



## Legislation Text

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Proclamation for Lafora Body Disease Awareness Day, August 24, 2018

### PROCLAMATION

Lafora Body Disease  
August 24, 2018

WHEREAS, Lafora Body Disease (Lafora Progressive Myoclonus Epilepsy) is an orphan disease that affects fewer than 200,000 people nationwide. It is extremely devastating to families as it usually manifests in healthy children in late childhood to early adolescence and often claims the lives of its victims within ten years of onset; and

WHEREAS, Lafora Body Disease is an inherited form of progressive myoclonus epilepsy. The disease affects the entire **body**, causing difficulty with mobility and speech. Other symptoms include convulsions, memory loss, hallucinations, dementia, frequent urination and loss of consciousness; and

WHEREAS, Ignorance of this disease is widespread, even among physicians, patients are frequently misdiagnosed as having Myoclonic Epilepsy. Though symptoms are very similar, only genetic testing or a skin biopsy can confirm the diagnosis; and

WHEREAS, Children with this diagnosis are sadly underrepresented in the field of research as the rarity of the disease means it receives little funding for genetic research. As a result of this, affected families are often financially strapped and left as the sole advocates for their children; and

WHEREAS, Help and hope is on the horizon for those suffering from Lafora Body Disease as many genetic advances have been made and clinical trials aimed at a cure are likely to begin in 2019.

NOW THEREFORE, I, Christopher Taylor, Mayor of the City of Ann Arbor, do hereby proclaim August 24th, 2018 as Lafora Body Disease Awareness Day and recognize the importance of increasing public awareness of this disease and its early and accurate diagnosis.

I hereby set my hand and seal  
This 24th day of August, 2018

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Christopher Taylor  
Mayor of the City of Ann Arbor