

Article from SIRS Discoverer Database; (ProQuest) Lexile:1110L

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CURRENT SCIENCE

March 2, 2001, pp. 8-9

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SAVING STEPHANIE

by Rene S. Ebersole

A Tricky Transplant Rescues a Girl from a Life-Threatening Condition.

French fries, hamburgers, ice cream, pizza--all were once forbidden foods for Stephanie Singh, now 9 years old. In fact, until last year, Stephanie had never tasted a single bite of any type of food! Day after day, her only nourishment came from a tube inserted in her arm.

More than anything, Stephanie said, she wanted "to live a normal life," one where she could eat a slice of pizza and even go to school. Thanks to a new medical procedure, Stephanie's wish has come true.

INTESTINAL ILLNESS

Stephanie couldn't eat like other kids because she was born with VISCERAL MYOPATHY, a rare condition in which the intestine doesn't develop properly. The intestine is the long, coiled organ in the human gut that breaks down food into nutrients that can then be absorbed by the body. Anyone whose intestine fails to do its job can starve to death. To keep Stephanie alive, her doctors supplied her with nutrients and fluids INTRAVENOUSLY--through a slender, flexible tube inserted in her veins.

Over time, Stephanie's intravenous feedings became less effective. The continuous poking and probing caused her veins to harden and the tissues surrounding the tube to develop infections. Stephanie's doctors decided that the only thing that might save her life was a transplant that would replace her ailing intestine with a healthy one.

HIGH RISK

Though organ transplants are becoming more common, intestinal transplants are a new frontier. Why? The intestine is rich in IMMUNE SYSTEM CELLS. Immune system cells exist throughout the body and protect it from invading MICROBES (viruses, bacteria). The immune cells that exist in the intestine guard the intestine against microbes that cling to the food we eat. However, they also make intestinal transplants complicated, said Stephanie's doctor, Allan Tschernia, a specialist at Mount Sinai Medical Center in New York City.

When a patient receives a transplanted intestine, the body's immune system cells attack the new organ, as they would any other transplanted organ or body part. In response, the immune system cells in the intestine fight back. The resulting "war" makes the transplant extremely risky and prone to

failure.

BALANCING ACT

That all changed when an arsenal of new IMMUNOSUPPRESSIVE DRUGS was introduced a few years ago. Such drugs keep the body's immune system from attacking foreign invaders, such as microbes and transplanted body parts. Since then, the number of successful intestinal transplants has jumped. To date, more than 440 people have undergone the operation worldwide. At least two-thirds are young children like Stephanie.

Unfortunately, immunosuppressive drugs have a hitch. Keeping the immune system from fighting off invaders leaves an organ recipient vulnerable to infections. "It's a very fine balancing act of dialing down the immunity to prevent rejection but not too much, or the patient could die of secondary infections," said Tschernia. "With every patient, we're walking this very fine line."

Stephanie knows what it's like to walk that line. In October 1999, she received a new intestine, then waited as her doctors watched closely for any sign of trouble. Six months after the surgery, the first alarm sounded.

REJECTION VS. INFECTION

An intestinal BIOPSY, or removal of a small piece of a tissue for examination, revealed that Stephanie's immune system was beginning to destroy her new intestine. The doctors responded by suppressing Stephanie's immune system further with a higher dose of the immunosuppressive drugs. That blocked the rejection but left Stephanie vulnerable to ADENOVIRUS, the virus that causes the common cold. The adenovirus is usually fought by the immune system.

With Stephanie's immune system impaired by the drugs, she did catch a cold, and the doctors worried about the havoc it would wreak on her body. They were forced to make a crucial decision: Keep Stephanie's immune system suppressed, or reduce her drug dose and let her immune system fight the virus.

The doctors chose the latter. Luckily, it worked. The virus vanished, and a few months later Stephanie was able to go home. "I must say she was very brave," said Tschernia.

WISH COME TRUE

Every day since her transplant, Stephanie has discovered a few new foods she likes to eat. Soon after the operation, she savored her first slice of cheese pizza. "She told me she never knew food could taste so good," said her mom, Ruth Singh.

A year later, pizza is still Stephanie's favorite--with macaroni and cheese and homemade soups close seconds. And Stephanie is also experiencing other things common among kids her age. Soon she'll fly to Orlando, Fla., for a visit to Disney World, where she hopes to meet Minnie Mouse. Then, when she returns, she plans to start fourth grade.

* * *

HOW YOUR INTESTINE WORKS

The intestine is a long tube made up of two parts. The first part is the SMALL INTESTINE, which is 2.5 centimeters (1 inch) wide and 6.5 meters (22 feet) long. The small intestine receives partly digested food from the stomach and digests it further. The resulting nutrients are then passed through the wall of the small intestine into the bloodstream, and the indigestible food moves along into the large intestine. The LARGE INTESTINE is almost three times wider than the small intestine but only

one-quarter as long. It eliminates food that can't be digested from the body in the form of feces.

The inner wall of the small intestine is lined with millions of tiny fingerlike projections called villi. The millions of villi increase the inner surface area of the small intestine to the size of a tennis court. That large but compact surface area maximizes the small intestine's ability to pass food into the bloodstream.