



February 6, 2019

Senator Michelle Benson, Chair
Committee on Health and Human Services Finance and Policy
State Capitol
Room 1200 Minnesota Senate Bldg.
St Paul, MN 55155

Re: NORD Support for SF 165 -- EMS Guidelines for Authorizing Patient-Assisted Medication Administration

Dear Chairwoman Benson and Members of the Health and Human Services Finance and Policy Committee:

On behalf of the 1-in-10 Minnesota residents with a rare disease, the National Organization for Rare Disorders (NORD) is proud to support SF 165, a bill to develop state Emergency Medical Services (EMS) guidelines 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.

SF 165, authored by Senator Frentz, is a common-sense reform of the EMS procedures in the state. This bill requires the Emergency Medical Services Regulatory Board to develop new guidelines that enable EMS personnel to better treat special needs patients in emergency situations. Once in place, these guidelines 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

Erica Barnes
Minnesota Rare Action Network State Ambassador