

Contact:

Ben Frech, Communications Manager ECD Global Alliance Ben.Frech@erdheim-chester.org

FOR IMMEDIATE RELEASE

ECDGA Applauds FDA Approval of Cobimetinib to Treat Erdheim-Chester Disease and other Histiocytoses

(DeRidder, LA – November 2, 2022) - Today, the Erdheim-Chester Disease Global Alliance is applauding the U.S. Food and Drug Administration's approval of cobimetinib as a treatment for Erdheim-Chester Disease (ECD). ECD is a rare type of blood cancer that results in the accumulation of histocytes, cells that typically fight infections in organs throughout the body.

Cobimetinib is an anti-cancer medication that was first approved for the treatment of melanomas.

"Living with ECD can be a hard thing to go through and even harder for your family to watch," said Scott Schriner, an ECD patient who participated in the trial. "New treatments, like cobimentinib, are a true blessing because they allow us to live fuller lives and spend more quality time with the ones we love. I would like to thank Memorial Sloan Kettering Cancer Center, the ECD Global Alliance, and all of the other ECD patients who contributed to this approval."

The ECD Global Alliance, which advocates for ECD patients and raises awareness of the disease, has long worked with the medical professionals at Memorial Sloan Kettering (MSK) who conducted the research and pursued this approval. The ECDGA played an active role in raising awareness of the cobimetinib study among ECD patients and their families.

"As a physician, there are few things better than providing patients with treatment options that make a significant impact on their quality of life and overall health," said Dr. Eli L. Diamond of MSK, who led the trial as its Principal Investigator. "I'm extremely excited about the opportunity for better health that this treatment offers ECD patients and would like to thank our collaborators who supported us throughout the process and the patients who entrusted us with their participation in the study."

"This approval will not only help ECD patients access a proven treatment, but also provides the knowledge that while the disease may be rare, there are people advocating for ECD patients and families and pushing for new advancements," Kathy Brewer, president of the ECDGA. "I'm honored that we were able to play a part in the process and would like to extend our sincere gratitude to the FDA, Memorial Sloan Kettering Cancer Center, and all the courageous ECD patients and families who participated in the research."

For more information on the ECD Global Alliance please visit https://erdheim-chester.org/.

<u>Erdheim-Chester Disease</u> is an ultra-rare condition that is believed to be underdiagnosed. 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 <u>ECD Global Alliance</u> is a 501(c)(3) non-profit organization dedicated to the awareness, support, education, and research related to Erdheim-Chester Disease.

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