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Testimony of Representative Colleen Madigan, sponsor of
LD 228, An Act to Require Substance Use Disorder to Be Disclosed as a Cause of Death on
Death Certificates

Before the Joint Standing Committee on Health and Human Services

Greetings Senator Baldacci, Representative Meyer and esteemed colleagues of the Health and Human Services Committee. My name is Colleen Madigan and I represent House District 64, which includes parts of Waterville and Winslow. I am here today to present **LD 228, An Act to Require Substance Use Disorder To Be Disclosed as a Cause of Death on Death Certificates**. This bill comes out of events that happened in my family. I didn't know it was a problem until I looked into it.

On January 6th, 2022, my sister died from alcohol withdrawal. I was holding her hands, about to help her with her shoes so we could go to the ER when the withdrawal seizures started. I held her as I called 911. When the EMTs arrived, she was too dehydrated for them to find a vein to get the medicine in her to stop the seizures. She went into cardiac arrest. She was revived by the defibrillator and CPR before she was transported to the ER. About 12 hours later, she was dead. It had all happened before my eyes. The doctor in the ICU explained she had no brain stem activity and would never breathe on her own. She recommended that the breathing tube be removed and we let her go. The doctor was with us as we did just that. I wept as I asked the doctor if her death certificate would list alcohol withdrawal as her cause of death. She said no; it would not. Perhaps that seems like a strange question to you as your sister is dying. But it didn't seem strange to me at all. My family and I had spent so long trying to get help for my sister, trying to get someone to listen. We felt like no one wanted to talk about substance use disorder. We felt like it should be on her death certificate. Not because of some desire to label her, but as an acknowledgement alcohol use disorder is a disease and sometimes it wins.

My sister's death certificate lists cardiogenic shock and multiple organ failure as the cause of her death. But make no mistake. My sister died of alcohol withdrawal. That's what started the cascade of gruesome events. Alcohol was a contributing factor in her death in numerous ways. So why shouldn't it be on her death certificate?

I looked into this more. I discovered that in Maine, and nationally, alcohol related deaths have risen dramatically. They were rising prior to the pandemic and have since risen more. I also discovered that we likely undercount these deaths. We undercount them because we don't always accurately list substance use disorder as contributing to someone's death. This leads our own statisticians at the Maine CDC to have to extrapolate some information from death certificates.

I think part of the reason we do not proactively put SUD on death certificates is our own unconscious bias and stigma. I have no doubt that some family members would be horrified to have alcohol use disorder or alcohol withdrawal listed on their loved one's death certificate. But why? We cannot break the stigma unless we are willing to talk about this. My surviving sister and I believe that our sister suffered enough in shame. We are not ashamed of her. Alcohol use disorder was not who she was. But it did kill her. Our fight to save more lives of those with substance use disorder will not get better unless we can talk openly of this. That includes being open and honest about how people die from Substance Use Disorder. Sometimes I feel like I keep talking about gross and tragic things. And I guess I do. But people need to know just how gruesome and tragic the end of substance use disorder is. Coffee grounds vomit is when blood and stomach acid mix. I hope you never have to clean it up. And when blood becomes too acidic because your one kidney is failing, it's not a fun sight to see your loved one go through. It cannot get better unless we can collect more accurate data about how many people it is killing and how.

In closing, I would like to suggest one possible amendment. I believe that the Maine CDC office that gathers data regarding substance use disorder mortality and morbidity needs to have better access to data. I suggest an amendment that allows de-identified data to be shared, access to claims data and the funding to make this possible.

I would be happy to answer any questions.