

The CCHS Network / The CCHS Foundation

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FOR IMMEDIATE RELEASE

**CCHS FOUNDATION ANNOUNCES FIFTH INTERNATIONAL CCHS DAY
WITH CELEBRITY CHAMPIONS HENRY WINKLER AND JONAH HILL**

Encinitas, CA, October 15, 2019 — The CCHS Foundation proudly announces the 5th Annual International CCHS Day on November 9, 2019.

The CCHS Foundation is the fundraising arm of the CCHS Network, a support and advocacy organization for families living with Congenital Central Hypoventilation Syndrome (CCHS). CCHS is a multisystem disorder of the central nervous system where, most dramatically, the automatic control of breathing is nearly or totally absent. Treatment for this rare medical condition is limited to mechanical ventilation and there is no available medication to date. There are approximately 1200 individuals affected worldwide.

CCHS patients and their families will honor CCHS Day 2019 by raising awareness and funds for the advancement of research and future treatments. This year's theme, "**It Only Takes A Second**," is a call to action that encourages the global community to give a moment of time to this orphan disease.

Actors and activists **Henry Winkler** and **Jonah Hill** recently learned of CCHS through personal connections and offered to lend their voices to the cause. They will be featured in a public service announcement designed to highlight the complexities of CCHS and need for better advocacy, funding and management options. The PSA launches November 6, 2019 on the CCHS Network and Foundation's social media platforms (Facebook: [The CCHS Foundation](#); Instagram: [@cchsnetwork](#); Twitter: [@cchsnetwork](#)). Supporters can follow CCHS Day related happenings around the world via the hashtag [#cchsday2019](#), [#CCHSawareness](#).

"The CCHS Network was started in 1989 with just five identified families in the United States", reports Melinda Riccitelli, CCHS Network President and CCHS Foundation Co-Chair. "Until then, CCHS was so rare that not a single organization or support group existed to ease the burden of this complicated disease. Exactly thirty years later, it is thrilling to witness the evolution of our organization to where we have the backing of influential people like Henry and Jonah."

Rebecca Martine, CCHS Network Vice-President and Foundation Co-Chair added, "This year is especially meaningful as we are on the brink of reaching our one-million-dollar goal since the Foundation's inception in 2014. The time has come for CCHS to gain awareness, harness resources, and secure the benefits of modern medicine."

To learn more about CCHS, visit www.cchsnetwork.org. The CCHS Network, Inc. is a registered 501(c)(3) non-profit organization (EIN #: 22-3634814).