

FOR IMMEDIATE RELEASE

February 23, 2016

Erdheim-Chester Disease Global Alliance

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Governor Bel Edwards Proclaims Rare Disease Day in Louisiana

Erdheim-Chester Disease is one of 7,000 rare diseases supported by the proclamation

DeRidder, LA, February 23, 2016

Louisiana joins twenty-one states in proclaiming Rare Disease Day on February 29, 2016. Newly-elected Governor John Bel Edwards made the official proclamation. The proclamation request was submitted by the DeRidder nonprofit, the Erdheim-Chester Disease (ECD) Global Alliance. The ECDGA and the state of Louisiana are supporting a global initiative to raise awareness of rare diseases and their impact on patients' lives amongst the general public and decision-makers. Even more important for Louisianans, the proclamation brings attention to a silent struggle that many in the state may be fighting with inadequate support from the medical system.

The ECD Global Alliance is one of the only registered rare disease advocacy nonprofits groups in Louisiana. The Alliance was founded after the president's devastating loss of her beloved husband to an extremely rare condition, Erdheim-Chester Disease. Both were residents of Louisiana.

Making the voice of rare disease patients heard this Rare Disease Day is the first step in improving the care and support provided to people suffering from a rare disease.

Rare Disease Day is an international event coordinated by the European Organization for Rare Diseases, [EURORDIS](http://www.eurordis.eu). In the United States, the National Organization for Rare Diseases ([NORD](http://www.nord.org)) is sponsoring the event. The event nationally is intended to support just a little less than 200,000 Americans affected by a rare disease according to the EURORDIS rare disease day website, www.rarediseaseday.org.

In Louisiana, it is difficult to tell how many people are affected by a rare disease due to the lack of recorded data and media coverage. NORD estimates 1 in 10 Americans are affected by one of the 7,000 rare diseases. To be sure, there are Louisianans right now desperately trying to deal with the emotional and financial weight of being unsupported and unheard. Many of which can painstakingly wait for 5 years or more for diagnosis.

Rare Disease Day activities include nationally organized [State House speaking events](#) and the virtual [Running on Air for Rare Disease Day](#) event, among other rare disease advocate specific activities.

Learn how Louisiana residents can show their support for Rare Disease Day and those affected by rare disease in Louisiana by visiting the official NORD Rare Disease Day website at www.rarediseaseday.us.

[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. Often described as an

inflammatory myeloid neoplastic (cancer-like) disease, ECD is characterized by the accumulation of histiocytes in tissue and organs. 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](#) was founded in 2009. It 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. Online donations can be made at the ECD Global Alliance [Razoo](#) page. Thank you for your support!

