

STORYBOOK

A Publication of Coastal Kids Home Care

Summer 2020

Nurturing Jonathan During COVID-19

Shortly after Jonathan Morado was born, his mom began to notice differences from her older children, “He wasn’t developing like his siblings, and I noticed his facial features and feet were not like those of my other children at that age.” After following up with his pediatrician and then specialists at Stanford, Jonathan was diagnosed with Marfan Syndrome, an inherited disorder that affects the heart, eyes, blood vessels and bones. As a result, he required complex surgery on his eyes and heart. Those months were a whirlwind of doctor visits and hospital stays.

When Jonathan was just four-months-old he received his first in-home nursing visit from Coastal Kids nurse, Lisa, followed shortly by a social work visit with Stephanie. While Lisa helped mom manage care for her fragile infant, Stephanie worked behind the scenes to identify financial assistance that enabled the family to get their own apartment. Things were looking up in early 2020, and then the global pandemic hit.

Jonathan’s dad, an agricultural employee, lost his job and his mom was newly overwhelmed by balancing 24/7 care for her infant while supporting distance learning for her other two children. The family also struggled with the fear that they would be exposed to the virus during Jonathan’s many visits to specialists at Stanford Children’s Hospital. Coastal Kids again stepped in to assist with basic home nursing and coordinating his overall care. Stephanie also helped the family to access local food assistance programs and delivered essential supplies in those early fear-filled days.



The Morado family continues to be very cautious about the health of their family, and especially Jonathan. “I am so happy that we had the support of Coastal Kids during the pandemic,” says mom. “They helped us get things we needed like diapers and it reduced the amount of times that we had to go to a medical appointment, which reduced his chances of contracting the virus.” Today, Jonathan is nearing his first birthday. Unaware of the global crisis outside his home, his sweet smile offers a beacon of hope for all of us.

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

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to our donors.

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

Happy 15th Birthday Coastal Kids!



Letter from the Executive Director

On June 5th, 2005, Coastal Kids Home Care—California’s only nonprofit pediatric home health agency -- began seeing pediatric patients in their homes. In 2020, I am thrilled to be celebrating our fifteenth birthday as an organization and beginning to explore new horizons. While we have cared for more than 9,000 children with illness and disability in the years since we have opened, two new services - shift nursing and individual counseling - expand our care to other vulnerable populations in our community.

This year we will provide over 120,000 hours of shift nursing, providing respite to 30 families caring for medically fragile children at home and offer 1100 one-on-one counseling sessions to 376 children and teens coping with mild to moderate behavioral health issues. Our home-based palliative care program is growing too, and today more than 50 children with life-limiting illness in four counties are benefiting from this critical family-centered care. Through all of this growth, Coastal Kids Home Care remains true to our core values - to offer exceptional health and mental health care to children and support to parents - all in the comfort of home. This commitment to excellence is reflected in the long-term relationships we have with patients, the longevity of our team, and the dedication of you -- our community of donors and volunteers.

During this time of incredible uncertainty in the world, Coastal Kids continues to provide a compassionate, steadfast presence for the families in our care. While new services enable us to address the growing medical and mental health needs of a greater number of children, expansion has led us to outgrow our current office space. In 2020, we are launching our first ever Capital Campaign to support our move to a permanent new facility with expanded space for counseling and therapy.

In this issue of Storybook, please join us as we celebrate our fifteenth birthday and look towards a future where all children have access to excellent home nursing, therapy and counseling.

Sincerely,

Margy Mayfield, RN, BSN

Executive Director, Coastal Kids Home Care

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A New Generation



Marci Alexander and Lewis Cantor have a special relationship. When she was diagnosed with Hodgkins Lymphoma at age twelve, he was her pediatrician. Determined to take excellent care of this fiery young girl, Dr. Cantor coordinated closely with her physicians at UCSF to provide her with chemotherapy treatments at his local office.

Back then, Coastal Kids Home Care was not an option. Instead, Marci’s life was filled with long hospital stays and drives to distant doctors. Dr. Cantor’s offer of local care was a relief for her and her parents, “I remember Dr. Cantor smiling and trying to keep things light. Dr. Cantor and the doctors at UCSF saved my life.”

Through her experience, Marci and Dr. Cantor became life-long friends. When he

reached out to ask if she would join the Board of Coastal Kids Home Care, she immediately agreed. “As a mother and survivor of childhood cancer and breast cancer – I want to do all that I can to help families get the help they need,” says Marci. “A huge help for kids and especially their parents is receiving care in their homes. The comfort and safety Coastal Kids provides, along with incredible medical and emotional care, fills my heart.”

When Dr. Cantor stepped down from his position as Board President in 2019, he left a legacy of compassionate care for children. Since then, the Board has welcomed six new members and elected new officers. This next generation of leaders brings a broad array of knowledge, experience and commitment to ensuring children have access to excellent home medical care well into the future.

A Grown-up Look

By now, you may have noticed that there is a new look for Coastal Kids Home Care. After 15 years, we are making some grown-up changes, including a logo that illustrates the complete circle of care:

HEART: The heart represents our compassionate home-based pediatric palliative care program. For children with life-limiting illness, home based pediatric palliative and end-of-life care combines excellent nursing care for the child with practical and emotional support for the whole family.

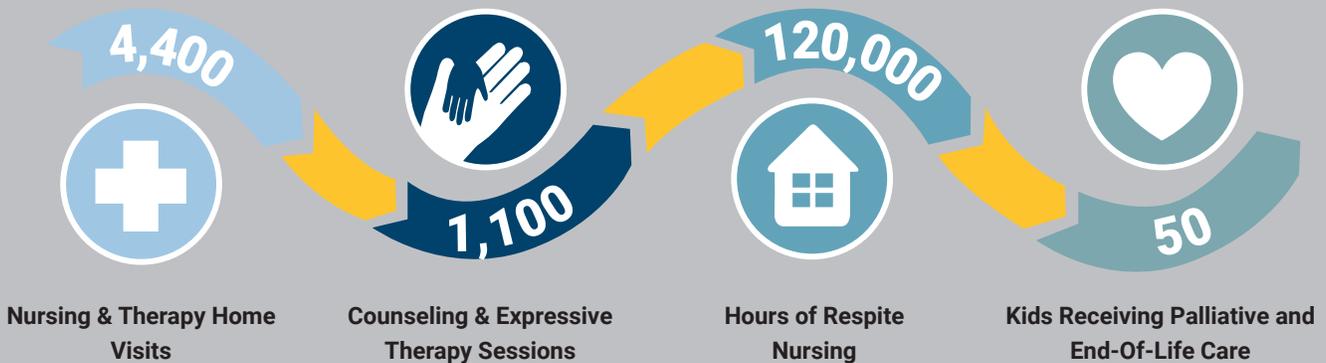
HOUSE: The house illustrates our new shift/respice nursing services. This program delivers skilled in-home medical care to children with medical complexity who require round-the-clock medication, equipment and healthcare monitoring, while offering valuable respice to their caregivers.

CROSS: The medical cross is emblematic of our pediatric home health services. These include skilled nursing, physical and occupational therapy for infants discharged from the NICU, children recovering from short term injury or illness, or those with serious-illness or medical complexity.

HANDS: The hands highlight our growing behavioral health services. Individual counseling is available to support children and their parents through the complex emotions of serious-illness and assist children and teens to cope with other mild to moderate behavioral health challenges.



each year coastal kids staff drive more than 150,000 miles caring for 600 kids at home



All Grown Up

At age 12, Lyla Hernandez has come a long way since she was diagnosed with acute lymphoblastic leukemia as a toddler. Today she has been cancer free for a decade. Back in 2009, however, her mom Noemi was overwhelmed with caring for a toddler with cancer and grateful to receive a referral to Coastal Kids Home Care for home nursing visits.

“Lyla was little and didn’t really know what was happening, but Margy and the nurses were so great and “hands-on,” Noemi recalls. “They let Lyla ‘help them’ which eased her way into all interactions with other medical providers throughout her illness.”

After a year of treatment, Lyla went into remission. When she hit the milestone of five-years cancer free, the Hernandez family threw a party and raised \$300 to support Coastal Kids Home Care. Over the years, Lyla and her family have stayed well connected to their nurses. In addition to attending Coastal Kids’ annual Touch-A-Truck event every year, the Hernandez family is always willing to help. A few years ago, Lyla and Margy were reunited at a cheerleading camp – Lyla was excited to see her favorite nurse again.

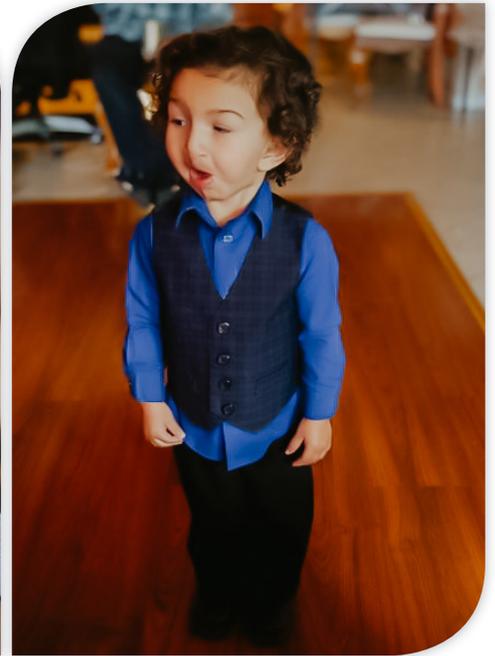
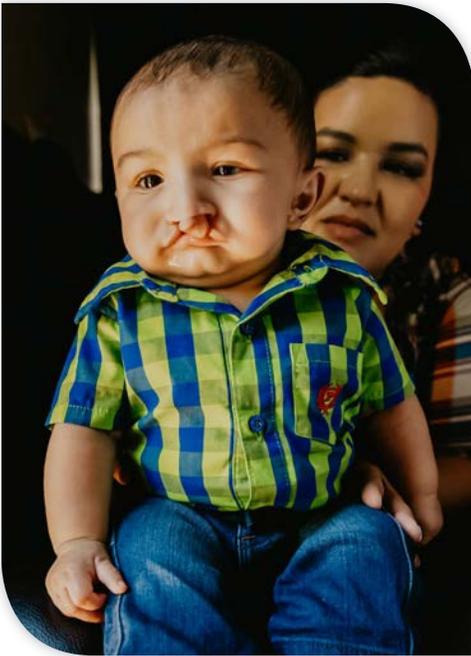
“Lyla has her own personality and when I asked her for permission to retell her story for this article she was thrilled,” said Noemi. “Margy was Lyla’s first nurse and to see where Coastal Kids Home Care is at right now is amazing. Margy holds a big space in our heart and we will never forget everything she and Coastal Kids did for us.”

Lyla is now ten years cancer free. Despite dire warnings about the after-effects of treatment on her development, she is thriving. Today, Lyla is excelling in middle school and doing well academically. She is a regular teenager with a passion for music, and art.

“The fact that Coastal Kids Home Care is a program that we have locally that keeps kids from going to the hospital every week for simple blood draws, or keeps kids from going to a hospital where they don’t specialize in kids, is amazing. It is such a help that alleviates a lot of added pressure and stress you don’t need when dealing with a sick child.”



Cultivating Care for Leo



Like many new moms, Leo's mom, Victoria, recalls her first year as a mom as "crazy". However, Victoria's first child was medically complex and it's no wonder she also describes it as "overwhelming". At birth, Leo was diagnosed with a cleft lip, cleft palate, and tetralogy of fallot--a rare condition caused by a combination of four heart defects that causes oxygen-poor blood to flow out of the heart and into the rest of the body.

"When Leo first came home from the hospital, it was very overwhelming to keep up with everything he needed," Victoria recalls. "I can honestly say I was not taking it day by day, I was literally taking it hour by hour." Shortly after birth he had his first heart surgery, followed by two more complex procedures and his cleft lip and palate repair. Weekly visits from Coastal Kids nurses, helped Victoria through the ups and downs of caring for her fragile infant.

"Nurse Kim would come and not only help with his medical needs, but also just be someone who would listen to me," Victoria says. "Confidence was not something that I had as a first time mom with a medically challenged kid. Kim always reassured me that I was doing the right thing and that was huge in helping me develop confidence as a mom."

Today, Leo is doing fantastic. In July he will be two and a half, and these days he is not only walking, he is running. Since his surgeries, he is now able to express himself much better and "talks a lot" according to mom. Leo loves counting, reading, and singing his ABC's.

"I wish my son was healthy enough to have never needed in-home nursing, but I am so grateful that Coastal Kids was there for him," says Victoria. "Coastal Kids helped me become the mom that I am and I am forever grateful for them."

A Community of Care in COVID-19



This March the advent of COVID-19 dramatically changed the way most Californians lived their daily lives. As essential healthcare workers, Coastal Kids Home Care staff were one exception. Nurses and physical therapists continued to provide essential care in the homes of our fragile patients utilizing enhanced cleaning and use of PPE to ensure their health and safety. Non-essential care continued through telehealth counseling and social work visits.

Although COVID-19 presented new challenges for some Coastal Kids families, many were all too accustomed to a life of social distancing. Caring for a child with serious-illness or long-term disability often means trips out of the house are rare, and social isolation is the norm. This is one reason access to exceptional care at home is treasured by these families and COVID-19 made these services even more vital.

During this unique time, local foundations went above and beyond to ensure services could continue apace. Nancy Buck Ransom Foundation and Pajaro Valley Community Health Trust made their current funding more flexible, while Community Foundation for Monterey County, Hospice Giving Foundation and Silicon Valley Community Foundation stepped in to provide relief funds to help with the purchase of laptops for remote work, a secure telehealth platform and essential PPE for our medical staff.

The broader community joined in too. The online campaign, "You Can't Quarantine Kindness" engaged talented kids to design t-shirts to raise critical awareness and nearly \$10,000 to support families in need during COVID-19. Individuals and businesses also stepped up to donate PPE and essential supplies for our families. Although it always takes a community to care for sick kids, in a global pandemic these words take on even greater meaning.



YOU CAN CONTRIBUTE TOO!

To donate visit our website at www.coastalkidshomecare.org or mail a check to

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

or to purchase merchandise go to www.bonfire.com/store/coastalkidshomecare

A Heartfelt Thank You...

Compassionate in-home care for children with illness and disability relies on the generosity of our community. Thank you to our 2019 donors:

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..... Looking Forward Together

Grieving the loss of a child can follow many paths, however, sharing the experience with other bereaved moms can make the journey a bit easier. Coastal Kids Home Care nurse, Robin Nacamuli, had this thought in mind when she encouraged three local moms to meet each other.

As a Pediatric Palliative Care nurse for Coastal Kids Home Care, Robin helped to care for their children in the last months, weeks and days of their lives. After watching each mother experience the loss of a child – thirteen year old Kayla unexpectedly from complications of Myotonic Dystrophy, seven-year-old Ziva from Leukemia and sixteen-year-old Calvin from a rare cancer – she sought to ease their grief.

“The only people who truly understand grief are those in your shoes,” says Nacamuli. “It wasn’t anything formal I was trying to create, I just wanted to introduce these moms so that they felt supported by each other.”

The informal group met once for dinner and a long walk on the beach, and then COVID-19 hit. The opportunity to laugh and cry with other bereaved moms offered a healthy outlet for their grief. While today they are social-distancing, they look forward to seeing each other again soon.





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



You're Invited! Join these initiatives benefiting Coastal Kids Home Care

NO Touch-A-Truck – Autumn 2020

In these unprecedented times, we have decided to reimagine our seventh annual Touch-A-Truck. Recognizing the challenges of COVID-19, this year we will bring Touch-A-Truck to our pediatric patients through a Cruisin' for Coastal Kids parade.

Holiday Gift Program – December 2020

The holidays are a special time at Coastal Kids Home Care. Each year, our community comes together to share holiday joy to the families we serve. If you would like to donate or volunteer please reach out to Outreach Specialist, Cassie Jimenez, at cwaggy@coastalkidshomecare.org!



www.coastalkidshomecare.org

Capital Campaign Launch – Autumn 2020

Coastal Kids Home Care is all grown up and is ready to send the message to kids with illness and disability that we are here to stay. Watch your mail and email for more information on how you can contribute to a new facility dedicated to home-based medical care for kids.

Coastal Kids Home Care Merchandise – All Year Round

Visit our online store at www.bonfire.com/store/coastalkidshomecare to browse dozens of creative t-shirt and sweatshirt designs highlighting essential home medical care for children living with illness and disability. Proceeds from your purchase will support Coastal Kids services year round.

For more information, visit our website at coastalkidshomecare.org/events