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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.



UPCOMING EVENTS

Bleeding Disorders Association of the Southern Tier

www.bdast.org

Dec. 8, 2013 Annual BDAST Holiday Party

Location: Elks Club, Vestal

Dec. 19, 2013 Persistent Pain: Considerations for the Hemophilia Community (Feat. Nyan Heath, RN CNE Speaker)

Location: P.S. Restaurant & Luxury Lounge

Call Jody Lasky, BDAST, (607)-972-3019 to RSVP

Bleeding Disorders Association of Northeastern New York

www.bdaneny.org

Dec. 7th, Snowflake Fest

Location: Hilton Garden Inn at Albany Medical Center

National Hemophilia Foundation

www.hemophilia.org

Hemophilia Association of New Jersey

www.hanj.org

Hemophilia Federation of America

www.hemophiliafed.org

New York City Hemophilia Chapter

www.nyhemophilia.org

Nov. 23, 2013 New York City Hemophilia Chapter 2013 Gala

Location: Historic India House Club

Nov. 24, 2013 NYCHC Education Day

Location: Crowne Plaza Times Square

Hemophilia Association of New York

www.hemophilia-newyork.org

ANSWERS:
1. FOLIAGE
2. THALLOWEEN
3. THANKSGIVING
4. PUMPKIN PIE
5. APPLE CIDER
6. HARVEST
7. AUTUMN
8. FOOTBALL
9. SCARECROW
10. CORN MAZE



BDRN BULLETIN

VOLUME 2, ISSUE 3

NOVEMBER 2013

STEM CELL AND GENE THERAPY RESEARCH

BY: TOM PULEO, R.PH.



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For many patients, having hemophilia means having to infuse on a regular basis. While a cure would be ideal, reducing the need to infuse anti hemophilic factor, the development of inhibitors, and the associated joint damage, would be a significant improvement. This is the goal of stem cell & gene therapy research currently being done. So far, research has mainly been done in animals. Stem cells have been engineered to produce factor IX and then infused into affected animals. Early results have shown several encouraging outcomes. Active bleeding stopped, spontaneous bleeds decreased, and existing joint damage was reversed. There was a downside. The treatment induced an immune response which would have to be abated. Another approach is genetic modification of liver cells to increase fac-

tor IX production. Cells are removed from patients, modified to replace the defective gene and reintroduced into the patient. The cells should then begin to produce factor IX. So far, the therapy has shown limited success in animals with factor IX deficiency as the treatment has a limited life span, due to development of immune responses, and other side effects. Once the problem with these side effects is overcome, it is hoped that the same theories will apply to factor VIII. It is too early to tell if these potential treatments can be translated to human subjects. This information can be found at: www.asgct.org/general-public/educational-resources/gene-therapy-and-cell-therapy-for-diseases/hemophilia.

TIME TO STUDY

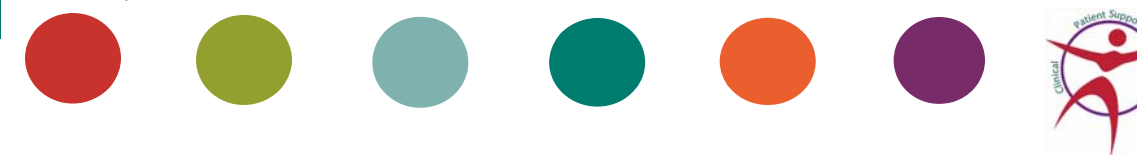
BY: HOPE WOODCOCK, RN BSN



How do you balance homework, after school activities, friends and family? Good study habits are a big part of school. Here are some tips. What is your learning style? Ask a counselor about a learning style quiz. It will help you plan study strategies. Make a plan of what, how long, or how much to study. Set a goal and stick to it. For procrastinators, start off with the easy or interesting part of the project. Remember to stay on your timeline to get it done. Where do you study? Take into consideration surroundings. Set a timer and study 30 to 50 minutes then

take a 10 minute break. Stand, stretch, relax, and have a snack. If you get bored, change to a different subject. Allow plenty of time for reading, research, and outlining when writing a paper. Use memory activities to review just before you go to sleep. Study with a friend. Quiz each other, compare notes, and predict test questions. Read all assignment and test instructions carefully. If you need help, ask for it! No one is going to do it for you, but teachers, parents, and friends are there to help you achieve your goals.

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.



CHILD HEALTH PLUS "OUTPATIENT FACTOR" BILL IS SIGNED INTO LAW!!!

BY: JON DAVIS, REGIONAL MANAGER



On October 23, 2013, Governor Cuomo signed legislation A962A (Kellner)/S2186A (Robach) into law. This act amends New York State public health law to ensure that persons with clotting protein deficiencies, enrolled in the Child Health Plus (CHP) program, will have access to reimbursement for outpatient clotting factors. Currently, this law goes into effect on April 1, 2014. BDRN congratulates Assemblyman Micah Kellner, Senator Joseph

Robach and Governor Cuomo for their leadership along with the many supporters of this overdue legislation, advocated for by the New York State Bleeding Disorders Coalition (NYSBDC). For more information on this law and bleeding disorders advocacy in New York State, be sure to visit: <http://nysbdcoalition.org>.

Legislation A962A (Kellner)/S2186A (Robach) was signed into law and will go into effect April 1, 2014.

“...Symptoms of depression include: difficulty concentrating, decreased energy, insomnia...”

“A log provides valuable information, such as when and how much factor was infused...”

DEPRESSION

Are you feeling hopeless, helpless, worthless, sad, fatigued on a daily basis? If so, this may be a sign of depression. Researches estimate that by 2020, depression will be the second leading cause of disability worldwide. According to the National Institute of Mental Health, there are approximately 14.8 million Americans suffering from depression. Other signs and symptoms of depression include: difficulty concentrating, decreased energy, insomnia (difficulty sleeping), irritability, loss of interest in activities that you once enjoyed, persistent aches and pains, and thoughts of suicide. For someone to get diagnosed with depression, these signs and symptoms need to be experienced for at least two weeks along with some type of clinical impairment. In addition to taking these signs and symptoms into consideration, your healthcare provider may also perform other diagnostic tests

BY: YAHAIRA ROMAN, RN BSN



to rule out the possibility of any other medical condition. There are several types of depression, therefore, if you experience any of these signs and symptoms, please speak with your healthcare provider. If you are having thoughts of suicide, you or your loved ones should call 911 or the suicide hotline at 1-800-784-2433 and DO NOT ignore these “thoughts” as their outcomes can be catastrophic. Depression treatment varies and it’s usually customized to the type of depression the individual has. The most common types of treatment are prescribed oral antidepressants, psychotherapy, and in the more severe cases electroshock therapy. Depression is treatable; remember there’s always a light at the end of the tunnel. For more information on depression, speak with your healthcare professional.

DO YOU RECORD YOUR INFUSIONS?

BY: RHONDA YARUSSI, REIMBURSEMENT SPECIALIST
YOLANDA VENTO, CO-PRESIDENT



Keeping a log is no different than keeping a diary, and with peel-off labels, clotting factor manufacturers make it more convenient to record them. A log provides valuable information, such as when and how much factor was infused, the purpose of the infusion, the site of the infusion, and the outcome. Why is this important? Most private, state, and federal insurance carriers now require a

copy of your logs to confirm that you are using your factor as ordered. If you are on prophylaxis or on-demand treatment, infusion logs can spot a trend of breakthrough bleeds that can help you and your healthcare team develop a plan to resolve and/or prevent them. Remember keeping infusion logs are as important as hand-washing whenever you infuse.

ONLINE SAFETY

BY: HOPE WOODCOCK, RN BSN

Have you ever searched for yourself online? Every time you create an account on a social networking site, post on a blog, or pick a name for instant messaging (IM), you are adding to your online identity. How do you protect yourself? Privatize your profile on a social network. Don't rely on the site's settings. Take the time to read each site's instructions to make sure your pictures and post aren't being shared with the world. Nothing is temporary online. Almost eve-

rything you type, share, or delete is easy for others to copy, save, and forward. Would you show your parents the comment or picture you are going to post? Remember that family members, colleges, and potential employers check social sites. For more information visit TeensHealth.org.

FALL SCRAMBLED WORDS

- | | |
|-----------------------|---------------------|
| 1. GFLOAEI _____ | 6. STHAVER _____ |
| 2. EHLAOLNWE _____ | 7. UTMAUN _____ |
| 3. KTGahnivGSNI _____ | 8. TOFBLOAL _____ |
| 4. MPUKNIP EPI _____ | 9. WSCREAO _____ |
| 5. PLEAP IRDEC _____ | 10. ORCN EMZA _____ |

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

IN THE HOT SEAT: OBAMA ADMINISTRATORS TESTIFY ABOUT THE FEDERAL EXCHANGE WEBSITE

BY: JON DAVIS, REGIONAL MANAGER

Marilyn Tavenner, Administrator of the Centers for Medicare & Medicaid Services (CMS) and Kathleen Sebelius, U.S. Department of Health and Human Services (HHS) testified in late October at U.S. House of Reps oversight hearings to answer questions about serious problems with the Federal Health Insurance Exchange Website: Healthcare.gov. The website went primetime on October 1, 2013 for eligible U.S. citizens to obtain health insurance options then have the ability to enroll in one of the options provided. However, for too many potential enrollees, it has been widely reported and admitted by President Obama that the website is not functional, let alone able to deliver the easy shopping experience that he promoted. While House Republicans asked both Ms. Tavenner and Ms. Sebelius reasonable questions such as “Why doesn't

the website work when you said it would?” and “How many people have actually enrolled in a plan?”; House Democrats touted the overall successes to date of the Affordable Care Act (ACA) and asked their Republican colleagues for their bipartisan support the ACA instead of just being outright against the law. Currently, below the political fray there is roughly 15% of the U.S. population that is without health insurance and citizens from both sides of the ACA debate have benefited from the law. President Obama says the website will work by November 30, 2013 and Ms. Tavenner says enrollment data will be released mid-November. For video coverage of the hearings, visit <http://www.c-span.org/>.

