

# SHOW YOUR STRIPES<sup>®</sup>



ON RARE DISEASE DAY<sup>®</sup>  
FEBRUARY 29, 2024

## HIGH SCHOOL CLASS CURRICULUM

### Activity B: Rare but Significant

**Overview:** This interactive classroom activity “Agree/Disagree” provides students a general introduction to rare diseases.

**Main concept:** Rare diseases affect close to 1 in 10 Americans. They affect people of all ages. Not all rare diseases can be cured or treated. They are an important public health issue.

**Material and supplies:** Divide the classroom into two sides with masking tape or some chairs.

**Time required:** 15-minute classroom activity

#### Procedure:

1. If this is the first classroom activity, spend a few minutes to talk to students about Rare Disease Day<sup>®</sup> and rare diseases (for information, refer to **Teacher’s Fact Sheet**).
2. Begin the activity by dividing the classroom into two sides using masking tape or some chairs. If needed, move chairs aside to give students rooms to move around. Assign one side of the classroom to be the side of “agreement,” and the other to be the side of “disagreement.”
3. Explain to students that in this activity, you will say a few statements, and if they agree with the statement, they should move to the side of “agreement,” and if they disagree, to the side of “disagreement.” If they cannot make up their mind, they can stand in the middle. Ask students to leave their seats, stand up, and get ready.
4. Help the students warm up and understand the rules by saying something quite obvious in the first few statements, like:  
“There are five seasons in a year.” (False)  
“There are 13 months in a year.” (False)
5. Say the following five statements about rare diseases. At the end of each statement, ask one or two students from both sides of the room to share why they agree or disagree with the statement. Ask them if they can give any examples to support their views. Briefly discuss after each statement.

Note: This activity can be adapted for virtual learning by polling students to identify each statement as true or false.

Questions? Write to NORD at [education@rarediseases.org](mailto:education@rarediseases.org).

1. **“Only very few people in the US have a rare disease. That’s why these diseases are called “rare” (False)**

Though each of the rare diseases by itself is very rare, if we look at all the rare diseases out there (about 7,000 of them), they affect a lot of people, close to 1 in 10 Americans.

2. **“If someone has a rare disease, you will be able to tell when you see them on the street.” (False)**

Though some rare diseases can affect physical appearance, such as gigantism (abnormally large growth) and dwarfism (abnormally short height), there are many rare diseases that are “invisible”. Some rare diseases affect speech and hearing, so you won’t know that this person has a rare disease unless you talk to him or her. For some conditions, there is no way to tell that someone has it, unless he/she tells you about it, such as cluster headache, which gives people episodes of intense headaches.

### TEACHER’S RESOURCES

With respect to the issue of “invisible disabilities”, some of the individuals with rare diseases have commented that:

*“People in society in general remain unaware of the existence of invisible disabilities. I have had great difficulty in getting accommodations and avoiding discrimination and disbelief. I need to use an elevator. However, because I am not walking with a cane or using a wheelchair, people don't believe I have joint problems.”*

*“I have health problems like retina detachment, hearing loss, joint problem, and heart problem. With Stickler syndrome, we look normal, but under the covers we see 7 different medical specialists and 5 educational team members. The syndrome is invisible and takes a toll on daily life.”*

To learn more about Stickler syndrome, please visit:

<http://www.rarediseases.org/rare-disease-information/rare-diseases/byID/421/viewAbstract>

3. **“Rare diseases can affect people of all ages.” (True)**

Some rare diseases will be obvious at birth, such as Spina Bifida. Some rare diseases will not manifest until later in life (like Huntington’s Disease). For some diseases, the symptoms can get progressively worse over the years (like Charcot-Marie-Tooth disease).

### TEACHER’S RESOURCES

**Spina Bifida:** also called open neural tube defect. It is characterized by incomplete closure of certain bones of the spinal column (vertebrae), leaving a portion of the spinal cord exposed. Spina bifida may cause difficulties with bladder control, walking, and other functions, depending on the severity of associated symptoms.

**Huntington's disease:** A genetic, neurodegenerative disorder characterized by the gradual development of involuntary muscle movements affecting the hands, feet, face, and trunk. It also involves progressive deterioration of cognitive processes and memory (dementia). In individuals with the disorder, disease duration may range from approximately 10 years up to 25 years or more. Life-threatening complications may result from pneumonia or other infections, injuries related to falls, or other associated developments.

**Charcot-Marie-Tooth disease:** Charcot-Marie-Tooth disease is a group of disorders in which the motor and/or sensory peripheral nerves are affected, resulting in muscle weakness and atrophy, as well as sensory loss. Charcot-Marie-Tooth disease is usually inherited. Symptoms usually begin between mid-childhood and early adulthood, and usually get progressively more disabling over time.

#### 4. "Not all rare diseases can be treated." (True)

Unfortunately, this is true. Not all rare disorders have effective treatment options. Most rare disorders do not have a cure. The lack of cure and effective treatment is a major issue for those with rare diseases. It has been estimated that only about 10% of rare diseases have an available treatment. Participants in the survey have shared with us:

*"Just the shock of finding out that my husband not only was terminally ill, but that it is such a rare disease that he is a virtual guinea pig, because the drug companies won't make any money by developing a drug to effectively treat this monster."*

*"When my husband received the diagnosis of Multiple System Atrophy, which is essentially a death sentence, there was (and is) no effective treatment and no way to know how long the course of the disease would be."*

To learn more about Multiple System Atrophy, please visit:

<http://www.rarediseases.org/rare-disease-information/rare-diseases/byID/242/viewAbstrac>

#### TEACHER'S RESOURCES

Students may ask what the difference is between a cure and a treatment.

Cure refers to a drug or a procedure that can end the medical problem. For example, when a tumor is surgically excised completely, the cancer is said to be cured. Treatment refers to a drug or a therapy used to remedy and manage a health problem. Most medical conditions, common or rare, cannot be cured. For example, diabetes can only be managed through medication or change of life style, but it cannot be cured. For a lot of rare diseases, there is neither any cure nor treatment.

#### TEACHER'S RESOURCES

Students may have heard of the term "orphan drugs". Orphan drugs are pharmaceutical agents that are developed specifically to treat rare diseases, which are also called orphan diseases.

#### ORPHAN DRUG ACT

Orphan Drug Act (ODA) was signed into law in 1983. It acknowledged the medical needs of patients with rare diseases and recognized the fundamental obstacle to the development of rare disease therapies. The pharmaceutical industry had been reluctant to invest in research and development of rare disease treatments which had little prospect of returns, because the product market was so small.

ODA offers various incentives to pharmaceutical companies developing rare disease treatments, including 7 years of US FDA-enforced market exclusivity for approved products, exemptions from FDA fees for regulatory submissions, regulatory advice, and tax credits. The 7 year period of exclusive marketing has been the biggest economic incentive, because many orphan drugs cannot be patented, as they were synthesized and published on before their medical use was established.

In the years since the ODA was introduced, more than 350 orphan drugs have been approved in the US, compared with only 10 such drugs in the decade preceding the ODA. The success of ODA in the US has also inspired orphan drug legislation in other countries.

5. **“Having a rare disease will make someone’s life difficult and miserable.”**

This is both true and false. Living with a rare disease poses unique difficulties and challenges, but not everyone with a rare disease is living a miserable life. Many individuals find creative ways to overcome their challenges and live meaningful lives. It’s important that we become aware of the challenges they face, try to understand their situations, and do what we can to help.

Many individuals living with a rare disease are very positive. They have said:

*“There are many challenges in life, but don't give up because of any rare disease. Life can be fulfilling.”*

*“Having a rare disorder does not mean your life is over. It just means that you have to be strong and be willing to fight to have a normal life or as much of one as you can manage.”*

6. Wrap up the activity by saying, “You all did a good job! Through this activity, we learned that rare diseases affect a lot of people, about 1 in 10 Americans! We also learned that they can affect people of all ages. Some of the rare diseases can even be “invisible” – you can’t always tell if someone has a rare disease by just looking at them. Many rare diseases cannot be cured or treated. Though people with rare diseases face difficulties and challenges, many of them still choose to live positively.”
7. If this is the last classroom activity, thank the students for their participation. Hand out the student take-home handout and wrap up the period (for information, see the Student take-home handout file).