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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](http://www.mybdrn.com)

## UPCOMING EVENTS

### Bleeding Disorders Association of the Southern Tier

[www.bdast.org](http://www.bdast.org)

Saturday, May 17<sup>th</sup> Blood Brotherhood Fishing Charter

Sunday, May 18<sup>th</sup> The Art Adventure

Saturday, May 31<sup>st</sup> “Just the Guys” Weekend

### Bleeding Disorders Association of Northeastern New York

[www.bdaneny.org](http://www.bdaneny.org)

Saturday, May 31<sup>st</sup> Family Fun Day

Saturday, June 14<sup>th</sup> A Night at the Joe!

### National Hemophilia Foundation

[www.hemophilia.org](http://www.hemophilia.org)

### Hemophilia Association of New Jersey

[www.hanj.org](http://www.hanj.org)

Thursday, May 29<sup>th</sup> HANJ Annual Meeting

### Hemophilia Federation of America

[www.hemophiliafed.org](http://www.hemophiliafed.org)

### New York City Hemophilia Chapter

[www.nyhemophilia.org](http://www.nyhemophilia.org)

Sunday, June 1<sup>st</sup> Hemophilia Walk

### Hemophilia Association of New York

[www.hemophilia-newyork.org](http://www.hemophilia-newyork.org)

Sunday, May 18<sup>th</sup> Belmont Racetrack

Monday, June 23<sup>rd</sup> “An Evening for Bleeding”

### Comprehensive Health Education Services, LLC

[www.comphealthed.com](http://www.comphealthed.com)

Friday, June 20<sup>th</sup>-22<sup>nd</sup> FVII Retreat

ANSWERS:  
1. SPRING CLEANING  
2. FLOWERS  
3. ALLERGIES  
4. BUTTERFLYS  
5. PICNICS  
6. MEMORIAL DAY  
7. APRIL SHOWERS  
8. BIKE RIDES



# BDRN BULLETIN

VOLUME 3, ISSUE 1

MAY 2014

## SPRING CLEANING

BY: TOM PULEO, R.PH.



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Its time for spring cleaning and this should include your medicine cabinet. Every medication you have, be it a prescription, or something you bought over the counter, has an expiration date. That doesn't mean that the product will suddenly become unsafe or ineffective, but it's the date the manufacturer guarantees the product will be at full potency and safe to use. It's a commonly accepted fact that medications are usable beyond their expiration date, and with a very few exceptions, that is probably true. The question is how far beyond? Since that varies greatly with each product, no general recommendations can be made regarding the use of outdated medications.

There are 3 types of medications that should be disposed of:

1. Medications that are out of date according to the expiration date on the package.
2. Prescription medications that you no longer use. This can be medications to treat a condition that has been resolved, or medication that has been changed to a different therapy. They could be harmful if taken by accident.
3. Any medication that has been recalled or taken off the market. So go through your medication cabinet and dispose of anything you no longer need, and be sure to dispose of them safely and properly. If you're not sure of something, ask your pharmacist.

#### Guidelines for Drug Disposal:

Follow any specific disposal instructions on the prescription drug labeling or patient information that accompanies the medicine. Do not flush medicines down the sink or toilet unless this information specifically instructs you to do so. Take advantage of community drug take-back

programs that allow the public to bring unused drugs to a central location for proper disposal. Call your city or county government's household trash and recycling service to see if a take-back program is available in your community. If no disposal instructions are given on the prescription drug labeling and no take-back program is available in your area, throw the drugs in the household trash following these steps.

1. Remove them from their original containers and mix them with an undesirable substance, such as used coffee grounds or kitty litter (this makes the drug less appealing to children and pets, and unrecognizable to people who may intentionally go through the trash seeking drugs).

2. Place the mixture in a sealable bag, empty can, or other container to prevent the drug from leaking or breaking out of a garbage bag.

Some additional tips:  
Before throwing out a medicine container, scratch out all identifying information on the prescription label to make it unreadable. This will help protect your identity and the privacy of your personal health information. Do not give your medicine to friends. Doctors prescribe medicines based on a person's specific symptoms and medical history. A medicine that works for you could be dangerous for someone else. The same disposal methods for prescription drugs could apply to over-the-counter drugs as well.

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.



NHF WASHINGTON DAYS 2014 BY: JON DAVIS, REGIONAL MANAGER

Educating members of Congress about bleeding disorders and policy issues that impact the bleeding disorders community is the goal at NHF Washington Days. This year over 300 bleeding disorders advocates went to Washington DC on February 26<sup>th</sup> -28<sup>th</sup> to continue that important work. Personal stories shared by individuals, families and community supporters help our nation's elected leaders understand what it takes for the bleeding disorders community to overcome challenges. This year advocates asked Congress again to maintain the \$16 million in annual funding that is shared among the 140 federally funded Hemophilia Treatment Centers and other bleeding disorders programs. Advocates explained to Congress how that funding is used and how any cut in that relatively small budget, affects their health care. Concerning health insurance, Washington Day Advocates asked Congress to support H.R. 460 – The Patients' Access to Treatments Act of 2013. This bill would prevent private health insurance plans from requiring higher copayments (aka coinsurance) nationwide for spe-

cialty or Tier IV drugs than what is required for non-preferred brand or Tier III drugs. Tier III copayments are typically a flat rate of \$75.00 or less. Unfortunately, Tier IV copayments range from 25 – 33% of a drug's total cost. Private payers originally introduced the Tier IV drug category in 2009 to discourage the use of expensive, name brand drugs, but in the case of clotting factors for which there are no generics or "biosimilars" approved in the United States, Tier IV copayments could leave a person with a severe bleeding disorder, annually responsible for \$150,000 - \$300,000 in out-of-pocket costs. At the state level, New York passed a law in 2010 similar to H.R. 460 that bans the existence of Tier IV drug copayments. Contact your local NHF chapter or HFA member organization today on how you can help to pass H.R. 460.



"...Symptoms of food poisoning are abdominal pain/cramps, diarrhea, vomiting..."



Dr. Chris Walsh, lead speaker, covered the current Hepatitis C treatment medications

FOOD POISONING

Food poisoning is an illness caused by eating foods that are contaminated with bacteria, parasites, and viruses. These harmful organisms are mostly found in any type of raw meats, fish, and eggs. Bacteria can also grow on food that is not properly stored, left outdoors or on countertops. The most common symptoms of food poisoning are abdominal pain/cramps, diarrhea, vomiting, high fever, and even bloody stools. For the most part, food poisoning is mild and symptoms tend to go away after several days. However, if they do not subside within 2 to 3 days or if you're experiencing signs of dehydration, call your doctor immediately. Your doctor may recommend that you take anti-

BY: YAHAIRA ROMAN, RN BSN

arrheals and rehydration drinks such as Pedialyte. Now that Spring is here and you're getting ready for picnics and barbecues, here are some easy tips to prevent food poisoning: always wash your hands before and after handling any foods, keep separate cutting boards; one for fruits and vegetable and the other for meats, fish, and poultry, wash all fruits and vegetables thoroughly, make sure that your meat, chicken, fish, and eggs are cooked according to recommended temperatures, and refrigerate any leftovers immediately. Last but not least, if you're not sure about how a particular food has been cooked or handled, Do Not Eat It!



HEMOPHILIA B ANNUAL SYMPOSIUM

I had the honor of attending the Coalition for Hemophilia B Annual Symposium on March 8<sup>th</sup> in NYC. Dr. Chris Walsh from Mt. Sinai was the lead speaker. He covered the latest hepatitis C treatment medications. He highly encouraged anyone who hasn't done treatment or failed in the past to seek treatment now through their provider. He also went on to explain different approaches to prophylaxis infusions. Many patients try to do prophylaxis treatment 3 to 4 times a week and

BY: HOPE WOODCOCK, RN BSN

have difficulty maintaining compliance. He recommended patients should have a discussion with their provider about trying an increased dose and infusing two times a week. An open discussion with your doctor may lead to a better treatment plan for you or your child. This year's meeting was enjoyable, with many hemophilia B families in attendance. It was a great opportunity to network and see old friends.



KNOCKING DOWN PINS IN HEMOPHILIA AWARENESS MONTH TO SUPPORT BDAST BY: JON DAVIS, REGIONAL MANAGER

On Sunday, March 9, 2014, over eighty bowlers and volunteers participated in the Bleeding Disorders Association of the Southern Tier's (BDAST) Annual Bowlathon Fundraiser at Midway Lanes, Vestal, NY. Community supporters and BDAST members pledged over \$2,200.00 in proceeds to support programs such as the Maureen Cook Memorial Scholarship and the Bob Payne Memorial Camp Fund. Throughout the afternoon, both

kids and adults all enjoyed food, prizes, and knocking down pins for a good cause! BDRN sponsored this annual fundraiser, while Hope Ross and Jon Davis from BDRN volunteered.



SPRING SCRAMBLED WORDS

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

- 1. NSPGRI NNGCLAEI \_\_\_\_\_
- 2. WFOLRES \_\_\_\_\_
- 3. GAELRLESI \_\_\_\_\_
- 4. UBTEFISERTL \_\_\_\_\_
- 5. INCPISC \_\_\_\_\_
- 6. IMMEOALR YDA \_\_\_\_\_
- 7. PARLI HWRESOS \_\_\_\_\_
- 8. KIBE DESIR \_\_\_\_\_

LEGISLATIVE ADVOCACY: ALBANY DAYS 2014 RECAP

BY: JON DAVIS, REGIONAL MANAGER

Individual and family members of the New York State Bleeding Disorders Coalition (NYSBDC) participated in Albany Days on Sunday March 23<sup>rd</sup> & Monday 24<sup>th</sup>, 2014. Participants received advocacy training on Sunday afternoon at the Hilton Albany, then attended meetings with their state representatives throughout the day on Monday. This year's advocacy agenda included thanking state Assembly and Senate members for their unanimous passage of bill A0962A/S2186A. This bill amends New York Child Health Plus (CHP) law to mandate coverage for "at home" clotting factor. Governor Cuomo signed the bill into law on October 23<sup>rd</sup>, 2013 and it went into effect on April 1<sup>st</sup>, 2014. During the event on Monday morning, Senator Robach and Assemblyman Gottfried were each presented with a special, recognition award by the NYSBDC, for their leadership in passing

the CHP bill. Another item on the agenda was educating the legislature about bill A5214A (Titone)/S2711A (Young). This bill stands to amend state insurance law, concerning the regulation of "step therapy" or "fail first" protocols established by private health insurance plans to promote their preferred, less expensive drug therapies. Passage of this bill would give physicians a concise process to exempt patients from "step therapy" or "fail first" protocols within a safe time frame. The NYSBDC has teamed up this year with a larger coalition that includes several different chronic health conditions to support this bill. If you are interested in attending state or federal advocacy events in the bleeding disorders community, contact your local Hemophilia Federation of America (HFA) organization or National Hemophilia Foundation (NHF) chapter. Anyone can be an advocate. Make your voice heard. Get involved today!

