The Cases of Three Teenagers

1. Billy Best

Billy Best was sixteen years old when he was diagnosed with Hodgkin’s Disease in 1994. Doctors in Massachusetts assured him that the disease is common, and that with treatments such as chemotherapy, radiation, and surgery it was likely that he could be cured. He underwent five chemotherapy treatments, but his parents failed to appreciate either the extent of his distress or his reluctance to continue what he felt was a dangerously toxic medical intervention. To avoid further chemotherapy, Billy ran away. Weeks later, he called his parents from Texas and explained that he would only return home if they agreed that there would be no more traditional medical treatment. Physicians counseled them that further chemotherapy was crucial to his recovery. His parents agreed, and Billy returned home.

2. Benny Agrelo, a Teenager

In 1994, Benny Agrelo was a fifteen-year-old Florida boy who had suffered from liver disease since birth. He had received his first transplant when he was very young, but eventually the immunosuppressant drug cyclosporin failed, and he received a second liver transplant in 1992. Benny was stalwart about taking a then experimental new immunosuppressant drug, FK-506 PROGRAF, until its side-effects proved too much for him. Crippled by severe headaches and arthritic-like pain, and with the transplanted second liver already failing, he decided unilaterally in 1994 to stop taking the drug, and then to forego a third transplant. Chances that he could survive for a year, even after a third surgery, were estimated at less than fifty percent. His mother, resistant at first, came to understand and accept his decisions.

An administrator at the transplant hospital in Pennsylvania called the Florida Department of Health and Rehabilitation Services, and social workers came to Benny’s home with five police cars. Officers physically forced Benny into an ambulance, against his will and without his mother’s permission, and his mother was charged with child neglect. At the hospital, Benny refused to submit to a biopsy or blood tests, and fought off attempts to administer the anti-rejection drugs.
3. ‘Child M’

‘Child M’ was a fifteen-year-old, apparently fit and healthy English girl when she developed heart failure in May of 1999. In a matter of weeks she and her parents were told that a transplant was her only chance to survive, and that she had only a week to live without the surgery. Her mother gave permission for the transplant, but ‘Child M’ insisted that she did not want it.

She said that she understood that “death is final—I know I can’t change my mind . . . I don’t want to die, but I would rather die than have the transplant and have someone else’s heart. I would rather die with fifteen years of my own heart . . . It’s hard to take it all in. . . . I feel selfish. If I had the transplant, I wouldn’t be happy. If I were to die, my family would be sad. . . .” She continued that, “If I had someone else’s heart I would be different from anybody else. I would feel different with someone else’s heart, that’s a good enough reason not to have a heart transplant, even if it saved my life.” Revealing the desperation she felt, she added, “Maybe some kind and gentle gun-wielding psychopath will put me out of my misery.”