



HIGH SCHOOL CLASS CURRICULUM

Activity C: Living with a Rare Disease

Overview: This activity includes a short video clip of someone living with a rare disease and a complementary lesson.

Main concept: Individuals with rare diseases need a lot of courage and strength to cope with the physical, emotional and social impacts of their disorders.

Material and supplies: Computer, video projector or TV connected to computer, sound system, YouTube videos (download in advance), PowerPoint slides on Friedreich's ataxia ([download in advance](#))

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® and rare diseases (for information, refer to **Teacher's Fact Sheet**).
2. Using [PowerPoint slides](#), give students a brief introduction of the condition Friedreich's ataxia (FA). If your class has done Activity A (Research and Learn), and one of your students has presented on FA, skip the introduction and simply help students refresh their memory about FA.
3. Ask students if they were to start having balance and coordination problems now, and later find out that they have FA, how would this change their lives and how would they feel? Have one or two students share their thoughts with the class.
4. Introduce the video of Kyle Bryant to the class by saying, "Now we will meet someone who is living with Friedreich's ataxia. His name is Kyle. Kyle found out he had Friedreich's ataxia when he was 17, around your age. In the video, we will see how this condition has impacted Kyle's life and learn about some of the amazing things he has done." Play the two clips.

youtube.com/watch?v=Bm9MXu4i8V8 (2'44)

youtube.com/watch?v=LdQnKloyJkc (20'15)

5. Ask a few students to share with the class their thoughts on Kyle Bryant, Friedreich's ataxia, and rare diseases in general.

6. Wrap up this activity by saying, "We've seen how this one rare disease, Friedreich's ataxia, has affected Kyle's physical ability. However, we need to understand that rare diseases not only affect someone physically, they can also impact someone's emotional health, family, work and social circles, as well as many small and big decisions in life. This is true for Friedreich's ataxia, as well as many other rare diseases."
7. If this is the last classroom activity, thank the students for their participation. Distribute the student take-home handout and wrap up the period (for information, see the Student take-home handout file).

For Teachers – Transparency on Friedreich's Ataxia Slides

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