

## **FOR IMMEDIATE RELEASE**

February 24, 2016

Erdheim-Chester Disease Global Alliance

(337) 404-6033

[www.erdheim-chester.org](http://www.erdheim-chester.org)

### **Culver's of Highland Supports Rare Disease Day**

Local rare-disease patient organizes fundraiser to raise awareness of Erdheim-Chester Disease

Highland, IN, February 24, 2016

Ultra-rare disease patient, Ashley Moss is bringing rare disease awareness to Highland, Indiana this February 29, 2016. From 4:00 p.m. until 10:00 p.m. at Culver's on 3950 Ridge Road, Ashley will be holding an Erdheim-Chester Disease (ECD) dine and donate fundraiser. The event generates awareness for world Rare Disease Day. If you are in the mood for a Cheddar Butterburger with some authentic Wisconsin cheese curds and want to support a good cause, mark your calendar.

Interested patrons can dine on the day of the event during the designated time. By grabbing an event flyer at the restaurant, 10% of the cost of their meal will fund ECD research and patient support through the Erdheim-Chester Disease Global Alliance.

Ashley's ability to place herself at the center of this Rare Disease Day event is brave. She is suffering from a debilitating ultra-rare disease, with less than 600 documented cases since the 1930s, that predominantly affects adults over 50. Making her, as a twenty-two year-old, an extremely rare case of the potentially deadly disease. Her bravery supports the Rare Disease Day mission to raise awareness of rare diseases and their impact on patients' lives.

Rare Disease Day is an international event coordinated by the European Organization for Rare Diseases, [EURORDIS](http://eurordis.europa.org). In the United States, the National Organization for Rare Diseases ([NORD](http://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](http://www.rarediseaseday.org).

In Indiana, it is hard 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 Indianans 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 Highland residents can show their support for Rare Disease Day and those affected by rare disease in Indiana by visiting the official NORD Rare Disease Day website at [www.rarediseaseday.us](http://www.rarediseaseday.us) or by just eating a burger.

[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!