

ECD Care Center Network Expansion Possible Because of Donors

Funding from ECD patients and their family and friends opens access to treatment facilities regardless of patient location.

DeRidder, LA, - July 13, 2017 – In 2017, six new international Erdheim-Chester Disease (ECD) Care Centers have been added to the expanding network. The ability to create, facilitate, and grow the care center network is made possible by the contributions of dedicated ECD Global Alliance (ECDGA) donors. Their funds support staff in enabling connections between physicians and the planning and execution of the annual ECD Medical Symposium, which is the number one way for ECD-interested doctors and researchers to join and further the fight against ECD. The expansion of the network means that donors have impacted improved outcomes for those affected by ECD and facilitated quickened diagnosis for those searching for the cause of their illness.



Of the six new ECD Care Center additions in 2017, five will help patients in Europe and Asia. Since the ECD Care Center Network program's start in 2015, 29 institutions have voluntarily joined together to treat ECD patients. Prior to the program, patients would have limited or no access to doctors aware of ECD or knowledgeable in how to treat the complicated disease. In addition, the journey for a confirmed diagnosis or proper treatment was longer and more arduous, at times leading to organ failure before diagnosis could be confirmed.

The development of a network of medical professionals and their respective hospitals has helped patients receive the latest treatments available for ECD by allowing access to a team of physicians versed in how to handle the multi-systemic condition. However, there is still work to do. The network needs to grow to help more patients, more physicians need to be trained to help expedite diagnosis, and research must be continued to better understand, treat, and ultimately cure this still potentially deadly disease.

Another important facet of the ECD Care Center Network is that regardless of where a patient is treated, their treating doctor can find and consult with an ECD Care Center physician to learn about the latest treatment options and best care for their patient. This opportunity through the network aids those patients unable to travel to a center for care. In addition, center physicians can help local specialists confirm diagnosis.

With the help of funding from its donors, the ECDGA has been the catalyst in bringing ECD-knowledgeable doctors from around the world together to help those affected by ECD. On average, the estimated cost to bring one ECD Care Center into the network and maintain the connection is estimated to be \$2,000 per year. Every ECD patient benefits from the growing referral network in that collaboration among the network produces improved best practices in care and treatment through advances in research.



Support the ECD Care Center Network expansion by connecting an ECD-knowledgeable physician with the ECDGA or by donating at www.fundECD.org.