

CENTRAL VIRGINIA CENTER FOR COAGULATION DISORDERS NEWSLETTER



Virginia Commonwealth University Medical Center

Way to Go!

Congratulations to Kathy Starling for being selected as a co-winner of the Caregiver of the year award from FactorHealth Management.

Kathy was selected among many nominees from across the country for her commitment and dedication to both her family and community. Congratulations on the well deserved award!

Programs/Activities for Patients and Families

Holiday Breakfast

VCU and the VA Hemophilia Foundation hosted the annual holiday breakfast on December 13, 2008. 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. Thanks too to the chapter and all the volunteers who continue to make this event a success!

Treatment Center News

Children's Miracle Network Grant for vWD Outreach

The center recently received grant funding from the Children's Miracle Network provide outreach to women through health department family planning clinics. The outreach initiative effort will provide NHF brochures on VWD to health department clinics, assist in developing a web based curriculum for family planning providers, and provide speakers for local health district teleconferences and the annual meeting. Special thanks to Children's Miracle Network for making this important outreach possible!

Thank you Dr. Dunn and Dr. Russell

Last year, Dr. Nancy Dunn and Dr. Cliff Russell both retired from their positions as pediatric physicians in the hem/onc clinic at VCU. Dr. Dunn and Dr. Russell provided care to many young patients with bleeding disorders during their careers. Join us in wishing them well in their retirement and thanking them both for all of the great care they provided over the years!

VCU Fellow presents abstract at NHF

Dr. Madhu Gowda, a fellow in pediatric hematology at VCU, presented a research abstract at the NHF annual meeting in Denver. Dr. Gowda's study, titled "Vitamin D deficiency in children with hemophilia" assessed Vitamin D levels in children with hemophilia. Co-authors on this study include Dr. Gita Massey, Dr. Anil Kumar, Dr. Asadullah Kahn, Mindy Nolte, RN, MSN and Jan Kuhn, RN, MPH.

CVCCD and VHF present at NHF

Lauren Dunn, CVCCD social worker and Kelly Waters, VHF executive director participated in a panel discussion and the NHF annual meeting in Denver. Lauren and Kelly discussed ideas and techniques to improved communication and collaboration between HTC's and chapters.

CVCCD abstract accepted at Pediatric conference

Jan Kuhn, RN, MPH will present a poster abstract at the 2009 Future of Pediatrics conference hosted by the American Academy of Pediatrics. The abstract, titled "Ensuring successful transition to adult-oriented care for youth with inherited bleeding disorders" summarizes the transition strategies developed by the subcommittee of the Hemophilia Advisory Board. Lauren Dunn, MSW was a co-author on this abstract.

Dr. Loughran named Clinician of the Year

The MCV Physicians Distinguished Clinician Award, which recognizes clinical excellence among faculty, was recently presented to Thomas P. Loughran, M.D., associate professor in the Department of Orthopaedic Surgery.

As team physician for VCU, Virginia Union and the Richmond Braves, Loughran's practice addresses a wide variety of injuries suffered among professional and college

athletes and those with everyday orthopaedic injuries. Dr. Loughran has treated many patients with bleeding disorders and joint disease through his practice at the VCU Sports Medicine clinic.

Congratulations Dr. Loughran!

Consumer Advisory Board

The Consumer Advisory Board meeting was held Nov. 3, 2008 at VCU Medical Center. CAB members reviewed plans for patient programs, made recommendation for changes to the VBDP Pool of Funds guidelines, and received updates about center grant funding cuts. If you'd like to learn more about the Consumer Advisory Board and how you can become involved, please contact the center.

Virginia Bleeding Disorders Program News

Hemophilia Advisory Board Meeting

The Hemophilia Advisory Board met on December 1, 2008. The meeting began with an overview from Dr. Karen Remley, the Commissioner of Health. Dr. Remley reviewed the priorities of the VA Department of Health. Annual reports on the work of the Virginia Bleeding Disorders Program (VBDP) and Patient Services, Incorporated (PSI) were presented. Agenda items included discussion of transition, NHF's standards of care, health insurance caps, life insurance, vWD outreach, childhood

obesity and emergency preparedness. The complete minutes of the meeting are available online at:

<http://www.townhall.state.va.us>

Changes to VBDP Pool of Funds Guidelines

Due to recent funding issues, the VBDP recently revised the pool of funds guidelines. The new guidelines instituted a \$15,000 yearly cap on home supply of factor for patients who access factor through the VBDP.

Chapter News

Chapter Mailing List

Don't miss out on any of the great programs offered by the chapter for 2009! If you're not already on the chapter mailing list, please take a few minutes to complete the membership application on page 5 and return it to the chapter as soon as possible!

Chapter Advocacy Day

The VA Hemophilia Foundation is hosting its 3rd annual advocacy training and lobby day on Sunday, January 18 and Monday, January 19. On Sunday, participants will attend a workshop to learn more about the General Assembly, how to enhance our advocacy skills, and the Virginia Hemophilia Foundation's (VHF) advocacy agenda. On Monday, participants

will meet with legislators to discuss VHF's advocacy agenda.

Call the chapter at 1-800-266-8438 to find out more information.

Youngblood 5K

Join the chapter 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

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 are due no later than June 30, 2009. 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.

Other News

Anthem Medical Specialty Pharmacies

As reported in the fall newsletter, Anthem has recently made changes to how it provides factor to patients with bleeding disorders. Several factor providers have no been added to Anthem's Medical Specialty Pharmacy program. At the time of this printing, the current providers include:

- Accredo/Hemophilia Health Services
- Caremark
- MedProRx
- Precision Rx

Remember, new providers are still being added so if you have a preferred pharmacy, please check with them to see if they are in-network with Anthem.

NHF Washington Days

Please mark your calendars for February 25-26, 2009, NHF's annual Washington Days event on the Hill.

Here's your chance to walk the halls of Congress, meet with your elected officials and put your faces on issues that affect our community. We provide the training, you provide the personal message. Your story is your most effective tool to convey the importance of insurance coverage, such as the overall benefit of raising lifetime caps, coverage for the full range of needed products and therapies, and other issues that affect you and your family directly. More information will be available soon through the NHF website, www.hemophilia.org.

In Memory

As we begin the New Year, we'd like to pause for a moment to remember the many friends in the bleeding disorders community who are no longer with us. May the memories we share bring comfort to us all.

I count myself in nothing
else so happy
As in a soul remembering
my good friends.

- William Shakespeare

Be Prepared – Make Sure You're Ready!

By Wanda Foster, RN, MS, CHE

Earlier this Fall, Hurricanes Gustav and Ike, with wave heights of more than 15 feet, 125 mile per hour winds and evacuations up and down the coast, provided real life reminders that families need to be prepared in case of an emergency or disaster. This is especially true in the hemophilia community.

As the mother of a son with severe factor VIII hemophilia, I am especially concerned about the additional challenges that emergencies and disasters create. The need to plan is particularly important in order to accommodate our family's unique needs. Disasters such as these hurricanes can disrupt access to care, create uncertainty and leave persons with bleeding disorders unable to get the treatment they need when they need it most. How can we avoid these disruptions and make sure we are prepared and ready if we have to seek medical treatment elsewhere in the event of an emergency?

The easiest way to begin is to use the resources already available in the hemophilia community. The National Hemophilia Foundation (NHF) recommends patients gather important emergency medical information and keep it with them. This is the most important first step to ensure uninterrupted treatment. To help families with this critical

piece of planning, a new program is being rolled out through which Hemophilia Treatment Centers (HTCs) systematically provide NHF recommended information to patients in a portable form. This program - called ATHNready - focuses specifically on the hemophilia community and is being led by the American Thrombosis and Hemostasis Network (ATHN).

ATHN is working in partnership with HTCs to apply lessons learned from past disasters, such as Hurricanes Katrina and Rita. With advice from NHF and members of the ATHN Community Liaison Group, including Ray Stanhope, Chair of the Board of Directors, NHF; and the Hemophilia Federation of America (HFA) President, Chad Stevens; members of the Committee of Ten Thousand (COTT), the National Alliance for Thrombosis and Thrombophilia (NATT) and others; ATHNready will ensure that medical information is safe and available where and when we might need it most. A pilot program is underway.

With ATHNready and through HTCs, patients will be able to:

- Get their core health information on a wallet sized flash drive, something that can be with them at all times and used wherever they are and whenever they need it.
- Enjoy comfort and peace of mind knowing that their core health information is

secure, backed-up regularly and available when they need it.

- Be protected by a virtual safety deposit box with electronic health information so that appropriate care can be provided in a timely manner.

In conjunction with the Centers for Disease Control and Prevention, ATHN has mapped the location of all HTCs around the country in an interactive format available on the ATHN web site (www.athn.org). Patients displaced by a disaster or moving to another location can quickly and easily identify a comprehensive HTC anywhere in the U.S.

Now is an ideal time to think about and begin to develop personal and family emergency plans. The ATHNready program can be part of your plan and will help to ensure you have all your medical information ready - where and when you need it.

To learn more about ATHN and ATHN Affiliate HTCs visit www.athn.org.

Wanda Foster, RN, MS, CHE, is the Vice President/Chief Nurse Executive at McDonough District Hospital in Macomb, IL, and a member of the ATHN Board of Directors. She is also the mother of a son with severe factor VIII hemophilia.



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 ?) ____

United Virginia Chapter is a 501(c)3 Corporation, tax ID -# 54-1183181



1-800-266-8438 or vahemophiliaed@verizon.net
www.vahemophilia.org

2009 Calendar

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

January

- January 18 and 19 - Advocacy and Lobby Day, Richmond, VA - Martin Luther King Day
- Greater Richmond YMCA Program Begins

February

- February 10 – Women's Program/Dinner
- February 21 - Youngblood 5K Race (Richmond, VA)
- February 25-26 - NHF Washington Days
- February 28-29 – NHF Leadership Meeting
- Winter Education Meeting - CHKD

March

- March 26-27 – Region III Annual Meeting
- Educational Dinner - Insurance Issues

April

- April 25 - Wine Tasting Fundraiser
- Women's Program/Dinner

May

- May – HFA Annual Educational Symposium
- May 22-24 - Family Weekend (Charlottesville, VA)
- May 30-31 – Adult Camp (Charlottesville, VA)

June

- BatterUp Event (Norfolk, VA)
- Festevents (Norfolk, VA)
- June 20 - Annual Meeting (Richmond, VA)

July

- Festevents (Norfolk, VA)
- July 26 – 31 - Camp Youngblood at Camp Holiday Trails (Charlottesville, VA)

August

- August - First Step Picnic

September

- Family Overnight Event
- September – Adult Retreat

October

- October - Golf Tournament Fundraiser

November

- November - NHF Annual Meeting (San Francisco, CA)
- November - A Night Under the Stars Fundraiser (Richmond, VA)

December

- December – Holiday Parties