



February 14, 2019

Sen. Matthew Lesser, Chair
Joint Committee on Insurance and Real Estate
Legislative Office Bldg #2800
Hartford, CT 06106

Re: Support for HB 5860

Dear Chairman Lesser and Members of the Joint Committee on Insurance and Real Estate:

On behalf of the approximately 1 in 10 individuals living in Connecticut with a rare disease, the National Organization for Rare Disorders (NORD) urges the Committee to support HB 5860, legislation that protects the ability of nonprofit organizations to provide third-party payments to insurers on behalf of beneficiaries in need of financial assistance.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. Since 1987, NORD, a 501(c)(3) charitable organization, has operated assistance programs to help patients with a rare disease obtain care they could not otherwise afford. Our assistance program (known collectively as RareCareSM Assistance Programs) provide eligible individuals medication assistance, as well as financial support with insurance premiums and co-pays, diagnostic testing assistance, and travel for consultation with disease specialists.

Despite protections that limit insurance beneficiaries' out-of-pocket costs and prevent them from being denied coverage on the basis of having a pre-existing condition, patients continue to face insurmountable cost-sharing and co-payment requirements.¹ Charitable assistance programs like NORD's Rare Care program make insurance coverage more meaningful by ensuring that it can actually be used to pay for incurred health care expenses. For the rare disease community, the need for comprehensive care that includes specialists and providers possessing an in-depth knowledge of rare diseases means their health care costs will likely always be higher than the general population. Without the ability of charitable organizations to provide assistance to patients, fewer people with a rare disorder would be able to access and stay in care.

The committees' consideration of HB 5860 comes at a critical time. Insurance companies are increasingly rejecting third-party payment from charities like NORD as part of a broader crackdown to prevent third parties from selectively covering patients in a way that would drive up overall health care costs. While this push is understandable, truly charitable organizations like NORD are not part of the problem. Patients turn to NORD in search of help after exhausting all

¹ Claxton, G., et al. Payments for cost sharing increasing rapidly over time. Peterson-Kaiser Health System Tracker Insight Brief. April 12, 2016.



other options (commonly including sacrifices to their other daily needs). RareCare Assistance Programs are based primarily on financial eligibility; therefore, these programs screen applicants through an extensive process in which patients are required to provide detailed medical and financial documentation to prove their eligibility. What's more, NORD's programs issue awards for up to 1 year, patient eligibility is monitored throughout the award period, and patients must reapply for assistance each subsequent year.

Thank you for the opportunity to comment on this issue. We look forward to working with you to ensure that nonprofit organizations in Connecticut can continue to provide third-party payments to insurers on behalf of beneficiaries in need of financial assistance.

If you have any questions, please contact me at tboyd@rarediseases.org. Thank you in advance for your consideration.

Sincerely,

A handwritten signature in black ink that reads "T Boyd".

Tim Boyd, MPH
Director of State Policy