

## **Support: LD 1301, “An Act to Prohibit the Use of Artificial Intelligence in the Denial of Health Insurance Claims**

Good afternoon, Senator Tipping, Representative Gramlich, and honorable committee members.

My name is Karen Angeline, from Brunswick, here to support LD 1301. I’m testifying on Zoom because I’m the 24-7 sole caregiver for my daughter, who is seriously ill, and there is no respite care available for me to leave her.

My 31 year old daughter has Down syndrome. She was an active, joyful member of the Brunswick community before she became sick. But almost overnight, she changed completely. She could barely move, speak, eat, and drink. She was disappearing before my eyes.

She appeared to have an autoimmune disease called Down Syndrome Regression Disorder (DSRD). It used to be called early Alzheimers. Fortunately, this disease can now be treated, and the National Institute of Health is conducting a clinical trial on it.

Once the diagnosis of DSRD was confirmed, the neurologist prescribed intravenous immunoglobulin (IVIG). He described DSRD to United HealthCare, included citations for five peer reviewed articles, and linked to the NIH trial.

But the prior authorization was immediately denied. The rejection letter made no sense to me. It read:

“You asked for intravenous immune globulin. This is for treatment of Down Syndrome.”

That is blatantly incorrect. There is no treatment for Down syndrome, and we didn’t ask for one. We asked for treatment for a disease called Down Syndrome Regression Disorder.

It just didn’t seem like the neurologist’s evidence was read by a human being, given that we were being denied a treatment that we didn’t even ask for.

Meanwhile, my daughter was developing severe catatonia, a consequence of DSRD. By January 2024, the catatonia was life threatening and she required emergency hospitalization.

Five and a half months after diagnosis, I contacted the Appeals and Grievance Unit of my state’s Insurance Administration. The Assistant Chief Investigator started working on my daughter’s case. And UHC lied to her, saying that my daughter was already receiving IVIG.

Once I had proven that this was, in fact, not true, the Investigator was able to get approval for my daughter to begin receiving IVIG within 48 hours.

I asked the investigator if our case had ever been considered by a human being, but because the investigation was a quasi-legal process, I was not allowed to know any details except that we had won.

No family should go through this. Only 2% of people who are denied prior authorizations are able to get the rulings reversed. I was one of the lucky ones.

But my daughter is significantly sicker and her care continues to cost far more than it would have if she had received treatment promptly, not to mention how much unnecessary suffering we have endured.

Thank you for your time, and I am happy to answer any questions.