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 treatment 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

developed within the last two decades make it possible for the majority of these children to grow to adulthood and live happy, productive lives in spite of their disability.

Spina bifida is not a new birth defect; it was referred to 2,000 years ago, and was described by a Dutch physician, Nicholas Tulp, friend of Rembrandt, in 1652. The technical terms, spina bifida aperta or spina bifida manifesta relate to a structural defect caused by failure of the neural plate to develop into a tubular structure. In the area where this occurs, the defect is technically referred to as myelomeningocele (G. myelos = marrow; meninx = membraine; kele = hernia). In development, plates of bone fail to close over the defective area of the spinal cord and there is a short spine on each side of open spinal cord rather than a single one in the midline, therefore the term spina bifida. If the bony plate does not close over the spinal cord during infancy, this defect is referred to as spina bifida occulta (hidden). This type generally causes no problems.

The newborn baby will have an obvious lump or cyst-like lesion on the back. It may be covered with skin, or more often wholly or partially covered with translucent bluish or white membranes. There may be a flat plate of imperfectly formed spinal cord on the surface of the cyst which may be leaking cerebro-spinal fluid.

While there are many claims or suggestions of causes of spina bifida, it is generally considered to be caused by an unknown environmental agent interacting with genetic factors, according to Dr. Swinyard, Stanford Unversity authority on spina bifida. Multiple complex problems presented by newborns with spina bifida have discouraged some physicians from applying the available intensive medical care and technologies to preserve lives of the more severely defective newborns. A number of physicians have advocated strongly that such treatment be withheld from newborns, presenting certain criteria with the expectation that these babies would soon die. This presents serious moral and legal problems, obviously, relating to rights of the children and the rights of parents to make such decisions, and since the predictability of death is quite uncertain, those who survive may have unnecessarily serious and lasting damage.

There are many problems associated with spina bifida besides the obvious surgery necessary, often immediately, to correct the condition. There is loss of awareness of touch, pain, pressure, and heat or cold in those areas of skin normally innervated by nerves involved in the spinal cord defect. There is muscle weakness in the lower limbs and lower trunk, the latter often resulting in weakness in muscles of the bladder and bowel, preventing normal control.

Nearly 70 percent of infants with spina bifida develop an associated defect known as hydrocephalus, causing a rapid enlargement of the head from the abnormal accumulation of fluid inside the brain. Although it does not occur in all of the infants, this problem is potentially a life threatening one which requires prompt attention of a neurosurgeon, and even then may often result in varying degrees of brain damage.

The degree of severity of these conditions associated with spina bifida varies widely. Some children will be able to walk without assistance, others may need braces or a wheelchair. Because spina bifida is such a complex condition, these cases are usually referred to a pediatric neurosurgeon who is part of an organized team. He will decide on the surgical closure of the myelomeningocele, carefully watch for signs of hydrocephalus, and be responsible for the management of this condition if it occurs.

Development of hydrocephalus would involve a serious neurosurgical emergency, as severe brain damage or death could result from the pressure of the fluid within the brain. A shunting procedure is used to reduce this condition, which consists of inserting one end of a flexible tube into a brain ventricle and passing the tube through a small opening in the skull. It is then passed underneath the skin from the head, either to the heart or to the abdomen, and includes a one-way valve which prevents the backward flow of spinal fluid. Even this procedure, a vital one to prevent pressure on the brain, is not totally free of dangers, as shunts can be obstructed or collapse, and revision is often necessary. However, it is the best procedure, and the only effective treatment currently available to allow the brain to develop more normally.

Besides the neurosurgeon, spina bifida children will be seen by a number of different specialists. A urologist may be necessary to control urinary infections, and to keep the lack of bladder control from becoming a problem. The pediatrician will watch the child's general health and work on management of the problems relating to lack of bowel control.

The orthopedic surgeon will have as his primary concern the growth and development of the bones and muscles. Children with spina bifida often have hip dislocation, club feet, scoliosis, kyphosis or lordosis. He will suggest

surgery, braces or crutches when needed. An orthotist will fill the surgeon's prescriptions and work with the child as he grows. In conjunction with the orthotist, a physical therapist will also help carry out the plans made by the orthopedic surgeon and will suggest others designed to strengthen weak muscles.

Finally, an occupational therapist may also aid in carrying out the physician's suggestions. She will work primarily with motor coordination and preceptual-motor impairment, and will assist in helping the child adapt to his physical environment in activities. Even with all of these trained experts' help, it is obviously the parents who are chiefly involved in the daily training and care of spina bifida children.

I feel fortunate to have been involved, along with my daughter, friends, relatives, and church member volunteers in a program of "patterning" with little Stephen a few years ago. The theory of the program was that an infant's ordinary body movements stimulate brain development through sensory-motor input. Gradually the child's movements become coordinated in cross-patterned crawling, creeping, and walking. By stimulating the body in various ways it was hoped we could "wake up" and condition the pathways to the brain and activate the millions of unused cells within the brain. The method involved artificially recreating patterns of movement in hopes of reaching the brain and having the brain take over these same movements on its own. With three people helping three or four times a day, we helped Stephen and his mother go through his prescribed exercise schedule according to the training his mother had previously received.

While some individuals with spina bifida have average or above average intelligence, those who also have hydrocephalus may, as a result, have some degree of mental retardation. The best school placement and curriculum planning will depend also upon physical limitations. The main consideration is that the child be placed in a flexible situation for effective learning.

Since many spina bifida children do have learning problems, teaching must be individualized, based on strengths and weaknesses. This may be possible in a regular classroom, mainstreamed partially, or in a self-contained situation, depending on the severity of the physical condition and the extent of the learning disability.

When Stephen was nine years old, he was completing first grade work, and beginning second, at the Fullerton School, in Addison. He was in a structured, protective environment with reinforcement of one full-time teacher and an aide to six or seven students; this was a self-contained room called Orthopedic-Learning Disabilities, with mainstreaming for music and art.

Having spina bifida means different things to different people. The actual physical condition varies greatly from person to person. How a person manages in life depends not only on the severity of the actual physical condition, but also upon the support he gets from others, the adaptations in the environment, and most of all, how the person feels about himself. With the tender, loving care and dedication of parents such as Pam and Kent Smith, spina bifida children like Stephen have a chance to grow up, able to cope with their own limitations, and to manage very well in life, feeling good about themselves.

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