



February 16, 2016

Honorable Kevin Cahill, Chairman
Insurance Committee
LOB 716
Albany, NY 12247

RE: Support for AB 5174

Dear Chairman Cahill:

The National Organization for Rare Disorders (NORD) respectfully requests the committee to consider and pass AB 5174, an act to amend the insurance law to require coverage for medical foods deemed necessary to mitigate and/or treat the symptoms of mitochondrial disease. The bill has the potential to benefit many of our organization's members, and with your support will be benefiting numerous patients suffering from mitochondrial disease in New York.

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 the medical care that is best suited for their medical situation and that is most likely to give them the best results. Based on the reports we receive from member organizations, as well as individuals, it is increasingly difficult for patients with a mitochondrial disease to receive optimum care if their health plan does not cover the medical treatment to manage their condition.

For many patients with mitochondrial disease, effective medical foods are the only viable treatment option available to them. AB 5174 will help by requiring commercial health plans in the state to cover medical foods for the treatment of this condition on the same basis as other prescription treatments. This benefit would only apply to appropriate treatments and only for patients with a confirmed diagnosis of mitochondrial disease.

Thank you for the opportunity to comment on this legislation. If we can supply additional information, please do not hesitate to let us know. Tim Boyd, NORD's Associate Director of State Policy, is available to assist as needed. Tim can be reached at (202) 545-3830 or via email at tboyd@rare diseases.org.

Sincerely,

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

Peter L. Saltonstall, President and CEO