

[Date]

[Sender First & Last Name]

[Address]

[City, State, Zip]

[Recipient First & Last Name]

[Address]

[City, State, Zip]

Dear Dr. [Recipient Last Name]

I have been diagnosed and live with [Erdheim-Chester Disease](#).

During my search for a diagnosis I visited you. I am writing you with hopes that I may be able to bring awareness of the rare disease I now live with.

Erdheim-Chester Disease (ECD) is an ultra-rare disease that has been [classified by the World Health Organization as a histiocytic neoplasm](#). The slow-growing blood cancer may originate in the bone marrow or a precursory cell. ECD results in the overproduction of histiocytes, a type of white blood cell created in the bone marrow. These cells collect in different organs resulting in ECD lesions and tumors that can manifest in several organs of the body including the brain, heart, lungs, kidneys and long bones amongst others.

Prior to the WHO announcement, ECD was an unclassified disorder and commonly described as a non-Langerhans histiocytosis. ECD has a strong inflammatory component that is common with histiocytoses. In ECD, histiocytes infiltrate within loose connective tissue, causing organs to become dense and fibrotic, which can lead to organ failure unless a successful treatment is found.

There is no cure for ECD and it is very often misdiagnosed. However, current trials and studies associated with ECD treatments are showing great promise. Lives are being extended and quality of life is improving for ECD patients on a proper treatment. To learn more about ECD and current research related to ECD please visit [www.erdheim-chester.org](http://www.erdheim-chester.org) for the most up-to-date information. A [physicians' informational guide](#) can be found on the website for a brief overview of the disease, its symptoms, diagnosis, and treatments.

Thank you for taking the time to learn about ECD. I am profoundly appreciative of the job you do and understand that working with and diagnosing a rare disease patient is difficult. I know the goal of any doctor is to help others and treat them well. For this reason, I believe that with more awareness of ECD perhaps others unknowingly suffering from ECD will be able to be diagnosed more quickly and begin treatment sooner. I hope that this information is useful and helpful to them and you.

Sincerely,

[Sender First & Last Name]

[Any additional contact information you would like to provide (ex. email or phone)]