



February 4, 2019

Senator Laurie Monnes Anderson, Chair
Committee on Health Care
900 Court St. NE, S-211
Salem, Oregon 97301

Re: NORD Support for SB 452 -- EMS Protocols for Patients Who Carry Emergency Use Medications

Dear Chairwoman Monnes Anderson, and Members of the Committee on Health Care:

On behalf of the 1-in-10 Oregon residents with a rare disease, the National Organization for Rare Disorders (NORD) is proud to support HB 452, a bill to develop state Emergency Medical Services (EMS) protocols for patients who carry emergency use medications. With your support, this bill will help ensure better emergency treatment for special needs patients when being attended to by EMS personnel.

NORD is the 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. We believe strongly that every patient deserves individualized medical care, particularly in the case of rare disease patients. In pursuit of this goal, it is critical to ensure that rare disease patients receive appropriate treatment in emergency situations.

SB 452, sponsored by Senator Beyer, is a common-sense reform of the EMS procedures in the state. This bill requires the State Emergency Medical Service Committee to work with the Oregon Health Authority to develop new protocols that enable EMS personnel to better treat special needs patients in emergency situations. Once in place, these protocols will mean that rare disease patients who often carry self-administered medication could have their medication administered by EMS personnel so long as it adheres to the established medical protocols.

NORD urges you to work to pass this vital legislation out of committee this session. Please let me know if NORD can do anything to help educate legislators and the public about the need for this reform. I can be reached at (202) 545-3830 or via email at tboyd@rarediseases.org.

Sincerely,

Tim Boyd, MPH
Director of State Policy