



April 18, 2018

Connecticut General Assembly  
State Capitol  
210 State Capitol Ave  
Hartford, CT 06106

**Re: Support for House Bill 5297**

Dear Speaker Aresimowicz, Majority Leader Ritter, and Minority Leader Klarides:

On behalf of the 1-in-10 people in Connecticut living with a rare disease, the National Organization for Rare Disorders (NORD) urges the committee to support HB-5297, an act requiring continuing medical education in screening for rare gastrointestinal cancers. This legislation will help ensure physicians stay updated on the latest screening techniques for gastrointestinal cancers (including, colon, gastric, pancreatic, and neuroendocrine) using colonoscopies and endoscopies.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare “orphan” disease and assisting the organizations that serve them. Since 1983, we have been committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

Based on the reports we receive from our member organizations, as well as individuals, it is often difficult for patients to receive an accurate and timely diagnosis of rare gastrointestinal cancers. In light of this challenge, requiring continuing medical education in screening for these disorders could allow for patients to receive a proper diagnosis earlier on.

The Stifle Cancer Foundation of Connecticut, an advocacy group dedicated to bringing awareness to a type of cancer comprised of Neuroendocrine tumors (NETS), is the leading advocate for this bill. NORD is a proud partner of the Stifle Cancer Foundation and strongly supportive of its efforts to hasten and improve the diagnostic journey for individuals with rare gastrointestinal cancers. Together, we believe that increased continuing medical education requirements could help patients receive a diagnosis sooner and, consequently, begin treatment sooner.

Once again, on behalf of the many individuals living in Connecticut who face the struggles of a rare disease, we strongly urge you to support HB-5297. This bipartisan piece of legislation would provide great benefit to the rare disease community in Connecticut by requiring continuing medical education in screening for rare gastrointestinal cancers. We appreciate the opportunity to comment on this legislation.



If we can supply additional information, please do not hesitate to reach out to myself or Greta Stifle, patient advocate and founder of the Stifle Cancer Foundation of Connecticut. I can be reached at [tboyd@rarediseases.org](mailto:tboyd@rarediseases.org), and Greta can be reached at [stiflecancerfoundation@gmail.com](mailto:stiflecancerfoundation@gmail.com).

Sincerely,

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

Tim Boyd, MPH

Director of State Policy

CC: Members of the Joint Public Health Committee