

PERSISTENCE GETS TEEN NEEDED TREATMENT



Steven Valenti / Republican-American

Pearl Pappas of Southbury recently helped a young Ecuadorian girl get to America and receive treatment for lupus, a life-threatening illness.

Life-saving mission flies Ecuadorian to U.S.

By Chris Gardner
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SOUTHBURY

On the other side of the equator, in a small village in Ecuador, a teenage girl lay dying in a bed, her body ravaged by disease. She was unable to walk, and she had gone blind in her right eye. When she moved, pain tugged at every joint. She hadn't had a full night's sleep in two years.

Pearl Pappas learned the details of the girl's condition in August. Her husband, Walter, had called from his Danbury muffler shop, distraught over a story that had been relayed by an employee.

Apparently, the girl's uncle was living in his car to save money so his niece could be flown to Connecticut for treatment of lupus. Without the care of

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skilled American doctors, the 15-year-old child would die.

Pappas, a social worker who lives with her husband and two daughters, Jane, 16, and Emmeline, 9, in the Purchase section of town, thought about the predicament for a moment. Then, with thoughts of her own 15-year-old daughter in mind, she picked up the phone, determined to get young Janina to the U.S. for treatment as soon as possible.

"It was like I was on a mission," she said, during an interview Thursday at her home. "I think it was because my daughter was 15. I kept picturing her in Ecuador in so much pain."

Through persistence and — admittedly — a few strokes of good luck, Pappas waded through several months' worth of bureaucracy in five days. After striking out with social service agencies and hospitals, a chance call to the Ecuadorian embassy in Washington, D.C., put her in touch with Ivonne A-Bald, the Ecuadorian ambassador, and her assistant, Pablo Yanez.

They helped to arrange an appointment for Janina and her family with the U.S. ambassador in Ecuador. In the meantime, Pappas' father, who speaks Spanish, helped to translate Janina's medical records from Spanish to English so they could be reviewed by U.S. officials in Ecuador.

The brown-haired girl with the round face was so ill that she had to be flown to the U.S. consulate in her homeland. Her family boarded a bus for the six-hour trip on the ground. When they arrived, they were bombarded with questions about Janina's condition. Then they had to find a place to spend the night while government officials decided whether to grant Janina and her mother an emergency visa.

The wait, according to Pappas, was agonizingly long for the family. "They wanted so badly to get her here. She was so sick," Pappas said. "Here they were so close to getting the answer they wanted and they had to spend the night in the big city."

The next morning, the family got the good news. The U.S. government had granted Janina and her mother temporary visas to fly to America. They were to arrive Sept. 11 and spend the weekend in Danbury before Janina was admitted to the Children's Medical Center in Hartford.

The employee who originally tipped Walter Pappas off to Janina's condition volunteered to pick the girl and her mother up at the airport. As if the excitement of arriving in a new country wasn't enough, Janina was about to see stars.

Through her contacts with the Ecuadorian embassy in Washington, Pearl Pappas found out about a party the embassy was throwing to benefit sick children in Ecuador. As fate would have it, the party was being held the weekend Janina arrived.

Headlining the star-studded event was pop singer Christina Aguilera, who had agreed to perform a couple of songs as a tribute to the ailing boys and girls. The Ecuadorian ambassador wanted Janina, her mother, and the Pappas family to attend and sit in the front row.

Pappas said she was concerned Janina would be too sick to go, so initially she declined the invitation. Then, she changed her mind.

"This was too big to pass up," she said. Her husband hired a limousine to whisk the group to Washington to meet Aguilera and A-Bald, the Ecuadorian ambassador.

The experience overwhelmed Janina, who weeks before had been so gravely ill she barely could get out of bed.

"Now you have to realize this is someone who lives in another country and who is very sick. She's barely been in this country 48 hours and she's picked up in a big white car and driven to see her own ambassador," Pappas said. "It turned out to be the time of her life."

Janina had her photo taken with A-Bald, and got to meet Aguilera. Pappas was bombarded with questions by government officials who wanted to know her secret to getting Janina to the U.S. so quickly. She thought back to her experiences as a social worker, and told them persistence was the key.

"This was something I felt like I had to do," she said. "When a child is in pain, it's torture. I really felt like the clock was ticking, and I felt if she were my own child, I would want someone to do this for me."

At the party, Pappas was finally able to meet the embassy staff who helped to arrange Janina's trip. When she first learned of the girl's condition, she called agencies like the Peace Corps and VISTA and several hospitals to inquire if they could help. She kept hitting brick walls until she reached the

embassy.

"I found out if I wanted to evacuate an entire town in Ecuador, it would be easier than to get a sick girl to this country," she said. "It was absolutely futile for days, but I just kept going."

After the party in Washington, the group returned home to Connecticut. Janina was to be admitted the following morning to the Children's Medical Center.

Pappas drove the girl and her mother to Hartford, where they were introduced to Dr. Lawrence Zemel, a pediatric physician at the hospital. Zemel and the staff put Janina through a week's worth of tests. They also took her off steroids, changed her medication and put her on painkillers, according to Pappas.

Since she arrived in the U.S. in September, Janina's condition has improved. The degeneration in her left eye has stopped, and she is able to walk. She goes to therapy five days a week, and has been tested for placement at a public school in Danbury, where she lives.

The U.S. government agreed to extend her visa for another two months so she could continue to be treated. Pappas said she does not know whether the visa will be extended again. Janina and her mother are torn about leaving because they have family in Ecuador who they desperately want to see. But they know Janina's chances for survival are better in the U.S.

Pappas said she hasn't seen Janina in about a month. Social workers are trained to help clients improve their lives and become independent. Admittedly Pappas is having trouble letting Janina go.

"Your goal is to have people be healthy, happy and independent," she said. "When they go off on their own, it is sad. But you get so much satisfaction watching them succeed."

Despite the urging of government officials who were so impressed with her persistence, Pappas doesn't think she will make a career out of helping sick children get to the U.S. from countries like Ecuador. She did arrange for another Ecuadorian child to be put in touch with the Shriner's Hospital in Boston for treatment for severe injuries following a motor vehicle accident.

All she had to do, she said, was pick up the phone.

"I got them connected. And that's all they wanted," she said.