



# Press Release

## Patient Education Summits to Address Special Challenges of Hemophilia Patients and Their Families

Novo Nordisk Helps Provide Unique Opportunity for Patients to Connect and Learn from Others with the Disease

**Princeton, NJ (August 27, 2009)** – More than 160 families of patients living with a rare form of hemophilia are coming together at educational summits sponsored this fall by the National Hemophilia Foundation (NHF) and the Center for Biomedical Continuing Education (CBCE). For the fifth year, the Inhibitor Education Summits will connect patients and their families with expert healthcare professionals and fellow patients to address pertinent topics such as effective pain management, exercise and nutrition, financial security, and psychological wellbeing. The summits are supported by an educational grant from Novo Nordisk.

Hemophilia is a chronic, inherited bleeding disorder that occurs because certain blood clotting factors are missing or do not work properly. Spontaneous internal bleeding can occur, especially in the joints and muscles.

The 2009 summits will take place in Hollywood, C.A., August 27-30 and in Washington, D.C., September 17-20. These summits are the first and only events of their kind that focus specifically on patients with inhibitors. Inhibitors are rare, affecting approximately 800 to 900 Americans.<sup>i</sup> Inhibitors are a serious complication that can develop after treatment in as many as 30 percent of people with hemophilia, most commonly in young children.<sup>ii</sup> These patients develop antibodies (or inhibitors) that circulate in the blood stream and actually neutralize, or attack clotting replacements, resulting in an increased risk of bleeding, arthropathy (or joint disease), physical disability and death.<sup>iii</sup>

People living with this disease often navigate tremendous challenges, both physically and emotionally. Sid Ramirez, age 21, has lived with hemophilia his entire life. He developed inhibitors at the age of three. His condition led to significant problems with his knee joints, leaving Sid wheelchair bound by age 11. He underwent lateral knee replacement surgery as a teenager, which enabled him to walk again.

“The summits allow others living with inhibitors and their families to learn from each other’s experiences and from experts. No one can understand what you go through as well as those who have experienced it themselves and their families,”

said Sid. "Hemophilia has significance in the decisions I make, but I will not let it be the deciding factor." Currently enrolled in culinary school to pursue his lifelong passion for cooking, Sid is excited about the future ahead.

NHF Chief Executive Officer Val Bias has a special reason for participating in the summits. He's also a person with hemophilia.

"Education has been a cornerstone of the NHF, and the Inhibitor Education Summit is a prime example of that," said Bias, who will also speak at both summits. "We believe it is critical to be able to provide these kinds of programs that help patients and their families achieve greater success in managing inhibitors."

In addition to education for patients and caregivers, there is a comprehensive Youth Camp for children with inhibitors and their siblings. Children attending the Youth Camp will have the opportunity to show their parents all that they have learned during their time at "camp." There is also ample time for networking with other families and "ask the experts" sessions to interact with physicians and other key opinion leaders in the field. Since the Inhibitor Education Summits began in 2005, hundreds of families have benefited from this unique opportunity to learn and connect with others who share their experience.

"Comprehensive management of hemophilia with inhibitors is vital for maximizing the quality of daily life for patients with this difficult condition," said Dr. Guy Young, Director, Hemostasis and Thrombosis Center, Children's Hospital Los Angeles and co-chair of the summits. "The 2009 Inhibitor Education Summits provide patients and their families with the opportunity to learn effective management strategies, connect with expert medical professionals, and share experiences with other families." Dr. Leonard Valentino, Director, RUSH Hemophilia and Thrombophilia Center, RUSH University Medical Center, is also co-chair of the summits.

For more information about The Inhibitor Education Summits, log onto [www.inhibitorsummits.org](http://www.inhibitorsummits.org).

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

The National Hemophilia Foundation is dedicated to finding better treatments and cures for bleeding and clotting disorders and to preventing the complications of these disorders through education, advocacy and research. Established in 1948, the National Hemophilia Foundation has chapters throughout the country. Its 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).

### **About CBCE™ (The Center for Biomedical Continuing Education)**

The CBCE™ is a full-service provider of accredited CME/CE with a circular scope of capabilities. Since 1999, the CBCE has partnered with clinical experts in solid tumors and hematologic malignancies to develop and implement local, regional, national and international medical education initiatives designed to accelerate the adoption of best practices and clinical breakthroughs in oncology. The CBCE is

dedicated to creating rigorous educational programs at the forefront of science, customized according to the target audience. Our unique experience in oncology and hematology has resulted in an in-depth understanding of the nuanced working lives and learning styles of the specialists, nurses, and pharmacists involved in cancer care, an understanding that informs the development of all interventions.

The CBCE vision is to encourage healthcare professionals to commit to change and to define distinct outcomes in their practices that will improve patient care and quality of life.

### **About Novo Nordisk**

Novo Nordisk is a healthcare company with an 86-year history of innovation and achievement in diabetes care. The company has the broadest diabetes product portfolio in the industry, including the most advanced products within the area of insulin delivery systems. In addition to diabetes care, Novo Nordisk has a leading position within areas such as hemostasis management, growth hormone therapy, and hormone therapy for women. Novo Nordisk's business is driven by the Triple Bottom Line: a commitment to economic success, environmental soundness, and social responsibility to employees and customers. With headquarters in Denmark, Novo Nordisk employs more than 27,000 employees in 81 countries, and markets its products in 179 countries. Novo Nordisk's B shares are listed on the stock exchanges in Copenhagen and London. Its ADRs are listed on the New York Stock Exchange under the symbol 'NVO'. For global information, visit [novonordisk.com](http://novonordisk.com); for United States information, visit [www.novonordisk-us.com](http://www.novonordisk-us.com).

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### **References**

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<sup>i</sup> Centers for Disease Control and Prevention. Universal Data Collection Project.  
<http://www2a.cdc.gov/ncbddd/htcweb/index.asp>. Accessed August 24, 2009.

<sup>ii</sup> World Federation of Hemophilia. "Frequently Asked Questions about Hemophilia."  
<http://www.wfh.org/index.asp?lang=EN>. Accessed on August 20, 2009.

<sup>iii</sup> Brown, M. et al. (2008) "Health Related Quality of Life of Hemophilia Patients with Inhibitors." Presented at ISPOR 13<sup>th</sup> Annual Meeting, Canada.