



Batten Disease Support + Research + Advocacy

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To whom it May concern,

Thank you for allowing me to speak on behalf of the Rare Community. I'm here today to ask your support in enacting H.R. 2144 Access to Genetic Counselor Services Act to update Medicare law to improve the lives of up to 60 million Americans, including those with rare diseases. Current Medicare policy denies Medicare beneficiaries direct access to highly trained, board-certified genetic counselors to navigate complex factors affecting their health. Limited access to genetic counseling services can result in increased wait-times for genetic testing and subsequent delays in diagnosis.

We understand the great desire to address socioeconomic disparities and access to genetic counselors is an area that needs continued reform. These disparities could hinder Medicare beneficiary access to genetic counseling services that are increasingly important in personalized medicine, such as therapies for high-risk cancer, or individualized treatment for Batten.

There has only been one instance of individualized therapy in Batten and it was a considerable financial burden to the family seeking care. By increasing Medicaid access for individualized therapies, we can narrow the disparity gap and truly make the pursuit of care accessible to all families who choose. By limiting the ability to choose care, we lose our ability to hope in treatments and cures for the children who are born each year with rare disease.

- H.R. 2144 Access to Genetic Counselor Services Act.
- Provide beneficiaries direct access to genetic counselors through direct access and billing.
- Help to address health disparities and inequities that affect those with lower incomes, improving care for vulnerable, dual eligible Medicare-Medicaid beneficiaries.
- Improve care for all patients seeking genetic counseling by facilitating the ability of additional physician practices and hospitals to employ genetic counselors.
- Enhance team-based care coordination for all patients, facilitate education and communication for patients and providers, and increase patient and provider satisfaction, and
- Improving Medicare beneficiary access to genetic counselors could also improve care for non-Medicare patients, including family members who could benefit from genetic testing.

By eliminating the barriers for genetic testing, we can diagnose, begin treatment, and pursue clinical trials. Batten disease is terminal and often the qualifying criteria for clinical trials is limited by the child's age of diagnosis. If we can establish early diagnosis, we give precious time to the family to work towards a cure for their child.

In confidence,

A handwritten signature in black ink, appearing to read "Morgan DeBoth".

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