



TEACHER'S FACT SHEET

Thank you for using this short-term curriculum about rare diseases for high school biology and health classes. This curriculum is intended to be used on Rare Disease Day® and/or on the days leading up to it.

WHAT ARE RARE DISEASES?

Rare diseases are medical conditions with prevalence of fewer than 200,000 cases each in the United States. Though these diseases are rare by themselves, collectively they affect a lot of people. It has been estimated more than 30 million Americans, close to 1 in 10, live with a diagnosis of one of the over 10,000 recognized rare diseases. Rare diseases are also called orphan diseases.

WHAT IS RARE DISEASE DAY?

Rare Disease Day is an observance held on the last day of February to raise awareness for rare diseases and improve access to treatment and medical care. Since its establishment in 2008, it has been observed every year in more than 40 countries around the world.

For more information about Rare Disease Day in the US, please visit:

rarediseaseday.us

For more information about Rare Disease Day worldwide, please visit:

rarediseaseday.org

WHAT ARE THE CHALLENGES WITH RARE DISEASES?

There is little knowledge of the causes and clinical courses of most rare diseases, resulting in delayed or wrong diagnoses. The time it takes to reach a correct diagnosis may range from five years up to 30 years from the time the first clinical symptom appears. The lack of effective treatment is another major challenge. It has been estimated that only about 10% of rare diseases have an FDA-approved treatment. In addition, individuals with rare diseases and their caregivers can bear psychosocial burdens including isolation, invisibility, and powerlessness. They may also face bullying and discrimination.

WHAT ARE SOME EXAMPLES OF RARE DISEASES?

There are more than 7,000 recognized rare diseases. It's impossible to describe all rare diseases in this curriculum. For some rare diseases, very little knowledge is currently available. Here are some examples of rare diseases that affect different body systems: (click on the link below it for a brief review each of the rare disease listed)

[Muscle – Duchenne Muscular Dystrophy](#)

[Respiratory – Cystic Fibrosis](#)

[Eye – Retinitis Pigmentosa](#)

[Blood – Thalassemia](#)

WHY WAS THIS CURRICULUM CREATED?

Rare diseases pose a strong burden on the affected individuals and their families. Because rare diseases impact close to 1 in 10 Americans, they are also an important public health issue. High school students need to understand the issues associated with rare diseases in order to make well informed choices as citizens.

WHO CREATED THIS CURRICULUM?

This curriculum was created by a graduate student, Julia Su, and the nonprofit organization, the National Organization for Rare Disorders (NORD®). NORD was founded in 1983 to help 330 rare disease-specific individuals and families with rare diseases through education, advocacy, research, and patient services. NORD represents over 2,000 patient support organizations in the United States.

HOW WAS THIS CURRICULUM CREATED?

We started with a survey sent to organizations in NORD's patient organization database to collect information about issues in the rare disease community. Individuals with rare diseases, their family members, health care providers, researchers, and patient advocates were invited to participate in the survey. The content of the curriculum reflects the themes and issues brought forth by the responses to the survey. Some of the written responses in the survey are also quoted throughout the curriculum (*italicized text*). After the curriculum was created, it was reviewed by staff members at NORD, high school biology and health teachers, and individuals from the rare disease community.

WHERE CAN I FIND MORE INFORMATION ON RARE DISEASES?

For more information about rare diseases, please visit:

National Organization for Rare Disorders (NORD®)

rarediseases.org

NIH Genetic and Rare Diseases Information Center (GARD)

rarediseases.info.nih.gov/GARD

DO I NEED PREVIOUS KNOWLEDGE IN RARE DISEASES TO TEACH THIS CURRICULUM?

No. You don't need previous knowledge in rare diseases to use this curriculum. The instructions for all the classroom activities are provided. Student handouts and other teaching materials are also provided. In addition, throughout the curriculum, you will find extra help in boxes called "Teacher's Resources."

TEACHER'S RESOURCES

Materials in these boxes will give you more background information about the issues discussed in the curriculum and can help you answer some of the questions your students may have. If your students would like to learn more or whenever you feel appropriate, feel free to share the materials in these boxes with your students.