**Upcoming Events 2015**

**MARCH**
- March 30, 2015, Share Your Ideas with HFO/Bulkinwille’s, Wilsonville - 5:30 pm
- March 31, 2015, Share Your Ideas with HFO/Papa’s Pizza, Beaverton - 6:00 pm

**APRIL**
- April 10-12, 2015, Parents Empowering Parents (PEP) Weekend/Hood River, OR
- April 20, 2015, Tom Advocacy Training/Grand Hotel, Salem, OR - 5:00 pm
- April 21, 2015, Advocacy Day/State Capitol, Salem, OR - 9:00 am
- April 23, 2015, Bend Support Group/Bend, OR - Time/Location TBD
- April 24, 2015, Southern Oregon Support Group/Hampton Inn, Medford - 6:00 pm

**MAY**
- May 14, 2015, Portland Support Group/Bulkinsville’s, Wilsonville - 6:00 pm
- May 15-16, 2015, Couples Retreat/Valley Inn, Eugene - 6:00 pm
- May 22, 2015, Southern Oregon Support Group, Hampton Inn, Medford - 6:00 pm

**JUNE**
- June 7, 2015, Eugene Support Group/Valley Inn, Eugene, OR - 6:00 pm
- June 19-21, 2015, Family Camp/Gold Hill KOA, Medford, OR
- June 27, 2015, The Bloody Run & OI Bleeding Disorders Walk/Terpenning Recreation Complex, Beaverton, OR - 9:00 am
- June 29-30, 2015, Summer Teen Programs/Leave from WALK/Portland, OR - 8:00 am

**JULY**
- July 9, 2015, Portland Support Group, Bulkinwille’s Family Fun Center, Wilsonville, OR
- July 11, 2015, Bend Support Group, Bend, OR
- July 19, 2015, Eugene Support Group, Newport, OR
- July 25, 2015, Eastern Oregon Support Group, Hermiston, OR

**AUGUST**
- August 2-8, 2015, Eastern Oregon Support Group, Hermiston, OR
- Sept. 10, 2015, Portland Support Meeting, Bulkinwille’s Family Fun Center, Wilsonville, OR
- Sept. 13, 2015, Eugene Support Meeting, Eugene, OR
- Sept. 19, 2015, HFO Annual Meeting, Oregon Zoo, 4001 SW Canyon Rd, Portland, OR
- October 25, 2015, Shooting for the Stars Fundraising Auction, Multnomah Athletic Club, Portland, OR

**NOVEMBER**
- November 13 – 15, 2015, HFO Women’s Retreat, Heathman Lodge, Vancouver, WA

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_The Hemophilia Foundation of Oregon has a new logo, and has moved. Our new contact information is:_

**office:** 456 SW Monroe Ave. #102, Corvallis, OR 97333  
**phone:** (541) 753-0730  
**fax:** (541) 753-0772  
**email:** info@hemophiliaoregon.org  
**web:** www.hemophiliaoregon.org

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**Hemophilia Walk 2015**

Join us for our 3rd Annual Hemophilia Walk on June 27, 2015! We are pleased to announce that we will be hosting this year’s Walk at the Howard M. Terpenning Recreation Complex which is a part of the Tualatin Hills Parks and Recreation District in Beaverton, OR. The Hemophilia Walk is the largest event dedicated to finding better treatments and cures for bleeding disorders, and to preventing the complications of these disorders through awareness, education, advocacy, and research. Last year we raised over $40,000. Your help and dedication this year will help us surpass last year’s achievement!

Much more than a fundraising event, the Oregon Hemophilia Walk will bring together individuals affected by bleeding disorders, their families, friends, support groups, and a diverse range of others who want to enjoy an amazing day at the Terpenning Recreation Complex while helping a worthy cause.

The Walk is about 2.5 KM in length (with options to go farther) and takes place along beautiful tree-lined paths and walkways throughout the complex. The Walk features food and refreshments, entertainment, exhibits, and fabulous giveaways! Community members and friends organize Walk Teams who hold special events throughout the year, raise funds and then proudly wear their colorful team shirts as they walk together in June! Most importantly, on Walk day everyone shares experiences, enjoys each other’s company, and has fun!

**REGISTRATION IS NOW OPEN:** Visit www.hemophilia.org/walk to sign up today. For more information please email Meghan McDonald at info@hemophiliaoregon.org.

**Bloody Run 2015**

Just before the Walk, join us for the second annual Run for Our Lives: The Bloody Run 5 mile race. It will be held at the same location as the Walk with registration beginning at 7:00 a.m. and the race beginning at 8:00 a.m. For just $25 you can participate in the race. Go to www.hemophiliaoregon.org to learn more about The Bloody Run.

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**From the Executive Director:**

Wow, what an exciting start to 2015! Change is the theme of 2015. We recently opened an office in Corvallis and have consolidated all of the storage, camp and administrative activity in one location. Shortly after moving in we experienced a leaky pipe that flooded our office. We have been in a state of turmoil ever since. We hope to have the mess cleaned up and be officially moved in very soon.

To go along with the theme of change, you probably noticed in this newsletter and on some of the correspondence you’ve received from HFO that we have introduced a new logo. The new logo sends a clear message that we represent bleeding disorders. It’s more in line with other organizations like ours across the nation. We will continue to phase it in to all of our documents, website, facebook page and so much more over the course of the next few weeks.

There continue to be exciting changes in the HFO staff as well. As you may know, I was able to move into the position of Executive Director on January 1, 2015 when Marita retired. Originally, Meghan McDonald assumed the role of Development/Events Manager but she has decided to pursue her dream of a career in dance. In her place, Kathleen Anderson, recently hired as the Administrative Assistant for HFO, has agreed to work full-time and cover her duties as well as organizing events. Good luck to Meghan and a big THANK YOU to Kathleen for assuming more responsibility in the organization.

HFO has so much to look forward to in 2015. The first annual Advocacy Day in Salem will be the highlight of the spring. In addition, we will be hosting numerous support group meetings, a Parents Empowering Parents weekend, a Couples Retreat, a Family Camp weekend and the 2015 Bloody Run and Hemophilia Walk.

We appreciate all of your comments and suggestions – we can’t always promise to implement everything that is suggested to us, but please feel free to share your thoughts with us. Warmest Regards, Madonna

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**HFO Mission Statement**

The Hemophilia Foundation of Oregon enhances the quality of life for individuals with bleeding disorders and their families through advocacy, assistance, outreach, education, and research support.

**HFO Website**

Please visit our website www.hemophiliaoregon.org and register as a member to receive information regarding upcoming events and programs. Thank you.


**NOW! Conference 2015**

For von Willebrand’s Disease

In a community that focuses so heavily on hemophilia, the NOW! Conference in Phoenix, Arizona is specifically designed for people affected by von Willebrand’s Disease. From attending lectures on dealing with this bleeding disorder to connecting with others all over the country who can relate to your stories and struggles, this all-ages event is a can’t-miss opportunity for everyone that has VWD.

My experience at NOW! (National Outreach for von Willebrand’s) with my mom was phenomenal. I attended the Teen Program where we spent our time discussing life with this bleeding disorder and advocating at a local mall. Not only did we experience the reality and importance of advocacy, but it gave us a chance to share our passion, stories, and obstacles. For the adult portion, they were given many options for different lectures or discussions they wanted to attend. My mom (who is unaffected) learned a lot of information that helped her understand my condition, how we can better manage it, and ways she can support me as I become more independent in my bleeding disorder.

This 3 day conference, generously sponsored by CSL Behring, was family-friendly and balanced education with entertainment. I would recommend this opportunity to everyone affected by VWD who is interested in meeting other affected families as well as learning how to make their everyday life more manageable.

Information on the NOW! Conference: http://www.ahemophilia.org/how

Thank you! Olivia DeSmonde, Age 14

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**Hemophilia of Oregon Day**

Friday, April 10, 2015

Hemophilia Foundation of Oregon will be hosting our first annual Oregon State Advocacy Day in Salem at the State Capitol. We are looking for interested individuals and families to join us for the day to speak to our elected officials about current and proposed legislation that could have an impact on those with bleeding disorders.

In preparation for our visit to Salem, HFO is hosting two webinars. The same information will be shared at both so please attend the one that works best in your schedule. Information about how to connect to the webinars will be emailed later.

Tuesday – April 7, 12:00 Noon, and April 14, 7:00 p.m.

Topics covered in webinars will include:

- **What to wear for the day**
- **How to tell your story as an elected official**
- **What points are we trying to share with your elected officials**
- **What role do our elected officials play in the world of bleeding disorders and how can we have an impact on their decisions**

Tuesday – April 14, 9:00 a.m. to 4:00 p.m.

We are asking all those affected with bleeding disorders, their families, caregivers, neighbors, teachers – anyone who experiences the challenges of living with a bleeding disorder to come to Salem this day and help us. We hope to have a large presence.

Please RSVP by April 3 to info@hemophiliaoregon.org if you would like to join us for the day. Once HFO has received your RSVP we will make appointments for you to visit with 3-4 elected officials throughout the day.

Please e-mail madonna@hemophiliaoregon.org for more information on travel and hotel room assistance. If there is enough interest we could arrange for a bus to and from Portland. Your support is greatly appreciated.

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**AmazonSmile**

Amazon’s website operates by Amazon that lets customers enjoy the same wide selection of products, low prices, and convenient shopping features as on Amazon.com. The difference is that when customers shop on AmazonSmile (smile.amazon.com), the AmazonSmile Foundation will donate 0.5% of the price of eligible purchases to the charitable organizations selected by customers.

How does AmazonSmile work? When first visiting AmazonSmile, customers are prompted to select a charitable organization from among almost one million eligible organizations. In order to browse or shop at AmazonSmile, customers must first select a charitable organization. For eligible purchases at AmazonSmile, the AmazonSmile Foundation will donate 0.5% of the purchase price to the customer’s selected charitable organization.

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**What is AmazonSmile?**

AmazonSmile, the charitable giving program from Amazon.com, asks customers must support their favorite charitable organization every time they shop. When first visiting AmazonSmile, customers are asked to designate the charitable organization that they would like AmazonSmile to support. By default, customers are given the option to support a charity from the AmazonSmile list, or to designate a different charity. Customers can change the charitable organization they support by logging into their Amazon account and clicking on the “Account & Lists” button, and then selecting “AmazonSmile.”

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**Parents Empowering Parents**

We are asking all those affected with bleeding disorders, their families, caregivers, neighbors, teachers – anyone who experiences the challenges of living with a bleeding disorder to come to Salem this day and help us. We hope to have a large presence.

Please RSVP by April 3 to info@hemophiliaoregon.org if you would like to join us for the day. Once HFO has received your RSVP we will make appointments for you to visit with 3-4 elected officials throughout the day.

Please e-mail madonna@hemophiliaoregon.org for more information on travel and hotel room assistance. If there is enough interest we could arrange for a bus to and from Portland. Your support is greatly appreciated.

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**What is PEP?**

• Parents Empowering Parents (PEP) enhances effective parenting skills for children with a bleeding disorder and educates and supports parents through discussion.

• You are invited to attend if you are a parent, grandparent, or a caregiver of a child with a bleeding disorder.

• PEP will provide a hotel room and all of your meals for the weekend. Lodging will be one room per couple or one room for a single parent.

• There will be no child care onsite.

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**Contact Us**

Dr. Minh Nguyen-Driver

Madonna McGuire Smith

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541-753-6750

nguyen@mco.edu

madonna@hemophiliaoregon.org

This event is funded by PEP (Parents Empowering Parents) and supported by the Hemophilia Center and the Hemophilia Foundation of Oregon.