



**Medical
Blueprints**

KIDS CREW: HAILEY CONNECTS KIDS OF ALL ABILITIES REPORT #2775

BACKGROUND: According to the World Report on Disability, over one billion people, or 15% of the world's population, live with some form of disability. Of these, between 110 and 190 million have significant difficulties in functioning. Children with disabilities are one of the most excluded groups of children. Discrimination arises due to lack of understanding and knowledge of its causes and implications, fear of difference, fear of contagion or contamination, or negative religious or cultural views. Added to that is poverty, social isolation, humanitarian emergencies, lack of services and support, and a hostile and inaccessible environment. Children with disabilities tend to be defined and judged by what they lack rather than what they have, and their exclusion serves to render them uniquely vulnerable, denying them respect for their dignity, their individuality, and even their right to life itself.

(Source: https://www.unicef.org/disabilities/files/Fact_Sheet_Children_and_Young_People_with_Disabilities_-_2013.pdf)

WHAT IS KIDS CREW?: Hailey Scheinman started Kids Crew initially in her local community and was focused on teaching kids about all types of special needs/disorders including epilepsy. The program caught the eye of the then President and CEO of the Epilepsy Foundation and he asked Hailey to create an Epilepsy Foundation Kids Crew focused on epilepsy. The program is open to all kids 14 and under either with or without epilepsy. The program was created with three areas in mind: creating epilepsy awareness to help educate family, friends, and the community; sharing stories so that others can learn from experiences; and participating in Lemonade for Livy, the Purple Pumpkin Project, and local walks. They encourage imagination and creativity and know kids have unique gifts that can be used to give back to others. They encourage each child to come up with ideas that can impact their community based on what they have experienced. In doing so, it allows for teamwork, helps each child learn more about epilepsy, and gives them confidence.

(Source: <https://www.epilepsy.com/make-difference/get-involved/kids-crew>)

POTENTIAL EPILEPSY BREAKTHROUGH: There are three million people with epilepsy in the U.S., and just over half of those can control their seizures with a single drug or combination of drugs. However, about 40% of epileptic patients have drug-resistant epilepsy, therefore, needing surgery if they're candidates. These patients have significantly lower quality of life, says Johns Hopkins neurologist and epilepsy specialist Gregory Krauss, with a significantly higher risk of impaired social interactions, employment issues, falls, and even unexpected death. In a recent clinical trial led by Krauss, a new drug known as cenobamate showed promise for patients with treatment-resistant focal onset seizures. To qualify for the trial, a patient needs to have a history of eight or more seizures during the past eight weeks. Their results showed dramatic effects for the two highest-dose groups in particular. Those taking either the 200 mg or 400 mg tablet had 55% fewer seizures overall, with 21% stopping seizures altogether.

(Source: <https://www.hopkinsmedicine.org/news/articles/a-potential-breakthrough-for-patients-with-drug-resistant-epilepsy>)

✉ **For More Information, Contact:**

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