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Death at 4, With Complications

Child's Last Days Pit Foster Care System Against Hospital's Policy

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LOS ANGELES - In the end, probably no one could have saved 4-year-old Carmen Castaneda, who died in March 2003 of cardiac arrest, pulmonary hypertension and reactive airway disease.

But maybe her last days could have been easier.

Instead, in the six months before her death, Carmen was taken from her home and placed with a medically trained foster mother because social workers didn't think her mom could care for her special needs.

Then, in a classic Catch-22, she was rejected for consideration as a lung transplant candidate by Children's Hospital of Los Angeles because hospital officials didn't believe foster care was stable enough to assure she would receive crucial post-operative care.

Just two months later, over the objection of county social workers, she was sent home in hopes that she would receive the organ transplant. Children's Hospital then began evaluating her suitability.

Carmen, described as a bright, lively child who, hands on hips, demanded pancakes, died a week before the evaluation was completed.

Child advocates called the case a classic example of a lack of coordination between county welfare workers and health care providers that leaves foster children in the lurch.

"I would like to think that, if this situation were to happen today, there would be a different response that would be more sensitive to kids in foster care and that the responsibilities of health care providers has moved slightly up on the chart," said Janis Spire, executive director for the Alliance for Children's Rights, a nonprofit that advocates on behalf of foster children.

The Department of Children and Family Services responded to Carmen's death by hiring its first ever medical director, Dr. Charles Sophy.

As a physician himself, Sophy said he can talk doctor-to-doctor with medical professionals to see that "medically fragile" foster children aren't prevented from receiving treatment.

"[Children's Hospital] had valid concerns about the level of post-surgical support available to the foster care provider," said Sophy, who met with hospital officials to discuss Carmen's case. "But I still had to make them understand that not all foster placements are the same and to find out how they can work with us so that foster children are not rejected."

Thomas Armitage, general counsel for Children's Hospital, said the hospital applies the same rigorous criteria to all transplant requests. Of critical importance, Armitage said, is the level of aftercare.

"Our position is to try to do these operations every opportunity we can," Armitage said. "We don't like to turn people away. That's not our mission."

Carmen's mom, Teresa Castaneda, declined to be interviewed for this story. At first, Castaneda said she wanted to put the experience behind her. Later, she said that she didn't want to have any problems.

The civil court index has no record of any action filed on behalf of Teresa or Carmen Castaneda, and county officials said no claim or lawsuit is pending.

Carmen's lawyer, Robert Vazquez, expressed outrage and frustration during a dependency court hearing but said he couldn't comment for this article without approval from his boss, Anne Fragasso.

Fragasso is director of the Law Offices of Anne Fragasso, one of three firms that compose the Children's Law Center.

Fragasso initially asked the Daily Journal to get clearance from everyone involved in the case before she would discuss Carmen's death.

However, after the Daily Journal obtained the waivers, Fragasso declined to let Vazquez talk, citing client confidentiality.

Despite her lawyers' silence, parts of Carmen's story emerged from her dependency court file, released to the Daily Journal by Juvenile Court Presiding Judge Michael Nash.

Parts of her story also were chronicled in interviews with county and hospital officials and outside lawyers familiar

with the case.

Carmen was born Aug. 11, 1998, at Pomona Valley Hospital Medical Center, the second-youngest of Castaneda's six children. To all indications, she appeared to be a healthy, normal 8-pound, 8-ounce girl.

When Carmen was 2, her father, Ruben Pineda, walked out on the family. At the time, Castaneda was pregnant with her sixth child.

Castaneda said Pineda has never been seen since, and he's never contributed to the support of his two children.

Castaneda's four older children were fathered by two other men.

After Pineda left, Castaneda, who is now 37, struggled to provide for her family, including her ailing mother. She received \$800 a month in welfare payments and \$350 in food stamps.

The eight family members lived in a 500-square-foot, two-bedroom, one-bath apartment in Pomona. After paying \$650 a month rent, Castaneda said, she had just enough money left for food and laundry. She had no phone and relied on public transportation or neighbors to get around.

In one of the social worker's reports, Castaneda said she's always lived in poverty.

Born July 15, 1967, in the state of Zacatecas, Mexico, Castaneda is the youngest of 10 children. She described her childhood as impoverished but loving.

She said her parents loved each other and the children and never abused them. There was no alcohol abuse or domestic violence, she said.

Castaneda attended school in Mexico until the third grade. She came to the United States with her father when she was 12, enrolled in high school in California but dropped out in the 11th grade.

She said she always hated school and never learned to speak English, though she understands a little of the language. Before the onset of Carmen's illness, the Department of Children and Family Services intervened in the family's lives twice, according to the file.

The first time was on July 15, 2001, when Carmen, not quite 3, was referred for general neglect. The report stated that the children were dirty and the apartment had no gas, heat or hot water and was infested with cockroaches.

Social workers ruled the case "inconclusive" and closed it.

The second report, on June 29, 2002, alleged physical abuse of Carmen. Social workers listed the allegation as "unfounded" and closed the case again.

Two months later, Castaneda brought Carmen to Pomona Valley Hospital Medical Center. The child was pale, lethargic and suffering from shortness of breath. Her skin was cold and clammy, and she had a heart rate of 220 beats per minute. The normal heart rate for a child Carmen's age is between 70 and 80, according to the Children's Heart Institute's Web site.

A referring physician stated that Carmen had been having respiratory problems on and off for the last two years. No more details were given about her medical history.

After trying several medications, doctors managed to lower Carmen's heart rate to 120 and sent her to Loma Linda Hospital for further evaluation and consultation. During an 18-day stay, she was diagnosed with pulmonary hypertension and ventricular hypertrophy, a degenerative heart and lung disease.

Marci Horowitz, a nurse at Pomona Valley Hospital, said the cause of pulmonary hypertension is unknown, but it's a permanent condition that can be cured only with a lung transplant.

Doctors at Loma Linda discharged Carmen Sept. 12 with a referral to Children's Hospital, the only Southern California facility that performs pediatric lung transplants. They told Castaneda to contact a lung specialist and the hospital's lung-transplant coordinator.

They also prescribed vitamin K and Viagra, a controversial treatment that has shown positive results for some forms of pediatric lung disorders.

Only individuals with irreversible lung failure can qualify for a lung transplant, and fewer than 50 percent of those who receive them survive more than five years, according to Cara Ugolini, a spokeswoman for the Silver Spring, Md.-based Pulmonary Hypertension Association. Rehabilitation is gradual, follow-up medical visits are essential, and the effects of powerful immunosuppression drugs must be monitored regularly.

The average wait for a lung transplant at Children's Hospital is a year. The Los Angeles facility has 21 children on its list; they have been waiting from three months to five years.

Children 11 and younger are given priority, but the donor lung must be a perfect match. A 4-year-old would be compatible only with donors of a similar age and size.

"Lungs or any organs [for transplant] are scarce among adults and even more so among children," Ugolini said.

"Generally, a lot more care and attention is given to children, and it is less likely they will be in a fatal accident or die from some other condition, where their organs could be used."

Back home, Castaneda failed to keep an appointment with the lung specialist.

She also was unable to get the pharmacy to fill Carmen's Viagra prescription because it wasn't approved on her Medi-Cal plan. While she was pleading with a pharmacist at a Rite-Aid drugstore, Carmen became sick again. On Sept. 20, Castaneda took Carmen back to Loma Linda.

Doctors said the little girl wasn't receiving her medication on time, ordered her placed on oxygen 24 hours a day and again recommended she see a lung specialist.

And they notified the Department of Children and Family Services that Castaneda might not be qualified to care for her daughter.

"There is no cure for the child's pulmonary hypertension, and it is of a critical nature which requires that she receive her medication in a timely manner and that she has timely medical follow-up by medical specialists at Children's Hospital," the doctors' assessment said. "The only way to correct the condition is by having the child undergo a lung transplant." Inspecting Castaneda's home again, investigators found it clean but crowded. There were cockroaches, and Carmen, 4, had head lice and shared a bed with her mother and 2-year-old brother, making her more susceptible to respiratory infection.

Social workers decided Castaneda would not be able to provide effective care for her daughter, and they recommended that Carmen move in with a medically trained social worker.

They blamed Castaneda for failing to administer Viagra on time and for missing appointments with the lung specialist.

Castaneda, according to children's social worker Laura Lopez, "lacks the education and the knowledge to understand the healthcare system."

"The child's multiple and critical medical problems would be overwhelming to the most affluent parent, and it is evident that the mother, Teresa Castaneda, is spread thin and has limited ability to follow through in a timely manner with the medical care," Lopez stated in a detention report written by children's social worker Kanea Gaines.

"Carmen has multiple medical problems, including but not limited to pulmonary hypertension, asthma, a liver mass and an enlarged heart that exceeds the mother, Ms. Castaneda's, ability to effectively provide the necessary care," Gaines wrote.

"In order to ensure that ... Carmen's medical needs are met adequately, giving her the best opportunity for survival and the optimal level of care, out-of-home-care through [the Department of Children and Family Services] intervention is necessary," Gaines concluded.

The report recommended placing Carmen with a medically trained foster caregiver on her discharge from Loma Linda.

It also recommended assessing Castaneda for "family preservation services," which included individual counseling and training to deal with Carmen's special needs, and referred the case to the public health nurse for a "full-time, in-home assessment."

The report was signed by the former interim director of Children and Family Services, Marjorie Kelly.

Kelly no longer works at the department, and Lopez was on vacation. But Gaines, in a prepared statement, said that removing Carmen from her mom was a "tough, heart-wrenching decision" but essential to ensure that she got the services she needed, while helping her mom get the necessary help in place so her daughter could be returned.

"As social workers, we always have to consider the well-being of the child and what is in their best interest," Gaines said. "Although the mom wanted what was best for her child and thought she could take care of her, the child's needs were beyond her ability to care for her at the time."

Sophy was not on board during Carmen's case. But he said that, in general, the needs of a medically fragile child can be so great that there is no choice but to entrust the child to a medically trained caregiver.

Sophy also noted that the family preservation services order indicated that social workers intended to give the child back to her mother as soon as she was able to care for her properly.

On Sept. 25, Los Angeles Commissioner Marilyn Mackel, acting on the recommendations, ordered Carmen placed with Linda Hawes, the county's medically trained children's social worker. Castaneda was allowed to have frequent and unmonitored visits with her daughter.

Castaneda did not attend the hearing. In a follow-up report by children's social worker Francisco Vazquez, she said she had not been notified of the hearing or of her daughter's being taken from her.

Castaneda added that she couldn't do much more to force the pharmacy to give her the Viagra her insurance plan didn't cover.

While she wasn't an "educated woman," she knew when her children were sick and used all the resources at her disposal, she said, using a neighbor's phone to see that Carmen was taken promptly to a hospital or doctor, Vazquez wrote. Castaneda's court-appointed dependency court lawyer, Roland Koncan of Santa Monica, said he couldn't discuss the case because of the dependency court's confidentiality rules.

Castaneda agreed to undergo counseling and training in order to regain custody of her daughter.

"I want to have my daughter in my home," Castaneda told social workers. "Nobody can care better for her than her own mother. I have not neglected my daughter. She is sick, but I can take care and provide for her."

During the month Carmen was with Hawes, Castaneda visited her twice. Hawes said Carmen enjoyed the visits and would cry when her mother left. When Carmen was sad, Hawes said she would phone Castaneda, and the mother was able to soothe her daughter.

"The child and mother have a very good bonding relationship with each other," Hawes said.

Carmen's health remained stable, except for one medical crisis, when Hawes took her to the emergency room for a low blood-sugar attack.

Carmen was attached to an oxygen tank, but a long tube allowed her to move about freely and play in the living room, Hawes said. The child wasn't potty-trained and still used a bottle, but Hawes was weaning her from it and teaching her to eat solid foods.

Hawes described Carmen as very active, alert and social.

"She also is very intelligent," Hawes said. "When I met her, I was told that she was monolingual, but as I got to know her, and she trusted me, she spoke fluent English to me. She speaks English very well."

Hawes said she had the same difficulty as Castaneda in obtaining Viagra and usually had to ask a children's social worker to intercede.

"The medication is not covered by Medi-Cal, so I have to do a lot of fighting whenever I go to the pharmacy to have the child's prescription filled," Hawes said.

Meanwhile, Carmen's lung transplant - the reason a very sick little girl was taken from her mother - had been requested. Hawes reported, however, that Children's Hospital officials had refused to assess Carmen's medical needs so she could be placed on the waiting list.

The reason? They did not consider Carmen's foster care situation a "stable home."

"The people at the hospital are giving me such a hard time. I can only imagine what they do with the child's mother, who can't communicate with them," Hawes said.

At that point, Vazquez tried his hand.

On Oct. 3, he was told by the hospital's transplant coordinator, Monica Horn, that foster children were not typically accepted into the transplant program because of the belief they tended to be "bounced around."

Reached by phone, Horn referred the Daily Journal to the hospital's media relations department. In a written statement, communications director Steve Rutledge said that state and federal law prohibit the hospital from discussing a specific patient's medical history even after death.

"Transplantation is an inherently high-risk procedure, and the requirements have been carefully developed over time for the protection of patients to assure that each and every decision to perform a transplant is made in a medically responsible manner, meeting all applicable requirements," Rutledge wrote.

Vazquez also tried to get help from the Alliance for Children's Rights. Alliance advocates and hospital staff had heated words but were unable to help Carmen.

The alliance advocate, Ida Bell, no longer works at the organization and couldn't be reached for comment.

On Oct. 17, Vazquez and children's social workers were back in court before Mackel.

"Apparently, Children's Hospital refuses to put the child on the list as a candidate for a transplant because of the fact she is a foster child," Vazquez told Mackel, according to a court transcript of the hearing.

"What do you mean?" Mackel replied. "Foster children are ineligible?"

"The way [Horn] described it to me is a foster-care child is not a good candidate for a transplant because there is a possibility they will be moved around a lot, and there is no continuity, and the transplant won't take," Vazquez said.

"The alliance has been in contact with Ms. Horn, who has said the same thing apparently to them."

The news brought cries of outrage.

"I think that is appalling," said Liza M. Samuelson, a deputy county counsel representing the Department of Children and Family Services. "I am going to say that flat out for the record."

Mackel ordered the Department of Children and Family Services to speed up its family preservation assessment procedure so that Carmen could be cared for at home.

"I know you are asking for a month, but we are talking about a child who needs a transplant and to get a physician," Mackel said.

This time, the department moved at lightning speed.

Castaneda's apartment was painted and fumigated. The public health nurse helped Castaneda obtain bunk beds for Carmen's siblings. A special hospital bed was provided for Carmen, and a visiting nurse was assigned to attend the

child. The nurse also was there to help Castaneda obtain Viagra through a doctor's order. Castaneda was provided with transportation to hospital appointments, in-home parenting classes and counseling. She also received a special phone to make emergency calls.

The court-appointed special advocate office also supplied a caseworker to help Carmen with any other special needs. On Nov. 13, the parties returned to court.

Social workers remained reluctant to recommend returning Carmen to her mother.

"The department would like to exercise extreme caution in making a recommendation to return the child home to the mother, notwithstanding the fact that the child will not be placed on a lung transplant list until she is returned home," social workers argued.

Mackel apparently thought otherwise.

"We do recognize the department's position is that the child not be returned, and the court exercises extreme caution in recommending the return home," Mackel said at the hearing.

"But apparently [Carmen's medical needs] can be met [at home]," he said, "and there is an inability to meet those medical needs while she is in foster care, as discriminatory as that may be, ... and she can only get that transplant if she is with her mother."

With Carmen back home, Children's Hospital agreed to evaluate her as a transplant candidate. Her first appointment was scheduled for Jan. 7, 2003.

Court-appointed special advocate Lorna Boyd, from the Superior Court's child advocates office, described Carmen as a "lively, insistent child, with chin jutted out and hands on hips, as she demanded pancakes."

"She maneuvered around her oxygen tank rather easily," the advocate wrote. "She didn't appear sickly or sedentary." Boyd depicted the home atmosphere as "low-key, but not depressive." She said that while the tiny apartment appeared overpacked with both people and possessions, it was clean and had multiple televisions and videos for the children. Castaneda, however, was frightened.

She told Boyd that Carmen's illness was very difficult and scary for her. Breaking into tears, the mother said she was worried that her daughter would not live long. A doctor at Children's Hospital had told her that the waiting time for a lung transplant for Carmen could be six years but that Carmen only had about six months to live, she said.

Castaneda took Carmen for her final transplant evaluation on Feb. 25. Doctors said they would notify her in three weeks of the hospital's decision.

On March 11, a week before the hospital's decision was due, Castaneda and a county caseworker, who had been assigned to provide in-home services, rushed Carmen to the doctor.

She was sweating profusely and looked ill. The doctor performed some lab tests and conferred with the chief pediatric internist at Pomona Valley Hospital. They decided there was no need for hospitalization and sent her home. Six hours later, Carmen complained of chest pains and fell down. Castaneda called 911. Paramedics arrived and performed CPR at her home and en route to Pomona Valley Hospital.

Carmen was pronounced dead on arrival. Castaneda was at her side.

Children's Hospital general counsel Armitage, citing patient confidentiality, would not say whether evaluators would have recommended her for a transplant.

In a final court hearing April 11, Mackel ordered the Department of Children and Family Services to pay for Carmen's funeral. She was buried at Holy Cross Cemetery in Pomona.

Mackel also ordered the county to continue providing services for Castaneda's family.

And the judge instructed Vazquez to write her a letter detailing the problems he encountered with Children's Hospital officials, particularly regarding children in foster care.

Vazquez wrote that he found the hospital's protocol "disturbing ... because of its apparent exclusion of a whole class of children."

The lawyer was unable to communicate with the hospital on what he considered vital issues, even after Carmen was returned home, he said.

After the ill-fated attempt to have the Alliance for Children's Rights intercede on his behalf, Vazquez said, "all meaningful communication with the hospital ceased."

This was especially significant, he said, because, at the time of Carmen's death, three hospitals were involved in her care, and there was little, if any, communication among them.

Vazquez said he tried to referee when doctors at different hospitals disagreed on the controversial use of Viagra. Instead of welcoming his help, however, officials at Children's Hospital became defensive and refused to talk to him. "Rather than seeing me as an ally, they appear to have seen me as an adversary," Vazquez wrote.

Mackel forwarded the letter to Nash, with a note that he look into "facilitating a change of policy at Children's Hospital concerning children in foster care."

By phone, the Juvenile Court's presiding judge said it was a "troubling issue."

Nash said he forwarded the information to the Department of Children and Family Services to see what could be done to change the hospital's policy.

Sophy said one of the reasons he was hired was to assess the needs of "medically fragile" foster children.

"Foster children go through me for requests," Sophy said. "As medical director, I do whatever I can to make a child a viable candidate. I work to eliminate roadblocks."

In Carmen's case, he said, she needed to be healthy or stable enough to be able to wait two to five years for an organ once she got on the hospital's waiting list.

Unfortunately, Children's Hospital didn't feel Carmen's foster placement was "strength-based" enough to sustain her through the long ordeal.

"These are situations where we are accountable for these procedures," Armitage said. "Our team has to have authority to make the determination, whether people agree or not, because the lives of these children are in our hands."

In her final report, Boyd said it was clear that Carmen's mother loved her daughter very much.

"It appears that Carmen received all the services that could be provided for her welfare and that she was much too sick to survive her illness," Boyd wrote. "Her prognosis was dismal from the beginning, and the necessary resources [were] unavailable to her."