

HELP IMPROVE ECD CARE

Advocate for ECD Patients

Help educate others about this disease and let your law makers know that funding for rare disease research and support is important to you. Your voice can make a difference.

Donate to Research

The ECDGA supports vital research and education to discover the cause and improved treatments for ECD patients.

Take Part in Research

People are needed for clinical trials that can help find effective treatments for ECD patients. Clinical trials are research studies that help ensure that new drugs are both safe and effective. Ask your doctor if a trial is right for you and how to volunteer for a clinical trial. A list of current clinical trials accepting ECD patients can be found at www.erdheim-chester.org/studies-trials/.



ERDHEIM-CHESTER DISEASE REGISTRY

The Registry for Patients with Erdheim-Chester Disease, managed by Memorial Sloan Kettering Cancer Center (MSK), unites leading researchers with patients like you, who are interested in taking part in building a longitudinal clinical database. www.erdheim-chester.org/patient-registry/

HOW TO DONATE

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



fundECD.org



FRIENDS & FAMILY

If you know someone with ECD, help them with daily activities, listen to them, and just take time to be with them. Caring for a loved one with ECD can be both physically and emotionally exhausting.

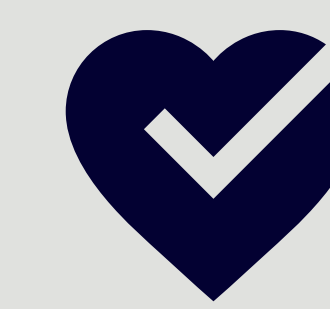
If you are caring for a family member or friend with ECD, take care of yourself, as well. Avoid the feeling that you have to do it all yourself. Get help from family, friends, and professionals. There are resources to help and a caregiver contact form on the ECDGA website.

What is ERDHEIM-CHESTER DISEASE?

INFORMATIONAL GUIDE FOR FAMILIES



Erdheim-Chester Disease (ECD)



DIAGNOSIS

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

Cardiac and head MRI are recommended for all patients at the time of diagnosis for comprehensive baseline assessment.

- A slow-growing blood cancer (a cancer of histiocyte cells), that originates from precursor cells in the bone marrow
- Characterized by excessive production and accumulation of immune cells, called histiocytes
- Can affect almost any organ
- Affects everyone differently
- Continued successful treatment is extremely important to manage this disease and prevent progression

The prognosis for patients with this disease is improving at a rapid rate due to new targeted treatments, but can still be variable between patients. It is important to know that there are patients who are living high quality lives with ECD for decades after diagnosis.



ERDHEIM-CHESTER DISEASE GLOBAL ALLIANCE

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

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



FIND AN EXPERT

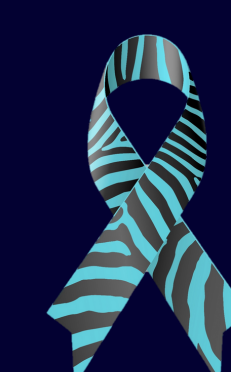
An ECD Referral Care Center network is available to treat patients and/or provide consultation to treating physicians when patients cannot travel. Find more information about these centers at www.erdheim-chester.org/care-centers/.



Patients affected by ECD are encouraged to contact the organization for more resources and support.

THIS MATERIAL IS FOR AWARENESS PURPOSES ONLY.

CONTACT US
support@erdheim-chester.org
www.erdheim-chester.org





TREATMENTS

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

- BRAF & MEK inhibitors (Zelboraf*, Tafinlar, Mekinist, Cotellic)
- Immunotherapy (interferon)
- Chemotherapy (cladribine, clofarabine)
- Anti-inflammatory medications (Anakinra, Actemra, Remicade)
- Immunosuppressants (Rapamune, Cellcept, Imurane, methotrexate)
- Steroids (i.e., prednisone)
- Surgery to remove tumors and parts of tumors

*FDA approved drug for ECD patients testing positive for the BRAF V600 mutation.



MANAGEMENT

For many patients, there is effective treatment, but unfortunately, there is no cure for ECD yet. As a result, patients with ECD need ongoing care, often from different specialists. It can be helpful to have one physician coordinate care.

- FDG-PET should be performed every 3-6 months until stabilized
- Organ-specific imaging of affected organs every 3 months until stabilized
- Monitoring of Vitamins B12 & E, and hormones to include testosterone, ADH, thyroid function, insulin, ACTH and PTH
- Initiation of rehabilitation (PT, OT and ST) as warranted
- Currently, most treatment is recommended indefinitely as tolerated

LIVING WITH ECD

ECD patients face many challenges. Patients can feel extremely tired, have pain, and can have feelings of anxiety and/or depression. Some patients experience these and other challenges for long periods of time. Other patients are able to cope for long periods of time with few of these issues.

To provide the best care, your doctor needs to know all about your symptoms and medical history. Likewise, you need to get answers to your questions. Keeping a notebook about your condition and bringing a few well-organized questions to your appointments can be helpful.

New targeted treatments are proving extremely effective. The newer medications can also be very expensive, so patients should work with their insurers and may benefit from patient-assistance programs sponsored by drug makers and other sources. Social workers, case managers and patient navigators may help patients to find the best resources for their care.

RESOURCES

For more information about ECD or the ECD Global Alliance visit our website at www.erdheim-chester.org.



BECOME A MEMBER

Become a member of the ECD Global Alliance! Registration is simple, confidential, and free. Access to resources and the latest news on ECD will be at your finger tips. www.erdheim-chester.org/join



ORGAN INVOLVEMENT

The following diagram shows the percentage of approximately 400 ECD patients who experience issues associated with each of the listed organs. These numbers have been compiled using several existing studies.

