



Testimony of The Leukemia & Lymphoma Society

In favor of LD 1539 "An Act To Provide Access to Fertility Care"

May 5th, 2021

The Leukemia & Lymphoma Society (LLS) is pleased to submit the following testimony to the Joint Standing Committee on Health Coverage, Insurance, and Financial Services in favor of LD 1539 "An Act To Provide Access to Fertility Care".

At LLS, our mission is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. LLS exists to find cures and ensure access to treatments for blood cancer patients.

Many of those blood cancer patients are young adults. Blood cancers, including leukemia, non-Hodgkins lymphoma, and Hodgkins lymphoma, are among the most common types of cancer diagnosed in children and young adults, and leukemia alone accounts for nearly a quarter of all cancers diagnosed in people under the age of 20.¹

The good news is that advancements in research and treatment of these conditions have led to significant improvements in survival rates for pediatric cancer patients. However, fertility preservation is an essential consideration for pediatric and young adult blood cancer survivors. Blood cancers and their treatments, particularly cell transplants, carry a significant risk of infertility.² LLS views LD 1539 as a medically responsible and compassionate proposal to help these survivors preserve their parenting options more fully.

Even with comprehensive insurance coverage, blood cancer patients can face significant treatment costs, particularly in the twelve months following diagnosis.³ No patient, or parents of a young patient, should be put into a position where they have to weigh the additional costs of fertility preservation services that are only necessary as a result of their cancer treatment against the costs of the treatment itself.

Sally Ekus, a member of the board of LLS' New England chapter, is herself a childhood blood cancer survivor, and shared her story for the Committee's consideration:

¹ "Childhood Blood Cancer Facts and Statistics." The Leukemia & Lymphoma Society. Available at: <https://www.lls.org/facts-and-statistics/overview/childhood-blood-cancer-facts-and-statistics>

² Loren, Alison W., and S. Senapati, "Fertility preservation in patients with hematologic malignancies and recipients of hematopoietic cell transplants." *Blood*, 2019. Available at: <https://ashpublications.org/blood/article/134/9/746/260765/Fertility-preservation-in-patients-with>.

³ "The Cost Burden of Blood Cancer Care." Milliman Inc. for The Leukemia & Lymphoma Society. October 2018. Available at: <https://www.lls.org/sites/default/files/Milliman%20study%20cost%20burden%20of%20blood%20cancer%20care.pdf>

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**BEATING
CANCER
IS IN
OUR BLOOD.**



My name is Sally Ekus and I am a childhood leukemia survivor. I was diagnosed with acute lymphoblastic leukemia (ALL) when I was just 3.5 years old. I went through over two years of intense chemotherapy.

Two years of chemotherapy.

Please let that really sink in. We have just been through a year of quarantine, now imagine doubling that time—that's how long I went through chemo when I was just pre-school age.

Guess what? The treatment worked and I have been cancer free for more than 30 years. Truly a miracle! That said, when I went through treatment my parents asked how these chemical body bombs would affect my growing body. There was speculation by the doctors but no real answers. It would be years before we would know if I would get my period (I did) and even longer before we would know if I could ever get pregnant. We were told my treatment could affect my fertility and there was no way to know for sure.

Fast forward to September of 2019, after 39 weeks of carrying a healthy pregnancy, I welcomed my daughter, Maybelline into my arms. Now, along with being a childhood cancer survivor, a sister, a business owner, a friend, and an LLS advocate, I can proudly add "mother" as an identifier. Parenthood comes in many forms, some biological. Every single cancer pediatric cancer patient deserves to explore parenthood without boundaries. Having cancer is scary enough. Absolutely ANYTHING that can be done to make the transition into survivorship more easeful and equitable is a social responsibility.

We urge the members of the Committee to vote **ought to pass** on this bill.

If you have questions about LLS's position on this matter, or would like further information from LLS, please contact Steve at steve.butterfield@lls.org or 207-213-7254.

Sincerely,

Sally Ekus
Board member, New England Chapter
The Leukemia & Lymphoma Society

Steve Butterfield
Regional Director Government Affairs
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