

Board Meeting Summary

RMHBDA Board of Directors held its regularly-scheduled Annual meeting on March 4, 2011 during Education Weekend in Billings MT.

The board elected Spencer Straub from Cheyenne, WY to a three year term. Current board members, Lisa Maxwell and Chris Graham, were re-elected to another three year term.

Officers were also re-elected for another one year term. For more information, go to the website at www.rockymountainhemophilia.org and click on the Board icon on the right side.

Obituary

Edwin C. Troester, Jr. of Frenchtown MT passed away on Nov. 4, 2010. He was married to Kathleen Juanita Taylor for 40 years. He is survived by his wife and their children, in Missoula: Alexander Troester, Katrina Dauven, and Barnabas Troester, McKenzie Troester; and Cassandra Moore of Seattle. He also is survived by his grandson, Joshua.

Ed enjoyed a wide variety of interests including Drag Racing. He worked as a salesman, was active in his community, and eventually received an associate degree in Theology. Memorials may be sent in Ed's name to the National Hemophilia Foundation or to the family home at P.O. Box 345, Frenchtown, MT 59834.

We send our sympathy to the Troester Family.

World Hemophilia Day

World Hemophilia Day is April 17, 2011. The first World Hemophilia Day began in 1989. April 17 was the birthday of the founder of the World Federation of Hemophilia (WFH) Frank Schnabel.

This year's theme is, "Be inspired, get involved in Treatment for All." WFH's mission is to see that all people with hemophilia and other inherited bleeding disorders have the ability to access care for the disease. They estimate that only 25% of the world's population receives appropriate treatment today.

There are many ways to celebrate this day and further educate others about bleeding disorders.

- Share your story on www.wfh.org/whd or read profiles about other people's lives.
- Play WFH's game on the same website as above called, "Journey Around the World."
- Wear red on April 17, 2011!

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ORGANIZATION INFORMATION

Membership 2011

Renewed Membership

Kevin and Jessica Amende
Barbara Arnold
Anne Arthur
Brad and Susan Benne
Forrest and Christy Berg
Kim Birkett and Jerome Hugs
Ruth Cahill
Jim Ferriter and Lisa Glass
Sharon Ferriter
Ken and Monica Foster
Brian and Marie Frame
Donald and Beryle Fromm
Chris and Jana Graham
Kristal Graham and John Keim
Amanda and Todd Hamper
David Cohenour and Heidi Hart
Bob and Mary Hunter
Chris and Dawn Hunter
Rick and Tanya Lasko
Mary Majerus
Lisa and Scott Maxwell
Sally McEldery
Jane and Brian Robertson
Ann Schrader
Ed and Ellen Sparks
Leroy and Andrea Stafford
Thelmar and Margaret Thorson

New Members

Sara and Josh Prindle
Aaron and Kelly Robertson
Jake and Erin Robertson
Christy and Van Savage
Spencer and Kaylee Straub

RMHBDA 2011 Calendar of Events

- Apr. 17, 2011: World Hemophilia Day
- Jun. 20-22, 2011: MSRHTC Billings Satellite Clinic
- June 24-26, 2011: Annual Family Camp, Livingston MT KOA Campground
- July 17-22, 2011: MSRHTC Camp

RMHBDA Board of Directors

President

Jim Ferriter, Helena, MT

Vice President

Lisa Maxwell, Great Falls, MT

Treasurer

Forrest Berg, Bozeman, MT

Secretary

Chris Graham, Billings, MT

Board Members

Kevin Amende, Bozeman MT
Kyrsten Brinkley, Missoula, MT
Brian Frame, Powell, WY
Jerome Hugs, Pryor, MT
Spencer Straub, Cheyenne WY

Rocky Mountain Hemophilia and Bleeding Disorders Association

RMHBDA

2100 Fairway Drive, #107, Bozeman MT 59715

Office and Fax: 406-586-4050

www.rockymountainhemophilia.org

Executive Director: Ann L. Schrader

ann.rmhbda@gmail.com

Cell: 406-579-3754

RMHBDA PROGRAMS

Women's Retreat a Huge Success!

RMHBDA hosted a women's retreat on January 21-23, 2011 at Chico Hot Springs Resort. 11 women affected by bleeding disorders from Montana and Wyoming attended.

The Retreat was sponsored by CSL Behring and the Dennis and Phyllis Washington Foundation.

Speakers included Suzanne R. Swietnicki, M.D. from Northern Montana Medical Group. She is an OB/GYN who specializes in women's bleeding disorders; Ashley Olsen, LCSW, of Praxis Healthcare, who focuses her practice on the combination of mental health and chronic disease; and Susan Blackwell Tate, RYT, whose business, Raising The Lantern, teaches stress reduction techniques using the Integrative Restoration model. Tamara Calhoon, massage therapist, provided massages to the attendees.

Education Weekend in Billings

RMHBDA Education Weekend was held on March 4-6, 2011 in Billings MT. 22 families attended with 43 adults and 43 youth. Families received registration packets that included their Membership Directory, MASAC Recommendations on using Emergency Identification Devices for Children; an order form for Medical ID jewelry; new RMHBDA Quick Facts Sheets and an organization brochure.

The overarching theme of Education Weekend was Physical Fitness and Nutrition. Families ate nutritious finger food for dinner while introducing themselves to the rest of the families. We enjoyed Native American Crow dancing, drumming and singing; skits, songs, dances, and lots of fun learning about one another.

Adults and teens received an update from Bridget M. Raleigh, APN, MSN, Clinical Manager of the Mountain States Regional Hemophilia and Thrombosis Center in Denver. She explained about the Center's move to The Children's Hospital of Denver and payment changes. Afterward, all people interested in learning to infuse, observing, or infusing as role models learned from Bridget about the basics of infusion and then practiced it.

Meanwhile, the older youth participated in a scavenger hunt and spoke to each exhibitor and learned one thing about their company or product. When they finished, the adults had the opportunity to speak with the pharmaceutical and home health care reps.

Our program funders included: Bozeman Area Community Foundation, Accredo Health, Inc., Bayer HealthCare, Baxter, CSL Behring, CVS Caremark, Grifols, HF Healthcare, Matrix Health, Novo Nordisk, Octapharma, Pfizer, Restore RX.

Adults and youth had the opportunity to hear a presentation from Heidi Lane, PT from Utah. She

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Plasma Derived Product Safety

by Ann L. Schrader

Blood product safety is an ongoing concern. While it is estimated that 70-75% of U.S. citizens use recombinant products to treat their hemophilia, medical professionals and patients are taking a second look at using plasma derived products. (People with von Willebrand Disease have only one choice – plasma derived products.)

Theories and studies in progress are discovering that people with Hemophilia A, using a recombinant factor product, with inhibitors, and failing at desensitization after high use of factor, may decrease their inhibitor levels and become tolerized when using a plasma derived product. It is estimated that 20-30% of people with inhibitors fail with their recombinant factor. Plasma derived products are also less expensive. For these reasons, some patients choose to use Plasma derived products, and for their peace of mind, it is important to ensure blood product safety.

Most of us are aware of the terrible tragedy people experienced after becoming infected by HIV and Hepatitis C, viruses that were transmitted through plasma derived products and transfusions. Recombinant factor products, not derived from plasma, and industry safety practices put into place after this tragedy, have vastly improved blood safety and alleviated most risks. However, the NHF Medical and Scientific Advisory Council (MASAC) continues to recommend using recombinant clotting factor concentrates.

With other hemophilia and bleeding disorder chapter leaders, I recently visited the

Grifols U.S.A. Los Angeles facility. We received presentations about what Grifols does to keep their plasma derived products safe from pathogens. We also got to tour a plasma collection center and the current and future manufacturing facility.

As a person who contracted HCV through a blood transfusion, blood safety is a huge concern for me. I felt reassured that Grifols, as well as the rest of the industry that follows approved practices, including viral inactivation, Qualified Donor Standards-close screening and monitoring donors' health, testing products for pathogen, limiting plasma pools to 60,000 units, holding donated plasma for 60 days, and performing new and more sensitive viral blood tests, are providing state of the art blood safety.

As always, speak with your doctor before changing factor products and discuss with your hematologist all risk factors to assist you in making the best choice for you or your loved one.

The RMHBDA office has several dvd's available about safety and manufacturing. Please contact us at 406-586-4050 for more information.

New MSRHTC Contact Information

Opening Day is April 12, 2011

13199 Montview Blvd.,
Suite 100

Aurora CO 80045

Phone: 303-724-0724

Fax: 303-724-0947

Education Weekend Summary

cont'd from page 3
spoke about the importance of appropriate physical exercise to build muscles and strong joints to help prevent bleeds and quicken recovery time. As part of her presentation she had the audience-work with stretch bands and gave pedometers to encourage movement!

While the adults heard more about the importance of state advocacy and got an update on federal health care reform from Kim Eisenberg, youth went to the Zoo or Geysers Park in the afternoon to have some fun and put into practice the idea of physical fitness. Some saw tigers and bears, while others played laser tag. Of course, swimming at the Reef ended the afternoon for all.

In the evening, we enjoyed another nutritious meal, watched a video from Senator Tester, and drew the names of our raffle winners.

As always, it takes all of us to have a successful event. Thanks to all the parents who took turns watching children, helping with craft activities, chaperoning youth at the Zoo or Geysers Park, or bringing snacks, toys and games to share. Special thanks to Heidi Hart, Dawn Hunter, Hunter Hart, Spencer Straub and Sean Jeffrey for serving on the Education Weekend planning committee and for Jana Graham and Kristal Graham's babysitters!

Education Weekend adult participants were surveyed before the weekend began. Your response is critical because it helps guide decision-making about future topics, speakers, activities and locations.

If you haven't responded to the Survey Monkey Post-Evaluation, please email or call Ann at the office and she will send you the link.

Donations

Barbara Arnold in honor of Nick Foster

Chris and Jana Graham

Mary Majerus

Sally McEldery in memory of Richard McEldery and in honor of Travis Parks and Cory Paulton

Ed and Lois Regan in honor of Nick Foster

Thelmar and Margaret Thorsen in honor of Jericho Hugs

Michael Palmer and Doug Warner

Education Weekend Raffle Winners

Sharon Ferriter...Ellen Sparks...Kevin Amende.....and-Samantha Robertson! Congratulations!

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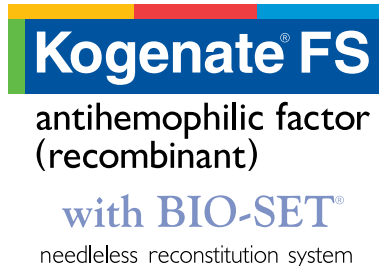
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Living a Vibrant Life

Jane Robertson, Master Herbalist and chapter member, gave an enlightening presentation to participants at our recent Education Weekend. Jane focused on the ability of people with bleeding disorders to build strong blood, blood vessels, bones and joints to help our bodies prevent or heal more quickly from a bleed. Anyone can improve their nutrition, intake of foods, herbs and vitamins, to improve their blood health.

Jane stressed the importance of making a good choice, saying, “that food you eat is either going to help or hurt you, black or white choices.”

Bad food choices that weaken our body's blood vessels and leach out calcium, include sugar, pastries, candy, salt, white bread, soda pop, tobacco, caffeine and alcohol, as well as food products that are made from chemicals.

Good food choices include those:

- Rich in flavonoids – plant products that are orange, yellow, red, and dark green
- High in Vitamin E, K and C, L Arganine, Alpha-Lipolic Acid, Folic Acid, Iron, Vitamin B6 and B 12
- High in Calcium and Magnesium

Apples – especially Winesap
Calf liver
Brewers Yeast
Bilberries, blackberries, cherries
Celery
Black Strap Molasses
Dried fruits, apricots, raisins
Turnip greens

Shell Fish
Dark green leafy vegetables
Dark chocolate
Bok Choy
Cabbage
Brussel Sprouts
Carrot Juice
Kale

Good herbal choices include:

Horsechestnut
Grape seed extract
Comfrey
Basil
Stinging nettles
Yellow Dock Combination
Horsetail
Calc-Tea

Pinebark extract
Hawthorne berries
Dill
Cayenne
Shepherd's purse
Hemaplex
Dr. Christopher's Herbal Calcium
Vitalerbs Herbal Calcium

EDUCATION WEEKEND PICTURES

by Jana Graham

Amende Brothers!



New family members: Sara, Carol, Robert Jestrab



Hugs Family Members Introduce Themselves



Robertson Family from Rigby, Idaho Introduce Themselves



Bridget Raleigh, R.N. from MSRHTC Helps Chris and Campbell Hunter Master Infusion Skills Photo taken by Dawn Hunter

CSL Behring



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I'm Unique. Like Everyone Else.

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2. Share the form with your doctor and discuss whether Helixate FS is right for you or your child.
3. Ask your doctor to complete the form and send it in for processing.

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You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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RMHBDA
2100 Fairway Dr.,
#107
Bozeman MT 59715