

FOR IMMEDIATE RELEASE:

Rare Disease Care Network Grows to Help More Patients

The Erdheim-Chester Disease Global Alliance adds four new ECD Care Centers in Canada and Europe

DeRidder, LA, - July 13, 2017 – The Erdheim-Chester Disease Global Alliance (ECDGA) welcomes four new ECD Care Centers into its care network. The ECDGA is the only non-profit organization dedicated to supporting those affected by the ultra-rare blood cancer, Erdheim-Chester disease (ECD). The growing group of hospitals and universities capable and willing to help ECD patients now includes the University of Alberta, Edmonton in Canada, the Université Libre de Bruxelles, Hopital Erasme in Belgium, Elisabethinen Hospital Linz in Austria, and St. James's University Hospital in the United Kingdom. These new centers will help to improve diagnosis, provide treatment, and support ECD patients, as well as facilitate collaboration among ECD knowledgeable medical professionals, increasing awareness and research.

Three out of the four new care centers are in Europe. There are 357 patient members registered with the ECDGA throughout the world. The ECDGA serves 85 patient members in Europe and 12 in Canada. Europe has the largest concentration of patients, after the United States with 190. Increasing the number of care centers will aid not only help patients but generate greater awareness of ECD among medical professionals who may be unfamiliar with the life-threatening disease.

The ECD Care Center network consists of Referral Centers and Emerging Centers. The difference is in the number of patients that have been seen at the institution. Referral Centers have seen five or more cases of ECD in their practice. The Emerging Centers are capable of treating ECD patients, but have seen less than five cases. Regardless of their designation, all institutions are required to communicate and collaborate with one another to ensure patients are receiving the most up-to-date treatment options and care available. The dedicated medical professionals at the centers work with a team of specialists to address the multifaceted nature of the disease, which can affect brain, heart, bones, kidneys, liver, and many other organs in the body. This approach ensures that all aspects of the disease are considered when diagnosing and treating the illness.

To facilitate collaboration and education, ECD Care Center medical professionals attend an annual medical symposium. The ECD Medical Symposium allows researchers and physicians a focused opportunity to discuss new findings in the ECD field and treatment options, and connect with one another on ECD-related issues. These doctors can also meet with ECD patients at the concurrent ECD Patient & Family Gathering event. The gathering provides a unique chance for practitioners to meet people affected by the disease and increase their real-life understanding of how ECD influences their lives.

With the addition of these new care centers, the ECDGA will have 29 international ECD Care Centers in its network. The ECD Care Center Network initiative began in 2015 and has seen steady growth since its inception. This year, the first Chinese care center was introduced as well as the expansion of the U.S. network with Vanderbilt University Medical Center in Tennessee. Due to the facilitation work of the ECDGA and involvement of participating medical professionals, patients now have resources in their regions, improving diagnosis and treatment. The ECDGA will continue to grow its care network globally to allow all patients the access to ECD-knowledgeable doctors and effective treatments.

To learn more about the ECD Care Center network or to support the ECDGA in its mission to provide care for all affected by ECD, visit www.Erdheim-Chester.org.

Erdheim-Chester Disease is a rare multi-systemic histiocytic neoplasm with no known cause that is challenging to diagnose and treat. Unless successful treatment is found, organ failure can occur.

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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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