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**Abstract**

This brief story is about a young boy who was adopted by his nurse after spending the first four years of his life in hospital because of his disability. She describes her experiences as a single parent, the changes the adoption caused in her life and the support of family and friends. **Keywords: Families**



## "He's A Delightful Kid"

Eight-year-old Rene spent his first four years living in a New York hospital intensive care unit. Suddenly, at age four, all his dreams came true when one of his nurses, Joann Colucci, took him home to live with her and began adoption proceedings. "Rene knew about families from books," Joann remembers, "and all he wanted was a home and family. In fact, when he came home he had a major adjustment problem because he was so afraid he'd have to go back."

Rene was born with Ondine's Syndrome (known medically as central alveolar hypoventilation syndrome), which means he is unable to breathe consciously. The condition is named after Ondine, a water nymph in Greek mythology who put a curse on a mortal who inappropriately fell in love with her. The punishment required the mortal to think about everything he did. He fell asleep, forgot to breathe and died.

So that he won't forget to breathe, Rene is almost always connected to a respirator, which requires a permanent tracheotomy (opening in the throat). Besides spending about 22 hours a day on a respirator, Rene has other serious medical problems, such as a colostomy, a growth hormone deficiency and severe asthma.

Still, Rene doesn't see himself as having major problems, according to his mother, Joann. "He has a great self-image and he gets such a thrill out of everything," she says. "I'll never forget the first time I took him to a supermarket and he saw a whole row of all the boxes of cereal he'd seen on TV. It was like being with someone who had just come from outer space."

problems and I'd say, 'How does this mother do this?' Now I see it from another perspective. These kids are very rewarding. Mentally and emotionally, he's the best kid in the world—so bright and cute and funny."

Although Joann is a single parent, she gets help from her own "informal system": her parents have an apartment downstairs and her sister shares her apartment. Although her friends and relatives couldn't understand at first why she was choosing to adopt Rene, they were very supportive as soon as they met him.

She also gets help from "the formal system," although that has taken more patience and persistence on her part. Initially her nursing supervisor at the hospital tried to block the adoption, saying it would ruin Joann's life. The actual adoption proceedings took two years. She had a hard time finding a school that would let him attend a regular class, despite the fact that he is very bright. Fortunately her sister teaches at a private school that agreed to accept him provided the family could work out arrangements such as transportation and medical supervision.

A few years ago her financial assistance as the adoptive parent of a child with a disability was discontinued with no warning. Now Medicaid pays Rene's expenses, but Joann says she must be persistent in dealing with "the system."

What if she weren't a nurse or if she weren't entitled to financial help as an adoptive parent—would she or could she keep Rene at home? "There are programs," she says, "but you have to look for them. SKIP can help. You do have to change your life a lot."

Joann chose to be a parent of a child with serious physical problems and to care for that child at home. She knew what the demands and restrictions would be; she had known and cared for Rene during his first four years in the hospital. Why did she do it?

"I never intended to adopt Rene," she says. "If you had told me 15 years ago that I would have even considered taking a child like Rene, I would have laughed. But I just got so attached to him—he kept getting cuter and cuter. Every discovery he makes is a major triumph. Everyone loves him—my parents, the kids at school—he's given us all so much. He's a delight. I'm always laughing. I wouldn't know what to do without him."

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*Seeing Families in Different Ways*

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**"I used to meet families who had kids with problems and I'd say, 'How does this mother do this?' Now I see it from another perspective."**

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Joann's life has changed a lot since she adopted Rene. She gave up her work at the hospital, taking a leave of absence at first but later resigning permanently. She now works at home for an organization called *Special Kids Need Involved People* (SKIP) that acts on behalf of children who require technological support to live. She goes to school with Rene for half of each day because he must have a nurse with him in order to attend. When he's too sick to go to school, she teaches him at home. She gets up at least twice every night to check the respirator and the rest of the time sleeps with an intercom in case the respirator alarm sounds.

But Joann has no regrets. "It's funny," she says, "I used to meet families who had kids with