

FOR IMMEDIATE RELEASE

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Erdheim-Chester Disease Global Alliance

www.erdheim-chester.org

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St. Louis on the Map for Rare Disease Care

Washington University in St. Louis joins growing Erdheim-Chester Disease Care Center Network

St. Louis, MO, March 14, 2016

The Erdheim-Chester Disease Global Alliance announces Washington University in St. Louis as one of two new additions to the Erdheim-Chester Disease (ECD) Referral Care Center Network. Dr. Armin Ghobadi is the ECD team leader at Washington University in St. Louis.

The leading care center network for treating the rare-disease also welcomes Drs. André Abdo, Juliana Pereira, and Vanderson Rocha of the Cancer Institute of São Paulo – University of São Paulo in Brazil.

These centers join an elite group of hospitals willing and able to treat ECD, a complicated and disabling disease resulting from a cancerous growth of white blood cells produced within the bone marrow.

As an ECD Referral Care Center, Washington University in St. Louis joins the ranks of medical institutions that have treated five or more ECD patients. Erdheim-Chester Disease can develop in many different organs in the body including the brain, bones, lung, heart, and kidneys requiring cross-specialty teams to work together to provide the best treatment available.

The St. Louis ECD Referral Care Center is the first of its kind in Missouri and will serve patients throughout the Midwest.

LaClaire, Iowa ECD caregiver, Gina Carstens and her husband commute 5 hours to the St. Louis care center because

"Having a treatment center gives us peace of mind.

We don't have to second guess the care we are getting."

The ECD Care Center project includes institutes such as The University of Texas, MD Anderson Cancer Center in Houston, Johns Hopkins Hospital in Maryland and Mayo Clinic in Minnesota.

There are now 22 international ECD Care Centers. The Cancer Institute of São Paulo is the first Referral Care Center in South America.

The ECD Global Alliance is a grassroots group based out of one of the smallest corners of the western Louisiana countryside. It is responsible for coordinating the ECD Care Center project.

Since the organization's founding in 2009, it has mobilized patients and their families globally to fight against ECD.

Thanks to the research networks facilitated by the ECD Global Alliance, the best care possible now includes precision medicine being developed through clinical trials and research.

The latest discovery, the BRAF V600E mutation in ECD patients, opens more effective treatment options. The care center system is designed to ensure these discoveries are not only communicated but put into practice.

Learn more about the [ECD Referral Care Center](#) network at the ECD Global Alliance website.



Center for Advanced Medicine at Washington University School of Medicine in St. Louis



Armin Ghobadi, MD

[Erdheim-Chester Disease](#) is an ultra-rare condition with no known cause.

It is a rare [non-Langerhans histiocytic disorder](#) that is challenging to diagnose and treat. It is often described as an inflammatory myeloid neoplastic disease.

The accumulation of histiocytes in tissue and organs characterizes ECD. Histiocytes are cells that normally fight infections. The infiltration of the histiocytes causes tissue and organs to become dense and fibrotic, leading to organ failure unless finding a successful treatment.

For more information, contact:

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The [ECD Global Alliance](#) is a 501(c)(3) non-profit organization dedicated to awareness, support, education, and research related to Erdheim-Chester Disease.

To donate, please send a check to ECD Global Alliance, P.O. Box 775, DeRidder, LA 70634. Make an online donation at the ECD Global Alliance [Razoo site](#). Thank you for your support!