



## Information and Support Resources

### Cleft Lip and Cleft Palate:

*Cleft Palate Foundation*

<http://www.cleftline.org>

*Operation Smile*

<http://www.operationsmile.org>

*American Cleft Palate – Craniofacial Association*

<http://www.acpa-cpf.org>

### Cystic Fibrosis:

*Cystic Fibrosis Foundation*

<https://www.cff.org/What-is-CF/About-Cystic-Fibrosis/>

*Sooner Chapter – Oklahoma City*

<https://www.cff.org/OKC/>

Phone: +1 (405) 787-0056

### Down Syndrome:

*U.S. National Library of Medicine – Down Syndrome*

<https://ghr.nlm.nih.gov/condition/down-syndrome>

*Down Syndrome Association of Central Oklahoma*

[www.dsaco.org](http://www.dsaco.org)

Phone: +1 (405) 330-5025

*Down syndrome Association of Tulsa*

<http://www.dsat.org>

Phone: +1 (918) 804-3728

### Epilepsy:

*Epilepsy Foundation*

<http://www.epilepsy.com/learn/epilepsy-101/what-epilepsy>

*Epilepsy Association of Oklahoma Associated with Epilepsy Foundation*

[www.okepilepsy.org](http://www.okepilepsy.org)

Phone: +1 (405) 271-3232



This information has been provided by the Oklahoma Family Network, Inc. NEST Project funded by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA Grant H84MC093680600) and by the Heartland Genetics Services Collaborative, supported by a grant from the Genetic Services Branch of the MCHB of the HRSA (HRSA Grant H46MC24089). Much of this information has been taken from “A Guide to Genetic Counseling” produced by a partnership between the Johns Hopkins National Human Genome Research Institute, Genetic Alliance, and the National Society of Genetic Counselors. This information is not intended to replace the judgment of a practitioner with respect to particular patients, procedures, or practices. Please seek the guidance of your medical professionals.



#### Huntington's Disease:

*U.S. National Library of Medicine – Huntington Disease*

<https://ghr.nlm.nih.gov/condition/huntington-disease>

*Huntington's Disease Society - Oklahoma Chapter*

<http://oklahoma.hdsa.org>

Phone: +1 (405) 236-4372

#### Multiple Sclerosis:

*National Multiple Sclerosis Society*

<http://www.nationalmssociety.org/What-is-MS>

*National Multiple Sclerosis Society – Oklahoma Chapter*

<http://www.nationalmssociety.org/Chapters/OKE>

Phone: +1 (918) 488-0882 or +1 (800) 344-4867

#### Muscular Dystrophy:

*Muscular Dystrophy Association*

<https://www.mda.org/>

<http://facebook.com/MDAnational>

*Muscular Dystrophy of Oklahoma*

<https://www.mda.org/office/oklahoma-city>

Phone: +1 (405) 722-8001

#### Sickle Cell Disease:

*U.S. National Library of Medicine – Sickle Cell Disease*

<https://ghr.nlm.nih.gov/condition/sickle-cell-disease>

*Sickle Cell Cure Foundation*

<http://sicklecellcurefoundation.org/>

#### Spina Bifida:

*Spina Bifida – Kids Health*

<http://kidshealth.org/en/parents/spina-bifida.html>

*Spina Bifida – HQ Oklahoma*

<http://www.spinabifida.net/spina-bifida-oklahoma/>



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Center for Learning and Leadership:

*Guide to Community Services in Oklahoma*

[www.ouhsc.edu/thecenter/products](http://www.ouhsc.edu/thecenter/products)

Phone: +1 (405) 271-4500 or +1 (800) 627-6827

NORD (National Organization for Rare Disorders):

<http://rarediseases.org>

Phone: +1 (800) 999-6673

Oklahoma Department of Human Services

*County Offices:*

<http://www.okdhs.org/countyoffices/Pages/default.aspx>

Phone: +1 (405) 521-3646

*TEFRA:*

[http://www.okdhs.org/services/adult/Pages/AFSFAQ\\_TEFRA.aspx](http://www.okdhs.org/services/adult/Pages/AFSFAQ_TEFRA.aspx)

Phone: +1 (405) 521-3646

Oklahoma Family Network:

*Provides family to family support, information and education for pregnant mothers and families of children with special health care needs state wide.*

<http://www.oklahomafamilynetwork.org>

<http://facebook.com/oklahomafamilynetwork>

Phone: +1 (405) 271-5072 or +1 (877) 871-5072

Oklahoma State Department of Education - SoonerStart:

<http://ok.gov/sde/soonerstart-families>

SoonerCare Online Enrollment:

*Oklahoma Health Care Authority – SoonerCare Online Enrolment*

<http://www.mysoonercore.org>

Phone +1 (800) 987-7767



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