

Lafora Disease Caregiver Registry Survey

Chelsea's Hope is offering a survey for caregivers to complete to help understand the unique challenges and experiences of those who provide care for individuals with Lafora Disease.



Your Voice Matters!

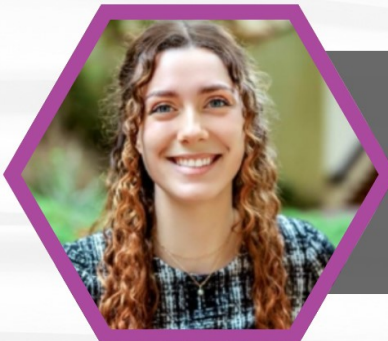
The Lafora Disease Caregiver Registry Survey will consist of a single survey split into three sections: a Caregiver Section, a Patient Section, a Chelsea's Hope and Research Goals Section. There are ~230 questions and it will take ~2-3 hours to complete, depending on your answers since some questions are prompted by specific answers. To get started, please scan the QR code!

Who is Eligible?

Any one who is a caregiver for someone with Lafora Disease on a regular basis is eligible to participate in this survey!



SCAN HERE!



This project is being led by Mariah Merriam, who has two siblings with Lafora Disease. Having experienced caregiving first-hand and the impact of caregiving on her parents, Mariah believes it is vital to survey these experiences to see how Chelsea's Hope can better support our Lafora Disease community!



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