

Newly Diagnosed Checklist

FAMILY & COMMUNITY

- Share the diagnosis with friends and family, when you are ready.
- Connect with your feelings and discuss with family, friends, or a therapist.
- Have a family member or friend accompany you to all healthcare appointments to help with your child or take notes, so you can focus.
- Suggest ways that family and friends can help. Create and share your list of needs.

ADVOCACY & SUPPORT

- Visit our website for information and support at www.dravetfoundation.org.
- Join the DSF Family Network to connect with other families and register for programs and resources. Register at www.dsffamilynetwork.org.
- Stay up to date on current research and clinical trials at www.dravetclinicaltrials.org.
- Register for an educational conference, workshop, or webinar. Events are listed on our website at www.dravetfoundation.org.

MEDICAL

- Keep a seizure log to share with the neurologist. Learn more at www.seizuretracker.com.
- Prioritize your child's medical challenges and focus on top concerns. Schedule appointments with specialists for baseline assessments.
- Find a specialist who understands Dravet syndrome at www.dravetdoctors.org.
- Learn about and develop a seizure action plan at www.seizureactionplans.org.
- Consider participation in a clinical trial. More information at www.dravetclinicaltrials.org.
- Learn about ICD10 billing codes that may ease access to testing and treatments at www.dravetfoundation.org/icd-10-codes.
- Discuss SUDEP (sudden unexpected death in epilepsy) with your child's neurologist.

STATE SERVICES & EDUCATION

- Children younger than 3 can receive Early Intervention services through their State Department of Health.
- Set up evaluations for ages 3 and older to determine their services in school and establish an Individualized Education Plan or 504 Plan.
- Check your state's website for waiver programs and sources of support.
- Provide school staff with educational resources on Dravet syndrome and your child's seizure action plan.
- Unsure where to start? Begin with your pediatrician or family doctor. Additionally, all schools and hospitals have social worker on staff who can help you.