

*The New York Times*

# A FAMILY BATTLES TO HAVE GIRL TREATED AT HOME

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Published: June 21, 1983

Four-year-old Julia Mikol of Manhattan, who was born without an immune system, has been hospitalized frequently and for extended periods during her short life.

Her parents want her treated at home but because of Federal rules, have been forced to keep her in hospitals so that her expensive treatment could be covered by Medicaid. Now, Julia's family believes it has been able to work out an arrangement so that she can qualify for Medicaid but receive the care she needs at home.

Her case, medical experts say, has become a poignant reminder to parents and to officials of the Medicaid program that perhaps thousands of other handicapped children are being institutionalized across the nation at great expense to taxpayers and with much pain to families when they could obtain the same medical care at home.

Julia's lack of immune system made her unusually susceptible to a variety of infections. Her case is similar to that of Katie Beckett of Cedar Rapids, Iowa. Katie attracted national attention in 1981, at the age of 3, when President Reagan intervened to help her return home from a hospital without losing the Medicaid coverage to the pay the bills for her continuing health care. A Fifth of the Cost

Much progress has been made toward giving Julia a normal immune system. Other serious problems remain, however, but they are problems that doctors feel can be treated at home, at a fifth of the cost of hospital care.

Julia cannot speak. Her hearing is badly impaired. Her right lung is in constant danger of collapse so that she is almost constantly connected to a respirator. Her body fills up with fluids and she needs a suctioning machine to relieve the condition several times a day. About two years ago, she was in such pain from a bone-marrow transplant that she required heavy doses of morphine, became addicted to it, and had to undergo withdrawal by using methadone, under hospital supervision.

Margaret Mikol, Julia's mother, said that last March, nurses and physicians at New York Hospital thought that Julia could go home, something that she and her husband, Yves, a Paris-born toxicologist now employed in research at Memorial Sloan-Kettering Cancer Center, had preferred.

An older brother, Christopher, died of the same genetically caused disorder a few years before and both parents felt that whatever happened now, they wanted Julia at home. Eligibility Reviewed

At that point, Medicaid had been paying the \$250,000 to \$300,000 a year it cost to treat Julia. Under Federal regulations, a child under 18 who requires institutionalization is considered separated from the parental household and therefore meets the income requirements for Medicaid. But after Julia came

home, her parents received word that her Supplemental Security Income status, which is used to determine Medicaid eligibility, was being reviewed. Then Medicaid was apparently terminated, although the Mikols received no formal notice.

But Julia's monthly Medicaid card did not arrive by May 1. That meant that the estimated \$50,000 it cost to keep Julia at home a year would have to be borne by her parents, a middle-income couple. They retained Ellice Fatoullah, a Manhattan lawyer specializing in health law, who was prepared to initiate a lawsuit to challenge the system.

However, Larry Knappe, deputy administrator of the Medical Assistance Program in New York City's Human Resources Administration, ordered a waiver of the rules and a Medicaid card was issued.

#### Sending Affidavits Along

Since the city Medicaid program is financed by the Federal Government, Mr. Knappe, aided by Miss Fatoullah, is submitting the affidavits that will go to the Secretary of Health and Human Services in Washington.

Approval of the department is essential if Julia is to keep her Federally financed Medicaid card. It remains unclear, however, as to when Washington will act or if it will uphold Mr. Knappe's decision. If there were a Federal turndown, the state would have the option of picking up her expenses.

"It is exactly the same as the Katie Beckett situation," said Mr. Knappe. "I think there are other children out there in the same situation - children who could be cared for at home at much less cost to the taxpayer but with a much more satisfying relationship with parents." Miss Fatoullah said she thinks there are thousands of such children in the state.

Julia seems to be a happy child who enjoys playing with her father's computer and learning how to communicate with other children at the Pre-School Learning Laboratory she attends at the Institute for Rehabilitation Medicine of New York University.

Ronnie Gordon, associate professor of clinical rehabilitation medicine at the institute and director of the school, said Julia is "doing amazingly well." Julia is learning a makeshift sign language, communicating with other children and actually walking, even though she remains tethered to her respirator. She is "animated, motivated and interested," said Professor Gordon.