



2013 Year End Report

Erdheim-Chester Disease Global Alliance

"Supporting those affected by ECD"

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Greetings to all Members, families, and friends!

It has been a truly outstanding year for the ECD Global Alliance because of your support and involvement, THANK YOU!

In this newsletter you will find a recap of the ECD-GA's 2013 activities and the upcoming goals we will be striving to meet in 2014.

Thank you again for all that you do, and a special thank you goes to all of the talented and dedicated medical professionals that are diligently working to understand more about ECD and their outstanding efforts to share this information across specialties and around the world!

Best Wishes and Warmest Regards,

ECD Global Alliance Board of Directors

Kathy Brewer, President

Rachel Mitchell, Treasurer

Pamela Fleming, Member

Glen Padnick, Member

Linda Adams, Member

Dr. Juvanee Estrada-Veras, Federal Government Liaison

To learn more about ECD and the ECD Global Alliance go to:

www.erdheim-chester.org

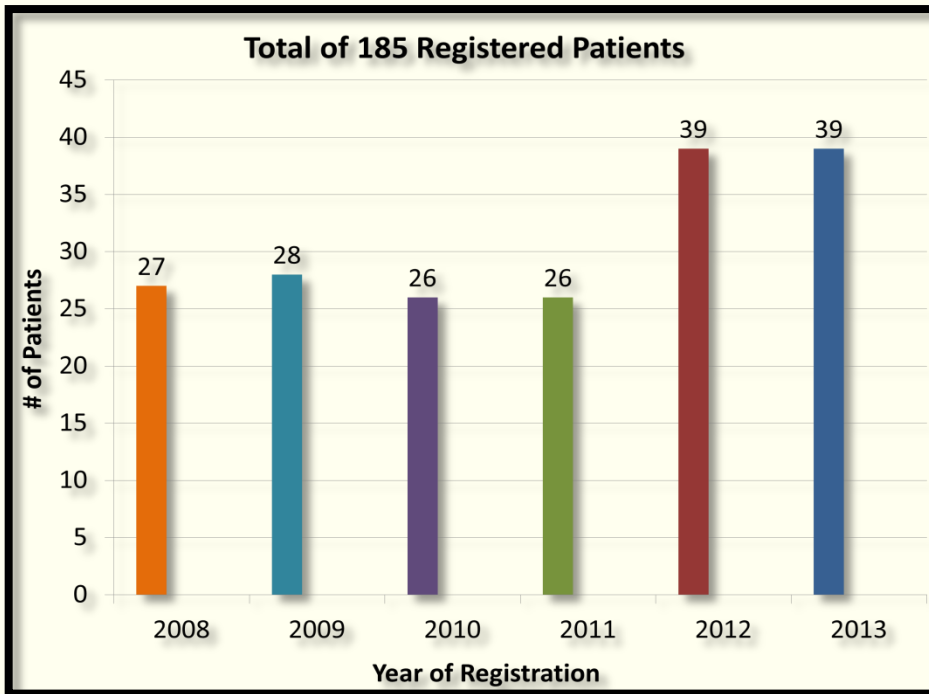
Volunteers in the Spotlight

- All the fundraisers & Donors!!!
- Blaine Butaud – 2013 ECD Event
- Bridget Gates – Bookkeeping; editor
- Cindy Livings – 2013 ECD Event
- Dearbhaile Dooley - 2013 ECD Event
- John Gates – "Post Master"
- Julie Jones - 2013 ECD Event

- Kathy Hedlund – 2013 ECD Event
- Nick – Website
- Patti Gates – 2013 ECD Event
- Randy Brown - CPA
- Sonia Maskas – 2013 ECD Event
- Simon – Chat Room
- Susie Cooper – 2013 ECD Event

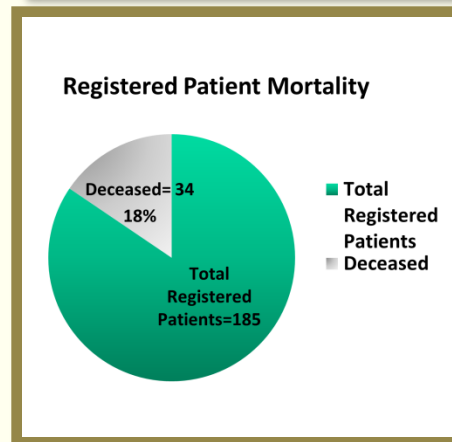
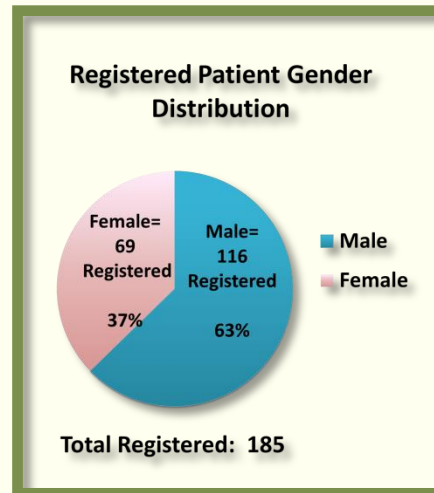
THANK YOU!

ECD-GA Organizational Data*



Registered US State/ Territory Locations	Number of ECD Cases
Alabama	1
Arkansas	1
Arizona	3
California	14
Colorado	2 (1 deceased)
Connecticut	1
Delaware	1
Florida	5
Georgia	2
Hawaii	1
Iowa	1
Idaho	2
Illinois	4 (1 deceased)
Indiana	4 (1 deceased)
Kansas	1 (1 deceased)
Kentucky	2 (2 deceased)
Louisiana	1 (1 deceased)
Maine	2 (1 deceased)
Maryland	2
Massachusetts	2 (1 deceased)
Michigan	6 (2 deceased)
Minnesota	1
Missouri	5
Montana	1
Nevada	2
New Jersey	2 (1 deceased)
New York	8 (1 deceased)
North Carolina	1
Ohio	3 (1 deceased)
Oklahoma	1
Oregon	1
Pennsylvania	8 (2 deceased)
South Carolina	2 (1 deceased)
South Dakota	1
Tennessee	1
Texas	7 (1 deceased)
Virginia	5 (1 deceased)
Washington	5 (1 deceased)
West Virginia	1
Wisconsin	3 (1 deceased)
Puerto Rico	1
Unknown State	5 (1 deceased)
Total	122 (22 deceased)

Registered Case Locations	Number of ECD Cases Represented in ECD Global Alliance
Argentina	1
Australia	11 (2 deceased)
Bahrain	1
Belgium	2
Brazil	1
Canada	7 (2 deceased)
Germany	1
Iran	1
Ireland	1
Israel	2
Italy	2 (1 deceased)
Korea	1
Nepal	1
Netherlands	2 (1 deceased)
New Zealand	1 (1 deceased)
Norway	2
Pakistan	1 (1 deceased)
Romania	1
Russia	1 (1 deceased)
South Africa	2
Spain	5
Sweden	1
Switzerland	1
United Arab Emirates	1 (1 deceased)
United Kingdom	13 (3 deceased)
United States	122 (22 deceased)
Total	185 (34 deceased)



*Through December 1, 2013



ECD-GA Mission and Support Activities

ECD-GA Mission

The ECD Global Alliance is dedicated to supporting everyone, around the world, affected by Erdheim-Chester Disease. Towards this mission the organization works with the global community to:

- 1) **Raise awareness of ECD**
- 2) **Provide support to those affected by the disease**
- 3) **Advocate for and support research programs**
- 4) **Share educational material and facilitate information sharing among interested parties regarding ECD**

....[Research support includes] collaborating with medical personnel, research personnel and other health organizations to help define areas where research is needed, to fund research, and to help promote the benefits of ECD research to other health agencies.

The ECD Global Alliance also serves as a conduit to transfer needed information from its members to the research community per documented guidelines.

The following activities are managed daily in support of the organization's mission:

Daily Support Activities

- Maintain the ECD Website
- Support Chat Room
- Manage the Patient Contact Registry
- Manage ECD Medical Directory
- Facilitate Patient-to-Patient Communication
- Facilitate Study-to-Patient Communication
- Raise Funds to Support Research
- Support www.rareconnect.org
- Administer research grants
- Organize and facilitate ECD-GA events
- Reach out to medical professional on behalf of the ECD-GA members
- Fund and manage special projects (e.g., ECD documentary)
- Write press releases & communicate with news media
- And much more!!!!



Year in Review

Activities and Milestones

\$50,000 Research Grant Awarded to Memorial Sloan-Kettering Cancer Center Research Group

[Read more...](#)

Picture - Memorial Sloan-Kettering Cancer Center Primary Investigators from left to right: David Hyman, MD; Raajit K. Rampal, MD, PhD; Omar Abdel-Wahab, MD; Kathy Brewer (ECD Global Alliance); Eli Diamond, MD; Juvianee Estrada-Veras, MD (NIH)



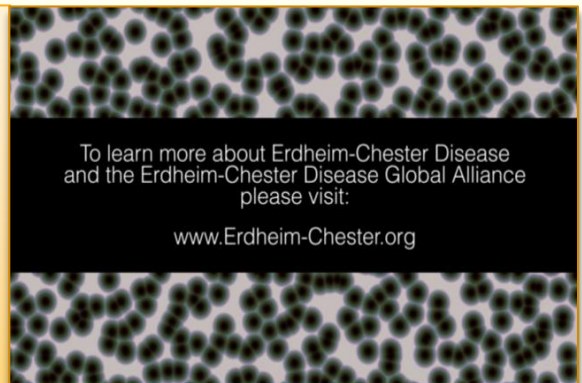
ECD Documentary Films Produced

20 Minute Version - For outreach and education for patients and general population

2 Minute Version - For raising awareness and hosting fundraisers

30 Second Version - For public service announcements/introduction to longer version that will pique the interest of viewers and provide a short explanation of the disease.

[View Films here...](#)



1st ECD International Medical Symposium (October 31)

An opportunity for scientists and clinicians from around the world and across specialties to share and discuss recent findings related to patient diagnoses, treatments and prognoses of ECD.

[Learn more about the information shared and the outcomes of the Symposium here...](#)



1st ECD Patient and Family Gathering (November 1 & 2)

The ECD patient community came together to fellowship with others in the organization and to meet with members of the medical community to learn more about ECD

[Learn more about the information shared and the outcomes of the Patient and Family Gathering here...](#)





Projected Objectives and Targets

Objective	Targets
AWARD RESEARCH GRANT - Continue to support ECD research in the medical community in an effort to better understand ECD, provide easier diagnoses, identify standard treatments, and ultimately discover a cure.	Provide \$100,000 for ECD research through a competitive grant process. Letters of Intent will be requested from interested researchers in early 2014.
SUPPORT ECD PATIENT REGISTRY – Develop and implement a managed medical history database that allows key medical outcomes to be tracked and improved upon.	Investigate and provide resources for the development of an online international ECD Patient Registry to collect and retrieve data in an effort to understand variations in symptoms, treatments, and outcomes.
REDESIGN WEBSITE –Provide timely information for those searching for information about ECD, especially patients, family members, and medical professionals.	Implement a new website that will make it easier to access ECD information, while allowing for timely and cost-effective updates and announcements.
IDENTIFY ECD CARE CENTERS – Create a network of medical facilities that will ease patient searches for treating physicians, and support the move toward standardized, quality ECD patient care.	Define the criteria by which to identify US ECD Care Centers which are knowledgeable in the diagnosis and treatment of ECD, and are dedicated to improving the care provided ECD patients.
SUPPORT NON-ENGLISH SPEAKING ECD COMMUNITY – Develop a “without borders” program to support ECD community members who do not speak English.	Provide ECD-GA information in additional languages in a manner that can be sustained with scarce resources.
SUPPORT THE 2014 ECD MEDICAL SYMPOSIUM – Continue to bring the international ECD medical and professional community together to share information and form collaborations.	Provide support for the 2014 International Medical Symposium hosted by the NIH and scheduled for September 18, 2014, in Bethesda, MD.
HOST THE 2014 PATIENT AND FAMILY GATHERING – Continue to bring the international ECD patient and family member community together to hear from the medical community about new research and treatments and also enjoy fellowship among the ECD community.	Host the 2014 International Patient and Family Gathering, in partnership with the NIH, which is scheduled for September 19 & 20, 2014, in Bethesda, MD.

Volunteer Committees

A wonderful outcome of the ECD Patient and Family gathering was an outpouring of requests from our members who asked how they could become more involved in the organization. In response, the ECD-GA Board of Directors has approved the formation of volunteer committees for the areas listed below. Each committee will have a charter that defines the scope, composition and governance. The ECD-GA is very excited about this new initiative! More information about the committees will be available soon!

"Never doubt that a small group of thoughtful, committed citizens can change the world; indeed it's the only thing that ever has." – Margaret Mead

"Volunteers do not necessarily have the time; they just have the heart." - Elizabeth Andrew

"The broadest and maybe the most meaningful definition of volunteering: Doing more than you have to because you want to, in a cause you consider good." Ivan Scheier



Outreach Committee – The purposes of this committee is to define and implement a social media plan, suggest and implement improved patient outreach programs, and suggest and implement improved caregiver support programs that are in keeping with the mission of the organization.



Website Development Committee – The purpose of this committee is to evaluate the existing ECD Global Alliance website and manage the development of a new, more functional website that meets the needs of the patient, caregiver and medical community. The website should allow for easy navigating, as well as tracking of timely updates.



Fundraising Committee – The purpose of this Committee is to define and implement fundraising programs that will raise awareness of Erdheim-Chester Disease and raise funds for the organization to meet its mission.



How You Can Support the ECD-GA and Those Affected By ECD

The ECD Global Alliance is a non-profit organization that is only able to exist and operate because of the generous donations made by you. If you can, please donate so that the mission of supporting those affected by ECD can continue; every little bit helps the organization to move forward. Here are some of the activities that your hard earned dollars can go toward supporting:

- ✓ \$10 Hosts the www.erdheim-chester.org website for one month
- ✓ \$25 Funds a Board of Directors Teleconference
- ✓ \$40 Funds a Medical Advisory Board Teleconference
- ✓ \$100 Hosts the www.erdheim-chester.org website for one year
- ✓ \$150 Prints ECD pamphlets and posters for awareness events
- ✓ \$500 Supports an awareness event at a medical conference
- ✓ \$1,000 Supports travel and lodging for a patient to attend the 2014 Patient and Family Gathering
- ✓ \$1,500 Pays the ECD Global Alliance insurance for one year
- ✓ \$50,000 Funds an ECD-focused research project for one year
- ✓ \$100,000 Could fund a full time Italian PhD student dedicated to ECD research for 3 years



Dr. Estrada-Veras (NIH) and Alice (ECD-GA Member) at the 2013 ECD Patient and Family Gathering in San Diego

To make a donation, please send a check made out to the ECD-Global Alliance and mail to:

**ECD Global Alliance
P.O. Box 775
DeRidder, LA 70634**

Or, you can make a donation online at

http://www.razoo.com/story/Ecd-Global-Alliance?referral_code=share

What the ECD-GA Members are Saying!



Dr. Estrada-Veras (NIH), Dr. Hyman (MSKCC), Dr. Dagna (San Raffaele Scientific Institute) and Dr. Vaglio (University Hospital of Parma) at the 2013 ECD Patient and Family Gathering

[Patient and Family Gathering] "Fantastic event; best week I had since I was diagnosed. Well Done."

"The ECD Global Alliance staff is wonderful, passionate, and motivated." *Medical Symposium Attendee*



ECD-GA patients and family members share lunch and fellowship at the 2013 ECD Patient and Family Gathering in San Diego

[Patient and Family Gathering] "I think you all did a fantastic job. Every speaker was informative. The discussion with the doctors was great. The time for the caregivers to get together was also great." *ECD-GA Member*



Kathy Brewer and RuthAnn Batchedler at the 2013 ECD Patient and Family Gathering. RuthAnn is presenting Kathy with a \$3,590.00 donation collected from the group and donated in her late husband's (Gary Brewer) name.

"I would like to thank you for organizing such a wonderful symposium." *Medical Symposium Attendee*

"Thank you for all you do, & for the financial assistance which allowed us to participate." *ECD-GA Member/Patient and Family Gathering Attendee*



Vivian (ECD-GA Member) and Dearbhaile (ECD-GA family member and volunteer) at the 2013 ECD Patient and Family Gathering in San Diego

ECD-GA member writes..."It takes more than 1 person to start a revolution and the ECD-GA is doing just that with an informed, but powerful social network."

"This connection has given us a lot of info – feeling we are not alone! HOPE! – *ECD-GA Member*



Dr. Colby, Mayo Clinic, presents a case study at the 2013 ECD International Medical Symposium poster session in San Diego