

Omphalocele

Version: April 2009



Image credit: Centers for Disease Control and Prevention (CDC)

Condition & Description

Omphalocele (Om'pha-lo-c,ele) is an abdominal wall (belly) birth defect that occurs between the 6th-12th week of pregnancy. The fetus' gut stretches and the intestines are pushed through the abdominal wall into the umbilical cord, but return during weeks 10-12. Omphalocele occurs when the intestines or other organs remain outside of the abdomen enclosed in a clear sac or membrane. If ruptured at birth, this may resemble gastroschisis¹. In California, omphalocele occurs in 1 out of every 5,400 births⁸.

Associated Conditions

About 50–70% of infants with omphalocele will have accompanying birth defects. Thirty percent of infants with omphalocele will have a chromosome defect (see Trisomy fact sheets) and 30–50% will have a cardiac (heart) defect²⁻⁵.

Causes & Risk Factors

The origin of omphalocele is unclear; however certain risk factors are related to this birth defect. The conditions listed below are known to be associated with omphalocele:

- Beckwith-Wiedemann Syndrome³
- Trisomy 18 (Edwards syndrome)

Prevention

There are a number of steps a woman can take that may reduce her risk of having a baby with a birth defect. Please see CBDMP's fact sheet on [Reducing the Risk of Birth Defects](#).

Preconception & Prenatal Care

Omphalocele may be detected by routine prenatal ultrasounds during the time that the omphalocele appears (the 10th to 12th week). Babies with omphalocele may suffer from intrauterine growth restriction (below-average growth before birth) and low birth weight; often, these babies are born premature².

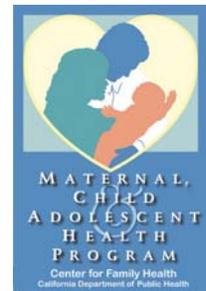
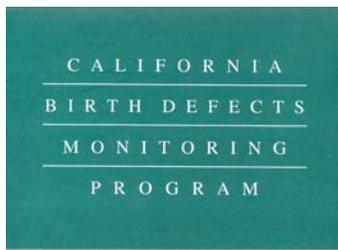
Medical Care

Omphalocele is treated in multiple stages. A surgical procedure is used to apply a silastic mesh over the omphalocele membrane until the organs have settled into the baby's abdominal wall. Once the organs have settled, a second surgery is needed to close the skin. During treatment, an intravenous (IV) feeding tube is inserted and medication is administered. If the lungs are unable to expand, mechanical ventilators are used for babies who have trouble breathing².

Heat loss is an important complication following birth, extra care must be taken to warm the baby without rupturing the omphalocele sac². Another complication of omphalocele is respiratory distress which results from a lack of abdominal pressure needed to expand the baby's lungs⁸. Other complications after surgery include wound infection and gastroesophageal (acid) reflux⁶. The fetus should be delivered at a facility that has personnel capable of handling all aspects of newborn care.²

Long Term Outcomes

Ninety to 95% of babies survive surgery and go on to lead healthy lives. Growth, weight gain, and nutrition are monitored to establish normal development. Mobility of the bowel may be altered and training is needed to establish normal bowel patterns. The health and recovery of babies with omphalocele is also related to other associated conditions⁷.



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Resources For Families

California Children's Services (CCS)

California Children's Services (CCS) is a state program for children with certain diseases or health problems. Through this program, children up to 21 years old can get the health care and services they need. CCS will connect you with doctors and trained health care people who know how to care for your child with special health care needs.

(Service eligibility is income-based, but you may be eligible for services if the health care costs exceed 20% of your income.)

Find your local CCS Office –

- In the phone book under *California Children's Services* or *County Health Department*
- Or online at: www.dhs.ca.gov/ccs

Family Resource Centers Networks of California

Their mission is to support families of children with disabilities, special healthcare needs, and those at risk by ensuring the continuance, expansion, promotion and quality of family-centered, parent-directed, family resource centers.

Find your local Family Resource Center –

- In the phone book business pages under *Social and Human Services for Families and Individuals* or *Family Resource Centers*
- Or online at: <http://www.frnca.org/>

California Healthy Families Program:

Healthy Families is low cost insurance for children and teens. It provides health, dental and vision coverage to children who do not have insurance and do not qualify for free Medi-Cal.

- Phone: 1-800-880-5305 if you do not already have a child enrolled in Healthy Families.
- E-mail: HealthyFamilies@MAXIMUS.com
Be sure to include your name and phone number.
- In person: Many community organizations have people who are trained to help you apply. Call to find a *Certified Application Assistants, or CAAs* in your area: 1-888-747-1222. The call is free.
- Website: www.healthyfamilies.ca.gov

Birth Defects Research for Children, Inc.

Birth Defect Research for Children is a resource for free birth defect information, parent networking and birth defect research through the National Birth Defect Registry.

- Birth Defect Research for Children, Inc.
800 Celebration Avenue, Suite 225
Celebration, FL 34747
- Phone: 407-566-8304
- Fax: 407-566-8341
- Website: <http://www.birthdefects.org/>

Other Information & Support Groups

- The Center for Children with Special Needs: <http://cshcn.org/support-connection/emotional-support-families-resource-list>
- American Pediatric Surgical Association: <http://www.eapsa.org/parents/resources/omphacele.cfm>
- Kids Health (for Parents): http://kidshealth.org/parent/system/ill/baby_has_birth_defect.html

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