Antiepileptogenesis (AEG) and Disease Modification
Perspective of Nonprofit Organizations

The epilepsies affect an estimated 3 million Americans, and 50 million people worldwide. There are many causes of epilepsy, yet for the majority of individuals the cause is not known. Seventy percent of individuals with epilepsy benefit from treatment, but the other thirty percent do not, leaving them at high risk for cognitive and social deficits, as well as an increased risk of death from a variety of causes, including Sudden Unexplained Death in Epilepsy (SUDEP).

Current medical management of epilepsy aims to prevent or stop seizures rather than to identify and treat the root cause. However, knowledge about anti-epileptogenesis is accumulating through basic studies utilizing human growth factor, immunosuppressive agents, anti-inflammatory agents, novel compounds, and several currently-available antiepileptic drugs. Expanded AEG research will move this basic knowledge toward identification of additional mechanism(s), leading to novel anti-epileptogenic and disease modifying therapies. Among the known risk factors for the development of epilepsy that may be amenable to AEG therapy are:

- Head trauma
- Cerebrovascular disease affecting blood supply in the brain.
- Central nervous system infections
- Perinatal complications
- Congenital and developmental conditions
- Family history of epilepsy
- Genetic diseases with associated epilepsy (e.g., Rett Syndrome, Tuberous Sclerosis Complex, Angelman Syndrome)
- Known voltage-gated and ligand gated ion channelopathy induced epilepsy (generalized familial epilepsies, Dravet syndrome)
- Epilepsies in which chronic neuronal inflammation is a known cause (Rasmussen's encephalitis)

The participating nonprofit organizations recognize that the community should identify epilepsy model(s) in which research can most rapidly result in significant breakthroughs for the affected patient population. Building on significant success, the community could then develop a plan to discover the causes of other types of epilepsy and develop treatments that will prevent the onset of seizures. This work on anti-epileptogenesis will complement current efforts to stop the progression of the epilepsy, and reduce the frequency and severity of seizures without significant side effects of the treatments. In addition, the non-profit organizations advocate for the development of new therapies in the chosen model(s) that will either prevent the onset of seizures or more effectively treat and halt the progression of the epilepsy. The organizations also recognize the need for a coordinated effort overall, including the development of a unified Epilepsy Tissue and DNA Bank (with adequate phenomic data) that can be utilized by the research community.

Participating nonprofit organizations:
CURE, Epilepsy Foundation, ICE Alliance, RE Children's Project, Tuberous Sclerosis Alliance