

**Madam Chair, distinguished members of the Senate Health Committee, my name is Madonna McGuire Smith. I have the privilege of serving as the Executive Director of the Hemophilia Foundation of Oregon and I am here today to testify in favor of SB 1568.**

**The Hemophilia Foundation of Oregon represents nearly 500 families and individuals living with bleeding disorders in Oregon and SW Washington.** 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.

- **The two main bleeding disorders, hemophilia & von Willebrand Disease (VWD), are inherited bleeding disorders caused by a deficiency in proteins required for normal blood clotting.** Patients use products made from human plasma or animal cells to replace proteins and control clotting.
- Many bleeding disorder patients were exposed to HIV and Hepatitis C prior to 1992 when the screening of blood products became the standard.
- **It is estimated that as many as 70% of all individuals with bleeding disorders who used factor products before 1987 may have been exposed to HIV and as much as 90% were exposed to Hepatitis C.**
- **About 20,000 people are affected by hemophilia in the U.S. and approximately 1% of the U.S. population is affected by VWD.**

**My husband and three children live with vonWillebrand Disease. Two of my children are severe and require regular infusions of blood product. Often our blood product bills can be more than \$150,000 annually. Although we have this hereditary disease, my children live a relatively normal life doing all of the same things other kids do across the US. In fact, we are fortunate to be living in the time we do because those with bleeding disorders now experience the same life expectancy of someone without the bleeding disorders.**

**The intent of SB 1568 is to "prohibit discrimination based on age, expected length of life, present or predicted disability, degree of medical dependency or quality of life in determination of medical services". These protections are currently guaranteed in the Patient Protections and Affordable Care Act (ACA). It is important to make these into Oregon law because states can waive these protections in 2017.**

- Extending these protections against discrimination to all Oregonians who are insured or covered under state regulated health plans, including Medicaid and commercial insurance plans, and
- Ensuring state-level enforcement of anti-discrimination provisions is the right thing to do!

**As a mom of children with a chronic medical condition, I understand certain discriminations when it comes to my children participation in some activities that can be dangerous throughout their lives.** My son recently experienced discrimination in a school related situation. While it was difficult to understand as a family, we realize it was in the best interest of our son. He was applying to take part in a science trip to Costa Rica. The night before the names were to be announced we received a phone call from the organizing teacher. She wanted to warn us that after talking it over with the school district attorneys, administration and the Costa Rica camp managers, it was decided that our son wouldn't be able to attend

because of the risks. We discussed fighting the discrimination because of his bleeding disorder but decided it wasn't worth the fight. **There are times when discrimination is tolerable, not easy to take and difficult to understand, but tolerable.**

**When it comes to discrimination in medical situations is not acceptable. If someone were to decide to deny one of my children proper medical care because they have a chronic bleeding disorder it would be intolerable.** As stated earlier, people with bleeding disorders have the same life expectancy as anyone without a bleeding disorder. **SB 1568 would protect my children from medical discrimination in the future. Who has the right to deny someone proper medical care based on a perceived disability? SB 1568 doesn't mean that people will begin to dictate their medical care. On the contrary, Oregonians don't dictate their medical now, SB 1568 simply makes certain the current federal law is incorporated into state law and extended to all Oregonians.**