



ECD GLOBAL ALLIANCE

Supporting those affected by Erdheim-Chester Disease worldwide.

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Uplifting Athletes Awards ECD Global Alliance Investigator Draft

A rare disease advocacy group awarded an Erdheim-Chester Disease Research Grant to conduct a survivor study.

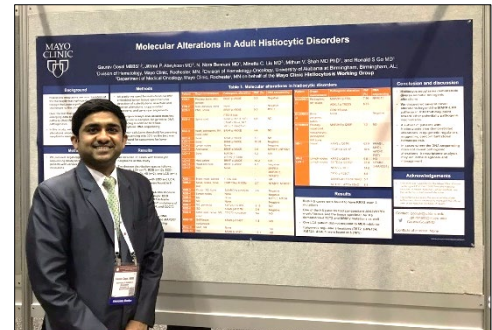
Uplifting Athletes is a nonprofit organization focused on using the platform of college football to shine a spotlight on rare diseases. Founded in 2007, Uplifting Athletes funds research and other initiatives, bringing hope to rare communities. Each year the organization grants research dollars through their Uplifting Athletes Young Investigator Draft. Proudly, this year a doctor nominated by the Erdheim-Chester Disease Global Alliance (ECDGA) was selected as a grant recipient!

The nominee, Dr. Gaurav Goyal is an Assistant Professor of Hematology-Oncology and ECD Care Center lead physician at the University of Alabama Birmingham. He will be awarded a \$20,000 grant for a Histiocytic Disorders Survivor Study (HDSS). Results from the study will be used to help devise guidelines for the follow-up care of ECD and other histio patients and develop intervention strategies in the future to mitigate long-term complications. Dr. Goyal adds, "The study aims to utilize the ECDGA Patient Registry to understand the spectrum of long-term health conditions that patients with ECD struggle with, including quality of life and chronic pain."

The ECD community has had the pleasure and honor of working with Dr. Goyal on multiple projects that have enhanced patient care, increased awareness, and contributed to the science of histiocytosis across the board. Dr. Goyal is a dedicated physician in his field that is passionate about helping patients and families every single day.

Nine grant recipients will be honored during the 2022 Uplifting Athletes Young Investigator Draft on Saturday, February 5 in Philadelphia, PA.

Research is a mission-critical goal for the ECD Global Alliance. Working with the Uplifting Athletes team to bring more research to fruition has been an honor. In the past, grant funding for ECD research has solely come from private donations, whereas the UA opportunity brings another \$10,000 to the initiative. By collaborating with a rare disease group that values the important work of discovery in rare science, The ECDGA has extended ECD research efforts. The ECDGA will continue to strengthen its connections with the rare community to aid in a firm foundation for histio care worldwide. These connections not only help with ECD and histiocytosis research, but also help to raise awareness of ECD within the medical community.



Goyal contributes to awareness and education frequently by collaborating and sharing data from his work in histiocytosis.



Erdheim-Chester Disease is considered a histiocytic neoplasm (type of blood cancer), an ultra-rare condition with no known cause, and is considered under-diagnosed. 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 the awareness, support, education, and research related to Erdheim-Chester Disease.

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