

June 23, 2026

Dear Members of the Subcommittee,

I am writing to express my strong support for funding the advancement of gene therapy research for CLN6 Batten disease.

Although I currently live in Pennsylvania, my roots are deeply tied to California. I am a third-generation Californian on my father's side and was raised in Southern California before leaving for college. My parents still live in the home where I grew up, and my family and I return nearly every year. My father remains a prominent figure in the Jewish community there. California is, and always will be, home.

My daughter was diagnosed with CLN6 Batten disease after the initial gene therapy trial had already begun. At the time of her diagnosis, we were hopeful she would qualify for a second phase of that trial, but unfortunately that phase never happened. While it is now uncertain whether she would qualify for a future trial, my wife and I feel strongly that this work must move forward as quickly as possible - not only for the families we know with children like ours, but for those who will receive this diagnosis in the future.

Currently, gene therapy is the only meaningful treatment pathway for this disease. Without it, families face a devastating and predictable progression with no viable alternatives.

I serve as my daughter's full-time Home Health Aide, caring for her throughout every part of her day. I witness firsthand the profound impact this disease has - physically, cognitively, and emotionally. This is not an abstract need for our family; it is a daily reality.

We are encouraged by the progress being made, particularly the decision to change manufacturing partners from the original trial. This shift, driven in large part by improved technology offered by the new manufacturer, demonstrates that The Gray Foundation is not only committed, but actively pursuing the most effective path forward. That level of responsiveness and dedication gives families like ours real hope.

I respectfully urge you to prioritize and support this effort. Advancing this therapy is not only an investment in innovation - it is an opportunity to change the trajectory of this disease for current and future generations.

Thank you for your time and consideration.

Sincerely,  
Zack