



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders

September 9, 2011

The Honorable Governor Mitchell E. Daniels
200 W. Washington Street, Room 206
Indianapolis, IN 46204

Re: Hemophilia Program

Dear Governor Daniels:

The National Hemophilia Foundation (NHF) is the nation's oldest and largest advocacy organization for people with bleeding and clotting disorders, including approximately 1200 Hoosiers, and is dedicated to ensuring that all consumers have access to high quality medical care and services, regardless of financial circumstances, place of residence, or other factors.

I am writing today in response to a recent decision by the Indiana State Department of Health to reduce funding for the Hemophilia Program by approximately 13%. This cut will have a devastating impact on the program and the many people it serves. Specifically, funding for this critical program is contained within the state's chronic disease fund. The program purchases health insurance policies through the state high-risk insurance pool (ICHIA) for otherwise uninsurable individuals affected by bleeding disorders. Currently, there are 32 individuals served by the program at a cost of approximately \$180,000 per year. The proposed cut reduces funding by \$23,000 and will result in a loss of health care coverage for 6-7 of these individuals. Further, this reduction will result in millions of dollars of uncompensated medical care being provided by disproportionate share hospitals across the state of Indiana since affected individuals will most definitely seek out these services.

Hemophilia is a rare genetic disorder that prevents blood from clotting normally. The main symptom is uncontrolled, often spontaneous, internal bleeding into the joints, which can result in pain, swelling and, if left untreated, can cause permanent crippling joint disease and in some instances premature death. The recognized standard of care involves preventative self administration of replacement clotting factor therapy in the home setting, often up to three times per week.

Clotting factor therapies are unique biologic products which are either plasma-derived or manufactured using recombinant technology. They require special storage, handling, and delivery by experienced specialists who have significant knowledge and experience in dealing with these products. The average cost of these medications for a person with severe hemophilia can range from \$250,000 - \$300,000 annually. This cost does NOT include physician or facility fees, nor does it include the cost of any other medications the individual may require to treat other health condition or co-morbidities such as HIV or Hepatitis C, which some individuals contracted as a result of contaminated blood products.

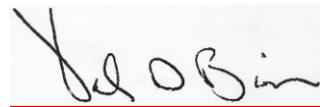
While we understand the State's need to limit its expenses and we support responsible use of public monies, under-funding of vital programs such as the state hemophilia program will actually lead to increased costs to the state and to reduced quality of life for the individuals in question. For example, impacted individuals will be forced to revert to the less effective and the more costly treatment option of receiving their care in a hospital setting, which will result in higher costs due to the addition of physician services, facility and other associated ancillary charges.

Both the state high-risk pool and Medicaid program have recognized significant cost savings over the years (i.e., ICHIA - \$8-9M per year; Indiana Medicaid \$4.5M per year) due to cost saving opportunities identified through the efforts of the local chapter of the NHF, Hemophilia of Indiana, and the Indiana Hemophilia & Thrombosis Center.

Access to health insurance coverage is not a luxury for a person affected by hemophilia and other bleeding disorders, but rather it can be the difference between life and death. Therefore, I urge you to intercede on behalf of these vulnerable individuals and reverse the Department's decision.

We thank you for allowing us to convey our concerns and for giving them your careful consideration. If you have questions, please do not hesitate to contact Michelle Rice, NHF's Regional Director of Chapter Services, at mrice@hemophilia.org or 371.517.3032.

Sincerely,

A handwritten signature in black ink, appearing to read "Val D. Bias", is written over a light gray rectangular background. A thin red horizontal line is drawn directly beneath the signature.

Val D. Bias
Chief Executive Officer