



Alone we are rare. Together we are strong.®

March 11, 2026

Chair Alyssa Black  
Vermont General Assembly  
115 State St  
Montpelier, VT 05633

Representative Patricia McCoy  
Vermont General Assembly  
115 State St  
Montpelier, VT 05633

Representative Francis McFaun  
Vermont General Assembly  
115 State St  
Montpelier, VT 05633

**Re: Updated NORD Comments on H.585 §5 Short-Term Limited Duration Plans & §9 Repeal of Copay Accumulator Protections**

Dear Representative McCoy, Representative McFaun, and Chair Black,

As discussions continue in Committee on [H.585](#) the National Organization for Rare Disorders ([NORD](#)) submits the following updated comments to reflect the latest bill iteration.

With regard to “Expanding Access to Short-Term, Limited-Duration Plans (STLD),” and efforts to align Vermont statute with the updated federal short-term plan rule issued in September 2024, NORD again strongly encourages the committee to codify existing regulatory consumer protection language.

**Short Term Plans Consumer Protections Using Existing Vermont Regulatory Language**

If §5 advances, NORD respectfully offers the following addition, drawn verbatim from existing Vermont regulations ([CVR 21-020-072](#)), to ensure current consumer protections remain intact:

*( ) In addition to complying with all insurance requirements and benefit mandates as set forth in 8 V.S.A. Chapter 107 and 18 V.S.A. Chapter 221, every policy of short-term, limited-duration health insurance delivered or issued for delivery in this State:*

- 1. Shall include a process for subscribers to appeal adverse benefit determinations that complies with the requirements of 8 V.S.A. § 4089f and Department Regulation H-2011-02;*
- 2. May not contain a provision purporting to reserve discretion to the insurer to interpret the terms of the contract or to provide standards of interpretation or review that are inconsistent with the laws of this State. Any such policy, contract, certificate, or agreement shall be null and void to the extent it conflicts with this subsection, pursuant to 8 V.S.A. § 4062f;*
- 3. Shall not contain an exclusion or limitation for pre-existing conditions or a waiting period on the coverage of pre-existing conditions.*

In August 2025, federal agencies announced they would deprioritize enforcement of existing federal STLD rules<sup>1</sup>. With reduced federal oversight, state-level protections now serve as the primary safeguard for patients. We appreciate your consideration of these comments and stand ready to serve as a resource as this legislation moves forward.

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<sup>1</sup> US Department of Labor, Health and Human Services, and Treasury STLD <https://www.dol.gov/index.php/agencies/ebsa/laws-and-regulations/laws/affordable-care-act/for-employers-and-advisers/short-term-limited-duration-insurance/stldi-statement-08-07-2025>

### **Prescription Drug Out-of-Pocket Costs (§9)**

Section 9 of H.585 would repeal Vermont's separate annual out-of-pocket maximum for prescription drugs (8 V.S.A. §4092(b)). NORD is deeply concerned with this repeal. For rare disease patients, who often depend on high-cost specialty medications, the existing drug-specific out-of-pocket cap provides a critical layer of financial protection beyond the general plan maximum. Removing it could expose patients to substantially higher annual drug costs.

Innovative treatments are allowing many rare disease patients to live longer, healthier lives. Unfortunately, the cost of these medications can be excessively high, placing them out of reach for many individuals who need care. According to a May 2025 Kaiser Family Foundation poll, one-third of adults (33%) reported taking cost-saving measures with their prescription medications in the past 12 months, including not filling a prescription due to cost, cutting pills in half, or skipping doses<sup>2</sup>. For rare disease patients, who may have no therapeutic alternatives, cost-driven non-adherence is not simply an inconvenience: it can be life-threatening.

NORD urges the committee to retain the separate annual prescription drug out-of-pocket maximum in state law.

We appreciate your consideration of these comments and stand ready to serve as a resource as this legislation moves forward.

Sincerely,



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<sup>2</sup> 2025 Brief American's Challenges with Health Care Costs, (2025, Dec 11). KFF <https://www.kff.org/health-costs/americans-challenges-with-health-care-costs/>