

CENTRAL VIRGINIA CENTER FOR COAGULATION DISORDERS NEWSLETTER

Virginia Commonwealth University Medical Center



The CVCCD team would like to congratulate the recipients of the Dr. Lyman Fisher memorial scholarship:

Daniel Warren
And
John McNeil

Dr. Fisher was the center's adult hematologist at VCU for many years and served as both a care provider and a friend to many of our patients. We wish Daniel and John the best of luck in college this Fall!

**Way to
Go!**

Programs/Activities for Patients and Families

Breakfast with Santa

The holidays will be here before you know it, and with that comes our most popular event of the year- the annual holiday breakfast! This year's breakfast will once again be hosted by the Hazel Gibbs Women's Circle at Ramsey United Methodist Church. VCU and the Virginia Hemophilia Foundation partner together to bring this wonderful morning of fun and fellowship to the community each year. Mark your calendars now for **Saturday, Dec. 12, 2009**, and watch your mail for an invitation.

Chapter Adult Retreat

The chapter's annual adult retreat was held **Sept. 19-20** in VA Beach, VA. The weekend topic was "Wellness" and approximately 35 attendees from all over the state participated in yoga, tai chi and sessions on nutrition and pain management. CVCCD social worker, Lauren Dunn, also

presented a session on the psychological benefits of exercise. Special thanks to Baxter for their continued sponsorship of the adult retreat.



Family Fun Day at the Children's Museum

On August 9, about a dozen families from across the state participated in the family fun day at the Children's Museum of Richmond. Parents and children enjoyed socializing over pizza and ice cream sundaes before heading into the museum. Special thanks to the First Steps mentors, the chapter, and Accredo for sponsoring this fun event. If you are interested in talking to a mentor family or participating in future first steps programs, please contact the center.

Fit For All

On July 14, the chapter and CVCCD hosted a special program at Dave and Buster's in Short Pump. The evening included a group dinner, a

presentation by CVCCD physical therapist, Valerie Cortez, and free time for fun and games in the arcade. Special thanks to Baxter for sponsoring this event.

VHF Chapter News

Don't miss out on the great programs offered by the chapter in the upcoming months!

Ladies Night Out

Join us at the Melting Pot Restaurant on Gayton Rd. in Richmond, VA 23233 on Monday, **November 9, 2009 from 6-9:30 p.m.** RSVP by Wednesday, October 28 1-800-266-8438 or vahemophiliaed@verizon.net

Richmond Days

Save the Date – **January 17-18, 2010** for our Annual Richmond Days. Join us as we walk the halls of our General Assembly and let our legislators know what is important to the bleeding disorder community.

Details to come.

Visit our updated website – www.vahemophilia.org where you can find out such things as upcoming events, how to donate to YOUR chapter, and to see copies of our quarterly newsletter.

Treatment Center News

We'll Miss You, Tamara!

After working with the Bleeding Disorder Program for many years, we are sorry to announce that

Tamara Quarles has moved to a new job in the VCU Department of Neurology. Beginning in April of 2005, she provided an invaluable service to the program as a reliable worker and as a helping hand for many of our patients.

We will miss her, and we wish her the best of luck at her new job!

Welcome Candice!

We would like to welcome Candice Robinson to the CVCCD. Candice recently received her BS in Community Health Education from VCU and has worked in the VCU Department of OB/GYN. She will begin on September 25th as or VBDP program specialist.

Holiday Hours

Please note the center operates on a reduced schedule during the Thanksgiving and Christmas holiday weeks. The office will be **closed** on the following dates: **November 25th (after 12pm), 26, and 27; December 23, 24, 25, 29, 31 and January 1.** There will be limited coverage in the office on **December 22, 26, 29 and 31.** If you have an emergency, please contact the pediatric or adult on-call hematologist at (804) 828-0951.

Please make arrangements to get prescription refills ordered early so that they are not delayed by the office closing.

The CVCCD Family Satisfaction Surveys were mailed out the week of September 14th to all patients. Surveys are anonymous and provide the HTC with valuable information regarding our services and programs. We are interested in hearing your feedback so make sure you complete yours and return it to us by October 19th ! Those participating in the Virginia Bleeding Disorders Program also received a survey to be completed and returned with the same mailing.

Welcome New HAB Members!

The CVCCD would like to welcome the new members to the Hemophilia Advisory Board. Laura Duncan is a Metabolic Dietician with VCU Medical Center and will be the general public representative on the board. Also new to the HAB is our licensed pharmacist representative, Sheila Elliott, who is a Clinical Pharmacist with Hampton Veterans Affairs Medical Center. We would also like to welcome Eric Werner, who will be representing the medical school and is with the Division of Pediatric Hematology / Oncology.

CVCCD to Host Webinar For Local Health Departments

The CVCCD, with the support of the chapter, will be providing education and outreach services by hosting webinars to local health departments for adolescent girls with von Willebrand Disease. The focus of this outreach will be to

provide in-service opportunities to nurse practitioners and public health nurses in family planning clinics and to provide educational materials to individuals seen in the clinic. The date of the webinar is scheduled for October.

Internet Resources

New vWD Web Resources

Please check out the new updates to the VBDP website. We have created a new section specifically designed to provide the readers with useful information and powerpoints regarding von Willebrand Disease. You can find the new section by going to the VBDP website:

<http://www.vahealth.org/bleedingdisorders/>

Simply click the 'Von Willebrand Disease' tab located on the left hand side of your screen to access this information.

Research

Recent Inhibitor Study Changes

The UDC (Universal Data and Serum Collection System for Hemophilia) Study has been ongoing since 2005. The purpose of the study is to identify factors that increase the risk of developing an inhibitor to factor concentrate.

Due to a change in research priorities, the CDC has decided to

refocus this study on patients who currently have no inhibitor or history of inhibitors. Because of this, we were forced to drop several of our study participants.

To those who are no longer with the study, we thank you for your participation, and we would like you to know that the information we received from you will help to further the knowledge of inhibitor development.

We would also 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. If you would like some pre-printed logs or are interested in logging software for your computer, please contact the treatment center at 804-827-3306.

Assistance Programs

Winter Heating Assistance

The Virginia Department of Social Service offered a purpose of Fuel Assistance program to assist eligible households with the cost of home heating. It is designed to help offset this expense rather than to pay all of it. Fuel Assistance applications are accepted from the second Tuesday in October through the second Friday in November at local departments of social services. Applications are processed as soon as possible and applicants should expect notification of their eligibility

determination by mid-December.

Holiday Help

There are a variety of programs available to help families with holiday meals and gifts for children. Information about programs in your area can be found by calling the Virginia 211 hotline. Simply dial 211 from any phone to be connected to information. Virginia 211 can also provide information on emergency assistance for food and housing, credit counseling, childcare, and many other services for the citizens of Virginia.

Dental Fluoride Treatment

Dental care is one of the most unmet health care needs of many children. Dental pain and oral disease significantly affect the overall health of a child by hindering their ability to eat, concentrate, and can also contribute to other developmental delays. Also, unhealthy or damaged teeth can have a significantly negative effect on a child's self esteem.

This is why we are glad to announce that the CVCCD clinic is now offering dental fluoridation services to children ages zero to three. This service includes the application of fluoride varnish, a temporary protective coating that prevents cavities from starting and slows cavities that have already formed.

Genetic Information Nondiscrimination Act of 2008

What's genetic discrimination?

Genetic discrimination occurs if people are treated unfairly because of differences in their DNA that increase their chances of getting a certain disease. For example, a health insurer might refuse to give coverage to a woman who has a DNA difference that raises her odds of getting breast cancer. Employers also could use DNA information to decide whether to hire or fire workers.

Who needs protection from genetic discrimination?

Everyone should care about the potential for genetic discrimination. Every person has dozens of DNA differences that could increase or decrease his or her chance of getting a disease such as diabetes, heart disease, cancer or Alzheimer's disease. It's important to remember that these DNA differences don't always mean someone will develop a disease, just that the risk to get the disease may be greater.

More and more tests are being developed to find DNA differences that affect our health. Called genetic tests, these tests will become a routine part of health care in the future. Health care providers will use information about each person's DNA to develop more individualized ways of detecting, treating and preventing disease. But unless this

DNA information is protected, it could be used to discriminate against people.

What's the Genetic Information Nondiscrimination Act (GINA)?

The Genetic Information Nondiscrimination Act of 2008, also referred to as GINA, is a new federal law that protects Americans from being treated unfairly because of differences in their DNA that may affect their health. The new law prevents discrimination from health insurers and employers. The President signed the act into federal law on May 21, 2008. The parts of the law relating to health insurers will take effect by May 2009, and those relating to employers will take effect by November 2009.

Why was the law needed?

The law was needed to help ease concerns about discrimination that might keep some people from getting genetic tests that could benefit their health. The law also enables people to take part in research studies without fear that their DNA information might be used against them in health insurance or the workplace.

What's included in the law?

The law protects people from discrimination by health insurers and employers on the basis of DNA information.

What's not included?

GINA does not cover an individual's manifested disease or condition--a condition from which an individual is experiencing symptoms, being treated for, or that has been diagnosed. The law also does not cover life insurance, disability insurance and long-term care insurance.

What does this mean for people with bleeding disorders?

This protection is particularly important to anyone for whom genetic information could indicate the potential for future medical problems, whether for themselves or for a family member. For example, female carriers of hemophilia are now protected by the new legislation.

Where can I learn more:

For more information, please visit these on-line resources:

The Genetic Alliance
www.geneticalliance.org/ginaresource

The National Human Genome Research Institute
National Institutes of Health
www.genome.gov