

PEDIATRIC DRUG RESISTANT EPILEPSY: GENETIC TESTING AND NOVEL NEUROTECHNOLOGIES



Many factors determine why caregivers pursue genetic testing for their children with drug resistant epilepsy (DRE).

Understanding the motivation of parents to pursue genetic testing for DRE may help others with their own decision-making.

ABOUT THIS STUDY



Perspectives gathered from interviews with parents who received positive, negative, or uncertain results about the genetic basis for their child's DRE.

MOTIVATIONS AND CONCERNS

Why do parents choose genetic testing?

MOTIVATIONS



Gain a better understanding of seizures.

- Determine the cause of seizures
- Target treatment based on results
- Improve child's quality of life
- Make informed reproductive decisions for themselves

CONCERNS



Consequences of results.

- Inconclusive or negative result may lead to continued uncertainty
- Findings that are unrelated to epilepsy may impact the child or family in unexpected ways
- Increased stigma or discrimination resulting from a positive result

POSITIVE OUTCOMES OF GENETIC TESTING

CONNECTIONS WITH OTHER FAMILIES



Receiving a positive result allows families to connect and support each other.

REDUCED GUILT OR BLAME



Receiving conclusive results may reassure parents about the medical nature of their child's condition.

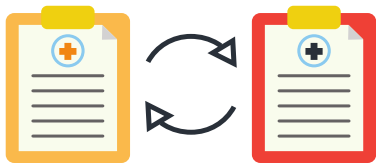
ALTRUISM



Regardless of the result, parents found value in supporting epilepsy research.

NEGATIVE OUTCOMES OF GENETIC TESTING

LIMITED CHANGE IN TREATMENT



Results may not alter the course of treatment, or inform use of novel forms of technology.

CONTINUED UNCERTAINTY



Negative or uncertain result may lead to feelings of frustration and despair.

TAKE-HOME MESSAGES



Parents consider that genetic testing is valuable regardless of results.



Before pursuing genetic testing, parents should consider both possible benefits and risks.

