



Letter from the Board President

This is the time of year when we pause and be grateful for all the good things in our lives. As a parent of children with bleeding disorders, I have many reasons to be grateful: for their good health, medical research and progress in treatment, and for the Rocky Mountain Hemophilia and Bleeding Disorders Association.

As one family recently told me, the Association has made a big difference in their lives. He said, “Rocky Mountain Hemophilia and Bleeding Disorder Association has provided us with knowledge, support and options. Through others we have learned about our child’s disease as well as treatment and networking possibilities. We have learned about options for a “normal” life - in school, at play, in sports and on a daily basis. This organization has opened doors for us that we didn’t know to knock on, it has taught us the answers to the questions we didn’t know to ask and it has provided us with the friendship and support we didn’t know we needed.”

This family member went on to tell me about a quote that reminds him of RMHBDA, “An 1800’s poet once said, “Never doubt in the darkness that which you knew in the light”. Thanks to RMHBDA we have stepped out of the darkness into the light. Although there are times of darkness in all our lives, support systems such as this one can help us remember that which we knew in the light.”

We all know that RMHBDA is a valuable resource to our community. I invite you to consider a donation to our organization. Show your gratitude and enable us to continue the mission in supporting the needs of the hemophilia and bleeding disorder community in Montana and Wyoming.

Happy New Year!

Kevin Amende

Be a Good Citizen –Build a Relationship with Government

By Ann L. Schrader

Lisa Maxwell and I attended advocacy training in November hosted by the Hemophilia Association of New Jersey and funded through a grant from Baxter BioScience. We learned a lot in the day and a half workshop. We heard from several different government officials, such as a New Jersey State Assemblyman, Assistant Commissioner of NJ Health and Senior Services, a representative from the Insurance Department, the paid lobbyist for the NJ Chapter, and Ruthlyn Noel, the NHF Manager of State Government Affairs.

In addition we received a presentations about the “Role and Influence of the Medicaid Pharmacy Director”, setting organizational goals and objectives, and how New Jersey has worked with their state legislature to get rid of lifetime caps, to get state funding to buy insurance for members, and pass a law to recognize MASAC Standards of Care for people with bleeding disorders.

Throughout the training, we heard how important it is for individuals to meet with their state and federal legislators. Basically, this process

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Global Perspectives

World Federation of Hemophilia – Working with bleeding disorders communities around the world

Maria del Carmen de Agurcia discovered her mission about 20 years ago when she first took her baby son, Carlos Humberto, who has hemophilia A, to an insensitive doctor in Honduras.

“He told me it was not worth caring for people with hemophilia because they would all die like chickens,” she says.

“I then decided that fighting for people with hemophilia was going to be my life’s work.”

Maria’s son is now a young man and he is very much alive largely through his mother’s public efforts to improve government supplies of factor concentrate, patient care and knowledge of hemophilia treatment.

Maria del Carmen attributes much of her success to advocacy training and other support provided by the World Federation of Hemophilia (WFH) to 113 of its member organizations.

While people with bleeding disorders in developed countries are living longer, fuller lives, only about 25 percent of patients in the developing world receive adequate treatment.

The others die young or face a life of pain and

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Rocky Mountain Hemophilia & Bleeding Disorders Association Newsletter

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disability.

For almost half a century, the WFH has saved or bettered the lives of thousands of these people worldwide.

The World Federation of Hemophilia is a global not-for-profit organization working to improve and sustain treatment of people with hemophilia and other inherited bleeding disorders.

With Treatment for All as its vision, the Montreal-based organization builds sustainable hemophilia care in cooperation with governments, medical practitioners, industry, and associations such as Maria del Carmen's Honduras Hemophilia Society.

For example, the Honduran association has been partnered with Hemophilia of Georgia as part of the WFH Twinning Program, which links hemophilia organizations and treatment centers in developing and developed countries.

Twinning partners share their experience in hemophilia treatment, patient education, outreach, organization, lobbying, fundraising, and the optimal use of resources.

"Exchange visits, training programs, and other activities forge friendships around the world and strengthen the global hemophilia community," says WFH president Mark Skinner.

"Feedback shows that twinning is a positive two-way experience that motivates staff and volunteers, attracts youth involvement, and enables both sides to learn from each other."

"It's a win-win situation; therefore we always welcome new twins."

Thousands of people are also helped each year by the WFH's Humanitarian Aid program, which distributes donated treatment products to hemophilia patients in developing countries.

More than 80 million units of factor have been channeled through the WFH to 65 countries for emergency cases of life-threatening bleeds or patients undergoing surgery.

In addition, the donations also support efforts by the WFH and national hemophilia organizations to lobby governments for ongoing purchases of

these products and sustainable hemophilia care.

"Donated factor saved my leg," says Parimal Chandra Debnath from the Hemophilia Society of Bangladesh.

Debnath was hit by a car on his way home from work and suffered a broken knee. Complications from severe hemophilia A threatened his future ability to walk and earn a living. However, a WFH emergency supply of factor enabled him to recover and devote his life to helping other people with hemophilia.

"We need to reach out to them," he says.

To promote such outreach, the WFH annually organizes World Hemophilia Day on April 17. Participants increase awareness of hemophilia and other bleeding disorders with activities ranging from concerts, workshops, family outings and swimming races to media campaigns, body building competitions and even storytelling.

Based on the theme Together, We Care, World Hemophilia Day 2009, focused on the importance of comprehensive care for treatment of the physical, emotional, psychological, social, and educational needs of people with hemophilia and other bleeding disorders.

"The involvement and dedication of volunteers from so many different countries united in a global celebration was very moving and inspirational," says Skinner.

"It showed that we can work together around the world to ensure that all people with bleeding disorders, no matter where they live, receive proper treatment and care."

For more information about WFH activities, visit www.wfh.org.

Permission to translate and/or reprint this article is granted to interested hemophilia organizations, with appropriate acknowledgement of the WFH.





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Has Your Factor Been Recalled?

By Dawn Rotellini, Regional Director of NHF Chapter Services

The Patient Notification System is a free, confidential, 24-hour communication system providing information on plasma-derived and recombinant analog therapy (factor) withdrawals and recalls. Consumers can also call its 24-hour, toll-free number:

1-888.UPDATE (1.888.873.2838).

The system was set up by an advisory panel of representatives from consumer groups to provide consumers with a single, convenient and confidential source for up-to-date withdrawal and recall information. Led by the Plasma Protein Therapeutics Association (PPTA), the Patient Notification System was developed/funded by manufacturers of plasma therapies.

Maintaining confidentiality was one of the primary considerations in developing the system. To ensure confidentiality, the system is operated by Stericycle, Inc., an independent organization that specializes in pharmaceutical notifications. All registrant information is held in the strict confidence by Stericycle, Inc.

HOW IT WORKS: Anyone interested in participating must register with the Patient Notification System and provide general contact information, including their preferred method of notification. Registrants have the opportunity of being notified by e-mail, telephone, mail or fax, whichever is most convenient for them. Please consider e-mail as the method of notification for the following reasons: instantaneous, trackable, accessible, even when traveling. If a therapy is withdrawn or recalled, the company involved immediately contacts Stericycle, Inc, which then directly notifies the registrant. Every effort is made to notify registrants within 24 hours. Each registrant will also receive a letter by first-class mail to ensure receipt of the information. To maximize the usefulness of the system, it is important for consumers to keep accurate infusion logs and record the lot number, therapy name and manufacturer for all therapies used.

Bozeman Christmas Stroll Fundraiser 2009

By Ann L. Schrader

We served pulled beef sandwiches and water at the Bozeman Christmas Stroll on Dec. 5, 2009. Jim Ferriter brought the beef and buns from Wheat Montana, Forrest Berg was the supply man, and Kevin Amende supervised the beef slicing at the Bozeman Senior Center kitchen. Then they all set up, cooked, served and took the booth down! These three members put in many hours to make this event fun and successful and their efforts are deeply appreciated. In addition, we had some great sponsors – CSL Behring, Hemophilia Alliance, CVS Caremark, Walgreens, The Wok, and Accredo. Couldn't have done the Stroll without everyone's assistance and support. Thank You!

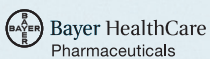


Picture: From Left to right: Ann Schrader, Jim Ferriter, Forrest Berg, Kameron, Kevin, Avery, and Wyatt Amende

RMHBDA Calendar

- **January:** RMHBDA Membership Drive and Education Weekend Registration
- **January 11:** Board meeting via teleconference
- **February 5-7:** NACCHO – Family Camp training, Phoenix, AZ
- **February 24-27:** NHF Washington Days and Leadership Weekend, Washington, D.C.
- **March 5-7:** Education Weekend, Billings MT
- **March 6:** Board Meeting in Billings MT
- **April 10:** Spring Fundraiser, Yellowstone Museum, Billings MT
- **April 17:** World Hemophilia Day
- **June 25-27:** Family Camp Weekend, Boulder MT

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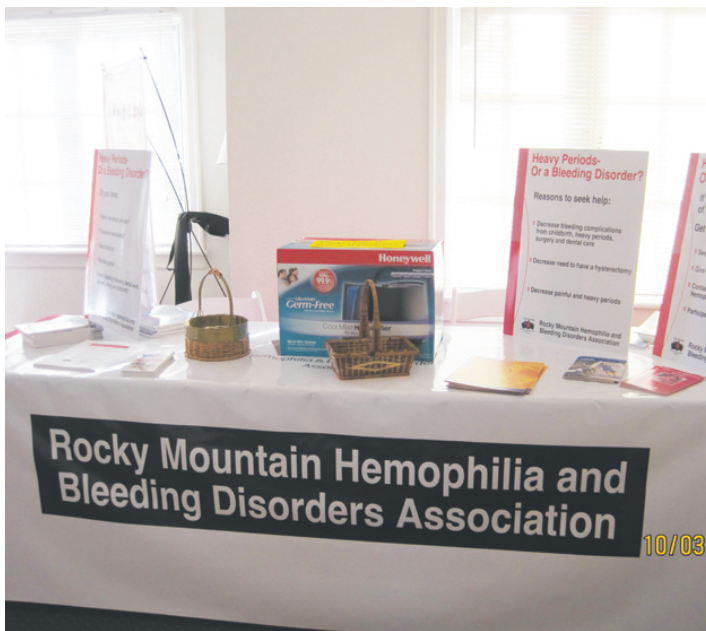
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is all about relationship building. The first step is to know who your representatives are. If you don't know that, get your 9 digit zip code and go online to the following address: <http://leg.mt.gov/css/find%20a%20legislator.asp> Click on Vote Smart and enter your 9 digit zip code when requested. From the next screen you can click on your representative's name and get their contact information.

Next step is to set up a time to meet with them in their home district office. Even though the Montana and Wyoming Legislatures are not in session in 2010, it is still critical to begin building your relationship. Be prepared to let your legislator know about what is important to you and your family. Introduce yourself, educate them about hemophilia and other bleeding disorders, and your family's difficulties getting and keeping health insurance, and access to all drugs, products and services. Ask them questions about themselves and their position on healthcare. Call us at the office if you have any questions or need supporting information. Let us know how it goes.



Ann Schrader and Jessica Amende at the Bozeman Women's Expo, Oct. 2009



RMHBDA Woman to Woman Exhibit courtesy of Hemophilia Alliance funding.

Did you know that in Montana you can call 211 and find out about community services and volunteer opportunities? You can also go online to www.Montana211.org for the same information. (Unfortunately, there is not the same service in Wyoming.)

RMHBD A

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