



## Free Genetic Testing Initiative to be Available Nationally at Hemophilia Treatment Centers

October 2, 2013

- My Life, Our Future pilot phase successfully completed –
- Initiative aims to offer genotyping to all people affected by the disorder in the United States –
- May help improve treatment and care today, and advance future hemophilia research –

ANAHEIM, Calif.--([BUSINESS WIRE](#))--Today, a coalition of leaders in hemophilia advocacy and treatment announced the national rollout of [My Life, Our Future: Genotyping for Progress in Hemophilia](#), which offers genetic testing, or genotyping, to people with hemophilia, a rare genetic disorder that impairs the ability of the blood to clot properly. Following the successful completion of an eleven site pilot program, hemophilia treatment centers (HTCs) across the U.S., where the majority of people with hemophilia receive care, can now participate in the program and offer genotyping to the patients they serve.

*My Life, Our Future* is a partnership of the [National Hemophilia Foundation](#) (NHF), the [American Thrombosis and Hemostasis Network](#) (ATHN), [Puget Sound Blood Center](#) (PSBC), and [Biogen Idec](#) (NASDAQ: BIIB). Through genotyping, it is possible to identify the specific DNA mutation(s), or change(s), responsible for a person's hemophilia and provide potentially useful information about his/her bleeding severity or risk for inhibitors, a major complication of hemophilia that involves an immune response to treatment. Through *My Life, Our Future*, participants can also contribute their data and samples to a secure central research repository, which can serve as a roadmap to greater scientific understanding of the disorder.

"*My Life, Our Future* is a potential opportunity to shape the future of hemophilia treatment and care," said Val Bias, chief executive officer, NHF. "I urge all people with hemophilia to participate; by enrolling at a participating HTC, they have a chance to learn more about their disorder today while furthering scientific advances tomorrow."

Barbara Konkle, M.D., director of clinical and translational research, PSBC, emphasized the value of genotyping the entire hemophilia community and creating a robust data repository for future research. "By examining a large amount of genetic material rather than individual samples, we may be able to answer important questions such as why some patients bleed more than others or experience greater joint damage. Armed with this information, physicians may be able to better care for their patients and scientists may be able to develop more targeted treatments."

*My Life, Our Future* was initially rolled out to eleven HTCs as part of a pilot program. Since the initiation of that pilot, 275 people with hemophilia enrolled in *My Life, Our Future*, with the majority opting to contribute to the research repository. Diane Aschman, MS, president and chief executive officer of ATHN, is hopeful that HTCs across the country will participate and provide this valuable service to patients who would not otherwise have access to genotyping.

*My Life, Our Future* is the first program to make a free genotyping test widely available to people in the U.S. with hemophilia A and B. In contrast to many developed countries where genotyping is considered standard of care, only about 20 percent of people with hemophilia in the U.S. have been genotyped, largely due to cost and insurance coverage barriers.

"*My Life, Our Future* enables us to offer something valuable to our patients," said Lisa Baker, hemophilia nurse, Hemophilia Treatment Center of Central Pennsylvania at Penn State Milton S. Hershey Medical Center, a HTC participating in the program. "We have long known the benefits of genotyping but many of our patients couldn't participate due to cost or insurance restrictions."

"As part of Biogen Idec's enduring commitment to help address unmet needs in the hemophilia community, we are honored to be a founding partner of this long-sought and important initiative," said Glenn Pierce, M.D., Ph.D., senior vice president of Global Medical Affairs and chief medical officer of Biogen Idec's hemophilia therapeutic area, which is providing scientific collaboration and financial support for the program. The company will not have special access to the data or samples generated by the initiative.

### **About *My Life, Our Future*: Genotyping for Progress in Hemophilia**

*My Life, Our Future* is a partnership of the National Hemophilia Foundation (NHF), the American Thrombosis and Hemostasis Network (ATHN), Puget Sound Blood Center (PSBC), and Biogen Idec Hemophilia. The program offers a free genotyping test to people in the U.S. with hemophilia A and B. Over time, the program will be expanded to include potential carriers in their families. For more information and a list of participating hemophilia treatment centers as they become available, visit [www.MyLifeOurFuture.org](http://www.MyLifeOurFuture.org).

### **About The National Hemophilia Foundation (NHF)**

The National Hemophilia Foundation (NHF) is 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 is based in New York City with 51 chapters throughout the United States. NHF's programs, initiatives and events 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). For more information, visit NHF online at [www.hemophilia.org](http://www.hemophilia.org).

### **About The American Thrombosis and Hemostasis Network (ATHN)**

The American Thrombosis and Hemostasis Network (ATHN) is a non-profit organization committed to advancing and improving care for individuals affected by bleeding and thrombotic disorders. ATHN's mission is to provide stewardship of a secure national database, adherent to all privacy guidelines, which will be used to support clinical outcomes analysis, research, advocacy and public health reporting in the hemostasis and thrombosis community. ATHN represents over 130 Hemophilia Treatment Centers. More information is available at [www.athn.org](http://www.athn.org).

### **About The Puget Sound Blood Center (PSBC)**

Puget Sound Blood Center is an independent, community-based nonprofit organization with a tradition blending volunteerism, medical science and research to advance transfusion medicine and improve patient care. A recognized leader in transfusion medicine, the Blood Center serves patients in more than 70 hospitals and clinics in 14 Western Washington counties. Patients with leukemia, cancer, hemophilia, thrombosis, sickle cell disease and traumatic injuries depend on Blood Center research. PSBC has a state-of-the art laboratory with world-class expertise in hemophilia mutation analysis. More information is available at [www.psbcc.org](http://www.psbcc.org).

#### About Biogen Idec

Through cutting-edge science and medicine, Biogen Idec discovers, develops and delivers to patients worldwide innovative therapies for the treatment of neurodegenerative diseases, Hemophilia and autoimmune disorders. Founded in 1978, Biogen Idec is the world's oldest independent biotechnology company, and patients worldwide benefit from its leading multiple sclerosis therapies. For more information, please visit [www.biogenidec.com](http://www.biogenidec.com) or [www.biogenidechemophilia.com](http://www.biogenidechemophilia.com).

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