



Contact:
Chesnee Green, Development Director
ECD Global Alliance
(828) 243-6861
Chesnee.green@erdheim-chester.org

FOR IMMEDIATE RELEASE

2019 Rare Disease Day

Erdheim-Chester Disease Global Alliance raises awareness on Rare Disease Day

DeRidder, LA – February 14, 2019 – The countdown has begun. February 28th, 2019 marks the 12th Annual Rare Disease Day around the world.

Over the last 11 years, Rare Disease Day has become iconic as the global campaign for raising awareness of rare diseases among politicians, clinicians, researchers and pharmaceutical companies. This year's theme is a testament to the challenges patients and families suffering from a rare disease face. According to EURODIS, the creators of Rare Disease Day, website: Bridging health and social care- "The 12th edition of Rare Disease Day will focus on bridging the gaps in the coordination between medical, social and support services in order to tackle the challenges that people living with a rare disease and their families around the world face every day."

A disease or disorder is defined as rare in the USA when it affects fewer than 200,000 Americans at any given time. Erdheim-Chester Disease (ECD) has been diagnosed in fewer than 1,000 patients worldwide. This ultra-rare disorder affects many organs of the body and presents in many different ways. Join the movement to raise awareness about rare diseases and their impact on patients' lives by sharing your story of living with a rare disease or caring for someone that does.

Get involved throughout the month of February!

- ◇ Show Your Rare, Show You Care - paint your face and/or hold up this board, take a selfie or photo and share on social media.
- ◇ Organize or get involved in an event: Thousands of events take place in over 90 countries around the world.
- ◇ Download the official Rare Disease Day 2019 poster and logo to put up in your workplace or home and for use at your events.
- ◇ Upload the Facebook frame or Twibbon to your social media profile pictures.
- ◇ Share your story with the local news outlets!
- ◇ Reach out to your local/state government; let them know the importance of funding rare disease research!

To learn more about ECD visit <http://erdheim-chester.org/>.

[Erdheim-Chester Disease](#) is an ultra-rare condition that is believed to be under diagnosed. It is considered a histiocytic neoplasm (type of blood cancer). The illness is characterized by the accumulation of histiocytes, cells that normally fight infections, in tissue

and organs. The tissue and organs become dense and fibrotic due to the infiltration of the histiocytes and can lead to organ failure unless a successful treatment is found.

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

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