



# Crescent Cove

A place of respite for kids & families

The mission of Crescent Cove, is to offer care and support to children and young adults with a shortened life-expectancy, and to their families who love them.

We are fulfilling this dream by opening one of only a handful of children's residential hospice and respite care homes in the United States.



## Ambassador Kit

**Connect with us!**

Visit [www.CrescentCove.org](http://www.CrescentCove.org)



3440 Beltline Blvd. Suite 207  
St. Louis Park, MN 55416  
952-426-4711

- Over **700 children under the age of 19** die each year in MN.
  - Many of those children could benefit from end-of-life care provided at a children's hospice home.
- There are currently **50+** children's hospice homes in the United Kingdom, **6** in Canada, **2** in Australia and many others around the world.
- In metro areas around the US, there are **over 4,700** hospice homes for adults.
  - Currently there are **only two** children's respite and hospice homes operating the entire US.
- There are thousands of children living with life-limiting conditions in MN who could benefit from respite care and associated services for the family.
- Accessing palliative care support can be difficult for children with life-limiting condition, which can result in unnecessary pain and suffering and excruciating strains on families.

## Did you know?

# How can you help?

- Being an ambassador means you are passionate about the importance of building awareness for a future children’s hospice and respite care home in MN.
- One of the most important ways you can help Crescent Cove is by providing **credible and valuable information** as well as **exposure and visibility** to the organization.
- By believing in this cause, spreading the word and helping raise money, you are grassroots campaigning for this cause.
- Engage your family, friends, and **everyone you meet**.

- There are no respite and hospice homes specifically for children in Minnesota. There are only two children’s respite and hospice homes in the entire U.S. They are Ryan House in Phoenix, Arizona and George Mark Children’s House in San Leandro, California (outside of San Francisco).
- Imagine what a hospice home could mean to a family whose child has a life-limiting condition. Imagine how that home could also provide vital respite care to help the family stay resilient and strong.
- Would you be a champion for this important cause in our community?

## Key Messages

## Sample 30 sec. Script

My name is \_\_\_\_\_ and I am a *(volunteer with/support of)* Crescent Cove.

- Did you know there are over a dozen residential hospice homes for adults in Minnesota, but none built to serve children?
- We all know a child whose life has been cut short. The mission of Crescent Cove is to open the first residential hospice home offering palliative care to children and young adults in the Midwest with a shortened life expectancy.

- It will be a place where families can go for the necessary break from the 24/7 complex care of a child who is medically fragile, allowing the family to emotionally recharge and gain strength, and a sacred place providing compassionate care at the end of a child's life.
- Help us open this much needed home. Learn more by visiting [www.CrescentCove.org](http://www.CrescentCove.org)

## Frequently Asked Questions

### To aid in conversations about Crescent Cove's mission:

#### ***What is Pediatric Palliative Care?***

Pediatric Palliative care aims to enhance the quality of life of children and young people with life-limiting conditions. It focuses on managing pain and symptoms, offers emotional and spiritual support, provides respite (restful) care, and supports the family through bereavement (following the death of their child).

#### ***What are life-limiting conditions?***

Life-limiting or life-threatening conditions may include **malignancies/cancers, rare genetic or chromosomal disorders, heart/lung conditions, rare neurological conditions and complex chronic conditions, such as:**

- **Cystic Fibrosis** is a recessive genetic disease that affects the entire body, causing progressive disability. Difficulty breathing is the most serious symptom resulting from frequent lung infections.
- **Muscular Dystrophy** is a hereditary disease that weakens the muscles that move the body that more commonly affects males.
- **Neurodegenerative Conditions** affect children in varying degrees but lead to an unfortunate progressive decline and loss of previously gained milestones. This usually progresses to intractable epilepsy (seizures) and loss of interaction with the outside world.
- **Rett Syndrome** is a neurological disorder of the grey matter of the brain which affects head growth, loss of hand use, stagnation and regression of previously acquired skills. Affects females more commonly and are prone to gastrointestinal disorders and seizures.
- **Spinal Muscular Atrophy** is a neuromuscular disease that results in progressive muscular atrophy (wasting away) and weakness. Requires comprehensive medical care and therapies.

### ***What is Crescent Cove?***

Crescent Cove is a non-profit, 501(c)(3) organization with a mission to offer care and support to children and young adults with a shortened life expectancy, and their families who love them. Crescent Cove is dedicated to opening and operating a children's respite and hospice care home in the Twin Cities. This home will be specifically built for children and young adults who have a shortened life expectancy due to a condition that is life-limiting or life-threatening from ages 0-21 years old and their families.

In addition to working to open and operate a residential children's hospice, Crescent Cove has two other strategic priorities – family services, and advocacy. We are currently covering the costs for families to access integrative therapies such as massage therapy, music therapy, art therapy, counseling and spiritual care, as well as covering the costs for respite get-aways. We are also advocating to raise awareness of the need for more support for the families we serve and hosting our 3rd annual Pediatric Palliative Care Symposium in September, 2017.

### ***Once the home is open, what services will be available?***

Our vision is to offer an optimal caring and healing environment with skilled professionals providing palliative and end-of-life care to children, including pain and symptom management, massage and hydrotherapy, play, music, pet and art therapies. Crescent Cove will not replace the child's primary care team, but will collaborate with those professionals. We will be dedicated to not only caring for children and young people, but will also provide a foundation of support and appropriate services to their families. This will include on-site accommodations so that the family may remain close, and still receive physical and emotional respite. This nurturing home environment will have open gathering spaces for children and families to spend rejuvenating time together as well as reverend space for end-of-life care.

### ***At what stage is the organization?***

Crescent Cove is working to open its home on Twin Lakes in Brooklyn Center in late 2017, while continuing to build awareness and support in our community. This effort is directed by the Crescent Cove Board of Directors, staff, advisory councils and dozens of volunteers. The organization's staff includes the Founder & Executive Director, Katie Lindenfelser who serves in a part-time role, Tara Anderson, the new Director of Engagement and Karla Vaughan, the part-time Office Manager.

Crescent Cove became a Minnesota non-profit corporation first as the name Children's Lighthouse of Minnesota on September 30, 2009 and received 501(c)(3) status from the IRS in June 2010 (retroactive to the 9/30/09 date). Crescent Cove is continuing to build relationships in the community and is raising the funds in order to open and operate this much needed home. In 2013 we conducted interviews with community leaders soliciting advice for successful campaign strategies. In 2016, a more formal campaign assessment was conducted by outside

consultants as well as an updated demand analysis, all verifying the need and available support in our community.

Concurrent with our efforts to raise funds for opening the facility, we are providing financial support and resources to families in need of short-term respite care. We are also providing resources to help families receive integrative therapy sessions at their home.

In April, 2015 RSP Architects was selected as the architect of record and they work closely with Gardner Construction, Cushman & Wakefield and our building committee to continue the progress towards opening this home.

### ***Is Crescent Cove a public charity?***

Yes. Crescent Cove is a Minnesota non-profit corporation recognized by the IRS as a 501(c)(3) public charity.

100% of donations are used for the development of the infrastructure, programs and services of Crescent Cove. ***Donations are tax deductible*** to the extent permitted by law, please consult your tax advisor with questions about tax deductions to public charities. (EIN: 27-1035515)

### ***Why is it called Crescent Cove?***

Our vision is that the hospice home will serve as a place of respite for children and families in our community.

- The crescent moon is in a phase of transition; a metaphor for life and represents night and rest.
- The moon itself is always present in one form or another; it revolves around us, as our team will always be there for families.
- The crescent shape represents an embrace.
- A cove represents a place to find shelter or respite during difficult times.

We chose the colors of our logo because of what each color represents:

**Blue and Turquoise** represent peace, tranquility, calm, stability, harmony, unity, trust, truth, confidence, conservatism, security, cleanliness, loyalty, sky and water.

### ***How is Crescent Cove different from Ronald McDonald House?***

Crescent Cove and Ronald McDonald House (RMH) are two independent, non-profit organizations that are governed by two separate Boards of Directors. Both organizations provide unique environments and services for children and their families, which make it important to distinguish the differences between the two organizations.

## **Crescent Cove**

*Crescent Cove's vision is to provide a home and care services to children with life-limiting illnesses and their families. Our goal is to open a freestanding, independent home-like facility with 6 bedrooms so that children with life-limiting conditions can receive **respite** and **end-of-life** care outside of the hospital or home environment. The home will be licensed by the State of Minnesota as a residential hospice facility. Families will be welcomed to stay at the home in family suites or may have the weekend away while their child receives compassionate clinical daily cares at Crescent Cove. This allows families the opportunity to concentrate on being parents, siblings, grandparents, etc. while the Crescent Cove staff attends to the daily needs of the child with a life limiting condition. There will also be additional support services available to the family, including social and spiritual support and grief counseling.*

## **Ronald McDonald House**

*RMH offers families a place to stay that is near the hospital where their child is receiving treatment. RMH provides a **home-away-from-home for families** who live farther distances from the medical facilities where their child receives treatment. It is a home available to family members who have a child actively receiving treatment in the hospital. Children may not stay at RMH without their parents and the house is not licensed to provide any medical care or intervention.*

Crescent Cove and RMH have distinct missions and visions for serving children with life-limiting conditions and their families. While there will hopefully be opportunities for the two organizations to work together by sharing referrals and support for children and families, it is important that the unique differences of these organizations are recognized, as well as the need for both of these services in our community.

### ***How does the hospice/respice home you envision compare to a hospital hospice?***

Not all hospitals have palliative care/hospice rooms available for patients and families. Palliative care rooms typically have more space and amenities for family members who wish to be near their child, whereas typical hospital rooms are usually tighter on space. Even though hospitals often have a larger room to accommodate a child who is dying and his/her family, they are typically near other hospital rooms where children are receiving care and treatment. Hospitals are necessary for urgent, acute care and treatments, but not always ideal or necessary for respite or end-of-life care unless the child is in need of, or desiring hospital-level, acute care and/or treatments.

Crescent Cove will be a home for children with life-limiting conditions to stay to have a short break (respite) or as a comforting and sacred place at the end-of-life, with space for the family to stay as desired and for their family to be supported as well. Daily cares that would otherwise

be provided at the child's home will be provided at Crescent Cove, as we will offer a home-like environment that differs from the hospital environment.

***How do you plan to work with the hospitals? Will they have a stake in this?***

Leaders, clinicians and clinical teams at Gillette Children's Specialty Center, University of Minnesota - Masonic Children's Hospital, Children's Hospitals and Clinics of Minnesota, Pediatric Home Service and Bayada Pediatrics all agree that there is a great need for this pediatric hospice and respite care home. It is our goal to work collaboratively with all of them.

We have been meeting together with professionals from the pediatric palliative care departments to determine the best care that can be provided at this free-standing, community-based children's hospice and respite care home. As part of our governance structure, we have a ***Clinical Advisory Council*** that represents an interdisciplinary team of professionals from various pediatric healthcare organizations in the Twin Cities. One of the pediatric palliative care physicians is on the Board of Directors for Crescent Cove.

At this time, the hospitals have not contributed financially, but have committed to working together to further Crescent Cove's mission. It is our hope that over time, each hospital would be able to contribute a portion of the operational costs, as this home will serve children cared for by each organization.

***What will be the criteria for children/families to stay at Crescent Cove?***

The home will be available for respite stays and end-of-life care for children diagnosed with a condition that is considered to be life-limiting meaning the child has a shortened life expectancy and will most likely not live to adulthood. Specific admission and enrollment criteria as well as the referral process are being determined and defined by the Clinical Advisory Committee. We anticipate that depending on the child's condition, the child and family may be welcome to stay for 10-15 nights of respite per year and may utilize that time in various increments. There will be no limit to the length of stay for children who are being cared for while they are actively dying through death, and their families.

***How does reimbursement work? What will the operational model look like?***

Currently, there is no reimbursement available for respite stays through Medicaid or private insurance providers. Crescent Cove had a bill passed by our state legislature in 2016 that added



children and young adults to the existing Residential Hospice License. This was the first step towards building a reimbursement model. Crescent Cove is now working with the Department of Human Services to add this facility to the Medicaid waivers and is also in conversation with private health insurance providers. Wipfli completed a financial proforma in 2013 and an updated version in 2016 that includes operational expenses without the assumptions of reimbursement opportunities, yet Crescent Cove continues to work towards a reimbursement model to sustain the operations.

Crescent Cove has learned from Ryan House in Arizona, George Mark Children's Home in California that as they navigate this discussion on an individual, case-by-case basis, they are slowly accessing some reimbursement for end-of-life care. Primarily, these homes, similar to those in the United Kingdom, Canada and Australia are funded by philanthropic funds.

Children do not access Medicare as adults do in order to receive respite or hospice support. Furthermore, adult hospice homes frequently operate on a fee for service. ***It is our goal to offer respite and end-of-life care to children and families at no cost.*** This is because we do not want to turn families away and know that many families who have a child with a life-limiting condition have often exhausted all of their financial resources and have tapped into their long-term savings to look after their child. This model differs from the adult residential hospice model where there is typically a room and board fee.

### ***How much money do you need?***

The Wipfli LLP accounting firm has reviewed and refined our operating budget projections and capital campaign goal. Our capital campaign goal is \$5 million, which includes purchasing, and renovating the existing hospice home on Twin Lakes and a year and a half of operational funds essential for sustainability. Our annual operating budget once the home is built is \$2.1 million serving an average of 2-4 children at the home. We are working with local Pediatric Home Care Providers to determine areas where we can share costs to benefit both of our operational budgets. In order to be sustainable into the future, Crescent Cove is working to understand a reimbursement model from third party payers like Medicaid or health insurance plans to support the ongoing operations. Ultimately, philanthropic funds will be needed to primarily support the ongoing operations of the home for the first 3-5 years.

### ***What is the Harmon Killebrew Hospice Home for Kids Fund?***

During his retirement years, Harmon Killebrew was a spokesperson for the hospice movement and embraced the role it plays at one of the most critical times we face in life. Along with the Board of Crescent Cove, Harmon's widow Nita Killebrew and close friends created a fund to help build our home. The Harmon Killebrew Hospice Home for Kids Fund is part of Crescent Cove, and donations received

through the fund are written out to Crescent Cove and tracked as a gift to this Fund. Since 2012 we have hosted an annual Home Plate gala to raise awareness and funds to help build this home, and have also have an annual day at the Twins game. Members of the advisory council for the Harmon Killebrew Hospice Home for Kids Fund include: Jack and Jennifer Morris, Tony and Gordette Oliva, Paul and Destini Molitor, Anita Oliva, Clyde Doepner, Rod and Rhonda Carew, Kevin Smith and Jim Hays.

***How does what you propose differ from palliative care?***

The care that will be provided at Crescent Cove is palliative care, providing comfort, and pain and symptom management as needed. Palliative care is the holistic approach (emotional, physical and spiritual support) to a person's care that has a condition that may be life limiting, though they may also be receiving treatment and still working to maintain the best quality of life possible.

***How soon do you think this can happen?***

We plan to open our home on Twin Lakes in late 2017. To date, we have raised \$2.5M of the \$5M needed to open and operate Crescent Cove.