Photos by Laurence E. Keefe

Spina Bifida

A Story of Hope

By PAT PETRASKE

In many ways, Sheila is like any normal nine-year-old child. She is learning to plink little songs out on the piano, goes to vacation Bible school and cools off from the heat in the family pool. But she has a little known birth defect, spina bifida, which has left her paralyzed from the waist down.

In spina bifida, some of the vertebrae — bony units which normally cover and protect the spinal cord — fail to develop fully. What results is the inability of muscles to contract since the defect interferes with the transmission of electric impulses from the controlling nerves in the spinal cord.

No two cases of spina bifida look exactly alike. In severe cases the nerve roots are exposed and a large sack of cerebrospinal fluid accumulates on the spine. A large one may even prevent a baby from lying on its back.

Luckily the only major operation that Sheila has had to undergo was the removal of this sack, ten days after birth.

Dr. Gary Myers, head of the Strong Memorial Birth Defect Center, stated that one or two out of every 1,000 babies born in the United States, including half of the patients who come to the center, have spina bifida. Many average ten operations in their lifetime.

Sheila faces three of the four problem areas that result from the defect: muscle weakness to the extent of paralysis, loss of skin sensitivity below the waist and incontinence of bladder and bowel. Holding herself up on parallel bars while singing a nursery rhyme was one of her earliest attempts to strengthen the upper muscles she could use. Although doctors had given her little hope, a proud moment came went she walked into church on Easter Sunday, said her mother, Mrs. Donald Mastin.

Swinging quickly along in her crutches and braces Sheila showed how their new house allowed her to walk to any room unaided. The rooms are also accessible by wheelchair if her braces break down. If neighborhood friends want to play in the basement, she simply crawls down the stairs. "But I can go up little steps," she added.

Like any other child, Sheila is constantly growing. But for her this means new braces costing around $550 every two or three years.

Another problem is not being able to detect heat, cold or pain. "We've taught her to feel her bath water with her hand instead of swinging in feet first," Mrs. Mastin said.

Having a child with spina bifida can be difficult and the Mastins were anxious to meet with anyone else who had the same problem. "We would go to the Al Sigl Center for therapy and I'd try to find other parents who might be able to help us," Mrs. Mastin said.

A group of four families became friends after discovering that each had a spina bifida daughter of the same age. From this core developed the Federation of Parents of Children with Spina Bifida which now has 20 active families, with an additional 35 on the mailing list.

Meetings featuring a guest speaker are held monthly at the Henrietta Town Hall. "Doctors are often too busy to answer all the parents' questions and our meetings provide an informal way to get some information," explained Mrs. Mastin. The families also get together for picnics and potluck suppers.

Additional information can be obtained by parents in the form of genetic counseling available free at Strong Memorial Hospital.

Spina bifida results from a combination of polygenic factors, that is, it needs a set of genes from each parent to be produced, explained Dr. Philip Townes, genetic counselor.

The risk of having a child born with spina bifida is about one in one thousand, but after having one such child it increases to one in twenty-five.

"What we do is sort of crystal ball gazing," Townes said. "We only tell the parents the facts on what the chances would be of having a second defective child. We don't tell them if they should or shouldn't have more children." Some parents do have more children and a few families have more than one spina bifida child. He added that genetic counseling is also necessary if spina bifida is found in a parent's medical history.

Until a few years ago doctors painted a very bleak picture for spina bifida children. Sheila is one of the oldest spina bifida children in the Federation but new techniques are increasing life expectancy. One technique can treat hydrocephalus, which is an abnormally rapid and excessive enlargement of the head.

Because of numerous physical handicaps, spina bifida children sometimes lag behind their contemporaries in school. Sheila however, "does quite well" according to Mrs. Mastin. "The bus driver lifts her up onto the school bus. And it's actually a learning process for the other kids; they learn to help each other.

"Besides, they love to play with her crutches," she laughed.

Irish Bishops Assert Crisis in Faith and Vocations

Dublin [RNS] — Asserting that a current "crisis" in vocations to the priestly and religious life in Ireland is essentially "a crisis of faith," the country's Catholic bishops have called for a renewal and strengthening of Christian belief and witness.

"A fervent Christian community assures its own continuity," said the bishops in a recent document titled, A Plan of Action for Vocations. "There will always be vocations where Christianity is deeply lived."

Indicating the scope of the vocation crisis in Ireland, the prelates said:

"In the six years between 1966 and 1972, the number of ordinations to the priesthood each year went down from 399 to 223. The new enrollments in major seminaries went down from 644 to 450 in the same period, while vocations among lay brothers went down from 173 to 59.

"But what is perhaps the greatest cause for worry is the great decrease in the number of girls who choose the religious life as their ideal. The entries into religious for women went down from 592 in 1966 to 176 in 1972."

The bishops insisted that any "plan of action" designed to meet the vocation crisis must, perforce, focus on a renewal and revitalizing of the faith of the whole Christian community.

"Whatever vocation crisis may exist in a country," they declared, "it cannot be met merely by new and better methods of recruitment, by more expensive handouts, by better audio-visual aids, or by more up-dated publicity campaigns."

"This apostolate," they added, "is not marginal to the life and activity of the Christian community. It is central. If there is a shortage of vocations, it indicates that the spirit of faith in the Christian community has declined, and the remedy lies in renewing and strengthening that spirit of faith."

The bishops scored what they called the "individual and collective counter-witness" of some who embrace their vocations "for the wrong reasons."

"There are priests and religious," said the prelates, "who extol celibacy as a liberation, but who exploit it to have more leisure time and freedom from family obligations. In other instances, religious, who have taken vows of poverty, manage to live like rich people."

This "counter-witness," the bishops said, constitutes a major obstacle to the acceptance in the Christian community of a call to live a life according to "evangelical counsels."