



April 13, 2017

Nevada State Senate
401 South Carson Street
Carson City, NV 89701-4747

Re: SB 265 Letter of Concern

Dear Nevada Senators:

The National Organization for Rare Disorders (NORD) would like to express concerns regarding Senate Bill 265.

NORD is a leading voice of the rare disease community dedicated to helping people with rare “orphan” diseases and assisting the organizations that serve them. Any disease affecting fewer than 200,000 Americans is considered rare. There are an estimated 7,000 rare diseases in existence that affect over 30 million Americans. We strongly believe that every one of these patients deserves access to quality and affordable care.

SB 265 may unintentionally threaten that access to care. Advance notice on price increases could lead to a stockpiling, which in turn could create shortages, and disruptions to access. For many patients, any disruption in access to needed medications could be life threatening.

SB 265 could also be harmful to future innovation, and places burdensome reporting requirements on non-profit organizations. Non-profit organizations are a critical aid to the patient community. Imposing additional obstacles to funding for these organizations would be damaging and unnecessary.

On behalf of NORD and the millions of Americans who face the struggles of a rare disease, we appreciate the opportunity to comment on this legislation. We strongly urge you to reconsider SB 265.

If we can supply additional information, please do not hesitate to let us know. Tim Boyd, NORD’s Director of State Policy, is available to assist as needed. Tim can be reached at (202) 545-3830 or via email at tboyd@rarediseases.org.

Sincerely,

A handwritten signature in black ink, appearing to read "Peter L. Saltonstall".

Peter L. Saltonstall, CEO

CC: The Honorable Brian Sandoval