

Flu Season—Getting Ready

By: Nancy Spomer, RN, BSN University of Colorado Hemophilia & Thrombosis Center

As we approach the end of the summer season and turn our attention to preparing for fall and winter, it is time to be aware of and prepare for cold and flu season. This year brings new information and guidelines for preventing influenza after a new strain of the disease was identified in the United States in April 2009. Originally called "swine flu" this new strain is officially novel influenza A or H1N1.

First, the usual seasonal influenza viruses are still expected in the United States with peak incidence in January but this can vary in different parts of the country. Vaccine for seasonal flu will be widely available this year beginning in September. Anyone who wants to reduce their chance of getting the flu should get the vaccine. Check with your health care provider about whether the flu vaccine is appropriate for you or family members. Persons with an allergy to eggs or a history of Guillian-Barre Syndrome should not get the flu vaccine.

H1N1 and seasonal flu may have the following symptoms: fever, cough, sore throat, body aches, headache, chills and fatigue. With H1N1 there have been reports of diarrhea and vomiting. Both flu viruses may be mild to severe and can vary in individuals who seemingly were infected by a common source. Different than seasonal flu which impacts all ages, it appears that children, adolescents, young adults and pregnant women may be more impacted than other age groups with H1N1. Although both seasonal and H1N1 can cause severe disease including death, there is some additional concern associated with H1N1 in the severe form which can occasionally cause severe pneumonia or respiratory failure. The Center for Disease Control and Prevention's (CDC) Advisory Committee on Immunization Practices (ACIP) are recommending the following persons a priority to receive the novel H1N1 vaccine as it becomes available:

- Pregnant women
- People who live with or care for children younger than 6 months of age
- Health care and emergency medical services personnel
- Persons between the ages of 6 months through 24 years of age
- People from ages 25 through 64 years of age who are at higher risk for novel H1N1 because a of chronic health conditions or compromised immune systems.

Transmission of seasonal and H1N1 flu is through coughing or sneezing, or by touching a surface or object that is contaminated and then touching the mucous membranes of the mouth or nose. To stay healthy this season, cover your nose and mouth with a tissue when you cough or sneeze, then throw the tissue in the trash. WASH YOUR HANDS often with soap and water, especially after you cough or sneeze. Alcohol based hand cleansers are also effective. Avoid touching eyes, nose or mouth. To quote Mary Pappas, a New York school nurse who first identified an outbreak of the new H1N1 flu at her

See: "Flu Season" on page 2

Contents

Flu Season—Getting Ready	1
RMHBDA Board of Directors	2
Thank You Members & Donors!	2
2009 Family Camp Memories	3
September is Emergency Preparedness Month	5
Scientists at University College Target Coagulation	7
Many Thanks to Our Camp Sponsors!	8



RMHBDA Board of Directors

President

• Kevin Amende, Bozeman, MT

Vice President

• Jim Ferriter, Helena, MT

Treasurer

• Forrest Berg, Bozeman, MT

Secretary

• Lisa Maxwell, Great Falls, MT

Board Members

- Orley Arthur, Roundup, MT
- Peter Brinkley, Missoula, MT
- Monica Foster, East Helena, MT
- Chris Graham, Billings, MT
- Jermone Hugs, Pryor, MT

Thank You Members & Donors!

Many thanks to our new and renewing members, as well as donors. We appreciate you immensely! If you know anyone who may want to join RMHBDA, please use the membership form located on our web site (www.rockymountainhemophilia.org).

Donations

• Thelmar Thornson

Grants

Hemophilia Alliance

From: "Flu Season" on page 1

school, "if it's wet and it's not yours, don't touch it." Stay home if you get sick and limit your contact with others. You should stay home for 24 hours after the fever is gone (except to seek medical attention). Listen for public health advisories regarding school closures and avoiding crowds.

You should contact your health care provider for advice about getting vaccinated in your community. Although not available in the same vaccine, you can receive both the seasonal flu vaccine and the H1N1 vaccine on the same day.

There are some special precautions for persons with hemophilia or bleeding disorders.

- 1. If you or your family member are currently taking prophylaxis factor infusions, try to coordinate the prophylaxis dose on the day of receiving the vaccine.
- 2. To help prevent a muscle hemorrhage, have the health care provider use the smallest possible needle to administer the vaccine.
- 3. Apply pressure and/or coban for 5-10 minutes after the immunization.

As you prepare for severe weather and seasonal viruses season, take inventory of your medication and infusion supplies—have the necessary medication available at all times.

For up-to-date information on seasonal flu and H1N1 see: http://www.cdc.gov/h1n1flu/ and www.flu.gov.

Rocky Mountain Hemophilia & Bleeding Disorders Association Newsletter

Executive Director: Ann L. Schrader

Editor and designer: Eve Armour.

Office hours: 1:00 pm to 5 pm; Monday - Wednesday. Send comments to: Office Manager, RMHBDA, 2100 Fairway Drive, Suite 107, Bozeman, MT 59715; 406-586-4050; eve.rmhbda@gmail.com.

2009 Family Camp Memories

As you will see from the paragraphs below, Family Camp 2009 went very well and everyone had a great time. In the next few weeks, we will email a request for input on where you think the 2010 family camp should be held and what makes the camp a memorable event for you and your family.

By: Jessica Amende, 2009 Camp Committee-

Family camp 2009 was refreshing! Our family had a great weekend. Even with the monsoon nights, Luccock Park was a beautiful and restful place for this year's family camp. My kids enjoyed being outside all weekend exploring on the hike, learning through play with the Knight's Crossing, and of course eating as many s'mores as possible during campfire (while their mom was busy socializing!).

Sleeping arrangements were an adventure this year with three families in our cabin! It was cozy and invited bedtime card games to all still awake! The only bummer was the narrow beds with slick liners (two of my three kids fell out of bed more than once!).

Although our overall camper numbers were small this year, the quality and time to engage with one another was great. From a participant's perspective,



camp was wellorganized and very balanced with activity and free time. From a planning team perspective, camp was very well planned out and the team I worked with was super! I appreciated serving with others who are so reliable and fun! Thank you to Ann, Lisa M., Lisa G-F.

Naomi McNabb, youngest member of 2009 Family Camp.

and Eve for all their creativity and organizationyou rock! A big "Thank you" to all of our industry support as well! It is so great that each of you comes to camp ready to push your sleeves up and help wherever you are needed. I appreciate your warmth and willingness to jump right in. See you all next year!

By: Lisa Maxwell, 2009 Camp Director-

The forecast called for 60% chance of rain. Families and friends gathered in Paradise Valley for "The Amazing Race" Family Camp 2009 and were

See: "Camp Memories" on page 7



Participants of the 2009 RMHBDA Family Camp.



September is Emergency Preparedness Month

- Wear a medical alert bracelet or necklace.
- Place multiple ice packs in the freezer.
- Always have, in the same place, enough cash/change for parking at HTC/hospital or cab/bus/subway fare to get you to the HTC or ER.
- Always take factor and supplies with you when you leave home.
- Fill our and regularly update the NHF Readiness card for each family member with emergency contact information, important phone numbers, diagnosis, prescription information, etc. NHF Readiness cards can be requested through HANDI (800-424-2634).
- Keep important phone numbers (HTC, homecare company, physicians, insurance, ER, etc.) in multiple locations: on fridge, in wallet, on child's car seat, in school bags/work bags/go-bag, with your health care insurance papers, etc.



for additional information. Models used for illustrative purposes only.

NovoSeven[®] is a registered trademark of Novo Nordisk Health Care AG. Novo Nordisk Inc., 100 College Road West, Princeton, New Jersey 08540 U.S.A. © 2008 Novo Nordisk Inc. 136018 August 2008





- Keep as much factor and supplies on hand as your insurance will allow.
- Teach extended family and friends how to infuse, as circumstances may require others to infuse the patient.
- Keep a family manual--a reference notebook with pertinent medical information, directions on mixing and infusing factor, maps of the area for the HTC/hospital, important phone numbers, diagnosis and treatment regimens, location of back-up HTC, etc.



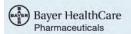
- Keep an infusion log and take it with you in case there is a need for evacuation.
- Keep a go-bag/small suitcase of factor and supplies packed at all times so it is easy to grab and go: make sure you take supplies on a regular basis in line with expiration dates.
- Program your emergency contact into your phone under "ICE" (In Case of Emergency). EMS responders now look for it in cell phones and call that number if needed.
- Program 800-424-2634 (HANDI) into your phone in case you need information on available HTCs and chapter services in areas to which you may have to evacuate.
- Contact your local emergency management office or public health department for information on sheltering-in-place and other safety procedures for your area.

RMHBDA Calendar

- September: Emergency Preparedness Month
- October 29-31: NHF Annual Meeting in San Francisco
- November 11: Board meeting Teleconference

We've expanded your playlist... Now available in a 3000 IU vial size





BAYER, the Bayer Cross, and KOGENATE are registered trademarks of Bayer. BIO-SET is a registered trademark of Biodome SAS. ©2009 Bayer HealthCare Pharmaceuticals Inc. All rights reserved Printed in USA 7/09 KN10000809



antihemophilic factor (recombinant)

with BIO-SET[®] needleless reconstitution system

6

Scientists at University College Target Coagulation

By: Pharma Business Week, August 3, 2009

"A retrospective review was carried out on the methods of obstetric analgesia/anesthesia used in 80 pregnancies amongst 63 women with inherited bleeding disorders (19 factor XI deficiency, 16 carriers of hemophilia, 15 von Willebrand disease, seven platelet function disorders, four factor VII deficiency, one factor VII and XI deficiency and one factor X deficiency). In 72 pregnancies, the woman was seen antenatally in a multidisciplinary clinic to discuss and plan pain relief options," researchers in London, the United Kingdom report (see also Coagulation).

"Regional block was performed for 41 pregnancies. The mothers were known to have a bleeding disorder in 35 of these pregnancies. Prophylactic cover was given in 10 pregnancies prior to the insertion of regional block but not required in the remaining 25 pregnancies because the coagulation defects had spontaneously normalized at term. There were six reported adverse effects from regional block similar to that found in the general population: inadequate anesthesia/analgesia (2), bloody tap (2), hypotension and a possible dural puncture which was treated conservatively. There were no reports of long-term complications," wrote C. Chi and colleagues, University College.

The researchers concluded: "The findings show that it is possible to offer women with inherited bleeding disorders the option of regional block provided their coagulation defects have normalized, either spontaneously during pregnancy or following adequate haemostatic cover."

Chi and colleagues published their study in Thrombosis and Haemostasis (Obstetric analgesia and anaesthesia in women with inherited bleeding disorders. Thrombosis and Haemostasis, 2009;101(6):1104-1111).

For additional information, contact R.A. Kadir, University College London, Dept. of Obstetrics & Gynecology, Pond St., London NW3 2QG, UK.

Publisher contact information for the journal Thrombosis and Haemostasis is: Schattauer GmbH-Verlag Medizin Naturwissenschaften, Holderlinstrasse 3, D-70174 Stuttgart, Germany.

From: "Camp Memories" on page 3

treated to perfect weather for all outdoor activities. The rains only came while we slept! This year's camp was a perfect blend of activities and family time. If you didn't hike, you could be in the bean-bag tourney; if you were a teen, the Knights Crossing kept your interest. Our family enjoyed the fire side s'mores, the astronomy lessons of today and of the past, sharing a cabin with other families, and settling the controversy of bean-bag Family Champion. Thank you to the families that came to share and reconnect. You are why we come to camp!



Participants of the 2009 RMHBDA Family Camp.

Our volunteer industry reps. are a great asset, always willing to play and help wherever needed—I could not do the Family Games without them! The camp committee team of Lisa Glass, Jessica Amende, Ann Schrader, and Eve Armour did an outstanding job. A huge "Thank you" to this creative, hard working group—you truly make the job of "director" just a title that someone has to be tagged with.



SITez TM , namszoð

