



Katie Beckett: The Little Girl Who Caught The Country's Eye

by Julie Beckett

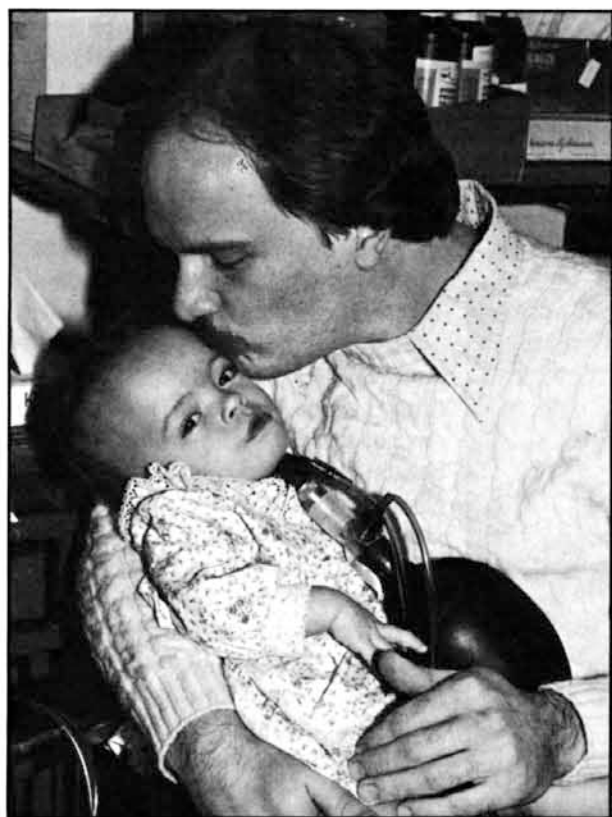
Mary Katherine Beckett was born March 9, 1978, at St. Luke's Methodist Hospital in Cedar Rapids, IA. Although premature and only weighing in at two pounds, three ounces, Katie had very few medical problems. She required only an oxygen hood for the first 48 hours and continued to grow at a rate which allowed her to come home May 6, 1978. She was a "normal" baby in every sense of the word. On Sept. 1, 1978, she was back in St. Luke's Hospital, only this time in the pediatric unit for observation. Later, it would be determined she was suffering from viral encephalitis. On Sept. 2, Katie aspirated and severe respiratory distress complicated an already serious illness. This is where our story begins.

It was a beautiful Sunday morning; a day I though could never replaced by another. But that is a story of sadness. That sadness turned to joy three years later, December 19, 1981. That's the day we began our new story; a story of hope, of happiness, of beginnings.

The problems we have faced have been difficult ones, but Katie has been labelled somewhat of a "miracle child" because she has made significant progress in overcoming the horrifying after-effects of viral encephalitis. That glimmer of hope has taken us through each incident seemingly making our bond stronger.

When Katie's doctors told us we could take her home, it seemed as if our prayers were answered. All the learning processes seemed minute compared to the joy of having us together. It was at this time we were notified our Medicaid coverage would not extend to home care costs.

We had always carried insurance to protect ourselves, but with the soaring medical costs, it was impossible to foresee that a catastrophic illness would use all of our private insurance. Having exhausted all lifetime major medical cov-



Katie Beckett, with the love and support of family, friends, and respiratory care staff, among others, has grown into a happy little girl. Her life is a model of what home care can do.



President's, and Secretary Schweiker's intervention, our daughter, Katie, was able to come home. But, hundreds of other children still do not have this advantage. Hopefully, because of our experiences, people can realize it can be done and life can be enriched for those children who have suffered so much.

Katie Beckett has led a very unusual life, but no one will ever say they saw no purpose in her living. She has been set as a model for home health care. Her success in overcoming the serious after-effects of encephalitis have made her truly a miracle child. No one could foresee how well Katie would do at home. It had to be lived day after day, not without worry and strain.

Before leaving the hospital in December, 1981, all efforts were geared by state and private professionals to help Katie improve at home. They have truly been successful.

Healthwise, Katie has improved remarkably. Serious illnesses are becoming less and less frequent since our initial discharge. We have been able to wean her off the respirator for nap times, and her rate has dropped several settings from the initial ten.

Katie was able to attend pre-school last year, and it was the consensus that Katie has grown the most of any of the other children. Her need for socializing skills was very evident in the beginning of the school year, but by spring, she was just one of the kids. It was a time when we saw peer pressure work in a very positive way.

Katie now attends kindergarten, mainstreamed with students in a private school. She is developing at a rate far beyond anyone's previous expectations. Reading, writing, and even a little arithmetic, the child with a trach is outstanding and may even be moved to the higher level of students because her learning ability is so far advanced.

Much of that ability can be credited to her speech therapy.

Katie must still have speech therapy three times a week, but for a child who has worked with a speech pathologist since the age of one year, learning has become a fun experience. It was believed before her discharge Katie would have to sign to be communicative. This is no longer the case. The growth in the last two years and her exposure to other children in a learning situation have improved Katie's speaking to a level where she no longer needs to sign and is not even asked to repeat to be understood. Her vocabulary ability alone was tested out at an average of seven years, and her level of understanding is that of a 6-year-old. This testing was done shortly after Katie's fifth birthday. She will need to continue speech therapy for more tongue control for several years, but there is now a light at the end of the tunnel.

The only educational drawback Katie seems to have is in the fine motor skills, but after working with a private tutor from the Grant Wood Area Education Agency since her discharge, she is able to get a tighter control and guide her hands through writing, cutting, and other fine motor skills.

All of these success stories occurred because we have worked together as a team. Speech therapists, physical therapists, respiratory therapists, public health nurses, teachers, school officials, psychologists, sociologists, and suppliers are committed to one thing — helping this child grow.

My husband, Mark, and I are not trained professionals, but the years we have spent watching Katie grow and the support we received from nurses, doctors, and therapists while she was in the hospital reinforced our belief that we could care for her at home. We knew also that once out of the hospital setting, we had a network of community-based support which once and for all showed how much people care and how much of a role we all need for them to play in our lives.

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erage on Blue Cross/Blue Shield, this child with a wonderful potential for a full life at the age of three years was left with no health insurance coverage and no governmental insurance should we take her home where she belonged.

The next few months were exhausting — fighting government red tape, reviewing the brushes with death that had occurred over the last few years, and facing rejection after rejection.

We also investigated private funding, but each organization we

contacted explained that we did not fit into their guidelines, since they were established mainly for educational and informational purposes.

We even attempted to apply for grants, but were rejected because Katie was an individual and the grants were designed for group aid. Their purpose was mainly for research in areas that would benefit a greater number of the general populace. There was no broad base for support; therefore, we

were non-essential to their pro-

gram.

In June, 1981, we turned to our congressman, Tom Tauke. Here, we met a willing response to our plea for help. It would be difficult, he said, to get Congress to schedule a private bill to alter the present regulations. It would be two or three years before the bill would even come up for debate, so he suggested we apply for an Exception of Policy.

This effort and analysis of the problems took months, with much correspondence with state agen-

cies. It was very agonizing and, by the end of the summer, our frustrations were high.

It was at this time that Congressman Tauke sent our case to then Secretary of Health and Human Services, Richard Schweiker. On Nov. 4, Congressman Tauke received a letter *rejecting* our Exception of Policy due to what President Reagan later termed "hidebound regulations." It was then that Congressman Tauke turned to Vice President Bush.

Through the President's, Vice

Katie

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Can other children progress so at home and can parents learn to care for their children in the home environments? I would say very definitely yes! We need to convince our society, however, that technologically-dependent children can and should do very normal growing. They should be allowed the opportunities that we afford any human being. We must be aware, however, that not every parent is able to cope physically, mentally, or emotionally with having a chronically ill child in the home. However, I do agree that with the right training and with a greater public awareness, the fears can be negated. We must also be aware that every child's case is different. I believe we need a strong case management program and assessment as follow-up to the release of children into their parent's care. This helps to carry the burden and takes a supportive effort by trained professionals. It provides a psychological boost to parents, especially in the first few months of home health care.

As health care professionals, you carry the on-going burden of continual support. You share in the family's successes as well as failures. You are a part of the problem-solving team; one who must be aware of the emotional bonds that pull the family together in time of crisis. Your role is essential and paramount to all others, with the exception of the parental role. You are forging a new frontier in home care and will be in demand the more *you* define your role.

This role, which was thrust upon Mark and myself, resulted from the growth of modern technology. However, preparation for this "new generation" of children dependent on technology for survival is still being expanded. We are lucky to have such wide, community-based support to develop a program essentially for Katie's needs. There-

fore, we know programs can be developed throughout the country, pulling all resources together to meet the needs of children who are ventilator-dependent, oxygen-dependent, or dialysis-dependent, among others.

I am currently working with an organization which acts as a parent-advocacy group to support programs for home health care for the technologically-dependent. Our goal is three-fold. First, to educate parents, health care professionals, community-based agencies, and the public on the advantages of and the need for home health care for these children. Second, we act as a resource for families and providers to assist in expanding programs and developing new resources to meet the needs of this "new generation." Lastly, our goal is to identify and access resource services necessary for family support. We feel this will lessen the handicaps imposed upon this nation's children dependent on technology and will promote child and family self-sufficiency and autonomy in the least restrictive environment possible.

SKIP, Sick Kids (Need) Involved People, is this organization with such lofty goals. These goals, which may seem extremely hard to achieve, can be reached through cooperation and support. SKIP is unique, because it is run by parents who have overcome the problems. They are the parents who have children living at home on medical technology. They have made their home the "intensive care unit" and afforded their children the same opportunities of family, home, and love which cannot be realized in an institution.

Katie did not lead a deprived life in the hospital. She was happy, loved, and stimulated; but the reality of home and family have changed and enriched her life so much more. Through SKIP, more children can live the reality of home care. ●