



THE INTERNATIONAL PYRIDOXINE DEPENDENT EPILEPSY (PDE) REGISTRY



www.pdeonline.org

YOUR EXPERIENCES MATTER

You are invited to participate in this research study because you / your child has a condition called Pyridoxine-Dependent Epilepsy (PDE) due to ATQ (*ALDH7A1*) deficiency.

With your consent we will collect medical data from you to learn more about the natural history of this condition and how a deficiency in ATQ produces the symptoms you experience. We also want to collect information on the effects of existing and/or new treatments. All of this information will serve to improve patient care and achieve better health outcomes for individuals with this condition.

WHO CAN PARTICIPATE?

Patients & families with a confirmed diagnosis of Pyridoxine-Dependent Epilepsy due to ATQ deficiency. Your participation in the PDE Registry is completely voluntary and you can withdraw at any time.

HOW TO HELP: JOIN THE PDE REGISTRY

We encourage you to contribute and to 'Make Your Experiences Matter' by joining the registry.

You can do so by asking your physician to enroll you into the PDE registry. For more information, go to www.pdeonline.org

WHY PARTICIPATE IN RESEARCH?

Have you ever wondered how new treatments are developed - or even how we gather clues to understanding the symptoms of Pyridoxine-Dependent Epilepsy? It is thanks to people like yourself who volunteer to participate in institutional ethics board-approved research studies such as these.

We value learning about your experiences, in particular symptoms, disease course and treatment effects. If you consent (for your child), your (child's) information will be entered by your physician into an online database after all personal identifying information has been removed. At regular intervals, study investigators will then access and analyze this database encompassing information from many participants around the world, to improve our knowledge and understanding PDE.

There is no direct benefit from participation in this study. However, the results of this study may, in the future, help scientists improve early diagnosis of individuals with PDE, enhance their management and ultimately prevent the majority of symptoms all together.

Still Have Questions?

Contact us by email: pde@cw.bc.ca