

Storybook

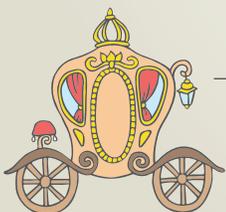
A TALE OF THREE BROTHERS

The Maglines twins – Beren and Christian – share big brown eyes and twinkling smiles. They also share weekly visits from Coastal Kids’ nurses to treat a condition called Duchenne’s Muscular Dystrophy. During the visits the home-schooled twins enjoy watching documentaries on ancient history while nurse Cecelia administers forty-five minute infusions of a newly FDA approved treatment to slow the progression of their disease. The treatment was a dream come true for the family.

Duchenne’s is caused by missing or damaged parts of DNA responsible for making dystrophin, a protein essential for strengthening and protecting muscle fibers. The twins were chosen for a test trial of a new drug, Eteplirsen, a from Sarepta Therapeutics, which provides a genetic bandage which allows the body to bypass damaged sections and produce a protein with a similar function to dystrophin.

The effects of treatment have been remarkable, enabling the twins to continue walking and talking with relative ease at age eleven. In contrast, their older brother Aiden who also has Duchenne’s was wheelchair bound by age nine. Now sixteen and a high school honor student, Aiden dreams of engineering a better wheelchair for kids like himself. With FDA approval coming through this spring, the Maglines just received word that Aiden is approved to use Eteplirsen. This has left their mom, Rosella, hopeful that the new treatment will benefit all three boys.

The Maglines were grateful to find Coastal Kids. With so many trips to the doctor, it is a relief to have the lengthy infusions administered in the comfort of home. According to Cecelia, “The boys are always patient, helpful and affectionate with each other. The whole family is truly amazing.” At Coastal Kids we have cared for several special kids with Duchenne’s over the years, so we feel very honored to bring this promising new treatment home to the Maglines family - and help them write a new future for their sons.



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

OVER THE RIVER AND THROUGH THE WOODS. More than 4500 home visits in 2016.

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COASTAL KIDS HOME CARE

ph: 1.800.214 (KIDZ) 5439
www.coastalkidshomecare.org

CREATING FAIRYTALE MOMENTS FOR FAMILIES



Letter from the Executive Director

Parents read fairytales to amuse and entertain their children, to stoke their young imaginations with dreams of happily ever after. At Coastal Kids when helping families cope with the stresses of childhood illness, we know that happy endings can seem far, far away – and for some families, we know that dreams may not come true.

Although top-notch medical care is our constant focus, our true purpose is to bring smiles to kiddos in tough moments, joke with teenagers about their favorite pop stars or sports heroes, calm the minds of worried moms and dads and make coping with pediatric medical issues just a little bit easier for the whole family.

And when families receive life-limiting or terminal diagnoses, our Palliative Care team works with them to fulfill wish lists... for trips to Disneyland, to Major League Baseball games, for treasured photos sessions, or visits from grandparents. We bring moments of joy to their children's precious last days.

This spring we are thrilled to introduce you to some of our miraculous kids and share stories of our perinatal and shift nursing programs. These new efforts fill critical gaps in the pediatric healthcare continuum in our community.

At Coastal Kids, we know that takes a village to care for sick children and support their families. We are especially grateful for our dedicated Board of Directors, tireless event volunteers and generous donors. They are all central characters in the story of our organization and the families we are privileged to serve each day.

In gratitude,

Margy Mayfield, RN, BSN
Executive Director



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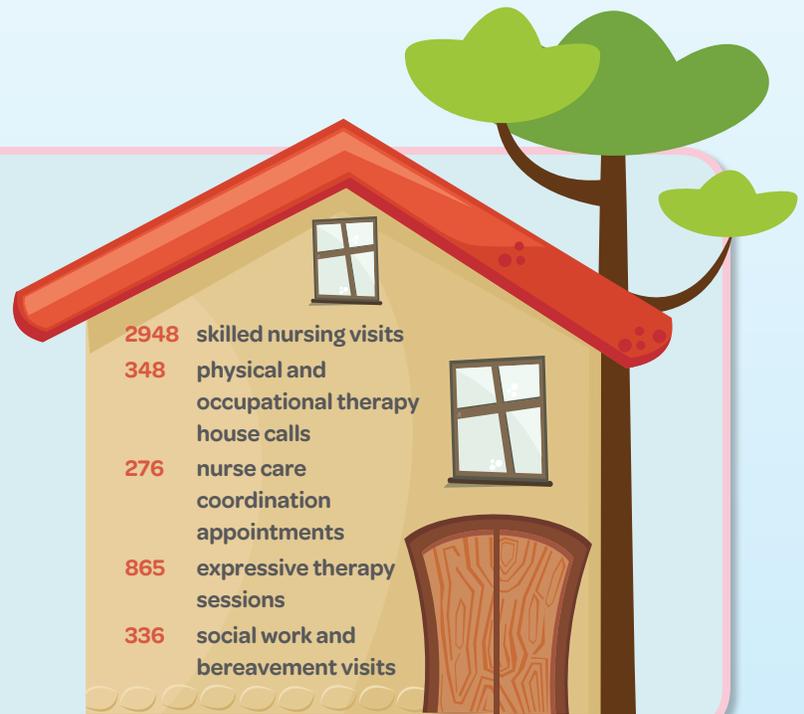
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OVER THE RIVER AND THROUGH THE WOODS

Coastal Kids staff crisscross four counties to provide exceptional medical care to exceptional kids. Nurses and therapists share medical expertise and developmental knowledge, they bring lighthearted jokes and little gifts to kids, and they offer peace of mind to parents. In 2016, our staff went over the river and through the woods for **4535** home visits with **623** children and their families. Our compassionate team cared for **8** children through the end of their lives and provided support to **15** bereaved families in the days, weeks and years following their loss.





WHEN DREAMS DON'T COME TRUE

COASTAL KIDS PERINATAL BEREAVEMENT SERVICES

The loss of a child at any age is devastating to a family. However, the loss of an infant during pregnancy or just after birth, called perinatal death, can be uniquely challenging. Often, mothers and fathers find themselves coping with grief on their own. Extended family members and friends are not aware of the loss, or uncomfortable acknowledging the complexity of emotions parents are experiencing.

According to one mom, whose infant passed away from Spinal Muscular Atrophy at three weeks old, “People never mention the baby I lost. They always ask about my healthy children, but do not acknowledge her at all. We still feel her loss deeply, but feel unable to share that with others.”

Through our new Perinatal Loss Bereavement Program, Coastal Kids Home Care aims to respond to the critical need within our community to support these grieving parents. Anticipating the birth of a healthy child brings with it an incredible sense of hope – and when pregnancy ends abruptly with miscarriage, an infant is stillborn or diagnosed with a medical condition incompatible with life – hope is replaced with emotions like despair, guilt or anger. According to Coastal Kids Executive Director, Margy Mayfield “Grief associated with perinatal loss is often overlooked by our society, Coastal Kids is grateful to respond to this critical need in partnership with local clinics and hospitals.”

At Coastal Kids, our experience guiding families through the process of grieving the death of a child is invaluable for families experiencing perinatal loss. In the autumn of 2016, Coastal Kids received a referral from Dominican Hospital to help a local family bring home an infant with Trisomy 18, a genetic condition affecting the development of the baby’s organs. She was not expected to live for more than a few weeks. Coastal Kids nurses helped her mom and dad to learn how to feed and care for her, and our social worker counseled the family and assisted them with end-of-life planning. During this time, our team worked to make every moment count, even arranging for a professional photographer to capture memories for the family.



Less than a month later, she peacefully passed away. Coastal Kids continues to support the parents with monthly counseling visits, and mom has expressed her deep gratitude for our assistance, “Coastal Kids was there for us and our precious baby.”

Another family from the Monterey Peninsula faced the terrible loss of an infant in the second trimester of pregnancy. For a couple who had long tried to conceive, this experience had a profound impact on their wellbeing. Ruth Emerson, Coastal Kids Licensed Clinical Social Worker, received the referral from Stanford Children’s Hospital and immediately reached out to the parents to offer bereavement counseling. These monthly counseling sessions proved a lifeline for them. Mom adopted cognitive behavioral therapy strategies to communicate with family and friends better about her experience, and dad worked through a period of intense anxiety, eventually becoming stable enough to return to work. One year later, both parents express their relief at the timely and invaluable support they received through Coastal Kids.

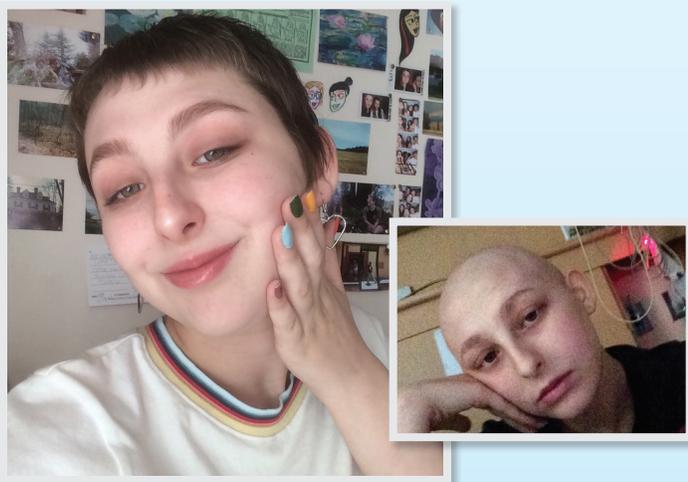


GRANTING SAVANNAH'S WISH

Most teenage girls worry about grades, prom dresses, and getting their drivers' license. Savannah Collins of Boulder Creek, is not a typical teenager. Last March, at age sixteen, she was diagnosed with metastatic osteosarcoma. Since then, Savannah has undergone multiple surgeries and aggressive chemotherapy. She has experienced debilitating symptoms and painful side effects. Through it all, her mom Carrie has been her rock. So, when asked by Social Worker, Ruth Emerson, what she most wanted – she did not have a typical teenage answer. “I want my mom to get massages like me.”

Savannah is enrolled in Coastal Kids Home Care Palliative Care Program. In addition to regular in-home nursing visits, she receives weekly massages to ease symptoms. Unlike many teenagers, Savannah has a unique appreciation of all that her mom does for her every day. So, when given the chance, she was excited to give her hardworking mom the gift of relaxation.

Ms. Emerson coordinated with Savannah's massage therapist and the families' insurance to arrange for Carrie to get twice monthly massages. Savannah is thrilled to share the benefits of massage with her mom. While both mom and daughter remain optimistic about the future, they are doing their best to enjoy every moment of the present.



PRINCE MAX OF GREENFIELD

Five-year old Max loves trucks. He watches truck shows, plays truck games on his tablet but most of all he enjoys playing with toy firetrucks, garbage trucks and more. He makes vroom-vroom sounds as he zooms around the living room of his parent's Greenfield home with his little brother Mateo not far behind.

Max was diagnosed with Acute Lymphoblastic Leukemia in 2016. He is almost finished with treatment, his hair is growing back and he is doing great. Though weekly lab draws from Coastal Kids Home Care are still essential to monitor his progress. When Coastal Kids nurses first met Max, he would run and hide, and often cry during his blood draws. Three months later, Max has learned from practice that lab draws are not too painful, and now when his nurses arrive he jokes around with them instead.

Recently, after checking his vitals and drawing blood when his nurse Taryn asked, “Can we be friends?” Max replied, “If you come play trucks with me under the table you can be my friend.” Taryn was thrilled to comply. Max and Mateo are the center of their parents' world. They are relieved to see Prince Max feeling more himself, and appreciative of nursing visits from Coastal Kids to help get him back on the road to health.



CAROLINE'S VILLAGE

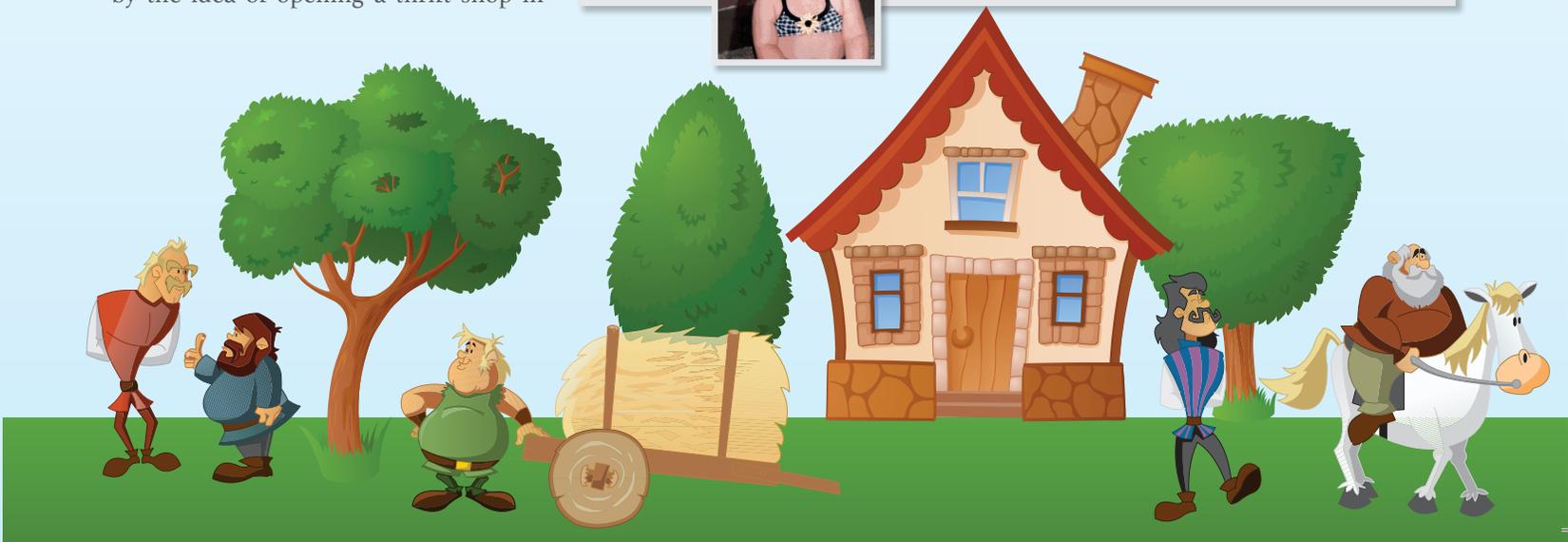
Caroline Licker was vivacious, resilient young lady with a bright sense of humor. She approached life head-on, overcoming incredible challenges with the help of her steadfast mom, Christy. Caroline loved being home. Born with an extremely rare genetic condition, Caroline was hospitalized for most of the first year of her life. She underwent dozens of painful procedures, saw numerous pediatric specialists, and they concluded she did not have long to live. Her mom knew better. Christy learned how to care for her fragile daughter's many medical needs and they left the hospital behind.

At home Caroline thrived. By age three she learned how to maneuver a wheelchair, and soon she was zooming around the house demanding her favorite books, toys and foods. Caroline's determination propelled her through sixteen precious years. During her life, the Licker family nurtured a community of care, with a pediatrician who made house calls, nursing students to assist with her care and friends to turn to in difficult moments. Caroline's joy-filled smiles left a strong impression on each person she met. When she peacefully passed away at home following complications from surgery, her loss was deeply felt by everyone.

In the year following Caroline's death, Christy sought out ways to work through her grief and was captured by the idea of opening a thrift shop in

her daughter's name. The community once again rallied around Caroline Licker and today her joy, fortitude and ability to inspire live on in Caroline's Non-Profit Thrift Shop in Aptos. With 84 volunteers contributing their time and talents, the thrift shop has generated more than \$1.125 million dollars – all given back to organizations serving children with special needs in the community.

Coastal Kids Home Care is incredibly grateful to have received \$75,000 from Caroline's over the past four years. We are honored to be using these funds to provide top-notch medical care to medically fragile children, like Caroline, who thrive at home in the arms of loving families and supportive communities.





Thank
You!

WE TREASURE OUR DONORS

Coastal Kids' Circle of Giving acknowledges the individuals, corporations and philanthropic foundations that provided financial gifts in support of in-home nursing and therapy for medically fragile children in 2016.

Circle of Compassion (\$100,000+)

Hospice Giving Foundation

Circle of Grace (\$25,000+)

Salinas Valley Memorial Healthcare System

Circle of Courage (\$10,000+)

Caroline's Non-Profit Thrift Shop
Community Foundation Santa Cruz County
Dunspaugh Dalton Foundation
Harden Foundation
Lucas Family Foundation
Monterey Peninsula Foundation
Nancy Buck Ransom Foundation
Pajaro Valley Community Health Trust
Palo Alto Foundation Health Care Endowment Fund
Rio Grill Resolution Run
Rite Aid Foundation
SanDisk Corporation Fund

Circle of Promise (\$5,000+)

Barnet Segal Charitable Trust
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Naturipe Berry Growers, Inc.
Palo Alto Medical Foundation/Sutter Health
Richard William Greenberg Foundation
Andrew and Steffanie Smith

Circle of Joy (\$1,000+)

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Premo Roofing Company
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Salinas Valley Ford
Sam Linder
Sigma Alpha of Omega Nu
Town N' Country Realty
Upjohn California Fund
Yellow Brick Road Benefit Shop



AN ENCHANTED EVENT

On New Year's Day 2018, Tony Tollner and a dedicated team of long-term volunteers will host the Rio Grill Resolution Run for the 28th year. According to Tollner, "We started this event to support non-profits in the community who were in need of resources and recognition. Children's issues have always been important to us and we feel Coastal Kids, and their services to sick children exemplify this need." In the past two years, more than 2000 runners have enjoyed this family friendly run resulting in more than \$70,000 in support of home nursing and therapy services for children in our community. Coastal Kids is honored to be a part of this storied Carmel tradition, and incredibly grateful to Tony and his team.



TREADING A NEW PATH IN PEDIATRIC HOME CARE

In 2016, Coastal Kids came to the rescue for families in our community caring for medically complex children at home. When the last pediatric shift nursing company closed in August, Coastal Kids Home Care agreed to pilot a program to offer shift care for families with complex medication, equipment and care needs in their homes. Our shift nurses and LVNs now work 3-8 hour shifts in a patient's home, addressing their moment-by-moment needs while offering their regular caregivers a much-needed break.

For these families, access to shift nursing can mean the ability to keep their child at home, out of the hospital or costly long-term care facility. One single mom of a wheelchair bound teenager said, "I was feeling ready to give up, then Coastal Kids stepped in to help." Coastal Kids is excited to walk this new path in pediatric home care alongside families caring for children with round-the-clock needs. We are hoping to expand in the coming years to serve more kids like Isabella and Cynthia (pictured here).



IF WE HAD A MAGIC WAND...

Coastal Kids relies on hardworking volunteers and generous donors to provide our services to medically fragile children in our community. Here are a few ways you help us bring a bit of magic into the homes of the children we care for every day.

- ★ **Sprinkle some fairy dust...** When our Art Therapist arrives in the home of a child coping with cancer or other serious-illness their world is magically transformed to a place where they can paint their worries away. Donate \$100 toward paintbrushes, palettes, paper... and glitter, lots and lots of glitter.
- ★ **Whistle while you work...** Volunteer your time to help Coastal Kids. Consider joining our hardworking Board of Directors, contributing to one of our committees or helping in the office. Are you a photographer? attorney, retailer, homemaker... whatever time and talents you have are welcome, please come join our band of merry folk.
- ★ **Be our fairy-godmother (or father)...** Create a fundraiser for Coastal Kids Home Care, by sharing our stories with friends online or throwing a party at your home. Raise \$100 or \$5000, every donation makes the difference in the life of a child coping with serious-illness in our community.
- ★ **Traverse hill and vale with us...** 7,000 square miles of distance to cover. Seventeen cars burning 80,000 gallons of fuel, traveling 150,000 miles from home-to-home across four counties. That is \$45,000 a year! A \$25 donation equals five home visits and \$50 funds 10 trips across hill and vale.

Donations to Coastal Kids are a piece of cake. Visit our website or Facebook page and click: **DONATE!**

Prefer to send us a check? Please mail to:

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Be our Guest... Join in these events benefitting Coastal Kids.

Touch A Truck - September 10, 2017, Salinas Rodeo Grounds. Clamber up the steps of a fire engine, imagine yourself behind the wheel of a big rig, climb inside a tractor... more than 50 vehicles will await you and your kids. Lots of exploring to be done, yummys to be eaten and family fun to enjoy. Mark your calendars!

Touch A Truck Santa Cruz - October 22, 2017 - The Central Coast's original Touch-A-Truck comes to Santa Cruz County! Please join us at the Santa Cruz County Fairgrounds on for a festive afternoon of trucks, tractors and everything else you can imagine from two-wheels to eighteen wheels and more. We'll see you there!



www.coastalkidshomecare.org

Evening of Pampering - October 2017, The stylists at Allure Salon, Salinas are planning a spectacular evening of massages, pedicures and more. Purchase a passport of pampering for yourself or a lovely lady (or gentleman!) in your life. All proceeds benefit home nursing and therapy for seriously-ill children in our community.

Rio Grill's Resolution Run - January 1, 2018. The only resolution you will need to make... 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.

Like us on **Facebook** to meet our families, learn about our events and share our accomplishments. We look forward to seeing you there!