



A Chance to Rest

*Amplifying Family Caregiver
Voices Panel*

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CEO, Founder



**Aweso
me Life**

**Way too
short**

Ryan was incredibly bright and mature

Very physically challenged...he needed an adult caregiver for all his daily living needs *eating, toileting and bathing, and even rolling over to change positions when he slept*

Spinal rod surgeries, hip surgeries, tons of physical therapy sessions, respiratory breathing machines, a power wheelchair for mobility

Many emergency room and hospital stays

The Journey of Building Ryan House – 1st Tipping Point



January 23, 2002
Ryan and Big Brother Ethan
9 mos.



March 2010
Ryan House Opening
"Rope Untying"

US Lacks Sufficient Respite Care



54

=



~~266~~

7



Supporting our most fragile families along the most difficult journey imaginable.



Bringing the Vision to Phoenix



The Board of Visitors
ryan house
open doors, open hearts

Ryanhouse.org

Play (k)

0:01 / 1:40

Ryan House, a House of Love

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A New Tipping Point



Ryan at 17 years



JOHNS HOPKINS

BLOOMBERG SCHOOL
of PUBLIC HEALTH



1982



+54



+13
Years



1995



+7



+9
Years

2004



2010



2011



2018



= ~~266~~

+7

National Center for
Pediatric Palliative Care Homes

Founding a National Movement

National Center for Pediatric Palliative Care Homes



Education & Awareness



Advocacy



Community Building

MISSION: To scale, strengthen and sustain the growing network of pediatric palliative care homes across the U.S.

VISION: All children with medical complexities and their families will be able to access a safe, compassionate, and skilled pediatric palliative care home in their community for trusted respite, and palliative care support.

40 Communities across 27 States
... and Growing!



93% of children and families have ZERO access to even one Children's Respite Home

Need

Find

Validate

Meet them where they are

Support current initiatives

Shape long-term vision

Identify opportunities and barriers

Develop Pathway to Sustainability

Open

n

A New License for Holistic Care

Existing Facility License Options



- Hospital (General acute care)
“Specialty” Hospital
- Skilled Nursing Facility (SNF)
Congregate Living Health Facility (CA specific)
- Intermediate Care Facility (ICF)
- Assisted living facilities (ALFs)
- Medical Group Homes (Pediatric / Youth)
- Community Based Children’s Healthcare Center (IL specific)**
- Adult day health care center
- Hospice**
Residential Hospice Facility
- Home Health Agency (HHA)
- Prescribed Pediatric Extended Care (PPEC)

Thank You



ChildrensRespiteHomes.org



[ChildrensRespiteHomesOfAmerica](https://www.facebook.com/ChildrensRespiteHomesOfAmerica)



Proud Dad

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