



# Storybook

## The Littlest Mermaid

A typical day for a newborn baby revolves around the basics – eating, pooping and sleeping. Sounds simple, right? For two-month-old Winnie things became complicated when her mom Holly made the surprising discovery that her precious infant was not pooping correctly. She noticed there was not an opening at her anus and a visit to their pediatrician confirmed the diagnosis of an imperforate anus.

This rare congenital defect meant Winnie could not have normal bowel movements. Her body had developed an alternative opening (a fistula) for her to poop. Winnie was referred to Lucile Packard Children's Hospital at Stanford where doctors performed immediate surgery to repair the malformation. The doctors created a temporary colostomy for her bowel movements while her newly opened anus healed. After a stressful hospital stay Winnie was finally able to return home to her family – where her adoring 2 1/2 and 5-year-old sisters, dad and grandpa were waiting to shower her with love. Her parents were grateful to be greeted by Coastal Kids nurse Kim, who supported Holly in caring for her delicate daughter and helped troubleshoot challenges for the precarious ten weeks of healing.

Under Kim's watchful eye, Holly took excellent care of Winnie. In April she was readmitted to Stanford for surgery to connect her colon to her newly opened anus and close the colostomy. This hospitalization was much easier, and Winnie once again returned home to her playful sisters and loving family. However, it was a bittersweet moment when Winnie no longer needed the extra care of nurse. On Kim's last visit, five-year-old Eleanor said, "Nurse Kim are you gonna come back and play with us soon?" With Winnie on her way to a full recovery, Coastal Kids was ready to step back and let her family get back to a typical routine. Kim did promise Holly that she would stay in touch to follow the adventures of the littlest mermaid in the family.



*Coastal Kids provides in-home medical care  
for kids and support for those who love them.*

**IMPACT:** More  
than 4100 home  
visits in 2017.

**P2**

**LOOKING FORWARD:**  
meet two sets of bold  
brothers.

**P3**

**PEDIATRIC  
PALLIATIVE CARE:**  
An Anchor in the Storm

**P4-5**

**A HEARTFELT  
THANK YOU to**  
our donors.

**P7**



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HOME CARE

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# Footprints in the Sand



## Letter from the Executive Director

When the Coastal Kids journey began thirteen years ago, I could not have imagined how many challenges we would face on the path to caring for children at home. I believed then, as I still do today, that children deserve the same high-quality healthcare options as adults. Coastal Kids is the only agency offering in-home medical care in the

Central Coast and South Bay, and the only provider of palliative and end-of-life care for children in these communities. Although this work is our most difficult, we are grateful to give families with terminal children the choice to care for their child at home – where they want to be.

Our team of nurses, therapists and social workers offers calm in a sea of uncertainty for more than 600 families each year. Most of our Coastal Kids return to health and race off into their teen and adult years without looking back at those bumpy weeks and months when we knew them. A few, however, receive a terminal diagnosis and come home to spend their last precious moments with their family. It is these special kids who leave the deepest footprints on our hearts. In 2017, we cared for twelve children at the end of life, and helped their families pick up the pieces after their death.

It is thanks to, you, our community of supporters that we can continue to care for these special kids. This spring, we are thrilled to once again share with you their stories and to introduce you to our pioneering palliative care team.

In gratitude,

*Margy Mayfield*  
Margy Mayfield

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## From Mountain View to King City and Ben Lomond to Hollister

Coastal Kids staff drive more than **150,000** miles each year on coastal highways, country roads and city streets to the homes of kids living with illness and injury. Nurses and therapists share medical expertise, developmental knowledge and peace of mind for the whole family. In 2017, our staff made **4,168** home visits with **617** children and their families. Our compassionate team cared for **9** children through the end of their lives and provided care and support for **20** bereaved families.

skilled nursing visits



expressive therapy and massage visits



one-on-one counseling sessions



physical and occupational therapy house calls



social work care coordination visits



hours serving sick kids in our community





# Wave of the Future



Bumps and scrapes are a normal part of childhood. For most kids, a tumble off a bike or a tough kick in a soccer game mean only a temporary bruise or a cut that heals quickly. However, for Christian Perez, these everyday mishaps can have serious consequences. Christian has hemophilia, a genetic disease that prevents his blood from clotting. As a result, simple injuries can result in significant blood loss or dangerous internal bleeding.

For an active eleven-year-old who loves sports, having hemophilia means he often misses out on playing soccer with his friends. Fortunately for him, he is able to receive Factor VIII transfusions, they replace the missing protein in his blood and make day to day activities safer. Since 2005, Coastal Kids Home Care nurse Kim has been checking in on him monthly - first to flush his port to ensure safe transfusions and later to work with his mom and him on learning how to do external transfusions so that his port could be removed.

Today, Christian is nearly independent of Coastal Kids. He receives transfusions 3-4 times each week from his mom and is even learning to do them on his own. Next up? With the help of Kim, Christian is hoping to help teach his nine-year-old brother Jeremiah to manage his hemophilia too. Soon both Perez boys will be playing fewer video games and more soccer - without the fear of those minor bumps and bruises.

*"Empowering kids like Christian and Jeremiah to take responsibility for their own care makes a huge difference in their confidence and their ability to just be kids."*

~Kim

Ryan Miller is a playful, positive, and outgoing 7-year-old boy. He is also a cancer survivor. After being diagnosed with Burkitt's Lymphoma, getting to meet his favorite player Russell Wilson, and beating cancer, a lot has changed. But what happens after cancer?

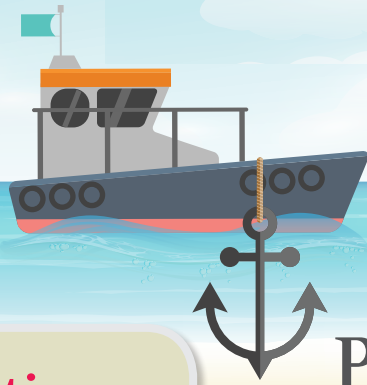
When Coastal Kids' Clinical Social Worker, Ruth Emerson met Ryan for the first time he was just finishing up chemotherapy. His mom sought out Ruth to help Ryan adjust -- to school, to home, and to being a 5-year-old kid again. During treatment for cancer, Ryan had missed school and was struggling with asking for help. He was also having difficulty sharing attention with his older brother, Scott. At mom's request, Ruth also stepped in to help Scott cope with the ups and downs of being a sibling of a child with serious-illness.

During one-on-one counseling sessions, which often took place over backyard basketball games, Ruth gave Ryan the necessary tools to communicate at home and school. With the help of some extra tutoring, Ryan was soon back on track in his schoolwork and despite the occasional brotherly battle, he was getting along better with Scott too. In turn, Scott was learning to step out of the shadow of his demanding little brother. In the two years that Ruth has been seeing Ryan and Scott she's seen amazing progress in both.

*"It was a wonderful time for me to be counseling the boys because it felt like Ryan's life was beginning again."*

~Ruth





## Palliative Care Team



**Margy Mayfield**  
*Pediatric Nurse*

**Ruth Emerson**  
*Licensed Clinical Social Worker*



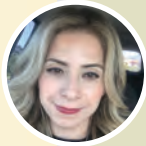
**Robin Nacamuli**  
*Pediatric Nurse*

**Kimberly Jimenez Hell**  
*Pediatric Nurse*



**Robin Ward**  
*Pediatric Nurse*

**Shannon Carnazzo**  
*Pediatric Nurse*



**Angelica Martinez,**  
*Medical Social Worker*

**Lacey Morris**  
*Art Therapist*



**Julie Roseman**  
*Music Therapist*

**Nell Counsell**  
*Massage Therapist*



# Pediatric Palliative Care: An Anchor in the Storm

When an infant is born with a complex congenital condition, or a child receives an unexpected diagnosis of cancer or other serious-illness, the whole family is thrust into stormy waters. Parents often feel powerless, unable to understand what their child's future – and their own – may hold. Access to home based palliative care services can provide the anchor that a child, and their whole family needs, to weather the storm ahead.

### What is pediatric palliative care?

Pediatric palliative care is specialized medical care for children living with acute serious-illness and those with life-limiting diagnoses. Palliative care can be offered alongside curative treatment and provides an extra layer of support to families. The overall goal is to improve the quality of life of the child and their family through a holistic, multidisciplinary approach.

Palliative Care helps to manage the physical pain and symptoms resulting from a disease while also supporting the emotional and wellbeing of the child and their family. It also assists families to better understand their disease and treatment options and facilitates communications with doctors and other care providers. Pediatric palliative care helps patients and their caregivers to cope with the everyday challenges of living with a serious-illness. Palliative care can begin at any stage of a child's illness and when necessary can continue through the end-of-life.

### Coastal Kids: Pioneers in Home Based Pediatric Palliative Care

Since 2005, Coastal Kids has provided in-home nursing and comfort care to children living with serious-illness and in 2010 were selected as a pilot provider of the California Children's Service Partners for Children Palliative Care Waiver Program. We have brought together a team of talented, dedicated and compassionate pediatric clinicians with extensive experience caring for children and families coping with serious-illness. During that time, we have provided dozens of families with comprehensive pediatric palliative care services – all in the comfort of home.



Coastal Kids comprehensive approach emphasizes patient and family preferences and our team coordinates with physicians and nurse practitioners from pediatric specialty hospitals to ensure continuity of care from hospital to home. Once a child is home, our care coordinators regularly assess and manage the physical and emotional comfort of the child and ensure the family is supported throughout the course of their child's illness. Our core team includes:

- **Pediatric Nurses** who are expert in pain and symptom management for children. Nurses are available 24/7 to respond to caregivers' questions or concerns.
- **Licensed Counselors** who can answer questions from the child, siblings and parents and support the family in talking about what is happening. All family members also have access to one-on-one counseling.

- **Expressive Therapists** help qualifying children to express their emotions through art or music therapy or assist to relieve symptoms through massage.
- **Medical Social Workers** assist with practical and financial issues around ongoing care and planning. They also facilitate communication with a family's faith community when appropriate.

If curative treatment is no longer possible for a child, our palliative care team can continue to respond to the needs of a child and their family without interruption. Decades of experience caring for children at the end-of-life have taught us that children and their parents prefer to remain with their familiar team. Coastal Kids offers compassionate in-home care for children at the end-of-life and ongoing emotional support for their families.

## Caring for Abigail

Abigail Marquez was born at a wee 1lb 10oz and her early months in the neo-natal intensive care unit at UCSF were complicated by challenges with breathing and eating. Doctors placed a g-tube to support nutrition and weight gain and a tracheostomy to protect her fragile airway.

She arrived home at age seven months to the room she shares with her mom, Nora, and two brothers in a small Watsonville apartment – and the reassuring help of Coastal Kids nurse Robin. Together Nora and Robin have navigated Abigail's complex care. And recently, she was admitted to Coastal Kids palliative care program, to offer Abby and her mom additional support through care coordination, social work support and massage therapy.

Already, Abby has begun receiving regular massages resulting in big smiles. Her mom, Nora, is thankful for the lifeline that Coastal Kids has offered. Recently, Abby celebrated her second birthday complete with new hair bows courtesy of her favorite nurse.



# Memories of Evelyn

Easter is a special time of year when little boys and girls get dressed in their best clothes and hunt backyards, parks and nearly everywhere for colorful Easter eggs. For the Hernandez-Acosta family, Easter 2017 will forever hold a very special place in their memory. Their cherished daughter Evelyn had been diagnosed with a terminal brain tumor just a few months before, and they knew it would be her last.

Despite the pain and discomfort of being sick, Evelyn was bubbling over with joy Easter morning. She excitedly searched for the treat-filled eggs, taking time to help her younger brother to fill his basket too. This scene exemplified Evelyn's special little spirit. As the only girl, with five rough and tumble brothers, she was doted upon by everyone. Yet she never acted spoiled, instead seeking to return the generous love two-fold.

Her diagnosis in early 2017 with DIPG, a rare terminal brain tumor, shook the foundation of her family. With a prognosis of only a few months to live, her mom Maribelle was thankful for the option to bring her baby home where Evelyn could be surrounded by the love of family. Coastal Kids Home Care Palliative Care team made this possible. Nurse Kim helped her parents monitor her pain and symptoms and clinical social worker Ruth assisted them with end-of-life planning and offered anticipatory grief counseling.

Just three months from diagnosis and after less than one month at home, Evelyn peacefully passed away in April 2017. One year later her family still feels the loss of their precious baby deeply. Ruth sees Maribelle twice monthly for bereavement counseling. During these sessions she also offers insights on how to help the boys cope with their sister's loss. Recently, Maribelle expressed that Coastal Kids helped her to feel less alone, and that she is beginning to feel hopeful for the future again.



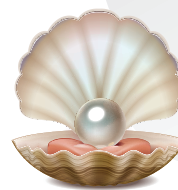
## Working Together for Grieving Kids

This past November, for Children's Grief Awareness Month, Coastal Kids Home Care partnered with the National Alliance for Grieving Children to host a local webcast of their conference on *Working with Children Anticipating Death*. The event was moderated by our Director of Bereavement, Ruth Emerson, LCSW and brought together nurses, social workers, chaplains and other individuals working with children in our community around these complex issues. Attendees gained valuable insights into developmentally appropriate ways to talk to children about death and dying. We are grateful to the Hospice Giving Foundation and Salinas Valley Memorial Hospital for their generous support of this event.





# A Sea of Gifts: Thank you to our 2017 Donors



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## Circle of Compassion (\$50,000+)

Hospice Giving Foundation

## Circle of Grace (\$20,000 +)

Caroline's Non-Profit Gift Shop  
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Monterey Peninsula Foundation  
Salinas Valley Memorial Hospital

## Circle of Courage (\$10,000+)

Community Foundation Santa Cruz County  
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Rio Grill Resolution Run

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Wendy Neale



## Be the Wind in Our Sails: Ways to Help Kids Thrive at Home



### MAKE A MONTHLY DONATION

**MAKE A MONTHLY DONATION** – Coastal Kids services stay afloat year-round thanks our monthly donors. Just \$10 a month (33 cents a day) fuels a nurse's trip to one child, \$50 a month will bring exceptional care to five kids. If your employer offers matching gifts, it is a terrific way to double your contribution.

**DONOR ADVISED FUNDS** If you have already set aside funds to support your favorite causes, consider putting those dollars to work in support of sick kids in our community. A \$500 gift offers ten one-on-one counseling sessions to a teen coping with cancer. And \$1000 supports 20 therapy house calls.

### DONOR ADVISED FUNDS



### VOLUNTEER WITH US

**VOLUNTEER WITH US**– Join us at our signature family events, Touch-A-Truck and the Rio Resolution Run or contribute your talents in the office. Know of a community group who would like to know more about our work? Contact us about community outreach too.

**CREATE A FUNDRAISER** – Ask your Facebook friends to support Coastal Kids, host an evening of wine and appetizers, or sponsor one of our signature events. 100% of donations go directly to compassionate in-home medical care for children living in our community.

### CREATE A FUNDRAISER



**DONATE** at [www.coastalkidshomecare.org](http://www.coastalkidshomecare.org)  
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## COASTAL KIDS HOME CARE

1172 S. Main Street, #125  
Salinas, CA 93901

# Navigate your way to these events benefiting sick kids.

**Touch A Truck** – September 9, 2018, Salinas Rodeo Grounds. Clamber into a fire engine, explore a bulldozer and climb behind the wheel of a big rig. With over 50 vehicles, food trucks, and music, it's a day of fun for kids and kids at heart. Mark your calendars!

**Holiday Gift Wrapping** – December 2018. Each year we receive hundreds of toys and gifts for our pediatric patients and their families. To make the holidays even more special, we wrap each gift for special delivery before Christmas. We are always in search of volunteer elves to help us brighten the holidays for sick kids!

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



**Rio Grill's Resolution Run** – January 1, 2019.

The only resolution you will need to make. Get ready to strap on your running shoes and explore the course, a 5 and 10k run through scenic Carmel benefitting Coastal Kids Home Care. Your heart will thank you and so will we.

**Hoops for Homecare** – March 2019. During March Madness the top 68 teams have made it to the NCAA tournament and millions of fans are ready to make bracket selections. While the players are making baskets and you can be making donations to Coastal Kids. Watch for this and other online fundraisers on Facebook and Instagram.

Like us on **Facebook** or follow us on **Instagram** to meet our families, learn about our events and share our accomplishments. We'll see you there!