

It's an unbelievable story:

Seemingly ordinary kids who stop breathing when they fall asleep. Without the immediate assistance of a respirator and a caregiver, they have no chance of surviving.

## What is CCHS?

CCHS, also known as "Ondine's Syndrome" is a rare and harsh neurological syndrome that affects approximately 120 people in Germany, 20 people in Israel and about 1,200 around the world.

The syndrome primarily causes those affected to stop breathing while they sleep. Some of those who carry CCHS also have difficulty breathing while they are awake and must rely on a respirator 24 hours a day. Most of those who have the syndrome are forced to use invasive respirators and must undergo a tracheotomy, surgery that creates a breathing hole in the neck, when they are only a few weeks old.

## Give us Hope

In recent years science has made promising steps to understand the syndrome and find a breakthrough in treatment. Top researchers believe and are confident that a medical solution for CCHS is possible and even stated during a recent conference that the question isn't "will a cure be found?" but rather "when will the cure be found?".

That said, because it is such a rare phenomenon, we need your help so that we can keep funding the scientific research and understand the syndrome as soon as possible.



### A German-Israeli initiative could make it possible



**Self-help group Undine  
Syndrom eV**  
DE NGO

The aim of the organization is to provide information about the clinical picture, help with the choice of ventilation mode, provide contact addresses for cchs patients and their relatives. We meet once a year to share ideas and discuss the latest research.

[www.undine-syndrom.de](http://www.undine-syndrom.de)

Your donations will help us move the scientific research forward and find the long-awaited cure so that we can allow our children to breath, to sleep and to dream.



**Yad La Neshima**  
IL NGO

Yad La Neshima's goal is advancing research of the syndrome in Israel and around the world, hoping to allow our children to live securely, without relying on a respirator, a caregiver and the constant threat to their lives.

[www.cchsisrael.org](http://www.cchsisrael.org)

## Only Research for a cure will save their lives, only with your support is the research possible

### German scientist - Dr. Matthias Frerick

Matthias Frerick is head of the sleep laboratory and out-of-hospital ventilation at the Dritter Orden Children's Hospital in Munich, as well as a German partner of the European CHS Network. He cares for and advises patients with CCHS from a total of 9 countries.



### Yad LaNeshima in house scientist - Dr. Avital Adato

research post doctorate in Paster Clinic in Paris.

As part of her role in the NPO, Dr. Adato designs and leads research projects, promotes collaboration with researchers from other institutions and facilities international consortia as part of submission requests to research funds.

**Yearly cost: 65,000 EUR**



### Our ongoing projects:

#### Dr. Gad Vatine, Ben-Gurion University of the Negev, Israel:

A disease-in-a-dish platform to uncover the mechanisms underlying central congenital hypoventilation syndrome (CCHS), using patient-derived induced pluripotent stem cells (iPSCs)  
**Yearly cost: 30,000 EUR**

#### Dr. Avraham Ashkenazi, Tel-Aviv University, Israel:

Studying the putative involvement of mutated PHOX2B in proteostasis defects of CCHS-neurons.  
**Yearly cost: 15,000 EUR**

### Our upcoming project:

#### CCHS biomarkers & dysregulated biological pathways

In this research we intend to harness multiple omics analyses in order to identify biomarkers and dysregulated biological pathways associated with the CCHS in patients' blood and urine.  
**Yearly cost: 40,000 EUR**

**The total annual budget to fund the research is:  
150,000 EUR**

### Donate Now:

**Purpose: Deutsch-israelisches project  
Selbsthilfegruppe Undine Syndrom e.V.**  
IBAN: DE73 5855 0130 0001 07227  
BIC: TRISDE55XXX

**Their lives cannot depend on breathing machines and caregivers. We have to find a cure.  
Donate now to help us.**