NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders

September 22, 2011

Mr. Charles E. Lehman
Executive Director
Maryland Department of Health and Mental Hygiene
Office of Systems, Operations and Pharmacy
201 W. Preston Street
Baltimore, MD 21201

Subject: Comments Regarding Proposed Pharmacy Reimbursement Changes for the Medicaid Program

Dear Mr. Lehman:

For more than sixty years the National Hemophilia Foundation (NHF) and Hemophilia Foundation of Maryland (HFM), an NHF chapter, have both advocated for the needs of individuals affected by hemophilia and other bleeding disorders. Our efforts are intended to improve the lives and health of these individuals through advocacy, education and research. One of the most critical issues we are dealing with at the national and state levels are the ever-increasing threats to the ability of patients to access treatments and necessary services they need to maintain optimum health and a good quality of life. Among these threats are attempts by health insurance carriers to reduce reimbursement for clotting factor to levels that prevents some patients from accessing necessary treatments and services. Unfortunately, it has come to our attention that the Maryland Department of Health and Mental Hygiene (DHMH) is considering certain changes regarding pharmacy reimbursement under the Medicaid program that could potentially endanger access to care and treatment for beneficiaries with bleeding disorders.

We know the complexities involved in treating hemophilia and related bleeding disorders can result in high medical expenses for both the patient and their health insurance plan. It is thus understandable why some health insurance plans are exploring cost containment strategies such as managed care, utilization review, and new pharmacy reimbursement structures. However, it is also crucial that health care payers—public and private alike—consider the impact those decisions may have on members with complex medical conditions who needs continuous access to care and treatment.

As you may know, there is no cure for hemophilia and related bleeding disorders which often cause painful internal bleeding, debilitating joint and tissue damages, and sometimes death. The vast majority of affected individuals will require lifelong infusions of blood clotting factor therapies derived from plasma or recombinant technology. These biological products are not interchangeable. Simply put, no generics or substitutions exist. Moreover, unlike other medications bought at retail pharmacies, these unique therapies require refrigeration and specialized handling, and can only be dispensed through specialty pharmacies where employees are trained to handle these complex drugs and understand the varying medical and nursing needs of each patient.

All of these mitigating factors make hemophilia and other bleeding disorders costly conditions to treat. But when care is managed appropriately, individuals will often experience less bleeding and reduced levels of emergency room visitations, hospitalizations and a host of other co-morbidities and costly complications. This ultimately reduces long-term health care costs for both the patient and the health insurance plan. The key factor though is ensuring that patients have timely and adequate access to health care providers, both medical and pharmacy.

The DHMH's recent decisions concerning the implementation of the Average Actual Acquisition Cost (AAAC) pricing benchmark and the corresponding Myers and Stauffer LC, *Cost of Dispensing* survey, forces us to question the impact of these changes on our members. We are particularly concerned about the long-term effects of maintaining the current low dispensing fee levels once the State moves to implement the new acquisition costs benchmark. We have heard from many Medicaid providers who have said they may be forced to reduce or end services for Medicaid beneficiaries with bleeding disorders. This increases the potential risk of beneficiaries not getting their clotting factor therapies in a timely manner, or being forced to use providers with little or no experience managing specialty medications. Such an outcome would be detrimental to those with bleeding disorders who receive benefits through the State Medicaid program.

While we understand there's intense pressure on the DHMH to reduce costs, it is worthwhile to remember that the agency does have a responsibility to ensure that all beneficiaries have timely access to care and treatment. Therefore, **we would like to strongly urge the DHMH to give full consideration to the higher costs endured in the manufacturing and dispensing of clotting factor therapies by granting a higher weighting, larger dispensing fee or, at the very least, creating a separate pricing benchmark for pharmacies that dispense clotting factor therapies under the fee-for-service program.** The uniqueness of these therapies and higher costs warrants them being treated differently from other drug classes. More importantly, a separate pricing benchmark and higher dispensing fee would ensure fairer provider reimbursement, better reporting and closer monitoring of patients all while protecting access to care for vulnerable individuals. We realize that all of these changes will require collaboration among all stakeholders, so we would like to encourage the DHMH to work with us and the other Medicaid stakeholders to ensure that implementation goes efficiently.

We thank you for your consideration of our views on this very important issue, and look forward to working with you to find a workable solution to the issues addressed and for other situations that may arise. If you have additional questions or concerns, please do not hesitate to contact Ruthlyn Noel, NHF's Manager of Public Policy, at (212) 328-3730 or rnoel@hemophilia.org.

Sincerely,

Val Bias
Chief Executive Officer
National Hemophilia Foundation

Emma Miller
Executive Director
Hemophilia Foundation of Maryland

cc: Joshua M. Sharfstein, M.D., Secretary
Charles J. Milligan, Deputy Secretary of Health Care Financing