



FOR IMMEDIATE RELEASE

Lafora Disease Receives ICD-10 Code, Taking Effect October 1, 2023

ICD-10 Code G40.C will expand diagnostic precision, healthcare billing, and treatment options for Lafora Disease.

SACRAMENTO, Calif. – September 22, 2023 – Lafora progressive myoclonus epilepsy, or Lafora Disease, an ultra-rare neurodegenerative disorder affecting children, has been assigned its own unique ICD-10 code, G40.C, falling under the G category of diseases representing nervous system disorders. This code will take effect on October 1, 2023.

Chelsea's Hope Lafora Children Research Fund is thrilled to announce this significant achievement in the fight against Lafora Disease! Thanks to continued advocacy, this development marks a crucial step in raising awareness and improving the accuracy of tracking Lafora Disease within the medical community.

Lafora Disease, a progressive myoclonic epilepsy, is caused by a genetic mutation that leads to a toxic accumulation of glycogen, which forms insoluble aggregates, called Lafora Bodies, in the heart, spine, and brain. This leads to severe neurological impairment, including seizures, cognitive decline, and loss of motor skills. It is terminal; there is no cure. Healthy, seemingly well-developing children first show symptoms around adolescence and typically die within ten years. Diagnosing Lafora Disease is also challenging, and many patients are misdiagnosed with Juvenile Myoclonic Epilepsy before receiving a correct diagnosis of Lafora. The establishment of a unique ICD-10 code for Lafora disease will accelerate the diagnosis process for new patients.

Chelsea's Hope remains committed to our vision of a world with a cure for Lafora Disease. The new G40.C ICD-10 code for Lafora progressive myoclonus epilepsy this year is an important milestone on that path. This dedicated code will facilitate improved diagnosis, tracking, and reporting of Lafora Disease cases, enhancing our understanding of its prevalence. Previously, Lafora Disease was coded under generic epilepsy codes. Those codes were useful for insurance billing and reimbursement, but they did not provide any way to accurately track Lafora Disease patients across multiple healthcare systems and learn from their experiences.

"We are grateful for the support of the medical community, our partners, and all the families who have tirelessly advocated for this important recognition," shared Frank Harris, Ph.D., President of Chelsea's Hope.

Chelsea's Hope Lafora Children Research Fund is an IRS 501(c)3 non-profit organization. Our mission is to improve the lives of those affected by Lafora Disease and help accelerate the development of treatments
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Chelsea's Hope urges healthcare providers, researchers, and advocates to use the newly designated G40.C ICD-10 code when diagnosing and documenting Lafora Disease cases. We encourage families to share the code with all their child's healthcare providers for use starting October 1st - doctors, dietitians, therapists, counselors, pharmacists, dentists, hospitals, Social Security Administration staff, Medicaid waiver coordinators, and school personnel. This code will help us build a more comprehensive understanding of the prevalence and impact of Lafora Disease, ultimately accelerating research efforts toward a cure.

The International Classification of Disease (ICD) is coordinated by the World Health Organization (WHO), along with the Centers for Medicare and Medicaid Services (CMS) and the Centers for Disease Control and Prevention in the United States. ICD provides a worldwide system for healthcare providers and agencies to classify patient diagnoses and symptoms. WHO introduced the ICD in 1948; the most recent update occurred in 2022 with the ICD-11 system.

In the U.S., proposals are submitted to the ICD-10 Coordination and Maintenance Committee. They may be selected for presentation at live hearings in March and September each year at CMS headquarters in Baltimore, Maryland. Chelsea's Hope, led by Vice President Jenifer Merriam, submitted a proposal to create a new code for Lafora Disease in December 2021. It was chosen for presentation at the March 2022 meeting, and a public comment period was open through May 2022 with letters of support provided by Chelsea's Hope Lafora Children Research Fund, the Lafora Epilepsy Cure Initiative, and several community stakeholders. The ICD-10-CM Committee approved the new code and announced it in August 2023.

"The G40.C ICD-10 code is a testament to our collective dedication to fighting Lafora Disease," said Lena Ismail, Executive Director of Chelsea's Hope. "I would like to thank Jenifer, Vice President of our Board, for her efforts in making this possible, along with her daughter Mariah. The advice and guidance from Glenna Steele from the Glut1 Foundation, Dr. David Berglund, and Dr. Matthew Gentry from the University of Florida were invaluable. I am also grateful to Dr. Berge Minassian from UT Southwestern for his presentation at the hearing that brought us closer to code G40.C. Finally, thank you to the Lafora Epilepsy Cure Initiative and all members of the Lafora community who wrote letters of support for our code."

For more information about Chelsea's Hope Lafora Children Research Fund and our ongoing efforts to combat Lafora Disease, please visit our website at www.chelseashope.org. For a more detailed description of ICD-10 code G40.C and its six other variations, please visit <https://chelseashope.org/lafora-icd/>.

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Please email info@chelseashope.org for media inquiries.

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About Chelsea's Hope Lafora Children Research Fund: The mission of Chelsea's Hope is to improve the lives of those affected by Lafora Disease and help accelerate the development of treatments. Chelsea's Hope began as a website in the fall of 2007 to share [Chelsea Gerber's Lafora story](#) with her family and friends and evolved into a US-based non-profit advocacy group for Lafora patients. Today, we aim to improve the lives of those affected by Lafora disease by raising awareness, connecting families worldwide, and accelerating research. For more information, visit www.chelseashope.org.