After spending his whole life watching other kids from his window, Mickey can finally play baseball and ride the bike he got for his eleventh birthday.

HARRY BENSON

the Comeback Kid

When **Mickey DeMartis** was 6 months old, doctors gave him a 2 percent chance of survival. Try telling him that now.

BY ESTHER DAVIDOWITZ

Mickey DeMartis, age 10, was dying. He'd survived a risky heart operation—his seventh—only 36 hours earlier, but now it appeared that something was terribly wrong.

"You have a *very* sick boy," a nurse whispered. Michael and Kathy DeMartis of Commack, New York, had heard such agonizing comments before. From the day their son was born with two holes in his heart and a seriously defective artery, he'd been given little, if any, hope of survival.

As Mickey grew into a toddler, his condition remained precarious. He often turned blue. One doctor predicted that the boy would not make it past age 4. Yet he continued to defy these predictions for more than 10 difficult years.

This time, however, doctors told Kathy and Michael it was only a few days before their son's heart would give out.

That was less than a year ago. Today Mickey, an outgoing, jovial 11-year-old, is playing catch with his schoolmates and, for the first time in his life, riding a bicycle.

Mickey and his parents defied the odds. Theirs is a story of how one ordinary family managed to beat the medical odds again and again. It is a story of determination, courage, hope and, most of all, love.

"We had to try."

May 23, 1983, the day Mickey was born, should have been one of the happiest days of the DeMartises' lives. Their daughter, Tracey, was 2½. A son completed their family.

Only 20 minutes after Mickey took his first breath, he suddenly "turned blue," Michael reports.

Doctors discovered that Mickey's pulmonary artery was as thin as a piece of thread. (The average newborn's is four times larger.) "He had profoundly restricted blood flow to his lungs," says Dr. Fredrick Z. Bierman, M.D., the boy's pediatric cardiologist.

Mickey's condition was extremely rare and often fatal. His parents could only pray that their son's artery would grow or that a cure would be found *before* it was too late. "We waited for a miracle every minute," Kathy says.

Although other blood vessels provided enough oxygen to keep Mickey alive at first, his need for oxygen grew as he did. By the time he was six months old, his lips, fingers, toes and nose were blue. Sometimes he'd pass out just from crying. "I was a nervous wreck," confides Kathy, 38. "I couldn't sleep. I kept putting my finger under his nose to see if he was still breathing."

Dr. Bierman says, "He was as sick as one can be and still survive." Doctors could think of only one way to help: Open up the infant's chest and try to attach an artificial blood vessel—a shunt—to get more blood to his lungs.

At best, this was only a temporary solution; the artificial blood vessel couldn't grow along with Mickey. What's more, the shunt would strain his overtaxed heart, and the surgery was very risky. "We were told he had an eighty percent chance of dying on the operating table," reports Michael, 40, a purchasing director. "One surgeon even had the gall to say that it would be best to lose Mickey at six months because he wouldn't live past four anyway."

When the first attempt to put in the shunt failed, doctors tried again. This time, his parents say, Mickey was given a 2 percent chance of survival. "We were beside ourselves," says Michael. "But if there was a glimmer of hope, we had to try. I told them two percent was all Mickey needed."

The surgery was a success, but, says Kathy, "the more he grew, the worse he got. It was terrifying." Another shunt was put in two years later. "We kept hoping that if we just kept him alive, technology would catch up," Michael adds. Mickey's new shunt had to be replaced when he was 4 and again at age 7.

"It was his last opportunity."

Despite temporary improvement after surgery, the boy's condition kept deteriorating. He was unable to spend more than three or four hours a day at school. Much to his chagrin, his lips would often turn purple. "I'd tell my friends I was cold—or just had a purple lollipop," Mickey confides. "I didn't want them to think I had something contagious." Nevertheless, the youngster says, "No one would hang out with me at recess. I was real sad. I'd think how lucky those other kids were. I'd wish I could run around, too."

By fourth grade, Mickey had grown so weak he had to be tutored at home. "I didn't get to see my friends," he says. "I was bored and frustrated." Sometimes just getting dressed was too strenuous. Often all Mickey could do was play cards with his sister, Tracey, 13, or watch from his window as other kids played ball or whizzed by on their bikes.

"I'd cry," Mickey now recalls. "It wasn't fair to be unable to have fun like everyone else." He tried not to complain, though. "He kept telling us not to worry," Kathy says. "He was always more concerned about us than himself."

The young boy also tried to squelch his fears. "Every time I went into surgery, I'd think about dying. But I knew it had to be done—and I knew I'd be a little better each time."

Mickey's parents tried to be strong, but sometimes their anguish was too great. "At times I felt like running away," Kathy says. Often, she'd weep in her bedroom. Michael would cry on his way to work.

The couple bought a special bicycle built for two and pedaled Mickey around. "I loved going downhill and feeling the wind in my face," Mickey recalls. They went sleigh-riding and took turns pulling the little boy uphill. "Mickey made us realize how precious life is," Kathy says.

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'1994'

Tracey, Kathy, Mickey and Michael DeMartis

"Instead of fretting over things we couldn't do, we concentrated on things we could do."

In January 1993, Mickey's condition worsened again. He often needed an oxygen tank to breathe. His arteries had not grown enough for more shunts. There was only one extremely long shot left: a heart and lung transplant. But hearts and lungs are difficult to obtain. Then Mickey was turned down for a transplant. He had too much scar tissue from all his other operations.

Profoundly scared and saddened—"I couldn't look at Mickey without bursting into tears," Kathy confides—the parents refused to give up. "We'd brought Mickey this far. What were we supposed to do? Just watch him die?"

Quickly, with a doctor's help, the couple drew up a "fact sheet" detailing Mickey's medical history and sent it off to hospitals and doctors across the country. They hoped there was a surgeon somewhere who could perform miracles.

One evening their phone rang. A doctor who'd received the fact sheet was on the line. "If it were my son," he declared, "there's only one doctor I'd take him to: Aldo Castaneda."

The DeMartises quickly made an appointment.

Dr. Castaneda, chief of the cardiac surgery department at Children's Hospital in Boston, carefully studied Mickey's files. Then he made a pronouncement that reduced the boy's anxious parents to tears. "He said he thought he could fix Mickey's artery," Kathy says. "For the first time in years, someone was telling us that our son had a future—that his artery could be *repaired*. I couldn't even say that word. I'd just cry."

With the help of Jim Lock, M.D., chief of the department of clinical cardiology, Dr. Castaneda planned to rebuild parts of Mickey's pulmonary artery. If he was successful, the artery would function like any other. But it would require four highly intricate procedures, including open-heart surgery, and would not be easy.

The first three procedures went well. On December 1, 1993, Mickey was wheeled into surgery for his final and most risky operation. His last words to his parents: "I'll be back."

"We were so frightened," Kathy remembers. "We didn't know if we'd ever see him again." Seven long, torturous hours later, Dr. Castaneda emerged and announced that the surgery went well. "I put my arms around him and wouldn't let go," Kathy remembers. Now, finally, the couple thought, their constant turmoil and pain were over.

"Death was knocking at his door."

They were wrong. Mickey did not bounce back from the operation. "At first we thought he was just weak from the surgery," says Kathy. As time passed, however, it became obvious that he was in deep trouble. He needed more and more medication just to keep his heart pumping. "We didn't know what was wrong, but we knew it was really bad," says Kathy.

Dr. Lock explained that the second hole in Mickey's heart, which had not caused problems before, was now killing him. Although surgery could easily close the hole, Mickey's weakened heart could not tolerate another open-heart surgery.

"Is there any hope?" Michael asked.

"Well," the doctor answered, "there is a device that might be able to close the hole without surgery." The device, which he had invented, would snake through a vein, then expand like an umbrella to plug the hole. But, Dr. Lock explained, the device had been tested and found to have a faulty part. The manufacturer had decided it had to be redesigned and was not making it available.

Mickey wasn't the first patient who needed this device. The hospital had tried numerous times to get one, but had not succeeded. Kathy and Michael knew it was up to them to persuade the manufacturer to release the device for their dying son. And the manufacturer told them (incorrectly, it turned out) that they had to have approval from the Food and Drug Administration (FDA) in order to release it.

And Mickey didn't have much time.

"It was Friday noon; we had to do it *before* offices closed for the weekend," Kathy explains. "Mickey was too sick to wait until Monday. That was the most frightened we ever were."

The couple enlisted the aid of four relatives and got to work. "We scattered to every pay phone in the hospital and began calling everyone we knew," Kathy says. "We called friends, relatives, doctors. We called our senators and every legislator we could think of. We pleaded with everyone to call the FDA to ask them to help us get the device." They even faxed the president.

"My son is dying," Kathy sobbed over the telephone. "You *have* to help me."

When it seemed there was no one left to call, the couple waited anxiously by the phone. "Mickey had a broken heart," Kathy declares, "but so did I. I believed I couldn't live without him—

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Eat More, Weigh Less

CONTINUED

The key to weight-loss success is finding a fat level you can live with—without depriving yourself of nutrients, needed calories or the joy of eating. The charts on these pages can help you determine how much fat you can eat, make low-fat choices, and work exercise into your schedule—no matter how busy you may be. WD

WHAT'S YOUR FAT ALLOTMENT?

Find the calorie count that's closest to what you eat when you're not dieting. Then look down the column to find your fat limit if your diet is 10 percent, 20 percent or 30 percent fat. (Packaged foods list fat grams per serving on the label.)

	DAILY CALORIES		
Fat in Diet	1,200	1,500	2,000
10%	13 g	17 g	22 g
20%	27 g	33 g	44 g
30%	40 g	50 g	67 g

The Magic of Exercise

How can some people eat more food—even more calories—than others and remain thin? By staying active. Swimming, biking, walking, gardening, housecleaning, climbing stairs and other activities burn calories and boost metabolism. Strength training (weight lifting and calisthenics) builds muscle, which burns more calories than body fat does.

To lose weight, first cut the fat in your diet without restricting calories, then add exercise. These charts suggest two different ways to burn 1,000 calories a week; choose the schedule that best fits your lifestyle. (Numbers are approximate, since we all burn calories at different rates.)

Fitness-Oriented Exercise

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
bike 30 min, 6 MPH (120 cal)	walk 30 min, 3 MPH (155 cal)	calisthenics, 15 min; walk 15 min (150 cal)	swim 30 min, 25 yds per min (135 cal)	bike 30 min, 6 MPH (120 cal)	walk 30 min, 3 MPH (140 cal)	strength-train 15 min; walk 15 min (175 cal)

Lifestyle Exercise

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
walk 30 min over course of day at 2 MPH (120 cal)	clean house, 45 min (190 cal)	mow lawn 20 min; rake 15 min (210 cal)	walk to & from movie at 2 MPH, 30 min (120 cal)	walk 20 min at 2 MPH to & from lunch (80 cal)	ballroom dance, 50 min (175 cal)	walk 20 min to & from store on hills (110 cal)

The Comeback Kid

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and I was terrified that I'd have to."

The minutes kept ticking away. "Mickey was dying," Kathy says. "I know the look. I watched my parents die. I knew death was knocking at his door." Then, with only 15 minutes left in the workday, Dr. Lock reported that the hospital would be able to use the device after all. Within an hour, it arrived by car from the manufacturing plant.

"Never give up; there is always hope."

Kathy and Michael were greatly relieved at first—then terrified. What if the experimental device didn't work? Michael, sobbing, could barely sign the consent form. "The paper was all wet. We didn't know if we were consenting Mickey's life away," he explained.

Each minute seemed like an eternity while doctors worked on Mickey. "We were shaking and holding on to each other," Kathy recalls. Then finally, four hours later, the family received the news they'd been longing to hear: The hole was finally closed and Mickey's heart was working fine. "We hugged the doctors and each other," Michael says.

Three weeks later, Mickey came home. Then, in April 1994, five months after the surgery, he returned to school.

Today, Mickey can bound up and down stairs without becoming breathless. He can play kickball with his friends. He can run around the bases and chase balls in his baseball league. "The first morning of baseball practice," his mother says, "he had his uniform on before we were out of bed." And Mickey can finally do the one thing he always dreamed of: He can ride a bike. "It makes me feel proud to do things like everyone else," he says. "I don't have to sit in the house and watch anymore."

His parents and sister are proud too. They say that Mickey's experience, as heart-wrenching as it was at times, has taught them all a valuable lesson: "Never take life for granted," Kathy says. "Live each day like it's your last so you can live it fully."

She adds, "Mickey taught us to never be afraid to say the hardest three words in the English language, 'I love you.' He says it so often. Yet it means so much every time he says it.

"Mickey taught us how to love when we thought we already knew how," Kathy continues. "And he taught us to never give up hope. When everyone kept telling us there was no hope, he would always pull through. We know that there is always hope." WD

All in the Family

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you don't have to worry about entertaining anybody," Beth says. "There's lots of food, lots of activity, and everybody has a good time."

A few years ago, Beth took a cruise with her husband, her teenage sons and her 75-year-old grandmother and was delighted to find that no one was bored. "While I sat in a deck chair, the kids went to the disco and Grandma played pinochle with three new friends she'd made. We had a ball."

Some families are more adventurous. Take Bob and Jeri Safarik of Lawrence, Kansas. Several years ago, they took a cross-country van trip from Colorado to California. Behind them in another van were Bob's parents, John and Helen, and his brother Dan's family. Using a CB radio for communication and a seat-of-the-pants approach to itinerary planning, they stayed in campgrounds and motels they found along the way. Since then there have been several other trips. "Everybody has a good time, and we get to know our children and grandchildren better," Helen says.

Not that they don't run into bumps in the road. "Whenever you get a lot of personalities together in a closed space over a long period of time, it becomes difficult to meet everyone's expectations," says Jeri. "For example, my in-laws' driving

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