

Kati Pelletier  
Indian Purchase TWP

May 5, 2021

Committee on Health Coverage, Insurance and Financial Services  
100 State House Station  
Augusta, ME 04333

Dear Senator Sanborn, Representative Tepler, and members of the HCIFS Committee,  
I strongly support LD 1539, An Act to Provide Access to Fertility Care and ask that you vote "ought to pass".

I am writing to you, because I represent an underreported side of infertility treatment. I am a genetic carrier for Menkes Disease. If you have never heard of it, I encourage you to google the disorder. It is a terminal X-Linked recessive gene that affects copper transportation on the ATP7A gene. I am a hereditary carrier for this disorder, and 50% of any boys I carry will be affected by this disorder, and 50% of any girls that I bear will carry this disorder into the next generation. In order to have more children, I would have to use fertility services in order to have genetic testing prior to implantation. The genetic testing alone is an extra \$6,000-\$8,000 on top of the cost of IVF, and my husband and I already have a high deductible (\$8,000 + 70/30 cosurance) on our commercial health insurance. It is a preexisting condition, but my insurance company will not cover these services. The cost of having another child in total, is roughly \$35,000. I am a pediatric registered nurse, a United States Air Force Veteran, and my husband is a logger in Northern Maine. We are a middle class family trying to build our family, but it has been challenging for us to say the very least.

My son Nathan was born, unbeknownst to us, with Menkes Disease. When he was six weeks old, he began having absence seizures. By four months old he began having infantile spasms. He was having 400-600 spasms per day. Each spasm damages the brain. He began regressing in development significantly and was in pain. By eight months, he was diagnosed and we were informed that his life expectancy would be 3-5 years. By one year he had a gastric tube placed as he couldn't eat anymore. He now has a tracheostomy and is vent dependent in order to breathe and requires 24/7 nursing care. He cannot walk, talk, or sit up on his own. The cost of his care is astronomical to our insurance company, the Katie Beckett program and to us as a middle class family. We desperately want to have more children, but without IVF and preimplantation genetic testing we will never be able to.

Thank you for your time and consideration to provide access to fertility care for many individuals and couples who rely on fertility treatments to build their families.

Sincerely,  
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