

What is ECD?

- Rare multi-system non-Langerhans Cell histiocytosis
- Characterized by excessive production and accumulation of histiocytes
- Increasingly recognized as a neoplasm (cancer)
- Can affect almost all organs
- Affects everyone differently
- Progressive, resulting in organ failure, unless successful treatment is found



You can help

- **VOLUNTEER** Help the ECD Global Alliance with their work by sending an email to support@erdheim-chester.org.
- **FUNDRAISE** Host a fundraiser to raise research funds.
- **ADVOCATE** Help educate others about this disease and let your law makers know that funding for rare disease research and support is important to you.
- **SHOW SUPPORT** If you know someone with the disease, help them with daily activities, listen to them and just take time to be with them.
- **GIVE**

Donations accepted by mail:

The ECD Global Alliance
P.O. Box 775
DeRidder, LA 70634 USA

Or Online

www.razoo.com/story/ECD-Global-Alliance

This material is for awareness purposes only.

**In Honor of F. Gary Brewer
and
All Those Who Suffer from ECD**

Erdheim-Chester Disease

A rare multi-system histiocytic syndrome

PATIENT GUIDE



A 501(c)(3) non-profit patient advocacy organization supporting those affected by ECD

Symptoms

Symptoms may vary depending upon the organ(s) involved. Common symptoms may include:

- Bone pain in legs and knees, usually on both sides
- General symptoms-weight loss; fever; night sweats; muscle and joint aches; feeling of discomfort, weakness; fatigue; flu-like symptoms that linger or continue to return
- Excessive thirst and urination (diabetes insipidus)
- Balance issues; difficulty walking; slurred speech; involuntary, rapid eye movements
- Lower back, flank or abdominal pain, often associated with kidney issues; reduced kidney function
- Bulging of the eye and/or vision difficulties
- Sore or bump under the skin, rash
- Shortness of breath
- Heart issues
- Increased susceptibility to infections

Each person will have a different combination of symptoms, making ECD difficult to diagnose.

Treatments

Based on individual experiences, the following treatment plans have been used with varying degrees of success:

- BRAF & MEK inhibitors (Zelboraf, Tafinlar, Mekinist)
- Immunotherapy (interferon)
- Chemotherapy (cladribine, clofarabine)
- Autoimmune treating drugs (Anakinra, Actemra, methotrexate, Remicade)
- Immunosuppressants (Rapamune, cellcept, imurane)
- Steroids (e.g., prednisone)
- Surgery to remove tumors and parts of tumors



Prognosis

In general, the prognosis for patients with this disease is variable. It is important to know there are patients who are living high quality lives with ECD for decades after diagnosis.



Living with ECD

ECD patients face many challenges. Patients can feel extremely tired, have pain, and feelings of anxiety.

Some patients experience these and other challenges for long periods of time. Other patients are able to participate in life for long periods of time with few of these issues.

New targeted treatments are proving extremely effective.

Additional Information

More information about ECD can be found at www.erdheim-chester.org. The website is continually updated with new information about treatments, trials, events and much more.