



ECD Global Alliance

Organizational Status

A nonprofit 501(c)(3) Organization

May 2011

A Personal View

by Simon Dedrick, MD (retired through ill health, age 45)



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When I got to the stage of being told by the doctors that I had “Erdheim-Chester Disease”, I, and my wife, felt relieved that having been unwell for quite a while and undergone LOTS of medical tests, the doctors had finally come up with a diagnosis! We believed that now they would get on with treating me. Wrong!! Things had hardly got started. I had been a family physician,

myself, for 20 years, and I, like most doctors, had never heard of ECD, let alone seen a patient with it! Very few doctors had ever seen a case. And there was, and still is, no “standard” treatment for ECD.

The ECD Global Alliance is working hard to make the journey from diagnosis into treatment easier for everyone involved. It provides a web site full of

information for patients, carers, and doctors. It produces useful publications, and funds research. It has an Internet Chat Room, which allows members of the Alliance to “talk” to one another. The Chat Room allows much needed and appreciated contact with others that are affected by ECD all over the world. That is why we call it the “GLOBAL ALLIANCE”.

Organization Activities/Accomplishments

Members of the ECD Global Alliance were excited to begin 2011 by funding the first ECD Global Alliance research grant to Dr. Lorenzo Dagna in Milan, Italy. He is performing laboratory tests to determine how drugs, already approved for human use, will interfere with the micro-environment inside ECD lesions. The aim of this study is to find new therapeutic options for

treating the disease.

The organization has also been working with Dr. Augusto Vaglio, of Parma, Italy, on a research study that is looking at medical records of patients in an effort to correlate the involvement of different organs with the response to therapy and patient outcome. The goal is to allow earlier diagnosis, better classification of the different disease forms, and more accurate

patient prognosis.

Medical records for all ECD patients, including deceased patients, are requested for use in this study. (For more information, please call 337-515-6987.)

Patient support remains a focus of the organization through the online chat sessions, a website devoted to disseminating information, and providing information as requested. Currently 91 patients

have registered with the ECD Global Alliance. It is with great sadness that we must report 14 of these patients have passed away.

We remain steadfast in our goal to find more effective treatment options and help reduce the suffering of all affected by Erdheim-Chester Disease. We pray that someday this will result in a cure.

Financial Status of the Organization

Thanks to fundraisers and generous private donations, the ECD Global Alliance completed 2010 on a solid financial base. At the end of the year, the organization had enough money to fund a \$50,000 research grant in 2011.

Because volunteers absorbed almost all of the expenses during this first year as a non-profit, the overhead costs of the organization were well below 1%.

Thanks to your help and that of an extremely generous private donation, 2011 is looking to hold even more promise as we strive to meet our goals. We need your help as we work to: (1) raise awareness, (2) learn more about ECD, and (3) support research to find more effective treatments, with a cure as our end goal.

Please join us by donating, hosting a fundraiser, or volunteering your time.

Together we can make a difference.

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For more information -

Website: www.erdheim-chester.org

Phone: +1-337-515-6987

E-mail: support@erdheim-chester.org

Donations Online at

<http://www.razoo.com/story/ECD-Global-Alliance>

Hosting a Fundraiser

Hosting a fundraiser or awareness event can be a very rewarding and fulfilling way to help those affected by ECD. The first step is making the decision to make a difference. Once you've made that commitment, you will need to decide what type event you would like to have. The possibilities are limitless, from a bake sale, to a concert, to an athletic event and more. Most people choose an event that fits with their interests. If you would like to do something in your community, we will be glad to do what we can to help. Please email us at - support@erdheim-chester.org.



Winners of 5K Run Held in Louisiana to Raise Funds for ECD Global Alliance

Erdheim-Chester Disease Facts

- *Cause is unknown.*
- *Symptoms vary among patients. Some patients MAY have some of the following symptoms, or others:*
 - * *Pain in lower legs/ knees*
 - * *General fatigue and feeling unwell*
 - * *Excessive thirst/urination*
 - * *Balance issues and/ or slurred speech*
 - * *Kidney, heart, or vision issues*
 - * *Shortness of breath*
- *Patients normally wait years for a correct diagnosis.*
- *Diagnosis often requires multiple biopsies and scans.*
- *No standard, scientifically proven treatment.*
- *Unless successful treatment is found, organ failure can result.*
- *Few doctors have ever heard of the disorder. Fewer yet have ever seen or treated a case.*
- *Your involvement is needed to help find answers about this puzzling and debilitating disease.*