



## Spina Bifida in Pennsylvania

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 Pennsylvania, 3.25 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 may be as high as 166,000. Based on this national estimate and the birth rate of Spina Bifida, approximately 4,000 people with Spina Bifida live in Pennsylvania.
- In Pennsylvania, there are an estimated 4.0 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 3,200 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 2,500 of these devices will fail within 10 years.
- 2,000 of the people living with Spina Bifida are adults, and 1,600 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.

*The mission of the Spina Bifida Association is to build a better and brighter future for all those impacted by Spina Bifida*

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Community Health Charities #10559

/spina.bifida.learn · @SpinaBifidaAssn · spinabifidaassociation.org

## Cost Related to the Care of People with Spina Bifida in Pennsylvania

- The estimated cost of lifetime care related to Spina Bifida for the 6,800 of the people living with Spina Bifida in Pennsylvania can exceed \$1,000,000 or \$4,000,000,000. 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:

Moss Rehabilitation Center for Adults  
60 Township Line Road  
Elkins Park, PA 19027  
215-663-6607  
<https://www.mossrehab.com/>

Shriner's Hospitals for Children Erie  
**(0 – transition)**  
1645 West 8th Street  
Erie, PA 16505  
315-464-8668  
<https://www.shrinershospitalsforchildren.org/erie>

Penn State Milton S. Hershey Medical Center  
**(Ages served: Information n/a)**  
500 University Drive  
Hershey, PA 17033  
717-531-7311  
<http://hmc.pennstatehealth.org>

Hershey Medical Center  
Pediatric Bone, Joint and Neurosciences Institute  
(0 – 18)  
30 Hope Drive, Suite 2200  
Hershey, PA 17033  
717-531-7123  
<https://hmc.pennstatehealth.org/display-location/-/location/73/pediatric-bone-and-joint-institute>

CHOP Buerger Center for Advanced Pediatric Care  
**(0 – 18)**  
Raymond G Perlman Campus  
3500 Civic Center Boulevard  
Philadelphia, PA 19104  
215-590-1000  
<http://www.chop.edu/locations/buerger-center-advanced-pediatric-care>

University of Pittsburgh Medical Center  
Mercy PM&R Office

**(adults)**  
1400 Locust St.

Pittsburgh, PA 15219  
412-232-8903  
<https://www.upmc.com/services/rehab/physical-medicine-rehab/conditions/spina-bifida>

University of Pittsburgh Medical Center  
Children's Hospital of Pittsburgh  
Spina Bifida Department  
**(0 – transition)**  
1 Children's Hospital Way  
4401 Penn Avenue  
Pittsburgh, PA 15224

412-692-5096  
<http://www.chp.edu/our-services/spina-bifida-clinic>

Geisinger Medical Center  
**(orthopedic and neurosurgery  
provider; ages served not available)**  
100 N Academy Avenue  
Danville, PA 17822  
<https://www.geisinger.org/patient-care/conditions-treatments-specialty/2017/03/15/14/33/spine-conditions>