



HIGH SCHOOL CLASS CURRICULUM

Activity A: Research and Learn

Overview: In this activity, students will pick a rare disease, do some research, and present their findings to their classmates.

Main concept: There are over 10,000 recognized rare diseases. They affect multiple body systems and have various causes. Learning about these rare diseases draws upon the knowledge of basic biology, medicine and genetics.

Material and supplies: Students' Presentation Guide (2nd and 3rd page of this file) provided to the class as handouts

Time required: Talk to your students about this project at least two weeks ahead of time. Allow five-seven minutes for each student presentation.

Procedure:

1. At least two weeks before the student presentation, spend a few minutes to talk to students about Rare Disease Day® and rare diseases (for information, refer to **Teacher's Fact Sheet**).
2. Tell students, "This year, our class will learn about some rare diseases together, explore how they affect people's lives, and find out ways that we can be help. I'd like you to participate by picking a rare disease or a topic related to rare diseases to do some research on, prepare a 5-7 minute presentation using poster boards or PowerPoint and present to your classmates."
3. Distribute Students' Presentation Guide, then allow students to choose presentation topics. If students have other rare diseases or topics not already on the list that they would like to work on, encourage them to do so. Encourage them to use a variety of methods and media to present their disease, such as drama, short skits, video, slideshows, etc.

Questions? Write to NORD at education@rarediseases.org.

Students' Presentation Guide for Activity A: Research and Learn

Dear students:

You will prepare a five-seven minute presentation on a particular rare disease (see Part I of this handout) or a topic related to rare diseases (see Part II). Feel free to use creative methods and different media in your presentation, such as drama, short skits, video, slideshows, etc.

PART I. PRESENTATION ON A RARE DISEASE

List of rare diseases to present on (They are categorized based on their main effects on the body.)

Metabolic Galactosemia PKU (Phenylketonuria) Canavan disease	Mobility Charcot-Marie-Tooth disease Spina bifida Spinal muscular atrophy Duchenne muscular dystrophy
Intellectual disability Fragile X syndrome Lowe syndrome Smith-Magenis syndrome Batten disease	Cancer Li-Fraumeni syndrome Multiple myeloma Cowden syndrome Von Hippel-Lindau syndrome
Connective Tissues Marfan syndrome Ehlers Danlos syndrome Stickler syndrome	Blood Thalassemia Hemophilia Fanconi anemia Sickle cell anemia
Other Epidermolysis bullosa (skin) Retinitis pigmentosa (vision) Long QT syndrome (heart problem) Cystic Fibrosis (respiratory) Wilson's disease (liver) Prader Willi syndrome	Brain/nervous system Pseudotumor cerebri Mal de Debarquement syndrome (MdDS) Niemann-Pick disease type C Amyotrophic lateral sclerosis (Lou Gehrig's disease)

There are over 10,000 recognized rare diseases and this list is just a guide. You can present on a rare disease that is not on the list, and if this is what you want to do, please let your teacher know.

Try to cover the following topics in your presentation:

1. Which part(s) of the body does this disease affect? Name the body system(s) and organ(s).
2. What age group does it affect/what is the age of onset for symptoms?
3. How do you think this disease affects someone's day-to-day life?
4. How does someone get this condition? (sporadic, infectious, inherited)
5. What are some of the treatment options? Is there a cure?
6. Is there a patient support group/organization for this disease? If so, provide the name what they do.
7. Is there a famous person who has/had this disease?

Some useful resources in researching about rare diseases:

- [NORD Rare Disease Database](https://bit.ly/Rare-Disease-Database): bit.ly/Rare-Disease-Database
- [NORD's Rare Disease Video Library](https://bit.ly/Rare-Disease-Video-Library): bit.ly/Rare-Disease-Video-Library
- [NIH Genetic and Rare Diseases Information Center \(GARD\)](https://rarediseases.info.nih.gov): rarediseases.info.nih.gov
- [Orphanet](https://bit.ly/Orphanet_Resource): bit.ly/Orphanet_Resource
- [Genetics Home Reference](https://medlineplus.gov/genetics): medlineplus.gov/genetics