



## Erdheim-Chester Disease Global Alliance

A Nonprofit 501(c)(3) Organization

P.O. Box 775, DeRidder, LA 70634 USA | [Support@Erdheim-Chester.org](mailto:Support@Erdheim-Chester.org) | [www.Erdheim-Chester.org](http://www.Erdheim-Chester.org)

*"Supporting those affected by Erdheim-Chester Disease"*

# The ECD Global Alliance Contributor's Update

For those supporting those affected by Erdheim-Chester Disease

*A kind gesture can reach a wound that only compassion can heal." - Steve Maraboli*

## You Helped Janet

Your kindness has supported someone affected by Erdheim-Chester Disease



Janet was diagnosed with ECD in 2015. At the 2015 ECD Patient & Family Gathering in Houston, TX USA she met a doctor from an ECD Referral Care Center who now collaborates with her regular oncologist allowing her to receive a breakthrough treatment close to home. Your donations made this meeting possible.

*"You go to something like the conference in Houston and you get the bigger picture of the people who have the disease but for me, it was amazing to get to meet the doctors."*

- Janet B. on the 2015 Patient & Family Gathering hosted in Houston, TX USA

### News Update

The World Health Organization Reclassifies ECD as Cancer



## Your Facts & Stats

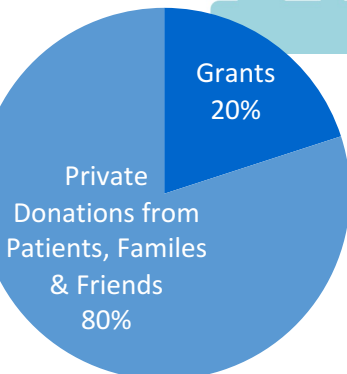
**\$603,312.00**

ECDGA Dollars Committed  
to Research Since 2011

**23**  
Number of Global Care Centers



Your  
Unselfishness  
is Treasured  
– Thank You



Funding Sources

**21**  
Number of Trials  
Involving ECD Patients



*"Some people grumble  
that roses have thorns;  
I am grateful that  
thorns have roses."*

Alphonse Karr

# Your Donations at Work

What your generous giving has accomplished

**The introduction of 5 new ECD Referral Care Centers in 4 different countries.** *Cross-specialty medical teams at ECD Referral Care Centers are committed to treating ECD patients and learning more about the disease. The hospital network facilitates collaboration and knowledge sharing with other institutions to improve patient outcomes.*

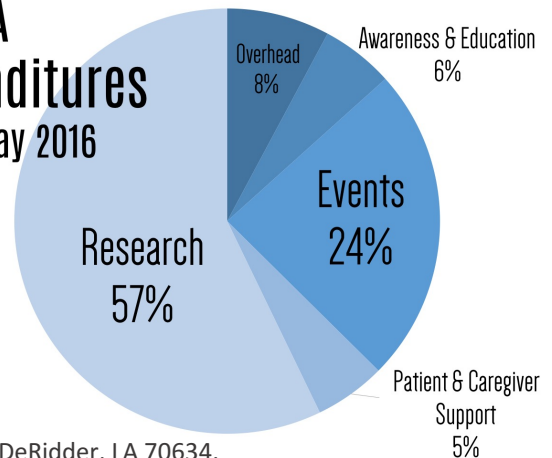
**10 new languages added to the ECD Global Alliance website.** *Resources are now available in Spanish, French, German, Dutch, Italian, Portuguese, Hebrew, Greek, Norwegian, and Chinese thanks in large part to our kindhearted volunteers.*

**The ECD Patient Registry development is underway.** *Registry data entry is scheduled for this fall once construction of the patient-centric database is completed. Global ECD researchers will have the opportunity to use collected and consolidated data to better understand and develop effective therapies for ECD sufferers. The one and only registry focused on furthering ECD research facilitates open sharing of data worldwide.*

**Three new research studies have started focusing on a variety of ECD issues.** *Research includes the understanding of neurological and cognitive issues associated with ECD, genetic mutations in ECD sufferers for better treatment options, and how malignant cells accumulate and interact with healthy cells to fuel the disease.*

**Support for ECD Awareness during World Rare Disease Day on February 29, 2016.** *See how we got involved at <http://erdheim-chester.org/news-press-releases/>*

## ECDGA Expenditures As of May 2016



## You Can Keep Making a Difference

To donate, please send a check to ECD Global Alliance, P.O. Box 775, DeRidder, LA 70634. Make an online donation at [www.fundECD.org](http://www.fundECD.org). Thank you for your support!

\$15	Prints an ECD awareness poster
\$30	Connects a patient or caregiver with others affected by ECD in real time at the International ECD Patient & Family Gathering fellowship social
\$100	Communicates life-saving information to a non-English speaking patient or caregiver at the International ED Patient & Family Gathering
\$200	Joins an ECD physician-scientist with other researchers to learn the most up-to-date findings on ECD at the International ECD Medical Symposium

## Save the Date

#ECDAwareness Week is September 12-17, 2016

Consider becoming a monthly contributor for as much as \$25 a month to sustain support for those affected by ECD.

You can help by shopping at AmazonSmile.com and through your company matching gift program by contacting your employer's human resources department.

**Save precious donation dollars by receiving future newsletters via email. Sign up at <http://goo.gl/QrEgRi>**

The ECD Global Alliance | P.O. Box 775, DeRidder, LA 70634 USA | [Support@Erdheim-Chester.org](mailto:Support@Erdheim-Chester.org) | (337) 515-6987  
[www.Erdheim-Chester.org](http://www.Erdheim-Chester.org) | Tax-deductible Donations: [www.fundECD.org](http://www.fundECD.org)  
The ECD Global Alliance is a 501 (c)(3) not-for-profit organization