

Angels On Board

St. Mary's Program Eases The Lives Of Parents And Children With Cancer

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Kristine Ford and her son Kieran, who has leukemia, receive loving care from a pediatric support group. SCOTT B. SMITH/FLORIDA WEEKLY SO QUICKLY. THINGS CAN CHANGE SO QUICKLY when a child is ill, can go from good to bad, from bad to Omigod in what feels like a heartbeat. So it is with Kieran Ford, age 19 months, on this recent Wednesday morning, when he is upright, pounding on the bongo drums in the playroom at St. Mary's Hospital in West Palm Beach, as his mom threads his IV-pole around some little plastic tables. Across the

Carbone, senior therapist for POST, the Pediatric Oncology Support Team, keeps Kieran's 3½-year-old brother Caleb occupied so that Kristine Ford can keep up with Kieran. The little boy coughs occasionally but, overall, his pneumonia seems on the wane, and home is the hoped-for target. Maybe tomorrow, maybe Friday.

"What is that you've got?" Ms. Carbone asks, as big-brother Caleb grabs a plastic rook off a chess board and tests it with his tongue.



St. Mary's Children's Hospital in West Palm Beach offers a support network for families of kids who have life-threatening diseases. SCOTT B. SMITH / FLORIDA WEEKLY "It's a ice cream," the boy announces.

Kristine Ford smiles. "I don't think these people realize the impact they make," she says, nodding toward Ms. Carbone and Barbara Abernathy, who heads POST. "I love every single one of them. They've had a huge impact on every single aspect of our lives. Financially, psychologically, emotionally."

And that is precisely the idea, the mission: to offer support of every sort, to be as much of an oasis as families in crisis can hope for. It provides help as tangible as emergency cash, as intangible as a shoulder to cry on, a reminder that a mother should eat lunch to keep up her strength for her child. At a time when considerable focus is on healthcare costs, this care comes without a price tag.



Keiran Ford plays the bongos. COURTESY PHOTO "There's no other program like this in the country. Nowhere," Barbara Abernathy says. "There are hospitals that have social workers, but nobody does the in-patient and out-patient support that we do. We meet families where they are."

One thing they cannot do, though: make days in the hospital pass more quickly.

Wednesday fades into Thursday, Thursday into Friday, the days blurring together like watercolor paints.

But Friday . . . well, on Friday, things fall apart. Kieran's cough intensifies. He gasps for air. He has developed pneumocystic carinii pneumonia, PCP, caused by a yeast-like fungus, an opportunistic infection not uncommon in people with cancer or HIV/AIDS, those whose immune systems are weakened by drug treatment.



Members of St. Mary's Pediatric Oncology Support Team include Karen Hansen (standing, from left), Terrie Johnson and Holly Carbone and Barbara Abernathy (seated). SCOTT B. SMITH / FLORIDA WEEKLY Dr. Vinay Saxena, his oncologist, orders the little boy placed on a ventilator, a tube that snakes down his windpipe, providing oxygen to his lungs and allowing him to breathe more easily. Nurses move him from Room 2514 to the PICU, the Pediatric Intensive Care Unit.

Alerted by a phone call, Holly Carbone comes running. Karen Hansen, the support team's child-life specialist, is already there. Their jobs overlap at times. A good thing, both say. Their mission is vague-sounding, shape-shifting, but essential to out-of-control lives: They do whatever a family needs them to do. Right now, that means hand-holding, providing company, conversation, reassurance, distraction for Kieran's mom. Her son is out of her sight, in a scary place where people are feeding a tube down his throat. He must be terrified, must be hurting, must be wanting his mommy, but she can't be there.

"Oh, I was a disaster," Kristine Ford says, a week later, recalling that day. "Now, I look back and laugh at myself. I was a lunatic. Hysterical. Crying. I was banging on elevator doors."

The POST women helped calm her. Now, every day, they visit. She knows them well. She has known them nearly half of Kieran's young life.

"THEY TOOK ALL HIS BLOOD OUT"

On Sept. 23, 2009. Kieran Ford was a 5-week-old, 9-pound armful of misery.

Angry red dots covered the tops of his feet. He whimpered. He fussed. He refused to sleep. His 2½-year-old brother Caleb would cup Kieran's tiny feet in his hands and kiss them, gentle little butterfly kisses. The kisses left bruises.

That's not right, Kristine Ford thought. So on Sept. 24, she took her infant son to his pediatrician. She expected to leave with a prescription to soothe her baby's apparent rash, then head home for Caleb's play date.

But no.

To the doctor, the bruising and the red dots under Kieran's skin, something called petachie, were an ominous combination. He drew blood from the boy for a CBC, a complete blood count. The results came quickly, and for Kristine Ford, they were life-changing. That day — emblazoned in her memory: SEPTEMBER 24 — became the day she will never forget, the day she heard the doctor utter the word "leukemia."

"Kieran's white (blood cell) count was 140,000," she says. Normal is between 4,000 and 10,000. "I was very close to losing him."

The doctor wasted no time. He sent mother and sons to Palms West Hospital, the nearest to their Port St. Lucie home. Palms West also acted fast, sending them, by ambulance, to Jackson Memorial Hospital in Miami. With a diagnosis of ALL, acute lymphoblastic leukemia, the most common form of childhood cancer, the little boy needed treatment, and he needed it to begin immediately.

“You only remember bits and pieces of the day,” Kieran’s mother says now, cradling him in her arms in the playroom of St. Mary’s. “Little flashes. We arrived at Jackson around 11 p.m. They did a double blood transfer. They took all of his blood out and put donor blood in. Twice. They put him on life support.”

For nearly a year, Kieran and his mother and brother practically lived at Jackson, a 230-mile roundtrip from home. Kristine Ford’s husband had left her, she says, when she was eight months pregnant, so friends from church sometimes would take care of Caleb, allowing her to devote herself to Kieran. And so it went until the phone call from Terrie Johnson, care coordinator for the Pediatric Oncology Support Team at St. Mary’s. The Leukemia and Lymphoma Society had notified her that a family from northern Palm Beach County was being treated in Miami and might benefit from learning about POST.

“I called Kristine, and we chatted for quite a long time,” Ms. Johnson recalls. “She has thanked me about 10,000 times since then.”

At first, last July, the family came in just to have blood work done on Kieran, Ms. Johnson says, but soon after his first birthday, he was transferred to St. Mary’s and came under the gentle, all-enveloping wing of POST.

HELPING FAMILIES GET BY

Barbara Abernathy never walked, or worked, the easy path.

For 10 years, based in Belle Glade, she counseled women who gave birth to HIV— and AIDS-infected children, counseled the children, too. Then, in 1998, a friend told her about a startup program at St. Mary’s for children with cancer and their families: Was she interested? She was. She took the job.

And the timing seemed right. The drug AZT was changing the medical landscape, making AIDS a chronic disease with a potentially long lifespan. Ms. Abernathy’s expertise — a licensed mental health counselor with a PhD in counseling — was likely to be less essential there. Still, she was reluctant to turn her back on her clients, so for seven more years, she made a weekly West Palm-to- Belle Glade trek to see them.

“You can’t make a commitment to these people,” she says, “and then say, ‘OK, goodbye, I have another job.’”

The \$100,000 seed money for that new job, the Pediatric Oncology Support Team, came from the Dana-Farber Cancer Institute in Boston. St. Mary’s, still a charity hospital in 1998, got donations from several area foundations to make up the difference. Three years later, in serious financial trouble, St. Mary’s was taken over by Tenet Healthcare Corporation, and the funding arrangement changed. Foundations could not donate money to the newly for-profit hospital, so POST became an independent, nonprofit entity renting \$10 a-year office space from St. Mary’s and existing on an annual budget — \$520,000 this year, down from \$600,000 a year ago — that comes from Dana-Farber; the Be a Star Foundation in North Palm Beach; Celebrities For Kids in Stuart; and several smaller foundations, including United Order True Sisters, the June C. Baker Foundation; and the H.A.N.K. Fund. The support team’s continued existence still depends on the success of the foundations’ annual fund-raising events.

POST serves Palm Beach, Hendry and all four Treasure Coast counties. So do St. Mary’s two pediatric oncologists, Dr. Saxena and Dr. Narayana Gowda, the only pediatric oncologists in the immediate area. If a child in, say, Fort Pierce, has cancer, the doctor will be either here or in Orlando.

The POST budget pays for nearly everything: the salaries for its 6½ staffers and the financial assistance fund that pays for a multitude of necessities.

“Families are often a month behind on electric bills, so they will come to us with a \$300, \$400 bill,” Ms. Abernathy says. “We have helped families with car payments, with car repairs, with food and, sometimes, the kids lose so much weight during treatment that they need new clothes.”

Kristine Ford and her family learned, firsthand, about those needs. In her eighth month of pregnancy, Ms. Ford ceased working as a behavior therapist for children with autism. Keiran's leukemia diagnosis, three months later, kept her at home.

With no income beyond the monthly \$615 Kieran got from SSI, she welcomed the \$50 Walmart cash cards POST gave her, which allowed her to buy diapers and fill her car with gas, and the referral to the Children's Cancer Society for additional financial aid. Rent was no problem, since her father, Lee McNamara, owned her house, but when its elderly stove quit working, burner by burner, she relied on a hot plate — until Celebrities For Kids, approached by the POST team, provided a new stove.

Ms. Abernathy, a native of Mobile, Ala. — “We call it L.A.: Lower Alabama” — loves telling these stories to illustrate the breadth of her job, a job she feels is simply doing what came to naturally. Her mom's a nurse, her dad a pharmacist. The second of five kids, she says, “We learned that we were lucky, fortunate. We had what we needed and more.” She wanted to help those who didn't.

“The day they put me out of work because they've cured childhood leukemia,” she says, “I'll happily stand in the unemployment line.”

“WHAT GOD CAN DO”

SOMETIMES, POST IS SIMPLY ABOUT being there, being present and offering silent support. It's like that with a Haitian mother and her 7-year-old daughter, who is fighting a brain tumor. On this recent morning, the woman wears a printed headscarf, common in St. Marc, the coastal town in western Haiti where she lived until moving to the U.S. 11 years ago. She is endowed with tremendous faith. She will share some of their experience but does not want her name or the name of her daughter in print. Not yet, not now. “When God heals her, I will tell everyone, everywhere,” she says. “I will tell people what God can do.”

At this moment, Barbara Abernathy finds the mother waiting for her daughter to emerge from a radiation session, the last in a series of high-energy X-ray treatments that seek to kill cancer cells.

“How's she doing?” Ms. Abernathy asks, enveloping the young woman in an embrace.

“She's OK.” The words are spoken softly but with conviction.

“She's so strong, emotionally,” Ms. Abernathy says. “She gets that from her mom.”

Just outside the radiation room is a sort of display-window showcasing a surf board, a couple of faux palm trees, a painted mural of sea and sand. It seems both out-of-place and welcome, tucked amid the otherwise sterile walls and fluorescent lights, the leatherette waiting-room chairs and the overhead sign that warns, “Beam On. Do Not Enter.”

The beach display, Ms. Abernathy says, is a reminder that sun rays share something in common with radiation rays. It also seeks to coax a smile.

The little girl is a second-grader, a voracious reader, math-and-science student of-the-month at Poinciana Elementary School in Boynton Beach before her diagnosis, last October. She misses school, faithfully completes the homework her teacher brings, wants so much to return to class. It was her teacher who sounded the something's wrong alarm.

“The school was calling me,” her mother recalls in accented English. “She had face drooping. When she smiled, the left side of her mouth would droop.” That was a sign of a neurological problem, her daughter's doctor said, maybe Bell's Palsy, maybe something else. If there are any changes, he said, bring her to the emergency room.

The changes came swiftly. Within days, the little girl grew weak, her walking difficult. Her mother takes a few shuffling steps to demonstrate. The diagnosis: a glioblastoma multiforme, an aggressive form of brain tumor, resistant to chemotherapy and with a generally low survival rate.

Her mother heard the diagnosis and wrapped it in her intense faith. “My doctor isn’t here,” she says, pointing to the floor, the hospital. “My doctor is up there.” This time, she points to the heavens.

Minutes later, when the radiation treatment ends, she navigates her daughter’s wheelchair into the waiting area: a pretty child with intense, dark eyes, her hair in braids except for an area above her left ear, where radiation made the hair fall out. There is a slight puffiness to her face, the result of steroids.

“I’m sorry I don’t have a book to give you,” Ms. Abernathy says, “but I’ll bring one later. I can tell you a story, though. Would you like that?”

The child looks up, expressionless. She nods. Since December, when her doctor opened a hole in her throat to put her on a ventilator, she has been unable to speak. She no longer needs the ventilator to breathe for her, but a portable oxygen tank takes its place.

“Once upon a time, there was a princess, the beautiful Princess . . .” Ms. Abernathy begins, and uses the little girl’s name, “and when she got lost in the forest, she began talking to the birds and the squirrels and the bunnies, who were her friends.”

As Ms. Abernathy spins her instant fairy tale about Princess Nameless, Patient Nameless fixes her solemn gaze on her storyteller’s face.

WALKING THE JOURNEY

IT DIDN’T TAKE KIERAN FORD LONG TO learn the lesson: Grown-ups are not to be trusted, especially grown-ups who wear white coats or have stethoscopes around their necks. The sight of either sets him to screaming, waiting for the next needle, the next tube, the next separation, however brief, from his mother. He doesn’t scream when he sees the POST women.

The team’s office, with its double-wall mural of trees and birds and flowers and butterflies, seeks to ease children’s fears. And it does.

“Good morning, Sunshine!” Terrie Johnson greets a 6-year-old girl, one recent morning. “I’m so glad you’re here. I’m hungry. Will you fix me breakfast?”

“Um-hmm,” murmurs the child, who has leukemia.

Ms. Johnson drags a red and a blue beanbag chair away from a child-size kitchenette set, where the little girl spends several minutes setting a small table with plastic muffins on plastic plates with a plastic coffee service. “Delicious!” Ms. Johnson pronounces, sipping from a demi-cup.

For a tall, thin 15-year-old boy, she fetches an X-box for the flat-screen TV, a gift from a former patient, to occupy him until his doctor’s appointment. The boy, a rally-cap covering his baldness, will not attend the annual “Prom to Remember” for teens with cancer, his mother says, because its date coincides with his next round of chemo. “Well, maybe next year,” Ms. Abernathy says, referring to the Fort Lauderdale event hosted by seven area hospitals, including St. Mary’s.

More than ever, “next year” is a reality for children with cancer. The cure rate for childhood cancer is approaching 80 percent — close to 90 percent for those with acute lymphoblastic leukemia, the type Kieran has — but some cancers remain very difficult to cure.

In 2009, Barbara Abernathy says, 19 of the support team's young patients died, "seven kids in seven weeks. We were walking around supporting each other. As much as we realize the journey is about the family, we do get invested."

Karen Hansen, POST's child-life specialist, takes a deep breath as she recalls Julia, who died a decade ago at age 10. "Julia made her presence known to everybody," Ms. Hansen says, her faraway gaze seeming to summon the child who refused to let cancer quiet her. "She underwent chemo, she had a bone marrow transplant," Ms. Hansen says. "She sang, she tap-danced. She could be a showoff; she could be loud and obnoxious. A lot of people didn't like her. It made me like her more."

Alongside her sit taller-than-toddler, Muppet-esque puppets named Corey and Molly; she uses them to comfort the frightened, reassure the shy, educate them all.

Corey is bald. He wears seersucker shorts but no shirt, so Ms. Hansen can show young patients his port, small chest tube into which doctors can inject chemotherapy. Molly is the shy puppet, who hides behind her hands until she gets to know a child:

"Hi, Sally. This is Molly. She has leukemia, just like you. She's 4 years old."

"Oh. I'm 4, too."

Ms. Hansen loves to recall the 6-year-old boy, a leukemia patient, who solemnly asked her to tell Molly that, "If she needs me, I'm here for her."

Molly Carbone cannot forget the morning — it was 4 a.m. — when she was awakened to learn that a 7-year-old patient had died. She drove to the family's home at once. "There's nothing that I'm going to say that's going to ease the pain," she says. "It's about being there and walking the journey with them."

After days like that, nights like that, she says, "I go home and hug my kid."

Finally, after more than a week, Kieran was extubated, freed of his ventilator tube, and released from the PICU to a non-emergency room. There, he began, once again, the chemotherapy regimen that had been temporarily halted lest it further suppress his immune system. On May 3, he was sent home to continue his treatment there. Twice a month, he will visit the hospital as an out-patient.

His mother counts the days, the minutes, until her little boy will complete his chemo regimen: Sept. 24, she says, two years after it began. On the day Kieran returned from the PICU, the young Haitian mother said her prayers for her daughter, as usual, and waited patiently, as usual, in the hope they would be answered.

And on that day, the members of POST carried on, doing whatever they could, whenever they could.

Terrie Johnson, the support team's care coordinator, remembers a woman she met not long ago, the mother of a young patient who transferred to St. Mary's after two years at another hospital where the medical care was good but the support element absent.

"How," she asked, "do people manage without you?"