Haitian girl lives full life with help from Oscoda woman, others

by Karen Rouse

OSCODA – Living with the effects of a rare disease has not diminished the joyful spirit of an 8-year-old girl.

She cannot walk, yet she dances. She does not attend school, yet her thirst for knowledge is provided to her at home. Her mother and younger sisters live in a one-room thatch hut in Haiti, yet she has traveled to the United States, visiting several places and inspiring countless people.

countless people.

Guerlande Delicate of Haiti was born with multicentric carpotarsal osteolysis, a rare congenital syndrome most dominantly affecting joints of the body. Delicate no longer has wrist bones – a result of the disease, said Ann Hume of Oscoda, the girl's Haitian guardian.

A friend called Hume about the young girl, concerned she was not gaining weight. When Delicate was just 3 years old, Hume took her in, however, no one could figure out what was going on with Delicate, Hume said.

Samples of her blood and her parents' saliva were sent to a genetic research center in Boston three years ago. Nine months later they had the diagnosis. "It took nine months!" Hume exclaimed.

Delicate acts like the happiest, most angelic girl, said Hume. "She never asks why and never feels sorry for herself."

Hume is the president of God's Children Haiti, where she has operated an orphanage, ensuring unwanted children are cared for and loved, while orchestrating medical care for her sick and disabled



Photo by Karen Rouse

BALLERINA - Guerlande

Delicate performs ballet while

flashing her signature smile.

wards. She is a Haitian guardian to 18 children (ages 1 to 21) and one 33-year-old paraplegic man.

Sunday, Sept. 24, Hume and Delicate left Oscoda for Shriners Hospitals for Children in St. Louis, Mo. The purpose of the trip was to allow the girl to be tested and examined for continuing research and for Hume to learn how to continue to take care of Delicate and which symptoms to watch for. She said she was taught the best diet for Delicate to eat and how to administer physical therapy to her.



Courtesy photo

ALL THE RIGHT MOVES – Ann Hume learns how to perform physical therapy for Guerlande Delicate, on table, at Shriners Hospital in St. Louis.



Courtesy photo FRIENDS – Guerlande Delicate, on left, with two friends she made during her stay at Shriners Hospital in St. Louis.

She said there are just two physicians in the world who know of this exact disease, and Delicate saw Dr. Michael Whyte at Shriners. The other physician is in Australia.

While at Shriners, Delicate also was seen by occupational and physical therapists, a pediatric endocrinologist and genetic and orthopedic specialists. She endured bone density testing, x-rays and lab work.

Hume said that Delicate's experience was such that the girl says she wants to go back to Shriners. They stayed for the most part at the hospital on its research floor.

"We were treated like royalty." Hume said the children's recreational room is filled with toys, games, prizes and special craft projects. She said she did not have to pay for anything except food and occasional side trips. Delicate and Hume also visited the St. Louis Zoo and the Arch, she added.

"I thanked them for everything they've done for her and then they thanked me for bringing her," Hume said about the hospital staff.

Medical facility staff also arranged for Wings of Hope, a humanitarian aviation organization based in St. Louis, to transport Hume and Delicate. Hume said, when arranging the flight, her contact was asking which airport would be the most convenient to fly out of. Hume mentioned airports in Midland, Flint and Detroit. She was told they didn't really want her to travel to the airport in the dark for an early morning flight and asked her about flying out from Oscoda-Wurtsmith Airport, located in Oscoda, the same town in which she lives.

"It's all God. It's how he blesses me," credited Hume.

She and Delicate boarded a six-seater plane and were flown directly to St. Louis, an approximate three-hour flight. They returned to Oscoda the same way, landing at OWA on Sept. 29.

Hume and Delicate left Monday, Oct. 9, to return to Haiti with medical follow-up scheduled for the child in two years. In the meantime, if there is a problem, such as Delicate's joints locking up, Hume was told to contact Shriners or the University of Michigan hospital in Ann Arbor, where the young patient was seen by a pediatric nephrologist in April.

Even though Delicate will not ever walk again, her zest for life keeps her smiling and delighted as each of her adventures have unfolded. Hume says her behavior is the result of Delicate's strong Christian faith, with the child, at times, pointing towards the heavens reminding Hume to keep believing when she is confronted with obstacles

More about Hume's ongoing mission with children in Haiti is online at www.godschildrenhaiti. org.



Courtesy photo

TRANSPORT – Ann Hume, left, and Guerlande Delicate about to board a Wings of Hope aircraft for their flight to St. Louis, Mo. from Oscoda-Wurtsmith Airport on Sept. 24.