**(Chapter Name) and NHF Launch “Better You Know” Campaign**

* CDC-funded initiative aims to reach women and men in (State) and across the country who experience bleeding disorder symptoms, but have not been diagnosed

**Atlanta, December 12, 2016** – While few (Name of State Residents, e.g., Georgians) have ever heard of von Willebrand Disease (VWD), an estimated one percent of Americans[[1]](#footnote-1) – including more than (Number representating 1% of state’s 2016 population) (Name of State Residents) – have VWD, a genetic disorder that is caused by a missing or defective clotting protein in the blood called von Willebrand factor. Most cases of VWD are not serious, however, this disease can prevent the blood from clotting normally, and can result in extended bleeding after injury, surgery or trauma, and be fatal if not treated effectively.

To reach individuals at risk for VWD and other bleeding disorders, (Chapter Name) and the National Hemophilia Foundation today launched the “Better You Know” Campaign, developed in partnership with and funded by the Centers for Disease Control and Prevention (CDC). The campaign website – [www.BetterYouKnow.org](http://www.BetterYouKnow.org) – features tools and other information to learn whether you are at risk for a bleeding disorder and the next steps you can take to seek care.

The centerpiece of the site is a risk assessment tool,[[2]](#footnote-2) an anonymous, multiple-choice questionnaire that takes less than five minutes to complete. Women’s questions include whether their menstrual periods are heavy and long-lasting, while men are asked if their nosebleeds are frequent and prolonged. These are common VWD symptoms for women and girls, and men and boys, respectively. Moreover, while VWD occurs equally in women and men, women are more likely to experience its symptoms because of the increased bleeding it causes during their menstrual periods, during pregnancy and after childbirth.[[3]](#footnote-3) In fact, 30 percent of women in reproductive age experience menorrhagia, periods characterized by abnormally heavy or prolonged bleeding.[[4]](#footnote-4)

*OPTIONAL: FEATURE A SNAPSHOT & QUOTATION FROM A LOCAL PERSON WITH VWD VWD. BE SURE TO SECURE A SIGNED CONSENT FORM FROM HER & TO SHARE THE RELEASE WITH HER IN ADVANCE FOR REVIEW & EMAIL APPROVAL.*

Among (Name of State residents) who have von Willebrand Disease is (Name), a (Age) resident of (City or Town), who (Add one to two sentences on her journey with VWD). (Add a two-sentence quotation.)

“According to the CDC, it takes an average of 16 years from the onset of their bleeding symptoms for women to be diagnosed with VWD, which is unacceptable,” said (Chapter CEO/ED’s Name), (Title), (Chapter Name). “Together, we can and we must take VWD out of the shadows and into the light. If you – or someone you love – has symptoms of a bleeding disorder, visit [BetterYouKnow.org](http://betteryouknow.org/) today, use the risk assessment tool, and, if you suspect you may have VWD, seek care, get treatment and reach out to (Chapter Name). We’re here for you.”

**About bleeding disorders**

Bleeding disorders, a group of disorders that share the inability to form a proper blood clot, include hemophilia, von Willebrand disease (VWD) and rare factor disorders. They are characterized by extended bleeding after injury, surgery, trauma or menstruation. Improper clotting can be caused by defects in blood components such as platelets and/or clotting proteins, also called clotting factors. Currently there are no cures for bleeding disorders and treatment for these conditions varies, depending on their severity. For some bleeding disorders, there are clotting factor concentrates that can be infused prophylactically or on-demand at home, to prevent or treat bleeds. To learn more, visit

(Link to bleeding disorders section of Chapter website).

**About (Chapter Name)**

(Add Chapter boilerplate language). Additional information on (Chapter Name) can be found at (Chapter website URL).

**About the National Hemophilia Foundation**

NHF (the National Hemophilia Foundation) is a 501(c)(3) nonprofit organization dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy and research. Established in 1948, NHF has 53 chapters throughout the country. Our programs and initiatives are made possible through the generosity of individuals, corporations and foundations, as well as through a cooperative agreement with the Centers for Disease Control and Prevention (CDC). Additional information on NHF can be found at [www.hemophilia.org](http://www.hemophilia.org).

Contact:

**(Chapter Communications Contact’s Name, Cell & Office Telephone Numbers)**

(Chapter Communications Contact’s Email Address)

1. Centers for Disease Control and Prevention, “Von Willebrand Disease (VWD): Data and Statistics,” <http://www.cdc.gov/ncbddd/vwd/data.html>. Accessed November 20, 2016. [↑](#footnote-ref-1)
2. The risk assessment tools featured on [www.BetterYouKnow.org](http://www.BetterYouKnow.org) are in no way a substitute for a diagnosis from a qualified medical provider, and the information on the site is provided for general information only. Please see NHF’s full [Medical Disclaimer](https://www.hemophilia.org/About-Us/Medical-Disclaimer). [↑](#footnote-ref-2)
3. Centers for Disease Control and Prevention, “Von Willebrand Disease (VWD): Data and Statistics,” <http://www.cdc.gov/ncbddd/vwd/data.html>. Accessed November 20, 2016. [↑](#footnote-ref-3)
4. [El-Hemaidi I](https://www.ncbi.nlm.nih.gov/pubmed/?term=El-Hemaidi%20I%5BAuthor%5D&cauthor=true&cauthor_uid=18007127), [Gharaibeh A](https://www.ncbi.nlm.nih.gov/pubmed/?term=Gharaibeh%20A%5BAuthor%5D&cauthor=true&cauthor_uid=18007127), [Shehata H](https://www.ncbi.nlm.nih.gov/pubmed/?term=Shehata%20H%5BAuthor%5D&cauthor=true&cauthor_uid=18007127), “Menorrhagia and bleeding disorders,” [Curr Opin Obstet Gynecol.](https://www.ncbi.nlm.nih.gov/pubmed/18007127) 2007 Dec;19(6):513-20, <https://www.ncbi.nlm.nih.gov/pubmed/18007127>. Accessed November 20, 2016. [↑](#footnote-ref-4)