

Newly Diagnosed Checklist

Family & Community

- When you are ready, share the diagnosis with family and friends. Be sure to direct them to our website for more information.
- Suggest ways that family and friends can help. They want to help but might not know how to support you. Create and share your list of needs.
- Connect with your own feelings about what has happened. Talk to your spouse, children, and family members, as well as 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 and remember important information.

Advocacy & Support

- Visit our website at www.dravetfoundation.org for information and support, regardless of your child's age.
- Visit www.dravetclinicaltrials.org to learn about current clinical trials and how you can participate.
- Join the DSF Family Network at www.dsffamilynetwork.org to connect with other families and register for programs and resources offered by DSF, including our private parent support groups.
- Register for a DSF conference, Day of Dravet workshop, or recorded webinars. Visit www.dravetfoundation.org to learn about upcoming events.

Medical

- Keep a seizure log to share with your child's neurologist. Seizure Tracker - www.seizuretracker.com - is a commonly used tool.
- See a specialist who understands Dravet syndrome. Our Find a Doctor tool at www.dravetdoctors.org can help.
- Learn about seizure action plans at www.seizureactionplans.org and develop one with your child's neurologist.
- Prioritize your child's medical challenges and focus on top concerns. Schedule appointments with specialists for baseline assessments.
- Discuss SUDEP (sudden unexpected death in epilepsy) with your child's neurologist.
- Dravet syndrome has its own unique ICD-10 billing codes, which may ease access to new treatments. You can visit www.dravetfoundation.org/hcp-resources/treatment-consensus/ for details.

State Services & Education

- Check on your state's website for waiver programs as well as Federal and State sources of support.
- Children younger than 3 can receive Early Intervention services through the State Department of Health.
- Set up evaluations for ages 3 and older to determine their services in school and to establish an Individualized Education Plan (IEP) or a 504 Plan.
- Provide school staff with information on Dravet syndrome, along with your child's Seizure Action Plan for emergencies.
- For caregivers of adults, your state's website will offer a list of disability waivers, financial support, and housing services that are available.
- Unsure where to start? Begin with your pediatrician or family doctor. Additionally, all schools and hospitals have social workers on staff who can help connect you with appropriate programs in your area.