

BDRN BULLETIN

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ASTHMA

BY: YAHAIRA ROMAN, RN BSN

Having difficulty breathing, experiencing tightness in your chest, or have you been wheezing (a whistling sound when exhaling)? You may be one of the millions of Americans diagnosed with asthma, a chronic disease that impairs or makes your breathing difficult. Asthma can occur at any age, however, if you have a family history of asthma or suffer from allergies you may be at greater risk. When an asthmatic person's body comes in contact with a trigger such as tobacco smoke, strong odors from cleaning solutions, pollen / mold spores, or sudden changes in the weather, their airway or bronchioles become obstructed (air cannot move freely),

inflamed (swollen), and constricted (narrow). If left untreated, asthma can be life-threatening and even fatal. There are several treatment options available. Here are some examples of the most common medications used: inhaled steroids (anti-inflammatory) help prevent asthma by decreasing the swelling and mucous production in the bronchioles. Bronchodilators, they relax muscles in the bronchioles and keep the airways open. Oral steroids are given temporarily to relieve a severe attack. If you experience any of these signs and symptoms or have any questions regarding your asthma, speak with your health care professional.

THE TAX PENALTY FOR NOT HAVING HEALTH INSURANCE COVERAGE IN 2014

BY: JON DAVIS, REGIONAL MANAGER

The “Individual Mandate” of the Patient Protection and Affordable Care Act (ACA) will require non-exempt individuals and families in 2014 to have health insurance coverage or pay a tax penalty when they file their 2014 federal tax returns. As reported by the Kaiser Family Foundation, the penalty will be \$95.00 per adult and \$47.50 per child (up to \$285.00 for a family) or 1% of the family income, whichever

is greater. In 2015, the penalty significantly increases and increases again in 2016. Visit <http://healthreform.kff.org/the-basics/requirement-to-buy-coverage-flowchart.aspx> for information on who will be exempt from the “Individual Mandate” tax penalty. For individuals and families that will need to purchase a health care plan in 2014 through their state's insurance exchange, checkout the subsidy calculator at: <http://healthreform.kff.org/subsidycalculator.aspx>.

Disclaimer: BDRN does not engage in the practice of medicine and does not endorse or support any particular factor concentrate or treatment protocols. References and links to other websites, organizations, products, services, or publications do not constitute endorsement or approval by BDRN. BDRN recommends that you consult with your physician prior to starting any course of therapy. Opinions expressed in this bulletin do not necessarily reflect those of BDRN.



\$\$\$ FOR COLLEGE IS A CLICK AWAY

BY: HOPE WOODCOCK, RN BSN

Apply for bleeding disorder scholarships that apply to you.

Are you planning to attend college or a technical school in the fall? Now is the time to apply for scholarships. Start with a search for bleeding disorder scholarships and then narrow it down to any that apply to you. The National Hemophilia Foundation at www.hemophilia.org and the Hemophilia Federation of America at www.hemophiliafed.org have an extensive list of scholarships for people with bleeding disorders. Most scholarships ask for a reference letter from a non-family member. This could be a teacher, coach, church youth leader or scout leader. Once you get a letter, make copies and use it for any of the scholarships

you apply, that way you won't have to go back and ask for another one. Your guidance counselor's office is a great place to find local scholarships to apply for. Many community groups have scholarship programs. When applying for scholarships, most colleges will ask you to write an essay. For ideas on your essay, think how your bleeding disorder has affected you and your family, how you have overcome challenges, and how you became a young adult while living with a bleeding disorder. The most important step is to start applying. You never know what you'll get unless you apply. Good Luck!

"Currently there is no recombinant form of factor 13 available"

Bayer representative presented a LINK program that is administered by PSI.

CORIFACT

BY: ALEX CHEBISHEV, R.PH.

Corifact is a factor 13 concentrate used to treat factor 13 deficiency in both adult and pediatric patients. It is administered as a slow IV push at a dose of 40 IU/ kg every 28 days. So a patient who weighs 120 lbs or 55 kg would require a dose of 2,200 IU every 28 days. Corifact is manufactured by CSL Behring from pooled human plasma and comes as single use vials of 1,000 IU to 1,600 IU with 20 ml of sterile water for injection. Currently, there is no recombinant form of factor 13 available. As with other plasma derived products, there is a theoretical risk of transmitting viruses such as CJD (Creutzfeldt-Jakob Disease) and is contraindicated if an individual has had a severe systemic reac-

tion to other plasma products. However, CSL Behring uses a 4 step process to inactivate and removes viruses. Although rare, there are reports of patients developing an inhibitor to Corifact. Factor 13 deficiency is very rare. NHF estimates that it occurs in anywhere from 1 in a million to 5 in a million births. That would mean that in a country with 330 million people like the US, there could be anywhere from 66 to 330 affected individuals. Corifact represents a significant advancement in the treatment of these individuals who previously had to be treated with fresh frozen plasma or cryoprecipitate. For more information on Corifact, please visit www.corifact.com

ANNUAL BDAST EDUCATION & HOCKEY

BY: JON DAVIS, REGIONAL MANAGER

On Friday, Jan 18, 2013, the Bleeding Disorders Association of the Southern Tier (BDAST) hosted an Education & Hockey Night. Over 100 BDAST members & friends convened at the Broome County Arena in Binghamton, NY for the event. Bayer representative, Christine Whipple presented a LINK program that included the new Kogenate FS Co-pay/

Co-Insurance Assistance Program. This new program is administered by Patient Services Inc. (PSI) and is funded by Bayer HealthCare. The event was capped off with fans watching the Binghamton Senators skate to a 4-2 win over the Toronto Marlies.



“BIOSIMILAR” LEGISLATION

BY: JON DAVIS, REGIONAL MANAGER

The Biological Price Competition and Innovation Law (BPCI) under the Patient Protection and Affordable Care Act (ACA), allows the FDA to develop an abbreviated approval system to license a “biosimilar” product as “interchangeable” with a specific, brand-name biological. The goal of this federal legislation is to lower the price of biological pharmaceuticals to patients and healthcare payers. Concerns expressed by bleeding disorder advocates surround the fact that “interchangeable” does not mean “exactly the same”. In anticipation of when the FDA will begin approving “biosimilars”, some states are currently considering legislation to prohibit automatic substitutions by providers. For FDA consumer information on this issue visit:
[http://www.fda.gov/Drugs/DevelopmentApprovalProcess/](http://www.fda.gov/Drugs/DevelopmentApprovalProcess/HowDrugsareDevelopedandApproved/ApprovalApplications/TherapeuticBiologicApplications/Biosimilars/default.htm)

[HowDrugsareDevelopedandApproved/ApprovalApplications/TherapeuticBiologicApplications/Biosimilars/default.htm](http://www.fda.gov/Drugs/DevelopmentApprovalProcess/HowDrugsareDevelopedandApproved/ApprovalApplications/TherapeuticBiologicApplications/Biosimilars/default.htm)

For specific information on “biosimilars” and the bleeding disorders community, checkout the position statements published by the Hemophilia Federation of America and the National Hemophilia Foundation at the following links:

http://www.hemophiliafed.org/uploads/Issue-Biosimilars_HFA2012.pdf

<http://www.hemophilia.org/NHFWeb/MainPgs/MainNHF.aspx?menuid=122&contentid=1359>

BDRN VENTURES INTO NY AND NY MEDICAID

BY: NELSON ESCOTO, CO-PRESIDENT

Bleeding Disorders Resource Network, LLC (BDRN, LLC) is pleased to announce the purchase of Wallkill Pharmacy in Walden, NY as of November 20, 2012. Wallkill Pharmacy is a retail pharmacy that initially served the Hamlet of Wallkill before being moved to the Village of Walden. The New York State Board of Pharmacy has approved the name

change to BDRN Pharmacy, LLC. The purchase of this retail pharmacy will now allow BDRN, LLC to service patients insured with New York Medicaid or dually insured New York Medicaid/Medicare patients. If you would like more information, please call BDRN, LLC at 888-692-3761.

BDRN
purchased
Wallkill
Pharmacy in NY
as of November
20, 2012

VISITING COLLEGES? HERE ARE SOME QUESTIONS TO ASK...

BY: HOPE WOODCOCK, RN BSN

Attending college is a big transition in your child’s life and the sooner you start planning, the better the outcome will be. Here are some questions that you may want to ask your child, potential college, or Hemophilia Treatment Center (HTC):

- How will your child deal with his or her bleeding disorder at college?
- Who in your child’s dorm should know about their bleeding disorder?
- Have you started letting them place their order for factor and supplies?
- Where will they store their factor and supplies at college?
- Where will their factor be delivered at college?

- What is the college’s policy on sharps containers?
- Does the student health center offer nursing support for venous access?
- If there is an emergency, who does your child contact?
- Does your HTC send a letter to the college health center?
- If your child is going to college outside of your home town, does your HTC allow a nearby HTC know of your child’s attendance at that college?

For more information or questions, speak with your HTC staff or school guidance counselor.



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BDRN pharmacy provides a full range of coagulation products and ancillary supplies. BDRN customizes all ancillary and infusion supplies to the patients specific needs. Medication profiles and history are reviewed and updated with each patient contact. Medication counseling is available 24/7/365 by a licensed BDRN pharmacist. BDRN will notify the Hemophilia Treatment Center staff as changes occur in the patient's clinical status. BDRN fosters and maintains a close relationship with all patients and the BDRN clinical care team provides medication adherence support in their individualized plan of care. BDRN will provide and/or coordinate nursing services as prescribed and allowed by law.

www.mybdrn.com

UPCOMING EVENTS

Bleeding Disorders Association of the Southern Tier

www.bdast.org

April 13th, BDAST Annual Meeting & Teaching Day
July 21st, Annual BDAST Summer Picnic
July 28th - August 3rd, Camp Little Oak
Aug 11th - Aug 17th, Camp High Hopes

Bleeding Disorders Association of Northeastern New York

www.bdaneny.org

May 25th, Family Fun Day

National Hemophilia Foundation

www.hemophilia.org

Hemophilia Association of New Jersey

www.hanj.org

May 11th, Testimonial “Man of the Year” Dinner

April 21st, Hemophilia 2013 WALK-A-THON

Hemophilia Federation of America

www.hemophiliated.org

April 27th -29th, HFA Symposium

New York City Hemophilia Chapter

www.nyhemophilia.org

June 2nd, Hemophilia Walk

Hemophilia Association of New York

www.hemophilia-newyork.org

May 19th, Day at the Races

