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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

August 23rd, 2014 BDAST2014 Golf Tournament

September 27th-28th , 2014 Annual Meeting & Family Education

Weekend

Bleeding Disorders Association of Northeastern New York

www.bdaneny.org

August 3rd, 2014 Annual Gold Tournament

New York City Hemophilia Chapter

www.nyhemophilia.org

National Hemophilia Foundation

www.hemophilia.org

September 18th-20th NHF Annual Meeting
(Washington, DC)

Hemophilia Association of New Jersey

www.hanj.org

September 13th, 2014 Annual Kelly Brothers Scholarship Benefit Picnic

September 27th, 2014 Rock Festival

Hemophilia Federation of America

www.hemophiliafed.org

Hemophilia Association of New York

www.hemophilia-newyork.org

Comprehensive Health Education Services, LLC

www.comphealthed.com

October 24th-27th, 2014 Inhibitor Family Camp

ANSWERS:
1. AMUSEMENT PARK
2. BARBECUE
3. FIREWORKS
4. WATERMELTON
5. HEAT WAVE
6. HURRICANE
7. SWIMMING
8. VACATION
9. SUMMER
10. SURFING



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MIGRAINES

BY: YAHAIRA ROMAN, RN BSN



It is estimated that 28 million Americans have migraine headaches; it affects women more than men. Although the exact causes of migraines are unknown, it is believed they are caused by changes in the brain as well as a genetic component. For instance, if one of your parents has migraines, that increases your risk to 50% and if both parents have it, your risk increases to 75%. Migraines can be triggered by certain factors such as: emotional stress, sensitivity to chemical ingredients and preservatives in foods, caffeine (drinking it in excess or withdrawal symptoms), menstrual cycle, changes in the weather, lack of sleep, and skipping meals. The symptoms are a very painful and pounding headache often accompanied with other symptoms such as nausea, vomiting, and light sensitivity; which can last

from several hours or up to a week. The pain is usually experienced in one side of the head or in the front of the head. Currently there is no cure for migraines. However, there are medications that can help to treat the symptoms (pain relievers, antinausea drugs) and some that prevent them from happening. Preventative medications help to lessen the severity and frequency of migraines and are usually prescribed daily. If your migraines are caused by any of the triggers listed in this article, you should consider avoiding them. Also, exercising several times a week and stress management can also be effective in preventing migraines. For more information on migraines speak to your healthcare provider.

SUM, SUM, SUMMER

BY: HOPE WOODCOCK, RN BSN



Why is it important to stay adherent with your factor regimen during your summer break? Summer activities, such as, swimming, biking, or going to amusement parks are physical activities that have the potential to cause bleeds/injuries. If you stay on your prescribed regimen, then you don't have to worry when you are out hav-

ing fun! If you do get an injury, remember to tell your parents and doctor so they can decide if you need extra infusions to treat it. Also remember to Rest, Ice, Compress and Elevate (RICE) with an injury as directed by your doctor or nurse. Most importantly, get out and have FUN!

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.



JOHN DILLION PARK BY: JON DAVIS, REGIONAL MANAGER

Give camping a try this summer in the Adirondack Mountains. The John Dillon Park is a fully accessible wilderness facility open to anyone with a disability, their family, friends and caregivers. This Adirondack Mountain park was designed and constructed by International Paper to give back to the community; especially to those with disabilities. The facility is named after John Dillon, a retired International Paper chairman, CEO and Paul Smith's College alumni. International Paper has partnered with Paul

Smith's College to manage the park which provides fully accessible trails, lean-tos and other services to accommodate people with disabilities. Call (518) 524-6226 to visit, make a reservation or just ask questions about the facility. The welcome center is open daily 9am – 6 pm. For more information visit, www.johndillionpark.com.



John Dillon Park was designed for those who have disabilities.

Biogen Idec Corporation has received FDA approval for Alprolix and Eloctate.

LONG ACTING FACTOR PRODUCTS COMING TO MARKET

BY: TOM PULEO, R.PH.

Biogen Idec Corporation has recently received FDA approval to market two long acting products. The first is Alprolix [Coagulation Factor IX (Recombinant) Fc Fusion Protein] for treatment of hemophila B. Alprolix has been approved for control and prevention of bleeding episodes, perioperative (surgical) management and routine prophylaxis in adults and children with hemophilia B. There are two recommended dosing regimens for routine prophylactic dosing. Based on patient need and response, it can be infused at 50 Units/kg once a week or 100 units/kg every 10 days. Dosing for control of bleeding episodes is based on severity of bleed and required factor IX levels. Dosing for surgical prophylaxis is based on the type of surgery and required circulating factor IX levels. The product is currently available in a kit containing a vial of factor, a prefilled syringe containing diluent and a vial adapter in assay ranges of 500, 1000, 2000, or 3000 units. More information on this product can be found at www.alprolix.com.

The second product is Eloctate [Antihemophilic Factor (Recombinant) Fc Fusion Protein] for treatment of hemophilia A. Eloctate has been approved for control & prevention of bleeding episodes, surgical prophylaxis, and routine prophylaxis. As with other products, control of bleeding episodes is based on severity of bleed and required factor VIII levels. Dosing for surgical prophylaxis is based on the type of surgery and required circulating factor VIII levels. Dosing for routine prophylaxis is 50 IU/kg every four (4) days, but may be adjusted to 25-65 IU/kg based on patient response. Doses for children less than 6 years old may be adjusted as high as 80IU /kg or may be administered more frequently. The product is available in a kit containing a vial of factor, a prefilled syringe containing diluent and a vial adapter in assay ranges of 250, 500, 750, 1000, 1500, 2000, or 3000 units. More information on this product can be found at www.eloctate.com.

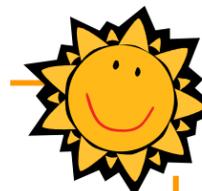


LIMITS ARE ALLOWED ON THIRD-PARTY PAYMENTS OF QUALIFIED HEALTH PLAN PREMIUMS

BY: JON DAVIS, REGIONAL MANAGER

The Centers for Medicare and Medicaid Services (CMS) and the Department of Human Services (HHS) under the Affordable Care Act (ACA) has enacted an interim final rule with a provision that allows health insurers, at their discretion, to reject some third-party payments made on Qualified Health Plan (QHP) premiums. QHP are health insurance plans that have been certified to offer essential health benefits and are obtained through the Federal Health Insurance Marketplace or a state health insurance exchange program. Exceptions to the provision include third-party, premium payments made by Indian tribes, tribal organizations and urban Indian organizations, as well as, payments made by state and federal government pro-

grams such as the Ryan White HIV/AIDS program. The rule is a concern within the bleeding disorders community because QHP premium payments made by PSI, a viable, longstanding charitable nonprofit that helps people with bleeding disorders and other chronic health conditions afford health insurance; can and have been rejected by some health insurers. The rule also includes the rejection of deductible and cost-sharing assistance. Currently, PSI is working with members of congress to establish guidelines for nonprofits to provide QHP premium assistance. Insurers stand by the provision because they claim it helps to prevent potential fraud.



SUMMER SCRAMBLED WORDS

- | | |
|-------------------------|--------------------|
| 1. TAMSUMNEE KPRA _____ | 6. EHUARCRIN _____ |
| 2. UBCERABE _____ | 7. WMNGSIMI _____ |
| 3. OFEKSIRWR _____ | 8. TNVAICAO _____ |
| 4. TWMNOAREEL _____ | 9. MMUSRE _____ |
| 5. AHTE VWAE _____ | 10. GRSFUNI _____ |

Try to unscramble these common Summer themed words. Answers on page 4.

THE NEW YORK 2013/2014 LEGISLATIVE SESSION ENDS

BY: JON DAVIS, REGIONAL MANAGER

The New York State, 2013/2014 legislative session ended on Friday June 20, 2014 without the passage of two bills concerning the bleeding disorders community: Anti-Mandatory Mail Order (AMMO) Reform S.3995-B/A.5723-B and Step-Therapy Amendment S.5110/A.6049. The AMMO Reform bill seeks to remove network requirements that negate the intent of the original law (S.3510-B/A.5502-B passed in 2011). Passage of this reform bill would allow more people with private insurance to obtain their prescription drugs from the pharmacy which best meets their needs, instead of being required to use a specific mail order pharmacy

chosen by their insurance plan. The Step-Therapy bill seeks to provide a concise and uniform method for providers to exempt their patients from first-fail protocols created by health insurers. Both bills are expected to be advocated for again in the upcoming 2014/2015 session. This year's session did include the passage of another on-time budget; a deal that legalizes some forms of medical marijuana and several tougher, anti-heroin laws.

