

CENTRAL VIRGINIA CENTER FOR COAGULATION DISORDERS NEWSLETTER



Virginia Commonwealth University Medical Center

Way to Go, Jamal!

Jamal Lundy was recently recognized by his summer daycare program for being the most well behaved and well mannered student in the program.

Jamal is 8 years old and has hemophilia A. He's in the third grade and really enjoys school.

Keep up the good work, Jamal!

Programs/Activities for Patients and Families

Holiday Breakfast

VCU and the VA Hemophilia Foundation hosted the annual holiday breakfast on December 12, 2009. 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

Consumer Advisory Board

CVCCD's Consumer Advisory Board is a group of persons with, or affected by, a bleeding disorder that meets on a routine basis to provide guidance, feedback and suggestions to the treatment center in an effort to help the center provide the most appropriate patient care.

We recently interviewed CAB member Terry Lamb, to learn more about the role of the CAB at VCU:

Q: What is the Consumer Advisory Board at VCU?

A: The Consumer Advisory Board is designed for us as consumers to be able advise VCU on matters within

the community.

Q: What does the CAB do?

A: The CAB reviews matters within the community so we can help come up with better solutions.

Q: What do you most enjoy about being on the CAB?

A: I enjoy working with friends.

Q: What kind of a commitment is involved in being on the CAB?

A: The primary commitment is to attend two meetings per year. CAB members can take on additional projects if desired.

Q: Who can be on the CAB?

A: The CAB is open to any patient, spouse/partner of a patient, or parent of a pediatric patient who receives care at VCU.

Q: Who do I contact if I want more information about

servicing on the CAB?

A: Individuals who are interested in servicing on the CAB can contact Lauren Dunn, VCU social worker and CAB chair at dunnlc@vcu.edu or (804) 828-2924. Membership on the CAB is decided by majority vote of the CAB members.

Chapter News

Chapter Advocacy Day

The VA Hemophilia Foundation is hosting its 4th annual advocacy training and lobby day on Sunday, January 17 and Monday, January 18. Participants will be able to 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 and will also 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 on **February 20th** 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.)

Visit <http://vahemophilia.org> and click on the 'upcoming events' tab. There you can find more information as well as the enrollment form for the 5K race.

NHF Washington Days

Please mark your calendars for **February 24-27, 2010**, 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.

Chapter Mailing List

Don't miss out on any of the great programs offered by the chapter for 2010! 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.

Medical News

2009 Inhibitor Education

Summit

Do you or someone you know have an inhibitor, or are you interested in learning more about inhibitors? If so, consider participating the webcast or ordering the DVD of the Inhibitor Education Summit held in August and September of 2009.

The webcast and DVD both address topics such as:

- Management options for patients with inhibitors, such as surgical interventions for arthropathy and immune tolerance induction
- Importance of daily exercise and good nutrition
- Available alternatives for safely treating and managing joint pain
- Strategies for insurance coverage and financial security
- Coping mechanisms for improving the psychological well-being of patients and caregivers

For more information, please call 1-888-706-6867 or e-mail inhibitorsummit@thebcce.com

Helixate FS 3000

CSL Behring has recently announced that they will be offering Helixate FS in a new dosage strength, 3000 IU. This

should come as a great convenience for patients requiring higher dosages as infusing now will require fewer vials and therefore shorten their preparation and infusion time.

In addition to the new dosage strength, CSL Behring is also introducing the Mix2Vial, which is a needle-free transfer device that offers a simpler way to mix Helixate FS. CSL Behring has also made some new updates to their HeliTrax data management to make the system easier and more user friendly for patients.

For more information, visit the Helixate website: www.HelixateFX.com/3000 or contact your factor provider.

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)

Medication Assistance Programs

For people living with bleeding disorders the ability to always obtain (factor) medication when needed is essential. There are medication assistance programs available for people who are having health insurance difficulties are underinsured or uninsured. Below is a list of medication assistance programs available to (you) people with bleeding disorders.

(Continued on Page 4)

Baxter CARE Program

Products: ADVATE, Recombinate, Hemofil M, Monarch-M, FEIBA VH, Bebulin VH, BAXJECT II

- To enroll in the CARE program, call 1-888-BAXTER9 or visit thereforyou.com
- Patient assistance is available for those who meet program eligibility requirements
- The CARE program can provide patient assistance based on individual financial, medical and insurance situations.
- Access these help lines to speak directly with experts who can provide assistance and advice: Baxter Insurance Assistance Helpline 1-888-BAXTER9 (1-888-229-8379), Bleeding Disorders Legal Information Hotline* 1-800-520-6154, Baxter's Healthcare Reimbursement Economic Support Team 1-800-968-9937
- With the CARE program, you do not have to accumulate or manage points, certificates or credits.

Bayer's HealthCare's Factor Solutions Program

Products: Kogenate

- Bayer HealthCare's Factor Solutions program can provide convenient insurance support to ensure you receive your Kogenate® FS, Antihemophilic Factor (Recombinant) with BIO-SET® treatment based on determination of program eligibility.
- Bayer HealthCare's enhanced Factor Solutions support program can help with:
 - Loss of insurance due to job changes
 - Coverage gaps while changing insurance plans
 - Insurance that doesn't cover a specific rFVIII
- For more information call Factor Solutions 1-800-288-8374 or visit www.kogenatefs.com

CSL Behring Assurance Program

Products: Helixate®, Humate-P®, Monoclate-P®, Mononine®

- The CSL Behring Assurance Program enables you to build up a reserve of complimentary product that can be easily accessed if there is a gap in your third-

party, private insurance coverage. It's a protection plan that costs you nothing and only requires that you complete a quick and easy enrollment process to start gaining its benefits.

- **Award Certificate** - Once enrolled in the Program, you will begin earning an Award Certificate for every 3 consecutive months of product use. Each Certificate is worth a complimentary, 1-month supply of product up to the maximum amount redeemable.
 - **Certificate Redemption** - You can redeem up to a year's worth of product (representing 12 Certificates or 3 years of continuous product usage) or just 1 month's worth of product—it all depends on your needs and how long your insurance gap is.
- For more information about the CSL Behring Assurance Program, please visit: www.CSLBehringAssurance.com.

Grifols Assurance for Patients

Products: Alphanate injection, AlphaNine SD, ProfilNine

- The Grifols PatientCare Program is a patient assistance program designed to help provide eligible patients with access to Grifols coagulation products.
- The Grifols Patient care program consists of two unique and distinct parts:
- **Grifols Assurance for Patients or GAP Program:**
 - Available to patients in the event they experience temporary lapse in insurance coverage.
 - Eligible patients have been treated with the Grifols' products for three continuous months prior to lapse in coverage through a non-government (state or federal funded) health insurance plan.
- **Grifols Patient Assistance or GPA Program:**
 - Available to patients without insurance coverage and in need of temporary assistance obtaining factor products.
- For more information visit: www.grifolspatientcare.com

Novo Nordisk SevenSECURE

Products: NovoSeven

- SevenSECURE® is a FREE service that may help you manage the costs that come with having inhibitors.
- SevenSECURE® has many ways to help including:
 - Help with health insurance and coverage including:
- Case managers who serve as active partners
- A yearly report of your lifetime cap
- Updates based on cap percentages
- Markers for certain usage levels (when these levels are reached, a process to find new coverage starts)
 - Grants and scholarships for education
 - Reimbursement assistance for medical and dental expenses
- For more information visit: www.novosevenrt.com. or call 1-877-NOVO-777 (1-877-668-6777) to enroll

Wyeth Factor Resource Program and Insurance-Coverage Program

Products: XYNTHA, ReFacto, BeneFix

- If you're eligible, the Wyeth **Insurance-Coverage Program** provides access to factor and case management professionals who will help you navigate complicated insurance issues.
 - If you have a lapse in coverage for XYNTHA, ReFacto, or BeneFIX, this may be the program for you.
- The Wyeth **Patients Assistance Program** is designed to ensure that eligible patients will receive factor, even if they don't have insurance.
 - If you meet the program eligibility guidelines, you will be provided up to a maximum of 100,000 IU of product absolutely free.
 - The Wyeth Patient Assistance Program is designed for ANY eligible patient who is factor VIII- or factor IX-deficient.
 - You do not have to earn, accumulate, track, or redeem points, certificates, or coupons.
- To enroll or evaluate your eligibility call 1-888-999-2349 or visit www.hemophiliavillage.com for more information.



2010 Calendar

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

January

- January 17 and 18 - Advocacy and Lobby Day, Richmond, VA - Martin Luther King Day

February

- February 20 - Youngblood 5K Race (Richmond, VA)
- February 24-27 - NHF Washington Days and Leadership Meeting
- February 25-26 - Region III Annual Meeting

March

- March - CHKD Annual Education Meeting
- March 13 - LunaFest (Richmond, VA)
- March - Women's Program

April

- April 25 - Wine Tasting Fundraiser (Richmond, VA)

May

- May 22 - Annual Meeting (Charlottesville, VA)
- May 28-30 - Family Weekend (Charlottesville, VA)

June

- June - Baseball Game (Richmond, VA)

July

- July 25-30 - Camp Youngblood at Camp Holiday Trails (Charlottesville, VA)

August

- August 8 - First Step Picnic (Virginia Beach, VA)

September

- September 11-12 - Family Overnight
- September 25-26 - Adult Retreat (Williamsburg)

October

- October 4 - Golf Tournament Fundraiser (Richmond, VA)
- October - Outdoor Fall Event

November

- November 11-13 - NHF Annual Meeting (New Orleans, LA)

December

- December 11 - 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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