

Sacral Agenesis

Condition Description

Sacral agenesis is the term commonly applied to a group of disorders characterized by absence of the variable portion of the caudal (end or bottom) portion of the spine. Patients with sacral agenesis lack motor function below the level of the normal remaining spine, similar to those with myelomeningocele. However, sensory function is impaired below the level of affected vertebrae. In more severe cases of sacral agenesis, part or all of the lumbar spine and even the lower thoracic spine may be absent.

Range of Outcomes

Sacral agenesis is classified according to four different types based upon whether the agenesis is partial or complete; on one side or both; the symmetry of the defect; and the condition of the iliac (the largest of the three bones that form the upper part of each side of the pelvis.) Outcomes vary by the type of sacral agenesis.

Regardless of type, fewer than half of the patients with sacral agenesis are able to ambulate in the community. The development of sitting balance can also be an issue. Repeated surgeries are often necessary to address contractures. In severe cases, amputation of the lower extremities is required to facilitate sitting balance.

Common Complications

The major orthopedic problems associated with sacral agenesis are spinopelvic instability, scoliosis, myelomeningocele, hip dislocation and contracture, knee contracture and foot

deformities. Nearly all individuals with sacral agenesis have disorders of the genitourinary tract – the most common being neurogenic bladder (a urinary problem in which the bladder does not empty properly). Depending on the type of neurological disorder causing the problem, the bladder may empty spontaneously (incontinence) or may not empty at all (retention with overflow leakage).

Anomalies of the gastrointestinal tract are common.

Side Effects of Treatment

Proper care of patients with sacral agenesis is best provided by a treatment team including an orthopedic surgeon, neurosurgeon, pediatrician, physical therapist and orthotist-prosthetist. Children with sacral agenesis can experience repeated hospitalizations. They may also require intermittent bladder catheterization throughout their lives.

One study showed a high incidence of psychological or behavioral problems. Children suffered from a number of complaints including temper tantrums, school refusal, soiling, and refusing to catheterize. The persisting bladder and bowel problems understandably lead to great strain within the family, often resulting in not just individual but family therapy. Further, the need to teach parents how to catheterize their child until the child is old enough to self-catheterize may cause strain and conflict.



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Sacral Agenesis – page 2

For More Information

This fact sheet was developed for use in determining eligibility for early intervention services only. For more complete information, the following resources might be useful:

MedlinePlus

MedlinePlus brings together authoritative information from NLM, the National Institutes of Health (NIH), and other government agencies and health-related organizations. Preformulated MEDLINE searches also give access to medical journals.

<http://medlineplus.gov/>

E-Medicine

eMedicine's clinical knowledge base contains peer reviewed articles on a number of different health conditions. There is a pediatric section available.

<http://www.emedicine.com/>

References

Wilmshurst, JM., Kelly, R., Borzykowski, M., "Presentation and outcome of sacral agenesis: 20 years' experience", *Developmental Medicine & Child Neurology* 1999, 41: 806-812.

Renshaw, TS., "Sacral Agenesis", *Journal of Bone and Joint Surgery*. 1978; 60: 373-383.

Letts, RM., Jawadi, AH, "Congenital Spinal Deformity: Sacral and Lumbrosacral Agenesis"., *emedicine*, www.emedicine.com, last updated 9/21/2004.