Linda Homer Southwest Harbor LD 1883

Senator Bailey and Representative Kristi Mathieson and other members of the Joint Standing Committee on Health Coverage, Insurance and Financial Services,

I support LD 1883: An Act To Enact the All Maine Health Act

My name is Linda Homer, I live in Southwest Harbor, Maine, and I have a pre-existing condition.

My sister had Stage 4 Metastatic Malignant Melanoma at age 24 and because of this I was checked extensively for skin cancer: a lot! At one of these preventative visits my physician found a "suspicious bump"... and then another and another, and another. After multiple excisions of these similar lesions, and biopsies, and additional testing I learned that I have a genetic mutation that leaves me with a predisposition to a very rare and aggressive form of kidney cancer. Therefore, it is extremely important that I be checked yearly to detect any tumors or changes in kidney cysts. I can not skip these cancer screenings under any circumstances as I have been told that by the time any symptoms appear, it would be too late to treat. An MRI, CT Scan and/or Ultrasound are required at every visit. I will need to be monitored this way for the rest of my life.

Several years later at an exam it was suggested that I have my children genetically tested, and all three of them tested positive for this same gene mutation. They too have to undergo the same annual cancer screening, and will for the rest of their lives.

With the threat of repeal of the Affordable Care Act, loss of protections for pre-existing conditions, possible lifetime or monetary caps on policies, denial of coverage for pre-existing conditions, and ever increasing cost of medical care – our lives would change dramatically and, quite frankly, put us in jeopardy.

Before the Affordable Care Act was enacted we paid over \$20,000 a year – my entire salary – JUST for insurance premiums, not even including any testing or medical care! If the ACA is repealed or reduced and we don't pass this bill, I and my family will be put back in that situation...along with many other Mainers.

We need to have a healthcare plan where we can choose our own physicians. It is close to impossible to find any doctor that has even heard of our condition, let alone one who understands what to look for and how to treat it. How can we have confidence in a physician who has never even heard of this genetic mutation?

For the same reasons I cannot count on someone on the other end of the insurance company to make a determination as to whether this testing is necessary and covered. We do not have the luxury to skip the diagnostic testing if someone decides it isn't covered, or if the copays and deductibles are too high.

My children and I have a rare genetic condition that is currently only being actively studied and treated in a very few places - fewer and fewer as HHS and the current administration cut research programs around the country. I remember Elizabeth Edwards, wife of Senator John Edwards, speaking once about her cancer treatment and the shortcomings of the healthcare system in the United States. She stated how lucky and privileged she was to be able to go where ever she wanted for care. She chose Johns Hopkins because, she said, "WHERE you go makes ALL the difference" (and can be the difference between life and death). She explained that it matters because you want to go to a provider where they see YOUR particular disease or condition on a daily basis and they have a lot of experience treating it.

The fact that we have to worry about this condition AND the possible outcome is scary enough. Adding the fear of not being able to get needed testing and treatment because we can't afford it is beyond comprehension. I think about this all the time. I am not so afraid for myself as I am for the lives of my three children. It is not fair to penalize us, or force our family into medical bankruptcy, because of something we were born with.

Without a universal healthcare system or affordable healthcare we will have no options, and will most likely just become another statistic.

I am asking you to vote "ought to pass" on LD 1883.

Please help us and other Mainers like us!