

## ECD GLOBAL ALLIANCE MEETING HIGHLIGHTS

# 2019

MILAN, ITALY



## 7th Annual Erdheim-Chester Events

The ECD Global Alliance is grateful to each and every participant! Volunteers from far and wide helped pull together an incredible group of meetings. Special thanks to our Patient and Family Gathering Sponsor, Fr. Charles Balnaves, for making this annual event a priority. The community cherishes this time together to share and to learn. Another special thank you to the hosts at San Raffaele Institute, Dr. Lorenzo Dagna and Stefania Laus, for going above and beyond preparing and executing the meetings and for the warmest welcome to Italy.

Now for the meeting highlights you've been waiting for!

### Medical Professional Highlights

Medical professionals from eight countries attended meetings in Milan this July to collaborate with other researchers and clinicians in the field. Case studies, ongoing scientific research, and trial data were shared by the most ECD-knowledgeable doctors in the world. The community continues to grow with new members attending each year to learn about the advancements in ECD knowledge and care.



Thank you to the dedicated team of ECD Care Center physicians who serve patients throughout the world by providing direct care and consultations. Your efforts to collaborate and work as a team toward this important goal is appreciated!



*"ECDGA provides important resources for my patients that has led to faster diagnosis. It also provides a community for patients with a rare disease to feel less alone."*

- Dr. Mark Heaney, Columbia University Medical Center

[3D culture of BRAF/KRAS-mutated Erdheim-Chester disease tissues unveils rewired histiocyte metabolism as a new therapeutic target by Dr. Marina Ferrarini](#)

[Erdheim-Chester with multiple lesions related to BRAF V600E mutation. A simple coincidence? By Dr. Francesco Pegoraro](#)

[Histopathologic Mimics of Erdheim-Chester Disease \(ECD\) by Dr. Jithma P. Abeykoon](#)

[MEK inhibition with trametinib in patients with non-Langerhans cell histiocytosis irrespective of BRAF mutation status by Dr. Filip Janku](#)

[Novel Alterations in CSF1R, RET, and Other Diverse Kinases in the Histiocytoses with Biochemical and Structural Insights into Their Mechanisms of Activation by Dr. Benjamin H. Durham](#)

*Videos coming soon!*

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## Patient & Family Highlights

### Patient & Family Members

During the ECD Patient & Family Gathering this July, over 70 participants engaged in learning more about ECD, meeting others affected by the disease, and supporting one another with education and experience. Families joined from eight countries to share their experiences with ECD, learn from professionals that truly listen and understand, and to feel less alone.



*"Fantastic contacts with other patients" - ECD Caregiver, Susie Smythe*

*"GRAZIE GRAZIE GRAZIE!!!" - ECD Patient*

### Medical Participants

A huge thank you to the speakers, panelists, moderators, and medical professionals who took time out of their busy schedules to share their research findings and general knowledge with the family members this year. The opportunity to hear from these compassionate doctors was uplifting and gave hope to all!



**Presentation Slides Available:**

[ECD and the Brain by Dr. Eli L. Diamond](#)

[Endocrine Manifestations by Dr. Courtillot](#)

[Renal and Ureteral Involvement by Dr. Augusto Vaglio](#)

[ECD and Skin Issues by Dr. Stephane Barete](#)

[Mutations in ECD by Dr. Mark Heaney](#)

[Patient-Reported Outcomes from the ECD Registry by Dr. Eli L. Diamond](#)

[Clinical Trials in ECD by Dr. Filip Janku](#)

*Videos and all photos coming soon!*

ECD Global Alliance | [erdheim-chester.org](http://erdheim-chester.org)

