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**NATIONAL HEMOPHILIA FOUNDATION LEADER
TO SPEAK IN ROCHESTER**

ROCHESTER, NY – The president and CEO of the National Hemophilia Foundation (NHF) will be in Rochester on Friday, June 17 for the Mary M. Gooley Hemophilia Center's annual meeting. Dr. Alan J. Kinniburgh was named to lead the national organization in January 2005. Previously, he served as the Senior Vice President of Research for the Leukemia & Lymphoma Society, overseeing the society's \$41.4 million annual research investment.

"Our affiliation with NHF dates back to 1953. When NHF chartered the Rochester chapter, we were the first chapter outside of New York City. As the first free-standing hemophilia treatment center in the country, as well as the NHF chapter for the Rochester region, we are pleased to host Dr. Kinniburgh in his new role with the national foundation," said Robert W. Fox, President and CEO of the Mary M. Gooley Hemophilia Center.

Dr. Kinniburgh worked in Western New York for 18 years, serving first as a cancer research scientist at Roswell Park Cancer Institute in Buffalo. He was the founding director of the institute's Laboratory of Molecular Diagnostics, a facility involved in gene analysis for clinical diagnosis of leukemia and lymphoma.

Currently, he also serves on the Department of Defense's Chronic Myelogenous Leukemia Integration Panel, an advisory panel that directs the department's chronic myelogenous leukemia grants program.

"Dr. Kinniburgh has been quite involved in research in his career, which bodes well for the future of hemophilia research," said Dr. Ronald Sham, the Hemophilia Center's medical director. "The integration of clinical research with individualized patient care is crucial to advances in the care of people with bleeding disorders."

One of the first major initiatives Kinniburgh instituted in his new position was to establish a Department of Public Policy within NHF. This was to address an immediate and critical need to focus on advocacy and public policy issues, such as threats to insurance coverage and access to products and health care. "Addressing these challenges in ways that are dynamic, strategic and forceful will be one of my top priorities," Kinniburgh said in February in announcing the creation of the department.

“Health care issues faced by everyone can be particularly intimidating to people with inherited bleeding disorders,” Fox said. “While our Center faces an uncertain financial future, we still see a growing hemophilia patient population under the age of 12, including increases in the number of newborns diagnosed with hemophilia over the past three years.”

The Mary M. Gooley Hemophilia Center is a not-for-profit organization whose mission is to improve the lives of people affected by bleeding disorders and iron overload. It is a diagnostic and treatment center established in 1959 by Mary Gooley. It was the first free-standing Hemophilia Center in the U.S. and served as a model for other treatment centers in the country.
