



*One World, One Family, One Hope*



To Whom It May Concern,

We are writing to you on behalf of the roughly 1,200 individuals worldwide living with Congenital Central Hypoventilation Syndrome (CCHS). We ask that you take a moment to reflect on the challenges facing our rare disease community, as well as the potential for hope, and consider ways that you can make a difference. This spring, our organization, the CCHS Foundation, will be hosting a Read-a-Thon fundraiser to increase funding for important scientific research. We are reaching out to you to ask for your help to make our fundraiser a success.

The CCHS Foundation is a subsidiary of the CCHS Family Network, Inc., a 501(c)(3) nonprofit organization. The CCHS Family Network and the Foundation work to educate the public about CCHS while raising money to fund vital scientific research. The CCHS Foundation is entirely composed of volunteers and our mission is to raise international awareness, facilitate educational programs, and to fund both CCHS families in need and support research. All donations for the Read-a-thon will be donated primarily to research.

CCHS is a rare genetic disorder that is typically diagnosed at birth. It affects the autonomic nervous system, and inhibits the ability to breathe spontaneously during sleep. There is currently no cure or even medication for CCHS, and most affected individuals are forced to rely on life-long mechanical ventilation. CCHS is poorly recognized and understood, trained medical facilities are sparse because of its rarity, and families are geographically isolated. We hope that by raising both awareness and funding for CCHS we will find better treatments, and one day, a cure for this disorder. But we can't do this alone, our efforts are best achieved when CCHS patients and families reach out to others in their local communities to support this worthy cause.

We will *not* be able to find a cure for CCHS without your help. The CCHS Foundation is launching its first-ever Read-a-Thon in the spring of 2017 and we sincerely hope that you will be able to take part.

Sincerely,

The CCHS Foundation