

Date	Referring Neurologist's Name and Address	
Participant Demographic Data	Sex	<input type="checkbox"/> Male <input type="checkbox"/> Female
Date of Birth		
Age in years of first symptom of Lafora disease		
What was the first symptom?		
Prescreening Inclusion Criteria	Check if true	
Genetically confirmed diagnosis of Lafora disease before or at enrollment (documented pathogenic mutations in known causative genes (<i>EPM2A</i> /laforin, <i>EPM2B</i> / <i>NHLRC1</i> /malin). Copy of genetic test result from genetic testing laboratory must be provided.	<input type="checkbox"/>	
Must have Lafora Disease Performance Scaler (LDPS) score ≥ 9 and LDPS motor subscore of ≥ 2 . LDPS score sheet, below, completed by the patient's neurologist must be provided.	<input type="checkbox"/>	
Must be able to walk independently, unassisted and with no ambulatory aids such as crutches or canes. A video showing the patient walking 10 steps independently must be provided. The video must be from the chest down. Patient's face must not be seen. Any video with the face visible will not be accepted and immediately deleted.	<input type="checkbox"/>	

Lafora Disease Clinical Performance Scale

Lafora Disease Clinical Performance Scale (0-18)	Score
[Bolden the correct score for each domain and provide the total score below]	
Domain 1: Generalized tonic-clonic seizures	
None	3
Less than monthly (sporadic)	2
More than monthly but less than daily (frequent)	1
Daily or status epilepticus (constant or near constant)	0
Domain 2: Myoclonus	
Absent	3
Mild (patient can eat and drink, but not write or draw)	2
Moderate (patient cannot eat or drink)	1
Severe (continuous myoclonus at rest)	0
Domain 3: Ambulation	
Independent ambulation	3
Able to ambulate independently but gait clearly abnormal	2
Unable to ambulate without assistance	1
Unable to ambulate	0
Domain 4: Cognition (from school performance)	
No decline in school performance	3
Mild impairment; decline at school, but still in school	2
Moderate impairment: student requires special help at school or placement in an alternative learning environment	1
Severe impairment; patient no longer able to attend school	0
Domain 5: Speech	
Normal	3
Mild impairment: hesitates but remains fluent	2
Moderate impairment: diminished word production, difficult to understand	1
Severe impairment: no speech	0
Domain 6: Function	
Normal (preserved Activities of Daily Living [ADLs] listed below)	3
Mild impaired: has difficulty in 1 or 2 ADLs but remains independent	2
Moderate impaired: requires assistance in 3 or 4 ADLs	1
Severe impaired: requires assistance in all 5 ADLs	0
Total Score	

Activities of Daily Living: Personal hygiene (bathing, grooming, brushing teeth), Dressing, Toilet hygiene, Ability to transfer (get in and out of bed/chair), and Ability to self-feed.