

Dear Policymaker,

March, 2025

Every parent of a child with a life limiting condition dreams of a cure. But their second biggest wish is often something much simpler—a **chance to rest**. Caring for a child with complex medical needs is exhausting, and parents often go for weeks, months, or even years without a break. Without proper community services, many families feel trapped, overwhelmed, and isolated.

Sadly, in the US, a child with a life limiting condition dies every **20 minutes, 26,000 children per year**. For the one million children who are medically fragile **and live** with these conditions, much of their care happens at home, leaving parents to carry a heavy burden. But despite the growing need for help, **93% of families** lack access to even **one skilled respite provider** in their community. The support families need isn't just scarce—it's almost non-existent.

While children who are medically fragile make up **less than 1%** of all kids, they account for **one-third of all healthcare spending** on children—and **40% of deaths** in children's hospitals.

## Respite Homes: A Haven for Families

Children's Respite and Palliative Care Homes ("Homes") give families the relief they need. These Homes offer **short-term overnight care** for children who are medically fragile in a safe, supportive environment with trained professionals who specialize in these services. Parents can sleep, recharge, and then continue the difficult journey feeling more prepared to tackle their child's next challenge, and the one after that.

These Homes offer more than just medical support—they give families emotional care and connections with other parents who understand their journey. Their child's **quality of life improves**, even if those lives are short.

The UK introduced these care models in the 1980s, and today they have **54 Homes** serving a population much smaller than the US. In comparison, we have only **7 such Homes**—far short of the **266** we need to provide the same level of care here.

Without access to these Homes, parents often **admit their child to the hospital** just to get a break or when their own health deteriorates. This adds stress to families and increases healthcare costs. But where Respite and Palliative Care Homes exist, families avoid unnecessary hospital stays and can stretch home-based health services even further.

## Why Pediatric Care Must Be Different

Caring for children with complex medical needs requires a **family-centered approach** that supports both the child and parents. Most of our healthcare system focuses on adults, forcing pediatric providers to fit into a framework that doesn't meet the needs of children. This makes it harder to open and run community-based respite, palliative, and end-of-life care programs for children.

We need **pediatric-specific policies** that allow Respite and Palliative Care Homes to provide a wide range of services—from **nursing care to emotional support**—all under one framework.

- **The problem:** Current state licensing rules and provider payment structures are designed for adults, not children, making it hard to offer holistic care.

- **The solution:** Create pediatric-specific licenses and provider payment structures that allow providers to offer respite care, emotional support, and family counseling.
- **The impact:** Expanding access to respite Homes will reduce hospital stays and help families stay strong through their caregiving journeys.

Children are not little adults. It's time to **rethink healthcare** so it works for them. With your help, we can build a system that supports families and gives them the care they need—at home, in the community, and through Respite and Palliative Care Homes.

We and other national pediatric thought leaders are ready to work with you to build a better system—one that ensures every child and family has the care they deserve. Together, we can close these dangerous gaps and offer families hope and relief.

Thank you for your time and leadership.

Sincerely,

*Jonathan Cottor*

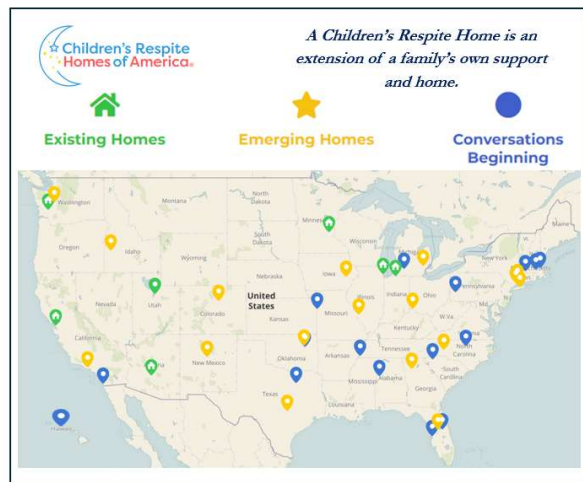
**Jonathan Cottor, Proud Dad,**  
 CEO/Founder of National Center for Pediatric Palliative Care Homes (NCPCH)  
[jcottor@ncppch.org](mailto:jcottor@ncppch.org) ; Direct: (480) 231-6810

Representing NCPCH Board, Government Affairs Council, and National Advisory Council members. NCPCH brings together 40 communities across 27 States all striving to deliver pediatric overnight respite and palliative care to local families and children.

**Our collective vision for a license:**



**Community leaders who need your help now:**



Children's Respite Homes of America (CRHA) is the unifying program building the movement for nationwide respite and palliative care within the National Center for Pediatric Palliative Care Homes (NCPCH). Healthcare providers, institutions, and policymakers: connect with NCPCH at [www.ncppch.org](http://www.ncppch.org). To join this nationwide movement to open 50 Homes in 50 cities in five years, learn about CRHA at [childrensrespitehomes.org](http://childrensrespitehomes.org).



**Participating Organizations and Pioneers with Shared Vision for  
Community-Based Children's Respite, Palliative and Hospice Care Home Programs**

**EXISTING (GREEN): Community-Based Homes in Operation**

 George Mark Children's House San Leandro, CA	 The Board of Visitors <b>ryan house</b> open doors, open hearts Phoenix, AZ	 Crescent COVE Brooklyn Center, MN	 <b>A ROSIE PLACE</b> FOR CHILDREN South Bend, IN
 Almost Home Kids Share the Care Chicago, IL	 POPE'S PLACE Centralia, WA	 Brades' Place Orem, UT	

**EMERGING (YELLOW): Local Organizations Working to Open a Community-Based Home**

 Sarah House Cincinnati, OH	 <b>LADYBUG HOUSE</b> Edgewood, WA	 LIFE HOUSE ATLANTA Kennesaw, GA	 Honey Pail Palliative Care Edgewood, NM
 Angela's HOUSE East Moriches, NY	 here4U Farmington, MI	 the pinwheel project New York, NY	 Loving Home Hospice for Children Westlake Village, CA
 JONE JESSEE MEMORIAL FOUNDATION St. Louis, MO	 Cardinal Kids Palliative Care and Hospice Program Newton, NC	 Rays for Rare Light when skies are gray Eagle, ID	 REGIONAL HOSPICE Making the Best of Every Day Danbury, CT
 ABIGAIL E. KELLER FOUNDATION Austin, TX	 Mason's Light House Iowa City, IA	 Kopke's Mountain House Immerleithalweg Denver, CO	 <b>WILL'S          HOUSE</b> Jenks, OK

**(BLUE): Local Pioneers with a Vision to Open a Community-Based Home**

- |                      |               |
|----------------------|---------------|
| Boston, MA           | Tampa, FL     |
| Hopkinton, MA        | Orlando, FL   |
| West Springfield, MA | Groveland, FL |
| Kaneohe, HI          | Coronado, CA  |
| Dallas, TX           | Memphis, TN   |
| Greenville, SC       | Durham, NC    |
| Kansas City, MO      | Galesburg, MI |

## National Thought Leaders & Organizations for Pediatric Community-Based Care

### Champions of families and children “our people”



**Allysa Ware, PhD, MSW**  
*Executive Director*



**Blyth Taylor Lord**  
*Founder and Executive Director*



**Pamela Gavin**  
*Chief Executive Officer*



**Amy Fenton Parker**  
*President & CEO*



National Tay-Sachs &  
Allied Diseases Association

**Kathleen M. Flynn**  
*Chief Executive Officer*



**Monica Coenraads**  
*Founder, Chief Executive Officer*



**Diane Fennimore**  
*Executive Director*



**Kim Hendry**  
*Executive Director*



**Gabrielle Conecker, MPH**  
*President, Co-founder*



**Sara Scaparotti**  
*Co-founder*



**Betsy Pilon**  
*Executive Director*



**Caroline Cheung-Yiu**  
*Founder*

### Champions of Improved Care & Caregiving



**Brynn Bowman, MPA**  
*Chief Executive Officer*



**Betsy Hawley**  
*Executive Director*



**Jill Kagan, MPH**  
*Program Director*



**Patricia Budo**  
*Executive Director*



**Joseph Matty**  
*President*



**National Alliance for Caregiving**  
**Jason Resendez**  
*President & CEO*