

NJ BRANCH – CORPORATE

1 South Corporate Drive
Suite D– 2nd Floor
Riverdale, NJ 07457
Phone: 973-513-9031
Fax: 973-513-9032
Toll Free: 888-mybdrn1
(888-692-3761)

NY BRANCH

108 Orange Avenue
Walden, NY 12586
Phone: 845-778-2620
Fax: 845-778-2611

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

July 21st, Annual BDAST Summer Picnic
July 28th - August 3rd, Camp Little Oak
Aug 11th - Aug 17th, Camp High Hopes
September 21st, Annual BDAST Gold Fundraiser

Bleeding Disorders Association of Northeastern New York

www.bdaneny.org

July 21st, BDANENY Family Picnic
August 4th, BDANENY Golf Classic

National Hemophilia Foundation

www.hemophilia.org

Hemophilia Federation of America

www.hemophiliafed.org

Hemophilia Association of New Jersey

www.hanj.org

September 14th, 21st Annual Kelly Brothers Scholarship Benefit Picnic

HANJ Brotherhood Events

July 28th, Classic Thyme Private Cooking Class
September 15th, Fishing Trip– Seahorse out of Atlantic Highlands

For Blood Brotherhood events contact:

Tom Russomano 732-236-8701

Rich Vogel 732-991-7373

New York City Hemophilia Chapter

www.nyhemophilia.org

Hemophilia Association of New York

www.hemophilia-newyork.org



BDRN BULLETIN

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HTN "THE SILENT KILLER"

BY: YAHAIRA ROMAN, RN BSN



The "silent killer" otherwise known as hypertension (HTN) or high blood pressure is considered one of the most common cardiovascular diseases worldwide. For the most part, people are unaware they may have high blood pressure because they may not experience any signs or symptoms. How do you know if you have high blood pressure? Start by getting a yearly routine physical and have your doctor check your blood pressure. Normal blood pressure ranges from 90/60 to 120/80. For someone to get diagnosed with HTN they must have a BP reading of 140/90 or higher within two occasions. Keep in mind that if you have a family history of HTN, diabetes, kidney disease, are overweight / obese, use certain medications such as decongestants, or illicit drugs such as cocaine / am-

phetamines, you're at greater risk for developing this disease. If left untreated, HTN can cause a heart attack, stroke, kidney failure, and other life-threatening conditions. To prevent HTN, start by making lifestyle changes, such as smoking cessation, losing weight, exercising regularly, eating a low salt / low fat diet, and limiting alcohol consumption. If you're diagnosed with HTN, in addition to these lifestyle changes, your doctor will prescribe medications (i.e. diuretics, ACE inhibitors, beta – blockers). Remember to monitor your BP regularly. This can be done with a home blood pressure monitor or wrist monitor. If you have any questions regarding HTN or its treatment, speak with your healthcare provider. For general information, visit www.cdc.gov.

NEW YORK STATE ADVOCACY UPDATE

BY: JON DAVIS,
REGIONAL MANAGER



In June 2013, the New York State Assembly and Senate voted unanimously to pass A962A (Kellner)/S2186A (Robach). The bill originally introduced in 2011, was created to close a gap of coverage in New York's Child Health Plus (CHP) plan; which is the only State Children Health Insurance Program (SCHIP) in the U.S. that does not cover self-administered "at home" blood clotting factor. If Governor Cuomo signs the

bill into law, it will take effect on April 1, 2014. For more information visit: www.nysbdcoalition.org. BDRN congratulates the legislative sponsors, the New York State Legislature and the New York State Bleeding Disorders Coalition for supporting this important health insurance legislation!

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.



NEW YORK CITY HEMOPHILIA WALK 2013 RECAP!

Awesome weather, a beautiful park, and great people!!! Over 1,500 families and friends made their way to Riverside Park, NYC on Sunday, June 2nd to support the NYC Hemophilia Walk. This year, the walk raised over its goal of \$250,000 to help support programs of the New York City Hemophilia Chapter (NYCHC) and National Hemophilia Foundation (NHF). BDRN's Walk Team Captain, Hope Woodcock and her fam-

BY: JON DAVIS, REGIONAL MANAGER

ily volunteered at team registration while the BDRN Service Team, enjoyed greeting people at the BDRN Display tent. BDRN congratulates everyone who made this another successful NYCHC fundraiser and community event! For more information about the NYC Hemophilia Chapter, visit: www.nyhemophilia.org.

The NYC Hemophilia Walk raised over its goal of \$250,000!

"Many environmental factors can affect the stability of your medications such as: heat, cold, moisture, and light."

The Supreme Court of the U.S. ruled that natural occurring genes cannot be patented.

MEDICATION STORAGE

Summertime is here, which means heat, spending time outside and vacations. It also means storing your medications properly. Medications needing refrigeration are labeled as such and should be stored as indicated. What about other medications, both prescription and the ones you buy over the counter? Many environmental factors can affect the stability of your medications such as: heat, cold, moisture, and light.

- Many medications are affected by moisture and should not be stored in bathrooms or refrigerators.
- Many medications can be affected by light and should not be stored on window sills, or counters which

BY: TOM PULEO, R.PH.



are exposed to direct sunlight.

- Many medications are affected by heat and should not be left in warm places, such as window sills, counters exposed to direct sunlight, dashboards of cars, or near stoves / ovens.

So how should you store your non refrigerated medications? Keep them in the containers they were dispensed in and store them in a cool (not cold) dry place that is protected from sunlight. Last but not least, Keep Them Out of the Reach of Children! If you're not sure how to store a medication give us a call and we'll be glad to help you.

SUPREME COURT RULING ON THE PATENT RIGHTS TO GENES

BY: JON DAVIS, REGIONAL MANAGER

On June 13, 2013, the Supreme Court of the United States (SCOTUS) ruled that naturally occurring genes cannot be patented. The original case filed in May 2009 and heard by the Southern District of New York in March 2010, decided that patents on the BRCA1 and the BRCA2 gene held by Myriad Genetics are invalid. In addition to those breast cancer related genes, the SCOTUS ruling will open the door for competition and create less expensive

testing for other isolated genes linked to health conditions. In regards to the bleeding disorders community, the ruling will prevent patents on any natural occurring, immunological genes that may determine a person's predisposition to developing a factor inhibitor. For more information on the ruling and what it means to the biotech industry; visit: www.scotusblog.com.

HANJ ANNUAL MEETING

BY: NELSON ESCOTO, CO-PRESIDENT



BDRN attended and displayed at the Hemophilia Association of New Jersey (HANJ) Annual Meeting on May 29, 2013. The meeting was held at the Hilton in East Brunswick, NJ. Over 150 people attended the meeting. On the agenda were the regular "housekeeping items" such as business meeting, Award and Scholarship presentations, and elections.

There were also guest speakers from Baxter, Bayer, Novo Nordisk, Octapharma, and Pfizer talking about their respective drug pipelines and the future of hemophilia care and treatment. If you would like more information on HANJ, please visit www.hanj.org or call 732.249.6000.

BDANENY FAMILY FUN DAY

BY: NELSON ESCOTO, CO-PRESIDENT

BDRN exhibited at the Bleeding Disorders Association of Northeastern New York's (BDANENY) Family Fun Day. The event was held May 25th from 10A-4P at The Crossings in Colonie, NY. The event drew 65 families who were treated to airbrushed tattoos, luau limbo, hula hoops, scavenger hunt, session on "hands on nutrition", and a "girls chat." Along with BDRN, there were other exhibitors including NHF, HFA, Camp Little Oak, Camp High Hopes, and the Regional Comprehensive Hemophilia Center at Albany. Al-

though it was raining outside, the Sun was shining indoors for the Family Fun Day and a great time was had by all.

BDRN exhibited at the BDANENY Family Fun Day on May 25th, 2013.



HOW TO SQUASH THE MOSQUITOES

BY: HOPE WOODCOCK, RN BSN



Mosquitoes are part of summer. Here are some safe ways to control them:

1. Mosquitoes love early morning and late evening hours. Try to plan your outdoor time accordingly.
2. Aerosol insect repellants can be very effective and safe when used correctly. Read all the directions on the container and proceed as directed. Products with DEET, oil of lemon eucalyptus, picaridin and those approved by the U.S. Environmental Protection Agency are ideal. Once inside wash the areas you sprayed. Use caution on

- children under three years of age. Never spray directly on face, eyes, or mouth.
3. Mosquitoes are attracted to your leftovers! Clean up after picnics, cover garbage cans, and make sure screen windows and doors are in good condition.
4. Dress to repel! Wear lightweight long sleeved shirts, long pants, socks, hats and closed shoes. Perfumes and scented soaps are like a magnet for mosquitoes!
5. Standing water attracts mosquitoes to breed and lay eggs. After it rains empty all flower pots, bird baths or other containers that hold standing water.

