



## What's happening in the community?

### ECD GLOBAL ALLIANCE

*2019 Summer Newsletter*

### What's Inside

10-Year Anniversary

Clinical Resources

1st Mexico Patient Story

2019 Event Videos

*Thank you for your interest and engagement in the work of the ECDGA!*

## The ECDGA is 10 Years Strong!

Ten years ago, the ECDGA started with a small group of people, including three amazing women - Joanna, Kathy, and RuthAnn. They were caregivers on a mission to ensure other patients and families did not feel as alone living with an ECD diagnosis! Thank you for being a big part of continuing the growth of the organization and improving care for those suffering.



View and share our community accomplishments!

[10 Years of Accomplishments](#)

## From the Mayo Clinic

Mayo Clinic released a consensus statement from their Histiocytosis Working Group. In-depth diagnosis and evaluation information is included to assist physicians in recognizing the manifestations of ECD and other histiocytosis.

In addition, the Mayo team also produced several videos to help ECD patients with some of their most frequent questions. Please share with your patients!

*Consensus*

*Treatment*

*Monitoring ECD*

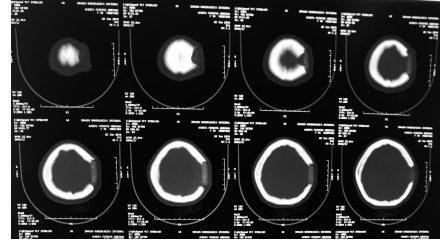
*ECD & Symptoms*

# Hope Without Borders

## *The First ECDGA Member from Mexico Tells Her Story*

"In the hole of my skull, my doctor told me that he put a bone mass called kryptonite ("Like Superman's kryptonite?" I said), and he explained to me that with passing of time the mass will be solidified and now is part of my skull."

[Read Patient Story](#)



The 7th Annual International Erdheim-Chester Disease Patient & Family Gathering in Milan, Italy was a success! Catch up with the video presentations, which include all slides. Please share with your patients!

*2019 Italy Presentations*

**THANK YOU** for making the ECDGA a success!  
*Together we will achieve great things for all affected by ECD worldwide!*

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