

January 25, 2018

Dear Health Care Committee Members,

I have oculopharyngeal muscular dystrophy (OPMD). Since OPMD is linked to French Canadian ancestry, there is a high concentration of people with OPMD living in New England,¹ and by extension, there are many who live in Vermont. The symptoms occur in midlife and include atrophy of the muscles of the eyelids and the esophagus, resulting in drooping eyelids (ptosis) and difficulty swallowing. Repair of ptosis caused by OPMD is now routine and is performed in most patients with OPMD.² This is because without surgical treatment, the ptosis can progress to the point where the eyelid is nearly covering the pupil, resulting in difficulty performing activities of daily living, including driving and working.³ A simple, low-cost, routine, and widely performed surgery would enable me to continue working and to remain a contributing member of society.

Despite the fact that the insurance handbook I received from Blue Cross Blue Shield of Vermont says that reconstructive surgery is covered, the surgery that is necessary on my eyelids is a contract exclusion “even if medically necessary.” What this means is that I could become functionally blind due to the severity of ptosis, and therefore disabled, because they refuse to pay for a surgery that costs around \$5,000. This is unconscionable, both because of the impact withholding this surgery has on my life, but also because disability would be an unnecessary waste of taxpayer dollars. While I am presently able to hold my eyelids open enough to function by contracting the muscles in my forehead, the ptosis will increase over time and this compensatory mechanism will no longer be sufficient. A visual field test revealed that I couldn’t see the upper portion of my visual field when my forehead muscles are relaxed. When these muscles tire, my vision is affected.

As a way to compensate for severe ptosis, patients with OPMD will tilt their heads back in order to see. This can aggravate swallowing difficulties resulting in aspiration pneumonia;⁴ this is why surgery for ptosis can literally be lifesaving.

Please consider this testimony as evidence that even with health insurance people are denied treatment that is medically necessary with consequential impacts to health and productivity.

Sincerely,
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References

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