HOPE for HIE

# EPILEPSY TERMS TO KNOW

## SEIZURE

- ✓ A burst of uncontrolled electrical activity between brain cells that causes temporary abnormalities in muscle tone or movements, behaviors, sensations, or states of awareness.
  - **Seizure onset** with HIE is most typical within 24-48 hours after birth or injury.
  - **Therapeutic hypothermia** is clinically shown to reduce seizure incidence in HIE.

## EPILEPSY

- ✓ Also called seizure disorder, it is a neurological condition characterized by recurrent seizures.
- ✓ **In the context of epilepsy & HIE:**
  - A child with HIE, across all outcomes, has 5x the risk of developing epilepsy than one without.

## NEONATAL SEIZURES

- ✓ Seizures that occur in newborns, often within the first 28 days of life.
- ✓ **In the context of HIE:**
  - HIE is reported to be the most common cause of neonatal seizures.
  - Neonatal seizures increase the risk of developing epilepsy later in childhood.

## FOCAL SEIZURES

- ✓ Also known as partial seizures, these are seizures in which seizure activity only occurs on one side of the brain.

## GENERALIZED SEIZURES

- ✓ Seizures that affect both sides of the brain.
- ✓ **The two most common types include:**
  - **Tonic-clonic seizures:** formerly known as grand-mal seizures (*see tonic-clonic*).
  - **Absence seizures:** brief seizures that involve staring spells, where a child may seem to zone out or not respond. They can easily be missed.

## TONIC-CLONIC SEIZURES

- ✓ Seizures that are characterized by two distinct phases:
  - **Tonic phase:** a sudden stiffening of muscles, often lasting 10-20 seconds.
  - **Clonic phase:** marked by rhythmic jerking of the limbs and face as the muscles relax and contract

## MYOCLONIC SEIZURES

- ✓ Seizures that cause quick, sudden jerks of a muscle or group of muscles, often in the upper body and limbs.

## ATONIC SEIZURES

- ✓ Also known as drop seizures, these seizures involve a sudden loss of muscle tone, causing the individual to fall or collapse.
- ✓ These seizures may be associated with more severe forms of epilepsy, such as Lennox-Gastaut Syndrome *(see LGS)*.

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## LENNOX-GASTAUT SYNDROME

- ✓ A severe form of epilepsy that begins in early childhood, often between ages 2 and 6, and is characterized by multiple types of seizures, including tonic, atonic, and atypical absence seizures.
- ✓ **Children with HIE are at higher risk for LGS,** which can also be associated with cognitive and behavioral challenges.

## INFANTILE SPASMS (IS)

- ✓ A rare type of epilepsy that requires quick diagnosis and frontline treatments and should be considered a medical emergency.
- ✓ **Infantile spasms often:**
  - Look like bnding forward of the body with stiffening of the arms and legs lasting for 1-2 seconds.
  - Occur in clusters, often upon awakening.

## DEVELOPMENTAL + EPILEPTIC ENCEPHALOPATHIES (DEE)

- ✓ A group of severe epilepsy syndromes where abnormal brain activity during sleep can lead to developmental regression or stagnation.
- ✓ **Includes conditions like:**
  - SWAS (Sleep-Related Epilepsy) and ESES (Electrical Status Epilepticus of Sleep)

## STATUS EPILEPTICUS

- ✓ A prolonged seizure lasting more than 5 minutes or a series of seizures without full recovery in between. Considered a medical emergency.
- ✓ Status epilepticus is more likely to occur in children with severe forms of epilepsy, including those with HIE.

## POSTICTAL STATE OF RECOVERY

- ✓ The period following a seizure when the brain is recovering.
- ✓ **Often characterized by:**
  - Confusion, exhaustion, weakness, headaches, or dizziness.
  - Prolonged periods of this state, especially in those with HIE.

## SLEEP/WAKE CYCLE

- ✓ Seizure activity is often linked to a child's sleep-wake patterns. Some children experience more seizures during sleep or upon waking.
- ✓ Many children with HIE experience sleep disruptions, triggering the potential occurrence of more seizures.

## EXTENDED EEG

- ✓ **Stands for electroencephalogram.** A test that records electrical activity in the brain over an extended period, often lasting 24-72 hours.
- ✓ Used to capture seizures or abnormal brain activity that might not appear in a standard short-term EEG and guide treatment.

## MRI

- ✓ **Stands for Magnetic Resonance Imaging.** A detailed imaging scan that shows brain abnormalities and areas of injury.
- ✓ It is used to assess the extent of damage after insult/ injury, attempt to predict the likelihood of developing epilepsy, and subsequently guide treatment plans

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## ASMs & AEDs

- ✓ **Stands for Anti-Seizure Medications and Antiepileptic Drugs.** While ASM is the up-to-date term, they are often used interchangeably.
- ✓ Refers to medications that are prescribed to manage epilepsy and control seizures by stabilizing electrical activity in the brain, potentially reducing the frequency and severity of seizures.

## SURGICAL TREATMENT OPTIONS

- ✓ Evidence-based research suggests many children benefit from epilepsy surgery earlier and not as a last resort. All surgical treatment options should be discussed with your medical team.
- ✓ **Surgical options are either:**
  - Resective (removes brain tissue) or functional (modifies function without removal of brain tissue)

## KETOGENIC DIET

- ✓ A high-fat, low-carbohydrate diet aimed at gaining some seizure control in some children with epilepsy, depending on their qualifications.
- ✓ This diet requires strict medical supervision to ensure proper nutrition, as it can cause damage to organs if not monitored properly.

## DRUG-RESISTANT EPILEPSY

- ✓ **Sometimes called refractory or intractable epilepsy.** Occurs when seizures cannot be adequately controlled despite trying two or more appropriately chosen and tolerated ASMs, either alone or in combination.
- ✓ Those with drug-resistant epilepsy may require alternative treatments, therapies, or interventions.

## SEIZURE FIRST AID

- ✓ A guide to help you know what to do during a seizure in a way that protects them from injury. Steps include turning them on their side, taking a video, timing its duration, and more.
- ✓ **Free seizure first aid training is available:**
  - Many organizations, like the Epilepsy Foundation, provide free online training.

## SEIZURE ACTION PLAN

- ✓ A personalized plan (with medical team input) that outlines what to do during a seizure, when to administer rescue medications, and when to seek emergency medical help.
- ✓ **There are free templates available:**
  - The Seizure Action Plan Coalition has templates, examples, and additional resources to help you build your SAP.

## RESCUE MEDICATIONS

- ✓ Seizure rescue medications or treatments are meant to be used in specific situations (like if a seizure lasts more than 5 minutes) to help stop them quickly/effectively. **They should never take the place of daily seizure medications.**
- ✓ **Common rescue medications include:**
  - Diazepam (Valium®), lorazepam (Ativan®), and midazolam (Versed®).

## SEIZURE ALERT MONITORS

- ✓ A wearable/bedside monitor designed to detect signs of a seizure, such as unusual movement or changes in heart rate, and alert caregivers or emergency contacts for quick assistance.
- ✓ **Other helpful monitoring equipment includes:**
  - Pulse oximeters and higher-quality video monitors, or even seizure service dogs.

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## SEIZURE TRIGGERS

- ✓ Factors that can provoke a seizure, such as missed medication doses, sleep deprivation, stress, illness, and more.
- ✓ Tracking seizure triggers and frequency can help better understand your child's epilepsy.

## EPILEPTOLOGIST

- ✓ A neurologist who specializes in the diagnosis and treatment of epilepsy. They provide diagnoses, tailored seizure management, long-term care planning, and more.
- ✓ They often work closely with neurologists, neurosurgeons, neuropsychologists, and other specialists to address the broad impact of epilepsy on cognitive, emotional, and social health.

## PEDIATRIC NEUROLOGIST

- ✓ They are specifically trained to diagnose and treat neurological disorders in children, from newborns to adolescents.
- ✓ They handle neurological conditions unique to children, such as developmental delays, epilepsy related to perinatal brain injuries (like HIE), and genetic or metabolic conditions affecting brain development.

## NEUROSURGEON

- ✓ Neurosurgeons are involved when surgical options, such as lobectomy, corpus callosotomy, Vagus Nerve Stimulation (VNS), and others, are being considered for seizure control.
- ✓ They work closely with epileptologists to evaluate if a patient is a candidate for surgery,

## NEUROPSYCHOLOGIST

- ✓ Neuropsychologists assess the cognitive and behavioral effects of epilepsy and brain injuries like HIE.
- ✓ **They help understand:**
  - How seizures and related treatments impact memory, learning, and overall development, guiding educational and therapeutic interventions.

## DEVELOPMENTAL PEDIATRICIAN

- ✓ Has additional training in child development, focusing on children with developmental, behavioral, and learning challenges, like those potentially impacted by epilepsy.
- ✓ **Key responsibilities can include:**
  - Performing assessments, creating tailored care plans, and making referrals for early interventions, educational supports, etc.

## EARLY INTERVENTIONISTS

- ✓ Early Interventionists involve a team of specialists who address developmental, physical, and social-emotional needs that are impacted by various conditions, like epilepsy.
- ✓ **Common ET specialists include:**
  - Physical therapists, occupational therapists, speech & language pathologists, behavioral therapists, and more.

## DIETITIAN/NUTRITIONIST

- ✓ For children undergoing dietary treatments for epilepsy, such as the ketogenic diet, dietitians play a critical role in managing and monitoring nutritional needs to ensure proper growth and health while controlling seizures.