

# Newsweek

## 15 People Who Make America Great

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*With this issue, Newsweek launches the "Giving Back Awards" in recognition of people who, through bravery or generosity, genius or passion, devote themselves to helping others. From hundreds of nominations, these folks were chosen for imaginative approaches to difficult problems. We hope they remind you of someone—maybe yourself.*



### **THE GENIUS**

Frederick Kaplan  
University of Pennsylvania

The disease was so rare, nobody wanted to deal with it, until he came along.

Gentle Healer: Kaplan, with Daniel, 12, says he won't quit until there's a cure  
Alessandra Sanguinetti for Newsweek

Dr. Fred Kaplan can't stop thinking about his kids. Daytime, nighttime, weekends. Their pictures cover his office walls; their smiles line the hallway of his lab at the University of Pennsylvania School of Medicine in Philadelphia. And their letters ("Your the best Dr. in the howl wild world") hang next to his desk, displayed more proudly than any medical degree or award. Kaplan's kids are his patients, children with a rare and immobilizing disease called fibrodysplasia ossificans progressiva. The first time he saw a child with FOP, says Kaplan, "it had the emotional impact of an atom bomb."

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FOP, which strikes roughly one in 2 million people worldwide, causes muscle and tendon to morph into hardened bone, imprisoning children in a second skeleton. The horror of the disorder—shoulders, hips and jaws fuse into locked positions—propels Kaplan's scientific mission. The children, whose average life span is 45, drive his devotion. Kaplan, 54, has spent more than 15 years unraveling the molecular and genetic blueprints of FOP. Early on, his colleagues told him he was wasting his time on a disease that afflicts fewer than 300 people in the United States. But Kaplan powered on. "It was a compelling problem screaming for a solution," he says. And nobody else was helping. "I wanted a mountain to climb."

In April, Kaplan, along with his colleague Dr. Eileen Shore, his team at Penn and international collaborators, reached the summit: they pinpointed a single gene mutation—one letter out of 6 billion in the human genome—that causes the runaway bone growth of FOP. Uncovering the "master key to the skeleton," as Kaplan calls it, could have dramatic implications. With a genetic target in hand, scientists may be able to design a drug that turns off the bone-growth switch in FOP. The discovery could also have an impact well beyond FOP, stopping the complication of extra bone growth after hip replacements or spinal-cord injuries. One day, says Kaplan, the skeleton key might even allow researchers to grow bone in a controlled way, helping people who suffer from osteoporosis or fractures that fail to heal. A rare disease? Yes, but as Kaplan suspected from the very beginning, one with universal applications.

As of now, there is no cure for FOP, no way to stop the explosion of new bone, which is exacerbated by falls, bruises, injections and surgery. Even today, few doctors know about the disease—close to 90 percent of patients are initially given incorrect diagnoses, including cancer. The FOP gene discovery gives Kaplan's patients great hope for the future, but it is his compassion and infectious optimism that keep them going day to day. Fred, as he's known to just about everyone, takes calls in the middle of the night and on weekends, always ready to answer questions and soothe concerns. "I don't think the poor man sleeps," says Carol Zapata-Whelan, whose son Vincent was diagnosed with FOP in 1995. "He has so much spirit and so much love and understanding," says Lori Henrotay, whose daughter, Carli, was diagnosed in kindergar-ten. The first time they met, Kaplan played patty-cake with Carli. "He knows how to make kids

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comfortable during a very scary time," says Lori. Carli, now 10, has bumps of extra bone on her back, and her jaw and right hip have fused. Still, she says she feels "lucky" to know Kaplan. "He gives us hope," she says. Daniel Licht, who was diagnosed on his 3rd birthday, remembers playing soccer with Kaplan, his "friend," in the long hallway of his lab. One recent day in the exam room, Kaplan's hands rested gently, reassuringly, on the bony knots on Daniel's back, neck and shoulders. When the visit was over, Daniel, now 12, smiled. He says he knows why Kaplan works so hard: "To help kids like me."

That help comes at no cost—Kaplan has never charged an FOP patient. "I find it unconscionable," he says. "Who else are they going to turn to?" Kaplan's salary comes from the university and an endowed chair; the majority of his research dollars are raised by FOP families at barbecues, golf tournaments and garage sales. Last year's total: \$1.2 million. Kaplan says he won't quit until there's an effective treatment—and a cure. In the meantime he's cultivating young talent. This summer Vincent Whelan, now 19 and a pre-med student, will spend a week working in Kaplan's lab. "Dr. Kaplan has really inspired me to want to be a doctor," he says. A great legacy for a hero of a man.

—Claudia Kalb