

# TimesOC

SUNDAY, MAY 10, 2020 /// Times Community News publication serving Orange County /// [timesoc.com](http://timesoc.com)



## A mother writes a memoir about 16 challenging, yet joyful, years of 'LOVING TIARA'

BY ALIESE MUHONEN

**T**wenty years ago, the Daily Pilot ran a story for Mother's Day about Costa Mesa resident Tiffani Goff and her then 18-month-old daughter, Tiara.

Even as a toddler, the characteristics that would define Tiara throughout her life were evident: her springy curls, wide hazel eyes and vivacious personality, which charmed everyone around her.

Yet the challenges Tiara faced — and that Tiffani faced in caring for her — were only beginning to become clear. Daily seizures impeded Tiara's development, erasing basic abilities she had learned and limiting progress she tried to make.

Gone was her ability to clap her hands, and her walking and balance skills varied by the day. Both Tiffani and Tiara's lives were consumed with doctor's appointments, medical procedures and endless therapy sessions.

"For a couple months, I'll forget she's sick," Tiffani told the reporter. "The next day, she's back in the hospital."

The article profiled Tiffani's reality: caring for a child with an incurable genetic disorder, severe disabilities and a shortened lifespan.

It was a story with an ending yet to be seen — one that Tiffani hoped wouldn't come too soon.

Tiffani's days were punctuated by heartache and question marks. Would Tiara live past infancy? And if so, would she have a normal life? Or at least a happy one?

The answers lie in "Loving Tiara," Tiffani's memoir published in November 2019.

Inspired by her popular eponymous blog, in which she chronicled the joys and challenges of her family's lives, "Loving Tiara" is as much a love letter to families raising children with disabilities as it is a tribute to a daughter gone too soon.

The memoir provides a portrait of parental love and endurance taken to its limits, as well as humorous vignettes of the Goffs' daily struggle for normalcy.

They found it helpful to focus on what their daughter could do, instead of what she would never be capable of.

Tiara's ability to learn and recover consistently surprised her family and physicians. Not only could she walk, but she sunk basketballs over and over through the hoop in her backyard — one of her favorite pastimes — and could speak in short sentences.

"And she brought so much joy," Tiffani added. "I don't know if I did a good job of conveying that in the book, but she was funny. Like, so funny."

With Tiara, there was always color, liveliness and loudness. She knew every scene in her favorite movie, "Legally Blonde," and enveloped her parents and sisters in bear hugs when they walked through the front door. She modeled clothes and jewelry, danced to music and enthusiastically celebrated at every party



Tiffani Goff's story first appeared in the Daily Pilot 20 years ago for a Mother's Day story about taking care of then-18-month-old Tiara, who had tuberous sclerosis complex (TSC).

Courtesy of Tiffani Goff

**TOP PHOTO: TIFFANI GOFF** recently celebrated her 50th birthday by self-publishing a memoir about her late daughter Tiara, who was diagnosed with a rare medical condition and died about 5 years ago at age 16.

Kevin Chang | Staff Photographer

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# Union leader cares for son, fears for her workers

COVID-19 has hit home for Ada Briceño, whose son was recently infected with coronavirus.

BY VERA CASTANEDA

From the confines of her living room in Stanton, Ada Briceño watched the pandemic take a toll on the lives and daily routines of her family, colleagues and the 32,000 workers represented by Unite Here Local 11.

Briceño, the co-president of Unite Here Local 11 and the chair of the Orange County Democratic Party, was already sheltering in place for about a week with her family when her 20-year-old son Donald Torres woke her in the middle of the night.

Torres had chills. She initially thought nothing of it, and he went back to bed.

"It hit me like a truck. One moment, I was relaxing and the other I was shaking uncontrollably and feeling really terrible," Torres said.

By the next day, he developed body aches and a high fever.

"I got scared. I knew at that moment that it was COVID-19," Briceño said.

The uncertainty of whether her son would live or die made the last two weeks of March seem like a year.

Torres was turned away from a coronavirus testing center, even though a St. Jude Medical Center doctor said he thought Torres was infected and recommended he get tested.

At the time, many centers were limiting tests to those experiencing shortness of breath.

That symptom never



Photo by James Carbone

**ADA BRICEÑO**, the co-president for Unite Here Local 11 union, speaks to Spanish-speaking hotel employees during a "ballot party" in February. Local 11 represents hospitality workers across Arizona, Los Angeles County and Orange County.

took a hold of Torres. Instead, he experienced hallucinations and headaches that felt like his brain was being squeezed. Briceño said he would be drenched in sweat every single day. She would go into his room and find water droplets on the walls from condensation.

Their household turned into a self-isolation waiting game for about a month.

Torres, who lost about 16 pounds from loss of appetite, was confined to his bedroom.

Briceño, who spent the

most amount of time caring for her son, isolated herself in the living room. Her husband, who is immunocompromised, stayed in another bedroom and took over the kitchen, including prep-meal duty for the entire family.

After a week, Torres' symptoms started to ease, and Briceño was able to make a few Zoom calls for work.

"That was the most difficult call I've ever done, because I wanted to make sure that the people who counted on me still had a

voice, but it was so hard because I was in the deep of it," she said. "I watched my union crumble down in front of my eyes in a week."

Local 11 represents hospitality workers across Arizona, Los Angeles County and Orange County — namely large employers like Anaheim Convention Center, Disneyland and Hilton hotels.

Union Communications Director Rachel Sulkes estimates 90% of the workers at hotels, casinos, airports and stadiums have been laid off due to the pandemic.

Since dues from their members dried up, the union also furloughed 51 out of 110 of their staff members.

Local 11 organized mass food distributions and helped union members apply for unemployment benefits.

The most recent initiative, "Serving Our Community," is in partnership with the Hospitality Training Academy of Los Angeles. The academy is using its resources to coordinate the preparation and delivery of meals to populations af-

ected by the coronavirus through a contract awarded by the state.

Some Local 11 members are working at the University of Southern California's kitchen, to provide meals for the surrounding at-risk senior citizens.

"They know how to churn out thousands of meals safely, quickly and reliably," Sulkes said. "We think it's the safest way to also put workers back to work."

She added that the union and the academy are working to bring a similar setup to Orange County.

"I try to find the silver lining in everything that happens," Briceño said. "I just got this passion that I feel right now toward this issue and making sure that our elected officials are doing everything possible to protect people like my family."

Briceño continues to have a dialogue with city council and school board members about their responses to the pandemic including rent moratorium, creating plans to reopen and petitioning to provide protective supplies to essential workers.

As for her son, he recovered and is a few weeks away from finishing an online class at Cypress College.

"This is real; it's not a lie," Briceño said. "That's why I'm sharing my story."

"We've got to stay in place right now — that's most important if we want to save lives," she added, referring to the beach protests and reopening plans. "And unfortunately I'm worried about people rushing into things."

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## Jamboree Housing continues fight against homelessness

BY BEN BRAZIL

Despite numerous obstacles posed by the COVID-19 pandemic, Jamboree Housing Corp. is continuing to develop affordable and permanent supportive housing throughout Orange County.

The Irvine-based nonprofit, currently in its 30th year, recently started construction on an affordable housing complex that it's been trying to develop on Manchester Avenue in Anaheim for more than a decade. It will include units for 102 families, 20 of which will be for the formerly homeless.

The group also just closed on an Econo Lodge motel in Anaheim that will be converted to 69 units of affordable housing for veterans, the mentally ill and the formerly homeless. The property is the first of its kind in Anaheim since the city passed an ordinance last year allowing motels and other commercial and office structures to be converted to affordable housing.

Both properties will play a crucial role in Orange County's goal to alleviate homelessness and add 2,700 permanent supportive housing units over the next five years.

With its 35 Orange County properties and more than 2,817 living

units, Jamboree has been on the front lines of that movement, especially over the last few years since several shelters were built in response to a lawsuit filed by homelessness advocates that attempted to stop the eviction of homeless individuals at a Santa Ana Riverbed encampment.

"In Orange County, we have played a key role and continue to play a key role because permanent supportive housing is the only proven strategy for ending homelessness," said Jamboree President Laura Archuleta. "Shelters are an interim fix, like a Band-Aid. Permanent supportive housing is the cure."

Due to the pandemic, Jamboree has had to cut back the residential support services it offers. These include school learning centers and other guidance for residents looking to get back on their feet.

The Manchester project is moving forward because funding had been secured prior to the pandemic. Construction workers have been equipped with masks and are distanced from each other while working.

Jamboree is also partnering with Orange County United Way to make sure renters have the means to purchase groceries. The nonprofit also kicked off a fundraising effort for rental

assistance for its tenants.

"The majority of our residents work in lower-income jobs," Archuleta said. "A lot of those jobs have been impacted, so our residents have been laid off or hours have been cut. We do anticipate that in May or June, we are going to have a higher percentage of families who cannot pay their rent. We are committed to deferring that rent and having them pay that back over time once they get back on their feet."

Like most nonprofits, Jamboree has been hit hard by the pandemic economy, but its decades-long tenure exemplifies tenacity and growth.

In its infancy, Jamboree's sole goal was to develop affordable housing in Irvine. Now with an office in Sacramento, the nonprofit has since developed more than 90 affordable housing and permanent supportive housing facilities throughout California, and it is now the second-largest nonprofit builder of quality affordable housing in California.

About 15 years ago, the organization started offering its resident services programs, and about 10 years ago Jamboree began focusing on providing housing to the formerly homeless and mentally ill. A flagship technique for Jamboree has been dedicating about 10%



Juan Tallo | Jamboree Housing Corp.

**JAMBOREE HOUSING** Corp. offers residents child learning services, though many of the residential services have been cut back for safety during the coronavirus crisis.

of a facility's units for those living with chronic mental illness.

"Jamboree is 30 years of building for good," Archuleta said.

Jamboree has properties in Brea, Fullerton, Orange, Anaheim, Santa Ana, La Palma, Garden Grove, Huntington Beach, Laguna Beach, Irvine, San Clemente and Mission Viejo.

Jamboree is currently developing five properties in Orange County with 1,187 units.

For every property, Jamboree partners with other nonprofits for the resident resource services it offers. For the Manchester facility, the nonprofit is partnering with Head Start and the Child Guidance Center, which aims to foster good mental health in children.

According to the Kennedy Commission, Orange County needs 111,996 more affordable rental homes for low-income households to meet the current housing demand. There are 6,860

homeless individuals in the county, according to the 2019 Point-In-Time count, which is the most current.

"Half of the homeless in Orange County are just economically homeless and cannot afford a home," Archuleta said. "We need to be creating housing for those folks to be able to move into ... The shelters were one way to quickly get folks off of the riverbed and into shelter. But then it's

See **Housing**, page R3

## Fountain Valley storyteller's online videos keep children engaged

BY BEN BRAZIL

With schools and libraries closed due to the COVID-19 pandemic, Penny Runyan is hoping to keep children engaged with reading with online storytelling videos filmed out of her Fountain Valley garage.

Using professional film lighting, cameras and a green screen, Runyan and her husband Ron Fenley have spent weeks shooting and editing videos of popular children's books, as a resource for parents and teachers trying to keep kids focused on learning.

The videos are a return to form for Runyan, who was a popular storyteller at the Huntington Beach Central Library from 1998 to 2006.

For the videos, Runyan goes by the moniker "Miss Penny," the name she used during her run at the li-



Scott Smeltzer | Staff Photographer

**PENNY RUNYAN**, a former storyteller at the Huntington Beach Central Library, is now producing and filming storytime videos at her home in Fountain Valley.

brary. "I want to encourage all children to read," Runyan said. "I want them to love books, and if they become readers they will be more successful in life." Runyan began producing

the videos at the end of March following the statewide stay-at-home orders.

Fenley, a director who runs his own production company, TurnKey Multimedia, films and edits the videos. Young was even inspired

by Runyan to make her own videos for her students. "She really is a role model and knows what she is doing," Young said of Runyan. "I wanted to stay connected to my students and families this way ... I admire what Penny is doing. Her videos are much more professional. She is a fantastic storyteller."

Runyan's shows at the Huntington Beach library attracted hundreds, and Time Warner even filmed her shows for a few years. Runyan remembered one time when a mother recognized her from the television show while shopping.

"It was exciting," Runyan said of being filmed. "It helped me reach more kids in Orange County. I tried to make it all as much fun as I could." Runyan ended her run

by Runyan to make her own videos for her students.

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as Miss Penny when she moved to the East Coast for a few years for family reasons. She's not the only one who's glad about her return to storytelling.

Dana Stimmler watched Miss Penny shows at the Huntington Beach library when she was growing up. Now, her 2-year-old is tuning into the online videos.

Stimmler said it's important to keep kids engaged in reading, and the videos also give her a nice break.

"I have a really high-energy toddler who needs lots of attention," Stimmler said. "When Penny releases a new video I can relax for 10 minutes. It keeps her busy the whole time. It really helps."

Visit the "Miss Penny's Storytime" YouTube channel to listen to her stories.

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# Local activists come to aid of Oak View neighborhood during COVID-19 pandemic

BY BEN BRAZIL

In the predominately Latino Oak View community in Huntington Beach, grassroots groups are lighting the way through the pandemic for struggling residents.

As many in the low-income neighborhood wrestle with joblessness, potential illness and an uncertain future in the post-pandemic economy, groups like Oak View Com UNIDAD and Mujeres de Oak View ComUnidad are stepping up.

"There are no resources available other than our grassroots organizations bringing in resources to the community," said Victor Valladares, who co-founded Oak View ComUNIDAD. "We are the ones on the frontlines."

Valladares, largely seen as the chief advocate for the underserved Huntington Beach neighborhood, has been bringing food and other resources into the community during the crisis.

In mid-April, Valladares said he worked with the Orange County Food Bank to bring food distribution to the neighborhood. Residents flocked to pick up much-needed supplies outside Valladares' home. He said he hopes to work with the food bank regularly.



Scott Smeltzer | Staff Photographer

**LAURA LAVIN** and Victor Valladares help out Huntington Beach's Oak View community.

Last week, Valladares raised \$2,400 through a Facebook fundraiser to purchase fresh produce for Oak View residents. Valladares is hoping he can set up weekly food drives.

"We are going to set up on the street corner," Valladares said. "It's really needed."

Laura Lavin, who leads the group, Mujeres de Oak View ComUnidad, advocates for the women of the Oak View community.

"There isn't much panic health-wise," Lavin said. "Financial-wise is a totally different story."

Valladares said many residents haven't been able to pay or are behind on their rent. Some have moved in with others, living "doubled-up."

"People were already living paycheck to paycheck," Valladares said.

With much confusion in the community about what state orders like the evic-

tion moratorium and stay-at-home orders mean, much of the work for the activists has been to provide guidance to the community.

Lavin has been holding webinars to educate residents on how to talk to their property owners about rent issues.

"There was much confusion about the state orders and what power they have," Lavin said.

Lavin and Valladares also

connect residents with legal counseling. Valladares said he's working with The Vazquez Group, a Santa Ana-based firm.

"Folks who don't know their rights are getting threatened to get kicked out of the neighborhood," Valladares said.

It's unclear if anybody in the community has tested positive for the virus.

Huntington Beach spokesman Eric McCoy said the city doesn't have data on coronavirus cases in Oak View. The OC Health Care Agency doesn't have a breakdown of cases by neighborhood.

Valladares said it's likely that the community is at high risk. Many residents who haven't been laid off have jobs that require them to go into work, Valladares said, pointing out that many work at local nursing homes. This week, a Huntington Beach nursing home recorded its sixth COVID-19-related death.

Jadira Lopez, who's lived in the neighborhood since she was a child, has been providing Zumba fitness classes online with the Zoom video conferencing application. Lopez had been providing the classes at a park in the neighborhood before the statewide stay-at-home order. The classes had become a community fixture, where many

could connect with each other while getting their daily dose of exercise.

Lopez said she started the online classes to keep the community connected and make sure that Oak View residents maintain their mental and physical health.

"I've come across a lot of the families, and many of them, at least one, either the mother or father, have been laid off or reduced hours," Lopez said. "I know with the kids being home and the parents being laid off, it has taken a toll financially."

"Being physically active is an important aspect of maintaining your mental health. People are stressing, and this brings a little bit of happiness."

Lopez was laid off from her job as an instructional assistant in the Ocean View School District, but she is still providing the classes for free. She charged a small fee prior to the pandemic. Lopez regularly goes to a nearby campus to get school lunches that are provided by the school district for her three children.

"I do it for free and don't ask for donations," Lopez said. "We just want to keep them active. I know everybody is struggling."

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## HOUSING

Continued from page R2

stuck like traffic. There's no place for them to go. We have a very low vacancy rate in housing, and how are folks going to jump from being homeless to paying \$2,000 or \$3,000 a month for rent?"

Carol Grunbaum, 43, has been a resident of Jamboree's Rockwood facility in Anaheim for about four years.

A recovering drug addict,

Grunbaum has wrestled with homelessness and had her children taken away years ago by child protective services.

Everything changed when she got housing.

She now lives with five of her children, and she and her partner have stable jobs.

"The feeling of not knowing if you're going to be able to eat or if you are going to be able to put a roof over their head," Grunbaum said of her kids.

"Deep down as a parent,

you want to provide that, but being altered by a substance and being caught up in difficult times ... it's rough and it takes a lot of energy. Being provided housing was the first most important thing that allowed me that time to clear my head and focus on everything else around me. If it wasn't for being able to be housed, I couldn't push forward."

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**VOLUNTEERS PERFORM** food distribution for Jamboree Housing Corp. residents, before the coronavirus outbreak.

Courtesy of Jamboree Housing Corp.

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# In her debut poetry collection, Anatalia Vallez explores her roots as a Latina writer in O.C.

BY ADA TSENG

The first poem in Anatalia Vallez's "the most spectacular mistake" is called "bond," and it's about honoring the generations of Mexican women who came before her.

"As a fetus my mother inhaled love," it reads. "it lingered in her vocal chords / then traveled to her stomach / through her umbilical cord / and into me / it now lives between my stomach and diaphragm."

"Perhaps that's why I exist / to exhale what was trapped in my mother's throat."

Vallez, who is named after her great-grandmother, dedicates her debut poetry book "to all survivors of violence — may we reclaim our power and our narratives."

"Para las mujeres que me rebozaron," which follows, is a reference to the women, but also to the rebozo, the long, thick garment often worn by indigenous women in Mexico.

It can be used for warmth or fashion, or also to strap a child around a woman's body. To Vallez, it's a symbol of strength in the way it holds tight the most vulnerable and keeps them safe.

"As a Chicana, Latina writer, a lot of our poetry is about pain, heaviness and how we're carrying this burden our family gave us — all the things that are woven that we need to unravel," Vallez said. "But that doesn't mean that the yarn isn't useful.

It's about learning to see it in a different way, weaving something new that works for you and leaving behind what's broken."

Published by FlowerSong Press, the book is orchid-pink and filled with indigenous-inspired illustrations by John Jairo Valencia. Valencia and Vallez were classmates at UC Berkeley, and she loves that his artwork is so joyful and vibrant.

"The most spectacular mistake" is divided into four parts.

"Roots" is her expression of where she comes from: her family, the legends and the history that's often not documented in textbooks.

"Core" represents the darker

emotions that are often suppressed: the grit, the anger over

injustice and the accompanying mental health struggles that are a part of the healing process.

"Heart" is her sentimental side: the ways she expresses different kinds of love.

And "Head" is the meditative ending: an attempt to integrate all these lessons and encapsulate her journey thus far as a young woman who identifies as Mexican American, Latina, Chicana, a poet, performer, playwright, and someone who has survived trauma but doesn't want it to define her.

Some of her poems, including "bond," are followed by Spanish translations, but she let the lan-



Photo by Xochitl Vallez

**ANATALIA VALLEZ** dedicates her book "the most spectacular mistake" to those who have survived violence and want to reclaim their narratives.

guage dictate these decisions.

"Some pieces didn't feel like they wanted to be translated, like it'd take away the essence of it," she said. "It wouldn't sound the same or evoke the same amount of feeling, so I wanted to honor that."

Vallez grew up in Orange County speaking Spanish to her parents and grandparents, but it wasn't until later that she could read or write confidently in the language. She remembers her schools discouraged speaking in Spanish, and she's grateful for her older brother, who made her speak to him in Spanish at home.

"He knew English, but he wanted to hear it in Spanish," she said. "He understood that because our parents don't speak English, part of our connection would be lost if we don't speak Spanish."

Her poem "pero me entendiste" is about the mix of languages spoken in her household. Her grandparents also speak Nahuatl, an indigenous language often used in central Mexico.

"Pero me entendiste" explains that her grandfather only swears in Nahuatl and can order beer in English. The family has different ways to say "I love you very much:" *te quiero mucho*, *te makti nimitzneki*.

"The ways I was bullied for speaking Spanish, my grandma was bullied for speaking Nahuatl," Vallez said. "The poem is talking about the ways that your

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## CHECK-IN

# Laura's House continues to help domestic violence victims

BY BEN BRAZIL

Our leaders remind us that it's important to check in with each other, even as we're sheltering at home and practicing responsible social distancing. In this ongoing series, TimesOC checks in with small businesses and nonprofits in Orange County during the coronavirus pandemic.

## Laura's House

**When:** Founded in 1994  
**Where:** 999 Corporate Drive, Suite 225, Ladera Ranch

### BACKGROUND

Laura's House offers counseling, support groups and other resources to victims of domestic violence. It was founded by a group of concerned citizens in honor of a woman who was killed by her abuser.

Laura's House has a facility with a counseling and resource center and corporate offices in Ladera Ranch, as well as a domestic violence advocacy center in Garden Grove. The counseling and resource center offers individual, couple, family and group therapy. It offers workshops on setting boundaries in relationships and addressing anxiety.

The domestic violence center also provides legal advocacy services, including preparing and filing restraining orders for clients; education on victim's rights; and safety planning. It offers therapeutic services like crisis counseling and workshops on co-dependency, parenting and



Courtesy of Laura's House

**LAURA'S HOUSE**, which provides resources for victims of domestic violence, has had to adjust to teleconferencing, making sure clients in their emergency shelter are safe and social distancing.

self-esteem.

### CURRENT STATUS

Laura's House made many changes in a short period of time. The two outpatient clinics, which would typically see clients in person, have converted to providing therapy over the phone. The hotline is available 24/7 at (866) 498-1511.

Most of the staff is working remotely. However, staff who took care of children while parents took part in the outpatient services are not currently working since the outpatient clinics are closed.

Even though courts are closed, the legal advocacy component is available online, where clients can still attain restraining orders.

The nonprofit is still taking in clients to its emergency shelter, though clients can no longer share rooms and mingle in the common areas.

"We have also limited the public areas to one family at a time," said Laura's House clinical director Greg Young. "One family goes in at a designated time to make their dinner or have lunch, then it's cleaned thoroughly. We do have shelter in place at the shelter. But we want our clients to be able to get out and get fresh air, so we allow a certain amount of time each day for them to be able to do that, maintaining social distance."

The nonprofit isn't currently providing its group program.

"They certainly help a lot of clients but we have to weigh the safety factor," Young said. "We are looking at other options to provide that info through online."

Another important component of Laura's House is a program that educates high school students on domestic violence. Last year, more than 15,000 teens took part in the county.

Jennifer Ponce, prevention education specialist for Laura's House, said the presentations are up online. She said teachers have reached out and they will be running presentations on Zoom, a video conferencing app.

### CHALLENGES

Due to the virus, many victims are now forced to

shelter in place with their abusers.

"Isolation is typically a key tactic and a tool that is used to maintain power and control over a victim," Ponce said. "Now we have all been forced into this isolation. We have victim survivors at home with the aggressor and abuser. There are children in the homes who are being exposed to the violence."

Ponce said with schools and work being closed, victims may be cut off from the one place that was considered their "safe space," and they may no longer have access to individuals who have supported them through the violent relationship.

"Now nobody has an outlet," Ponce said. "A lot of our kids, they feel safe at school where they have their teachers, counselors and friends. That has been eliminated. It's created a huge barrier for them to access their support networks. It's cut that off completely."

Being confined to the house also makes it difficult for survivors to report the abuse. Ponce said one of the most substantial barriers is how a victim can access resources without tipping the abuser off. The nonprofit's text line, which is usually available for teenage victims, has been expanded to all ages. That line is available by texting "HEART" to (949) 484-8440 to chat with an advocate online.

### WHAT WOULD HELP

Laura's House is also contending with financial is-

sues. The nonprofit has had to reschedule events and fundraisers for summer and fall.

"It's the biggest challenge a lot of nonprofits are facing is the fact that some have their bigger fundraisers and galas scheduled for the spring," Ponce said.

The nonprofit has also had to shutter its two retail stores, "resale stores" where it sells items donated from the community. The proceeds support their programs.

"That is really a big part of how we get our funding," Young said.

To donate, visit [bit.ly/2xg6iWQ](http://bit.ly/2xg6iWQ).

### OVERALL MOOD

Staff has had to adjust to the new system.

"For the staff, it has been a big adjustment for them to work from home," Young said. "Everyone initially thinks it's awesome and fantastic to work from home, but as far as the therapists are concerned, it's a really tight team. Being on site and supporting one another — that part is gone."

The staff has been taking part in online chats to keep morale up. Young said they organized a company happy hour online.

The staff knows the work they're doing is vitally important to victims.

"I feel like there is a big spirit of enthusiasm," Ponce said. "We are still being able to provide such a critical resource in such a critical time."

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# Tustin student wins first place in an international video contest

BY VERA CASTANEDA

Little did 18-year-old Bryan Nguyen know that iPhone shots of a Lego mini-figure sitting on a toilet would win him a first-place \$1,000 cash prize.

The AP environmental science assignment was to create a 60-second video that highlights a population growth issue and presents a solution. Topic categories included sustaining water systems, ensuring economic opportunities or improving climate resiliency.

Nguyen, an Arnold O. Beckman High School senior, chose to address sanitary water systems for the project.

It took him 12 hours to shoot and edit, using childhood Legos and his mom's iPhone 7 to create a stop-motion animation video.

Through the video's

voiceover, Nguyen explains that out of 7 billion people worldwide, 2 billion don't have access to safe sanitation, and it causes diseases that spread through waterways. He poses hydro-powered public sanitation units as the solution. The units, installed in well-populated areas, would allow people to safely dispose of bodily waste without fear of spreading diseases.

"There are a number of different waterborne pathogens, and it's problematic in developing areas where they don't have adequate sanitation," said Tracy Scott, Nguyen's teacher who has taught science for about 17 years. "As a whole, the number one killer of babies in the world is diarrhea from diseases like cholera. So the topic is pretty substantial and compelling."

Each student in the class was required to complete a video, but the prompt comes from Population Education — a national nonprofit program providing teachers with curriculum resources focusing on human population issues.

Scott gave students extra credit if they submitted their video entry into the contest.

The program started in 1975 and launched the "World of 7 Billion" student video contest nine years ago. This year, Population Education received 2,593 video submissions from middle and high schools in 35 countries.

According to Pam Wasserman, the program's vice president of education, 42 of the submissions came from Orange County alone. The previous O.C. winners came from Cypress High

School in 2014 and Troy High School in 2013.

"The judges really liked that Bryan used some humor to try to get across a really important message," Wasserman said.

"I get excited about seeing their videos and hearing their ideas," she added. "I feel like all the problems we have right now — we're going to be looking to these kids to be the innovators. To see that they're already thinking about these really challenging topics is heartening."

Nguyen plans to donate his winnings to local animal shelters and follow the footsteps of his older sisters who are both studying public health at UC Irvine.

"I'm touched to hear that's an area he's interested in," Scott said. "Public health is an area where we could use some kind and



Courtesy of Bryan Nguyen

**BRYAN NGUYEN**, an Arnold O. Beckman High School senior, shoots a stop-motion animation video that won first place.

brilliant minds."

Scott plans to incorporate the contest into her classroom again in the next school year.

The Population Education program staff has re-

ceived requests from teachers to add health topics related to the current pandemic.

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## LOVING

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she was a part of.

A line from Tiara's obituary captures her exuberant nature best: "In her presence no happy birthday song went unsung, no guitar unplayed, no bowl of guacamole was safe and no heart untouched."

The Goff family's medical saga began when Tiara was diagnosed with tuberous sclerosis complex (TSC) at 8 months old. A rare genetic disorder affecting an estimated 50,000 people in the United States, TSC causes benign tumors to grow in vital organs, most commonly in the brain, heart, eyes, kidneys, skin and lungs.

There is no cure, though some people with TSC have symptoms so mild that the disorder goes undetected. This was not the case for Tiara, who had three different types of tumors in her brain alone and experienced multiple seizures a day when she was diagnosed at Children's Hospital of Orange County.

A team of doctors gently relayed the grim prognosis to Tiffani and her husband, Louis Goff. Tiara's tumors would likely result in severe developmental and intellectual delays, autism and intractable epilepsy — all of which Tiara eventually experienced.

It was not certain whether she would be able to walk and talk, or how long she would live.

The news was an emotional gut punch.

"I had to make a plan," Tiffani writes in "Loving Tiara." "How was I going to survive this new reality?"

A devout Catholic, she decided to make a promise to God: "Please, just keep her alive," she prayed, "and I will do everything I can to care for her."

It's a promise she kept through the duration of Tiara's 16 years.

Months before Tiara's diagnosis, Tiffani had completed a law degree at Western State University in Fullerton. Now that her daughter was unwell, Tiffani put aside her legal aspirations in order to be a full-time caregiver for Tiara and stay-at-home parent to her other two daughters, Tabitha and Trinity.

Supervising Tiara and being her medical advocate proved to be 24/7 commitment.

Perhaps the best way to illustrate the demands of Tiara's medical care is with numbers.



Mara Blom Schantz

**MARA BLOM SCHANTZ**, who also took the photo on the cover of "Loving Tiara," took this photo of the Goff sisters in 2007. From left to right, Trinity, 4, Tabitha, 14, and Tiara, 8.

On a typical day, Tiara needed to take up to 25 pills of various medications morning and night. A minimum of two to three seizures struck at any time of day, and sometimes she experienced more than 10. She underwent two brain surgeries to remove tumors, endured dozens of hospitalizations — some lasting months — and between follow-up visits with doctors and occupational, physical, and behavioral therapy consultations, had too many appointments to count.

Out of necessity, Tiffani quickly became an expert on TSC and seizure medications. Many of the physicians had never seen or treated a case like Tiara's, and at times Tiffani had to advise them on what to prescribe.

Tiffani's existence was a constant balancing act. The day-to-day grind, as she discovered, could be more difficult than the impending loss of a child.

She wanted Tiara to have the best care possible but didn't want to neglect her other children.

There was no time left for herself. "My life was doing stuff for my kids," Tiffani said, "and trying to give the other girls a somewhat normal life. Because it wasn't normal at all."

Though the Goffs were grateful to have help from family members — both Tiffani and Louis' parents live in Orange County — and sometimes hired trained aides to watch Tiara, they had

little respite. Not many people could safely handle Tiara's unique needs for more than a few hours at a time.

The situation was, in Tiffani's words, "survival mode pretty much for 16 years."

"Nobody had any idea what really went on in our world," she said. "They're just kind of shocked that that was our life."

Another challenge was the silent scrutiny from strangers, who were often concerned by Tiara's behavior or appearance. Due to brain damage from her constant seizures, Tiara had the mental capabilities of a 3- or 4-year-old child and still acted like one: she needed diapers every day of her life, played in sandboxes, sang loudly and sat on her mother's lap, even when she reached her teenage years.

Her changing physique drew stares as well. At multiple times in her life, Tiara was either severely obese or dangerously emaciated. She gained a massive amount of weight for her 5-foot-4 frame — topping over 300 pounds at her heaviest — as a side effect of one of her anti-seizure medications. Her weight dwindled to 80 pounds before and after brain surgery, and when a rare type of seizure caused daily vomiting.

When Tiara grew larger and stronger than her mother as a teenager, Tiffani's fight to survive became literal. Tiara lashed out with increasing aggression and

physically violent behavior — the worst side effect of her medication. Though she didn't mean to hurt her mother, Tiara hit, bit, kicked and in one terrifying instance tried to choke Tiffani while she drove in Friday afternoon traffic on the 405.

"I don't really touch on it [in the book] as much because I didn't want it to be too negative, but I feared she would kill me at the end," Tiffani said. "And I was so afraid that she would hurt me or one of the girls, and then someone would take her away."

Louis tried to intervene when he could, rushing home from his job as a luxury car salesman to help subdue Tiara. But he couldn't always get home in time.

He shakes his head, remembering. "It was just, I don't know, scary as could be."

It wasn't that the Goffs hadn't tried to get professional help for Tiara's aggression. If anything, they'd exhausted their options. A behaviorist they worked with gave up after his methods failed to quell Tiara's attacks.

The Goffs reluctantly had Tiara admitted to a psychiatric ward at the recommendation of her doctors, but staff called the next day and asked for Tiffani to come back.

"That process isn't made for a kid like her," Tiffani said with a sigh. "It's made for a kid who's bipolar and needs some meds adjusted or whatever. It's not for

somebody [like Tiara] who is wearing a diaper and is on oxygen. And that's the sad part, that people don't realize: there is nowhere for these kids, these families."

Tiffani started her blog when Tiara was 13, and it quickly gained traction online. Some of Tiffani's posts had over 10,000 readers, and she and Tiara would get recognized as they walked around neighborhoods in Newport Beach and Costa Mesa.

When people read about the Goffs' hardships, they wondered how they dealt with them. How did they cultivate hope and find happiness in the midst of perpetual uncertainty?

For Tiffani and Louis, the answer is to take life one second at a time.

"If you had told me that this was going to happen, [that] we were going to have a special needs daughter that's this sick and has this many issues going on, I would have said, 'There's no way I could handle that,'" Louis said. "Sometimes you don't feel like you're going to. But there's always that next second, that next minute, next hour, next day."

Tiara suffered multiple cases of pneumonia throughout her life, the last of which proved too strong. She died on Jan. 15, 2015, at age 16 — years older and with a fuller life than many had predicted.

Her story has been an encouragement to thousands of readers, many of whom have children with disabilities. It was the blog's fans that motivated Tiffani to write "Loving Tiara," which she finished in honor of her 50th birthday and the fifth anniversary of Tiara's death.

She still works on the blog and runs an interior decorating business that she started in the months after Tiara's passing.

Tiffani hopes her daughter's life will continue to have an impact through the memoir.

"People tell me every day [that] by telling the truth, it makes them feel better. And so I think that was part of Tiara's thing. She wasn't here very long, but she helped a lot of people. And I am continuing to do that for her."

For more information about the memoir, go to [tiffanigoff.com](http://tiffanigoff.com). Tiffani Goff hopes to have more book signings and events when COVID-19 restrictions end. May 15 is TSC Global Awareness Day.

**ALIESE MUHONEN** is a contributor to TimesOC. Follow her on Twitter @AlieseMuhonen

## POETRY

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language is mixed around and not 'right.' We speak Spanglish, variations of different languages, and are still able to understand each other."

Vallez has been a writer and performer most of her life but didn't always see a career in the arts as a possibility. As a teenager, she was in the first inaugural class of Barrio Writers," a reading and writing program for teenagers in underserved communities started in Santa Ana by Sarah Garcia Rafael, local professor, writer and arts advocate behind Libromobile.

Since then, she's written and performed with Orange County's Breath of Fire Latina Theater Ensemble and Los Angeles' Teada Productions, which creates theater about immigrants and refugees.

Debuting her first poetry collection in the midst of a pandemic, on April 1, while people were sheltering in place, was also not a part of Vallez's plan.

But she's always believed that the people who need to hear her poetry will find it, whether it's a poems like "how to have a good cry" and "for folks that are soft," or "misogyny invites itself in with a joke" and "round-up," a twist on the popular "99 bottles of beer" folk



Photo by Xochitl Vallez

**ANATALIA VALLEZ** holds her debut poetry collection "the most spectacular mistake," published by FlowerSong Press in April with illustrations by John Jairo Valencia.

song that comments on the ways people in detention centers are rounded up and "snatched in plain sight."

She's also proud of the coming-of-age monologues in the book like "Y si no me quieren," which translates to "And if they don't want me."

Much of her work is about the importance of self-care.

"I think the pandemic really shows us that we are all connected," she said, noting how those who don't feel free to travel right now can empathize with undocumented Americans and those feeling vulnerable to illness can now relate to her sister, who has an autoimmune disease.

So whether the timing is

"a mistake" or not doesn't matter.

"Ever since I was small, I'd feel the need to sit down and behave," she said. "And that can be good, because teachers thought of me as a good student and you survive. But creativity and life is really better when you allow yourself to make mistakes. To know that this might not come the way I wanted it to, but at least I tried."

As her poem "breaking patterns, leaving notes" reads: "If loving yourself is a mistake / let it be the most spectacular mistake you make."

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A Times Community News publication serving Orange County

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TimesOC is published Sundays by Times Community News, a division of the Los Angeles Times. Subscriptions are available only by subscribing to The Times, Orange County.

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# Finding peace in the storm

**There's no need to fear for I'm your God.  
I'll give you strength. I'll help you.  
I'll hold you steady, keep a firm grip on you.**

**Isaiah 41:10, The Message Bible**

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