

# THE ROCKY MOUNTAIN

## Hemophilia & Bleeding Disorders Association Newsletter

### Message from the Executive Director

Dear Friends,

My name is Brad Benne, and I am the new Executive Director for the Rocky Mountain Hemophilia & Bleeding Disorders Association. I am honored to serve the families in the bleeding disorder community in Montana and Wyoming. This year, our Chapter is taking a big step by having our 1<sup>st</sup> Annual Montana and Wyoming Walk for Hemophilia this September. Our walk can be successful, but we need your support!

Join us for our 1<sup>st</sup> Annual Montana and Wyoming Walk for Hemophilia!

**When:** September 8, 2012

**Where:** Bozeman, MT (Bogert Park)

**Time:** Registration starts at 9:30 a.m. (Walk starts at 11:00 a.m.)

We will be having "Call to Action Walk" meetings at 6 p.m. in Billings on May 15<sup>th</sup> and in Bozeman on May 16<sup>th</sup>. These meetings will follow "Power of Choices", a presentation by Baxter.

**RSVP:** Contact Brad Benne, Executive Director of Rocky Mountain Hemophilia & Bleeding Disorders if you can join us by calling (406) 586-4050 or emailing [brad.rmhbda@gmail.com](mailto:brad.rmhbda@gmail.com). RSVP by Wednesday, May 9. For more information about our Hemophilia Walk and other chapters across the country visit <http://www.hemophilia.org/walk/>

Thank you for your continued support of RMHBDA!

Sincerely,

*Brad Benne, Executive Director*



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### **WE LOVE DONATIONS AND MEMBERS!**

Rocky Mountain Hemophilia and Bleeding Disorders Association (RMHBDA) is a 501 (c) (3) nonprofit organization. Contributions are tax deductible. We appreciate you considering our Chapter and the families we serve by your membership and charitable giving. An envelope is enclosed for your convenience!



# 1st Annual Montana and Wyoming Walk for Hemophilia

## “Call to Action Walk” Meetings

Our “Call to Action” meetings are a great opportunity to get hands-on knowledge about the walk and teams. Here's the kind of helpful information you'll get at our “Call to Action” meetings:

- Receive guidance & support on fundraising from the pros.
- Get inspired by past success stories.
- Learn about starting your team and register your team at our “Call to Action” meetings.
- Find out how the chapter staff can support you.
- Discuss the best ways to communicate with team members and motivate them.
- Learn how to lead your team by example.
- Ask questions about the Walk and starting a team.
- Find out about our new online fundraising platform.
- Get info on our Walk Kick Off event & sponsorship.
- Meet and talk with other community members participating in the Walk.
- Have fun... and a free dinner!

The “Call to Action” meeting is great for ANYONE who is interested in starting a team or fundraising for a team. All are welcome... spread the word!

Here are all the details – RSVP today! For those of you who are unable to attend the meeting, but would like to participate, please contact Brad Benne at 406-586-4050 to join the Montana and Wyoming Walk for Hemophilia team!

### Spring Meeting Schedule

#### Billings, MT

When: May 15, 2012 – 6:00 p.m. – 8:00 p.m. (“Power of Choices” seminar presented by Baxter immediately followed by “Call to Action” walk meeting)

Where: Rib & Chop House, 1849 Majestic Lane, Billings, MT.

#### Bozeman, MT

When: May 16, 2012 – 6:00 p.m. – 8:00 p.m. (“Power of Choices” seminar presented by Baxter immediately followed by “Call to Action” walk meeting)

Where: Montana Ale Works, 611 East Main St, Bozeman, MT.

Summary of “Power of Choices” presented by Marykay Thrower of Baxter

Knowing more about bleeds, factor, and healthy options means you can make good choices that may improve your life.

RSVP: Contact Brad Benne, Executive Director of Rocky Mountain Hemophilia & Bleeding Disorders if you can join us by calling (406) 586-4050 or emailing [brad.rmhbda@gmail.com](mailto:brad.rmhbda@gmail.com). RSVP by Wednesday, May 9.

For more information about our Hemophilia Walk and other chapters across the country visit <http://www.hemophilia.org/walk/>





## A Message from our Board President

Spring is here and with it comes the promise of new beginnings. Fourteen years ago a very wise woman named Mary told me my newly diagnosed son would grow up and just like spring, the promises of a new beginning would unfold. At the time, I doubted everything she told me. How could this diagnosis not ruin our lives? How do we deal with the progress moving forward only to be pushed back by unforeseen complications that are part of living with a bleeding disorder? The answer came by sharing this journey. Because of RMHBDA, we were not alone trying to find the strength and answers. The friendship, support and knowledge we have received have been immeasurable. Our organization has been a blessing to me and my family. Attending this last Education weekend, I looked around at all the young people and babies and wanted to call Mary. She was right. My son did grow up as he was now the oldest child there, helping with the younger ones. A new beginning had unfolded and I almost didn't recognize it.

I am excited for our Chapter as we begin preparing for our Walk. This will bring us to a new level of self-sufficiency and enable our Chapter to be here for generations to come. It is through all our hard work and commitment that we grow and share. Thank you to all who have been a part of this adventure, sharing their talent and hard work. Welcome to all that have just begun. Spring is here and together we can achieve that promise of new beginnings.

Sincerely,

*Lisa Maxwell*

### RMHBDA

#### Board of Directors

##### *President*

**Lisa Maxwell, Great Falls, MT**

##### *Treasurer*

**Forrest Berg, Bozeman, MT**

##### *Secretary*

**Jane Robertson, Cody, WY**

##### *Board Members*

**Kyrsten Brinkley, Missoula, MT**

**Jim Ferriter, Helena, MT**

**Spencer Straub, Cheyenne, WY**

**Sean Jeffrey, Missoula, MT**

### RMHBDA

#### Calendar of Events

**April 17:** World Hemophilia Day

**May 15:** Facts First Seminar: Topic Power of Choices Presented by Baxter 6 p.m. at the Rib & Chop House, 1849 Majestic Lane, Billings, MT

**May 16:** 2012: Facts First Seminar: Topic "Power of Choices" presented by Baxter, 6 p.m. at Montana Ale Works, 611 East Main, Bozeman, MT

**June 18 – 20: (a.m. only on 20th)** MSRHTC in Billings

**June 21 - 22:** MSRHTC in Missoula

**June 22- 24:** Family Camp, Bear Lodge Resort, 5600 US 14A at Burgess Junction, Dayton, WY 82836

**July 15 – 20:** Mile High Colorado Camp, for more information contact Amy Board at 303-724-2309



## **RMHDBA Contact Information**

Please let us know how we are  
doing and we would love to  
hear from you!

2100 Fairway Drive, #107  
Bozeman, MT 59715

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

Tax ID: #81-0533720

Executive Director, Brad Benne

Email: [brad.rmhbda@gmail.com](mailto:brad.rmhbda@gmail.com)

## **Renewed Membership 2012**

**Kevin and Jessica Amende**

**Barbara Arnold**

**Anne Arthur**

**Brad and Susan Benne**

**Forrest and Christy Berg**

**Ruth Cahill**

**Jim Ferriter and Lisa Glass**

**Sharon Ferriter**

**Chris and Jana Graham**

**Kristal Graham and John Keim**

**Amanda and Todd Hamper**

**David Cohenour and Heidi Hart**

**Bob and Mary Hunter**

**Rick and Tanya Lasko**

**Mary Majerus**

**Lisa and Scott Maxwell**

**Jane and Brian Robertson**

**Ed and Ellen Sparks**

**Leroy and Andrea Stafford**

**Thelmar and Margaret Thorson**

**Susan and Doug Scott**

**Robert, Carol, Kimberly, and Sara Jestrab**

**Gene and Sharren Cohenour**

## **DONATIONS**

**Sharon Ferriter in honor of Connor Ferriter**

**Thelmar and Margaret Thorsen,  
in honor of Jericho Hugs**

**Mary Brinkley in honor of Peter Brinkley Family**

**Sharren and Gene Cohenour in honor of Hunter, Coy,  
and Montana Cohenour**

**Annette and Tony Epple-Hafla/Tanda, Inc.**

**Donald and Beryle Fromm**

**Lee and Sandra Hart, Broken Hart Ranch**

**Sally E. McElderly in tribute to Richard D. McElderly**

**Barbara Arnold in memory of George H. Arnold**

**In honor of Jaxon Stafford**

## **Education Weekend Raffle Winners**

**Sharon Ferriter...Mary Crichton...Ethan Frame...and  
Bev Ball! Congratulations!**

# RMHBDA Education Weekend

*would not be possible without support from our generous program funders:*

**Bozeman Area Community Foundation, Accredo Health, Inc., Bayer HealthCare, Baxter, Biogen Idec, CSL Behring, Grifols, HF Healthcare, Novo Nordisk, Octapharma, Pfizer, Restore RX, and Walgreens Infusion Services.**

**RMHBDA Education Weekend was held March 2-4, 2012 in Billings, MT. 20 families attended with 24 youth and 40 adults. Educational sessions during Education Weekend included presentations on Health Care, Insurance, Dental Health, and Encouraging Early Independence for Youth and Adults.**

**Adults and youth participated in a scavenger hunt and spoke to each exhibitor as chapter members were seeking answers to a clue from each exhibitor as they also learned more about each company and their products. When they finished, the adults had the opportunity to speak with the pharmaceutical and Home Health care representatives.**

**Children enjoyed field trips to Steepworld, Geyser Park, the Kids Clubhouse, and the Reef water park. Thank you to all the parents who volunteered watching and chaperoning during the field trips. Special thanks to Heidi Hart, Jana Graham, and Kristal Graham for assisting with the organization of the event!**



# *World Hemophilia Day 2012*

Every year on April 17, World Hemophilia is celebrated around the world in order to increase awareness of hemophilia and other inherited bleeding disorders.

On April 17<sup>th</sup>, help the World Federation of Hemophilia spread the message to “Close the Gap” of care around the world. Together, we can work towards a day when treatment will be available for all globally. There are many ways to celebrate this day and further educate others about bleeding disorders:

- Become a fan of the WFH Facebook page ([www.wfh.org/facebook](http://www.wfh.org/facebook)) and encourage your friends to visit and ‘like’ the page.
  - Wear red on World Hemophilia Day
- Support the work of the WFH by becoming a member. Visit [www.wfh.org](http://www.wfh.org) for more information.

## **Board Meeting Summary**

RMHBDA Board of Directors held its regularly scheduled Annual meeting on March 3, 2012 during Education Weekend in Billings.

The board elected Jane Robertson and Forrest Berg both to serve 3 year terms. Sean Jeffrey was elected to fill a vacant 1 year term. The board nominated Lisa Maxwell to serve as the President, Forrest Berg to serve as Treasurer, and Jane Robertson to serve as Secretary. The Vice-President position is open.

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

## **2012 Scholarship Opportunities**

*for Students K – 12 (ranging from \$500- \$7000)*

**Biogen Idec Hemophilia Scholarship Program.** We’re helping students with Hemophilia further their education –and their lives – by providing scholarships for various levels of higher learning. Go to <https://aim.applyists.net/Biogen> for more information.

Visit [www.hemophiliavillage.com](http://www.hemophiliavillage.com) for more scholarship opportunities or contact Brad Benne at 406-586-4050 for more information.



# Washington Days 2012 Report

## ~A Program of the National Hemophilia Foundation~

**NHF Advocacy Priorities: Please contact your state senators and members of congress to voice your opinion in regards to important legislative issues that will affect our community. Your voice and willingness to fight for what you believe does make a difference!**

### Issues

- **-Increase Lifetime Insurance Caps**
- **-Funding for Hemophilia Treatment Centers**
- **-Elimination of Travel Ban for people with HIV**
- **-Allow for the continued implementation of the Affordable Care Act**
- **-Congress ONLY: HR 1919 to increase screening and diagnosis of bleeding disorders in adolescents**
- **-NHF Position on Biosimilars**



“This was my first year participating in Washington Days! I was not sure what to expect when it came to meeting with our legislators, however I think that their offices listened thoughtfully. Sean and Lisa blew me away with their stories and how effortlessly they made advocating look! I was very nervous sharing my story since everyone has their own in this community, but once it was over it felt good to show our leaders that even in Montana, our access to health care is not perfect. This experience has empowered me to follow the SAFE Act of 2011! Not everyone has the opportunity to participate in Washington Days, but don't let that discourage you from advocating locally. You never know how far that can go!” **By Sara Jestrab**



This was my second year participating in Washington Days. It was a much different experience compared to my first year. I knew what was going to happen and what was to be expected which definitely eased my nerves about talking to the Senators, Congressmen and women and their Aids. Lisa as always did an absolutely wonderful job and she is the reason I had such a positive experience my first year as well as felt so confident and at ease my second year. Brad and Sara both did stellar jobs, especially for it being there first year! All of us had very different but very valuable experiences that we shared with the offices. Washington Days is an amazing opportunity that I hope everyone can experience at some point in their lifetime. Advocating doesn't just happen once a year though - it happens 24/7, 365 days a year, locally, regionally, nationally, and globally - so get out there and share your story! **By Sean Jeffrey**



The Matthews Family, Capital Heights, MD



**C A R E**

COVERAGE - ASSISTANCE - RESOURCES - EDUCATION

# Proactively manage your insurance situation

Contact your local Baxter representative to enroll.

Ryan Smith  
(801) 450-7845  
[ryan\\_smith@baxter.com](mailto:ryan_smith@baxter.com)

The CARE program is open to all hemophilia A patients and inhibitor patients regardless of brand of therapy.

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[LivingWithHemophilia.com/FactorTrack](http://LivingWithHemophilia.com/FactorTrack)

**FactorTrack™ is part of Living Fit! A Joint Effort™.**

\*Please note that an Internet connection is required to receive infusion reminders. This app is not intended to offer or replace professional medical advice. Speak to your nurse or physician if you have any health concerns. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch) or call 1-800-FDA-1088.





## Biotherapies for Life™

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