



Our mission is to improve the lives of children and families who are affected by PCDH19 Clustering Epilepsy. The Alliance focuses on raising and directing funds to scientific research with the goal of finding better, more effective treatments and, ultimately, a cure; providing information and support to affected families; and assisting the efforts of the medical community, so that no family suffers without a diagnosis and the most appropriate medical treatment.

PCDH19 Alliance Patient Assistance Grant Program

The PCDH19 Alliance purchases goods and services for qualified recipients through their Patient Assistance Grant Program. The purpose of this program is to offer grants to patients with PCDH19 Epilepsy for necessary medical expenses associated with these conditions that are not covered through private insurance or other assistance programs.

Items that are currently covered under this program:

- Durable medical goods (such as pulse-oximeters, seizure monitors, cooling vests, etc.)
- Therapy programs
- Communication devices (iPad, tablets, etc.)

If the equipment or therapy you are interested in is not listed above, please contact us with more details on the requested item and we can review its eligibility. This program does not cover seizure dogs.

Our grant application period typically begins on June 1st at 12:01am PST. When funds are depleted for the year, the program will be closed until the next application cycle and notification will be placed on our website. Applications will be reviewed and approved on a first-come, first-served basis. An applicant may apply once per grant cycle with a yearly maximum of \$1,000 and a life-time award maximum of \$5,000. The Board of Directors will review information on all applications and will make a determination. We request up to 45 days to review your application.

Your returned application packet should include the following:

- Completed application
- A recent letter from the child's physician or health care professional explaining the medical necessity of your request
- A letter of denial from the insurance provider stating that the requested equipment and/or service was denied (if applicable)
- Any other documentation pertaining to the nature of your request

All information is kept confidential. Applications that are incomplete or missing requested additional information will not be reviewed until complete.

All information provided with an application will be reviewed and/or verified, including:

- Letters from medical professionals, teachers, or therapists involved in the child's care attesting to the child's need for the item(s) requested
- Letters of denial for insurance coverage (if applicable)
- Additional documentation

We reserve the right to contact companies and organizations that provide requested equipment and/or services to verify price and availability. We will attempt to procure discounts or donations of equipment and/or services to allow us to meet the needs of more children and families.

All applicants will receive an email stating approval or denial of their application. Denied applicants wishing to re-apply must provide additional documentation of a change of status in circumstances or that other alternatives have failed.

By awarding these grants, The PCDH19 Alliance is making no recommendation to the appropriateness or safety of a particular piece of equipment or therapy in treating PCDH19 Clustering Epilepsy. The PCDH19 Alliance and its Board of Directors is not responsible for the safety and use of awarded equipment or therapies. Applicants are strongly urged to consult with their medical professionals and therapists regarding equipment and therapies that would be most beneficial for their situation.

We will not divulge application information without written consent from the applicant or their legal guardian.

Send your completed application via email to:

julie@pcdh19info.org

If you have any questions on this program, please email julie@pcdh19info.org or call 925-209-6307 (Mon-Fri 9am-5pm PST).