



# DOOSE SYNDROME EPILEPSY ALLIANCE

Joining Forces to Create Change

Dear Sir or Madam,

I am writing you today to introduce the creation of our **new Non-Profit organization Dose Syndrome Epilepsy Alliance**; a sub-chapter of the Chelsea Hutchison Foundation. We are not only the Creators/Founders of DSEA, but also parents of young children living with epilepsy, specifically Dose Syndrome, a rare and catastrophic form of epilepsy. **Our DSEA mission** is to support the young children and families suffering with this debilitating seizure disorder and to improve the lives of those touched by Dose Syndrome.

Myoclonic-Astatic Epilepsy (MAE), or Dose Syndrome, is an epilepsy syndrome of early childhood that is often resistant to medication. For this reason, it can be difficult to treat. MAE is an idiopathic generalized epilepsy, meaning that there is no known cause for the seizures and the seizures originate from all over the brain as opposed to coming from one focal area. Onset of MAE commonly occurs in the first five years of life.

The National Institute of Health (NIH) has research for epilepsy, but nothing specific to Dose Syndrome. Current treatment for most children with Dose/MAE consists of long-term use of a mixture of antiepileptic drugs. Because it is considered "intractable" or "refractory," drug therapy is generally not successful in controlling seizures. Brain surgery, high fat dietary therapies (Ketogenic, MAD, LGIT,) or the use of an electronic implant, i.e. VNS (vagal nerve stimulator) may be tried. The majority of children with this diagnosis continue to have seizures despite treatment and experience unpleasant side effects due to the treatments. With more knowledge of how epilepsy develops before birth, it may be possible to develop treatments that will stop the process and prevent epilepsy. At this point the future for most of these kids is unknown.

Fatality is also a concern and rarely mentioned after diagnosis as a probability. In fact, thousands of children die every year from "Sudden Unexplained Death in Epilepsy (SUDEP.)" SUDEP applies to a sudden death in someone known to have epilepsy, in the absence of an obvious cause for the death. Although most instances are presumed to occur during a seizure, not all do and a seizure at the time of death is not a requirement for diagnosis of SUDEP.

Areas of focus are; the need for early detection and diagnosis, improved access to epilepsy specialists and comprehensive care, criteria for quality care of epilepsy and co-morbid conditions, mobility devices and an improved understanding of epilepsy's effects on cognition, mental health, and other aspects of life.

Additionally, there is a need to foster empowerment and independence for people with epilepsy and the need for public education to overcome stigma and to improve seizure recognition and first aid.

Children with epilepsy have an increased risk of depression as well as social, emotional, physical, behavioral and cognitive discrimination due to the brain damage caused by continual seizures, or treatment. This can lead to discrimination and socially awkward behavior. These children spend most of their lives be labeled as social outcasts by their peers.

Some insurance companies do not cover specialists such as an epileptologist, surgery, brand name medications or psychological therapy. For children living with such a destructive disorder, it is imperative that our children are able to live a life of quality without their families having the added financial stress of the intangible costs and the financial burden of living with this disorder.

Our goals are to create a better understanding of Doose Syndrome by helping fund quality care needed by families that are suffering through hundreds of seizures a day. Whether it is direct financial support for medications, hospital bills, medically related transportation, mobility devices, durable medical equipment or protective helmets, our goal is to help ease the distress and pain of living with a destructive disorder. In addition, we plan to enable the collaboration of health care professionals and families across the world by providing a platform through which information, research and resources can be shared.

We are dedicated to helping to change the quality of children's lives, but as a new non-profit organization, we need your help. Your generous donation will be the key to our success! You can be a part of that excitement by supporting our goals with a small tax-deductible donation. We are happy to acknowledge your donation on our website and at our numerous events as well as our facebook page where we have almost 7000 followers.

I would like to thank you for considering this opportunity to partner with our organization. If you have any queries regarding our organization, our fund management policy, or the project itself, please feel free to contact me on our website at [www.doosesyndrome.org](http://www.doosesyndrome.org) Our EIN is 27-1317638.

Warm regards,

Jenee Cummings and Heather Jackson-Founders and Creators of DSEA

Some of our children:  
Emmett-  
[tinyurl.com/DSEAemmett](http://tinyurl.com/DSEAemmett)  
Ethan-  
[tinyurl.com/DSEAethan](http://tinyurl.com/DSEAethan)  
Lauren-  
[tinyurl.com/DSEAlauren](http://tinyurl.com/DSEAlauren)

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