



HAS YOUR BABY BEEN DIAGNOSED WITH A GENETIC DISORDER DURING PREGNANCY?



What is a genetic abnormality?

This brochure is intended for pregnant mothers who are concerned about risks of genetic abnormalities or birth defects, or whose unborn child is diagnosed with a genetic abnormality. Many resources may be helpful to you. With your doctor's advice, you can decide which resources are right for you and your family.

Genetic abnormalities are defects, diseases, or other disorders that are caused by a person's genes. Genes are the building blocks of the body. They give instructions to the body's cells to control how someone's body will look or work. When a baby is conceived, he or she inherits a set of genes from each parent. The genes combine and match up while the baby is still in the mother's body. A genetic disorder can result when the genes match up in a way that causes a problem in the body. It can be inherited from a parent, or it can happen on its own. It is important to talk to your doctor about what to expect if your baby is found to have a genetic disorder. Fortunately, many children with a disorder can live very happy and high-quality lives, and there are many resources, programs, and services in place to help families.

Where can I find help for myself and my baby once a genetic disorder is diagnosed?

Learning that your child has a genetic disorder can be overwhelming. Fortunately, there are community agencies, non-profit organizations and state programs that are available to individuals and families who are dealing with the news of a pregnancy and a diagnosis of a genetic disorder. These agencies can assist people with getting information, medical treatment, genetic testing, counseling and education about genetic disorders.

Resources:

LOUISIANA DEPARTMENT OF HEALTH

Louisiana Genetic Diseases Program

ldh.la.gov/index.cfm/page/465

Diagnoses, counsels and treats those with genetic disorders. The program's genetics clinics provide genetic testing, genetic counseling, education, treatment and referrals.

The Louisiana Birth Defects Monitoring Network Family Resource Hub

ldh.la.gov/index.cfm/page/3017

Provides information about programs and services for children with special health care needs. Also provides information about local and national resources for families.

Children's Special Health Services

ldh.la.gov/cshs

Assists children and youth who have special health care needs. Services include clinic-based care and care coordination.

The Office for Citizens with Developmental Disabilities

ldh.la.gov/index.cfm/page/1920

Provides services and supports to individuals with developmental disabilities, including public and private residential services.

EarlySteps

ldh.la.gov/index.cfm/page/139

Provides services to families with infants and toddlers who have a medical condition likely to result in a developmental delay, or who have developmental delays. Most genetic disorders make a child eligible for EarlySteps.

Partners For Healthy Babies

1800251baby.org/parent/

Provides a helpline and website connecting women and families to resources and information regarding pregnancy and parenthood. All services are confidential, available 24/7, and are offered in Spanish.

MEDICAID COVERAGE

Healthy Louisiana

ldh.la.gov/index.cfm/subhome/48

Healthy Louisiana is the way the majority of Louisiana's Medicaid and LaCHIP recipients receive their health care services. Coverage includes hospital and doctor visits, medical transportation, therapies, medications, rehabilitative services and other medical care.

Family Opportunity Act Medicaid

ldh.la.gov/index.cfm/page/1559

Provides health coverage to children with disabilities in families that earn too much income to qualify for Medicaid or LaCHIP.

Medicaid Health Plans

myplan.healthy.la.gov/choose/compare-plans

Five Medicaid health plans manage medical care for Healthy Louisiana enrollees. The plans offer additional resources or services for pregnant women who have a diagnosis of a fetal genetic abnormality and for children born with a disability. Enrollees are encouraged to review each plan and the services offered, as services vary by plan.

Aetna Better Health: 855-242-0820

Amerihealth Caritas Louisiana: 888-756-0004

Healthy Blue: 844-521-6941

Louisiana Healthcare Connections: 866-595-8133

United Healthcare Community: 866-675-1607

LaMOMS Medicaid Program

ldh.la.gov/index.cfm/page/231

LaMOMS, a special-eligibility Medicaid program for pregnant women, provides no-cost health care coverage for pregnancy-related services, including doctor visits, lab work, prescription medicines, delivery, hospital care and coverage for up to 60 days after pregnancy.

Children's Choice Medicaid Waiver

ldh.la.gov/index.cfm/page/218

Offers supplemental support to children with developmental disabilities. Participants are eligible for all medically necessary Medicaid services, support coordination, family support services and center-based respite care.

COMMUNITY PARTNERS

March of Dimes

marchofdimes.org

Researchers, volunteers, educators, outreach workers, and advocates with the March of Dimes work together to improve premature births, birth defects and low birth weight babies.

The Genetic Alliance

geneticalliance.org

The Genetic Alliance is a national coalition of consumers, professionals, and genetic support groups who voice the common concerns of children, adults, and families living with, and at risk for, genetic conditions.

Families Helping Families

ldh.la.gov/index.cfm/page/1564

Families Helping Families is a network of individual, non-profit, family-driven resource centers. They are a group of families, who, through their own experiences, promote advocacy and are committed to reaching other families who have members with disabilities.

