

**SOBI, INC. AWARDS ERDHEIM-CHESTER DISEASE NON-PROFIT GRANT FOR CARE CENTER CREATION**

*FIRST OF ITS KIND - ECD REFERRAL CARE CENTERS MADE POSSIBLE IN PART BY PHARMACEUTICAL FUNDING*

**DERIDDER, LA, September 25** - Sobi Inc., a healthcare company dedicated to rare diseases, awarded the Erdheim-Chester Disease Global Alliance (ECDGA) \$15,000 to help in the creation of a network of Erdheim-Chester Disease (ECD) Referral Care Centers. On Friday, October 9, 2015, the first ECD Referral Care Center meeting will be held in Houston, Texas. This meeting will follow the Third Annual International ECD Medical Symposium held at MD Anderson. The development of care centers allows patients with ECD to access dedicated medical professionals who are educated in ECD treatments. Patients treated at these centers are expected to have better outcomes and quality of life.

ECD is a debilitating disease. Until recently, it was reported to result in a death rate of 50% or more within three years of diagnosis. However, today, a patient's quality of life and survival rate are increasing dramatically for patients treated by specialists familiar with emerging ECD treatments. With joint efforts among treating centers, the rapid discoveries made in the treatment of ECD are likely to continue. In addition, clinical trials will become easier to manage across institutions. This allows for formal approval of ECD treatments, which currently do not exist. As a result, patient outcomes can be greatly improved now and into the future.

It is strongly believed that ECD is an under diagnosed disease as it is largely unknown by members of the the medical community and extremely complex. Patients often go years searching, unsuccessfully for a diagnosis due to their varied medical issues. Knowledgeable doctors are required to make a firm diagnosis. The ECD Referral Care Centers will provide centers of expertise to link medical professionals across locations and specialties to aid in the diagnosis and treatment of the disease. The care centers will provide a self-sustaining long-term care program for ECD patients around the world from North and South America, Europe, and the Middle East.

About the Erdheim-Chester Disease Global Alliance:

The ECD Global Alliance, founded in 2009, is a 501(c) 3 non-profit organization dedicated to awareness, support, education, and research related to Erdheim-Chester Disease. To donate please send a check to ECD Global Alliance | P.O. Box 775 | DeRidder, LA 70634 or go online to <http://www.razoo.com/story/Ecd-Global-Alliance> Thank you for your support!

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