

## Board Meeting Summary

The Board met on Oct. 17, 2011. Kevin Amende, Forrest Berg and Ann Schrader presented a modified financial report that included the approved budget as well as the budget verses actual report for the current time period. It was simpler, easier to read, and well received. The next year's budget will be presented at the board meeting in December.

The board agreed that our First Annual Fundraising Walk will take place on Sept. 15, 2012 in Billings probably at Zoo Montana. Chris Graham is the Walk Chair. We are looking for an intern to help with the Walk logistics.

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.

### Milestones

David Cohenour was elected to the NHF Board of Directors!

Sara Jestrab was selected as a member of the NHF National Youth Leadership Institute!

Congratulations and thank you for your service.

## Regional NHF Meeting

- This past August the National Hemophilia Foundation was on the road to Seattle to present their third and final Regional Leadership Seminar of the year. This seminar covered a wide variety of topics related to current research, HTC's, and operational strategies for Boards. A variety of speakers presented on topics like: how to grow your Board, diversifying your revenue, budgeting, and scheduling yearly activities. The information presented and ensuing discussions provided me with a renewed energy towards strengthening our already amazing Montana and Wyoming "bleeding disorder family." I look forward to sharing some of the tools I took away from the seminar with you all over the next few months. Stay tuned!
- By Kevin Amende

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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

#### 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  
Jermone Hugs, Pryor, MT  
Spencer Straub, WY

### **RMHBDA 2011-2012 Calendar of Events**

- November 10-12, 2011 NHF Annual Conference, Chicago IL
- December 5, 2011 - Board meeting via teleconference, 7-9 p.m.
- February 6, 2012 - Board meeting via teleconference, 7-9 p.m.
- March 2-4, 2012 - Education Weekend, Billings.
- June 22-24, 2012 - Family Camp Bear Lodge Resort, WY
- September 15, 2012 - Fundraising Walk, Billings, Zoo Montana

### **Memorial Donations**

#### **In memory of:**

***Jane Campbell Berg* : Ann Schrader**

***Nealy Campbell's father*: Christy and Forrest Berg**

***Orley Arthur* – Heidi Hart and David Cohenour; Milt Fuller Family; Anne Arthur; Sharon McHenry; Anonymous contributions; Ann Schrader, Marie Rath**

Rocky Mountain Hemophilia and Bleeding Disorders Association

RMHBDA

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# Gene Therapy Advances

The first successful gene therapy for hemophilia (B) was reported at the small World Federation of Hemophilia meeting I just attended in Montreal. The investigator, Amit Nathwani, is in London, and his trial is being supported by the Medical Research Council (i.e. British govt) not a commercial company, but scale-up will require commercial buy-in. As you know, successful gene therapy (i.e. factor IX levels adequate to prevent bleeding, but not in the normal range) was achieved in dogs over a decade ago but the adeno-associated viral vectors caused liver “transaminitis” in humans which destroyed the factor IX-producing hepatocytes. These were the well-known studies of Katherine High and Mark Kay. The FDA became very uptight about gene therapy trials in the USA and progress in trying safer variations halted.

Nathwani also used an adeno-associated virus but a strain of that ubiquitous virus that has not been found to infect humans. The route of administration was just an IV infusion in the arm, not the hepatic artery or anything fancy. The first six patients have been treated, two at each of three dose levels. Some low-level transaminitis was seen in some but was subdued quickly with a reasonable level of corticosteroids. Patients receiving the higher doses have stabilized with 8-12% factor IX levels, for less than a year. These are very desirable levels. Other patients are to go on trial. He'll later try something with hemophilia A.

As you all know, this has been a long time coming. Gene therapy trials for hemophilia started around 1990 and were expected to show positive results in a decade. The obstacles were many. More than 20 years later, a success. Now it would be good to make sure that the production of factor IX lasts a year, a few years, etc. Of course, many questions remain.

Attendees from developing countries were immediately worried about cost, however, it's expected that “tier pricing” would be in effect, that is, it would cost less in poorer countries.

By: Carol K. Kasper MD, Emerita Professor of Medicine, University of Southern California, Orthopaedic Hospital 2400 S. Flower Street Los Angeles, CA 90007 FAX 626-666-6970

## Member Profiles

**Avery and Nick were chosen as our chapter's nominees to participate in "Gettin' in the Game," an athletic program sponsored by CSL Behring. We had them draw straws to decide who got to go...**

### By Avery Amende

Ever since my Dad told me I had a chance to play golf at a tournament in Texas I was ready to go. Even though I didn't know if I would end up going or not, I would definitely try my best. Right at that moment, to the split second, I picked the correct "stick" out of Ann's hand I was eager to go to Texas!

Some people probably thought I was giddy and too excited to be allowed on the plane, though if anyone asked I would tell them that I was going to play golf in Texas. That's all I'd say.

Once we got there we hopped on a bus and rode to the Marriott. I never get to go to hotels, so the Marriott was fancy and very nice to me. Texas is humid and hot! That is the place for me to live.

All the activities and practicing we did was fun, not easy, but very fun. I had a really nice person named Eric help me with golf during the tournament.

All the days we were in Texas it was beautiful out and our food was great! That was probably the best trip I've ever been on! All the people at Gettin' in the Game were extremely nice! I even met a friend from Oklahoma City! All in all, it was amazing and I think we should do it again next year!

Below: Avery Amende practicing her short game!



### By Nick Foster

When I was in Dallas I had lots of fun. I like to play baseball. It was fun to be able to play baseball with other kids who also have Hemophilia. We got to play at a minor league stadium, called LaGrave Field. It was fun. We got to compete in fielding, hitting and pitching. (I think I did good).

There were even kids from Hawaii and Alaska. Everyone was very friendly and nice.

It was cool learning from and talking to the coaches, like Ivan and Jessie. I liked hearing about how they grew up playing sports and dealing with their Hemophilia. They showed us their medical alert necklaces and why it's important to wear one. Corey Parker told us how he got hit in the throat by a baseball and couldn't talk. He wasn't wearing his medical alert necklace and he was scared he would die because no one knew about his Hemophilia. He woke up a week later and is okay now, he wears his necklace everywhere now.

The most exciting part of the trip, besides the playing baseball and the nacho cheese at dinner, was meeting C.J. Wilson, the pitcher for the Texas Rangers. He was really nice. He talked to us about a lot of things, like the difference between being sore and having pain. He told us how he broke his back once because a coach told him to "suck it up." He couldn't play baseball for a year. He said he should have listened to his body and we should listen to our body also. Now we watch him pitch in the World Series- Go Rangers!



Above: "Getting in the Game" athlete Ivan Sada and Nick Foster



## Are You Listening to Me?

by Ann L. Schrader

Earlier this month, I read an article in the Bozeman Daily Chronicle's Balance Magazine. It spoke to one of my biggest pet peeves: most people don't listen with interest and curiosity. They don't attempt to learn about the other person.

How many times do you meet someone new and after the preliminary questions, name, employment and family, the conversation stalls? I find I can wait in silence for a long time, rarely getting asked follow-up questions that drill down more deeply into who I am and what my experience of life is. Usually I give in and walk away or ask the questions myself.

Listening is more than just hearing. It is putting in the time and effort to find out about the other person and understanding their uniqueness. It's about genuinely wanting to learn more about them by asking questions.

**NEWSFLASH:** You don't have to share the same interests to do this!!!

*Listening cont'd*

I can guarantee that when you are more inquisitive, you'll learn something new and the other person may more readily ask about you!

Conversation is a crucial skill in our relationships and work. By listening consciously, with curiosity, we develop a clearer picture about what makes a person tick, how they think, what they care about and what special insights or gifts they have to offer. Your life will be better as a result. As a group facilitator, I get so excited to work with people who are great listeners. Their groups function at the highest level and most often produce innovative ideas, clear goals, and consensus decisions.

As parents, consistently listening deeply to our children is one of the most important tasks we do. Through listening, we can more quickly identify when our child is suffering pain, having a bleed, getting sick or struggling with the restrictions of their bleeding disorder. Armed with this information we can better relay accurate information to medical personnel and provide appropriate care for our child's physical or emotional needs.



Top row: Dawn Rotellini, Kevin Amende, Kent Pointer, Monica Foster. Bottom left to right: Gino Rotellini, Avery Amende, Nick Foster.

On the right: Sara Jestrab. Her application to the NHF National Leadership Institute was recently accepted. She will join David Cohenour and Spencer Straub at the NHF Annual Conference in Chicago November 10-12, 2012.



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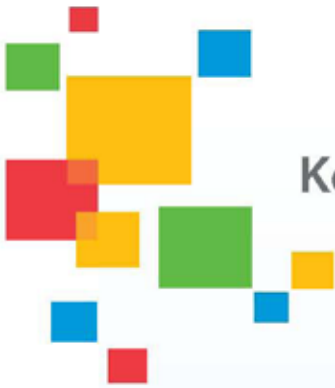
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# Dr. Orley Arthur, Jr., DVM Remembered



Born June 9, 1933 in Lander WY and died August 1, 2011 in Roundup MT.

Orley lived a full life and had many successes. He was married to his wife, Anne, for fifty years and had 5 sons. When his son, Kevin, fell ill with AIDS from a blood transfusion for hemophilia, Orley's research with weak calf syndrome and his ability to boost their immune system through copper shots, proved helpful in AIDS research.

While Kevin was still alive, the Mann Committee formed and Kevin talked his Dad into going to St. Louis for a Mann meeting. Out of that group, the Committee of Ten Thousand was formed and worked to make blood products safe.

Orley did his best to support his 2 sons with hemophilia in their crises, and Anne is sure that Kevin would be proud of the part Orley played in the origin and support of Rocky Mountain Hemophilia and Bleeding Disorders Association.!

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