

PRESS RELEASE: CCHS Day, 2016

CCHS Network, Inc.

PO Box 230087
Encinitas, CA 92023-0087

FOR MORE INFORMATION, CONTACT:

Melinda Riccitelli, Foundation Co-chair
The CCHS Foundation
(760) 633-3141 E-Mail: mycchsfoundation@gmail.com



FOR IMMEDIATE RELEASE

CCHS FOUNDATION ANNOUNCES SECOND INTERNATIONAL CCHS DAY

Encinitas, CA, [October 3, 2016] — The CCHS Foundation proudly announces the second annual International CCHS Day on November 12, 2016.

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. A CCHS patient's respiratory responses are sluggish when awake and absent to varying degrees during sleep, serious illness, and/or stress. 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 across the world will celebrate CCHS Day by raising both awareness and funds for the advancement of research and future treatments. Planned fundraising events include a social media campaign named "Light up Social Media", a Read-a-Thon, bake sales, and Dine and Donate events across the United States, as well as numerous international happenings. Supporters can keep up with the various projects using the hashtags *#CCHSDay2016* and *#OurCurseIsOurCause*. You can follow the CCHS Foundation on Facebook @ <https://www.facebook.com/TheCCHSFoundation> and Twitter @CCHSNetwork.

Additionally, the Academy Award nominated documentary on CCHS, *Our Curse*, can be viewed on the New York Times webpage

(<http://www.nytimes.com/video/opinion/100000003489430/our-curse.html>)

"The CCHS Family Network was started in 1989" reports Melinda Riccitelli, Ph.D., CCHS Foundation Co-Chair. "Up until then, CCHS was so rare that not a single organization or support group existed to ease the burden of this complicated disease. Twenty-seven years later, we continue the work of advocating for CCHS patients and families. CCHS Day 2015 was a resounding success, allowing us to fund two important CCHS research projects. We are thrilled to announce our second **International CCHS Day, November 12, 2016**. We hope this day again brings greater awareness, harnesses resources and leads to better treatment options for our orphan disease." The CCHS Foundation and CCHS Network gratefully acknowledges the help and support of all its volunteers and board members.

The CCHS Network, Inc. is a registered 501(c)(3) non-profit organization.