The New York State Hemophilia Advocacy Coalition (NYSHAC) strongly supports initiatives that promote system-wide changes in a manner that improves delivery of health care services while preserving access to care and services. We are especially encouraged by many of the recommendations put forth by the Medicaid Redesign Team (MRT), and believe this is a positive step toward enhancing care and services for all Medicaid recipients. However, we are concerned about the potentially harmful impact of some of the recommendations on New Yorkers living with bleeding disorders.

Proposal #11: Expansion of Medicaid Managed Care to Include Pharmacy

This cannot and should not be a one-size fits all initiative. Medicaid managed care plans have proven in some instances to be unable to ensure adequate care for individuals with complex health care needs. For example, various managed care plans have denied access to necessary specialty care and services for people with bleeding disorders, have contracted with providers who have little or no experience managing bleeding disorders, or have imposed restrictions that make it difficult for these individuals to access necessary care. The risk of having the same thing happen in New York is significant and has the potential for dire consequences.

People with bleeding disorders require access to health care specialists and service providers who are knowledgeable about treating and managing their conditions. These include not only highly specialized clinicians affiliated with Federally recognized hemophilia treatments centers (HTCs), but also specialty pharmacies whose employees are specifically trained in the complex handling of clotting factor products. We request that individuals with bleeding disorders be exempt from managed care plans until the State is able to guarantee that these plans can adequately and effectively provide the specialized care needed for this population.

Proposal #15: Limitations on Access to Prescription Drugs

This proposal consolidates various pharmacy fee-for-service recommendations, including initiatives to reduce pharmacy reimbursement and dispensing fees, eliminate the “prescriber prevails” provision allowing the State Medicaid Director to make final determinations regarding prior authorization, expanding the preferred drug list to include exempt drug classes, and change the reimbursement formula for clotting factor products. Many of the initiatives included as part of Proposal 15 are new additions by the Department of Health which were never included for discussions during the public hearings. The changes to reimbursement for clotting factor products are one such example. We ask the Legislature delay implementation of the changes to reimbursement for clotting factor until it can be demonstrated that these changes will not impede access to these life-saving treatments. We do not believe this will increase costs to the State given that MRT has determined the proposal to be cost-neutral.

Further, stripping the “prescriber prevails” protection that ensures that a doctor’s decision regarding a specific treatment be honored could jeopardize the health of Medicaid recipients with bleeding disorders.
We are especially concerned about the possibility of patients with bleeding disorders being relegated to a “fail first” approach, also known as step therapy, where access to a drug the physician determines will work best for that patient is denied until the patient “fails first” on so-called “preferred drugs” which are often less costly but may not be as effective. Individuals with hemophilia and other bleeding disorders require lifelong infusions of clotting factor to replace missing or deficient blood proteins. These are biological products for which there is no generic or therapeutic equivalent. Each product has unique characteristics that often result in varying effectiveness and tolerability from individual to individual, as explained in the attached document by National Hemophilia Foundation’s Medical and Scientific Advisory Council (MASAC).\(^1\) It is thus essential for every individual with bleeding disorders to have access to the full range of clotting factor therapies, allowing the physician to determine which therapy will work best. Not having timely access to life-saving products could have consequences for the health and well-being of these individuals and for public health. This may also lead to an increase in overall health care costs should delayed access to the most appropriate therapy result in hospitalization, immune responses, or other complications. For these reasons, we respectfully request that lawmakers maintain “prescriber prevails” protections for individuals with hemophilia and other bleeding disorders.

**New Addition: Ensuring Coverage for Outpatient Products and Services**

Any discussion of Medicaid Redesign and reducing costs must include coverage provided to individuals through Child Health Plus, Family Health Plus and Healthy New York, three programs tightly linked to the Medicaid system and the State’s “safety net” for at-risk and underserved populations. Presently, these programs do not cover clotting factor products and related services when they are provided on the generally preferred and less costly outpatient basis. This leaves Medicaid as the only insurance option for many individuals, and limits employment options for many individuals as well. The ability to manage bleeding disorders at home instead of in the hospital setting has vastly improved the health, well-being and quality of life for individuals with bleeding disorders and is often therefore generally the preferred model of care. We believe that allowing access to outpatient therapies and services can ultimately reduce the number of individuals on Medicaid.

We ask that the Legislature pass pending legislation mandating that Child Health Plus, Family Health Plus, and Healthy New York programs cover outpatient blood clotting factor concentrates as well as other treatments and services necessary for individuals with hemophilia and other clotting protein deficiencies.

NYSHAC looks forward to working with the Legislature to assure that New Yorkers with bleeding disorders will have access to the care and services they need to stay healthy and be productive members of society.

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1. MASAC is a world renowned group of medical experts which establishes quality of care guidelines for the treatment of hemophilia and other bleeding disorders in the United States.