

### Fact Sheet

#### What is Erdheim-Chester Disease?

Erdheim-Chester Disease (ECD) is a disorder in which particular types of cells the body uses to fight infection, called histiocytes, multiply and spread like an aggressive cancer. These cells infiltrate the bone, nervous system, lungs, heart, kidneys, eyes, pituitary gland, lymph nodes and various other organs causing them to become thickened and scar-like.

#### Symptoms can include, but not be limited to:

1. Bone pain
2. Balance issues
3. Diabetes insipidus ( a disorder where the body cannot manage fluid levels which results in the excretion of large amounts of urine)
4. Loss of appetite
5. Shortness of breath, leading to respiratory failure
6. Kidney failure
7. Heart failure

Very little is known about ECD. ECD most often affects adults in their 40's to 60's. Diagnosis of ECD is most often made based on biopsy, bone scans and symptoms. There is no agreed upon “best” treatment for ECD because there has been so little research performed. It can take years for a patient to be correctly diagnosed with ECD. Once diagnosed, it can be difficult to find a doctor who can treat the disease.

#### What is it Like to Have ECD? Imagine -

- You are very sick and getting sicker every day
- You are so tired all you want to do is sleep
- You might have a pain level that forces you to occasionally seek medical attention in an ER
- You might have no appetite and begin losing weight at an alarming rate
- You might be finding it difficult to catch your breath after walking only a few steps
- Your medical team can tell you little or nothing about what is making you so sick, does not know how to treat it, and is unable to provide information about the possible progression of the disease.

This is what it is like to suffer from ECD. This is why the ECD Global Alliance was formed, to reach out and provide help to those affected by ECD. It is our mission to provide support to patients and loved ones, to raise awareness of ECD, and to promote research to find successful treatments and ultimately a cure.

#### ECD GLOBAL ALLIANCE

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