

# CENTRAL VIRGINIA CENTER FOR COAGULATION DISORDERS NEWSLETTER

Virginia Commonwealth University Medical Center



## Way to Go, Jamal!

Jamal Lundy is an 8 year old boy with factor VIII deficiency who recently learned to do his own IV infusions.

Congratulations on this great accomplishment, Jamal!



## Programs / Activities for Patients and Families

### Chapter Adult Retreat

Mark your calendars! The chapter's annual adult retreat will be held **September 25th and 26th** in Williamsburg, VA. Further

information to come in the Fall 2010 newsletter. Also please check [www.vahemophilia.org](http://www.vahemophilia.org) for continuing updates between now and then.

### 'Back To School' Picnic



Say goodbye to Summer with your friends of the VHF! VHF will be having its first Back to School picnic on Saturday, **August 28, 2010** from 5 - 7 pm at Crump Park/Meadow Farm Museum in Glen Allen. Families, couples, and individuals of the bleeding disorder community are all invited to attend. Join us for food, games, and fun.

Lodging assistance is available to those families and teens who attend the picnic on August 28 and will be traveling greater than 45 minutes. Join us at the picnic and also

receive movie tickets for Saturday night.

Please RSVP to Kelly Waters at 1.800.266.8438 or [vahemophilaed@verizon.net](mailto:vahemophilaed@verizon.net)

### 'Just for You' Teen Event and River Adventure



VHF has planned a river tubing adventure for Sunday, **August 29, 2010** from 9 am - 12 pm. This event is open for teens ages 13-18 and their parents. Lodging assistance is available to those families and teens who attend the 'Back to School Picnic' on August 28 and will be traveling greater than 45 minutes. Lunch will also be provided. Join us at the picnic and receive movie tickets to Movieland.

Please RSVP no later than *July 30, 2010* with Kelly Waters

(1.800.266.8438 or [vahemophiliaed@verizon.net](mailto:vahemophiliaed@verizon.net)).

### First Step Picnic at Ocean Breeze Waterpark



Join the chapter for a picnic at Ocean Breeze Waterpark on **Sunday, August 8, 2010 11:30 AM!** This event is designed especially for families of children who have been diagnosed with a bleeding disorder in the last 7 years.

Highlights include a delicious lunch, networking with other parents and children, and plenty of time to enjoy the water park.

Reserve your spot at this event by calling **1-800-266-8438** or e-mailing: [vahemophiliaed@verizon.net](mailto:vahemophiliaed@verizon.net)

Also Visit [www.oceanbreezewaterpark.com](http://www.oceanbreezewaterpark.com) for further information about the park and driving directions.

### Help VHF Make a Difference!

There are many ways in which you can help the Virginia Hemophilia Foundation help the bleeding disorder community. Attached to the end of this newsletter is a flyer with fun and easy ways to contribute.

Another way to help is to be an advocate for the bleeding disorder community. Telling your story and teaching your legislators about your own first hand experience of dealing

with a chronic medical condition can make a difference in what changes Virginia will make on health insurance and other bills that have a direct impact on families with bleeding disorders.

If you are interested in being an Advocate, please contact [info@vahemophilia.org](mailto:info@vahemophilia.org) or call (804) 740-8643. Be sure to ask about for further information regarding their ongoing advocacy contest.

### Family Overnight at the Virginia Living Museum



Please join VHF **Friday September 17<sup>th</sup>** through **Saturday September 18<sup>th</sup>** for a fun evening for kids, and an educational opportunity for parents at the Virginia Living Museum!

A special program planned just for our group (which may include a planetarium show, time in the observatory (weather permitting), a partial exhibit tour, and some crafts and games).

An evening snack and continental breakfast will be included as well as free admission to the museum on Saturday. Adults will also be treated to an educational program on bleeding disorders.

RSVP: Call or email Kelly Waters at 1-800-266-8438 or [info@vahemophilia.org](mailto:info@vahemophilia.org).

Space is limited this year – so please RSVP early to reserve your space.

\*\* If you attend, make sure you bring a sleeping bag, mattress, pillow, and overnight supplies!

### Health Care Reform WebChats

The Department of Health and Human Services (HHS) is hosting weekly WebChats with information about the new changes coming with health care reform. Past sessions have focused on reforms related to persons with disabilities, young adults, early retirees, and seniors. You can view these WebChats live or watch previously broadcast sessions on the HHS health reform website: [www.healthreform.gov](http://www.healthreform.gov)

### Medical News

#### **Lyme Disease in Virginia**

Since 2000, the Virginia Department of Health has witnessed a steady increase in the number of newly identified Lyme disease cases. While several types of tick-borne diseases are found in Virginia (including Ehrlichiosis, Anaplasmosis, and Rocky Mountain Spotted Fever), Lyme disease is the most common tick-borne infection reported in Virginia.

Most cases occur during the late spring and early summer with illness onset most likely to occur in June, July, and August. This is why

particularly during the summer, it is encouraged to maintain a heightened vigilance regarding Lyme Disease.

Common symptoms of Lyme Disease include the following:

- Fever, headache
- Malaise, fatigue
- Erythema migrans skin lesion or 'bulls eye rash' (pictured below):



- Myalgia, migratory arthralgias
- Stiff neck

It is important to know that Lyme disease is easily preventable and the fear of it should not deter you from enjoying the outdoors.

Some of the steps you can take to prevent tick bites include:

- Wear light-colored clothing that covers most of your skin when going into wooded or overgrown areas.
- Using tick repellants
- Check your skin carefully for ticks after being outdoors

Following these simple rules will greatly decrease your risk of acquiring Lyme disease.

For more information regarding Lyme disease in Virginia, you can view an online presentation titled

"Lyme Disease Tracking and Prevention in Virginia" at:

<http://www.vdh.virginia.gov/epidemiology/DEE/Vectorborne/HCPs>

## Resources

### Safelink Wireless Phone Program



Safelink Wireless service is U.S. government supported program for income eligible households provided by TracFone Wireless, Inc. This program provides one free cellular phone and 68 minutes per month of talk time per household. Virginia residents who participate in one of the following assistance programs are eligible for the Safelink Wireless program:

- o Federal Public Housing Assistance / Section 8
- o Food Stamps
- o Low Income Home Energy Assistance Program (LIHEAP)
- o Supplemental Security Income (SSI)
- o National School Lunch (free program only)
- o Temporary Assistance for Needy Families (TANF)
- o Medicaid

For more information about enrolling

in the Safelink Wireless program, please visit their website <https://www.safelinkwireless.com/EnrollmentPublic/home.aspx> or call 1-800-977-3768.

Special thanks to Lee Dashiell for sharing this information with the center.

## Online Resources



If you use Facebook or Twitter, then consider subscribing to or following the following groups dedicated to helping individuals with hemophilia

### National Hemophilia Foundation:

- Facebook:  
<http://www.facebook.com/NationalHemophiliaFoundation>
- Twitter:  
[http://twitter.com/NHF\\_hemophilia](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)

## Treatment Center News

### ATHN Affiliation

During your next visit to this treatment center, you may be given a pamphlet about this center's involvement with the American Thrombosis and Hemostasis Network (ATHN).

This means our center is a part of a group of HTC's across the country called ATHN Affiliates. HTC's and ATHN want to improve the care of people with bleeding and clotting disorders. ATHN is helping HTC's to create a safe and secure national database of patient health information. The national database follows all HIPAA privacy guidelines to protect your confidentiality. From this national database, a smaller subset of patient health data, called the ATHN dataset, will be managed by ATHN.

Doctors, scientists, policy makers, and other health care providers need a large pool of patient information from a lot of patients to answer scientific, public health and policy questions about the best way to treat bleeding and clotting

disorders.

Having your or your child's health information in the ATHNdataset will help us better understand bleeding and clotting disorders, the complications of these disorders, the social and economic costs, and the effectiveness of treatments and interventions.

All research using the ATHN dataset will be reviewed and approved using an established process that takes into account community priorities and interests.

When you sign your ATHN consent form at your next visit, you are allowing your HTC to share your health information with researchers. Any health information taken will not directly identify you; your name will not be linked to the data in any way and your name will never be used in any reports produced as a result of studies using this data.

If you agree to let your health information be included in the ATHNdataset, the information will regularly updated to reflect your current health status. The kinds of information that will be sent to ATHN include:

- Type of Blood Disorder
- Date you were diagnosed
- Family history of the disorder
- Laboratory tests results
- Medication issues

- Types of bleeds
- Effective treatments you've tried
- Routine care and trauma
- Allergies

The database used by your / your child's HTC to generate the ATHNdataset is kept in an encrypted form (this means that people cannot read the information when they look at it).A back up is stored on a highly secure server. All information will be sent through a secure internet-based data transfer mechanism than is password protected and encrypted. This offers more protection and security than paper records and e-mail.

Further information about the ATHN affiliation will be provided to you during your next visit. If you would like to know more about ATHN, please visit: <http://www.ATHN.org>



The Virginia Hemophilia Foundation (VHF) needs your help as we continue to grow and strengthen our services to the bleeding disorder community.

### *Top Ten Ways to Make a Difference*

Circle the ways you would like to get more involved.

1. Bring a toy to our next event. Donations will be part of “Santa’s Bag” and given out by Santa at our annual holiday parties.
2. Mail our “Send a Kid to Camp” campaign letter to 10 of your friends and family asking them to support Camp Youngblood and help change a young person’s life.
3. Become one of our Golf Tournament Hole Sponsors. Did you know that for \$150 you can have a hole In Memory or In Honor of someone?
4. Volunteer to sell tickets for the NHF/VHF new Sweepstakes Fundraiser. Details to come.
5. Recruit a new company or organization to sponsor one of our major fundraisers Youngblood 5K, Wine Tasting and Raffle Event, Golf Tournament.
6. Bring someone along to an event that needs volunteers or plan to meet them there. Make that commitment. It's more fun to do it with someone you know!
7. Volunteer to write 1 letter to a representative about hemophilia needs. Just 1. You can get hooked. Check out the chapter's website for info.
8. Sign-up TODAY for a committee, i.e. advocacy work group, fundraising, scholarship, etc.
9. Write an article for the newsletter. Tell us about your experience having a bleeding disorder and/or about a program you attended.
10. Make an online donation to your chapter ([vahemophilia.org](http://vahemophilia.org)) or put a check in our donation box today. See what incredible things your money can do for the bleeding disorder community.

Other ways I would like to get involved:

Please contact me to further discuss the chapter and how to get involved:

Name:

Address:

Email:

Phone Number: