THE POWER OF ONE

Rx: Home Care.

A mother works to get sick kids the help they need—where they need it

CAROLINE KENNEDY

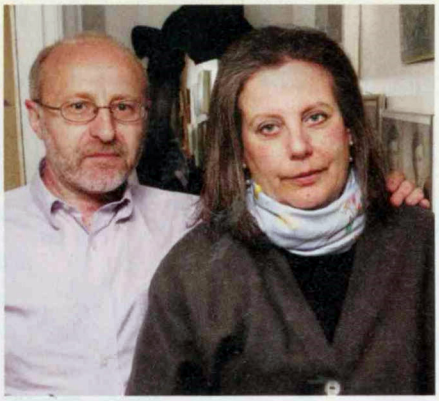
ONE OF THE MOST INTRIGUING QUALITIES OF extraordinary people is that they often don't feel that they are special. As they transform the lives of those around them, they say they are just doing what they have to do. Margaret Mikol is one such hero. In 1978, her daughter Julia was born with severe combined immunodeficiency, which required her to be kept in a completely sterile hospital environment—like the "boy in the bubble." When Julia was 3 months old, she had a bone-marrow transplant that left her with a functioning immune system but unable to breathe on her own. Her hearing was impaired as well. She spent the next two years in the intensive-care unit at Memorial Sloan-Kettering Hospital in Manhattan.

Margaret moved into the hospital with Julia; her husband Yves continued working back home in Maryland and commuted to New York City on weekends. Julia's hospital bills were about $350,000 annually. The Mikols quickly exhausted their medical insurance and had to rely on Medicaid. Caring for Julia at home would have been about $50,000 a year, but while the Federal Government would reimburse hospital care, it wouldn't cover the cost of caring for a child at home.

'I had been a shy and timid person ... I changed into a beast to protect my child.'

—MARGARET MIKOL, FOUNDER OF SICK KIDS NEED INVOLVED PEOPLE

Determined to create something closer to a normal family life for their daughter, the Mikols applied to a new federal program that allowed Julia to retain Medicaid coverage while being cared for at home. After a lengthy bureaucratic struggle, Margaret and Yves became the first parents in New York and the second parents in the nation to take home a child on life support. "The process transformed my personality," says Margaret. "I had been a shy and timid person, and I became brassy and obnoxious. I changed into a beast to protect my child."



On a mission *Clockwise from top left: SKIP founders Yves and Margaret Mikol; a gallery of family photos in their home; the Mikols with son Jonathan, 21; a baby photo of their deceased daughter Julia*

For the next five years, the Mikols did everything they could to give Julia a normal childhood. But when Julia's condition worsened, the 8-year-old refused the recommended heart-and-lung transplant, and her parents reluctantly agreed with her decision. Before her death, Julia asked her mother to promise to help other children. "You got me home," she told Margaret in the sign language she used to communicate. "You've got to get them home too."

Sick Kids Need Involved People (SKIP) is the fulfillment of that promise. The organization has helped more than 7,000 families deal with the myriad issues that come up with home care for children on life support as well as those battling cancer, HIV/AIDS, sickle-cell anemia, muscular dystrophy, cerebral palsy, autism and other conditions. Margaret and her staff of 250 help families navigate the hospital, insurance and Medicaid systems; assist them with school and housing issues; and counsel parents on how to care for the healthy siblings of a sick child.

Some SKIP clients, like Amy Goldman Putman, are relatively fortunate. Her son Jacob was born with serious lung disease and related complications. For the first few years of his life, he was dependent on a respirator and needed a feeding tube and round-the-clock nursing care (he threw up 18 to 20 times a day), all of which kept him going in and out of the hospital. Putman thought she was on the verge of a nervous breakdown. "When Jake was born, the world as I knew it disappeared," says Putman. "Margaret knows the patient's rights, comes up with a plan, tells you what you need to do and somehow makes it happen," Putman says. "But most important, she gives you hope." Jacob, now 14, is able to participate fully in school and recently traveled to Europe.

MORE ON HELPING SICK CHILDREN

For more about the organization Sick Kids Need Involved People (SKIP), go to **www.skipofny.org**

Other parents like Claudine Votto, the mother of four autistic children—4-year-old triplets and a 3-year-old son—fear that their children will need assistance throughout their lives and worry about who will help them get it. "I called so many agencies looking for help, and SKIP was the only one that even called me back," she says. But there is a waiting list of thousands more families that SKIP, on its shoestring budget, cannot take on without additional resources. Margaret hopes one day to be able to build a clinically staffed residential community. "These families need a respite; they never get a break. They need to be supported in this effort," she says. "Yet it is just indescribable how hard we make it for them. There is so much need wherever you look—all you need is a heart." A heart like Margaret Mikol's. ■