

# Rare Diseases

## What is a **RARE DISEASE**?

Rare diseases are very **uncommon** and impact very few people.

People with rare diseases often have seen **several doctors** who may not understand their health.

People with rare diseases may go a **long time** before finding answers.

Once diagnosed, people with rare diseases often do not have approved **medications**.

People with rare diseases may have few **support resources** available to them.

People with rare diseases may also be **misdiagnosed**. This means they are diagnosed with a disease but are later told they don't have that disease.



I think I have a rare disease.  
**What should I do?**

Speak with your doctor about your options.

Seek information about groups conducting research in rare diseases, for example, the UDN.

Learn whether your insurance provides for genetic testing.

Look for financial resources if you are uninsured or underinsured.

Join support groups with others who have rare diseases or conditions.



The Undiagnosed Diseases Network (UDN) is a **research study** that helps patients find a diagnosis.

Learn about our case submission process:  
<https://undiagnosed.hms.harvard.edu/participate/>