

Board Meeting Summary

RMHBDA Board of Directors held its regularly scheduled meeting on June 25, 2011. The meeting was conducted by Lisa Maxwell, Vice President, as Jim Ferriter could not attend. All other board members were present. Lots of camp participants also attended the meeting.

The board noted its appreciation of all the camp sponsors and agreed to make thank you notes for each one.

Education weekend will be in Billings next March and Family Camp will be in WY.

Our funding this year is down from last year.

We agreed to participate in the NHF walk next year and not do the Bozeman Christmas Stroll.

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

Remember to...

Do The Five

- **One:** Get an annual comprehensive checkup at an HTC.
- **Two:** Get vaccinated: Hepatitis A & B are preventable!!!
- **Three:** Treat bleeds early and adequately.
- **Four:** Exercise to protect your joints.
- **Five:** Get tested regularly for blood borne infections.

Milestones

Margaret Thorsen turned 80 years old in July! Happy Birthday!

Jan Campbell Berg, Forrest Berg's mother passed away on July 5, 2011. The chapter sends our condolences to the family.

Orley Arthur passed away on August 1, 2011. He was one of the early and long-time supporters of the hemophilia organization in Montana. The chapter sends our love and condolences to his family.

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“The mission of Rocky Mountain Hemophilia and Bleeding Disorders Association is 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

- August 1, 2011- Board meeting via teleconference, 7-9 p.m.
- August 8-9, 2011 - NHF Regional Meeting in Seattle attended by Kevin and Jessica Amende
- August 24, 2011- NHF Conference Registration Due.
- October 3, 2011 - Board meeting via teleconference, 7-9 p.m.
- November 10-12, 2011
- December 5, 2011 - Board meeting via teleconference, 7-9 p.m.
- February 6, 2012 - Board meeting via teleconference, 7-9 p.m.

Big Thanks to our Recent Donors

Bayer HealthCare

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Rocky Mountain Hemophilia and Bleeding Disorders Association

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Family Camp 2011 - Paradise Valley MT



Roasting marshmallows at our campfire!



Even Ann likes S'mores...yum!

***Big Stick Award Winner
for 2011: Mick Graham***

RMHBDA Family Camp was held on June 24-26, 2011 at the KOA Campground just south of Livingston MT. 35 youth and 38 adults attended. We had a great time playing camp games, making s'mores, building race cars and hanging out with each other.

From the camp evaluation that 26 people completed, we learned that campers overwhelmingly (34%) liked best the time to network with families. Next they enjoyed the relaxed atmosphere of the camp, the location, the cabin, mixing everyone did, and the friendliness of the group.

Thank you to the camp committee for a great job! Lisa Maxwell successfully finished her long run as camp director and has passed the mantle to Jessica Amende. Andrea Stafford and her mom, Sue Scott, Brad Benne and Kevin Amende have volunteered to serve on the camp committee. If you would like to join us, give Ann a call at 406-586-4050 or email her at ann.rmhbda@gmail.com.



Member Profile:

by Anne Arthur and Kristal Graham

A Conversation Between Anne and Kristal Over Coffee

Anne remembers Tom Choate was known as a cowboy/rancher around the Billings' Stockyards. Often seen hobbling around on his crutches, happy as could be. No one thought of him as a hemophiliac, for he could take care of himself as a rancher and a stockman.

As a veterinarian, Anne and Orley Arthur knew about Tom's hemophilia. Anne met him at one of the first hemophilia clinics in Billings. Her son Keven was about 10 years old and Jeff about 4.

At the next Clinic he wrote the first Montana Hemophilia Chapter, had it signed by an attorney general. The chapter was formed to assist Montana children to go to the Colorado hemophilia camp in Denver. He elected himself as the first president, and gathered a few board members, like Anne's son, Nelson, Norman and a couple of others. The NHF wanted us to have frequent meetings, which was impossible for us in the state of Montana. We agreed to try to meet during our hemophilia clinics which came once a year.

When Keven was 12, Tom Choate died from a stroke at the hemophilia clinic. Unfortunately, his family relationships were not that great, which often happens in families with a disability like hemophilia. Parents protect the affected child and the unaffected child may react to his exclusion by trying to hurt or punish the other sibling. The affected child can often feel left out.

Kristal is glad for the family camps and their ability to unite affected and unaffected children with others in the same situation.

Kristal's sister doesn't want her children to know about hemophilia. Therefore, the cousins don't know each other very well. She has a daughter who could be a carrier and one son who is not a hemophiliac, but Kristal knows the gene can still be passed on to her own two daughters.

Kristal wonders aloud how many other families with hemophilia have broken up due to the fear of

being associated with the imperfect human being and the judgment laid on them.

Tom Choate lived in a time when many hemophilia died young on lived in hospitals in wheel chairs completely crippled up.

(Note From Kristal. . .I intend on looking into this more as I am now very interested the Mr Choate)

A Starter Story of a Hemophiliac Written by Kristal Graham

July 10, 2011

My story starts with my grandmother, Alice Choate. She was a carrier of hemophilia. Her husband was Rufis Choate. They had 4 children. One girl and three boys. Two of the three boys had hemophilia. One of the boys died at a very young age. I would say around 3or 4. He was riding his tricycle in the house and fell down the stairs. He was flown to Denver by my Grandpa, but he didn't survive.

The other boy (Ted) lived with hemophilia during a time of no treatment. He spent many hours on the couch and could only get around with a wheel chair or crutches. I remember as a young girl my Uncle Ted walking with crutches, or running rather. He could handle them as if they were a part of his body. He also used elbow splints wrapped with ace bandages. In my youth I remember him sitting in the garage with his IV line hanging down, giving himself medication. This was the norm I never thought much of it.

My Uncle Ted took his own life in 1991. Family speculated it was because he had been living with HIV and that it may have progressed to AIDS. (no one really knows as there was no note)

My grandmother Alice passed away a year before my Uncle Ted. This was when a huge family feud began. As a result, I have lost touch with part of my family. I have one uncle that is still alive (I think) I have not spoke to him since I was 9. I don't think he liked my Uncle Ted much. I think that he was very jealous of him and the attention that was always given to him. I remember his statement "well why does he get...?" I think that was probably true for all of Jim and Teds lives. As a result, I try to remember that and try to treat my children equally.

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It wasn't until I was about 8 or 9 that I realized that my brother had hemophilia. He is 14 years older than myself and we were not close. Mom had taken me to see him and we went to the water park in Sacramento CA. My brother forgot his towel so I told him he could use mine, then my mother would not let me use the towel. I was very upset, I did not understand. I later learned that my brother had contracted HIV from a blood transfusion after a car wreck. He is still fighting with HIV and it has been over 20 years that he has had it. He has many problems with his joints as he rebelled after being diagnosed with HIV and wouldn't use factor replacement for many years, causing much damage to his joints.

I found out that I was a carrier when I was 11 years old. I had went on a trip to California from Washington to see some friends. When I returned, my mother took me to the Hemophilia Center in Seattle and had me tested. When I found out that I was a carrier I was very upset, and mad, but didn't know much about what it meant.

When I found out that my second child was a boy, I immediately called the hemophilia center in Denver and spoke to the nurse (Sue Gerhagty). She was very informative and sent me lots of books and websites to look at. I guess I am a bit of a book worm as I read everything I could find.

I then had an amniocentesis test done during pregnancy and found out that the boy did have hemophilia, factor VIII, less than 1%. This changed my birthing plans. I changed hospitals because Billings Clinic refused to do a circumcision on a hemophiliac. I went with St. Vincent's. We infused him beforehand and had no problems. I was planning on having Mick naturally however his umbilical cord came out before him and we had to do an emergency C-section. (A note on my pregnancies. I recovered from the c-section fine. However after I had the other three children I had a lot of problems with hemorrhaging. With my last child I ended up back in the hospital 3 or 4 times after my release due to uncontrollable bleeding.

I have 5 children, two girls and three oys. Only one of the three has hemophilia. I have not yet tested the girls to see if they are hemophilia carriers. The girls have a 50/50 chance of being a carrier and having children with hemophilia.

Mick is 6 he mixes his own meds and does his own self-infusions. He is in my opinion amazing. We teach him that there is nothing wrong with him.

He just has to do a few extra things than other kids his age. I think he feels that its kinda cool that he is a hemophiliac. He had his first bleeding episode when he was three months old in his finger. His most traumatic bleed so far has been a hip bleed. He went to bed one night and the next morning couldn't walk. After that I ordered a set of crunches. Mick must have a pretty high pain tolerance, as when he has bleeds he hardly ever complains. I have learned if I think there might be a bleed, treat first then figure out if he really does. It is less dangerous for him to have an extra dose of his meds then to cause a little bit of permanent damage.

I just started attending RMHBDA Ed days and Family camp in 2010. I love going. It gives my children so much. They are all treated equally. It gives something to all of them. They all feel included. I feel it is really important to show them they are all alike, all important, and all part of the fun. When Mick gets his shot the others all get a bandage too. They don't do it as much anymore but they use to love the one-on-one attention. I still have a nurse come to do Mick's shots, even though Mick is doing them on his own. When I asked Mick what his favorite thing about being a hemophiliac was, he said the best part of his hemophilia is seeing his nurse Micheal Lavoie every other day.

So to wrap this up, oh how I would like to go on but...we treat Mick's hemophilia as a really cool thing. Its not a disability in our house, it just really cool. The generations of hemophilia sufferers that have come before us might be surprised that this is what it has come to, I wonder what my grandmother would say to, "Hey, hemophilia is kinda cool!" I think she would say we were crazy. So I want to thank the great hemophilia team from Denver, RMHBDA and the home healthcare companies, especially Restore RX, for making our lives so much better. We wouldn't be where we are today with out you.

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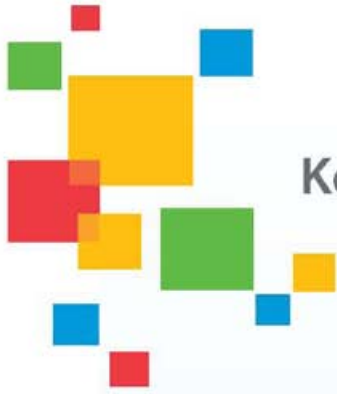
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