



WRITTEN TESTIMONY

In Support Of

LD 372: An Act To Provide Maine Children Access to Affordable Health Care

Tracey Gideon

Executive Director, Hemophilia Alliance of Maine

and on behalf of the New England Hemophilia Association and the New England Bleeding Disorders Advocacy Coalition

Before the Committee on Health and Human Services

Wednesday, February 24, 2021

Provided to: HHS@legislature.maine.gov

Senator Claxton, Representative Meyer - and members of the Joint Standing Committee on Health and Human Services:

My name is Tracey Gideon, and I am offering this written testimony today on behalf of the Hemophilia Alliance of Maine (HAM), the New England Bleeding Disorders Advocacy Coalition (NEBDAC), the New England Hemophilia Association (NEHA), as well as the bleeding disorder community here in Maine. HAM is a state-wide non-profit organization whose mission is to assist and enhance the quality of life for Maine's people and families who have a bleeding disorder. NEBDAC and NEHA provide advocacy and education about bleeding disorders in all 6 New England States.

I urge your support for LD 372, a bill which offers important adjustments to the Cub Care program, including modifications to eligibility, waiting periods, and coverage.



As you may know, people affected by bleeding disorders have complex, lifelong medical needs. They depend on prescription medications (clotting factor or other new therapies) to treat or avoid painful bleeding episodes that can lead to advanced medical issues. They also rely on expert care from specialist providers, including those at federally-recognized hemophilia treatment centers (HTCs). Treatment for bleeding disorders, including clotting factor and non-factor replacement therapies, prevents and stops bleeding episodes that can be painful, dangerous, and sometimes deadly. These medications, while expensive, are essential to everyday functioning and it is essential that young Mainers with a bleeding disorder do not lose access to treatment, even for short periods of time. Without access, young Mainers end up in the emergency room, with disabling conditions, and with enormous medical bills. It is imperative to have access options for our community.

We believe this bill will improve access for young Mainers, especially during a global pandemic, when many families and young Mainers are at risk of losing their employment based insurance, or have lost employment hours, income, and the ability to afford necessary health care. Expanding eligibility for Cub Care, removing the waiting period for enrollment, and repealing premiums – as proposed by LD 372 – will remove barriers to care, protecting the health and security of children with bleeding disorders and their families. I urge your support for these important changes, thank you for your public service, and would be happy to speak with you further about issues impacting the bleeding disorders community here in Maine and New England.

Tracey Gideon, Executive Director
The Hemophilia Alliance of Maine