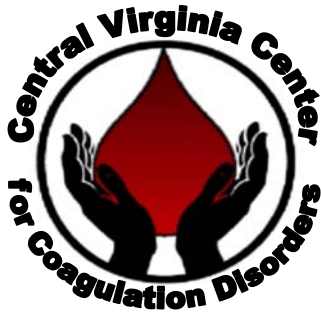


CENTRAL VIRGINIA CENTER FOR COAGULATION DISORDERS NEWSLETTER

Virginia Commonwealth University Medical Center



Welcome, Ann!

The CVCCD would like to welcome Ann Scott to our team! Ann is the center's new nurse for the Thrombophilia clinic.

Ann has previously worked at MCV as a nurse practitioner for the cardiothoracic surgery inpatient step down unit.

Programs/Activities for Patients and Families

'The X Factor' Hits the Road

VHF will be offering a free evening performance of 'The X Factor' at 7:00 pm on **Monday, October 25, 2010** at the Tuckahoe Area Library (1901 Starling Ave., Henrico, VA 23229). 'The X Factor' is a one-

person, interactive play focusing on hemophilia that is written and performed by Steve Kohrher. The premise of the show is that we're all different in some way. Each section of the play has audience participation.

The play is free and targeted for children ages 6 and up (in particular 3rd-7th grade), but is appropriate for anyone interested in learning about hemophilia. There will be food, Mardi Gras beads, and door prizes. Bring your friends as we send our program off with a fun New Orleans celebration.

Family Fall Festival



Join VHF for their Family Fall Festival at Shenandoah Caverns! The festival will be on **Saturday, October 30th**, from 10 AM to 2 PM. Families can enjoy a guided tour of

the caverns from 10-11 AM. (Please dress warm for this event, the temperature in the cavern is 54 degrees!). Lunch featuring a presentation on Healthy Lifestyles will be held at 12:15.

A costume contest will also be held- so come dressed to impress! Prizes will be awarded for best family/group costumes, best individual costume, and most creative costume.

For more info, please check out: www.shenandoahcaverns.com

Please RSVP to Kelly Waters by October 25th if you plan on attending: 800-266-8438 or e-mail vahemophiliaed@verison.net

\$25 gas cards are available for families needing assistance.

Internet Resources



Infusion Logging with Advoy.com

If you or your child infuses regularly and you are looking for an easier way to keep track of your infusion logs, Advoy may be the solution for you. Advoy.com is a great internet based infusion logging resource; all you need is e-mail address and internet access.

Check out www.advoy.com for a flash tour of the program. If you are interested in using Advoy, please contact Jamie Leonard at 804-827-3306 and she will set up an account for you.

Healthcare Reform

Health Insurance for Young Adults

The Affordable Care Act requires plans and issuers that offer coverage to children on their parents' plan to make the coverage available until the adult child reaches the age of 26.

Key elements include:

- **Effective for Plan or Policy Years Beginning On or After September 23, 2010.** Plans

and issuers that offer dependent coverage must offer coverage to enrollees' adult children until age 26, even if the young adult no longer lives with his or her parents, is not a dependent on a parent's tax return, is married or is no longer a student.

- **All Eligible Young Adults Will Have A Special Enrollment Opportunity.** For plan or policy years beginning on or after September 23, 2010, plans and issuers must give children who qualify an opportunity to enroll that continues for at least 30 days regardless of whether the plan or coverage offers an open enrollment period.

- **Same Benefits/Same Price.** Any qualified young adult must be offered all of the benefit packages available to similarly situated individuals who did not lose coverage because of cessation of dependent status.

Access to Insurance: What Young Adults and Parents Need to Do:

- **Watch for Open Enrollment:** Young adults will qualify for an open enrollment period to join their parents' family plan or policy beginning on or after September 23, 2010. Insurers and employers are required to provide notice for this special open enrollment period.

New Tax Benefits for Adult Child Coverage

Under a new tax provision in the Affordable Care Act and the Treasury guidance, beginning March 30, 2010 the value of any employer-provided health coverage for an employee's child is excluded from the employee's income through the end of the taxable year in which the child turns 26. This tax benefit applies regardless of whether the plan is required by law to extend health care coverage to the adult child or the plan voluntarily extends the coverage.

For more information, visit:

http://www.hhs.gov/ociio/regulations/adult_child_fact_sheet.html

Research



PK-PD study of FVIII Levels

The CVCCD has initiated a study to determine the most appropriate tests for monitoring the treatment of patients with severe hemophilia who receive rFVIII prophylactic treatment.

Adult patients with severe FVIII deficiency without an inhibitor are eligible to participate in this study. Individuals that enroll in this study will be paid \$300 if they complete the three scheduled study visits.

The first visit will include a brief medical exam and a blood draw for routine lab tests. The second visit will take place within a week of the first visit and will require to be admitted into the VCU General Clinical Research Center for up to 24 hours. A single dose of FVIII will be infused and blood samples will be collected at 0.5, 1, 2, 4, 8, 12, 24. The third visit will take place 48 hours after infusion and it includes a blood draw to assess the effect of rFVIII on blood clotting. If you are interested in participating in this study, please contact the center for information.

Vitamin D Study

The purpose of this study is to understand why patients with hemophilia have thinner bones and whether low levels of Vitamin D and physical activity have a role in developing thinner bones. Patients with Hemophilia A or B between ages of 2 and 21 are eligible to participate in this study. Individuals that enroll in this study will receive a \$20 gift card when enrolling in the study, and a \$30 gift card at the end of the study. Procedures done during this study include history and examination, blood and urine tests, and a bone x-ray test called bone density test. If Vitamin D and Calcium levels are found to be low, Vitamin D and Calcium supplements will be given to take each day. Participation in this study lasts up to a year.

PATH Study

The purpose of the Personalized

Approaches to Therapies for Hemophilia (PATH) Study is to investigate race differences in inhibitor development and to explore the genetic and immune factors involved. This study will look at immune responses in people with and without inhibitors. Patients with Hemophilia A with and without inhibitors above the age of 2 (children and adults) are eligible to participate in this study. Also, adult non-Hemophilia A family members of Hemophilia A patients are eligible to participate in this study. Participation in this study includes donating one or more blood samples during a two year period.

UDC Inhibitor Study

The UDC (Universal Data and Serum Collection System for Hemophilia) Study has been ongoing since 2005.

Some of the major recent findings in the UDC study are that there have been no reports of new blood borne viruses, related to the use of blood products or factor replacement. As expected, the risk of joint complications has been shown to correlate with the severity of the bleeding disorder. Data analysis has also shown that increased body mass index (BMI) is associated with increased joint disease.

As there is a substudy of the UDC study that is looking at inhibitor development in patients with hemophilia A and B. The purpose of this study is to identify factors that increase the risk of developing an inhibitor to factor concentrate. All patients with hemophilia A or B who

receive care at an HTC are eligible to participate in this study. Participation in this study includes logging infusions, collecting some information about health status and donating blood samples during the annual comprehensive exam. The information from this study will help your center plan your medical care and help the CDC develop and evaluate programs to reduce or prevent complications of hemophilia. One of the major findings of this study is the connection between the type of genetic mutation that caused the hemophilia with the risk of inhibitor development.

We would like to take this time to remind all patients who use factor products of the importance of keeping infusion logs. Please bring these logs to your clinic appointments so that the HTC team can review and assess any changes in bleeding patterns.

CHAVI Study and FIX-GP Study

The CHAVI and FIX-GP studies are now closed. We would like to thank those who participated in these studies. Your participation will help further our knowledge in treating bleeding disorders.

A Second Line of Help for New Orleans

by Lauren Dunn, MSW

Second line parades are a tradition in brass band parades in New Orleans, Louisiana. The "main line" is the main section of the parade, or the members of the actual club with the parading permit; those who follow the band just to enjoy the music are called the "second line." This year, the National Hemophilia Foundation Social Work Working Group (NHF SWWG) needs your assistance in bringing a "second line" of help to New Orleans.

As the region III representative to the NHF SWWG, I am excited to spread the word about this new initiative planned as part of the NHF annual meeting.

The NHF SWWG is responsible for planning the social work educational track for the NHF annual meeting, which is being held this year in New Orleans. During our winter planning meeting, one of our members, Jennifer Buttell, the social worker at the HTC at Tulane University, shared stories of the on-going efforts to rebuild New Orleans following Hurricane Katrina. Our group was inspired by these "main line" efforts and decided that we could help contribute to these efforts through a "second line" community service project.

This year, for the first time, the NHF SWWG is conducting a service project in conjunction with the NHF annual meeting. We will be collecting supplies and gift cards for

the Lower 9th Ward Community clinic in New Orleans. All participants at the annual meeting are encouraged to bring at least one of the following items to donate to the clinic:

- Office supply store gift cards (Office Depot, Staples)
- Antibacterial liquid hand soap
- Alcohol preps
- Ink pens (black)
- Post it notes
- Lysol spray or Antibacterial wipes

The Lower 9th Ward Community Health Clinic is a community-driven response to fill the unmet healthcare needs that emerged in the wake of the post- Katrina floods. The clinic

officially opened on February 27, 2007 with a mission "to provide high quality, cost-effective, culturally sensitive healthcare services to the community, regardless of ability to pay."

For more information about the clinic, please visit their website at <http://www.l9whc.org>

Even if you are not attending the meeting, you can still participate! If you are interested in donating items, please contact me at dunnlc@vcu.edu or (804) 828-2924.

We hope this will be the first of many social work service projects to come. Thank you for your help in making this a success!

It is amazing what we can accomplish when we put our talents and God-given gifts together for the betterment of our community. This is a time of reflection, but also a time of rebuilding. In the words of Nehemiah, "Let us rise up and build."
— Alice Craft-Kerney



Before & After — The photo above shows the front room in Pat Berryhill's home after it was gutted after Katrina's floods. The photo on the right shows that same room now, facing back towards the direction from which the first photo was taken. This is the lobby of the Lower 9th Ward Community Health Clinic.