

Board Meeting Summary

The Board met on Dec. 5, 2011. As Jim Ferriter's job has prevented him from fulfilling his duties, Lisa Maxwell was approved as the Acting President.

The proposed budget was reviewed and approved. The contracts for Education Weekend and Family Camp were also approved. The NHF 3 Year Charter agreement was reviewed and approved with minor changes.

The Executive Director advised the board of her resignation. A hiring committee was formed to include Kevin Amende, Forrest Berg and Lisa Maxwell. Ann assured the board she is committed to assisting in hiring and training, as they desire. Her last day will be in mid-January.

For more information, go to the web site at www.rockymountainhemophilia.org and click on the Board icon on the right side.

What a Great Ride!

Dear Friends,

The time has come for me to say goodbye. My last day will be around the middle of January. I will be sure to finish as many arrangements as possible for the upcoming year before I leave.

I have thoroughly enjoyed getting to know all of you and will miss our interactions.

I have decided to leave because my consulting business is growing and I need to devote more time to fostering it.

With my best wishes for a very Happy Holiday Season!

We Love Donations!

RMHBDA is a 501 (c)(3) nonprofit organization. Contributions are tax deductible.

We would appreciate you considering the chapter in your year end giving.

An envelope is enclosed for your convenience!

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“The mission of Rocky Mountain Hemophilia and Bleeding Disorders Association is to improve the quality of care and life for persons with inherited bleeding disorders, including hemophilia and von Willebrand Disease through education, peer support, resources and referral. ”

Please let us know how we are doing...see our contact information below....

RMHBDA Board of Directors

President

Jim Ferriter, Helena, MT

Acting 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
Jermone Hugs, Pryor, MT
Spencer Straub, WY

RMHBDA 2012

Calendar of Events

- January 16, 2012 - Board meeting via teleconference, 7-9 p.m.
- Jan. 27-29, 2012 - NACCHO Tempe.
- February 6, 2012 - Board meeting via teleconference, 7-9 p.m.
- March 2-4, 2012 - Education Weekend, Billings, Big Horn Resort Hotel.
- Mar. 7-9, 2012 - NHF Washington Days
- Apr. 12-14, 2012 HTC Regional meeting in Colorado Springs, CO.
- May 21-23, 2012 NHF Regional Conf.
- June 22-24, 2012 - Family Camp, Bear Lodge Resort, WY
- September 15, 2012 - Fundraising Walk, Billings, Zoo Montana

Did you know that...

Our new brochure won an award from the 2011 American Graphic Design Awards competition (AGDA)!

The 2011 awards event attracted a remarkable 8,000+ entries; a very select 15 percent were recognized with an Awards Certificate of Excellence!

Fifth Street Design developed the brochure.

RMHBDA
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www.rockymountainhemophilia.org
Tax ID # 81-0533720

Insurance, Home Therapy, and Prophylaxis in U.S. Youth with Severe Hemophilia

by: Judith R. Baker, MHSA, Brenda Riske, MS, MBA, MPA, Mariam Voutsis, RN, MPA, Susan Cutter, MSW, MPA, Rodney Presley, PhD

(Note: The Denver HTC's Brenda Riske is a co-author of a study that is summarized below.)

Background: Home infusion therapy, particularly on a prophylactic regimen, is linked with reduced morbidity among youth with severe hemophilia. However, the association of insurance coverage with these home therapies is unknown.

Purpose: This study explores the connections among insurance, home infusion therapy, and prophylaxis treatment in a nationwide cohort of 3380 boys and young men (aged 2 to 20 years) with severe hemophilia. These youth obtained care at one of 129 federally supported hemophilia treatment centers (HTCs), and enrolled in the CDC's bleeding disorder surveillance project.

Methods: Multiple regression was used to analyze the independent association among risk factors, including insurance, and both home infusion and prophylaxis. Data were obtained between January 1, 2008, and December 31, 2010, and analyzed in 2011.

Results: Ninety percent used home therapy and 78% a prophylaxis regimen. Only 2% were uninsured. Health insurance was significantly associated with prophylaxis, but not with home therapy. Lower prophylaxis utilization rates were independently associated with having Medicaid, "other," and no insurance as compared to having private insurance. Race, age, inhibitor status, and HTC utilization were also independently associated with both home therapy and prophylaxis.

Conclusions: Youth with severe hemophilia who annually obtain care within the U.S. HTC network had a high level of health insurance, home therapy, and prophylaxis. Exploration of factors associated with insurance coverage and yearly HTC utilization, and interventions to optimize home infusion and prophylaxis among youth of African-American and "other" race/ethnic backgrounds are warranted.

(Am J Prev Med 2011;41(6S4):S338 –S345) © 2011 American Journal of Preventive Medicine

Member Profile

by Susan Benne

My husband, Brad and I have grown through hemophilia and in many respects it has shaped our personal and professional journey. Growing up, my father had hemophilia. He was not diagnosed until he was in his twenties, married, and with children.

If I'm fortunate to get him to talk about growing up with hemophilia the stories usually end in him expressing his pain. Raised a Christian Scientist, he was always made to feel like it was his fault. When a first cousin died of AIDS this pain continued. Thankfully, he missed that bullet but does have hepatitis.

Thus, when my sister's first son was born and diagnosed with hemophilia our learning continued. It changed the course of Brad and my life together when we tried to join the Peace Corps. That vision was shattered when I could not pass medical clearance. The hang up being that I was a symptomatic carrier.

At 26, young in love and ready to change the world this was not easy for either of us. Now we both reflect gratefully on this because John was born within the year. We knew when they told us we had a beautiful baby boy that he would have to be tested. Oddly enough, we had no idea about cord blood and we took John to be tested when he was a week old. Given the deep pain in my family, Brad and I hesitated in communicating the positive results.

Through John's hemophilia, Brad was incredible about helping me overcome my family's history. He sought resources, education, and a treatment center. All of which I am eternally grateful for because it led us to RMHBA, as well as empowering us to make good decisions for John and Will's care. John had his first bleed before his second birthday when we were new to Bozeman. Regrettably we went to the ER for treatment.

Thankfully, a kind pharmacist facilitated an introduction to the Bergs. This was the first step in helping me speak openly about hemophilia and understanding that you need support. Later that year Will was born, also with hemophilia. As we continue to learn and understand. Both Brad and I are thankful for the knowledge, understanding, and community we have found through RMHBDA.

NHF Annual Meeting

Sara Jestrab attended her first NHF Annual meeting as a newly selected member of the National Youth Leadership Institute (NYLI). The Institute's purpose is to get young adults involved in advocacy for bleeding disorder issues and training the members in leadership skills. Sara's term is for 3 years. (RMHBDA chapter also has another member of the NYLI - Sean Jeffrey!)

Sara said there were about 30 representatives at the meeting. They had a lot of fun doing scavenger hunts with pharmaceutical representatives. They also divided into 2 teams and had 3 hours and a \$50 budget to choreograph a Flash Mob. Their group was dropped off at a park and had to convince people they weren't with the "Occupy Wallstreet" demonstrators!

NYLI participants have a 3 year term. They are required to attend 4 events each year. Their next meeting will be in March when they attend Washington Days in D.C.

(Below Sara Jestrab is in the right foreground and Sean Jeffrey is second from the right in the back)



NHF Annual Meeting continued

Board member **Spencer Straub** attended the Annual Meeting in Chicago as a representative of RMHBDA. Spencer relayed that he had lots of fun meeting people from all over the United States. He especially enjoyed the keynote speaker who was "hilarious!"

Spencer got around to meet some pharmaceutical reps and had many interesting conversations with other attendees. He was shocked to learn that some chapters struggle with membership participation at events due to geographical distance - like 200 miles. He informed them that he drove over 600 miles to get to our events!

Spencer's take aways were the importance of having a variety of perspective on the board - young to old, with or without a bleeding disorder.

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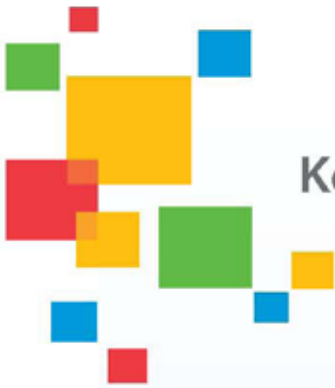
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and a
Happy and
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