



**Board Action Summary**

RMHBDA Board of Directors held its regularly scheduled meeting on June 26, 2010 at Fairmont Hot Springs. The following decisions were reached:

RMHBDA will assist NHF in raising funds for research for the Judith Graham Pool Post Doctorate Fellowship. Members will be asked to contribute and the organization will match up to \$500.

The board is considering changing the format of the newsletter to electronic, with a few hard copies sent to interested people who are unable to use or access the Internet. Jessica Amende agreed to research this issue further. Let us hear your thoughts at 406-586-4050.

An initial discussion about adopting an industry representative policy took place. The board will review the policy template received from Dawn Rotellini and discuss at the next meeting.

It was agreed that our next Education Weekend will take place at the Wingate in Billings on March 4-6, 2011. It was further decided that Family Camp will take place at the Livingston/Paradise Valley KOA on June 24-26, 2011.

The board is in conversation about a fundraising event. Due to large geographic distances, we are looking for an event that could be replicated in each member's hometown. Let the office know if you have a good idea!

The next board meeting will take place via teleconference on Monday, August 9, 2010 at 7 pm.

For more information, go to the website at [www.rockymountainhemophilia.org](http://www.rockymountainhemophilia.org) and click on the Board icon on the right side.



**Board meeting at Fairmont on 6/26/2010**

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## 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
- Orley Arthur, Roundup, MT
- Kyrsten Brinkley, Missoula, MT
- Brian Frame, Powell, WY
- Jermone Hugs, Pryor, MT

## Thank You To All Family Camp Supporters & Volunteers

Accredo-Jean McFarlene

Baxter BioScience-Steve Kimball

Bayer Healthcare-Steve Petty

CSL Behring-Kent Pointer

Grifols-Suzanne Hocker

Mountain States Hemophilia and Thrombosis Center-Dr. Marilyn Manco Johnson

Pfizer-Lynn Barker

Walgreens Optioncare-Dan Bloch

## New Members and Donors

### New and Renewed Membership for April-June 2010

Kyrsten and Peter Brinkley

Julie McNabb

Dawn Rotellini

### Donations:

Peter and Kyrsten Brinkley

Marilyn Manco-Johnson, M.D.

Lisa and Scott Maxwell

### Grants:

CSL Behring LEAD Grant for Advocacy Program Development

Hemophilia Alliance for New Brochure Design and Printing

### Rocky Mountain Hemophilia & Bleeding Disorders Association Newsletter

Executive Director: Ann L. Schrader

### RMHBDA

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## Big Stick Awards

Avery Amende and Coy Cohenour were given the “Big Stick Award” at Family Camp 2010. In order to earn this award, they were able to:

- 1). Identify his/her bleeding disorder and know basic facts about their disorder.
- 2). Recognize a bleed or situation that could result in a bleed.
- 3). Be able to take the initiative for treating his/her bleeding disorder.

Coy was nominated by his brother, Hunter, and Avery was nominated by her mother, Jessica.

Lisa Maxwell presented the awards, and was assisted in building and decorating the sticks by her father, Don Fromm. Many thanks to both of them!

The award is given yearly at Family Camp. If you know someone who deserve this recognition, go to the website at [www.rockymountainhemophilia.org](http://www.rockymountainhemophilia.org), click on the Resource page, complete the application and mail it in to the office by next June 1, 2011.



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## Blood Safety Today

by Ann L. Schrader

As reported in a recent article published by the San Francisco Chronicle: “patient safety is (our) most important concern, said Val Bias, chief executive officer of the National Hemophilia Foundation. He said currently the U.S. blood supply is the safest it’s ever been.” Bias went on to say that, “Our philosophy has been what’s called the precautionary principle, meaning that if you can’t prove there’s a real benefit to changing our current blood safety policy, then don’t do it,” Bias said. “The people who bear the responsibility at the end of the day aren’t necessarily the decision makers but the end users.”

Blood safety issues arose in the 1970s and 80’s, when our community, as well as many others who received blood transfusions, suffered grave illnesses and enormous losses due to the transmission of HIV and Hepatitis C in blood plasma products. The good news is that no HIV has reported to have been transmitted via factor products since 1986, and Hepatitis C Since 1987.

The community and manufacturers addressed the safety of the products in several ways including:

- Producing recombinant products that don’t directly use animal proteins in the manufacturing process, such as Kogenate FS by Bayer. Significantly increasing the blood plasma collection, manufacturing, and purification process standards to inactivate or partition model and/or infectious viruses, including holding collected plasma for 60 days to assure no viruses are present, such as the CSL Behring (Humate®) or Grifols’ process. To watch a brief video on plasma safety, view it at [www.grifolsusa.com](http://www.grifolsusa.com).
- Use of standards from the FDA and industry standards from the International Quality Plasma Program (IQPP). This is a set of industry standards different from FDA requirements that additional layers of product safety. Some of the standards included in IQPP are:

1. Only plasma from repeat or “qualified” donors is accepted – plasma from someone who

donates only once is never used.

2. Every donation must be held in inventory for a minimum of 60 days so if the donor is disqualified, prior donations can be destroyed.
3. Every donation must be tested using special DNA techniques called nucleic acid testing (NAT), for HIV, hepatitis B virus (HBV), and hepatitis C virus (HCV).
4. Every donor center must meet strict criteria for the health and safety of the types of people they attract as donors.

The concerns that challenge us today include inhibitors; and blood safety protection from new and evolving viruses such as Xenotropic Murine Leukemia virus (XMRV) that is possibly related to chronic fatigue syndrome; West Nile and Parvovirus B19 and Creutzfeldt-Jakob Disease (CJD) and variants of CJD called VCJD. To read the complete text of the April 2010 CDC article “Assessing Emerging Infectious Threats to Blood Safety for the Blood Disorders Community,” published in the April 2010 issue of the *American Journal of Preventive Medicine*, go to [www.ajpm-online.net/article/PIIS0749379709009489/fulltext](http://www.ajpm-online.net/article/PIIS0749379709009489/fulltext)

As end users of factor, we are responsible to be educated about blood safety. We need to hold blood collection centers to the highest level of safety and communicate any concerns to manufacturers. In May 2010, the FDA announced revised VCJD Industry Guidelines. This document incorporates donor deferral recommendations for donors who have received a transfusion of blood or blood components in France since 1980, providing updated scientific information on CJD and vCJD and revising labeling recommendations for whole blood and blood components intended for transfusion, and approving a questionnaire to be used to screen plasma donors. For more information, go to “Guidance for Industry: Revised Preventive Measures to Reduce the Possible Risk of Transmission of Creutzfeldt-Jakob Disease (CJD) and Variant Creutzfeldt-Jakob Disease (vCJD) by Blood and Blood Products”. At [www.fda.gov/BiologicsBloodVaccines/GuidanceComplianceRegulatoryInformation/Guidances/Blood/ucm074089.htm](http://www.fda.gov/BiologicsBloodVaccines/GuidanceComplianceRegulatoryInformation/Guidances/Blood/ucm074089.htm)



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## Member Profile

by Christy Berg

At least 15 years ago, I was so happy to hear that there was a “Hemophilia Group” in Bozeman. My Daddy had died in 1980 from the complications of Hemophilia and probable Aids. It saved my loss to identify personally with a group dedicated to helping those with “his” disorder.

Six years ago, I became a “Grammy” for the first time. Soon my elation turned to heartbreak, grief, fear, and even guilt. We hoped against hope that precious Campbell would “dodge this bullet”, but it wasn’t meant to be. I shall never forget the call at my office of my daughter asking me to come home. The Dr.’s office had called with the diagnosis of **Factor 8 Hemophilia (moderate)**. Suddenly, I wanted **no** part of the “Group” I was once so glad to find!

My husband, Forrest’s, approach was to become very active in the RMHBDA. However, it has taken me six years to be able to attend most of the annual Education Day or to talk about his infusions without crying. To all of you Grandmas, Grandpas, Moms, Dads, or the rest of your family who feel you don’t identify with those who seem so brave and accepting of this disorder, you may not be that different. Everybody’s **journey** is different, everybody’s **perception** is different, and everybody’s **reaction** is different. As in all “grief” experiences, there is **no right or wrong way** to feel.

In retrospect, I surely see the tremendous benefits our entire family has gained from our various degrees of participation in RMHBDA. Campbell has gained the courage to be compliant when infused when he saw other children infuse. It has helped his Mom and Dad to have the camaraderie and support of other parents. We all have learned so much from the information presented at Education Days and by sharing the experiences of other families.

Becoming a Grammy is always a “work in progress”. It has been a learning experience for Forrest and I to know when and how to react to injuries, how to emotionally and physically support both Dawn and Chris (his parents), to just listen, to respect their choices in caring for Campbell, and to share Daddy’s experiences and how they do or do not relate to today. A parent today has many more decisions to make and so much to learn. I saw Daddy living with the disease, unaware of the **internal** damage to his body. Although the hemophiliac of today has complex challenges, the **quality** of his life is **dramatically** improved.

To the family of newly diagnosed hemophiliacs, you are not alone. The “family” of RMHBDA is here to help. We are happy to share our experiences, **stumbles and all**. Please feel free to call on us. Remember **your experiences help us!**

### RMHBDA Calendar

Montana Comprehensive Health Association Board Meeting-Kalispell, August 11-12, 2010

Montana Public Health Association Conference-Helena, September 13-15, 2010

Caspar Women’s Expo, October 1-2, 2010

Billings Women’s Expo-October 29-30, 2010

Bozeman Health Fair, November 13, 2010, Bozeman Holiday Inn, 10 am-5 pm

NHF National Conference- November 11-13, 2010 – New Orleans

Womens’ Retreat, TBD

Education Weekend – March 4-6 2011 – Billings Wingate/Reef

Family Camp – June 24-26, 2011 – Livingston/Paradise Valley KOA