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**
- 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.