Spina Bifida in New Jersey

Spina Bifida, the most common, permanently disabling birth defect that is also compatible with life in the United States, affects approximately 1,500 births each year. Spina Bifida is a serious and life-long condition which occurs when the spinal cord fails to close properly during the early stages of pregnancy. Approximately 10% of babies born with Spina Bifida do not live into adulthood.

- In New Jersey, 1.97 babies are born with Spina Bifida per 10,000 births (data collection period: 2010).

- Recent research has estimated that the number of Americans living with all forms of Spina Bifida is approximately 166,000. Based on this national estimate and the birth rate of Spina Bifida, about 1,710 people with Spina Bifida live in New Jersey.

- In New Jersey, there are an estimated 2.8 million women of childbearing age. All are at-risk of a Spina Bifida pregnancy. If women of childbearing age were to consume 400 micrograms (mcg) of the B-vitamin folic acid every day before pregnancy, the risk of Spina Bifida and other serious birth defects could be reduced by up to 70%.

- Approximately 1,368 of individuals with THE most serious form of Spina Bifida, myelomeningocele (MMC), suffer from hydrocephalus, a dangerous fluid build-up around the brain, which necessitates surgery to implant a shunt in the brain. Unfortunately, shunts require frequent revisions, and 1,095 of these devices will fail within 10 years.

- 855 of the people living with Spina Bifida are adults, and 684 of them have MMC. Very little is known about aging with Spina Bifida. Very few physicians are willing to treat people with Spina Bifida or have the knowledge of treatments and interventions associated with its management.
Cost Related to the Care of People with Spina Bifida in New Jersey

- The estimated cost of lifetime care related to Spina Bifida for the 4,740 people living with Spina Bifida in California ranges between $3,014,640,000 and $1,710,000,000. Among adults with MMC, only half live independently as adults, accruing substantial costs for the lifetime care.

- Out-of-pocket costs for direct medical care for children born with MMC are 13 times more than children born without MMC. These additional costs continue into adulthood, when individuals with MMC pay 7 times more in medical cost than those without MMC.

- Family caregivers for Spina Bifida patients are 25% less likely to be employed and, when they are employed, work 25% fewer hours compared to those not providing Spina Bifida-related care.

Clinics:
Children's Specialized Hospital, 150 New Providence Rd., Mountainside, NJ 07092
Children's Specialized Hospital, 815 Broadway, Bayonne, NJ 07002
Children's Specialized Hospital, 629 Cranbury Rd, East Brunswick, NJ 08816
Children's Specialized Hospital, 3575 Quakerbridge Rd, Hamilton, NJ 08619
Children's Specialized Hospital, 1135 Broad Street, Clifton NJ, 07013
Children's Specialized Hospital, 6106 Black Horse Pike, Egg Harbor Township, NJ 08234
Children's Specialized Hospital, 182 Lyons Ave, Newark, NJ 07112
Children's Specialized Hospital, 10 Plum St, New Brunswick, NJ 08901
Children's Specialized Hospital, 368 Lakehurst Rd, Toms River, NJ 08755
Children's Specialized Hospital, 94 Stevens Rd, Toms River, NJ 08755
Children's Specialized Hospital, 286 King George Rd, Warren, NJ 07059
Kessler Institute for Rehabilitation, 1199 Pleasant Valley Way, West Orange, NJ 07052