

STORYBOOK

A Publication of Coastal Kids Home Care

Spring 2021

Grit: (n): Determination and courage; Strength of character.

Today, Niko Macias is in remission. Through a year when most people were focused on COVID-19, Niko's family was preoccupied with another difficult disease. In August 2019, Niko was diagnosed with Ewing's Sarcoma, a soft tissue cancer that was causing pain in his hip joint. The journey that followed involved painful surgery, difficult chemotherapy treatments and months relearning how to walk. Through it all, Niko exhibited grit and optimism.

"Regardless of what Niko was going through, he was always sunshine when I walked through that door." Coastal Kids nurse Kimberly Jimenez Hell was unaccustomed to being greeted with such enthusiasm by her pediatric patients. "Kids are usually a bit scared to see their nurse, but not Niko, he was always happy to see me."

Niko's exuberance spilled over into his physical therapy too. When Coastal Kids physical therapist Trish Krall first met Niko, he was walking less than ten feet with the support of a walker. Nine months later he was doing karate, having dance parties with his brother Andres and riding his bike around the neighborhood. Trish was impressed by his fun approach to therapy, "Niko was always excited to see what games or activities we were going to play, his favorite was Silly Walks -- he saw it as a game, but we were training strength, endurance and balance."

Nurse Kim stayed connected to Niko throughout his treatment as well, providing port blood draws and chemotherapy injections that kept him safe and healthy at home. In fact, for Niko's family the stay-at-home order was a blessing in disguise. The opportunity to work and learn from home provided the time and space they needed to help their young son to recover his health and regain strength and



mobility under the guidance of Coastal Kids Home Care.

According to Niko's mom, "Having a resource like Coastal Kids was a life-saver. Knowing we could request lab orders and certain treatments at home was really helpful. The services provided by Coastal Kids relieved the stress of a difficult time. Kim and Trish always listened to Niko and made him feel important and they made Andres feel special too. Niko is now a cancer survivor and Coastal Kids was a big part of helping him to get there." Although Kim and Trish miss seeing Niko weekly, they both are excited to see what the future holds for this determined optimist.

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

Grace: (n):
Determination and courage; Strength of character.

p3

Gratitude (n):
feeling or showing an appreciation of kindness; thankful;

p3

Growth (n):
Increase, as in size, number, value, or strength;

p4-5

**grit,
grace and
growing
up**

p6



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Reflections on a year of grit, grace, gratitude and growth



Letter from the Executive Director

As we look back on this landmark year and seek to honor the experiences of patients, families, staff, volunteers and donors - three words seemed to capture the essence of our experience - **grit, grace and gratitude**. In the following pages you will see how through embracing these values (and with a little help from YOU and our compassionate providers) families caring for children with health and mental health challenges thrived during 2020.

Your donations supported a 60% increase in shift nursing and a fivefold increase in home-based palliative care as parents sought a safe alternative to overburdened hospitals. Counselors responded to a 40% increase in referrals from families concerned about their children's mental health. And in response to rising demand for bereavement care, Coastal Kids has incorporated adult and youth support groups into our programming.

Thus, a fourth word - **growth** - is the inevitable result of increasing demand for these vital services. Fortunately, Central California Alliance for Health and a community of donors from the Salinas Valley to Silicon Valley have stepped up to help us purchase and renovate a facility for children's health and mental health care. Read on to enjoy stories of the grit, grace, gratitude and growth of Niko, Cataleya, Kepler, Keyla and Leyla, their parents and caregivers, and YOU, our generous donors.

Sincerely,



Margy Mayfield, RN, BSN
Executive Director, Coastal Kids Home Care

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RODGER'S CENTER FOR CHILDREN'S HEALTH

A grant of \$1.2M from Central California Alliance for Health initiated an effort to purchase and renovate a building to give our compassionate staff a place to respond to the health and mental health needs of our communities' children. Generous donors like T.J. and Valeta Rodgers (\$300,000) and the Sally Hughes Church Foundation (\$200,000) among others stepped in to make the **Rodgers Center for Children's Health** a reality. In March of 2021, just a year after the stay-at-home order took effect, Coastal Kids Home Care moved into a permanent home at 427 Pajaro Street in Salinas. Stay tuned for information on our upcoming grand-opening.



Grace: (n): kindness which benefits or serves another.



Kepler Otero exemplifies grace. At just six years old, his bright smile and bubbling laugh, are memorable to all who meet him. His joy filled approach to life is perhaps even more amazing since his six years have been filled with greater challenges than most will experience in a lifetime. Born with CHARGE Syndrome, a rare genetic condition that affects his hearing, vision, balance, coordination and ability to eat

and breathe safely, Kepler underwent multiple surgeries in the first fragile years of his life. Today, although he relies on a tracheostomy to breathe and g-tube for nutrition, these are minor obstacles in his quest to learn and have fun.

Kepler's Coastal Kids shift nurse, Marta Escobar, LVN, is there to pave the way for this bright and talented young boy, "He is a very verbal little kid, and there are a thousand

funny stories about him," laughs Marta. "He knows how to communicate what he wants and every single day is a different adventure with him." Marta is with him 40 hours each week, providing the skilled medical care he needs to boldly live his life. Soon, Marta and Kepler will be off on a new adventure together - returning to in-person elementary school.

Kepler's parents, Margarita and Manuel, are grateful that Marta will be able to join him when he goes back to the classroom. "Kepler loves Marta. It is so nice to know that they have that special bond because when something is wrong, he feels comfortable letting her know. We love having her there for him." Having a trusted caregiver brings incredible peace of mind. Manuel also wanted to share a message for other special needs parents, "I am more than happy to share our story, I know what it is like to have a child with a condition that isn't commonly heard of. If there is a family out there going through something like this for the first time, I hope they see this story and know that they are not alone." It is clear that grace runs in the family.

Gratitude (n): Showing an appreciation of kindness; thankful.

They are an adorable duo. With rhyming names and matching pigtails, two year old twins Keyla and Leyla elicit "oohs" and "aahs" wherever they go. However, like most of us, they have been isolated at home throughout the pandemic. For their mom, Reyna, this posed a unique challenge. With her toddler twins at a critical stage of development the lack of access to early intervention services at home had her worried about their progress.

Born early at 30 weeks gestation, Keyla was less than four pounds and Leyla less than two pounds. The more fragile twin, Leyla, had a heart condition that required surgery last summer. Afterward, Coastal Kids physical therapist, Patricia Krall did an evaluation to monitor her progress toward gross motor milestones. At that visit, mom observed that Keyla was behind as well. One week

later, Trish evaluated the second sister.

This spring, both twins are progressing beautifully. When Trish first started, they were crawling, but not yet pulling to stand or cruising on furniture. Now, Keyla is taking five independent steps and Leyla is getting comfortable walking while holding on to her mom's



hands. Trish delights in working with the girls, "I've been really impressed with how receptive mom is with any suggestions, and her follow through is excellent."

The feeling is mutual. For mom, having a physical therapist come to her home, while the twins' other services are taking place via zoom, has made an enormous difference. "They see [Trish] in the window and they get so excited. They love working with her. Of all their therapists, they definitely love her the most." Meanwhile Trish is grateful to be providing safe, nurturing physical therapy to the twins, while Keyla and Leyla's smiles clearly show how grateful they are to have Trish in their life.

Growth (n): Increase, as in size, number, value, or strength.

In 2005, Margy Mayfield co-founded Coastal Kids Home Care with a vision of bringing excellent pediatric home health care to children and vital support to families in crisis. Over the past sixteen years, as the organization weathered difficult times, Margy maintained this steadfast focus and Coastal Kids Home Care has never turned a child in need away. Thanks to her leadership, the perseverance of our compassionate staff, the support of our dedicated Board of Directors and the generosity of our community of donors, Coastal Kids Home Care is here today to provide in-home health and mental health care to our community's most vulnerable children. In a year of difficulty for many, Coastal Kids Home Care experienced unprecedented growth.

SIZE

From a start-up with two nurses, Coastal Kids Home Care now employs more than 90 nurses and clinicians caring for 700 children living with illness and disability each year. As the only pediatric agency serving four south bay and central coast counties, demand for our vital health and mental health services continues to grow. In 2020, while the world sheltered at home, our nurses added PPE to their routine and cared for our communities' most fragile children, social workers helped newly unemployed parents access food and financial resources and licensed counselors responded to an increase in demand for counseling.



NUMBER

Amid chaos in the world, our team continued to bring excellent care to families in crisis. As families sought a safe haven from hospitals, Coastal Kids home-based palliative care program welcomed 45 new children with life-limiting conditions, while also expanding in-home shift care hours for children with round-the-clock medical needs to by over 40%. In addition, children and teens impacted by the isolation of learning from home reached out for mental health counseling in greater numbers and families affected by loss due to COVID sought bereavement care.

GROWTH BY THE NUMBERS

	2018	2019	2020
# OF CHILDREN SERVED	608	603	660
# OF PATIENTS ON PALLIATIVE CARE PROGRAM	9	9	54
# OF CLINICAL HOME VISITS	3,860	4,452	5,503
# OF SHIFT NURSING HOURS	11,568	28,832	49,472
# OF MENTAL HEALTH COUNSELING CLIENTS	58	60	104
# OF MENTAL HEALTH COUNSELING SESSIONS	419	520	703

VALUE

A hallmark of recent growth has been deepening services to families caring for medically fragile children at home. Recognizing that families are the primary source of care, Coastal Kids has identified ways to relieve the immense burden of caregiving through offering shift nursing, expressive therapies, social work support and counseling to more families than ever before. High-quality in-home care leads to better health outcomes for children and greater quality of life for families at a fraction of the cost of hospital or institution-based care. Now that is value.



STRENGTH

In 2021, Coastal Kids Home Care is stronger than ever. In addition to a new facility, long-time staff are stepping into full-time leadership roles.

LEADERSHIP TEAM

Margy Mayfield, RN, BSN – Executive Director

Maria Ceja, MA – Director of Finance

Ruth Shapiro, LCSW – Director of Palliative Care

Kimberly Hell, RN – Director of Visit Nursing

Robin Nacamuli, RN – Director of Shift Nursing

Kelli Mullen Brown, MA – Director of Development

With access to critical new office space, the administrative, billing and development teams expanded as well, ensuring the organization continues to have strong systems in place to secure vital services for vulnerable children. Finally, a dynamic Board of Directors, including 6 new members over the past two years will take the lead in governance, strategic planning and financial oversight. This strong team will enable children with health and mental health issues to thrive while offering parents the knowledge and confidence to help their children to heal, or live well, where they most want to be – at home.



Growing Bereavement Care Together

As our community copes with incredible loss, families are increasingly reaching out for help. Beginning in January of 2021, Coastal Kids Home Care took over community bereavement services from Papillon Center for Loss and Transition. The Madison Rose Memorial Library will have a new home at the Rodgers Center for Children's Health in Salinas and Adult Drop-in Groups will continue uninterrupted via zoom. Coastal Kids Home Care will ensure the sustainability of these

services in Monterey County, while also offering one on one bilingual counseling to grieving children and expanding the Good Grief for Kids + Teens programs to include more comprehensive services.

Going forward, the addition of bereavement resources will complement Coastal Kids palliative care and counseling programs, while expanding the reach of these vital services at a time when our community needs them most. Long-time Papillon supporters can continue to support quality bereavement care for children, teens and adults through contributing to our bereavement fund. Please visit www.coastalkidshomecare.org/counseling or mark "bereavement care" on the enclosed envelope. Thank you for bringing healing to individuals experiencing loss.

Grit, Grace and Growing Up

Bringing a medically-fragile infant home from the hospital during a global pandemic takes a village. Born in September of 2019, baby Cataleya was just 600 grams (1.3 pounds) and could fit in the palm of her mom's hand. Nearly eight months later in April of 2020 under the threat of COVID-19, doctors at Stanford Children's Hospital knew the safest place for Cataleya was at home. However, with a ventilator, tracheostomy care, suctioning, g-tube feeds and daily medications to monitor caring for her at home would be a formidable challenge. While her mom Maria was an excellent caregiver, she could not care for her fragile daughter alone.



Thus, Cataleya's family was referred to Coastal Kids Home Care, where Margy Mayfield found several nurses with pediatric experience who lived near the family and were excited to provide in-home care. Even so, for mom leaving the hospital was scary, "On the one hand, we were thrilled that [Cataleya] was finally getting to come home; but on the other hand we were terrified to bring her home in the middle of a pandemic," says mom. "However, between the hospital and Coastal Kids, they all assured us that this was the best decision because it would minimize Cataleya's risk of contracting the virus. I am so happy we made that decision."

Since then, Cataleya's nurses Maribel, LVN and Rashelle, RN have become essential to her family, "I wasn't aware that there were so many kids that needed help," Maribel explains.

"It's awesome that parents are able to bring their kids home and have some type of 'normalcy' where they are able to have their family together and not go to the hospital everyday. And personally, I love working for Coastal Kids. It's a lot of teamwork to reach Cataleya's goal of no longer needing us and I am grateful that we are all on the same page."

Today, Cataleya is almost 19 pounds, she is gaining strength and reaching critical milestones. Her parents are starting to take a sigh of relief. Just the other day they went to the grocery store together, something they have not done in more than eighteen months. Cataleya is getting out more too. Maribel has begun to take her on walks in her stroller, "Because of the virus, we were scared to take her anywhere," nurse Maribel explains. "She would really only go out for appointments, so now we go for walks in the stroller and are working on just getting used to sunlight and being outside."

As sweet little Cataleya becomes accustomed to sunshine, we are all beginning to see the light at the end of the COVID-19 tunnel. Fortunately, with or without a pandemic, Coastal Kids Home Care nurses like Maribel and Rashelle, are here to support families caring for medically-fragile kids at home. For this compassionate team of caregivers, grit, grace and gratitude are both essential job skills and every day values -- after all it takes a village to care for special kids like Cataleya.

In Humble Gratitude

Tribute donations to Coastal Kids Home Care hold a special place in our heart. These gifts not only convey sympathy to the bereaved, but also commemorate the life of a loved one. Early this year our long-time Board Member, Grace Feldeisen, honored us with donations in memory of her son, Joey. Not long after three families of sweet girls that Coastal Kids cared for at the end-of-life asked their friends and families to support home health care to other medically fragile children through donations to Coastal Kids. It is with humble gratitude that our compassionate team accepts these generous gifts. A heartfelt thank you to all of the friends and families of Coastal Kids Home Care who, while facing their own devastating loss, offer hope to other families caring for vulnerable children at home.

*Gratitude is
the memory of
the heart.*

- French proverb

With Sincere Appreciation for Our Donors

Compassionate in-home care for children with illness and disability relies on the generosity of our community. Thank you to our 2020 donors:

Circle of Gratitude (\$100,000+)

Central California Alliance for Health
Sally Hughes Church Foundation
T.J. and Valeta Rodgers

Circle of Compassion (\$50,000+)

Broadway Bingo
Caroline's Non-Profit Thrift Shop
Hospice Giving Foundation

Circle of Grace (\$20,000+)

Community Foundation for Monterey County
Community Foundation Santa Cruz County
Don and Barbara Chapin Foundation

Harden Foundation
Kaiser Permanente
Maryles Casto
Monterey Peninsula Foundation
Salinas Valley Memorial Healthcare System
Silicon Valley Community Foundation

Circle of Courage (\$10,000+)

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Joanne Shapiro
Nancy Buck Ransom Foundation

Pajaro Valley Health Trust
Steffanie and Andy Smith
The Nicholson Family Foundation

Circle of Promise (\$5000+)

Barnet Segal Charitable Trust
Dale and Katherine Handley
Dunspaugh-Dalton Foundation
Harry A. Merlo Foundation
Richard William Greenberg Foundation
Vicki and Gordon Rosenberg

To see more 2020 donors visit | www.coastalkidshomecare.org/donors

Finding Grace in Shared Loss

When Stephanie Gonzalez joined Coastal Kids Home Care in July of 2019, she knew her job as a social worker would be challenging. Yet she had no clue what 2020 would bring, and that when tragedy struck her own family, her experience would help her to relate to her pediatric clients.

One family that Stephanie helped was a mother and her fifteen-year-old son Alex.* Living with renal failure, the mother was concerned about her son's ability to cope with her serious-illness. Then in November, Stephanie received a frantic text from Alex's mother. She'd been admitted to the ICU after testing positive for COVID-19. She was being intubated and wanted Stephanie to prepare her son for the worst-case scenario. Stephanie agreed to help.

Alex's mother died the next day. Through it all, Stephanie provided support. She met with the teenager outside at a picnic table where they played with slime and talked through his experiences. Tragically, Stephanie would soon experience her own devastating loss.



OFELIA AND STEPHANIE

In late December she arrived home to find her mother, Ofelia, unresponsive. Stephanie performed CPR and awaited the ambulance. Ofelia was life-flighted to one hospital, only to learn that she could not be treated because she had tested positive for COVID-19. Instead, she was transferred to UCSF where doctors explained to Stephanie and her family that their mother had suffered multiple aneurysms. A few days later Ofelia died in the hospital. Like Alex, Stephanie was unable to say good-bye to her mother.

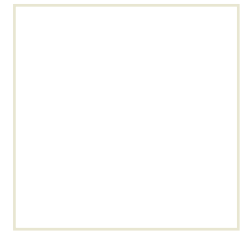
When Stephanie returned to work, she found that in a bittersweet way her experience of shared loss was a benefit in

serving clients like Alex. "I saw in him a lot of withdrawal," said Stephanie, "So sharing that I knew what it was like to lose a mom allowed us to reconnect." Brave individuals like Stephanie, are the true heroes of the pandemic. Through telling her story, we seek to honor the many loved ones lost during this difficult year. For more information on Coastal Kids bereavement care please visit www.coastalkidshomecare.org/counseling or call **800-214-5439**.

*names are changed to protect the identity of the minor patient.



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Join Our Community of Care

Share – Are you the parent or grandparent of a Coastal Kid who would like to share their story with us? We'd love to hear from you! Reach out via Facebook, Instagram or email Cassie Jimenez at cwaggy@coastalkidshomecare.org.

Participate – Have you, or a child close to you, recently lost a loved one? Bereavement groups for adults are meeting via zoom, and Good Grief for Kids + Teens will be starting soon. Email Ruth Shapiro at remerson@coastalkidshomecare.org for more information.

Contribute – Bring care home to children with illness and disability through contributing to Coastal Kids. Become a monthly donor at www.coastalkidshomecare.org/donate or return the enclosed envelope and guarantee excellent care for kids year-round.

Promote – Is there someone in your life who has shown grit, grace or gratitude during the past year? We have a shirt for that! Buy Coastal Kids merchandise at www.bonfire.com/coastalkidshomecare and let the world know that you value quality care for kids.



www.coastalkidshomecare.org