



What is Erdheim-Chester Disease (ECD)?

www.erdheim-chester.org

MEDICAL FACTS

- Extremely rare, debilitating and life threatening disease with less than 750 cases documented in the world. The cause is unknown.
- Affects different organs in different people, but can affect almost all organs; unless successful treatment is found, organ failure can result.
- More common symptoms/signs can include bone pain in legs & knees (More than 50% of ECD patients share this symptom.), bulging eyes, balance issues, excessive thirst/urination, shortness of breath, excessive fatigue, weight loss, cardiac issues, vision problems, and/or reduced kidney function.
- To date, there is no “cure” for ECD, although more effective treatments are being discovered. The best treatments available today control and sometimes shrink the growths associated with the disease.

The World Health Organization has reclassified Erdheim-Chester Disease as a **histiocytic neoplasm**. This means the rare disease is now considered a slow-growing blood cancer that may originate in the bone marrow or a precursor cell.

WHAT IS IT LIKE TO HAVE ECD?

You are so tired and sick feeling all you want to do is sleep. You have difficulty eating. You are getting sicker every day.

Your pain level sends you to the ER periodically. New and more serious health issues continue to occur.

You find it difficult to walk only a few steps because of breathing issues and you have no balance. You find it difficult to walk only a few steps because of breathing issues and you have no balance.

Your medical team may be unfamiliar with the disease, making it likely that you will have to travel a long distance to reach an ECD Care Center that will be able to help you.



ERDHEIM-CHESTER DISEASE
GLOBAL ALLIANCE

501(C)3 ORGANIZATION

The ECDGA is an international patient advocacy group based in DeRidder, LA, providing support to patients and research funds to find treatments.

Founded in 2009 in Memory of F. Gary Brewer

fundECD.org

