

# January 13, 2003

## Highlights of Formerly Conjoined Twins' Stay at UCLA

**June 7, 2002:** Conjoined twin sisters Maria de Jesus and Maria Teresa Quiej Alvarez arrive at UCLA's Mattel Children's Hospital with their mother, Alba Leticia Alvarez, and volunteers from Healing the Children, the nonprofit group that arranged for the twins to be brought to UCLA. Craniopagus twins — those who are fused at the tops of their heads — are one of the rarest types of conjoined twins. An estimated two percent of conjoined twins suffer from this type of birth defect. Although the 10-month-old girls are conjoined, each exhibits a very different personality. Maria Teresa, the larger of the two, is outgoing and loves attention. Maria de Jesus is more quiet and thoughtful. They both love to play, smile and laugh as they roll around in the giant bed fashioned by securing two hospital beds together. Both girls easily charm everyone who meets them.

**June 10–14, 2002:** Doctors perform a variety of tests on the twins to evaluate the possibility of separation surgery. Developmental testing shows the twins are physically and mentally developing on target for their age. More good news comes from a magnetic resonance imaging (MRI) of the infants that reveals they possess distinct brains under their shared skull. However, an angiogram and computed tomography angiogram (CTA) illustrate that although each baby possesses normal arteries feeding the brain, a portion of the veins that drains the brain returns back to the other twin. The plastic and reconstructive team also starts evaluating how it will cover the skull defect once the twins are separated.

**June 24, 2002:** Doctors surgically implant two balloons under the babies' scalp. They plan to inject the balloons with saline solution to help the surrounding skin grow new tissue, which will eventually be used to cover the skull defect. During the surgical procedure, the delicate skin under one of the balloons tears, but doctors later state that enough tissue has grown from just one of the balloon expanders.

**July 25, 2002:** Maria Teresa and Maria de Jesus celebrate their first birthday at a party with their mother, local relatives, medical staff and Healing the Children volunteers at UCLA's Mattel Children's Hospital. Doctors also announce the date of the surgery has been set for Aug. 5.

**Aug. 3, 2002:** The twins' father, Wenceslao Quiej Lopez, who had remained in Guatemala to work, arrives in Los Angeles to be with his family.

**Aug. 5, 2002:** The highly anticipated day arrives. The twins are moved into the operating room at 7:53 a.m. and the anesthesiologists begin their work at 9:05 a.m. At 12:09 p.m. the surgeons begin their preparations, with the first incision at 1:49 p.m.

**Aug. 6, 2002:** The separation is completed at 12:56 a.m. The plastic and reconstructive surgery team completes its work to close the wounds at 5:40 a.m., and the girls are both moved into the Pediatric Intensive Care Unit (PICU). Maria Teresa returns to surgery to repair a hematoma later in the morning.

**Aug. 15, 2002:** Maria Teresa and Maria de Jesus are upgraded from critical to serious condition with stable vital signs in the PICU. Maria Teresa is taken off the ventilator and although still slightly sedated, she is breathing on her own. Maria de Jesus, whose breathing tube was removed on Aug. 13, also continues to breathe on her own and is now feeding from a baby bottle.

**Aug. 16, 2002:** Maria Teresa undergoes a three-hour surgical procedure after tests show a bacterial infection in the lining of her brain.

**Aug. 22, 2002:** Maria Teresa undergoes a third scheduled procedure for the final removal of a subdural hematoma that had occurred during the initial separation surgery. Maria de Jesus continues to be alert and active and shows signs of improvement. Doctors anticipate a gradual, slow healing process for both girls and remain cautiously optimistic about their long-term prospects for recovery.

**Aug. 29, 2002:** For the first time since she was separated from her sister, Maria de Jesus returns to the operating room for a non-emergency surgery to clean her incisions, inspect how the scalp flap is healing and make any needed reconstructive repairs. After examining the skin flaps covering Maria de Jesus' head, surgeons move the two pieces closer together in order to eliminate a small gap in her scalp. The defect was caused when a part of the scalp tissue died after surgery — a common result that the doctors felt might be expected.

**Sept. 17, 2002:** UCLA plastic surgeons complete a series of bedside procedures to promote skin growth in sections of the twins' scalps that continue to heal slowly. Doctors clean debris from Maria Teresa's skin flaps and apply a special skin substitute that encourages cell growth and promotes rapid healing. Maria de Jesus' scalp has now grown enough to cover her entire skull and brain. UCLA physicians are hopeful that the skin substitute will enable Maria Teresa's scalp to grow enough to completely cover her head before she goes home with her sister. Both Maria Teresa and Maria de Jesus remain in serious condition with stable vital signs in the PICU. In the meantime, Maria de Jesus, who is improving more quickly than her sister, likes to watch the nurses read books to her, eats solid food, holds her own bottle and interacts with visitors. Maria Teresa makes eye contact with visitors, reacts to touch and responds to musical toys.

**Sept. 18, 2002:** The twins receive a visit from United States Secretary of Labor Elaine L. Chao. Chao, who is promoting careers in nursing, tours UCLA's Mattel Children's Hospital and meets with nurses who participated in the surgery to separate the conjoined twins, as well as the nurses who have been caring for them during their recovery.

**Sept. 26, 2002:** Maria de Jesus is upgraded to good condition and moved from the PICU into a regular patient room. Her sister is also upgraded to fair condition, but remains in the PICU for a few more days.

**Oct. 1-27, 2002:** The twins continue to recuperate and show signs of improvement. The plastic and reconstructive team performs additional minor repair procedures. Occupational and physical therapists work steadily with the girls to help them overcome the developmental delays caused by their previous condition. Both girls are eating solid foods and love soup, especially cream of potato and clam chowder. They also like riding in the hospital's child-sized red wagons and being pulled up and down the corridors. Maria de Jesus raises one hand for "high-fives" and blows air kisses. She craves attention and enjoys dropping her bottle to keep the nurses near. She can push herself up when resting on her stomach, but hasn't begun crawling. She sleeps through the night. Although she is recovering more slowly than her sister, nurses say that Maria Teresa is improving a great deal since the surgery. She kicks her legs when placed on her belly and her muscles are less rigid. She looks at visitors when they speak to her. Because she sucks and chews slowly, she requires supplemental feedings though a nasal tube in order to consume adequate calories. She often sleeps during the day and wakes during the night.

The hospital and Healing the Children also begin making arrangements for the twins' discharge from UCLA's Mattel Children's Hospital and return trip back to Guatemala.

**Oct. 28, 2002:** A Catholic mass and a farewell celebration are held at the hospital in honor of the twins and are attended by the twins' parents, relatives, Healing the Children volunteers and hospital staff. However, the doctors decide to postpone the twins' scheduled return trip back to Guatemala because Maria de Jesus has not fully healed from her most recent surgical procedure to clean and close her scalp incisions. Doctors want to monitor the healing process over the next few days before judging when she will be able to leave the hospital with her family. Despite the minor delay, doctors emphasize that the twins are progressing very well.

**November 2002:** Doctors perform a minor surgical procedure on Maria de Jesus' scalp to graft skin to the back of her head. Although the graft itself heals perfectly, a small section of skin surrounding the graft on the back of her head does not heal as swiftly as anticipated. Doctors determine that the weight of Maria de Jesus' head on the bed is diminishing the blood flow to the area and preventing healing. To relieve the pressure, they request special bed cushions from the physical therapist and ask nurses to reposition Maria de Jesus periodically. This helps the wound improve tremendously. Doctors also begin applying a topical growth factor gel donated by Ortho-McNeil Pharmaceutical to Maria de Jesus' wound to accelerate wound healing. Called Regranex, the gel contains a factor normally found in the body (referred to as a platelet-derived growth factor) that is part of the body's natural healing process. Maria Teresa faces a different challenge. A recent series of tests shows that she is hearing-impaired, so she is fitted with a hearing aid, which quickly results in her ability to interact more with others. Doctors emphasize that both sisters are thriving and improving each week. In particular, Maria Teresa, whose recovery has lagged behind her sister's since the surgery, is looking around her and making eye contact with visitors, responding to "coos" from family and staff members, and displaying jealousy when her twin steals the attention. In addition, the twins continue daily sessions of physical and occupational therapy to help strengthen their mobility.

**December 2002:** Maria de Jesus' wound from a graft procedure continues to heal smoothly and the doctors clear Maria Teresa and Maria de Jesus Quiej Alvarez for discharge. However, the Guatemalan medical team receiving the twins requests additional preparation time to ensure that the twins' care will continue in a seamless manner upon their arrival. The UCLA medical staff and Healing The Children volunteers help the family celebrate Christmas and New Year's at the hospital. Both girls continue to make impressive strides in their rehabilitation.

**Jan. 13, 2003:** The twins are discharged from UCLA's Mattel Children's Hospital. To help UCLA cover the cost for the twins' care, Cris Embleton of Healing The Children presented two checks to hospital officials at a farewell press conference. The first check was a gift of \$450,000 from an anonymous donor. The second check was for \$20,652 in individual donations from people around the world wishing to contribute to the 17-month-old sisters' medical expenses. After the press conference, the twins, their parents, Healing The Children volunteers and a team of UCLA medical staff board a donated FedEx Express corporate jet flight back to Guatemala. The twins are then transferred to a private hospital upon their arrival in Guatemala City to continue their recuperation with physical and occupational therapies.

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