

Spina Bifida . . .

From the Editor

This issue of *C.P.O.* differs in tone from past issues. The Cuchnas' are a family, one member of which has spina bifida. Obviously they do not write with that measure of objectivity and detachment that is commonly considered appropriate for a journal of *C.P.O.*'s mission. It would, however, be illogical and contrary to reason to expect them to.

As a family and as individuals, they demonstrate that intangible element that we so frequently find ourselves exhorting from our patient: commitment. All of us at one time or another have found ourselves saying to a patient "You are the one that has to wear this prosthesis/orthosis. Only you can make it work for

you." Obviously, the Cuchnas have decided to make it work for them.

It was decided to publish the Cuchnas' contributions in this issue, devoted to Spina Bifida, as a reminder that we must constantly remember that the patients we see are not just an extremity or trunk in need of a prosthesis or orthosis. Rather, they are individuals who function in larger contexts and have needs and concerns that cannot simply be addressed with a device. Upon behalf of myself and the members of the Editorial Board of *C.P.O.*, I wish to thank the Cuchnas for taking the time and effort of writing when asked to by John Billock, CPO.

Lead Articles

The Parents Experience

by James R. Cuchna*
Anna Mae Cuchna

A new birth . . . another miracle . . . a baby is born . . . but why is our baby not made perfect like our friends and relatives? Life began, but it was not surrounded by complete joy. We were confronted with the inevitable—"Your child was born with spina bifida. She will, probably, live no longer than a week." We were asked, "Do you want to put her in an institution or leave her in the hospital?" Try to imagine the feeling that would rush through your mind at the onset of this occasion. It is unbelievable.

Our immediate and only reaction was to take this child and love her just as if she were born "perfect." We accepted our daughter and were determined to treat her as if nothing was wrong. We had faith that God would help us through the problems we might encounter. This happened on March 21, 1966.

Today, Cindy is 18 years old and is entering her first year of college. We also have a 17 year old daughter and a 9 year old daughter. We feel we have been richly blessed.

Even though our first child was the one born with a physical problem, spina bifida, we really don't feel she has ever been "the problem." Society in general . . . everyone else's opinion, the medical profession, the people in government passing legislature, etc. are "the problems." Everyone thinks they know what "life is going to be like" for these children, what a "burden" they will be on the family. These statements infuriate us.

Having had other children helped us substantiate our thoughts and feelings that a child born with a physical problem is "no different" than a child born "normal." We have had to deal with medical problems, hospital stays, doctors visits, etc. with all our children—maybe not as many problems as with Cindy, but, all have been traumatic for us. We have also had parents

*Mr. and Mrs. Cuchna reside in Ohio and are the parents of Cynthia Cuchna.

inflicted with cancer and have cared for them. To us, life is what a person makes of it. It is the positive attitude that surrounds any child or person that is so important. One can only try to make the best of things and live each day to the fullest.

We are concerned for the babies that have doctors who perceive spina bifida as a dreadful defect/disability and make the decision of whether to treat or not. Cindy was not treated at birth but survived. Thoughts arise as to what more she could do had she been treated. Would her degree of paralysis and the kidney damage be less severe? We'll never know. Some doctors hesitate on treating babies born with spina bifida, but wouldn't give a second thought to treating victims of automobile, industrial or other accidents even though the outlook may be very bleak. An example of this is the president's aide, James Brady. What makes the difference?

Another concern lies in the high cost of the medical supplies and equipment she will need the rest of her life. It doesn't seem fair that urostomy bags bought 11 years ago cost \$13.95 and today are \$42.50, that a set of full braces is \$5,000 or more, that a wheelchair is over \$1,000, that vans with lifts are \$20,000, or that urine analysis that were \$2.00 are now \$10.00. Most of the people with physical problems have limitations in job opportunities. Very few will be able to hold high paying jobs. Where will the money come from to pay for their needs?

Some places now want the money first and then they will bill your insurance. Where will she get the start to save money when she needs something? What happens when our 80 percent group insurance coverage lapses because she is an adult and then she cannot get insurance of her own because of her medical/physical involvement?

Cindy feels good about herself and has ac-

cepted her handicap. She realizes that she has limitations but that these should not preclude her from being able to achieve the goals she sets. The fact she is paralyzed from the waist down and requires orthopedic bracing brought Cindy to the realization that she would have to work very hard for what she wants very early in life. She knows that nothing is going to be handed to her on a silver platter and does not think that she deserves special treatment because she is "physically challenged." All she wants is an equal opportunity to contribute to society and earn her way.

Cindy has been a constant source of strength, love, and courage for us. As we watch her grow and see her achieve, our admiration for the child/young lady/soon-to-be woman grows. We truly believe that we have been more dependent on Cindy than she has been, or ever will be, upon us.

We have been very fortunate in having benefited from the professional services of very dedicated, talented, competent, and caring people in the areas of medicine, education, and orthotics. Yes, there have been differences of opinions between themselves as well as with us. There were goals that took longer than anticipated to be reached. But, can't we all say this happened to us also in our "normal" lives.

It is one of our dreams and goals to see more medical professionals get involved with the National Spina Bifida Association of America and its local chapters. We don't need people to be afraid of spina bifida. We need help to spread a positive image, to achieve the establishment of a hospital for research and for the needs of all people with spina bifida. People need to know that children who are physically challenged don't need sympathy and things done for them. What they need is the opportunity to live, learn, grow in love and be loved—just as we all do.

A Personal Experience

by Cynthia L. Cuchna*

Most people would say, "It would be terrible to be born with a birth defect." Well, I know

*Cynthia Cuchna was born with spina bifida on March 21, 1966. Now she is 18 years old and is entering her first year of college.

firsthand that it really isn't so terrible. I have been blessed with family and friends who have not let me feel that my disability should get in the way of reaching my goals.

My parents have never let me use my handi-