

## Newly Diagnosed Checklist

Below are suggestions from families of things to do after receiving a diagnosis:

- Connect with other Dravet families to hear about their personal experiences, ask questions and share advice. DSF moderates a private Facebook support group for families.
- Keep a seizure diary where you record seizures along with other relevant information, such as dietary changes, timing of medication intake of anticonvulsants and other drugs, amount and quality of sleep, etc. This is a useful tool when working with your neurologist and may assist in identifying seizure triggers. Seizure tracker is an online tool that is free and easy to use and allows you to print reports and graphs that can be shared with medical professionals.
- Make sure to have literature that explains more about Dravet syndrome and related epilepsies when meeting with therapists, teachers, and other professionals who will care for your child. You can order free brochures from the [dravetfoundation.org](http://dravetfoundation.org) website.
- Learn about the Birth to Three Program or other early intervention program where you live. This program will provide a developmental screening and assessment and will offer therapies, early education programs, as well as parent education and support.
- In the US, enroll your child in your state's PUNS (Prioritization of Urgency of Need for Services) list through the local Department of Family & Children Services. Also, educate yourself on the Home & Community-Based Waiver (Katie Beckett waiver) program and other services that are available for your child in your state. The HCBW is a federal waiver that is intended for children from birth to eighteen years of age with a chronic disability. It entitles children to Medicaid who would not otherwise qualify due to their family's financial status. It was originally intended for children at risk of institutionalization, but is also for children that have lifelong medical needs. Each state sets their own criteria on how they will administer the program, therefore it varies greatly state to state and most states have a wait list. Programs in some states offer respite care and/or funding for home modifications. You can find out about the program in your state and how to enroll by contacting your local Department of Family & Children Services. **Parents in the Facebook support group are a great resource for information about State programs.**
- If possible, see a neurologist who is an expert in Dravet syndrome. Even if they are not your primary neurologist, they can work in tandem with your local neurologist to establish a protocol that deals with the intricacies of this syndrome and how it impacts your child. There is a directory of physicians on the [dravetfoundation.org](http://dravetfoundation.org) website. Work with your neurologist on a written emergency protocol for your child in the event of a seizure. Make sure copies are kept with the child when they are away from you, such as at school or when visiting with relatives. There is a protocol example on the [dravetfoundation.org](http://dravetfoundation.org) website.
- Put together an emergency kit of your child's medications, along with dosage information, that can be easily grabbed for an unexpected hospital stay or in the event of a natural disaster.
- Look at equipment that may help lower your child's seizure threshold in certain situations, as well as equipment which allow you to monitor and keep them safe. Items that families have found helpful include: cooling vests for summer heat; specially tinted glasses for photosensitivity; seizure monitors; pulse oximeters; adaptive strollers; and closed-circuit cameras in the child's bedroom. DSF offers Patient Assistance Grants for many of these items.

**For more information, visit [www.DravetFoundation.org](http://www.DravetFoundation.org)**