

First LLU International Conference on Pediatric Heart Transplantation

by Kent D. Seltman



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The pioneering work of the Loma Linda University Medical Center's Heart Transplant Team has produced a significant quantity of data, which has been used to address the scientific and ethical issues surrounding pediatric heart transplantation. With by far the largest series of pediatric heart transplantations in the world—106 by the end of January 1991—and with actuarial survival rates of 82 percent for one year and 73 percent for two years post-transplantation, Loma Linda has earned the position of scientific leadership on this medical frontier.

The issues, medical protocols, and surgical and clinical management techniques in pediatric heart transplantation were addressed in the First Loma Linda International Conference on Pediatric Heart Transplantation, March 11-14, 1990, in Palm Desert, California. Nearly 500 physicians, nurses, and social workers from 34 states and 23 foreign countries attended.

A distinguished international faculty of 21 pediatric cardiologists, heart transplant surgeons, immunologists, and ethicists joined with 20 members of the Loma Linda Heart Transplant Team to provide the most detailed and concentrated discussion of pediatric heart transplantation ever conducted. In late spring of

1991, the *Journal of Heart Transplantation* will publish a special supplement edition containing a summary of the conference proceedings.

The most fundamental scientific/ethical questions raised by successful infant heart transplantation deal with the quality of life experienced by children who have been transplant recipients. Are physical and mental development within the normal ranges? Do they enjoy normal social relationships with their peers, or do they have to live within a fragile protective shell?

If the clinical outcomes can produce an acceptable quality of life, a purely ethical question follows in the real world of limited resources: "Can society afford pediatric heart transplantation?" Is this a technology that we should adopt as a standard of care for children with end-state congenital or acquired heart disease?

As reported at the conference, analysis of the growth and development of Loma Linda infant heart transplant recipients indicates that, overall, pediatric heart transplant recipients do fit normal patterns. The immunosuppressant cyclosporine, which is widely used today, appears to support an almost normal development. Earlier steroid-based regimens did suppress growth.

All transplant recipients, of course, live on a delicate balance between suppressing their immune response sufficiently to keep their immune system from rejecting the transplanted tissue and keeping their immune response sufficiently strong to meet the challenge of infections. Sandra Nehlsen-Cannarella, Ph.D., head of the Loma Linda Immunology Center, reported on the "Window of Opportunity" that Loma Linda sci-

entists have discovered. It appears that very young recipients are more tolerant of a foreign tissue graft than are older children and adults. Heart-transplant recipients who receive their grafts when less than three months old usually require a lower level of immunosuppression to ward off rejection episodes than do older children and adults.

Child heart transplant recipients appear to live successfully with their

siblings and peers and also perform normally in school. Of course, as Jay Fricker, M.D., of the Children's Hospital of Pittsburgh, reported, the normal problems of adolescence are intensified in many transplant recipients. To the normal teenage questions about the appearance and function of one's body are added questions about how boyfriends and girlfriends might feel about someone with a transplanted heart. Non-

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compliance with family expectations is normal in adolescence, but it can be lethal for a youth whose life depends on a regimen of immunosuppression. However, the testimony of children and teenagers suggests that these challenges can be successfully addressed in this difficult period of life.

Denton Cooley, M.D., an American adult heart transplant pioneer from the Texas Heart Institute, was joined by a number of pediatric cardiologists in suggesting that heart transplantation is viable therapy for many infants and children today.

This is, of course, in sharp contrast to the situation as recently as five years ago. Then, pediatric heart

transplantation in general and infant heart transplantation in particular was considered "experimental." So, today, many families with children suffering from end-stage heart disease do have an alternative to certain, imminent death for the child. (Within a few weeks after the conference, California Children's Services, Medi-Cal, and Blue Cross of California, whose medical directors were represented at the conference, removed infant heart transplantation from the "experimental" classification and approved Loma Linda as a pediatric heart transplant center.)

Roger Evans, Ph.D., medical coordinator of the Battelle Seattle Research Center and a leading ethicist in the area of medical resources allocation, stated that society certainly could afford pediatric heart transplantation programs. His argument was, however, based in part on the fact that the very limited supply of donor organs provides a natural limit on the impact of pediatric heart transplantation on the total health-care costs to society. At most, a few hundred children will receive heart transplants each year. He also suggested that society might choose not to support heart transplants in children. Children, he noted, have little political clout and no strongly organized advocacy group.

Both Dr. Evans and Arthur Caplan, Ph.D., of the University of Minnesota Center for Biomedical Ethics, addressed the ethical issues surrounding the equitable distribution of donor organs. Children in the

United States are the age cohort most poorly covered by private or governmental insurance programs. It is vital that organs not be donated by a segment of society that would not potentially benefit as recipients because they were poor or uninsured.

Two major ethical controversies were addressed by Loma Linda physicians. Joyce Peabody, M.D., chief of neonatology, reported on the now-discontinued Loma Linda protocols testing the potential of using anencephalic infants as organ donors. And Stephen Ashwal, M.D., associate professor of pediatric neurology, spoke on the definition of brain death in infants and children.

Infant heart transplantation was first successfully performed by Leonard Bailey, M.D., at Loma Linda University Medical Center in November 1985. Bailey transplanted a heart into Baby Moses, who is now more than five years old. Infant heart transplantation is now performed in more than 35 centers in the United States.

The intense interest in the pediatric heart transplantation is perhaps best demonstrated by the international participation in the conference. Registrants came from Argentina (2), Australia (5), Austria (4), Belgium (3), Brazil (1), Canada (24), Colombia (1), England (11), France (5), East Germany (1), West Germany (11), Italy (10), Japan (5), The Netherlands (2), Poland (1), Portugal (2), Russia (4), Saudi Arabia (1), Scotland (2), Sweden (6), Turkey (2), Venezuela (1), and Yugoslavia (1).

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