

What is ECD?

ERDHEIM-CHESTER DISEASE

Facts about an ultra-rare cancer.

STATS & FACTS

ECD IS AN EXTREMELY RARE,

debilitating and life threatening disease with less than 1,000 reported cases in the world. The cause of ECD is unknown. The diagnosis of ECD is challenging due to its non-specific symptoms. Therefore, ECD is likely underdiagnosed.

COMMON SYMPTOMS OF ECD

include pain in the bones of legs & around knees (more than 50% of ECD patients share this symptom), bulging eyes, vision problems, skin rash/bumps, balance difficulties, excessive thirst & urination, shortness of breath, excessive fatigue and weight loss. ECD can also affect the heart and kidneys.

THERE IS NO CURE FOR ECD,

although more effective, targeted treatments have been recently discovered. The best treatments available today shrink the growths associated with ECD and control the disease to improve outcomes.

MORE INFORMATION

can be found at www.erdheim-chester.org, which is continually updated with new information about treatments, trials, events, and more.

WHAT'S IT LIKE TO LIVE WITH ECD?

- You feel very tired and sick, and all you want to do is sleep.
- You have difficulty eating.
- You are getting sicker every day.
- Your body pain 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 or poor 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.

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



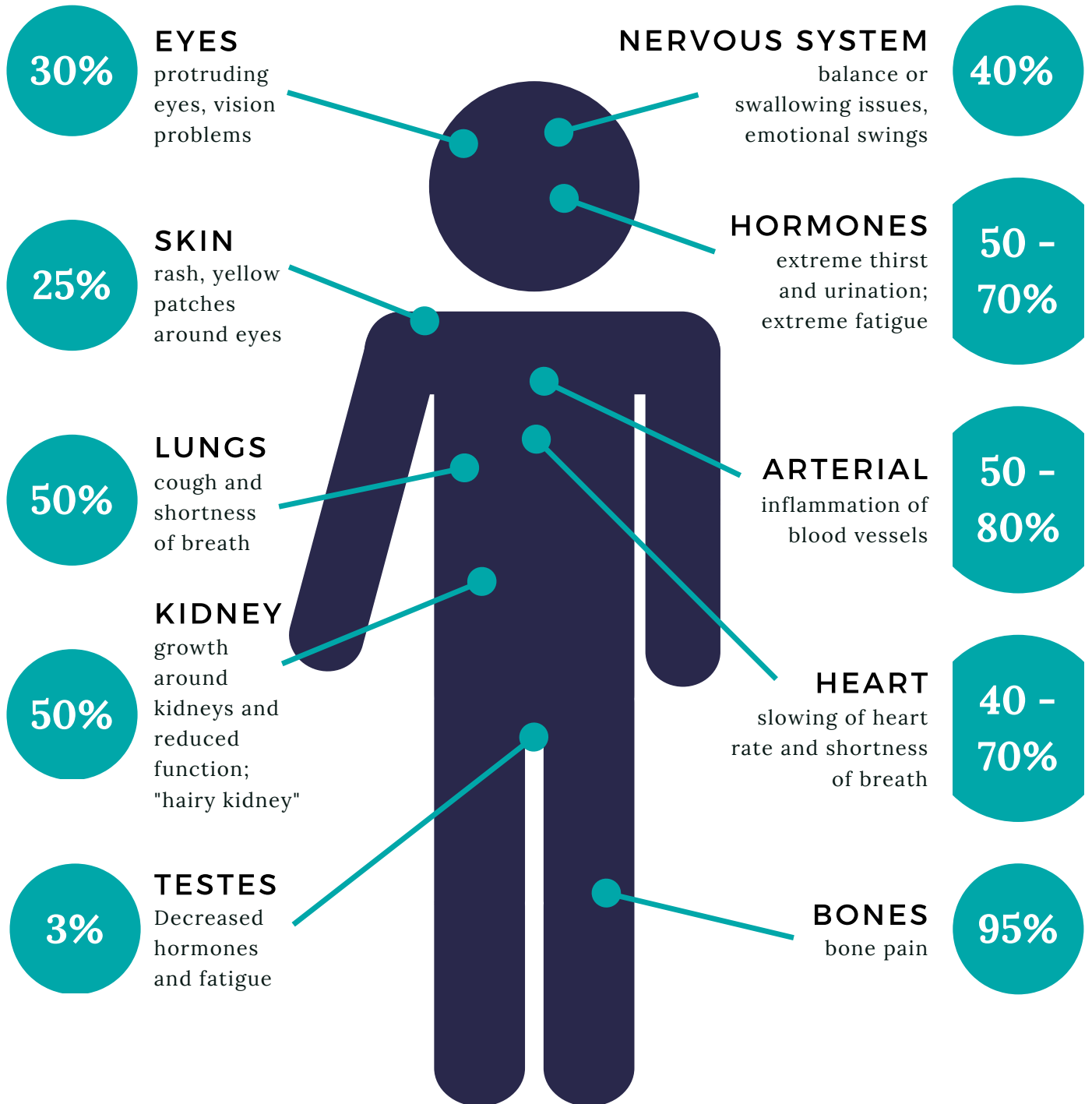
ECD GLOBAL ALLIANCE

Supporting those affected by Erdheim-Chester Disease worldwide.

www.erdheim-chester.org

ECD AFFECTS VARIOUS ORGANS

in different people, but can affect almost all organs. Unless successful treatment is found, organ failure may result. This diagram represents organ involvement frequency based on existing studies from ECD Care Centers.



Adapted from Goyal G. et al. Mayo Clin Proc. 2019 Aug 28. doi: 10.1016/j.mayocp.2019.02.023