

# Erdheim-Chester Disease

*A rare multi-system histiocytic syndrome*



Erdheim-Chester Disease (ECD) is a debilitating, underdiagnosed rare condition. It is classified as a non-Langerhans histiocytosis and is increasingly described as an inflammatory myeloid neoplasm (blood cancer).

- Histiocytes, cells that normally fight infection, accumulate in tissue and organs.
- Affects different organs in different people, yet can affect virtually every organ system.

## Symptoms & Diagnosis

Common early symptoms may include: bone pain in legs and knees, fever, night sweats, weakness, fatigue, excessive thirst & urination, balance issues, lower back pain, bulging of the eye/vision issues, rash, shortness of breath, and heart issues.

Usually diagnosed through biopsy, scans (bone, PET & MRI), and clinical symptoms.

## Prognosis

Unless successful treatment is found, organ failure can result.

## Treatments

All treatments are off-label. These include gene inhibitors, immunotherapy, chemotherapy, immunosuppressants, and steroids, all of which have been used with varying degrees of success.

Recent breakthroughs identifying genetic mutations found in ECD patients are leading to targeted and effective treatments for a subset of patients.

**ECD research, with extremely limited funding, is on the forefront of science and “precision medicine,” illustrating that therapies targeting a specific genetic mutation can be effective, regardless of where a cancer originates.**

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## Erdheim-Chester Disease Global Alliance

*A 501(c)(3) non-profit patient advocacy organization supporting those affected by ECD from around the world*

### **Purpose of the ECD Global Alliance**

**The ECD Global Alliance is dedicated to awareness, support, education, and research related to Erdheim-Chester Disease.**

#### **Raise awareness of ECD**

Facilitate early diagnosis and stimulate concern and efforts to increase knowledge regarding the disease and treatments.

#### **Provide support to those affected by the disease**

Lessen the burden of those affected by ECD by providing information, referrals, and one-on-one contact with others affected by the disease.

#### **Advocate for and support research programs**

Fund and advocate for research programs to learn more about the disease and find effective treatments.

Encourage collaboration within the research, medical and pharma communities.

Facilitate information sharing between patients, caregivers, medical providers and the research community.

#### **Share educational material and facilitate information sharing**

Provide current, reliable, and factual information about ECD to patients, loved ones, medical personnel, research personnel, media, and other organizations.

Promote, sponsor and conduct workshops, symposiums and other meetings to achieve the goals of the alliance.

**ECD research is underway at the National Institutes of Health (NIH) and a handful of other institutions in the U.S. and Europe. Research funding, physicians' lack of awareness, and treatment access are a few of the many challenges facing the ECD community.**

Website: [www.erdheim-chester.org](http://www.erdheim-chester.org)

E-mail: [support@erdheim-chester.org](mailto:support@erdheim-chester.org)

Online donations: [www.razoo.com/story/ECD-Global-Alliance](http://www.razoo.com/story/ECD-Global-Alliance)



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