



Miracle Drugs, Million Dollar Price Tags Lesson Plan

playing god? in the classroom is an educational resource designed to accompany the *playing god?* podcast, for use by instructors to introduce bioethics concepts and facilitate discussions of ethics among high school and above students. The *playing god? in the classroom* resources are free and available for non-commercial uses, with attribution to the Johns Hopkins Berman Institute of Bioethics. For other uses and more information, please contact playinggod@jhu.edu.

This Lesson Plan accompanies Episode 8, Season 1 of *playing god?*

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Summary

Cheryl Yoder’s son Jase was born with an incurable rare disease called spinal muscular atrophy (SMA), which meant he was unlikely to live beyond two years old. Jase managed to get a spot in a clinical trial for an experimental drug. It halted the disease and allowed him to grow up as an active little boy—a miracle cure.

A growing list of uniquely tailored drugs can treat, and even cure, some debilitating and fatal diseases. But often these so-called “miracle drugs” can cost a fortune. In this episode: why miracle drugs cost so much, why it’s so hard to do anything about the costs, and how challenging it is to work towards equitable access for patients who can benefit from them.

In this Lesson Plan, students will learn how new drugs are developed and approved in the United States, and how drug companies determine the price of a drug. They will learn about ethics considerations that inform decisions about how to pay for healthcare when funds are limited. Students will identify and articulate the values and viewpoints of various stakeholders affected by expensive drug prices.

Vocabulary

The following are key terms used in the Episode and their definitions. The terms are marked in bold when they appear elsewhere in the Lesson Plan.

Cost-effectiveness

The relationship between something's positive effects like benefits, and its costs, usually the amount of money paid.

Degeneration

When the structure and/or function of tissue or organs breaks down.

Equity

An ethics principle focused on fairness, with an aim to reduce unfair differences between people.

Food & Drug Administration (FDA)

The United States government agency that is responsible for regulating drugs, medical products, and devices, making sure they are safe and that they work (efficacy). It is also responsible for the regulation of cosmetics, food products, and radioactive products.

Gatekeeping

To control or limit access to something.

Medical Necessity

Healthcare services or supplies that are needed to diagnose or treat an illness, injury, condition, disease, or its symptoms, and that meet accepted standards of medicine.¹

→ Health insurance companies only cover healthcare services that they determine to be medically necessary.

Medicare

A federal health insurance program in the United States that provides coverage for people aged 65 and over, and for people with disabilities.

Presymptomatic

Not yet displaying symptoms or evidence of a disease.²

Trade Name

Drugs are given a generic name that describes their purpose and the chemical compound in the drug. When drugs are approved by the **Food and Drug Administration (FDA)** for sale to the public, the pharmaceutical company that manufactures the drug often brands them with a **trade name** that is used in marketing the drug. Sometimes referred to as a brand name.

→ Nusinersen is the generic name of the expensive drug Jase was given. Its **trade name** is Spinraza®. Advil® and Motrin® are the **trade names** for the same generic drug, ibuprofen, each marketed by two different drug companies.

Recessive Genetic Disease

A disease that manifests when someone has one copy of a disease-causing gene from each parent (homozygous recessive).³

Discussion Guide

The following Assessment Questions can be used by instructors to evaluate student comprehension of Andrea's story and the bioethics concepts featured in the Podcast Episode. The Discussion Questions can prompt students to make claims and provide evidence and their reasoning. Student comprehension and views can be assessed before and after listening to the Episode and/or participating in the group activity.

Assessment Questions

- Spinal muscular atrophy (SMA) is a **recessive genetic disease**. What does that mean? How did Jase get SMA?
- How did nusinersen (**trade name** Spinraza®) help Jase, who was born with SMA?
- How does Spinraza® affect the following patients?
 - For a **presymptomatic** infant diagnosed with SMA.
 - For a young child with severe, progressive SMA, who already has symptoms of **degeneration**, such as the inability to walk.
 - For an adult with milder symptoms of SMA, who will live a long life, but will need a wheelchair.
- How did the Yoder family afford this drug when Jase first started treatment?
- What factors are considered in pricing a drug?
 - Who has a say in this process?
- What role do insurance companies play in allowing or preventing patients from receiving Spinraza®?
- What role does the **FDA** play in drug development? What role does the **FDA** play in drug pricing?

Discussion Questions

- What factors would you consider if you were deciding the price of a drug like Spinraza®?
- Whom do you think should have a say when prices are decided? *Sample answers below.*
 - *Lawmakers and regulators*
 - *Insurance companies*
 - *Pharmaceutical companies*
 - *Members of the public*
 - *People with rare diseases or their family members*
 - *Doctors*
 - *Economists*

- Consider **medical necessity** for the below scenarios. How would you decide **medical necessity** for SMA patients? Who do you think is most likely to receive insurance coverage for the drug? Who should be part of the decision-making process?
 - For a **presymptomatic** infant diagnosed with SMA.
 - For a young child with severe, progressive SMA, who already has symptoms of **degeneration**, such as the inability to walk.
 - For an adult with milder symptoms of SMA, who will live a long life, but will need a wheelchair.

- How do different ethics considerations influence how society spends money on healthcare?
 - **Cost-effectiveness** or value?
 - **Equity**?

Sample Activities

The activities allow students to actively engage with the bioethics questions at the center of the Episode. Students will develop critical thinking skills and reason-based judgment by citing evidence from the Podcast and other sources. In bioethics, there often isn't a single "right" answer to a particular question; ideally, students will express and evaluate diverse viewpoints about complex, real-world problems.

Large Group Activity: Sliding Scale Drug Pricing

Description:

Students can show how they think a drug should be priced after learning about Spinraza® and hearing from different stakeholder groups and their values. This exercise can be done after students have listened to the Episode and are familiar with the Episode's discussion of the drug approval and pricing process, as well as associated ethics considerations like **cost-effectiveness** and **equity**.

Instructions:

Before class: Print one copy of the Lesson Plan 8 Handout. This handout has four pages, one for each stakeholder role.

In class: Assign four students to play the roles indicated on the Handout. Give these students a few minutes to read about their role and prepare to articulate their stance on the price of the drug.

The classroom space will be used to represent a pricing scale, with one side of the room indicating a price of zero dollars and the other side of the room indicating one million dollars. Throughout this exercise, students will decide how much the pharmaceutical company should charge *for one dose* of the drug. Remind students that patients will need three doses a year for their entire lives. After listening to the Episode, all students should take their initial position on the scale.

The teacher calls on each of the students assigned a specific role. This student explains their role, articulates the values and other considerations relevant to this role, and applies these considerations to justify their position on the scale. After each role-playing student articulates their position, all students have the opportunity to move their position on the scale. After all role-playing students have shared, other students are given the opportunity to rebut or to explain their own reasoning for their position.

After the activity: Use the **Discussion Guide** to debrief with the class and assess how their views and reasoning have changed after the activity.

Individual Activity: Ask An Adult

Ask your family members what type of insurance/insurance provider they have. Look up the benefits that this type of coverage provides. If someone in your family needed Spinraza®, how much would you estimate that they personally must pay for each dose? Each dose costs approximately \$125,000.

- You may find new terms like: out of pocket costs, premiums, co-insurance, co-payment.

Individual Activity: Research & Writing

Spinal muscular atrophy (SMA) is a **recessive genetic disease**. Research another **recessive genetic disease**. Describe the disease, its genetic heritability, and its prevalence. Describe the treatments that are available for this disease. Find a patient advocacy group that provides support for people with this disease. How does this organization help patients? Do they take a position on drug pricing or affordability? If so, what is their position?

Apply the ethics considerations from the Episode to what you've learned about this disease. Are the available treatments **cost-effective**? Is there **equitable** access to them? Are there any policies or programs in place to make sure patients have access to treatments?

Finally, write a policy proposal that would, in your opinion, make access to treatments more ethical. This can be a new policy proposal, or an amendment to any existing policies or programs you find. What challenges does your proposal address? What would the benefits of your proposal be?

Examples of other recessive genetic disorders:

- *Sickle cell disease*
- *Cystic fibrosis*
- *Tay-Sachs disease*
- *Gaucher disease*
- *Congenital adrenal hyperplasia (CAH)*
- *Wilson disease*
- *Thalassemia*
 - *Beta-thalassemia is a single gene disorder*
 - *Alpha-thalassemia is a two-gene disorder*
- *Maple Syrup Urine disease*
- *Phenylketonuria (PKU)*
- *Galactosemia*
- *Familial Mediterranean Fever (FMF)*
- *Bloom Syndrome*

Additional Resources

Further readings about key topics covered in the Episode.

[The costliest drug on the planet will treat infants with rare disease. The market fight focused on cost and safety is just getting started.](#) *The Washington Post*, 2019.

- This article is about a newer treatment for SMA that only requires one lifetime dose.

[A Search For New Ways To Pay For Drugs That Cost A Mint](#), *NPR*, 2018.

[High Drug Prices and Costly Care Raise Ethical Concerns for Neurologists: A New Position Statement from the AAN](#), *Neurology Today*, 2021.

[Ethical Challenges Confronted When Providing Nusinersen Treatment for Spinal Muscular Atrophy](#), *JAMA Pediatrics*, 2018.

Careers Mentioned

Physician:

Thomas “Tom” Crawford, MD
(pediatric neurology)

Bioethicist:

Holly Fernandez Lynch, JD, MBE
(law, bioethics)

About This Lesson Plan

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The Podcast Episode and this Lesson Plan are not designed to answer patient-specific clinical, professional, legal, or ethical questions. Information contained herein is not intended as a substitute for professional consultation.

¹ Healthcare.gov Glossary, retrieved 2025

² Merriam-Webster, retrieved 2025

³ "Autosomal Recessive Disorder," National Human Genome Research Institute, Talking Glossary of Genomic and Genetic Terms, retrieved 2025