A baby in CHOC's care brings a nurse and a mother together

A lifelong bond forms in CHOC's neonatal ICU, forged by the love for a baby.

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ORANGE - It was time to ask the question.

Stacy de Santiago, a nurse who cares for critically ill babies at Children's Hospital of Orange County, knew of no other way to put it.

She had asked the question before, to another parent. It was even more excruciating this time, as she looked into the eyes of Tina Rhee, a mother from Cerritos.

Rhee didn't need to say anything for de Santiago to understand her answer.

The women, both mothers, had become close during the 1 1/2 years that de Santiago helped care for Rhee's baby boy, Alexander.

Rhee could tell whether Alex was having a good day simply by the way de Santiago would greet her on the telephone, updating her on his status.

Rhee knew that today, Alex would be breaking the heart of not one mother, but two.

Intense bonds

Nurses like de Santiago who care for critically ill children know the dangers of getting too attached to patients.

They also realize the folly of thinking they won't.

De Santiago got attached to Alex quickly.

He was born prematurely, at 31 weeks, on May 28, 2003. His medical complications at birth included an esophagus that was not connected to his stomach, a hole in his heart, and abnormally developed lungs. He weighed 3 pounds, 5 ounces.
Alex was impossible to resist. De Santiago adored his fat cheeks and the way he slapped people on the face with his tiny fists.

She loved his long eyelashes, his big smile, and the way he was so proud of himself when he first rolled over.

**Draining job**

While most babies in the 42-bed neonatal ICU get better – many are born near or full term, but with heart defects and other conditions – the tiniest ones and the most critically ill don't make it.

Some babies are as young as 23 weeks old, the so-called "micro-preemies" whose wrists can fit inside a wedding band.

About 25 babies in CHOC's NICU die each year. When this happens, the baby's primary nurse usually takes some time off.

Some nurses request never to be assigned as the main caretaker for a critically ill child.

The attachment can be devastating when a baby dies.

When that happens, De Santiago, 35, or another nurse will hang a colorful stencil of a butterfly on the outside of a patient's room, signaling others to keep quiet.

She will take imprints of the baby's feet and hands in a molding – part of CHOC's commitment to palliative care.

Nurses will dip into a "bereavement cart," giving families a disposable camera, a gown for their child – even tiny shells used to scoop up water, should the parents want their baby baptized.

De Santiago has had to carry a deceased baby to a holding area below the hospital. There, she has cleaned and changed the baby and put the baby under a warmer.

Then she has taken the deceased child upstairs to parents for them to hold one last time.

**Devoted mom**

When Alex arrived at CHOC right after delivery, transferred from St. Joseph Hospital next door, de Santiago had been a nurse for 1 1/2 years. The former grocery clerk figured she'd make a good nurse. So did her husband, Javier, a teacher.

"She cries during movie trailers," he said. "Sometimes I think she cares too much about others. I tell her I'm glad she's not a teacher, because she'd end up adopting all the students."

De Santiago is thoroughly devoted to her
three children, shuttling them to band practice, cheerleading, cross-country, basketball and baseball. Ryan is 16, Christian is 14, and Cassandra is 12.

The de Santiagos also have two dogs, two cats, two lizards, one rabbit and a hermit crab. Like the NICU, there’s always someone or somebody in need of attention.

Typically, on a normal shift at CHOC, de Santiago will be assigned to two, at most three, babies. Nurses can request to be the primary caretaker for one baby.

That's what de Santiago decided to do with Alex, the firstborn child of Tina and Albert Rhee.

For years, the couple had tried to get pregnant before succeeding with in-vitro fertilization. Tina's pregnancy was difficult.

Tina Rhee, 39, had to stop working as a bank manager a month into her pregnancy. She experienced abnormal bleeding in the first trimester and was hospitalized for a month.

Preeclampsia, a hypertensive disorder of pregnancy, is believed to be the reason why Alex was born prematurely. He was very frail and momentarily stopped breathing before doctors inserted a breathing tube down his throat.

At first, Tina Rhee says she was angry. Anger soon gave way to resignation, resignation to hope, hope to determination, and determination to resolve that Alex would come home soon.

"You just deal with the cards you’re dealt," Rhee says. "You learn to adjust."

Soothing voice

Adjusting to the pediatric intensive care unit takes time.

The soundtrack of all critically ill babies is a constant stream of ambient noises: clicks, alarms and buzzes, the whoosh of an automatic door, the shuffling of nurses' feet on a linoleum floor.

Rhee wanted to make sure Alex heard her voice. So she recorded herself talking to him and reading stories.

"Hello, Alexander, this is Mom," Rhee's soft, cooing voice purrs on one recording. "I love you, honey. Are you being a good boy? Mommy misses you so much."

De Santiago played the tape often for Alex, who would wriggle in his crib, his body connected by wires to severe-looking machines that recorded his vitals. He also was connected to a ventilator and had to be fed through a gastric tube.
"You be a good boy and get stronger and bigger and chunkier for Mommy and Daddy," Rhee tells her son on the tape. "I love you so much, honey."

De Santiago often would talk to Alex. She would cuddle him, place a mat on the floor for playtime, and string up toys and mobiles for him.

She would bathe Alex in the morning before Tina Rhee would show up in the early afternoon, sometimes holding her son for six hours without taking a bathroom break.

Albert Rhee, 39, would take over in the evenings. Tina Rhee kept a detailed journal of Alex's life. In a September 2004 entry, she wrote:

*Football season. Alexander is dressed up in his Saints jersey, hat and booties. He looks soooo cute!*  

Alex spent his first birthday at CHOC, then his second at a sub-acute facility where he stayed for a couple of months before returning to the hospital.

**The question**

In October 2004, Rhee became pregnant with twins. Brandon and Sabrina were born healthy, in June 2005.

A month later, on July 31, 2005, Tina Rhee started a journal entry with these words:

*Alexander is in heaven today.*

Unexpectedly, he had suffered massive bleeding in his head after being on a dialysis machine. Doctors knew he could not be saved. De Santiago had to talk to Rhee.

She had to ask her the question. De Santiago looked into Rhee's eyes.

"Would you like Alex to die on the operating table, or in your arms?"

Alex died in his father's arms, his mother by their side.

De Santiago spoke at Alex's funeral. She talked about seeing his first teeth come in, and the first time he rolled over by himself.

"Not only did I fall in love with Alexander," she said, "but also with his amazing family, who gave him love unconditionally."

De Santiago tries to keep the pain of her job at the hospital. She'll often cry in her car on the way to her home in Westminster.

She'll embrace her loved ones.

She'll work harder on doing everything
she can for her next sick baby.

She has gotten philosophical about grief, believing there must be some purpose – a reason why Alex spent about 90 percent of his life in critical condition, then died.

"Alexander's purpose was greater then we'll ever know," de Santiago said at his funeral. "He taught me that every day is a gift, he taught me about unconditional giving, and that we are not always the ones in control – that there is a greater plan."

De Santiago and Rhee get together every month or so. De Santiago usually comes to Rhee's house in Cerritos, bearing sweets.

They know they will be lifelong friends, watching each other's kids grow up – and continuing to learn about unconditional giving.

"Alex was her child, too," Rhee says.

On the day Alex died, Rhee wrote:

I feel like we've made you stay when God wanted you with Him. ... Looking back, we put you through so much because we didn't want to let you go. I'm so sorry, baby.

Motivation

De Santiago shares the hard-earned philosophy of Rhee and other parents who've had to say goodbye to their babies:

"Everything you encounter in life is for a reason," Rhee says. "Good or bad, difficult or easy, it's a learning experience that's going to prepare you for something in your future."

During a recent shift, de Santiago busily tended to a girl, Darryleneisha Ghist, 6 months, who was born with her intestines in her chest cavity. She was crying. De Santiago picked her up.

"I know, I know," de Santiago said, trying to calm her.

De Santiago changed Darryleneisha into a pink outfit.

She rubbed her back, and then made the most comforting sound a mother can make:

"Shhhh."

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