



## Board Meeting Summary

RMHBDA Board of Directors held its regularly scheduled meeting on Oct. 4, 2010.

The board discussed the election of officers for the National Hemophilia Foundation, selected a template for an Executive Director personnel review, voted to award Patient Assistance funding support to help a family with travel expenses to medical care, and acknowledged that Brian Frame, board member, will be representing the chapter at the upcoming NHF Annual Conference in New Orleans.

The next board meeting will take place via teleconference on Monday, Dec. 6, 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.

## Happy Thanksgiving

Recently a mother shared with me how much she loved her young children, and would never change a thing, even the severe bleeding disorder both her sons have. She was grateful for all of her children, and passed on to me how she keeps a positive outlook on her life - by focusing on each moment in her day and not getting ahead of herself with worry or fear.

I am so grateful for this mother's wisdom, and for the world view my parents gave to me - being thankful for what has been given to me, and when I have been challenged, to choose to make lemonade out of lemons! (or was that pumpkins into pumpkin pie?)

Happy Thanksgiving to all of you and may you be filled with gratitude and hope every day of your life!

*Ann L. Schrader*, Executive Director

### You've Got Mail!!!

#### Spring 2011 Newsletter to Arrive by Email?

Beginning with the Spring 2011 newsletter, you can receive your copy through email. We have decided to offer this electronic method to decrease expenses and reduce paper usage.

*We will still print newsletters upon request.*

So here's your chance! Please complete the form on top of page 2 and return it to the office by December 1, 2010 so we know how to deliver your future issues!

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## Newsletter Delivery Preference

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Cut this square out and mail it to RMHBDA - see address info below!

### 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

### RMHBDA 2010-2011 Calendar of Events

- Nov. 11-13 - NHF Annual Meeting, New Orleans
- Nov. 13: Bozeman Health Fair 10-5 pm
- Dec. 6: Board meeting teleconference 7-9 pm
- Jan. 3, 2011: Board meeting teleconference 7-9 pm
- Jan. 21-23, 2011: Women's Retreat, Chico Hotsprings
- Jan. 28-30, 2011: NACCHO, Arizona Chapter
- Feb. 16-18, 2011: NHF Washington Days
- Mar. 4-6, 2011: Education Weekend, Billings
- Mar. 17-19, 2011: Bi-Regional HTC Meeting, Portland
- Jun. 20-22, 2011: MSRHTC Billings Satellite Clinic
- June 25-27, 2011: Annual Family Camp, Livingston MT KOA Campground
- July 17-22, 2011: MSRHTC Camp

### Big Thank You to our Donors this Quarter!

**Dennis and Phyllis Washington  
Foundation**

**National Hemophilia  
Foundation**

### Rocky Mountain Hemophilia and Bleeding Disorders Association

Executive Director: Ann L. Schrader

RMHBDA

2100 Fairway Drive, #107, Bozeman MT 59718

Office and Fax: 406-586-4050

Cell: 406-579-3754

[ann.rmhbda@gmail.com](mailto:ann.rmhbda@gmail.com)

[www.rockymountainhemophilia.org](http://www.rockymountainhemophilia.org)

## **Mile High Greetings from Mountain States Regional Hemophilia and Thrombosis Center (HTC)**

*by Bridget Raleigh, ANF, Clinical Nurse Manager*

The summer of 2010 seemed to disappear. June Outreach clinics in Missoula and Billings were successful. Staff always enjoy the time they get to share with patients in those areas. We look forward to seeing patients again next year. Our 2011 Billings' Outreach clinic is tentatively scheduled for June 20th-22<sup>nd</sup>. Dates for Missoula 2011 are pending.

This summer our team welcomed Michael Wang, MD as clinical director of our center. Due to the growth of our program, his help and expertise has been a wonderful addition! Dr. Wang is also a staff physician at the Center for Cancer & Blood Disorders at The Children's Hospital and Assistant Professor, of Pediatrics at the University of Colorado Denver. He is board certified in Pediatrics and Pediatric Hematology-Oncology.

In 2011 the HTC will be relocating to a brand new space on the perimeter of the University of Colorado campus. We have outgrown our current space and are excited to have a new location near our current location. Tentative move in date is March 1<sup>st</sup>, 2011. Stay tuned for more details.

Our website has also moved to a new address <http://medschool.ucdenver.edu/htc> The website contains helpful contact information, resources and educational information. It is always a work in progress.

Easter Seals Camp 2011 for our pediatric patients will be held the week of July 17<sup>th</sup>—22<sup>nd</sup>. Mark your calendars!

### ***HTC Staff pictured below:***

**Front row:** Left to Right: Nancy Spomer, RN; Ray Wilson, volunteer; Pat Casias, Admin.Asst.

**Back row:** Djuana Dubois, Admin. Asst; Bridget Raleigh, ANP/Nurse Mgr; Mike Wang, MD/Ctr. Dir.; Cricket Fortarel, Admin. Asst.; Erin Stang, Social Worker.



## Member Profile: von Willebrand and Me

by Jane Robertson

The mind of a child is an extraordinary thing and mine was no different. I knew I was one of the luckiest on earth as I roamed freely the river-bottoms and marshes of our homestead on Hart Mountain. Being raised on a farm allowed me to be intimately acquainted with hard work, in the fields and in the gardens. I learned about life caring for sheep, chickens, cows and horses. My love for this life style still remains and I count myself blessed that I still can enjoy my passions of strong family life, horses and gardening.

As I look back on those years I realize that the relentless bloody noses and continuous bruising were “normal” for me. My school teachers and friends just referred to me as a “bleeder”. I missed many days of school, many activities, ball games and dances because of very untimely bloody noses. I spent many days in the hospital with my nose packed as the medical profession tried to help me. I did not however let this keep me from enjoying life to fullest.

I was in softball, basketball and volleyball. Each game being played with a prayer that I would not get a bloody nose because that meant I was out for the count. I sang in many choirs and there again always the fear that I would not be able to perform because of bloody noses or uncontrolled menstrual bleeding.

As I came into adulthood I was still unaware that I had a disorder. I was extremely blessed to have six children. With each birth came a grave concern about how much I would bleed and could it be stopped. After Christy (my youngest) was born the doctor explained that I would either bleed to death or I must have a hysterectomy as he done all he could. This truth was obvious even to me. I had the surgery done which proved to nearly be my demise. I had internal bleeding which they were unable to control. I had a reaction to the blood transfusions and they had to be stopped. I was left in the hand of God. Those days were grim as I had six small children at home. Eventually the bleeding stopped but it took me months to recover my strength.

It was not until I was sitting in a doctor’s office ten years later with Christy that I first heard of Von Willebrands disease. I was waiting to take Christy in for her pre-op checkup for a tonsillectomy. As I waited, I glanced through the ‘Better Homes and Gardens’ magazine. They had an article on ‘The Ten Most Misdiagnosed Diseases in Amer-

ica’ that I was reading. When I came to Von Willebrands, and they listed the symptoms, I realized I had them **all** and so did Christy. I took the magazine into the Doctor, put it open on his desk and said, pointing to the article, “This is me, this is Christy, this is Marie”.

He replied, “I doubt it, but, if you would like we could have a bleeding time test done.” I agreed and proceeded immediately with the test. I got a call later that day saying we certainly had something and we were referred to the Billings specialists. The rest is history. I am certain that article saved our family from disaster.

Our journey, knowing we have Von Willebrands has been very different. We still have had some brushes with death. Our guard is constantly up. We continue however to do those things we enjoy. Marie and Christy still ride and train horses. We all ride horses, camp, play sports etc, but we prepare ourselves better and take more precautions.

Being a Master Herbalist has given me many insights as to how to make the risks less. We take this knowledge serious and do all we can to keep the advantage of good health. Education days have helped us immensely as we learn how to help ourselves and make use of what is available to those with this disease.



Jane Robertson with her horse, JJ

# The Universal Data Collection System: How I Play an Important Role

by Brenda Riske

As all persons attending hemophilia clinic know, you are invited each year to participate in a clinical study on hemophilia that was first started in 1998. Most of you routinely agree to participate but you may wonder what you get out of your participation. This study was originally designed and coordinated by the Centers for Disease Control and Prevention (CDC) in conjunction with the more than 140 hemophilia centers around the country. We have collected information on all persons (who agree) with hemophilia. This gives the US the largest database worldwide of information about persons with hemophilia. There are groups of people from the CDC and at HTC's that are looking at and analyzing these data and there have been a number of papers written about the results.

One paper was written on the high school completion rates among men with hemophilia (Drake JH, Soucie JM, Cutter SC, Forsberg AD, Baker JR, Riske B. High school completion rates among men with hemophilia. *Am J Prev Med.* 2010 Apr;38(4 Suppl):S489-94.) The benefits of a high school diploma are well documented. This study showed that men with factor VIII deficient hemophilia had a higher or similar high school graduation rate across all racial and ethnic groups and across all levels of severity compared with the US population of men of the same age.

Another paper (approved for publication) detailed the impact of insurance on hemophilia home therapy and prophylaxis in children from age 2 to 20 years. The results showed that 91% of the persons with severe hemophilia used home therapy and 71% were on prophylaxis. Health insurance was associated with higher rates of prophylaxis (as expected) but not significantly with home therapy. The study results demonstrate that youth with severe hemophilia who are seen at HTC's and, and who are enrolled in the UDC surveillance project, had high rates of health insurance, home therapy, and prophylaxis. The type of insurance did not affect the rates of home therapy or prophylaxis.

The third paper to be reviewed here included data from the non-identified information that is collected annually by each HTC and reported to the CDC and HRSA (both federal agencies that provide some funding to the HTC's). This paper looked at the trend of patients served by all the HTC's in the US between 1990 and 2008. Between 1990 and 2008, the HTC population experienced growth and change.



*Brenda Riske, MS, MBA, MPA works at the MSRHTC in many capacities.*

While the general U.S. population grew 24%, the HTC population grew 80% from 17,177 to 30,912. Specifically, the HTC hemophilia population with FVIII deficiency grew by 29% from 9,805 in 1990 to 12,667 in 2008. During that same time frame, the HTC hemophilia population with FIX deficiency grew by 58% from 2,531 to 4,000. HTC patients with VWD grew by 135% from 5,326 in 1996 to 12,524 in 2008; they now nearly equal the HTC FVIII population.

Numerous other papers have been published or are in the process of being written. More information will be available for those who are interested in the next edition.

## Women's Expo Humidifier Raffle Winners:

Donna Young, Billings, MT w  
Lenora Lee Gregg, Evansville, WY

A vertical rectangular advertisement with a blue background. At the top, it says "Hemophilia Health Services" in white, followed by the tagline "...for the human factor\*" in a smaller font. Below this, the text "REST INSURED." is written in white. The main body of text, also in white, reads: "We understand how costly and inconvenient living with hemophilia can be. Our team of reimbursement specialists will navigate the insurance process for you, so you can enjoy life with a little more ease." This is followed by "A personal touch from people who know bleeding disorders." and the phone number "1 888 709-6004". At the bottom, there is a small logo for "accredo." in a green, lowercase font. The entire advertisement is enclosed in a thin black border.



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# Advocacy Activities

by Ann L. Schrader

In September, I attended the Montana Public Health Association Annual Conference. My purposes were two-fold- to identify and educate others about our organization and needs, and determine where our interests and Public Health's priorities intersect so that we can join with others to accomplish our goals.

I made several contacts with people who provide health insurance benefits or services to people with hemophilia and other bleeding disorders. I listened to speakers including Anna Whiting Sorrell, MT Director of Department of Health and Human Services, Cara McNulty, MN Director of their state-wide health reform initiative that focuses on policy and system change to decrease obesity and tobacco use; attended a special session on "The Science and Art of Advocacy: A Workshop for Public Health Professionals," where several state senators and politicians, and the mayor of Helena, discussed their need for input from their constituents and how they preferred to receive it; and learned a lot from Peggy Baltrone, a former Cascade County Commissioner, who is passionate about local governments ability to increase physical fitness and nutritional health and decrease obesity.

As we all know, our local, state and federal governments are struggling over limited revenue/tax dollars to fund a variety of services. It is their job to listen to the public and then establish priorities for tax dollar spending. Yes – everybody talks to them about their needs, and as citizens, we need to educate them about bleeding disorders. The state of Montana is expected to have to reduce the budget for the next two years by \$400 million.

*Remember, budgets are statements of our values and priorities. It remains very important to people with bleeding disorders to have health insurance that covers diagnosis and treatment with choice of medicine as their physician has prescribed.*

I discovered many ways that RMHBDA can and should partner with public health professionals. As there are very few people with bleeding disorders, it is so important to collaborate with other patient

education groups. Among public health their state priorities are:

*Obesity prevention*

*Disease prevention, such as Hepatitis A, B,*

*Food Safety and inspection*

*Air/water quality*

*Primary Seat Belt Law – can be pulled over if not wearing a seat belt*

## **Highlights from the Advocacy Session:**

- **Constituents matter** – survey says key drivers for politicians are Votes, Money, Media
- You are very important because you can educate them about human side as well as the facts – become a credible and reliable source that they can use to inform them about bleeding disorders. Be sure to use the RMHBDA Fact Sheet, located at <http://rockymountainhemophilia.org/advocacy>
- Meet with your house representative and state legislator before election – very busy after elections, that's when they meet with lobbyists.
- After elections and during the legislative session, contact them about upcoming issues by phone at the: **Session Information Desk, 406-444-4800. This service is available from 7:30 a.m. to 5 p.m. Mondays through Fridays, and from 8 a.m. to adjournment on Saturdays;** or by email at: <http://leg.mt.gov/css/Sessions/62nd/legwebmessage.asp>
- Be sure to write in the subject line that you are a constituent. As relative, write a letter to committee chairs, attend and/or give testimony at committee meetings. Meetings are in Helena during the legislative session, usually in the morning. Call the RMHBDA office for more information at 406.586.4050
- Develop ongoing relationship with local public health department and county commissioners.

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RMHBDA  
188 Lucille Lane  
Bozeman MT 59715