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Lesley Bennett
30 Soundview Drive
Stamford, CT 06902
(203)348-1321

TESTIMONY to the Insurance and Real Estate Committee in SUPPORT of
SB 200, An Act Expanding Health Insurance Coverage for Specialized Formula
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Thank you Senator Crisco, Representative Megna and members of the Insurance and Real Estate Committee for the opportunity to testify in SUPPORT of **Senate Bill 200, An Act Expanding Health Insurance Coverage for Specialized Formula**. My name is Lesley Bennett. I am a Stamford, CT resident and a volunteer with the President's Council for the National Patient Advocate Foundation (NPAF). NPAF is a national non-profit organization that is focused on ensuring that all patients have access to medically necessary treatments. Our companion organization, the Patient Advocate Foundation (PAF), provides patients with cancer and chronic diseases with case management services for medical debt and health-insurance or employment related issues at no cost. NPAF translates the stories of patients helped by PAF and provides patients with a voice in state and national legislative reform concerned with improving access to, and reimbursement for, high-quality healthcare.

NPAF supports Senate Bill 200. We feel this bill is a preventive measure that will help Connecticut residents reduce healthcare costs by keeping rare disease patients healthy and out of the hospital. This bill will also help relieve the financial burden placed on (~50-100) Connecticut families to cover the cost of medically necessary, life-sustaining specialized formulas for individuals age 13-26 who suffer from rare metabolic disorders or severe gastrointestinal conditions that limit a person's ability to absorb nutrients. Much the same as a prescription medication, medically necessary, specialized formulas are prescribed by a physician and administered to patients under the direction of a physician. Current legislation requires Connecticut health insurance plans to cover the cost of medically necessary, specialized formulas for patients age 12 and under who suffer from rare metabolic disorders. However, many of these rare conditions are chronic, life-long disorders and the only FDA approved treatment is a life-sustaining specialized formula that often costs more than \$1,000 per month. The out-of-pocket costs of these formulas place a huge burden on the average Connecticut family. Parents not only have to cope with all the problems associated with their child's illness, they also have the added burden of knowing that the only way to provide their child with the medically necessary nutrition needed to grow or thrive costs more than they can afford. When Connecticut families cannot afford their child's special formula, the child often develops medical problems resulting in hospitalization.

Our only concern with this bill is the vague language. While the bill clearly defines coverage for inherited metabolic disorders and cystic fibrosis, it does not clearly mention or define severe GI disorders that limit a person's ability to absorb nutrients. We fear that insurers will see this as a loop hole and not cover GI disorders such as short bowel syndrome, severe food allergies, pseudo-obstruction, food protein-induced enterocolitis, or eosinophilic esophagitis.

My daughter, Kelly, is a 24 year-old with an eosinophilic gastrointestinal disorder (eosinophilic esophagitis and gastritis). Several years ago, our family was faced with the tough decision of either paying for Kelly's formula or making our mortgage payment when our health insurer refused to pay for her specialized formula. Despite pleas to our insurer and letters from our daughter's physicians clearly stating that her specialized formula was a life-sustaining medical necessity, we were forced to switch our daughter to a different formula/treatment. One month later, Kelly was admitted to the hospital for failure to thrive--she had lost 15 pounds and was showing signs of severe malnutrition, dehydration, and cognitive impairment. She was hospitalized for 12 days at an average cost of \$2000/day. Ironically, Kelly's hospitalization was fully covered by our insurer. After this hospitalization, our insurer finally agreed to cover the cost of Kelly's formula when her physicians pointed out that she would have more hospitalizations in the future if we were unable to provide her with the specialized formula. Her formula costs were approximately \$12,000/year and the cost of her hospitalization exceeded \$25,000. Coverage for specialized formula is not only a good choice for improving the health of Connecticut residents with rare metabolic disorders; it is a good financial approach to reducing healthcare costs and hospitalizations.