



INTERNATIONAL **ECD**
PATIENT & FAMILY
GATHERING

5TH ANNUAL | NEW YORK | 2017

ECD GLOBAL ALLIANCE

Kathleen Brewer, President

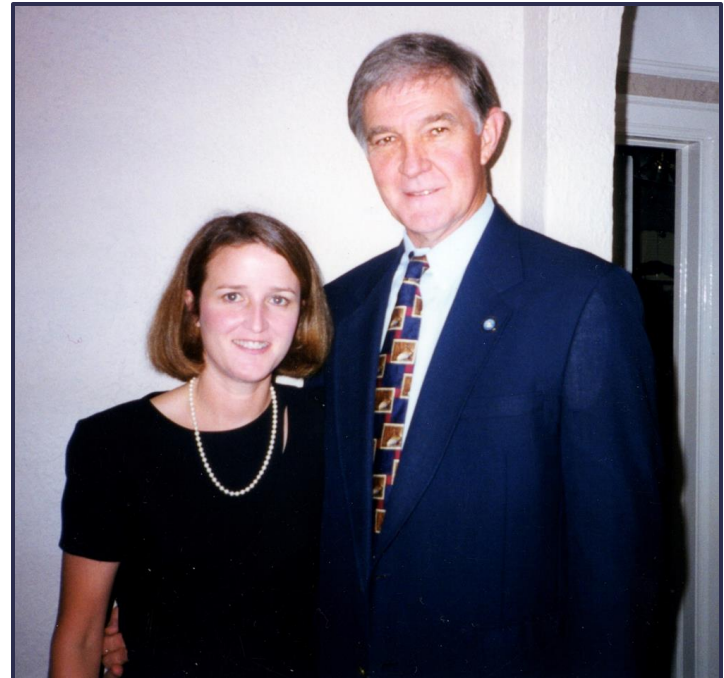
Jessica Corkran, Staff

SUPPORTING THOSE AFFECTED BY ERDHEIM-CHESTER
DISEASE



THE REASON WHY

F. Gary Brewer



The Beginning: 1st ECD Chat Session

April 4, 2008

- ▣ “If nothing else, we'll have support, Kat.”
- ▣ “feeling like I have people out there battling this with us”
- ▣ “The unknown stinks”
- ▣ “I think we need to be proactive in helping the doctors any way we can”
- ▣ “you all need to get this information in one spot for now and future ECD cases. It would help everyone. Dr names phone numbers. cases and the like. DAD of ECD”

“Unless someone like you cares a whole awful lot, nothing is going to get better.”

– Dr. Seuss

Medical Community





"We all need a place where somebody understands, and I hope our group is that place for our RBD caregivers."
- Ruthann

VOLUNTEERS & DONORS

Your contributions make it possible!

Patient & Family Gatherings



2013 | San Diego



2014 | Bethesda



2015 | Houston



2016 | Paris



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THANK YOU



Alice

- Diagnosed with ECD in Feb 2011
- Began vemurafenib 2014
- Gave birth to Marie Sept 2017

Congratulations to Pål & Alice!!
&
THANK YOU!!!

SAVE THE DATE

2018 Patient Gathering
Orlando, FL

November 15 – 16, 2018