

# The Californian

LOCAL

## Salinas cafe spills the beans on rare diseases in heartfelt promo

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Proceeds from the sale of Cinnacloud for a Cause, a special cold brew drink at Castle Rock Cafe & Mercantile during February will go to support Coastal Kids Home Care as part of the agency's Rare disease Month Awareness campaign.

Provided By Coastal Kids Home Care

Escaping the brisk, morning chill on Monday, a steady stream of customers head into the Castle Rock Cafe & Mercantile on Highway 68 in Salinas.

The cafe is a popular stop on the way to nearby Laguna Seca Raceway or the trailheads at Toro County Park and Fort Ord National Monument.

Inside the cozy spot, folks were chatting, and baristas are serving up a selection of classic espresso drinks, the perfect start to a no stress, leisurely President's Day.

This month, in addition to the usual lattes and teas, the menu includes a special drink, Cinnacloud for a Cause, a cold brew topped with a cinnamon, coconut, and vanilla cloud foam.

A portion of the drink's sale proceeds are going to support Coastal Kids Home Care, California's only non-profit pediatric home health agency serving Northern California during the month of February, which is Rare Disease Month.

The agency, which has a home-base in Salinas and a satellite office in San Jose, launched the "We Care for Rare" awareness campaign to shed light on conditions that affect more than 30 million people in the United States according to the Food and Drug Administration (FDA), with more than half of those children.

"It's a hidden giant group of diagnosis that not a lot of people understand," said Coastal Kids Home Care Executive Director, Margy Mayfield.

The agency's campaign, which involves local businesses like the Castle Rock Cafe & Mercantile, Old Republic Title Company and schools, aims to highlight the challenges faced by children and their families and raise money to help them continue providing care to those who need it most.

About 75% of the pediatric patients that Coastal Kids Home Care serve each year live with a rare disease, according to the agency.

Nichole Wright, owner of Castle Rock Cafe & Mercantile, said she was drawn to the awareness campaign, dubbed "Special Beans for Rare Genes," because when she was growing up her best friend had cystic fibrosis.

"I saw the struggle her parents had to go through to take care of her," Wright said. "There were a lot of missed work days — missed school days."

Her friend died at the age of 14, and Wright said she remembers the feelings of unbelievable loss and strain for the family.

Now a mother herself, she said she appreciated the opportunity to give back to the community and help families undergoing similar challenges as those of her late friend.

Ada's Cafe in Palo Alto, a nonprofit known for empowering individuals with disabilities through employment, is also donating proceeds from every coffee sold in February to Coastal Kids Home Care.

This year, Sacred Heart School in Salinas and Old Republic Title Company are joining in on the awareness campaign by "wearing jeans for genes" on select days of the month.

### Only about 5% of nearly 10,000 identified rare diseases have FDA-approved treatments

While millions of Americans have a rare disease, only about 5% of the nearly 10,000 identified rare diseases have Food and Drug Administration (FDA) -approved treatments, according to the U.S. Government Accountability Office.

Developing rare disease drugs is challenging, according to the FDA, which operates 18 rare disease programs to address such complexities, as the diseases are not well understood, and the small patient populations can limit clinical trials.

"You do not hear much about it, but there is a lot of research going on behind the scenes because it affects so many people, it's just very quiet," Mayfield said.

Recent moves by the Trump Administration to cut federal funding for medical research spurred a multi-state lawsuit that includes California and left many in the medical community worried of its impacts to life-saving patient care.

Because of improved medical treatments, the median life expectancy for a person with cystic fibrosis, a genetic condition that impacts an estimated 30,000 children and adults has risen, but there is still no known cure.

### Rare diseases are prevalent, but often go under the radar

While rare diseases and genetic disorders are more prevalent in the population than one may think, they often go under the radar, Mayfield said.

Any disease or condition affecting fewer than 200,000 people in the United States is rare, according to the National Organization of Rare Disorders, and all pediatric cancers are considered rare.

Mayfield, who worked as a pediatric nurse before starting Coastal Kids Home Care in 2005, said some of the conditions she has come across in the over 20 years she has been practicing are so rare they are referred to only as a sequence of numbers and letters.

"We have gotten incredibly sophisticated in our medical technology that we can break down a disease to the gene," said Mayfield, adding that families impacted by a genetic diagnosis have to become expert in the science behind it.

Most rare diseases are genetic, according to Rare Diseases International, and many are chronically debilitating, progressive, and life-threatening.

Some of the children that Coastal Kids Home Care serves are living with conditions that make it difficult or impossible for them to breathe or eat on their own, others are at end-of-life.

"We just need to take care of those people who need a little extra help in life," Mayfield said. "They know they are different, and they bring us so much joy — they are strong, feisty kids."



Emma Zepeda with mom Iliana. Emma is a client of Coastal Kids Home Care and has Hypoplastic Left Heart Syndrome, a congenital heart defect that occurs when part of the heart does not develop correctly as it should during the first 8 weeks of pregnancy.

Provided By Coastal Kids Home Care