

The logo for iSACRA, featuring the text "iSACRA" in a stylized, serif font. The "i" is lowercase and red, while "SACRA" is uppercase and red. To the right of the text is a graphic element consisting of several curved, overlapping bands in shades of grey and black, resembling a stylized spine or a ribbon.

# International Sacral Agenesis/ Caudal Regression Association

iSACRA  
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**iSACRA** provides support and information to persons with sacral agenesis/caudal regression syndrome and their families worldwide.

**iSACRA** promotes awareness and collaborates in research and advocacy to enhance the quality of life of persons with this condition and to advance medical knowledge.

**iSACRA is here to help!** Visit us at [www.isacra.org](http://www.isacra.org) for more information and opportunities to become involved.



## What is sacral agenesis/caudal regression syndrome?

Sacral agenesis (SA) is a condition that occurs very early during pregnancy. Some or all of the lower parts of the baby's spine (the sacrum) do not form. In some cases, both lumbar and sacral parts of the spine are missing (lumbosacral agenesis). Sometimes part of the thoracic spine is also missing.

Caudal regression syndrome (CRS) is another name for sacral or lumbosacral agenesis. It is the same condition in which parts of the spine are absent. Different medical professionals may use either term to refer to the same condition. A number of physical conditions are associated with SA/CRS. These conditions may include small size and stiffness or webbing of the legs. The kidneys may be horseshoe shaped or one kidney may be missing. Paralysis may affect parts of the body below where the spinal cord ends.

## How will SA/CRS affect my child?

Children with SA/CRS can enjoy full, active lives. There is no cure for SA/CRS, but certain surgical procedures and medical devices can improve mobility and function. Some children benefit from leg braces, prosthetics, crutches, or other devices for walking. A wheelchair is also an excellent option for independent mobility for some children. Bowel and bladder control is almost always impacted and may require surgical intervention. Because some children are very tiny with a slow growth pattern, clothing may need to be altered for size. School accommodations may include modified seating, wheelchair access, goals for development of self-advocacy skills, and assistance with toileting. Despite some challenges, the smiles in our photos show that having SA/CRS does not prevent us from enjoying all that life has to offer.



Individuals with SA/CRS, regardless of the range of ways in which this condition may affect them, can achieve in many areas, including academics, sports, music, and art. With the correct supports, people with SA/CRS can and do live full, healthy, and productive lives.

## What causes SA/CRS?

The exact cause of SA/CRS is unknown and may be due to several factors. It has been linked to improper expression of the HLBX9 gene, and because that gene is also expressed in the pancreas, links to maternal diabetes have been suggested. However, most babies with SA/CRS do not have mothers with diabetes. Other mechanisms such as umbilical ischemia (a blockage of the blood supply through the umbilical cord), hyperglycemia, infections, and exposure to toxins or retinoic acid are also suspected.



## When is SA/CRS diagnosed?

SA/CRS may be diagnosed before or shortly after birth. In some cases, when there are no outwardly visible signs, a diagnosis comes later, after age 3 or 4 years. A diagnosis may be determined after a child experiences difficulty with walking, toilet training, or urinary tract infections. SA/CRS is rare, and some doctors have never seen an individual with this condition.

So many things scared me in the beginning—that he'd be made fun of, that he wouldn't have any friends, that he'd be in pain all the time and have a horrible life. None of these things came true. He has some great friends, and he is very healthy and happy. This whole thing has really made me see what is important in life—family, friends, fun, good health—and has helped me to cherish the “little things.” It turns out they aren't so little after all.

—Danielle, an *iSACRA* parent

**To join our private Facebook group, email [contact@isacra.org](mailto:contact@isacra.org)**

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