

# Brainstorm to Breakthrough: A Surgical Procedure Is Born

By DENISE GRADY

In the early 1990's, while he was a medical student, Heung Bae Kim watched a difficult intestinal operation on a child and found himself thinking there had to be a better way. As he watched the surgeons work, a radically different approach began to take shape in his mind. Later, he sketched it out and showed it to one of his professors, a surgeon.

"He said it would never work," Dr. Kim said. "Being a student, I just sort of chalked it up as a stupid idea and forgot about it."

But the idea came back to him 10 years later, after he saw the arduous operation performed again. By then, Dr. Kim, who went to medical school in New York City, had moved on to Children's Hospital in Boston, and was completing a fellowship in pediatric surgery.

This time, he sketched his plan for another surgeon, Dr. Tom Jaksic.

"I just thought it was brilliant," Dr. Jaksic said. "And we certainly had a patient who could use it."

The patient was Alex Malo, a year-old baby from Beverly, Mass., whose small intestine was too short to function properly. The standard operation to lengthen it had failed, and Alex, unable to eat, had to be fed intravenously. But he could not stay healthy indefinitely with that kind of feeding. His parents and doctors were desperate for another way to help, and Dr. Kim's idea to create a longer, better-functioning intestine

looked promising.

"I had little doubt that it would work," Dr. Jaksic said.

A clever idea, a desperate family, a pair of doctors willing to do the unorthodox: it was a classic tale of how a new operation is introduced into medical practice.

Surgeons who want to try something new have a great deal of leeway, because new operations, unlike new drugs, are not regulated by the

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government. As a result, many surgical techniques have simply been brought into practice by doctors who invented them, started using them and then taught them to colleagues. But that approach did not appeal to either surgeon.

"We didn't just think of it and grab some kid and do it on him," Dr. Kim said.

The two surgeons wanted to determine the safest way to take Dr. Kim's idea from a sketch to a patient — and yet do it in time to save Alex.

The new operation was so different from anything done before that Dr. Kim and Dr. Jaksic decided they had to test it first on animals. Then, if it worked and was safe, they would seek permission from their hospital's ethics board to perform it on babies.

With Alex in mind, they moved ahead as fast as they could with animal experiments.

"Time really was running out for Alex," Dr. Jaksic said.

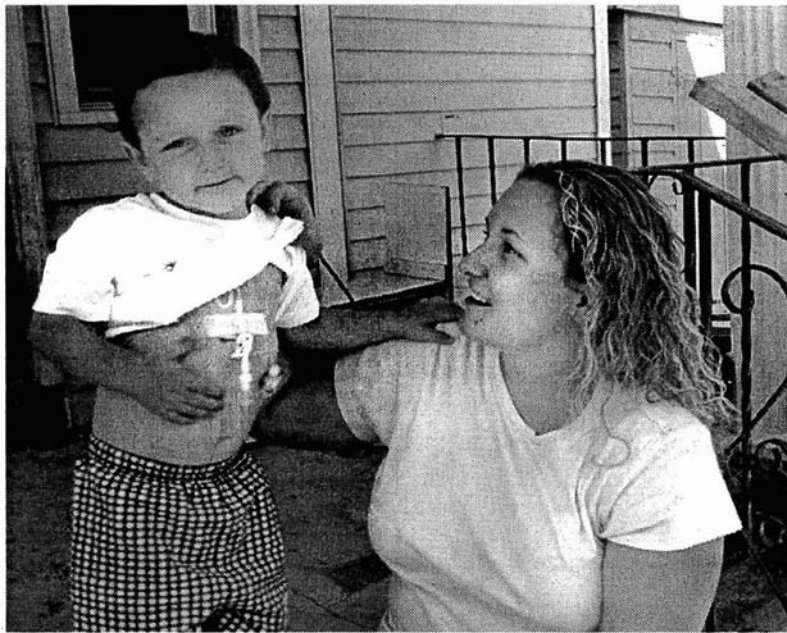
Alex Malo was born with several feet of his small intestine hanging outside his body. The loop of intestine had slipped out through an abnormal opening in his abdomen while he was still developing in the womb. The tight opening pinched the intestine, cutting off its blood supply and killing the tissue. The day Alex was born, doctors operated to remove the dead stretch of intestine.

His remaining small intestine was too short to absorb enough nutrients to keep him healthy. In that condition, short bowel syndrome, the intestine tries to compensate by dilating, but that only makes matters worse. When it dilates, the bowel loses its ability to perform peristalsis, the contractions that move food through the digestive tract. Food builds up in the stretched-out part of the intestine. Bacteria feast and multiply excessively. Infection looms. Unable to eat, the child becomes malnourished and sick.

Doctors estimate that 20,000 people in the United States, children and adults, suffer from intestinal failure; many have short bowel syndrome. In babies, the disorder can result from a birth defect like Alex's or from problems linked to prematurity.

For a time, a child with short bowel syndrome can be kept alive by a special type of intravenous feeding called total parenteral nutrition, or T.P.N. But many children who receive all their nutrients this way develop liver failure within a few years. Doctors are not sure why; many suspect that T.P.N. starves the liver. In any case, once the liver fails, the child will die without a transplant of both the liver and the small intestine. But small intestine transplants are risky, with high rates of rejection, infection and death.

Sometimes surgery to narrow and lengthen the intestine can help it work better, get a child off T.P.N.



Alex Malo and his mother, Erica McNeil, at home in Beverly, Mass. Dr. Heung Bae Kim, far right, devel-

and prevent liver failure. When Alex was 11 months old, he had such an operation, called a Bianchi procedure, in which surgeons divided the dilated part of his bowel lengthwise into two narrower tubes, separated them and joined them end to end. The operation appeared successful at first, but Alex still could not eat, and his bowel dilated again.

Meanwhile, Dr. Kim and Dr. Jaksic were testing Dr. Kim's new operation on pigs, and it was working.

It was the difficulty of the Bianchi procedure, Dr. Kim said, that drove him to devise an alternative. The concept of the new operation is so simple, he said, that when he shows it to other surgeons, many say they are surprised nobody thought of it before.

Surgeons make a row of slits along the dilated stretch of intestine, alternating from one side to the other and stapling shut the edges of each side of the "V" that results. They use a small surgical stapler, which both cuts and staples. What results is a zigzag tube that is much longer and skinnier than the original distended bowel. The surgeons named the operation the STEP procedure, for serial transverse enteroplasty.

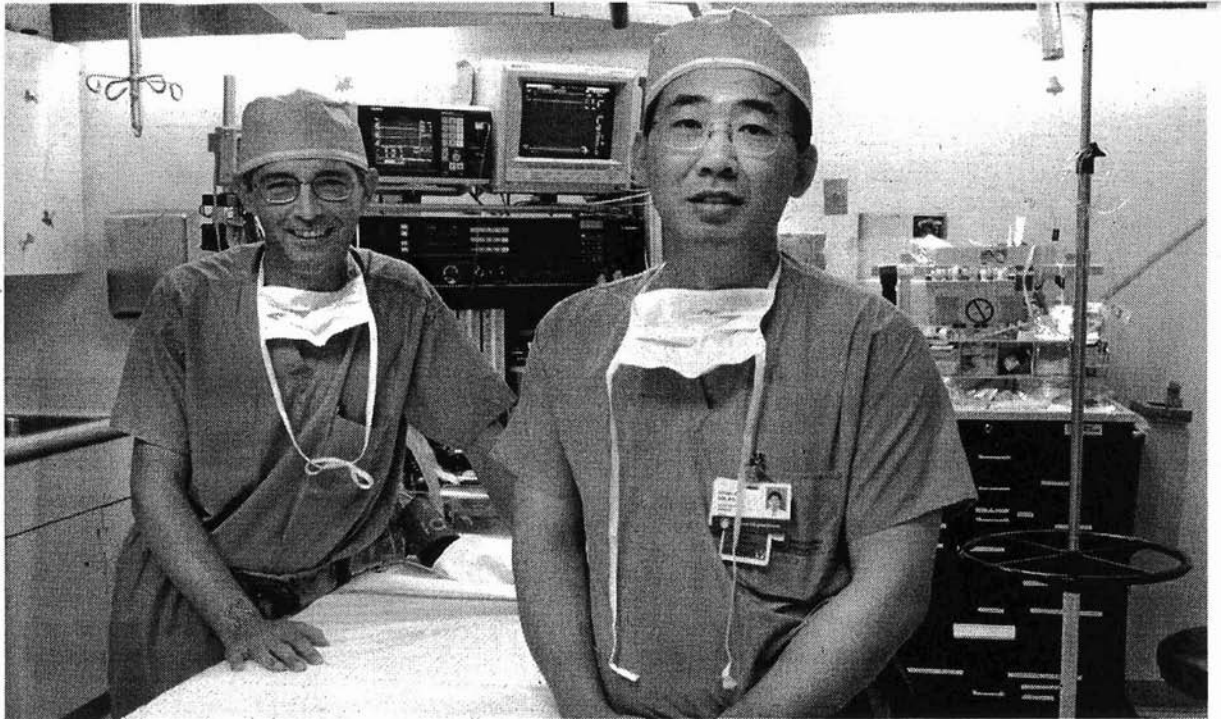
As his second birthday approached, Alex was still on T.P.N., and doctors feared that liver damage was inevitable. He was also suffering repeated infections from the intravenous line, often with a 105-degree fever, and had to be dosed again and again with antibiotics. His mother, Erica McNeil, grew frustrated and anxious as months passed with no improvement. She knew his doctors were trying to develop an operation that might help him, and she kept asking about their progress. The animal experiments and other preparations took them about a year.

Ms. McNeil said that when the surgeons finally described the opera-

tion to her, they urged her to take time to think it over and discuss it with her family.

She recalled: "I said, 'I'd prefer not to wait until his liver failed. We're getting nowhere. If you think this is going to work, just go for it.'"

Dr. Jaksic and Dr. Kim consulted the hospital's institutional review board, which has a special consent process for innovative procedures.



Photographs by Rick Friedman for The New York Times

eung Bae Kim, far right, developed the technique that he and Dr. Tom Jaksic used to operate on Alex's intestine.

Ms. McNeil said. "It's kind of difficult to sign a piece of paper saying there could be a fatality."

But frightening as it was, she added, she believed the surgery was her son's best chance at survival.

In February 2002, a month before he turned 2, Alex became the first patient to have a STEP procedure. The operation, which involved 28 slits, added about two feet to his small intestine, making it six to seven feet long, about the right length for a child his age. So far, his bowel has not dilated again. Tests show that his small intestine's ability to absorb nutrients has climbed into the normal range.

Gradually, Alex is being weaned from T.P.N., but getting off it completely may take a few years, Dr. Jaksic said. Alex now receives only about half his nutrition that way. The other half comes through a stomach tube. That should be enough to spare his liver, Dr. Jaksic said.

Alex does not yet eat much. Because of his long illness, Ms. McNeil said, he developed an "oral aversion," meaning he is reluctant to put food in his mouth. The condition is not uncommon in children who have had digestive disorders, and therapists are working with Alex to help him develop an interest in eating.

In every other way, Ms. McNeil said, he is a normal little boy, and she hopes he will be able to enter preschool this fall.

"He never stops talking," she said. "He runs, he rides his bike, digs in the ground, plays with trucks. He loves computer games. He slides off the couch on his stomach despite the tube, and gives me heart failure. He loves playing with other kids. He's never noticed he's different, that they don't have stomach tubes and he does."

Since operating on Alex, Dr. Kim and Dr. Jaksic have performed

STEP procedures on three other children. One came off T.P.N. completely, Dr. Jaksic said. Another, who had suffered liver damage and was headed for a transplant, regained normal liver function. But a third had irreversible liver damage and eventually did need a transplant.

The surgeons and their colleagues have also published two articles on the operation in *The Journal of Pediatric Surgery* and described it at medical conferences. The idea is catching on, Dr. Jaksic said, adding that he knew surgeons had used the technique in Alabama, Nebraska, Michigan, Ohio and Canada.

"As this operation spreads throughout the world, the main question will be, what is its overall effectiveness?" Dr. Jaksic said. "We would like to start a worldwide registry to follow up the cases."

Dr. Mark Siegler, director of the MacLean Ethics Center at the University of Chicago, said Dr. Kim and Dr. Jaksic deserved high praise for working with an institutional review board and a special consent process. But now, he suggested, they would be the ideal ones to organize the first study of patients who have had the procedure, to see how well it really works, and in which patients.

Dr. Jaksic said: "We don't think this is a panacea for short bowel syndrome. But it will certainly aid some children. It can be taught and done easily, and done around the world."

Dr. Kim said he had not discussed the new operation with the surgeon who told him a decade ago that it would never work.

"You have to have the right environment," he said, "where people are open to new ideas and really try to push the envelope with innovative surgery, for this kind of crazy idea to eventually make it to the bedside to treat children with disease."

In addition to making sure the family understands that an operation is new, the process requires that other doctors evaluate the idea and judge it reasonable. The board approved STEP.

"They make you sign a million pieces of paper saying you know this is innovative, it's never been done before, a fatality could occur, they don't know, they don't think it will,"

# Lengthening the Small Intestine

A new procedure can correct short bowel syndrome, a condition resulting from the surgical removal of part of the small intestine because of disease or birth defect. The remaining intestine widens, and can no longer work properly.

NORMAL BOWEL



SHORT BOWEL



## STANDARD PROCEDURE



In the Bianchi procedure, the widened bowel is cut lengthwise to form two narrower sections. These are attached to each other end to end, making a narrower, longer bowel. However, the bowel often widens again over time.

## THE NEW PROCEDURE



For the new procedure, called serial transverse enteroplasty or STEP, surgeons use a cutting stapler on alternating sides of the widened bowel. The slits are pinched together by the stapler to reshape the intestine into a longer, narrower zigzag passageway.

Source: *Children's Hospital Boston*