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/.

WHAT IS ERDHEIM-CHESTER DISEASE?
Informational Guide for Families

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/

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

Thomas A. Roboz, M.D. Diagnosed 2010

ERDHEIM-CHESTER DISEASE
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.
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.

**EYES**
- protruding eyes, vision problems (30%)
- rash, yellow patches around eyes (25%)
- cough and shortness of breath (50%)
- growth around kidneys and reduced function, “hairy kidney” (50%)
- decreased hormones and fatigue (3%)

**NERVOUS SYSTEM**
- balance or swallowing issues, emotional swings (40%)

**HORMONES**
- extreme thirst and urination; extreme fatigue (50 - 70%)

**ARTERIAL**
- inflammation of blood vessels (50 - 80%)

**HEART**
- slowing of heart rate and shortness of breath (40 - 70%)

**KIDNEY**
- growth around kidneys and reduced function, “hairy kidney” (50%)

**LUNGS**
- cough and shortness of breath (50%)

**SKIN**
- rash, yellow patches around eyes (25%)

**BONES**
- bone pain (95%)

**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