RMHBDA Quick Facts

The mission of RMHBDA is to improve the quality of care and life for persons with inherited bleeding disorders, including hemophilia and vonWillebrand Disease through education, peer support, resources, and referral.

- founded in 2000
- 501(c)(3) nonprofit Montana corporation
- volunteer-driven organization
- nine board members
- our paid staff includes only our full-time Executive Director and part-time Programs Coordinator
- chartered chapter of the National Hemophilia Foundation
- serving Montana and Wyoming, including 50 people diagnosed in Montana and 35 in Wyoming*

Our actions support:

- individuals affected by serious bleeding disorders and their family members
- medical professionals and researchers in blood disorders
- proactive self-care education
- reduction of medical costs
- access to reasonably priced health insurance
- reduction of the number of hospital emergency room admissions

As a result of a survey of our members reporting details of their difficulties in receiving appropriate and timely treatment for their bleeding disorders, in January 2011, the RMHBDA Board of Directors passed a policy statement supporting:

- reasonable access to affordable healthcare
- no lifetime medical insurance coverage caps
- no pre-existing conditions exclusion clause in health insurance
- importance of physician-prescribed treatment

Medical Facts

- The most common bleeding disorder is hemophilia, a rare, chronic disorder primarily affecting males.
- 20,000 people in the United States, have been diagnosed with hemophilia [www.cdc.gov/ncbddd/hemophilia/data.html].*
- Hemophilia requires lifelong treatment with expensive clotting factor drugs and specialized care.
- Mortality rates and hospitalization rates for bleeding complications from hemophilia were 40% lower among people who received care in hemophilia treatment centers than among those who did not receive this care [www.cdc.gov/ncbddd/hemophilia/data.html].
- Left untreated, patients suffer debilitating damage to their joints, neurological systems, and other organs, or death, and this negatively impacts the quality of their lives, families, and communities.
- The U.S. Centers for Disease Control and Prevention (CDC) summarized in its Universal Data Collection (UDC) Project National Report that there were 6,513 people with the combination of bleeding disorders and HCV — 6,196 with hemophilia, 317 with vonWillebrand Disease. With the implementation of hepatitis C testing in 1992, as well as other improvements in donor screening and product safety, the risk of HCV transmission from plasma-derived clotting factor has been greatly reduced. No seroconversions to HCV have been reported with any of the FVIII products currently marketed in the U.S. [www.hemaware.org/story/hepatitis-c-and-hemophilia].*
- Monitoring blood product safety is an ongoing need.
- vonWillebrand Disease (vWD)
  - vWD is a blood clotting disorder found in 1–2% of the population; estimates project 15,000–30,000 people in Montana and Wyoming may be affected.
  - Both males and females are affected, although it impacts women more frequently.
  - RMHBA has recently begun a public awareness campaign and program to address the impacts of vWD on women.

Cost Issues

Inherited bleeding disorders are very costly to treat and a burden to families and their communities; for example:

- a patient with hemophilia average factor cost is $175,000 annually*
- for those with an inhibitor, the average is $1,122,000 annually*