



## 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.

*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 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](http://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](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://lluch.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](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>