2024 IMPACT REPORT



Pediatric Epilepsy Surgery Alliance

134

PARENTS SUPPORTED

personalized matches made based on surgery commonalities create a lifeline of support. 264

CONVERSATIONS

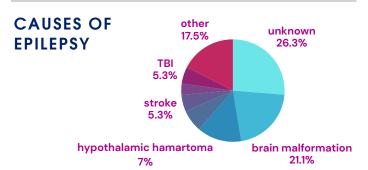
one-on-one phone calls guide families, give hope, reassurance, and critical information. Over 100 school staff were trained on the educational impacts of epilepsy surgery. Most training requests were about hemispherectomy.



Dreams for Danny, our surgical evaluation travel scholarship fund, helped 48 families from 27 states get to an epilepsy center for care.



Because of skyrocketing airfare costs, most funds were used to pay for flights. A majority of awardees traveled from rural or suburban communities to large urban epilepsy centers.



More than one in four children who received travel funds had unknown causes for their epilepsy; it's why they need to get a comprehensive epilepsy center for advanced testing and imaging to find the cause of seizures.

410 PATIENTS ENROLLED

Data from our parent-powered registry has already contributed to multiple publications and medical conference presentations, helping our community better understand cognitive, behavioral, and quality-of-life outcomes after epilepsy surgery.

quite a bit 91%

somewhat

7%

Over 90% of parents in our patient registry report that their child's quality of life improved "quite a bit" after epilepsy surgery. Only 2% reported "not at all" or "a little."

IMPROVED QUALITY OF LIFE



A record number of young adults who had surgery in childhood attended our family conference.

Two outings for teens and young adults provided opportunities for our self-advocates to build meaningful connections and lifelong friendships. A dedicated session track of young-focused topics provided them with tools and resources to navigate the transition to adulthood.

50+
RESEARCHERS
ENGAGED



Neurosurgeons, neurologists, neuropsychologists, and other clinicians from as far as Japan and Belgium joined our satellite research meeting at the American Epilepsy Society where we discussed symptom and screening recommendations after hemispheric epilepsy surgery.