

Children's news

November 2006

[[back](#)]

Living with a transplant, the virtual way

For patients undergoing organ transplantation, the operation is only the beginning of the challenges. It's followed by a lifelong series of drug regimens to prevent organ rejection, hospital visits for biopsies and other tests and, for some, dietary restrictions and extreme efforts to avoid exposure to germs. And for teenaged patients, the process can be especially difficult: Just when appearance feels overwhelmingly important, they have to deal with drug side effects like weight gain, acne, a puffy "moon" face, unwanted hair and stunted growth. "I've been teased at school about being short," says Jimmy Yee, 13, who had a heart transplant as a baby. "These kids don't know what I went through."

But in the virtual world known as Zora, adolescents aged 11 to 16 can forget that they're "transplant kids"—or vent their feelings with others. Zora is an online city built entirely by post-transplant patients. Logging on from home computers, the kids create their own houses and fill them with items of their choosing: furniture, family photos, TVs tuned to favorite shows, a movie theater, a hot tub, even a Patriots scoreboard. Teens choose a cartoon character or "avatar" to represent them as they roam their three-dimensional world.



Jimmy Yee

For many, Zora is just a way to have fun. But its underlying theory, known as constructionism, holds that people learn and develop socially by actively building things together, says **Marina Bers, PhD**, a Tufts child development professor who designed Zora at the MIT Media Lab. Through an appointment in Children's Hospital Boston's Department of Psychiatry, Bers will track Zora's users, looking for the "6 C's" of positive youth development: competence, confidence, connection, character, caring and contribution to society.

Children's clinical staff hopes these traits will help patients take more responsibility for their health. Adolescents are notorious for not following their drug regimens, often finding they feel better when they go off their drugs. "Adolescents have the worst transplant outcomes of any age group," says **William Harmon, MD**, Children's chief of Nephrology. "They don't want to take their medications, and they're always looking for some reason not to."

Zora came along just when doctors, nurses, social workers and Child Life staff at Children's were trying to find new ways to support children who've had a transplant—especially those who live far from the hospital. "The technology is intriguing to the kids," says **Elizabeth Blume, MD**, medical director of Children's Cardiac Transplant Program. "We've tried to do support groups, but most kids don't want to sit around and talk to other kids who've had a heart transplant. They see themselves as normal kids."

When Zora began in September, it was just an open field. Today, it's a busy landscape of houses, notice boards and public places like a restaurant, a zoo and a building offering technical help. Zora's citizens, now numbering about two dozen, come from all over New England and remain as anonymous as they choose. "I talk to a lot of people when I'm there," says Megan Chapman, 14, who plans to contribute to Zora's newspaper. "I'll wander into different houses. Everyone wants to search around."

Jimmy, an active Zora builder, erected many of the buildings—but others, like the City Hall, were provided by Tufts University staff. Noticing that some of the girls were engaged in a chat about their transplants, staff suggested they create a place for their stories, and the Transplant House was born. Ultimately, it's hoped that patients from hospitals all over Boston—and perhaps the nation—will move in.

It's clear, though, that Zora users don't want an agenda imposed on them, says Children's psychiatrist [Joseph Gonzalez-Heydrich, MD](#). Several years ago, he and Psychiatrist-in-Chief, [David DeMaso, MD](#), helped pilot Zora with dialysis patients. Nurses set up a virtual restaurant, hoping to educate their patients about safe dietary choices. Instead, the kids filled the menu with forbidden foods—they wanted no dialysis-related information intruding in their city.

So this time, while a health museum and a pharmacy are planned, their function will be left to Zora's users. And if the constructionist theory is proven correct, the kids will learn more about life after transplantation on their own—while making friends and having fun with cutting-edge technology.

:: [Erin Graham](#), Editor :: [Masthead](#) ::

©2006 [Children's Hospital Boston](#). All rights reserved.

All information provided on diagnosis and therapy reflects the care environment of Children's Hospital Boston and related physician practices. It is not a substitute for the professional judgment of a qualified health care provider based upon actual examination of a patient's condition and history. Therefore, it should not be construed as medical advice for any particular patient's condition, and may need to be altered in different care environments. Please contact us if we can be helpful in answering any questions or to arrange for a visit or consult.