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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

April 9th, Night of Art

May 17th, Blood Brotherhood Fishing Charter

May 18th, The Art Adventure

Bleeding Disorders Association of Northeastern New York

www.bdaneny.org

New York City Hemophilia Chapter

www.nyhemophilia.org

March 15th, Spring Event at the New York Hall of Science

National Hemophilia Foundation

www.hemophilia.org

Feb. 25th-27th, Washington Days

Hemophilia Federation of America

www.hemophiliafed.org

March 26th-28th, HFA Symposium 2015

Hemophilia Association of New York

www.hemophilia-newyork.org

April 18th, Educational Session on The CEO Program

May 17th, Day at the Races

Hemophilia Association of New Jersey

www.hanj.org

April 18th, Thirty –Fifth Annual Testimonial Dinner Dance

May 3rd, Hemophilia Walk



1. Snow Boarding
2. Milk and Cookies
3. Snowball
4. Snow Suit
5. Snow Tubing
6. Weather
7. Fire Place
8. Hot Chocolate
9. Scarf
10. Ice Fishing

BDRN BULLETIN

VOLUME 3, ISSUE 4

FEBRUARY 2015

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OBIZUR

Obizur® [Antihemophilic Factor (Recombinant), Porcine Sequence], a new drug has recently been approved by the Food and Drug Administration (FDA) for treatment of acquired hemophilia A. The approval of this product provides an important therapeutic option for use in the care of patients with this form of hemophilia. Acquired hemophilia A is a rare, but potentially life threatening, bleeding disorder caused by the development of antibodies (immune system proteins) directed against the body's own FVIII. When FVIII is inactivated by these autoantibodies, a person's blood doesn't clot normally, resulting in excessive bleeding that can occur spontaneously or following an event such as an injury or surgery. Unlike inherited hemophilia, acquired hemophilia A is not a genetic disorder and affects both males and fe-

BY: TOM PULEO, R.PH.



males. The development of acquired hemophilia A has been related to other medical conditions such as pregnancy, cancer, or the use of certain medications. However, in about half of the cases, no underlying cause can be found. Diagnosis of this condition can be difficult and the severity of the bleeding can make treatment challenging. Obizur contains a recombinant analogue of porcine (pig) FVIII. Porcine FVIII is used because it is similar to human FVIII and is effective in blood clotting, but is less likely to be affected by the antibodies against human FVIII that are present in people with acquired hemophilia A. Currently Obizur has been studied in patients with acquired hemophilia A and is not currently approved for treatment of inherited hemophilia A.

BLEEDING DISORDERS ADVOCACY IN NEW YORK STATE: SIGN UP FOR ALBANY DAYS

BY: JON DAVIS, REGIONAL MANAGER



The New York State Bleeding Disorders Coalition (NYSBDC) has announced that Albany Days is scheduled for March 22nd – 23rd. Albany Days is an opportunity for residents of New York State to educate their elected state legislators about bleeding disorders and government policy that affects their access to appropriate health-care. This year the event includes a tour

of the Senate and Assembly Chambers with an opportunity to learn how New York State government works. If you would like to be a part of Albany Days or learn more about bleeding disorders advocacy issues, contact your local chapter association now or visit: nysbdcoalition.org

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.



CHOICE survey ends on March 2015.

"Not being prepared can quickly crash the vacation fun..."

"Cold and windy weather are one of the many reasons that can cause your skin to become dry and flaky"

The purpose of the CHOICE (Community Having Opportunity to Influence Care Equity) survey is to collect healthcare related experiences from people diagnosed with a bleeding disorder to help improve treatment. The CHOICE project is a cooperative agreement with the Centers for Disease Control and Prevention (CDC) with the goal of improving the lives of all in the bleeding disorders community, but time is running out to be part of the project. The CHOICE survey ends in March 2015! To take the survey, preview it, or learn more about the project, call 800.230.9797 or visit online at: choice.hemophiliafed.org.

Ever been on a trip away from home and find yourself without enough factor, ancillary supplies, a medical travel letter or contact information for the nearest hemophilia treatment center? Not being prepared can quickly crash the vacation fun or hinder your performance on a business trip. Preparing teenagers for travel without a parent can lead to a contentious discussion as they strive for independence. Reviewing the "what if this happens" scenarios with your teenager, could help them better understand the importance of taking the time to prepare for the unexpected when traveling alone. For in-depth information on domestic or international travel concerning bleeding disorders, visit:

<http://www.hemophilia.org/sites/default/files/document/files/Nurses-Guide-Chapter-15-Travel-Vacation-Planning.pdf>

<http://www.hemophiliafed.org/resource-library/travel-tips/>

<http://www.wfh.org/en/page.aspx?pid=902>

TRAVEL & BLEEDING DISORDERS BY: JON DAVIS, REGIONAL MANAGER

DRY SKIN BY: YAHAIRA ROMAN, RN BSN

Winter is in full swing and so are the changes in your skin. Cold and windy weather are one of the many reasons that can cause your skin to become dry and flaky. Other causes of dry skin can be related to medical conditions such as changes in your hormones, diabetes, malnutrition, and even a family history of dry skin. Dry skin can become problematic when your skin begins to swell, crack, or bleed. If these symptoms are left untreated, it can lead to a skin infection. Here are some helpful tips to prevent dry skin: avoid harsh soaps; instead use shower gels with some type of moisturizer, minimize long, hot showers or baths; instead

regulate water temperature to warm, keep hydrated by drinking adequate amounts of water, use a humidifier in the winter, and always moisturize your skin within 3-5 minutes of any exposure to water. The reason for this is because your skin will absorb any cream or moisturizer better and it will lock in that moisture in your skin. If your dry skin worsens, does not improve with over the counter products, or you experience any of the symptoms listed above, please consider scheduling an appointment with your primary healthcare provider or with a dermatologist.



STAYING FIT DURING WINTER

Do you want to build a snowman? By now most of us know this line well! How do you stay fit during the winter months? As the temperatures drop, how do you move indoors to keep joints active? First, always check with your doctor to make sure the activity you are planning will not change how you infuse. Second, plan your activity. Some activities that might be of interest are: walking at the mall, swimming at school, yoga and dance classes, or

BY: HOPE WOODCOCK, RN BSN



even playing physically interactive video games. Make time on your schedule and stick to it. Keep track of your activity and reward yourself. Third, ask a friend to join you. Studies have shown that by having a workout buddy, you may stick to your plan better. Whatever you pick, it will help you be fit for the next season!

FIVE FUN FACTS ABOUT EXERCISING REGULARLY BY: YAHAIRA ROMAN, RN BSN

- Helps maintain your current weight.
- Helps you fight health conditions and diseases such as diabetes, high cholesterol, and high blood pressure.
- Helps balance and improve your mood.
- Helps increase your energy.
- Helps you sleep better at night.

WINTER SCRAMBLED WORDS

1. WONS GBROADNI

2. KILM NAD KOCOEIS

3. LBSONWAL

4. WSONSITU

5. NSWU UTIBNG

6. THWERA

7. EFRI APCEL

8. THO CCLTEAOOH

9. CSFAR

10. EIC GFIIHNS

