

Resources for Families in North Carolina with Rare Diseases



Health & Medical Resources:

North Carolina Community Health Center Association

NCCCHA promotes and supports patient-governed community health care organizations and the populations they serve. They envision every NC community having access to a patient-centered, patient-governed, culturally competent health care with high quality medical, pharmacy, dental, vision, behavioral health, and enabling services without regard to a person's ability to pay.

919-469-5701

<http://www.ncchca.org/>

North Carolina Department of Health and Human Services

NC DHHS manages the delivery of health- and human-related services for all North Carolinians, especially for more vulnerable citizens – children, elderly, disabled and low-income families. The Department works closely with health care professionals, community leaders and advocacy groups; local, state and federal entities.

919-855-4800

<https://www.ncdhhs.gov/>

Health Equipment Loan Program (HELP)

HELP recycles and restores donated medical equipment and loans it for reuse free of charge to any Durham County resident in need.

919-471-7281

<http://www.projectaccessdurham.org/HELP/>

ProjectMEND

Project MEND is committed to improving the quality of life for individuals living with disability and illness through the refurbishment, reuse and distribution of medical equipment and other assistive technology.

888-903-6363 (MEND)

<http://www.projectmend.org/>

Food & Drug Administration (FDA) Disaster Info:

Safe Drug Use After a Natural Disaster

<https://www.fda.gov/Drugs/EmergencyPreparedness/ucm085200.htm>

Information Regarding Insulin Storage and Switching Between Products in an Emergency

<https://www.fda.gov/Drugs/EmergencyPreparedness/ucm085213.htm>

Reporting Prescription Drug Sample Losses, Known Thefts, and Possible Diversion to the FDA in the Aftermath of a Natural Disaster

<https://www.fda.gov/Drugs/EmergencyPreparedness/ucm085256.htm>

General Resources:

NIH - GARD (Genetic and Rare Disease Information Center)

GARD is a program of the National Center for Advancing Translational Sciences to provide access to current, reliable, and easy to understand information about rare or genetic diseases in English or Spanish.

1-888-205-2311

<https://rarediseases.info.nih.gov/guides/pages/96/patients-families-and-friends>

Supplemental Security Income (SSI) Benefits:

SSI is a program within the Social Security Administration that pays benefits to disabled adults and children who have limited income or resources.

1-800-772-1213

<https://www.ssa.gov/disabilityssi/ssi.html>

Family Voices

Family Voices is a nonprofit organization that promotes quality health care for all children and youth, especially those with special health care needs. This organization seeks to ensure that health care systems include, listen to, and honor the voices of families.

505-872-4774

www.familyvoices.org

Rare Disease Report

RDR provides numerous reports and articles on the news of rare disorders, it is a great way to stay informed on the issues and updates facing the rare disease community.

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

Baby's First Test

Baby's First Test provides information on the importance and issues surrounding newborn screening.

<http://www.babysfirsttest.org/>

Joyful Journey Mom

Joyful Journey Mom offers a wide range of resources, such as lengthy lists concerning wish organizations, medical equipment, free gifts and services, as well as free places to go.

joyfuljourney4me@gmail.com

<http://joyfuljourneymom.com/ultimate-list-of-grants-and-resources-for-families-with-special-needs/>