What is CCHS?
Congenital Central Hypoventilation Syndrome is a disorder of the central nervous system. Every time someone with CCHS falls asleep they are at risk of not breathing. Some struggle to breathe even when they are awake.

Can you imagine having to be hooked up to a machine whenever you doze on the couch, snooze on a car ride, or nap in the sunshine? Can you imagine living with a device protruding from your neck for everyone to see? And never being able to join in pool parties or even learn to swim because of your tracheostomy? Or getting leads implanted in your chest to electronically force you to breathe?

For children and adults with CCHS, one of the rarest disorders in the world, survival means being tethered for life to mechanical ventilation. It means coping with afflictions of the heart and other organs that are damaged by the same gene mutation.

But now hope is on the horizon.

Your help will do more than ever before.
Science has made promising strides toward finding a breakthrough treatment for CCHS. Researchers recently reported in the journal Science the discovery of a regulatory protein that could free CCHS patients and their families from many of the hardships of this condition. And, on another front, researchers are working on better ventilation techniques.

Your investment will push these efforts forward. Give Liam, Mollee and all the children and young adults afflicted with CCHS their dream of breathing just like everyone else.

You can give now at cchsnetwork.org
Why we’re here.
The CCHS Foundation is a division of the CCHS Family Network, a 501(c)3 charity. We champion scientific advances that will empower CCHS patients and their loved ones to lead full and productive lives.

Our vision is a future where CCHS is no longer a life-threatening diagnosis.

Our curse is our cause.
The original name for CCHS was Ondine’s Curse, taken from a German folk tale:

“You swore faithfulness to me with every waking breath, and I accepted your oath. So be it. As long as you are awake, you shall have your breath, but should you ever fall asleep, then that breath will be taken from you and you will die.”

— Ondine

Together, we can undo Ondine.
CCHS is an orphan disease. For generations, funding to investigate causes and seed treatments has been extremely limited. Now that researchers have found ways forward, imagine the revolutionary leaps in science that that your tax-deductible gift will make possible.

Please re-imagine life for Liam, Mollee, Angelina, Mike, Jack Ian — and for all CCHS patients. Give now.

CCHS FOUNDATION
Give online and read our stories at cchsnetwork.org

Or contact us at mycchsfoundation@gmail.com
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“Researchers are on the cusp of discovering the next generation of treatment options for CCHS, including possible drug therapies. Please consider donating to this worthy cause.”

— Dr. Diego Fornasari, M.D., Ph.D.
University of Milan