



Supporting those affected by Erdheim-Chester Disease worldwide!

ECD Medical Professional News

What's Inside

2019 Medical Symposium Registration
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2019 ECD Medical Symposium

Milan, Italy | July 10 - 12, 2019



[REGISTER](#)

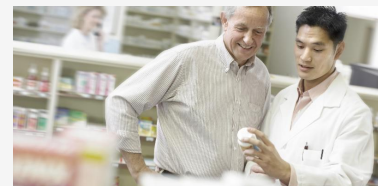
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Drug Trial News

United States and France

MD Anderson Cancer Center in Houston, Texas takes lead on Dabrafenib and Trametinib drug trial.



Who: ECD patients with *BRAF V600* mutation who have not previously been treated with a BRAF- or MEK-inhibitor and are 18-years or older.

What: Phase II Clinical Trial for ECD patients to be treated with Dabrafenib and Trametinib.

When: The trial is currently open for enrollment. Patients can receive treatment with dabrafenib and trametinib for up to 12 months. Then patients will be followed and if their disease worsens within 48 weeks then the treatment can be restarted.

Where: MD Anderson Cancer Center in Houston, Texas

For more information contact: Principal Investigator at fjanku@mdanderson.org or Study Coordinator at aadat@mdanderson.org

[Press Release](#) [Clinical Trial Webpage](#)

Pitie Salpêtrière Hospital in Paris, France opening a new trial soon!

Who: All patients with L or R group histiocytosis, including ECD and LCH or RDD, without the *BRAF V600* mutation.

What: No cost for European patients (All French and EU patients are welcome if they meet the inclusion criteria.)

When: Open enrollment will begin March 2019.

Where: The trial will be held at Pitie Salpêtrière Hospital in Paris, France.

For more information, contact: Principal Investigators at julien.haroch@aphp.fr or fleur.cohen@aphp.fr

ECD TRIALS

ECD REGISTRY

Rare Disease Day

February 28, 2019

How can you get involved with this national movement to bring awareness to the 7,000+ rare diseases?

Here are some resources to get your team involved in the Rare Disease Day coming soon!



*Submit picture of
you or your team
with this flyer!*

*Enter a coloring
contest - for all
ages!*

*Submit a
#ShowYourRare
face painting!*

Are you attending the annual Endocrine Society conference?

LOCATION

New Orleans, LA

DATE AND TIME

03/23/19 -03/25/19

The ECDGA will be hosting a booth at the ENDO Expo. This is a great opportunity to collaborate and we hope to see you there!



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there
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