**HFA’s Community Research Portal and You**

1. **What is the HFA Community Research Portal?**
   The HFA Community Research Portal is a platform HFA will use to collect data for research on the bleeding disorders community to more effectively serve the needs of bleeding disorder patients and their families.

2. **Why Did HFA Choose to Use a Portal to Collect Research Data?**
   HFA set up the Portal using a grant from the Robert Wood Johnson Foundation through the Portal provider, Genetic Alliance. The White House Champions of Change for Precision Medicine honored the Portal platform for innovation. HFA selected to apply for our Portal because it is the research platform for the Robert Wood Johnson Foundation, the Food and Drug Administration (FDA), and PCORnet (National Patient-Centered Clinical Research Network).

3. **What Kind of Data Will HFA Collect on the HFA Community Research Portal?**
   Initially, HFA will collect privacy-assured, health information from bleeding disorder patients via the Portal. HFA will gather this information through survey questions but the Portal enables patients to share medical records and biological specimens as well.

4. **Who Can Use the Portal?**
   Initially, anyone with a diagnosed bleeding disorder (any type of hemophilia, von Willebrand Disease, platelet disorder, etc.), the caregivers of a child (under 18) with a diagnosed bleeding disorder, and any adult female who has a child with a bleeding disorder and knows, or believes, they are a carrier of a gene that causes hemophilia.

5. **Who Will Control Access to the Data I Provide?**
   The data you enter into the Portal is under your control. You control what data you provide, who has access to this data, and whether you want to delete that data entirely.

6. **Will My Data Be Safe?**
   The security of your data is of the utmost importance to HFA. The Portal uses bank level security for access. This includes using 256-bit Advanced Encryption Standard to collect and store your data in an encrypted state. All data that you provide is protected from unauthorized discovery, access, use and/or export through intense security protections in concert with specially designed user tools and services.

7. **How Do I Get Started?**
   Sign-up on the HFA Community Research Portal, http://bit.ly/2ni4qWT. Once you have an account, you can choose to participate in any survey on the Portal. The Portal is accessible by desktop and mobile computers using Apple iOS, Microsoft Windows XP or later, and Android operating systems, and all major Internet browsers, as well as mobile devices such as iPad, iPhone and Android devices.

8. **Will HFA Make My Data Available to Non-HFA Staff?**
   No, not without your consent. We cannot grant anyone access to your data on the Portal, only you can do that.

9. **How Do I Get Started?**
   We hope you will join the HFA Community Research Portal. Sign-up for a secure, personal account on the HFA Community Research Portal and complete the “Tell Us About You” survey. Please contact us with any questions at research@hemophiliafed.org.

For more information, contact us at research@hemophiliafed.org, or 202.675.6984.