

## Your Own Insurance Company

Reference the phone number on the back of your insurance card. Request a case manager or an advocate who assist families experiencing complex health challenges.

## Human Resources (HR)

The HR department of your employer that provides health insurance to you may be able to help with insurance issues.

## State Department of Insurance

[www.state.gov/insurance](http://www.state.gov/insurance)

Your state's Department of Insurance can be contacted for help if you've exhausted options with your health plan. Search online "State Department of Insurance" to identify your state department.

## State Ombudsman

[www.usombudsman.org](http://www.usombudsman.org) or

[www.state.gov/bureaus-offices/secretary-of-state/office-of-the-ombuds/](http://www.state.gov/bureaus-offices/secretary-of-state/office-of-the-ombuds/)

Search online "ombudsman+your state name" to identify your ombudsman. The state ombudsman investigates complaints and helps resolve issues with institutions for Medicare and Medicaid, as well as other public authority issues. Each state has an ombudsman who is an official appointed to investigate individuals' complaints against maladministration.

## National Human Genome Research Institute (NHGRI)

[www.Genome.gov](http://www.Genome.gov)

Learn about genetic discrimination and your rights under the Genetic Information Nondiscrimination Act (GINA).

For more information and resources about Genetic Testing, visit the CNF website at [www.childneurologyfoundation.org/geneticTesting](http://www.childneurologyfoundation.org/geneticTesting) or call (859) 551-4977.



Genetic Testing

## Genetic and Rare Diseases Information Center

[www.RareDiseases.info.nih.gov](http://www.RareDiseases.info.nih.gov)

888-205-2311

This information center may help with insurance and reimbursement for genetic and rare diseases.

## No Surprises Act

[www.cms.gov/nosurprises](http://www.cms.gov/nosurprises)

800-958-3059

No Surprises Act is a federal law that protects you from unexpected medical bills.

## Officials

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

202-697-RARE (7273)

Your local Congressman or the Rare Disease Legislative Caucus can be contacted for advocacy support.

## Local and State Officials

[www.house.gov/representatives/find-your-representative](http://www.house.gov/representatives/find-your-representative)

to find your local member of Congress

[rareadvocates.org/rarecaucus/?s=](http://rareadvocates.org/rarecaucus/?s=) for Congress participation in the Rare Disease Legislative Caucus

## Patient Advocate Foundation - [www.PatientAdvocate.org](http://www.PatientAdvocate.org)

800-532-5274

Free case management is available for insurance denials and appeals through the Patient Advocate Foundation.

If you have specific questions about navigating your insurance, contact the CNF Family Support Program at [www.childneurologyfoundation.org/family-support](http://www.childneurologyfoundation.org/family-support) or call (859) 551-4977.



Family Support