

## Residents at LSUHSC Shreveport Learn About ECD

*“Erdheim-Chester disease: Characteristics & Management” is presented by Filip Janku, MD, PhD*



Filip Janku, MD, PhD from The University of Texas MD Anderson Cancer Center gives talk on the characteristics and management of Erdheim-Chester disease to medical students and faculty at LSU Shreveport.

Shreveport, LA, May 26, 2017 – Medical residents and physicians at Louisiana State University (LSU) Health Sciences Center (HSC) in Shreveport learned about Erdheim-Chester disease (ECD) from ECD Care Center lead, Filip Janku, MD, PhD from The University of Texas MD Anderson Cancer Center. The audience listened to Dr. Janku discuss the characteristics and management of ECD. This awareness talk was made possible through contacts made at LSU by Gwendolyn Royal-Miller, the ex-wife of a deceased ECD patient and an ECD Global Alliance (ECDGA) volunteer. This presentation, and others like it, are playing a vital role in educating medical

professionals about this ultra-rare blood cancer. As a result of these presentations, doctors are better able to recognize ECD and potentially diagnose patient sooner and raises their interest in further helping those affected by ECD.

ECD is an ultra-rare, potentially life-threatening blood cancer that affects several organs of the body, in a variety of ways, making diagnosis elusive. Generating physician awareness is a key activity in helping those affected by ECD. Targeting the education of young doctors via talks, such as the one Dr. Janku gave, helps ensure more doctors will become knowledgeable of ECD. With increased knowledge, diagnosis can be expedited and those affected can have better access to treatment and care.

Volunteer, Gwendolyn Royal-Miller, comments on the importance of raising physician awareness. “I believe this awareness activity is important. I watched my loved one decompensate from a vibrant, constantly on-the-go person to an invalid just a few months prior to his death. For years, he constantly nagged the doctors that something was wrong and growing inside of him. His doctors ran every test that they could possibly think of, yet they were still unable to see what was happening to him or diagnose him. It is important that a patient can find that “1” physician that may have heard of ECD and start to take a second look.”

The ECD medical awareness presentation was the second in Louisiana since April of this year. The ECDGA is working toward facilitating medical awareness presentations at medical schools through its ECD Care Center network physicians.

The ECDGA, through the support of its generous donors, is able to provide this awareness program. The program requires staff to facilitate and plan the talks through medical school contacts and provide travel expenses for the speaking doctors. The program has successfully reached young doctors in Louisiana, so far, and has been well received by students and faculty alike.

To host or organize a medical professional ECD awareness event at a local university or medical institution contact [support@erdheim-chester.org](mailto:support@erdheim-chester.org) for more information and help.



Left to right: Kathleen Brewer, ECDGA President and Gwendolyn Royal-Miller.