



ple who could empathize with us and offer practical help such as taking Ruth and Matthew out for a day, or looking after chores to give us a break.

We also prayed. God's presence was very real, and I was surprised by the inner calm amidst the raging storm. After the first week, Janice had stabilized and was weaned off the respirator and intravenous inotropes.

After 2 weeks, she came home. I encouraged Bonnie to take CPR training and we learned to give Janice 5 different medications. Compliance was a struggle because she often vomited. I quickly learned how easy it is to write a prescription without understanding patient barriers to compliance. We felt exhausted and overwhelmed, and I was a doctor! What must other parents feel like?

Over the next 3 months Janice was in and out of the hospital with heart failure, feeding problems, failure to thrive and viral infections. Each time her frail body became a pin cushion during endless tests and attempts to insert IVs. Her pain became our pain. When at home she required 24-hour care and had to be fed small amounts hourly. She vomited whenever she coughed, and this meant cleaning up and starting over.

Friends and relatives did not know how to respond to our pain. Many remained silent, while others made hurt-

ful remarks without intending to. The remarks indicated that they did not understand our suffering. The uncertainty was the hardest thing to deal with because we had to prepare for both life and death. As physicians, we sometimes forget that behind an illness there is a family in pain. Physicians who acknowledge and validate family suffering provide both strength and courage.

Janice's last admission came 4 months after the initial diagnosis. She deteriorated and I paged her cardiologist, who agreed to admit her directly to spare a long wait in emergency. Janice needed a new heart, and the transplant team ushered us into the cardiologist's office to discuss the options. They were surprised that we were so relieved, but at least there was hope. A heart transplant may introduce new problems, but at least they would be more manageable.

Janice was kept alive through total parenteral nutrition and 10 to 14 medications. Our daughter was skin and bones, close to her birth weight at 6 months of age.

I asked the hospital librarian to do another MEDLINE search on cardiac transplantation in children. I learned that even though this was a successful and accepted treatment, one-third of the younger children died while waiting for a donor heart. We jumped to answer each phone call, and our pager became the beeper of hope. We also



Janice Wong: "Your baby might die today"

Sources of organ-donor information

The following organizations can provide physicians with information, posters, pamphlets and videos about the need for organ donation.

- Organ Procurement Exchange Network, Health Science Centre, 2443 Prince Philip Dr., Rm. 4133, St. John's, NF A1B 3V7; 709 737-6600
- Multiorgan Transplant Program, Victoria General Hospital, 1270 Tower Rd., Bethune Bldg., 4th Floor, Halifax, NS B3H 2Y9; 902 473-5500
- Anne Secord, New Brunswick Transplant Coordinator, 8 Castle St., PO Box 5001, Saint John, NB E2L 4Y9; 506 643-6848
- Quebec Transplant, CP 1560, Stn. C, Montreal, QC H2L 4K8; 514 286-1414
- MORE Program of Ontario, 984 Bay St., Ste. 503, Toronto, ON M5S 2A5; 416 921-1130; 800 263-2833
- Manitoba Health Sciences Centre, Rm. GE 441, 820 Sherbrook St., Winnipeg, MB R3A 1R9; 204 787-7379
- Saskatchewan Organ Donor Program, Box 86, Royal University Hospital, 103 Hospital Dr., Saskatoon, SK S7N 0W8; 306 655-1054
- Human Organ Procurement and Exchange Program, Foothills General Hospital, 1403 29th St. NW, Calgary, AB T2N 2T9; 403 283-2243
- Human Organ Procurement and Exchange Program, University of Alberta Hospital, 8440 112th St., Edmonton, AB T6G 2B3; 403 492-1970
- BC Transplant Society, East Tower, 4th Floor, 555 West 12th Ave., Vancouver, BC V5Z 3X7; 604 877-2100