

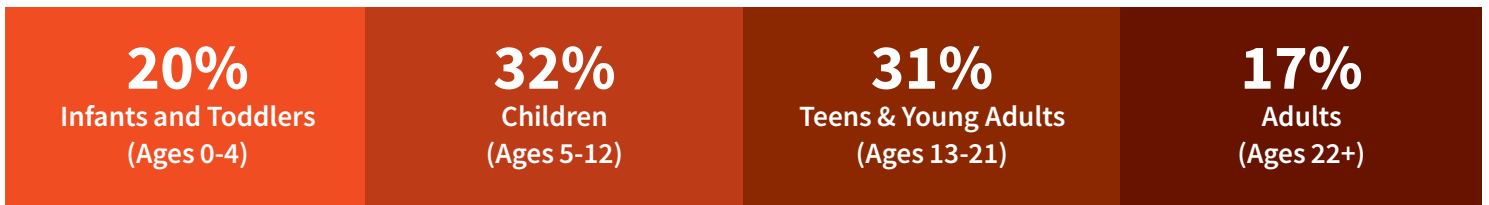
THE NATIONAL SPINA BIFIDA PATIENT REGISTRY



In the United States, about 1 in every 2,750 babies are born with spina bifida each year. The National Spina Bifida Patient Registry was created by the Centers for Disease Control and Prevention in 2008 to learn more about spina bifida and how to better take care of people living with this condition.

The Registry collects information from more than 11,000 infants, children, and adults to better understand the care and services received and the relationships between medical procedures, health outcomes, and quality of life. What we learn from this information will help people with spina bifida better plan for the care they need and help healthcare professionals improve care and quality of life for their patients.

The Registry looks at health outcomes across the lifespan. Participants range from birth to 84 years of age.



Although spina bifida care has improved over time, there is still a lot to learn about how this condition affects people and how best to manage it. We have used the Registry to learn about things such as...

Bladder Health
68 in 100 participants lack bladder control

Bowel Health
48 in 100 participants lack bowel control

Pressure Sores & Skin Breakdown
27 in 100 participants have experienced issues with skin health

Mobility
30 in 100 participants exclusively use a wheelchair

Thank you to all those currently participating in the Registry. Your participation will help improve the quality of care received at spina bifida clinics nationwide.

If you would like to join the Registry, please let your clinic know!

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