

2021

STATE FACT SHEETS



SPINA BIFIDA
ASSOCIATION

Alabama

Alaska

Arizona

Arkansas

California

Colorado

Connecticut

Delaware

D.C.

Florida

Georgia

Hawaii

Illinois

Indiana

Iowa

Kansas

Kentucky

Louisiana

Maine

Maryland

Massachusetts

Michigan

Minnesota

Mississippi

Missouri

Nebraska

Nevada

New Hampshire

New Jersey

New Mexico

New York

North Carolina

North Dakota

Ohio

Oklahoma

Oregon

Pennsylvania

Rhode Island

South Carolina

South Dakota

Tennessee

Texas

Utah

Virginia

Washington

West Virginia

Wisconsin



Spina Bifida in Alabama

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 that 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 Alabama, 3.04 babies are born with Spina Bifida per 10,000 births (data collection period: 2010).
- Research has estimated that the number of Americans living with all forms of Spina Bifida is about 166,000. Based on this national estimate and the birth rate of Spina Bifida, approximately 1,417 people with Spina Bifida live in Alabama.
- In Alabama, there are an estimated 1.6 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 1,134 of individuals with THE most severe 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 907 of these devices will fail within 10 years.
- 708 of the people living with Spina Bifida are adults, and 566 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

1600 Wilson Blvd., Suite 800, Arlington, VA 22209 · 800-621-3141 · SpinaBifidaAssociation.org

Cost Related to the Care of People with Spina Bifida in Alabama

- The cost of lifetime care for Spina Bifida patients is \$901,212,000 though it can often exceed \$1,417,000,000. Among those patients with the most serious form of Spina Bifida, myelomeningocele (MMC), only half can live independently as adults, accruing substantial costs for 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 costs 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 Hospital of Alabama
Spina Bifida Program
(pediatric – transition)
1600 7th Avenue S.
Birmingham, AL 35233
205-939-5281
<https://www.childrensal.org/SpinaBifidaProgram>

UAB Spain Rehab Adult Transition Clinic
Comprehensive Spina Bifida Transition Clinic
(pediatrics – adult)
1717 6th Ave S.
Birmingham, AL 35233
205-934-4131
<http://www.uabmedicine.org/locations/spain-rehabilitation-center>

Alabama Department of Rehabilitation Services, Children's Rehabilitation Service
(pediatric – adult)
251-432-4560
<http://www.rehab.alabama.gov/individuals-and-families/childrens-rehabilitation-service>



Spina Bifida in Alaska

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 that 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 Alaska, 3.96 babies are born with Spina Bifida per 10,000 births (data collection period: 2010).
- Research has estimated that the number of Americans living with all forms of Spina Bifida is about 166,000. Based on this national estimate and the birth rate of Spina Bifida, approximately 400 people with Spina Bifida live in Alaska.
- In Alaska, there are an estimated 219,000 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 320 of individuals with THE most severe 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 256 of these devices will fail within 10 years.
- 200 of the people living with Spina Bifida are adults, and 160 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.

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Cost Related to the Care of People with Spina Bifida in Alaska

- The cost of lifetime care for Spina Bifida patients is around \$1,000,000. Among those patients with the most serious form of Spina Bifida, myelomeningocele (MMC), only half can live independently as adults, accruing substantial costs for 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 costs 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:

**Providence Medical Group
Pediatric Subspecialties Clinic
3340 Providence Drive, Suite A-351
Anchorage, AK 99508
907-212-4824
Ages Served: 0-18
<https://alaska.providence.org/locations/p/providence-medical-group-pediatric-subspecialties>**



Spina Bifida in Arizona

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 Arizona, 3.84 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 2,500 people with Spina Bifida live in Arizona.
- In Arizona, there are an estimated 2 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 2,000 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 1,500 of these devices will fail within 10 years.
- 1,200 of the people living with Spina Bifida are adults, and 1,000 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.

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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 Arizona

- The estimated cost of lifetime care related to Spina Bifida for the 1,100 of the people living with Spina Bifida in Arizona can exceed \$1,000,000 or \$2,500,000,000. 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:

District Medical Group Children's Rehabilitative Services

3141 N 3rd Avenue
Phoenix, AZ 85103
602-914-1520

Ages Served: 0-21

<https://www.dmgaz.org/phoenix-pediatrics-az/>

Phoenix Children's

1919 E. Thomas
Phoenix, AZ 85016
602-933-KIDS (5437)

Ages Served: 0-25

<https://www.phoenixchildrens.org/conditions/spina-bifida>

Children's Clinic Rehabilitation Services (CCRS)

2600 N Wyatt Drive
Tucson, AZ 85712
520-324-5437

Ages Served: 0-21

<https://www.childrensclinics.org/services/>



Spina Bifida in Arkansas

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 Arkansas, 4.01 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 1,145 people with Spina Bifida live in Arkansas.
- In Arkansas, there are an estimated 900,000 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 916 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 733 of these devices will fail within 10 years.
- 573 of the people living with Spina Bifida are adults, and 458 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.

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Cost Related to the Care of People with Spina Bifida in Arkansas

- The estimated cost of lifetime care related to Spina Bifida for the 1,145 people living with Spina Bifida in Arkansas ranges between \$728,220,000 and \$1,145,000,000. 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:

Arkansas Children's Hospital

Spina Bifida Clinic/Program

(pediatric only)

1 Children's Way

Little Rock, AR 72202

501-364-4000

<https://www.archildrens.org/programs-services/a-to-z-services-list/spina-bifida/spina-bifida>



Spina Bifida in California

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 that 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 California, 2.08 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 7,645 people with Spina Bifida live in California.
- In California, there are an estimated 11.6 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 6,116 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 4,893 of these devices will fail within 10 years.
- 3,820 of the people living with Spina Bifida are adults, and 3,056 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.

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Cost Related to the Care of People with Spina Bifida in California

- The estimated cost of lifetime care related to Spina Bifida for the 7,645 people living with Spina Bifida in California ranges between \$4,862,220,000 and \$7,645,000,000. Among adults with MMC, only 1,528 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:

National Rehabilitation Center
Rancho Los Amigos
(pediatric - adult)
7601 Imperial Hwy., JPI 3145
Downey, CA 90242
(562) 401-7111
www.rancho.org

Miller Children's and Women's
Hospital Spina Bifida CCS Center
(0-21)
2801 Atlantic Avenue
Long Beach, CA 90806
562-933-8832
<https://www.memorialcare.org/miller-children-hospital-long-beach/locations/spina-bifida-ccs-center-long-beach-2801-atlantic>

Children's Hospital of Los Angeles
(0 – 21)
4650 Sunset Boulevard
Los Angeles, CA 90027
323-361-2384
<https://www.chla.org/spina-bifida-program>

Orthopedic Institute for Children
(0 – 18)
403 West Adams Boulevard
Los Angeles, CA 90007
213-741-8352
<https://ortho-institute.org/>

Valley Children's Healthcare
(0 – 21)
9300 Valley Children's Place
Madera, CA 93636
559-353-6215
<https://www.valleychildrens.org/>

Regional Spina Bifida Program, Kaiser
Oakland Medical Center
(adults)
280 W. MacArthur Boulevard
Oakland, CA 94611
510-752-6920
https://mydoctor.kaiserpermanente.org/ncal/specialty/genetics/specialty_clinics/SBC/index.jsp

UCSF Benioff Children's
Hospital Oakland
(Ages served: Information n/a)
747 52nd Street
Oakland, CA 94609
510-428-3000
<https://www.childrenshospitaloakland.org/main/home.aspx>

Children's Hospital of Orange County
Spina Bifida Clinic
(Ages served: Information n/a)
1201 West LaVeta Avenue
Orange, CA 92868
714-509-8514
<https://www.choc.org/orthopaedics/neuromuscular-disease-program/spina-bifida-clinic/>

Shriners for Children Medical Center –
Pasadena
(0-18)
909 South Fair Oaks Avenue
Pasadena, CA 91105
626-389-9300
<https://www.shrinershospitalsforchildren.org/pasadena>

Shriners Hospital for Children –
Sacramento
(0-18)
2425 Stockton Boulevard
Sacramento, CA 95817
916-453-2000
<https://www.shrinershospitalsforchildren.org/sacramento>

Loma Linda University Children's
Hospital Spina Bifida Clinic
(0 - 21, 0 - transition)
2195 Club Center Drive #G
San Bernardino, CA 92408
909-558-6272
<https://luch.org/services/specialty-team-centers?rsource=childrens-hospital.lomalindahealth.org/our-services/specialty-team-centers>

Rady Children's Hospital
Spinal Defects Clinic
(0 - 21, 0 - transition)
3020 Children's Way
San Diego, CA 92123
858-966-8896
<https://www.rchsd.org/>

Sharp Allison deRose Rehabilitation
Center
(Ages served: Information n/a)
2999 Health Center Drive
San Diego, CA 92123
858-939-3097
<https://www.sharp.com/hospitals/memorial/departments/rehab.cfm>

UCSF Benioff Children's Hospital,
Pediatric Rehabilitation Clinic
(0 – transition)
1855 Fourth Street
San Francisco, CA 94158
415-476-3899
https://www.ucsfbenioffchildrens.org/clinics/spina_bifida_program/index.html

Stanford Children's Health
Specialty Services
(0 – 18)
1195 West Fremont Avenue
Sunnyvale, CA 94087
408-426-5625
<https://www.stanfordchildrens.org/en/service/spina-bifida/careteam>



Spina Bifida in Colorado

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 percent of babies born with Spina Bifida do not live into adulthood.

- Research has estimated that the number of Americans living with all forms of Spina Bifida is about 166,000. Based on this national estimate and the birth rate of Spina Bifida, approximately 1,689 people with Spina Bifida live in Colorado. (*data collection period: 2010*).
- In Colorado, there are over 1,550,000 women of childbearing age. All are at-risk of a pregnancy affected by Spina Bifida. 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 percent.
- In Colorado, approximately 1,351 people 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, thus about 1,081 of these devices will fail within 10 years.
- In Colorado, 845 of the estimated people living with Spina Bifida are adults, and 676 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.

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Costs Related to the Care of People with Spina Bifida in Colorado

- The cost of lifetime care for Spina Bifida patients in Colorado is \$1,074,204,000 though it can often exceed \$1,689,000,000. Among those patients with the most serious form of Spina Bifida, myelomeningocele (MMC), only half are able to live independently as adults, accruing substantial costs for 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 costs 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 Hospital Colorado
Spinal Defect Clinic, Rehabilitation Department

(Ages served: Information n/a)

13123 E 16th Avenue

Aurora, CO 80045

720-777-1234

<https://www.childrenscolorado.org/doctors-and-departments/departments/pediatric-rehabilitation/spinal-defects-injuries-clinic/>

University of Colorado-Memorial Hospital Central

(Ages served: Information n/a)

1400 E Boulder Street

Colorado Springs, CO 80909

719-365-5000

<https://www.uchealth.org/>

Rocky Mountain Hospital for Children

Spinal Disorders Center

(0 – 18)

2001 N. High St.

Denver, CO 80205

(720) 754-1000

<https://rockymountainhospitalforchildren.com/service/spina-bifida>



Spina Bifida in Connecticut

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 Connecticut, 2.89 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 1,012 people with Spina Bifida live in Connecticut.
- In Connecticut, there are an estimated one 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 810 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 648 of these devices will fail within 10 years.
- 506 of the people living with Spina Bifida are adults, and 405 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.

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Cost Related to the Care of People with Spina Bifida in Connecticut

- The estimated cost of lifetime care related to Spina Bifida for the 1,012 people living with Spina Bifida in Connecticut ranges between \$643,632,000 and \$1,012,000,000. Among adults with MMC, only 203 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:

Connecticut Children's Medical Center

Spina Bifida Clinic

282 Washington Street

Hartford, CT 06106

(860) 545-9100

www.connecticutchildrens.org/

Yale New Haven Children's Hospital

Spina Bifida Clinic

1 Long Wharf Drive, 2nd Floor

New Haven, CT 06510

(203) 688-4221

<https://www.ynhh.org/childrens-hospital.aspx>



Spina Bifida in Delaware

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 that 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 Delaware, 7.56 babies are born with Spina Bifida per 10,000 births (data collection period: 2010).
- Research has estimated that the number of Americans living with all forms of Spina Bifida is about 166,000. Based on this national estimate and the birth rate of Spina Bifida, approximately 500 people with Spina Bifida live in Delaware.
- In Delaware, there are an estimated 281,000 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 400 of individuals with THE most severe 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 320 of these devices will fail within 10 years.
- 250 of the people living with Spina Bifida are adults, and 200 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.

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Cost Related to the Care of People with Spina Bifida in Delaware

- The cost of lifetime care for Spina Bifida patients is around \$1,000,000. Among those patients with the most serious form of Spina Bifida, myelomeningocele (MMC), only half can live independently as adults, accruing substantial costs for 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 costs 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:

**Nemours/Alfred I. Dupont Hospital for Children
1600 Rockland Rd.
Wilmington, DE 19803
302-651-4200
Ages served: 0-18**



Spina Bifida in District of Columbia

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.

- 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 300 people with Spina Bifida live in D.C.
- In D.C., there are an estimated 200,000 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 240 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 200 of these devices will fail within 10 years.
- 150 of the people living with Spina Bifida are adults, and 120 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.

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

Cost Related to the Care of People with Spina Bifida in D.C.

- The cost of lifetime care for people with Spina Bifida is \$1,000,000 though it can often exceed 300,000,000. Among those patients with the most serious form of Spina Bifida, myelomeningocele (MMC), only half are able to live independently as adults, accruing substantial costs for 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 costs 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 National Health System, Spina Bifida Program

111 Michigan Avenue, NC

Washington, D.C. 20010

202-476-3094

Ages served: 0-18



Spina Bifida in Florida

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 Florida, 3.21 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 10,000 people with Spina Bifida live in Florida.
- In Florida, there are an estimated 5.5 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 8,000 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 6,400 of these devices will fail within 10 years.
- Five thousand of the people living with Spina Bifida are adults, and 4,000 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.

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Cost Related to the Care of People with Spina Bifida in Florida

- The cost of lifetime care for Spina Bifida patients is \$636,000,000,000 though it can often exceed \$100,000,000,000. Among those patients with the most serious form of Spina Bifida, myelomeningocele (MMC), only 2,000 are able to live independently as adults, accruing substantial costs for 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 costs 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:

UF Health Pediatric Neurosurgery

836 Prudential Dr.

Ste 1205

Jacksonville, FL 32207

904-633-0780

<https://hscj.ufl.edu/directory/location/47/uf-health-pediatric-neurosurgery-prudential-drive/>

Holtz Children's Hospital at Jackson Memorial Hospital

Comprehensive Spina Bifida Program

1611 NW 12th Ave.

Miami, FL 33136

305 585-3627

<https://jacksonhealth.org/holtz/spina-bifida/>

Nemours Children's Health System

Spina Bifida Program

13535 Nemours Pkwy

Orlando, FL 32827

(407) 650-7715

www.nemours.org

Spina Bifida Program at Arnold Palmer Hospital for Children

Orlando, FL

1725 Cook Avenue

321-841-5683

<https://www.arnoldpalmerhospital.com/pediatric-specialties/pediatric-spina-bifida-program>



Spina Bifida in Georgia

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 Georgia, 3.94 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, approximately 5,287 people with Spina Bifida live in Georgia.
- In Georgia, there are an estimated 3.1 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 4,230 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 3,084 of these devices will fail within 10 years.
- 2,644 of the people living with Spina Bifida are adults, and 2,145 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.

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Cost Related to the Care of People with Spina Bifida in Georgia

- The estimated cost of lifetime care related to Spina Bifida for the 5,287 people living with Spina Bifida in Georgia ranges between \$3,362,532,000 and \$5,287,000,000. 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 Healthcare of Atlanta
5641 Meridian Mark Road
Suite 200
Atlanta, GA 30030



Spina Bifida in Hawaii

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.

- 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 400 people with Spina Bifida live in Hawaii.
- In Hawaii, there are an estimated 400,000 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 300 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 250 of these devices will fail within 10 years.
- 200 of the people living with Spina Bifida are adults, and 150 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.

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Cost Related to the Care of People with Spina Bifida in Hawaii

- The cost of lifetime care for people with Spina Bifida is \$1,000,000 though it can often exceed 400,000,000. Among those patients with the most serious form of Spina Bifida, myelomeningocele (MMC), only half are able to live independently as adults, accruing substantial costs for 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 costs 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.

***There are currently no known Spina Bifida clinics for children or adults in Hawaii.**



Spina Bifida in Illinois

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 Illinois, 2.86 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 3,700 people with Spina Bifida live in Illinois.
- In Illinois, there are over 4 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 2,960 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 2,368 of these devices will fail within 10 years.
- 1,850 of the people living with Spina Bifida are adults, and 1,480 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

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Cost Related to the Care of People with Spina Bifida in Illinois

- The cost of lifetime care for Spina Bifida patients is \$2,353,200,000 though it can often exceed \$3,700,000,000. Among those patients with the most serious form of Spina Bifida, myelomeningocele (MMC), only half are able to live independently as adults, accruing substantial costs for 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 costs 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:

Ann & Robert H. Lurie Children's Hospital
of Chicago
Spina Bifida Center
2515 N. Clark
Chicago, IL 60614
(312) 227-5340
www.luriechildrens.org

Shirley Ryan Ability Lab
345 Superior Street
Chicago, IL 60611
(312) 238-1000
www.ric.org

Shriners Hospital for Children
Myelomeningocele Clinic
2211 N. Oak Park Avenue
Chicago, IL 60707
(773) 622-5400
<http://www.shrinershospitalsforchildren.org/Hospitals/Locations/Chicago.aspx>

Lutheran General Children's Hospital
Spina Bifida Clinic
3rd floor, Yackman Pavillion
1675 Dempster Street
Park Ridge, IL 60068
(847) 723-5065
www.advocatehealth.com

St Francis Hospital INI
Spina Bifida Clinic (**pediatric and adult**)
420 N.E. Glen Oak, Suite 201
Peoria, IL 61603
(309) 655-3800
www.osfsaintfrancis.org



Spina Bifida in Indiana

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 Indiana, 3.95 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 2,519 people with Spina Bifida live in Indiana.
- In Indiana, there are an estimated 2,014,180 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 2,015 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 1,612 of these devices will fail within 10 years.
- 1,259 of the people living with Spina Bifida are adults, and 1,008 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.

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Cost Related to the Care of People with Spina Bifida in Indiana

- The estimated cost of lifetime care related to Spina Bifida for the 2,519 people living with Spina Bifida in Indiana ranges between \$1,602,084,000 and \$2,519,000,000. 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:

Riley Hospital for Children at Indiana University Health

Spina Bifida Program

(0 – transition)

705 Riley Hospital Dr.

Indianapolis, IN 46202

317.396.1401

<https://www.rileychildrens.org/departments/spina-bifida-program/>

Riley Hospital for Children at Indiana University Health

Center for Youth & Adults with Conditions of Childhood (CYACC)

(transition - adults)

705 Riley Hospital Dr.

Indianapolis, IN 46202

317-944-7458

<https://www.rileychildrens.org/departments/center-for-youth-adults-with-conditions-of-childhood/>



Spina Bifida in Iowa

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 Iowa, 5.13 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 1,600 people with Spina Bifida live in Iowa.
- In Iowa, there are an estimated 1 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 1,230 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 1,000 of these devices will fail within 10 years.
- 800 of the people living with Spina Bifida are adults, and 620 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.

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Cost Related to the Care of People with Spina Bifida in Iowa

- The estimated cost of lifetime care related to Spina Bifida for the 1,600 of the people living with Spina Bifida in Iowa can exceed \$1,000,000 or \$1,600,000,000. 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:

University of Iowa Stead Family Children's Hospital
Center for Disabilities and Development

(Ages served: Information n/a)

100 Hawkins Dr., 213 CDD

Iowa City, IA 52242

<https://uichildrens.org/medical-services/center-disabilities-and-development>

1-855-543-2884



Spina Bifida in Kansas

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.

- 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 1,500 people with Spina Bifida live in Kansas.
- In Kansas, there are an estimated 1 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 1,200 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 960 of these devices will fail within 10 years.
- 750 of the people living with Spina Bifida are adults, and 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.

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Cost Related to the Care of People with Spina Bifida in Kansas

- The cost of lifetime care for people with Spina Bifida is \$1,000,000 though it can often exceed 1,500,000,000. Among those patients with the most serious form of Spina Bifida, myelomeningocele (MMC), only half are able to live independently as adults, accruing substantial costs for 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 costs 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:

Cerebral Palsy/Medically Complex Clinic KU Wichita Pediatrics

620 North Carriage Parkway

Wichita, KS 67208

316-962-1824

Ages served: Information not available at this time



Spina Bifida in Kentucky

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 Kentucky, 4.12 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 1,800 people with Spina Bifida live in Kentucky.
- In Kentucky, there are an estimated 1.4 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 1,400 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 1,126 of these devices will fail within 10 years.
- 879 of the people living with Spina Bifida are adults, and 704 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.

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Cost Related to the Care of People with Spina Bifida in Kentucky

- The estimated cost of lifetime care related to Spina Bifida for the 1,800 people living with Spina Bifida in Kentucky ranges between \$1,481,880,000 and \$1,800,000,000. 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:

Norton Children's Hospital

(0 – 18)

231 E. Chestnut St.

Louisville. KY 40202

<https://nortonchildrens.com/>

502-629-5437

Shriner's Hospital for Children Lexington

(Ages served: Information n/a)

110 Conn Terrace

Lexington, KY 40508

<https://www.shrinershospitalsforchildren.org/lexington>

859-266-2101



Spina Bifida in Louisiana

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 that 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.

- 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 2,400 people with Spina Bifida live in Louisiana.
- In Louisiana there are an estimated 2 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 1,900 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 around 1,500 devices will fail within 10 years.
- In Louisiana, 1,200 of the estimated people living with Spina Bifida are adults, and 960 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.

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Cost Related to Care of People with Spina Bifida in Louisiana

- The estimated cost of lifetime care related to Spina Bifida for the 2,400 people in Louisiana who live with Spina Bifida can often exceed one million dollars, or \$2,400,000,000. Among those patients with the most serious form of Spina Bifida, MMC, only half are able to live independently as adults, accruing substantial costs for 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 costs 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:

Ochsner Health System Primary Care Pediatrics

1514 Jefferson Highway
Jefferson, LA 70121
504-842-7538
Ages served: 0 - Transition

Children's Hospital New Orleans

200 Henry Clay Avenue
New Orleans, LA 70118
Maine: 504-899-9511
Urology Department: 504-896-2888
Ages served: 0 - 18



Spina Bifida in Maine

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 percent of babies born with Spina Bifida do not live into adulthood.

- Research has estimated that the number of Americans living with all forms of Spina Bifida is about 166,000. Based on this national estimate and the birth rate of Spina Bifida, approximately 720 people with Spina Bifida live in Maine. (*data collection* period: 2010).
- In Maine, there are over 400,000 women of childbearing age. All are at-risk of a pregnancy affected by Spina Bifida. 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 percent.
- In Maine, approximately 575 of people 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, thus about 460 of these devices will fail within 10 years.
- In Maine, 360 of the estimated people living with Spina Bifida are adults, and 290 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.

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Costs Related to the Care of People with Spina Bifida in Maine

- The estimated cost of lifetime care related to Spina Bifida for the 720 people in Maine who live with Spina Bifida can often exceed one million dollars, or \$710,000,000. Among those patients with the most serious form of Spina Bifida, MMC, only half are able to live independently as adults, accruing substantial costs for 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 seven times more in medical costs 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 in Maine

Maine Medical Partners
Scarborough Pediatric Neurology
49 Spring St. #2
Scarborough, ME 04074
(207) 883-1414



Spina Bifida in Maryland

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 that 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 Maryland, 3.62 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 2,039 people with Spina Bifida live in Maryland.
- In Maryland, there are an estimated 1.8 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 1,631 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 1,304 of these devices will fail within 10 years.
- 1,020 of the people living with Spina Bifida are adults, and 816 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

Cost Related to the Care of People with Spina Bifida in Maryland

- The estimated cost of lifetime care related to Spina Bifida for the 2,039 people living with Spina Bifida in Maryland ranges between \$1,296,804,000 and \$2,039,000,000. Among adults with MMC, only 408 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.

Clinic:

Kennedy Krieger Institute
The Keelty Center for Spina Bifida and Related Disorders
(all ages)
707 N. Broadway
Baltimore, MD 21205
<http://www.kennedykrieger.org>
(443) 923-9130



Spina Bifida in Massachusetts

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 Massachusetts, 1.61 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 1,046 people with Spina Bifida live in Massachusetts.
- In Massachusetts, there are an estimated 2,161,809 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 837 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 670 of these devices will fail within 10 years.
- 523 of the people living with Spina Bifida are adults, and 418 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

1600 Wilson Blvd., Suite 800, Arlington, VA 22209 · t 800-621-3141 · f 202-944-3295

Community Health Charities #10559

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Cost Related to the Care of People with Spina Bifida in Massachusetts

- The estimated cost of lifetime care related to Spina Bifida for the 1,046 people living with Spina Bifida in Massachusetts ranges between 665,256,000 and 1,046,000,000. 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:

Boston Children's Hospital
300 Longwood Avenue
Boston, MA 02115
617-355-8532

Ages Served: 0-Transition

https://www.childrenshospital.org/centers-and-services/programs/o_-_z/spina-bifida-center-program

Shriners Hospital for Children – Springfield
516 Carew Street
Springfield, MA 01104
413-787-2065

Ages Served: 0-Transition

<https://www.shrinershospitalsforchildren.org/springfield>



Spina Bifida in Michigan

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 Michigan, 4.71 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 4,712 people with Spina Bifida live in Michigan.
- In Michigan, there are an estimated 3,206,599 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 3,769 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 3,015 of these devices will fail within 10 years.
- 2,356 of the people living with Spina Bifida are adults, and 1,885 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.

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Cost Related to the Care of People with Spina Bifida in Michigan

- The estimated cost of lifetime care related to Spina Bifida for the 4,712 people living with Spina Bifida in Michigan ranges between 2,996,832,000 and \$4,712,000,000. 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:

Michigan Medicine Physical Medicine & Rehabilitation (adults)

1500 E. Medical Center Dr.

Ann Arbor, MI 48109

734-936-5062

<https://medicine.umich.edu/dept/pmr/divisions-programs/rehabilitation-psychology-neuropsychology/adult-inpatient-services>

Children's Hospital of Michigan Myelomeningocele Care Center

(0 – transition)

3901 Beaubien St.

Detroit, MI 48201

313-745-5437

<https://www.childrensdmc.org/our-services/all-specialties/chm/myelomeningocele-care-center>

Sparrow Hospital - Sparrow Professional Building (0 – 21)

1200 E. Michigan Avenue, Suite 460

Lansing, MI 48912

517-364-1000

<http://www.sparrow.org/myelodysplasia>



Spina Bifida in Minnesota

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.

- 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 2,900 people with Spina Bifida live in Minnesota.
- In Minnesota, there are an estimated 1.6 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 2,300 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 1,800 of these devices will fail within 10 years.
- 1,400 of the people living with Spina Bifida are adults, and 1,100 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.

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Cost Related to the Care of People with Spina Bifida in Minnesota

- The estimated cost of lifetime care related to Spina Bifida for the 2,900 of the people living with Spina Bifida in Minnesota can exceed \$1,000,000 or \$2,900,000,000. 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:

Gillette Lifetime Specialty Healthcare
435 Phalen Blvd, St Paul, MN 55130
<https://gillettechildrens.org/>

Shriners Hospital Twin Cities
2025 E Rover Pkwy, Minneapolis Mn 55414
www.shrinershospitalsforchildren.org/minneapolis

Mayo Clinic
200 1st Street S.W.
Rochester, MN 55902
www.mayoclinic.org



Spina Bifida in Mississippi

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 that 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 Mississippi, 2.08 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 an estimated 611 people with Spina Bifida live in Mississippi.
- In Mississippi, there are an estimated one 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 489 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 391 of these devices will fail within 10 years.
- 306 of the people living with Spina Bifida are adults, and 244 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.

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Cost Related to the Care of People with Spina Bifida in Mississippi

- The cost of lifetime care for an individual with Spina Bifida is about \$1 million. Among those patients with the most serious form of Spina Bifida, myelomeningocele (MMC), only half can live independently as adults, accruing substantial costs for 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 expenses 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:

There are currently no Spina Bifida clinics in Mississippi.



Spina Bifida in Missouri

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 Missouri, 4.58 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 3,200 people with Spina Bifida live in Missouri.
- In Missouri, there are an estimated 1.8 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 2,560 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 2,048 of these devices will fail within 10 years.
- 1,600 of the people living with Spina Bifida are adults, and 1,280 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.

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Cost Related to the Care of People with Spina Bifida in Missouri

- The cost of lifetime care for Spina Bifida patients is \$2,035,200,000 though it can often exceed \$3,200,000,000. Among those patients with the most serious form of Spina Bifida, myelomeningocele (MMC), only half are able to live independently as adults, accruing substantial costs for 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 costs 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 Mercy Hospital & Clinics
Spinal Defects Clinic (**pediatric to 21**)
2401 Gillham Road
Kansas City, MO 64024
(816) 234-3790 or (816) 234 3005
www.childrens-mercy.org/

Cardinal Glennon Children's Medical Center
Myelomeningocele Clinic (**pediatric to 18**)
1465 South Grand Blvd.
St. Louis, MO 63104-1095
(314) 268-2700 ext. 4178
www.cardinalglennon.com

St. Louis Children's Hospital SB clinic (**pediatric to transition**)
One Children's Place
St. Louis, MO 63110
(314) 454-5333
www.StLouisChildrens.org



Spina Bifida in Nebraska

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.

- 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 1,000 people with Spina Bifida live in Nebraska.
- In Nebraska, there are an estimated 500,000 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 800 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 640 of these devices will fail within 10 years.
- 500 of the people living with Spina Bifida are adults, and 400 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.

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Cost Related to the Care of People with Spina Bifida in Nebraska

- The cost of lifetime care for people with Spina Bifida is \$1,000,000 though it can often exceed 1,000,000,000. Among those patients with the most serious form of Spina Bifida, myelomeningocele (MMC), only half are able to live independently as adults, accruing substantial costs for 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 costs 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 Hospital & Medical Center's Children's Developmental Clinic (CDC)

8200 Dodge Street

Omaha, NE 68114-4113

402-955-4160

Ages served: Information not available at this time



Spina Bifida in Nevada

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.

- 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 1,400 people with Spina Bifida live in Nevada.
- In Nevada, there are an estimated 800,000 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 1,110 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 900 of these devices will fail within 10 years.
- 700 of the people living with Spina Bifida are adults, and 560 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.

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Cost Related to the Care of People with Spina Bifida in Nevada

- The estimated cost of lifetime care related to Spina Bifida for the 1,400 of the people living with Spina Bifida in Nevada can exceed \$1,000,000 or \$1,400,000,000. 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:

***There are currently no known Spina Bifida clinics for children or adults in Nevada.**



Spina Bifida in New Hampshire

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 that 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 Hampshire, 2.1 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 718 people with Spina Bifida live in New Hampshire.
- In New Hampshire, there are an estimated 400,000 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 574 individuals with THE most severe 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 460 of these devices will fail within 10 years.
- 360 of the people living with Spina Bifida are adults, and 287 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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Cost Related to the Care of People with Spina Bifida in New Hampshire

- The cost of lifetime care for Spina Bifida patients is \$456,648,000 though it can often exceed \$718,000,000. Among those patients with the most serious form of Spina Bifida, myelomeningocele (MMC), only half can live independently as adults, accruing substantial costs for 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 expenses 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.

Clinic:

Dartmouth Hitchcock Medical Center

Spinal Dysraphism Program (**pediatric and adult up to age 25**)

Clinic 6L, One Medical Center Dr.

Lebanon, NH 03756

(603) 653-9623

<http://chad.dartmouth->

[hitchcock.org/pc/health_care_services/list_of_services/spina_bifida.html](http://chad.dartmouth-hitchcock.org/pc/health_care_services/list_of_services/spina_bifida.html)



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 1,710 people living with Spina Bifida in New Jersey is about \$1,000,000 per person or \$1,710,000,000 for the state. 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:

- [Kessler Institute for Rehabilitation](#)
1199 Pleasant Valley Way
West Orange, NJ 07052



Spina Bifida in New Mexico

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 Mexico, 5.63 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 1,100 people with Spina Bifida live in New Mexico.
- In New Mexico, there are an estimated 620,000 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 880 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 700 of these devices will fail within 10 years.
- 550 of the people living with Spina Bifida are adults, and 440 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

1600 Wilson Blvd., Suite 800, Arlington, VA 22209 · t 800-621-3141 · f 202-944-3295

Community Health Charities #10559

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

Cost Related to the Care of People with Spina Bifida in New Mexico

- The estimated cost of lifetime care related to Spina Bifida for the 1,100 of the people living with Spina Bifida in New Mexico can exceed \$1,000,000 or \$1,100,000,000. 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:

Carrie Tingley Hospital

127 University Blvd NE, Albuquerque, NM 87102

<https://hsc.unm.edu/health/locations/carrie-tingley-hospital.html>



Spina Bifida in New York

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 York, 2.06 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 4,015 people with Spina Bifida live in New York.
- In New York, there are an estimated 6.3 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.

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Cost Related to the Care of People with Spina Bifida in New York

- The estimated cost of lifetime care related to Spina Bifida for the 10,640 of the people living with Spina Bifida in New York can exceed \$1,000,000 or \$4,015,000,000. Among adults with MMC, only half live independently as adults, accruing substantial costs for 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 costs 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:

Montefiore Medical Center, Function Clinic
(pediatric – adults)
111 E 210th St.
Bronx, NY 10467
(844) 438-3862
<http://www.function.center/home.html>

Columbia University / New York-Presbyterian
ColumbiaDoctors
(pediatric - transition)
630 W 168th St.
New York, NY 10032
(212) 305-3535
<https://www.columbiadoctors.org/condition/spina-bifida-pediatric>

NYU Langone Health
(Pediatric services provider)
550 First Avenue
New York, NY 10016
<https://nyulangone.org/conditions/spina-bifida-in-children>

NYU Langone Initiative for Women with Disabilities
(adult)
550 First Avenue
New York, NY 10016
<https://nyulangone.org/locations/initiative-for-women-with-disabilities>

Golisano Children's Hospital
University of Rochester Medical Center

(Ages served: Information n/a)

150 Crittenden Blvd.
Rochester, NY 14642
(585) 275-7520
<https://www.urmc.rochester.edu/pediatrics.aspx>

Upstate Golisano Adult Spina Bifida Clinic
(adult)
750 E Adams St
Syracuse, NY 13210
(315) 464-4014
<http://www.upstate.edu/hospital/services/pediatric-services-clinics.php>

Upstate Golisano Children's Hospital
(0 – transition)
1 Children's Circle
Syracuse, NY 13210
(315) 464-5280
<http://www.upstate.edu/hospital/>



Spina Bifida in North Carolina

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 North Carolina, 4.21 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 3,883 people with Spina Bifida live in North Carolina.
- In North Carolina, there are an estimated 2.9 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 3,106 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 2,485 of these devices will fail within 10 years.
- 1,941 of the people living with Spina Bifida are adults, and 1,553 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.

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Cost Related to the Care of People with Spina Bifida in North Carolina

- The estimated cost of lifetime care related to Spina Bifida for the 1,145 people living with Spina Bifida in North Carolina ranges between \$3,202,260,000 and \$3,883,000,000. 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:

Levine Children's Specialty Center

(0 – transition)

1628 E Morehead St.

Charlotte, NC 28207

(704) 381-8840

<https://atriumhealth.org/medical-services/childrens-services>

UNC Department of Physical Medicine and Rehabilitation

(0 – transition, 0 - 21)

1807 Fordham Boulevard

Chapel Hill, NC 27514

984-974-9747

<https://www.uncmedicalcenter.org/uncmc/care-treatment/rehabilitation-therapies/>

Lenox Baker Children's Hospital

(0 – adults)

3000 Erwin Rd, Durham NC 27705

919-681-5456

<https://www.dukehealth.org/locations/lenox-baker-childrens-hospital>



Spina Bifida in North Dakota

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 North Dakota, 5.76 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 400 people with Spina Bifida live in North Dakota.
- In North Dakota, there are an estimated 200,000 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 300 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 200 of these devices will fail within 10 years.
- 200 of the people living with Spina Bifida are adults, and 150 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.

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Cost Related to the Care of People with Spina Bifida in North Dakota

- The estimated cost of lifetime care related to Spina Bifida for the 1,145 people living with Spina Bifida in North Dakota ranges between \$3,202,260,000 and \$400,000,000. 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:

Sanford Health Care

237 Broadway N

Fargo, ND 58102

701-234-6600

Ages served: 0-18



Spina Bifida in Ohio

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.

- 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 6,300 people with Spina Bifida live in Ohio. (*data collection period: 2010*).
- In Ohio, there are an estimated 3.7 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 5,000 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 4,000 of these devices will fail within 10 years.
- 3,100 of the people living with Spina Bifida are adults, and 2,400 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.

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Cost Related to the Care of People with Spina Bifida in Ohio

- The estimated cost of lifetime care related to Spina Bifida for the 6,270 people living with Spina Bifida in Ohio ranges between \$3,977,720,000 and \$6,300,000,000. 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:

Cleveland Clinic (adults)

9500 Euclid Avenue
Cleveland, OH 44195
216-444-4899
<https://my.clevelandclinic.org/>

University Hospitals Rainbow Babies & Children's (0 – transition)

2101 Adelbert Road
Cleveland, OH 44106
216-844-3911
<https://www.uhhospitals.org/rainbow/services/pediatric-neurology/conditions-and-treatments/spina-bifida-program>

Dayton Children's Hospital Myelomeningocele Clinic (0 – transition)

3333 W Tech Blvd.
Miamisburg, OH 45342
937-641-3000
www.childrensdayton.org

Mercy St. Vincent Medical Center (Ages served: Information n/a)

2213 Cherry St.
Toledo, OH 43608
419-251-3232
<https://www.mercy.com/locations/hospitals/toledo/mercy-health-st-vincent-medical-center>

Nationwide Children's Hospital
(0 – transition, 0-21)

700 Children's Dr.

Columbus, OH 43205

614-722-5725

<https://www.nationwidechildrens.org/>



Spina Bifida in Oklahoma

Spina Bifida, the most common, permanently disabling birth defect in the United States 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 that 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 Oklahoma, 3.74 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 1,362 people with Spina Bifida live in Oklahoma.
- In Oklahoma, there are an estimated 1.1 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 1,090 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 872 of these devices will fail within 10 years.
- 680 of the people with Spina Bifida in Oklahoma are adults, and 544 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 treatment and interventions associated with its management.

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Cost Related to Care for People with Spina Bifida in Oklahoma

- The estimated cost of lifetime care related to Spina Bifida for people with Spina Bifida in Oklahoma is \$866,232,000 though it can often exceed \$1,362,000,000. Among adults with MMC, only about 272 live independently as adults, accruing substantial costs for their 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 costs than those without MMC.
- Family caregivers for people with Spina Bifida 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:

OU Physicians Urology

(adults)

620 Elm Avenue

Norman, OK 73069

(405) 271-8156

<http://www.ou.edu/healthservices.html>

OU Children's Physicians

Pediatric Urology Clinic

(0 - 18)

1200 Children's Ave

Oklahoma City, OK 73104

405-271-3800

<https://www.oumedicine.com/oumedicine/pediatric-services/urology>



Spina Bifida in Oregon

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.

- 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 2,100 people with Spina Bifida live in Oregon.
- In Oregon, there are an estimated 1.2 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 1,680 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 1,300 of these devices will fail within 10 years.
- 1,050 of the people living with Spina Bifida are adults, and 840 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.

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Cost Related to the Care of People with Spina Bifida in Oregon

- The cost of lifetime care for people with Spina Bifida is \$1,334,600,000 though it can often exceed \$2,100,000,000. Among those patients with the most serious form of Spina Bifida, myelomeningocele (MMC), only half are able to live independently as adults, accruing substantial costs for 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 costs 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:

OHSU Child Development &
Rehabilitation Center
University of Oregon Campus, Clinical
Services Building
(Ages served: Information N/A)
901 E. 18th Avenue
Eugene, OR 97403
541-346-3575
<https://www.ohsu.edu/xd/health/child-development-and-rehabilitation-center/>

Doernbecher Children's Hospital at
Oregon Health and Science University
(pediatric - adult)
700 S.W. Campus Drive
Portland, OR 97239
503-346-0640
<https://www.ohsu.edu/xd/health/services/doernbecher/programs-services/brain-and-spine-care/conditions/spina-bifida.cfm>

Legacy Health Randall Children's
Neurosurgery
Legacy Emanuel Medical Center
(Ages served: Information N/A)
Medical Office Building 2, Suite 330B
501 N. Graham Street
Portland, OR 97227
503-413-3690
<https://www.legacyhealth.org/health-services-and-information/health-services/for-children-a-z/neurosurgery.aspx>

Shriners Hospital – Portland
(pediatric - 18)
3101 SW Sam Jackson Park Road
Portland, OR 97239
503-241-5090
<https://www.shrinershospitalsforchildren.org/portland>



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.

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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>



Spina Bifida in Rhode Island

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 that 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 Rhode Island, 3.27 babies are born with Spina Bifida per 10,000 births (data collection period: 2010).
- Research has estimated that the number of Americans living with all forms of Spina Bifida is about 166,000. Based on this national estimate and the birth rate of Spina Bifida, approximately 600 people with Spina Bifida live in Rhode Island.
- In Rhode Island, there are an estimated 350,000 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 500 of individuals with THE most severe 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 400 of these devices will fail within 10 years.
- 300 of the people living with Spina Bifida are adults, and 250 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

1600 Wilson Blvd., Suite 800, Arlington, VA 22209 · 800-621-3141 · SpinaBifidaAssociation.org



Cost Related to the Care of People with Spina Bifida in Rhode Island

- The cost of lifetime care for Spina Bifida patients is around \$1,000,000. Among those patients with the most serious form of Spina Bifida, myelomeningocele (MMC), only half can live independently as adults, accruing substantial costs for 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 costs 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:

**Hasbro Children's Hospital at Rhode Island Hospital
Children's Neurodevelopment Center**

335R Prairie Avenue, Suite 1A

Providence, RI 02905

401-444-5685

Ages served: 0-21, 0-Transition

<https://www.lifespan.org/centers-services/childrens-neurodevelopment-center>



Spina Bifida in South Carolina

Spina Bifida, the most common, permanently disabling birth defect that is 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 South Carolina, 3.90 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 1,747 people with Spina Bifida live in South Carolina.
- In South Carolina, there are an estimated 1.5 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 1,398 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 1,118 of these devices will fail within 10 years.
- 874 of the people living with Spina Bifida are adults, and 699 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

1600 Wilson Blvd., Suite 800, Arlington, VA 22209 · t 800-621-3141 · f 202-944-3295

Community Health Charities #10559

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

Cost Related to the Care of People with Spina Bifida in South Carolina

- The cost of lifetime care for Spina Bifida patients is \$1,558,200,000 though it can often exceed \$1,747,000,000. Among those patients with the most serious form of Spina Bifida, myelomeningocele (MMC), only half are able to live independently as adults, accruing substantial costs for 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 costs 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:

Medical University of South Carolina

Spina Bifida Program & Clinic

(pediatric, adult urology)

135 Rutledge Ave., Rm. 412

Charleston, SC 29425

(843) 792-1414

<https://musckids.org/our-services/spina-bifida>

Shriners Hospital for Children

(pediatric only)

950 W. Faris Road

Greenville, SC 29605

(864) 271-3444

<https://www.shrinershospitalsforchildren.org/greenville>



Spina Bifida in South Dakota

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 that 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.

- 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 1,500 people with Spina Bifida live in South Dakota.
- In South Dakota there are an estimated 246,000 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 80 percent 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 many of these devices will fail within 10 years.
- Over half of the people living with Spina Bifida are adults. 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.

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Cost Related to Care of People with Spina Bifida in South Dakota

- The cost of lifetime care for people with Spina Bifida exceeds \$1,000,000.
- 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 costs 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.

***There are currently no known Spina Bifida clinics for children or adults in South Dakota.**



Spina Bifida in Tennessee

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 that 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 Tennessee, 4.09 babies are born with Spina Bifida per 10,000 births (data collection period: 2010).
- Research has estimated that the number of Americans living with all forms of Spina Bifida is about 166,000. Based on this national estimate and the birth rate of Spina Bifida, approximately 2,542 people with Spina Bifida live in Tennessee.
- In Tennessee, there are over 2 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 severe birth defects could be reduced by up to 70%.
- Approximately 2,033 of individuals with THE most severe 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 1,626 of these devices will fail within 10 years.
- 1,271 of the people living with Spina Bifida are adults, and 1,016 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.

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1600 Wilson Blvd., Suite 800, Arlington, VA 22209 · 800-621-3141 · SpinaBifidaAssociation.org

Cost Related to Care of People with Spina Bifida in Tennessee

- The cost of lifetime care for Spina Bifida patients is \$1,616,712,000 though it can often exceed \$2,542,000,000. Among those patients with the most serious form of Spina Bifida, myelomeningocele (MMC), only half can live independently as adults, accruing substantial costs for 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 costs 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:

T.C Thompson Children's Hospital
Walter E. Boehm Birth Defects Center

(all ages)

975 E. Third St.
Chattanooga, TN 37403
(423) 778-2222

<https://boehmbdc.com/116.36/about-spina-bifida-and-hydrocephalus>

Le Bonheur Children's Medical Center
Spina Bifida Clinic

(0 – 21)

50 N. Dunlap St.
Memphis, TN 38103
901-287-PEDS

<https://www.lebonheur.org/our-services/neuroscience-institute/spina-bifida/>

Vanderbilt Children's Hospital
Spina Bifida Program,
Children's Rehabilitation Services

(0 – 18)

One Hundred Oaks Mall
719 Thompson Lane
Nashville, TN 37232-9080
(800) 526-4299 or (615) 343 4673

<https://www.childrenshospitalvanderbilt.org/program/spina-bifida-clinic>



Spina Bifida in Texas

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 Texas, 3.58 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 8,709 people with Spina Bifida live in Texas.
- In Texas, there are an estimated 7.6 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 6,967 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 5,574 of these devices will fail within 10 years.
- 4,355 of the people living with Spina Bifida are adults, and 3,484 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.

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Community Health Charities #10559

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Cost Related to the Care of People with Spina Bifida in Texas

- The estimated cost of lifetime care related to Spina Bifida for the 1,100 of the people living with Spina Bifida in Texas can exceed \$1,000,000 or \$8,709,000,000. 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:

Dell Children's Medical Center
Marnie Paul Specialty Center
(0 – transition, adult)
Austin, TX 78723
512-324-0137
<https://www.dellchildrens.net/service-s-and-programs/specialty-care-center/spina-bifida-program/>

Moody Clinic
(0 – 22)
1901 East 22nd St
Brownsville, TX 78521
956-542-8504
www.moodyclinic.org

Texas Scottish Rite Hospital for
Children Spina Bifida Clinic
(Ages served: Information n/a)
2222 Welborn Street
Dallas, TX 75219-3993

<https://scottishritehospital.org/care-and-treatment/other-treatment/developmental-disabilities>

Texas Tech Orthopaedic Surgery
and Rehabilitation
(Orthopedic, all ages)
4801 Alberta Avenue
El Paso, TX 79905
915-215-5480
<http://www.elpaso.ttuhsc.edu/som/Orthopaedics/>

Cook Children's Hospital
(0 – 18)
801 7th Avenue
682-885-2500
Fort Worth, TX 76104
<https://cookchildrens.org/neurology/conditions/Pages/Spina-Bifida.aspx>

Baylor College of Medicine
Transition Medicine Clinic

(transition)

7200 Cambridge St.
8th Floor, Suite 8A
Houston, TX 77030
(713) 798-6333
<https://www.bcm.edu/healthcare/care-centers/transition-medicine/>

Shriners Hospital for Children
Houston

(0 – 18)

977 Main Street
Houston, TX 77030
713-797-1616
<https://www.shrinershospitalsforchildren.org/houston>

Texas Children's Hospital Spina
Bifida Clinic

(0 – 18)

6701 Fannin St.
Suite 1610.01
Houston, TX 77030
832-822-4308
<https://www.texaschildrens.org/departments/spina-bifida-program>

Methodist Children's Hospital
Pediatric Specialty Clinics

(0 – 18)

Methodist Plaza, 4499 Medical
Drive, Sublevel One
San Antonio, TX 78229
(800) 297-1021
<https://sahealth.com/service/methodist-pediatric-specialty-clinics>



Spina Bifida in Utah

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 Utah, 4.22 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 1,100 people with Spina Bifida live in Utah.
- In Utah, there are an estimated 800,000 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 1,000 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 700 of these devices will fail within 10 years.
- 600 of the people living with Spina Bifida are adults, and 450 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

1600 Wilson Blvd., Suite 800, Arlington, VA 22209 · t 800-621-3141 · f 202-944-3295

Community Health Charities #10559

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Cost Related to the Care of People with Spina Bifida in Utah

- The estimated cost of lifetime care related to Spina Bifida for the 1,500 of the people living with Spina Bifida in Utah can exceed \$1,000,000 or \$1,100,000,000. 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:

Primary Children's Medical Center

Spina Bifida Clinic

(0 – 18)

100 N. Mario Capecchi Drive

Salt Lake City, UT 84103

801-662-1675

<https://intermountainhealthcare.org/locations/primary-childrens-hospital/medical-services/brain-and-spine-care/brain-and-spine-programs/spina-bifida/>

Shriners' Hospital for Children

(Ages served: Information n/a)

1275 E. Fairfax Road

Salt Lake City, UT 84103

801-536-3500

<https://www.shrinershospitalsforchildren.org/salt-lake-city>



Spina Bifida in Virginia

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 Virginia, 3.95 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 3,000 people with Spina Bifida live in Virginia.
- In Virginia, there are an estimated 2.5 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 2,500 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 2,000 of these devices will fail within 10 years.
- 1,500 of the people living with Spina Bifida are adults, and 1,200 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.

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Cost Related to the Care of People with Spina Bifida in Virginia

- The estimated cost of lifetime care related to Spina Bifida for the 4,200 of the people living with Spina Bifida in Virginia can exceed \$1,000,000 or \$3,000,000,000. 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:

University of Virginia Child
Development and Rehabilitation
Center

(Ages served: Information n/a)

1204 W. Main Street

Charlottesville VA, 22908

434-423-5500

<https://uvahealth.com/locations/profile/uva-child-development-and-rehabilitation-center>

Children's Hospital of the King's
Daughters

Spina Bifida Program

(0 – 21)

601 Children's Lane

Norfolk, VA 23507

(757) 668-9021

<http://www.chkd.org/Our-Services/Specialty-Care-and-Programs/Spina-Bifida-Clinic/>

Children's Hospital of Richmond
Spina Bifida Clinic

(0 – 18)

Children's Pavilion, Level 3

1000 East Broad Street

Richmond, VA 23219

(804) 828-CHOR (2467)

<https://chrichmond.org/services/spina-bifida-clinic.htm>



Spina Bifida in Washington

Spina Bifida, the most common, permanently disabling birth defect that is compatible with life in the United States, affects approximately 1,500 births each year. Spina Bifida is a serious and life-long condition that 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 Washington, an unknown number of babies are born with Spina Bifida because the state keeps no data on it.
- Recent research has estimated that the number of Americans living with all forms of Spina Bifida may be as high as 166,000. Since no data is kept in the state, but by applying the national estimate to the state population, we can estimate that 3,575 people with Spina Bifida live in Washington.
- In Washington, there are an estimated 2.1 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 2,860 of individuals with THE most severe 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 2,288 of these devices will fail within 10 years.
- 1,788 of the people living with Spina Bifida in Washington are adults, and 1,430 of them have MMC. Very few physicians are willing to treat people with Spina Bifida or have the knowledge of treatments and interventions associated with its management.

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Cost related to the Care of People with Spina Bifida in Washington

- The estimated cost of lifetime care related to Spina Bifida for the 3,575 people living with Spina Bifida in Washington ranges between \$2,273,700,000 and \$3,575,000,000. Among those patients with the most severe form of Spina Bifida, myelomeningocele (MMC), 715 live independently as adults, accruing substantial costs for 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 expenses 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 Hospital and Regional Medical Center
Neurodevelopmental & Birth Defects Clinics (**pediatric to 21**)
4800 Sandpoint Way NE
Seattle, WA 98105
(206) 987-2184
www.seattlechildrens.org



Spina Bifida in West Virginia

Spina Bifida, the most common, permanently disabling birth defect that is compatible with life in the United States, affects approximately 1,500 births each year. Spina Bifida is a serious and life-long condition that 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 West Virginia, 3.89 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 990 people with Spina Bifida live in West Virginia.
- In West Virginia, there are an estimated 600,000 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 790 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 630 of these devices will fail within 10 years.
- 500 of the people living with Spina Bifida are adults, and 400 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.

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Cost Related to the Care of People with Spina Bifida in West Virginia

- The cost of lifetime care for Spina Bifida patients is \$629,640,000 though it can often exceed \$990,000,000. Among those patients with the most serious form of Spina Bifida, myelomeningocele (MMC), only half are able to live independently as adults, accruing substantial costs for 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 costs 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.

Clinic:

West Virginia University Medical Center
Children with Special Health Care Needs/Myelo Clinic (**pediatric and adult**)
One Medical Center Drive
Morgantown, WV 26505
(304) 598-4830



Spina Bifida in Wisconsin

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 that 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 Wisconsin, 2.6 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 1,500 people with Spina Bifida live in Wisconsin.
- In Wisconsin, there are an estimated 1.8 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 1,200 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 960 of these devices will fail within 10 years.
- 750 of the people living with Spina Bifida are adults, and 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.

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Cost Related to Care of People with Spina Bifida in Wisconsin

- The cost of lifetime care for Spina Bifida patients is \$954,000,000 though it can often exceed \$1,500,000,000. Among those people with MMC, 300 live independently as adults, accruing substantial costs for 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 costs 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:

Gundersen Health System
Spina Bifida Clinic (**pediatric to transition**)
1900 South Avenue
La Crosse, WI 54601
(800) 362-9567
www.gundersenhealth.org

American Family Children's Hospital
Pediatric Spina Bifida Clinic (**pediatric to 21**)
1675 Highland Ave.
Madison, WI 53792
(608) 263-6420
(800) 323-8942
www.uwhealth.org

Children's Hospital of Wisconsin
Spina Bifida Program (**pediatric to 18**)
9000 W. Wisconsin Ave.
Milwaukee, WI 53201
(414) 266-2690
www.chw.org

Marshfield Clinic (**pediatric to 18**)
1000 N. Oak Ave.
Marshfield, WI 54449
(800) 782-8581
www.marshfieldclinic.org/