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Chelsea's Hope
Lafora Children Research Fund

LIVING WITH LAFORA

ANTI-SEIZURE MEDICATION GUIDELINES

Expert opinion from Lafora Clinical Working Group, Chaired by Dr. Roberto Michelucci.

Lafora disease is a rare and progressive form of epilepsy, and families are often told early on that seizure control will require more than one medication and ongoing adjustment over time. This expert opinion summarizes the discussion and survey results from a clinical working group of physicians experienced in treating Lafora disease. It is intended to give families a starting point for discussion with their own healthcare providers.

Disclaimer: *This article reflects the opinions and survey responses of a clinical working group and is shared for general informational purposes only. It is not medical advice and should not replace guidance from your own healthcare provider. Please review this information with your doctor before making any changes to a treatment plan.*

ANTI-SEIZURE MEDICATIONS FAVORED FOR LAFORA DISEASE

When managing seizures in Lafora disease, clinicians routinely combine multiple anti-seizure medications (ASMs). When selecting which medications to combine for a patient, the clinician considers the efficacy of each drug, as well as the potential side effects. They will also take into account possible drug-drug interactions, the age of the patient, their weight and mental health. Therefore, seizure management may look very different for each patient, which is why it is important to consult with your personal physician. However, the clinical working group determined that the following medications are most commonly used as first-line treatments:

- Levetiracetam, valproic acid, and perampanel are typically the first medications prescribed for newly diagnosed patients
- Clonazepam is frequently used in everyday treatment plans, largely for its effect on myoclonus. It is also commonly used as a rescue medication when symptoms worsen
- Brivaracetam, topiramate, and zonisamide are frequently added to a seizure treatment regimen, often to help reduce myoclonus
- Phenytoin may be useful for short-term treatment of status epilepticus, but it is not recommended for long-term, chronic use

MEDICATIONS GENERALLY AVOIDED IN LAFORA DISEASE

Certain Anti-seizure medications, like sodium-channel blockers, are usually avoided because they can worsen myoclonus or fail to control seizures effectively. Some examples include:

- Carbamazepine
- Phenytoin (becomes a problem with chronic, ongoing use)
- Lamotrigine
- Gabaergic drugs
- Most anti-focal ASMs

PLANNING FOR EMERGENCIES

Status epilepticus, prolonged or repeated seizure that doesn't stop on its own, is a medical emergency. Clinicians most commonly reported the use of clonazepam or midazolam as first-line emergency treatment, sometimes followed by levetiracetam, brivaracetam, perampanel, or valproic acid or phenytoin in refractory cases.

Every family should have a written seizure action plan in place. This helps ensure that emergency responders and caregivers know what to expect and how to respond, and may help avoid unnecessary ICU admissions.