OBJECTIVES:
SOME OF OUR MAIN OBJECTIVES ARE:
1. To protect and promote the interests of all persons with Spina Bifida and Hydrocephalus and related disabilities.
2. To promote and/ or support measures which will prevent or reduce the occurrence of disabling conditions and their effects.
3. To promote, undertake and or support such accessible and equitable community-based medical, educational, vocational, social, recreational rehabilitation and social services and facilities as may be required by persons with disabilities to achieve independence.

WHAT IS SPINA BIFIDA?
It is a congenital defect where some of the bones that make up the unborn baby’s spinal column, do not join together properly, leaving an opening in the spine usually in the lower part of the back.

The soft parts of the spinal cord may push through this opening. These soft parts consist of the spinal nerves, fluid and meninges. This is the lump that may be visible on the baby’s back at birth.

The spinal cord has been damaged; messages from the brain do not get down the spinal cord to the lower part of the body. As a result there is loss of sensation, bladder and bowel control and mobility problems. Disability varies from child to child depending on the level of the lesion on the spine.
WHAT IS HYDROCEPHALUS?

Every person has fluid in their brain but children with Spina Bifida tend to collect more fluid than normal in the brain, which is called HYDROCEPHALUS or “Water on the brain”. This will cause the head to become bigger if it is not treated. If the child has hydrocephalus a small tube (shunt) is placed in the head and the extra fluid is drained away to the abdomen.

While the majority of children have normal intelligence, those with Hydrocephalus may have learning problems, although most of them attend mainstream or special schools.
**MANAGEMENT REGIME**

Long-term quality of life in a person born with Spina Bifida, as in any disability, is dependent on the challenges of that disability being recognised, met and overcome, to prevent patients becoming handicapped.

The primary goals of bladder and bowel management is to achieve social continence. Understanding Spina Bifida and Hydrocephalus and its management is VITAL.

**PREVENTION**

There is overwhelming evidence that women administered folic acid from before conception either as a vitamin supplement or through food fortification, have a substantial reduction in their risk of having a baby with Spina Bifida and Hydrocephalus.

**CHECK-UPS? FOLLOW-UPS?**

Regular follow-ups of all children at hospitals or any private institutions are vital.

Red Cross War Memorial Children’s Hospital, Spina Bifida clinic every Wednesday
Contact: 021 658 5033 / 658 5363 / 658 5569

“When all is said and done, managing these patients well is very gratifying. Despite the many problems they face, hope and support enables a rewarding and meaningful life.”
Kieran Roberts was born on 6 April 1989. He is the youngest of 2 children. He started and completed his schooling at Vista Nova School and passed matric in 2007. He achieved Western Province colours for Wheelchair Table Tennis, Athletics, Swimming and Basketball.

Bulelwa Madlongwana; I was born on the 4th November 1975. I was born with the disability called Spina Bifida. Due to my disability I underwent some few operations on my lower body and urinary system. My disability never stopped me from reaching my dreams.

Veronica Marcus and I was born with Spina Bifida. Without going into too much detail, suffice it to say that Spina Bifida is the most common spinal defect in children, occurring when a child is born with a hole in the spine. Because of the severity of my problem, doctors did not expect me to live very long. After projecting a very short lifespan, they eventually settled on age 12.

Deoni: I am thankful to all those who said no to me. Because of them I did it myself.
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