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Baby born three months early is now healthy and at home

NEWPORT - Ronald McDonald may be a red-haired clown, but visitors to his house in Providence aren't greeted with a buzzing handshake or a fake flower that squirts water. They're welcomed in with compassion and kindness and showered with attention typically reserved for grandparents visiting over the holidays.

Nancy Barboza and Joe Muscarella found themselves at the doorsteps of the Ronald McDonald House of Providence in late March. The haggard Newport couple was scared and nervous. Their attention was focused on their newborn baby, hooked up to tubes, wires and machinery across the street at Women & Infants Hospital.

They hadn't spent a night in their Newport apartment since late January, when they were rushed from a scheduled OB-GYN appointment to Newport Hospital. Barboza's doctor told the young couple that their baby likely wouldn't make it. They were stunned, as a five-month ultrasound done just the week before had shown a healthy baby girl.

"They just looked at me and knew something was wrong," said Barboza, who didn't feel particularly ill when she arrived at her doctor's office that life-changing day. "We were devastated."

"I just wanted to die," Muscarella said.

The couple spent five days at Newport Hospital, where Barboza's water broke. She was just more than 23 weeks into the pregnancy. Doctors there gave their child little chance of surviving. It was suggested politely that funeral arrangements be made.

Muscarella, a religious man, prayed a lot. So did friends and family.

After meeting with doctors from Women & Infants', Barboza was admitted to the Providence hospital in early February.

During his fiancée's grueling six weeks in a Women & Infants' bed, Muscarella spent day and night in the small hospital room. He sat and napped in a comfortable chair that quickly felt cramped after repeated use. He slept on an air mattress given to him by a friend. He helped the hospital staff care for his pregnant girlfriend, washing her and handling bedpan duties.

Their baby girl was born March 3, three months early. She weighed 1 pound, 15 ounces. She was 14.2 inches long. They were able to hold her three days later. They named her Philumena, after St. Philomena, who was martyred at about age 14 in the early days of the Roman Catholic Church.

After their daughter's berth, Barboza and Muscarella moved into the neighboring Ronald McDonald House, about a 100-yard walk to the incubator their baby would call home for the next eight weeks. Her neighbors were 79 other newborns attached to bulky machines because of various health reasons.

Thanks to the accommodations offered at the Ronald McDonald House, the doting parents were able to keep a near-constant vigil at their sick child's bedside. They spent hours holding her hand and cradling her tiny head. They changed her diapers while carefully avoiding the wires that attached their daughter to eight different devices, which monitored her heart rate, body temperature, pulse and oxygen saturation level and kept her lungs from collapsing.

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"We were continuously looking at monitors," said Muscarella, who has a notebook full of numbers and readings to prove it. "We were at her bedside as often as physically possible. I didn't feel like I could breathe some days.

"They caught their breath at Ronald McDonald's inviting house, especially the nights before and after their daughter received a blood transfusion after becoming anemic. A good friend donated the blood.

At the Gay Street home named after a fast-food mascot, they relaxed in donated furniture, had meals cooked for them by volunteer students and senior citizens and were provided toiletries, blankets and clean sheets. They stayed there for two months and all that was asked of them was a \$10 donation per day.

"You don't have to think about anything but your child," Muscarella said. "It's an unbelievable place. I can't tell you enough what it meant to be there."

The nonprofit Ronald McDonald House of Providence opened in 1989, after a group of concerned parties from Women & Infants' and Rhode Island hospitals met to discuss concerns about parents and relatives sleeping on hospital chairs or on the floor in order to stay close to sick children. The original idea was born in the early 1970s; the Providence house now is one of more than 125 nationwide.

During the past 18 years, the Ronald McDonald House of Providence has served as a temporary home to more than 5,000 families whose children received medical care for premature birth, serious injury, illness or surgery. This year alone, the home has served 192 families from around the world, including 89 from Rhode Island and 11 from Aquidneck Island, according to Liza M. Gentile, public relations associate for Ronald McDonald House of Providence Inc.

As for the reasons for this year's nearly 200 house visits, premature births top the list at 49 percent. These stays are the longest, many times upwards of three months, Gentile said.

After nearly 100 days away from their Newport apartment, Barboza, Muscarella and their beautiful little girl spent their first night together on the island May 21. The first-time parents were nervous.

"I was afraid," Barboza said. "I cried after we left the neonatal unit."

The family is preparing to celebrate Philumena's 8-month birthday on Nov. 3.