# PEDIATRIC DRUG RESISTANT EPILEPSY: CAREGIVER CONSIDERATIONS



Many factors affect how families consider neurotechnology treatment for their child with drug resistant epilepsy (DRE).

Knowing how some parents and caregivers made their decisions may help others.

#### **ABOUT THIS STUDY**



Views gathered from 22 parents of youths diagnosed with pediatric DRE and treated with neurotechnology.

# **TREATMENT VALUES**

Features of the neurotechnology treatment that parents consider to be important.

### **POTENTIAL BENEFITS**

- Improved quality of life
- Freedom from seizures and medication
- Greater independence

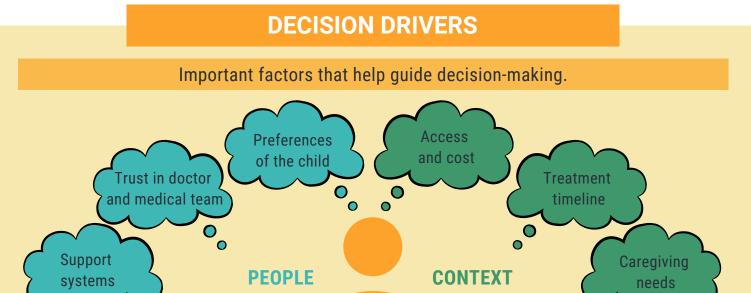
While physicians focus on seizure reduction, caregivers also emphasize overall quality of life.



## PERCEIVED RISKS

- General risk of epilepsy treatments
- Invasiveness of procedure

Some parents are unaware of the risks posed by untreated or insufficiently treated seizures.







# **FINDING INFORMATION**

Resources parents use to learn more about treatment options.

#### **SOCIAL MEDIA**



Connecting to others with similar experiences





Guidance from doctor and medical team

#### **ONLINE RESEARCH**



Video blogs, media coverage, and educational sites

# **TAKE-HOME MESSAGES**



Caregivers consider treatment in terms of benefit to overall quality of life.



It is important to have input from everyone involved in treatment strategy.



Trust in the medical team plays a large role in the decision-making process.



Openness and transparency are key to helping caregivers navigate the complexities of neurotechnologies for children with DRE.

LEARN MORE AND PROVIDE FEEDBACK AT WWW.NEUROETHICSCANADA.COM



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