Spina bifida and other related neural tube defects (NTD) are the most common birth defects leading to long-term disability. Research increasingly suggests that there is no single cause of NTDs, but rather a complex interaction of genetic and environmental factors that lead to their development. Individuals with spina bifida are now living longer due to several important improvements including advances in MRI, antibiotics, prenatal diagnosis, newborn care, and shunt materials.

Today:
- Each year in the U.S., approximately 1,500 babies are born with moderate to severe spina bifida (SB) that requires medical treatment.¹
- SB is a condition that impacts nearly 200,000 individuals.²
- As many as 75% of children with SB are now reaching adulthood, and 67% of the overall SB population now consists of adults.³,⁴

How Research Saves Lives:
- The addition of folic acid (vitamin B9) into many common food products has reduced the incidence of SB by over 25% since 1998.¹
- Fetal surgery to close the hole in the spine that typifies SB may improve health and quality of life outcomes. In the NIH-funded Management of Myelomeningocele Study (MOMS), prenatal surgery doubled the likelihood that patients could walk at 30 months of age.²
- If all women of childbearing age consumed 400 micrograms of folic acid daily, 70% of NTDs could be prevented.³

How Research Saves Money:
- The addition of folic acid in the U.S. food supply has resulted in about 1,000 fewer cases of SB each year, saving over $13 billion in direct medical costs, lost wages and lost productivity since 1998.⁴
- Approximately 80% of individuals with MMC have hydrocephalus, a dangerous fluid build-up around the brain that necessitates a shunt. Shunts often require frequent revisions and 80% of these devices will fail within 10 years.⁵,⁶
- Research, like the kind being conducted using the National Spina Bifida Patient Registry (NSBPR), is vital to help both adults and children with the management of hydrocephalus.⁷

The Cost:
- The cost of lifetime care for people with SB can often exceed $1,000,000. ¹
- Family caregivers for SB patients are 25% less likely to be employed, and when they are employed, work 25% fewer hours compared to those not providing SB-related care.²
- Among those patients with the most serious form of SB, myelomeningocele (MMC), only half are able to live independently as adults, accruing substantial costs for care.³
- 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.⁴

Perspective:
Clarissa Gonzalez
AGE: 29
CONDITION: Spina Bifida

Clarissa is engaged to be married, working on her masters in social work, has a degree in culinary arts and loves to cook for her family and friends. Born with spina bifida, her parents worked hard to ensure she had the best care and taught her to self-advocate.

She considers herself lucky even though she will have lifelong bladder and kidney issues. Because of a neurogenic bladder that is a typical condition associated with spina bifida, Clarissa has had bladder surgery and kidney scarring. Clarissa self-catheterizes six times a day and faces a lifetime of monitoring and interventions to help ensure her bladder and kidney function is as optimal as possible.

Clarissa will tell you that she faces challenges every day, but again, considers herself lucky because she can attend school and engage in social activities—many that include friends with spina bifida who she met at the camp she attended for 15 years.

Clarissa is committed to helping others with spina bifida, providing strategies on how to be more independent and teaching self-advocacy. She volunteers her time to talk with young girls with spina bifida whose parents don’t speak English.

Clarissa will continue to live a “full life”. She is quick to point out that more research is needed to figure out ways to prevent the many problems that come with a complex condition like spina bifida, what models of care are best for adults and how to manage kidney and bladder problems. And she is worried about her friends with spina bifida—in the past year, she’s lost five and doesn’t know why.
Hope for the Future:

- Without appropriate management, 50% of children with SB will experience kidney damage by age 5. The NSBPR Urologic Protocol for infants and young children will determine the best way to manage the urinary tract so that this damage can be mitigated.\(^1,2\)

- Research at the CDC using the NSBPR aims to learn what interventions, at what age, result in better outcomes in continence, mobility and the prevention of skin breakdown for people of all ages living with SB. Using findings from this research, the SBA can explore what makes care at some clinics yield better outcomes and which best practices can be shared with all clinics to improve the care everywhere.\(^3,4\)

The Bottom Line:
Spina bifida is a complex, chronic condition for which there is no cure. More than half the population of people living with spina bifida today are adults, who until recently were not expected to survive. Individuals affected by spina bifida experience their own journey that includes challenges to the entire body. Little is known about which interventions will yield the best outcomes for health, productivity and independence. The NSBPR can provide the research opportunities to help find solutions.