

Testimony for LD1540

I am a pediatric palliative care nurse practitioner who has worked with hundreds of children and families living with complex chronic conditions who also face serious crises from time to time. One such patient is Reilly who is now 18 years old and has a rare genetic condition. He communicates with his loved ones with his eyes, gestures and occasional vocalizations. He is wheelchair bound except for rare occasions when he can ambulate, with assist, a short distance. All his nutrition and medications are given through a tube. He needs care 24/7 which is mostly provided by his parents. They have never been able to fill his allotted 'care hours' with health care providers. Parents and guardians such as Reilly's deserve validation of their expert care, as well as reimbursement. I fully support there being minimal barriers to their certification and payment for care they tirelessly and passionately provide for their children, our Maine children.

Janet Duncan
Portland
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