Lobby Day, Richmond, VA - Martin Luther King Day

February

- February 16-18 - NHF Washington Days
- February 19 - Youngblood 5K Race (Richmond, VA)

March

- March – Ladies Night Out

April

- April 7-8 – Region III Annual Meeting
- April 14-16 – HFA Annual Meeting and Educational Symposium (Louisville, KY)
- April 17 – World Hemophilia Day
- April 17 - Wine Tasting Fundraiser (Richmond, VA)

May

- May 6 – Lyman Fisher Scholarship is Due
- May 27-29 - Family Weekend (Charlottesville, VA)

June

- June 18 – Annual Meeting (Richmond, VA)

July

- July 24-29 - Camp Youngblood at Camp Holiday Trails (Charlottesville, VA)

August

- August - First Step Picnic
- August – Back to School Picnic

September

- September – Family Overnight
- September – Adult Retreat

October

- October - Golf Tournament Fundraiser (Richmond, VA)
- October – Fall Event

November

- November 10-12 – NHF Annual Meeting (Chicago, IL)

December

- December – Holiday Parties (Charlottesville, Richmond, and Norfolk, VA)



VA Hemophilia Foundation
P.O. Box 188, Midlothian, VA 23113
(800) 266-8438, FAX (804)740-8643
www.vahemophilia.org

Your contribution supports our mission of serving the needs of the genetic bleeding disorder community through education, advocacy, and the support of research to find a cure. It includes access to all VHF programs, mailings, and consumer advocacy.

Member Information

Date: _____

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Home Phone (_____) _____ Other Phone (_____) _____

Email: _____

Membership to VHF is FREE.
 A donation of \$25 is suggested, but donations are welcome in any amount to support our educational and advocacy programs.

- Donation\$ _____
 - Patron \$100.00 Grand Patron \$250.00 Benefactor \$500.00
- ____ Check/Cash ____ Visa ____ MasterCard ____ American Express

Credit Card # _____ Security Code _____ Exp. Date _____

Name (as it appears on credit card) _____

Billing Address: _____

Affected Person __ Parent/Guardian __ Health Care Provider __ Pharma/Homecare __ Friend ____

Would you like to volunteer to assist with Chapter Activities? __ Yes ____ No

In order to provide programs that are pertinent to you, please provide the names of family members with bleeding disorders and dates of birth:

Hemophilia VIII __ IX __ Other (Type?) ____ Mild ____ Moderate ____ Severe ____

Von Willebrand Disease Type 1 __ Type 2 __ Type 3 __ Other Bleeding Disorder (Type ?) ____

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