



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders
The Pennsylvania Chapters



April 6, 2011

The Honorable Tom Corbett, Governor
Commonwealth of Pennsylvania
225 Main Capitol Building
Harrisburg, PA 17120

Dear Governor Corbett:

We, the two Pennsylvania Chapters of the National Hemophilia Foundation, are writing to voice our strong concerns to you. Our organizations represent more than 2,000 Pennsylvanians with hemophilia, a rare bleeding disorder. We are concerned that your proposal to collapse several medical programs including hemophilia into one line item in the 2011-2012 state budget and then cut this line item by 43% will have disastrous effects on the people we serve. These actions will place an already vulnerable population at further medical, social and psychosocial risk.

The Pennsylvania Hemophilia Program, a model for other states and the federal government, has supported comprehensive, expert care to PA residents with hemophilia for 37 years. There are seven, state-recognized hemophilia treatment centers (HTCs) in Pennsylvania that rely on state support annually to provide medical care and services to more than 2,000 people with hemophilia.

State funding has helped to support dedicated and expert staff at multiple HTCs so that the most current, comprehensive care can be provided. As a result, hemophilia care has dramatically changed from supporting disabled children and adults to promoting individuals in achieving full, active, healthy lifestyles.

The hemophilia line item within the Department of Health budget ensures that patients have access to a multidisciplinary team of skilled care providers, highly specialized laboratory tests, and individual treatment plans to provide clotting factor concentrates necessary to prevent and treat repeated life and limb-threatening bleeding episodes. Comprehensive services include diagnosis, clinical management, orthopedic and dental care, patient education and counseling, and home factor infusion training and supervision.

In spite of this, state financial support for the Pennsylvania Hemophilia Program has continued to decrease. Over the past 16 years, the state appropriation for hemophilia has steadily declined. In FY92-93, \$2,418,000 was allocated to support HTCs within the Commonwealth. For FY 10-11, only \$1.595 million was allocated. This represents a 40% reduction in funding during which time enrollment at the 7 HTCs has increased by nearly 40%.

Simply put, reduction or elimination of the line item for hemophilia would increase health care costs to the Commonwealth. Hemophilia care is a highly-specialized field not widely understood by hematologists who

are not associated with HTC. Without adequate care, the cost of hemophilia treatment will rise tremendously, not only to treat the bleeding disorder, but also the multiple complications from irreparable joint and soft tissue damage from recurrent bleeding. Many individuals will no longer be able to work and provide their own insurance, and will become dependent upon Medicare and Medicaid, further increasing healthcare costs to the Commonwealth.

HTCs need to stay funded to reduce the risk of death from bleeding, to decrease the overall cost of hemophilia care, and to decrease health care utilization.

The Centers for Disease Control and Prevention (CDC) has determined that patients using HTCs have a 40% reduction in risk of death and complications. HTC care also provides substantial socioeconomic benefits to these patients and to the agencies paying for their healthcare by reducing resource utilization, increasing employability and lowering the cost of care. Patients need these HTCs to receive the specialized care necessary to avoid crippling complications from inadequate treatment and to remain productive citizens of the Commonwealth.

If state support is reduced or eliminated, we can expect the following:

1. Reduced services for those without safety net providers
2. Reduced services to a very vulnerable population in PA
3. Reduced services will result in poorer outcomes
4. Reduced services will result in loss of quality of life
5. Reduced services will fracture and dismantle coordinated care, the lynchpin for hemophilia care
6. Reduced services will drive some patients to emergency rooms, and increase morbidity and mortality.

We are requesting that full funding for these essential services be included in the Pennsylvania 2011-2012 state budget.

Sincerely,



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CC: ALL MEMBERS OF THE PENNSYLVANIA GENERAL ASSEMBLY

References:

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