

A Need for Information

by Kent Smith

April 6, 1971. My wife and I were eagerly anticipating the birth of our second child. I accompanied her to the hospital in suburban Chicago. It had been a normal pregnancy, much like the pregnancy two years earlier when our daughter was born. Shortly after midnight the joyous moment arrived. The doctor came to the father's waiting room; he was not smiling. Our son was born with a birth defect known as spina bifida. As we look back on that moment, we've realized how much the birth of our son Stephen has affected our lives.

As a news writer/producer for a major television station in Chicago, I had access to a great deal of information. I had been trained to ask the right question, investigate the story thoroughly, and report both sides equally.

My wife had received her education in library science and enjoyed the research involved in establishing a library and developing good reference systems. Nowhere in our professional experience had either of us come across information on the birth defect spina bifida, nor were we to realize how difficult it would be to get the information that should be so readily available to new parents of a spina bifida child.

Parents find themselves very vulnerable after having given birth to a child with spina bifida. The hospital and medical staff appeared intimidating. We knew little about birth defects in general and nothing about our own child's specific needs. We looked to the "experts" whom we hoped would help.

Our first attempt to get information was through the local chapter of the March of Dimes. Their personnel were courteous, sympathetic to our needs, but could not answer specific questions on how other families were coping with a child with spina bifida. We tried to gain understanding on a variety of terms. How did it affect our Stephen? Were we unique with this problem? What was the outlook for our son's future? Those questions went un-

swered, although we did receive some pages copied directly from a well-known book on birth defects.

Good friends stood by us trying to provide a sympathetic ear. They couldn't answer questions, but wanted to do the best for our family, even encouraging us to look at places where our child could be placed and be raised in a loving atmosphere; then we could go on with our own lives. This only frustrated us, for we wanted to help our son, who—by some quirk of fate—had problems that we knew were serious but we didn't understand. He was part of our family and we wanted to provide him with the best medical care available.

As parents, we had to depend on others for guidance. The most obvious person to turn to is the family physician. Clearly, new parents of a disabled child need information on the disability and its treatment, as well as the names of agencies and support groups available to assist the family unit. Other parents who have faced the same situation can share their knowledge and give comfort and assistance.

My wife and I were steered to a support group of parents and adults with spina bifida. This group met every month at the hospital. Our physician had been working with this parent group. Although he could not share the parental experience of raising a handicapped child, he respected the support that was freely given by parents "sharing their experiences." From our point of view, it was the best medicine that he could provide. It gave us hope that our son might make advances similar to other children.

Information is the key to knowledgeable parents raising their children with spina bifida. My wife and I became active in this parent support group to learn more about the birth defect. From those adults with spina bifida we learned some problems they had faced and how we could help our son.

Our involvement with a national organization

wasn't something we planned, it evolved. In 1979, I was asked to establish a central office to provide information to new parents and be a resource to chapters consisting of parents, adults, and professionals in many cities. Under a letter of agreement with my employer, the American Broadcasting Company, I took a year's leave of absence to establish the office. I've never gone back to ABC.

The leadership of Spina Bifida Association of America (SBAA) comes from the active participation of adults with spina bifida and parents working together. When SBAA was formed as a volunteer group in 1972, the greatest need was to provide printed information written in lay language. Today, the Association has 11 booklets directed to educators, new parents, adults with spina bifida, and to children. As a journalist, I was able to work with the writers in developing a distribution system that now has over 50,000 pieces of literature circulated each year.

One concern we have is the misinformation that others continue to tell new parents regarding the current treatment or the lack of potential of people born with the birth defect today. In 1979, the SBAA established a policy that encourages early evaluation and medical/surgical treatment of every infant with spina bifida, and recommends that the evaluation be performed by professionals experienced in that care and treatment.

Improved medical treatment within the last 25 years minimizes the disabling effects of spina bifida. Recent statistics from major treat-

ment centers in New York, Pittsburgh, Chicago, Seattle, and elsewhere indicate that approximately 90 percent of those infants born today with spina bifida can lead a competitive life with some adjustments for physical disabilities.

The majority of infants who receive aggressive treatment early do not suffer mental retardation. Lack of bowel and bladder control can be dealt with and should not take the "opportunity for life" away from the child. Some amount of paralysis often occurs, but the degree of involvement varies widely and cannot be determined at birth.

The SBAA also sponsors an Adoption Referral program which offers a viable alternative to parents who feel unprepared to raise a child with a disability. The program has placed 70 babies in loving homes and has a waiting list of parents willing to take infants with spina bifida.

During these last five years I have met hundreds of parents with similar stories, all with a commitment to provide information to a new parent who, like each of us, needed someone or some group to answer questions. The adults with spina bifida hold challenging jobs, and in general make worthwhile contributions to society. They have devised innovative ways in which to overcome their disabilities. Each represents a realistic goal which our child born with this birth defect can hope to achieve.

If you would like further information on Spina Bifida and our Association, please call 1-800-621-3141.

What is Spina Bifida?

by Jeannie Gruse

I have chosen to do this report on spina bifida because of little Stephen Smith, a happy, loving, well-adjusted boy, who was born thirteen years ago with this condition. Stephen's parents are friends and neighbors, and I well remember the day that Kent came over to tell us about the birth of their first son.

When he described their handsome baby boy, and then explained that he had a birth defect called spina bifida, I had no idea what he was saying; I had never heard of this condition. Pam and Kent knew very little at that time, either, but in nine years of surgery, emergencies, difficult care, exercising, training, and learning,

this has certainly changed for them. Kent is currently the Executive Director of The Spina Bifida Association of America, dedicated to "making the public, professional and all governmental agencies more aware of this worldwide health problem and assisting parents in helping their children." The program is also directed toward improving comprehensive medical care for children and adults with spina bifida, and expanding research programs which will search for the cause of this birth defect.

Spina bifida is a serious condition, and until thirty years ago, few babies born with it survived beyond infancy. The treatment techniques