



Emily's Entourage

**PRESS RELEASE**

April, 29, 2019

For Immediate Release

## **Emily's Entourage Announces 4th Annual EENY: ULTRA VIOLET**

*Groundbreaking CF Foundation Joins Forces with Eesho in Race for a Cure During Signature NYC Event*

**NEW YORK, NY** -- [Emily's Entourage](#) (EE), an innovative 501(C)3 foundation that has raised over \$4 million since 2011 to accelerate groundbreaking treatments and a cure for nonsense mutations of Cystic Fibrosis (CF), announced that it will hold its fourth annual *Emily's Entourage New York* (EENY: ULTRA VIOLET) event on Saturday May 4th, 2019 at Anderson Contemporary in Manhattan at 7 P.M.

Last year, EENY raised over \$150,000, and this year's event aims to reach new heights through EE's collaboration with [Eesho](#), a community that partners with artists, musicians, DJs and creators from a range of disciplines to host experiences that inspire connection. The event will be headlined by renowned DJ FDVM, and includes two opening DJs, a live harpist, immersive Ultra Violet-themed visual art from six contemporary artists, dance performances, an open bar, and a presentation by EE Co-Founder, Emily Kramer-Golinkoff.

The headline "Violet" Corporate sponsors for this year's event include Tito's Handmade Vodka, Vertex Pharmaceuticals, and Eloxx Pharmaceuticals.

"There are game-changing breakthroughs for roughly 90% of the CF population, but those of us with nonsense mutations fall into the outlying 10% for whom there's still nothing," said Emily Kramer-Golinkoff, EE Co-Founder. "Events like EENY—and the work of Emily's Entourage—propel our singular goal to accelerate breakthroughs for 100% of the CF community, driven by the belief that *everyone* with CF deserves a healthy, hopeful future, nobody left behind."

EE was founded in 2011 by Emily and her family as they decided to take action into their own hands to find breakthroughs and a cure for Emily, and those like her, who are battling nonsense mutations of CF, a fatal genetic disease that affects the lungs and digestive system. Nonsense mutations, while rare among those with CF, are the cause of approximately 12% of all genetic diseases, affecting roughly 30 million people around the world. The impact of EE's revolutionary research and drug development has the potential to extend far beyond the CF community to those with a wide variety of genetic diseases caused by nonsense mutations, including certain forms of muscular dystrophy, blood disorders and even some forms of cancer.

In a race against time, EE has turned into a global community of changemakers who are upending traditional methods of disease research by applying a business-like approach to accelerating cutting-edge treatments. EE has awarded over \$3.5 million in grant funding to preeminent researchers around the world, developing a portfolio of 11 active research grants at top institutions. EE also provided seed funding to launch a novel CF gene therapy company called Talee Bio, which received a \$4.5 million grant from the Cystic Fibrosis Foundation earlier this year.

Funds raised through this year's EENY event will fuel EE's lifesaving research to accelerate breakthroughs and a cure for CF. Tickets and sponsorships for the event are [available here](#).

###

### **About Emily's Entourage**

[Emily's Entourage](#) accelerates research and drug development for nonsense mutations of Cystic Fibrosis. By providing critical leadership and coordination, Emily's Entourage drives high-impact research, cultivates multi-stakeholder collaboration, and facilitates information exchange to speed breakthroughs. Our goal is singular: to expedite life-saving treatments and a cure for those with nonsense mutations of CF who are waiting with bated and fading breath.

### **Media Contact**

Kira Rentas  
Marketing and Program Coordinator  
631-902-1993  
[kira@emilysentourage.org](mailto:kira@emilysentourage.org)