



NORD®

National Organization for Rare Disorders

How to Make Your Health Insurance Work for You

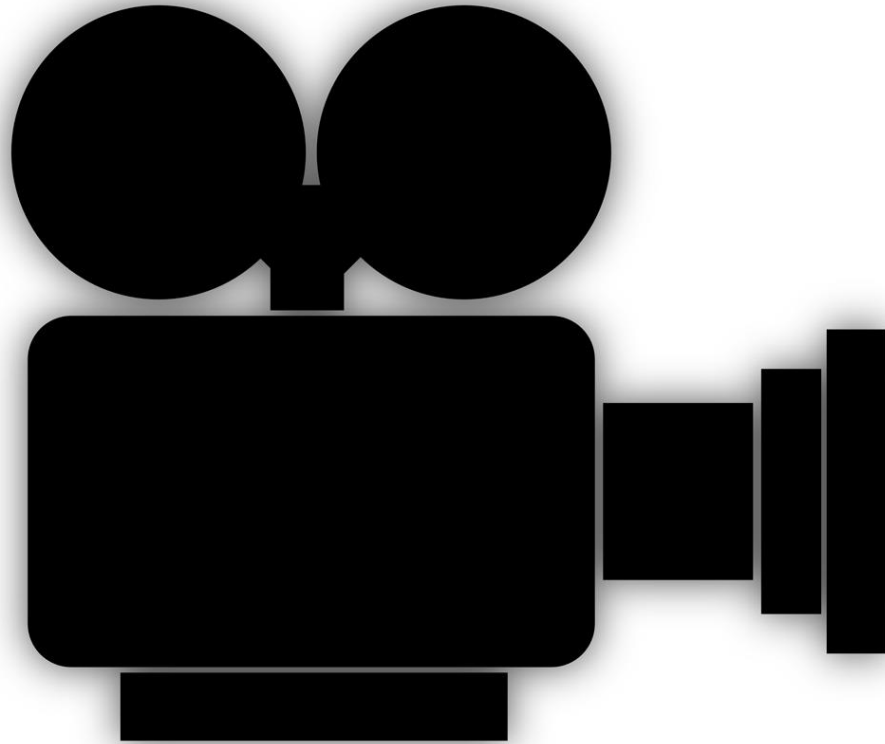
For sound, stream audio through your speakers.

If you are having trouble accessing sound, please send a message using the chat box in the lower left hand corner.

Alone we are **rare**. Together we are strong.®

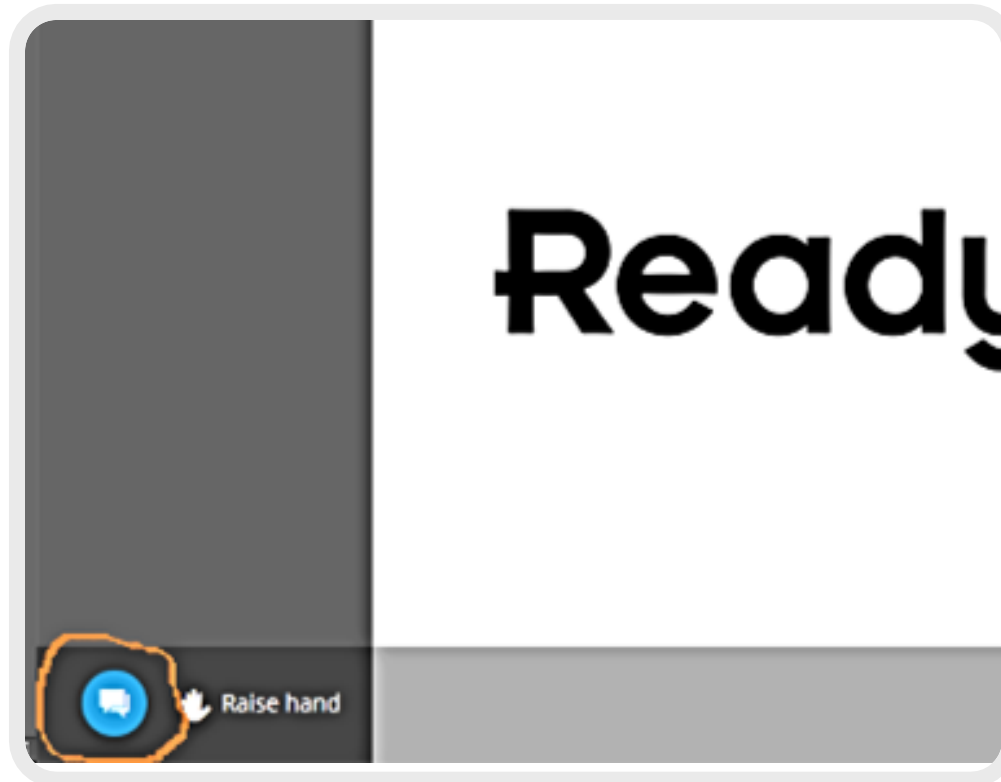


This webinar is being recorded.



Question and Answer Session

Submit your questions using the chat function. It can be found at the **lower left hand corner** of the window.



1 in 10
Americans
has a rare disease.

that's **30 million** people
two-thirds of which

are
children



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NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.



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Notes & Updates

- Rare Disease Day – February 28, 2019
- NORD Living Rare, Living Stronger Forum & Rare Impact Awards – June 2019



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Speaker: Lisa Massey



- Program Manager, Office of Strategic Planning, NORD
- Diagnosed with a primary immunodeficiency in 2003
- Seasoned insurance advocate
- Formerly affiliated with Association of American Medical Colleges

Navigating Your Insurance



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Agenda

- Introduction
- Key Takeaways
- Insurance 101
- Navigating Authorization
- Appealing Adverse Decisions

NORD was
founded in
1983



along with the Orphan Drug Act

280⁺
NORD
member
organizations



(& growing each year)

4,100⁺

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Key Takeaways

- In today's webinar, we plan to cover the following:
 - How insurance is structured
 - Different parts of insurance
 - How tests and treatments get approved
 - What to do when your treatment is denied
 - How the appeals process works – Internal vs. External

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Insurance 101



This is a general overview of how insurance and appeals work. Not all items pertain to all insurance plans or companies. Without having your plan documents and information, I can't speak to the specifics of your case.

7,000
rare diseases exist.

95% 
of rare diseases
have NO treatment.

80% of rare
diseases

are genetically based.



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Insurance 101

Each insurance plan has three main parts:



Inpatient hospital
costs





Outpatient
professional and
treatment fees –
sometimes referred to
as major medical



Pharmacy

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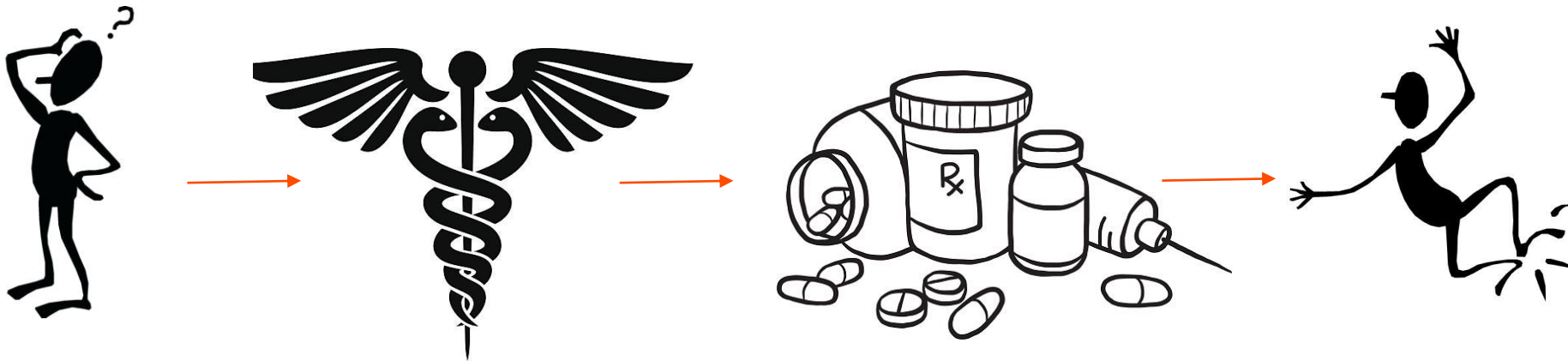
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Insurance 101

In an ideal world...



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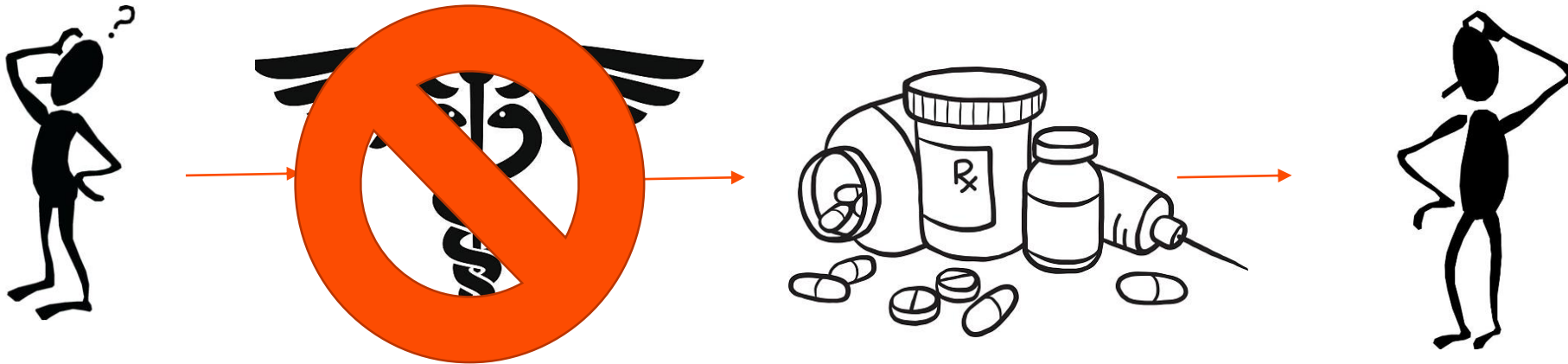
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Insurance 101

Network:



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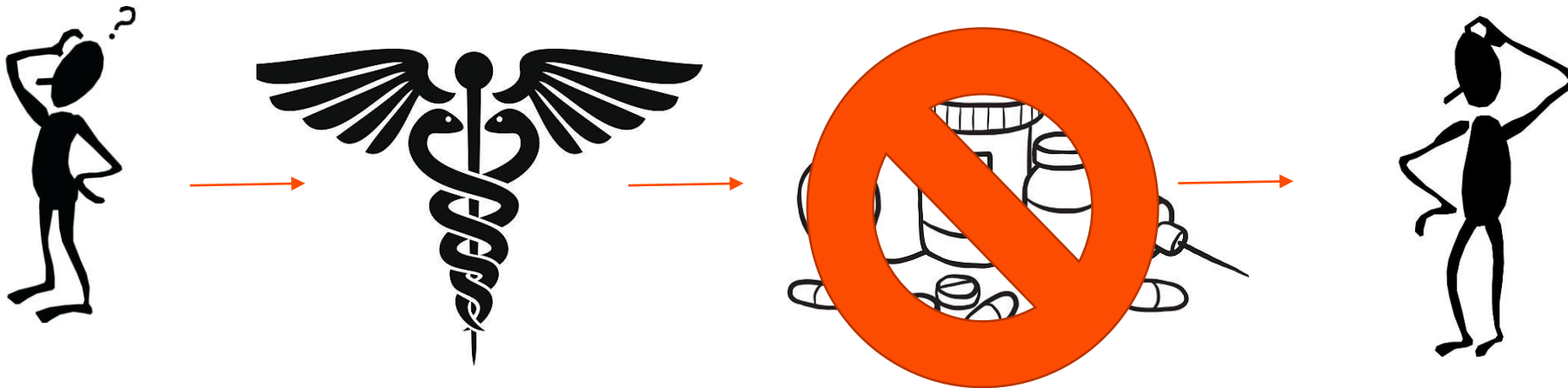
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Insurance 101


Formulary: The list of drugs covered by a particular insurance company



Step Therapy: Requiring patients to begin with the most cost-effective therapy for a particular diagnosis, working up to more costly or risky options if the less-expensive are ineffective.

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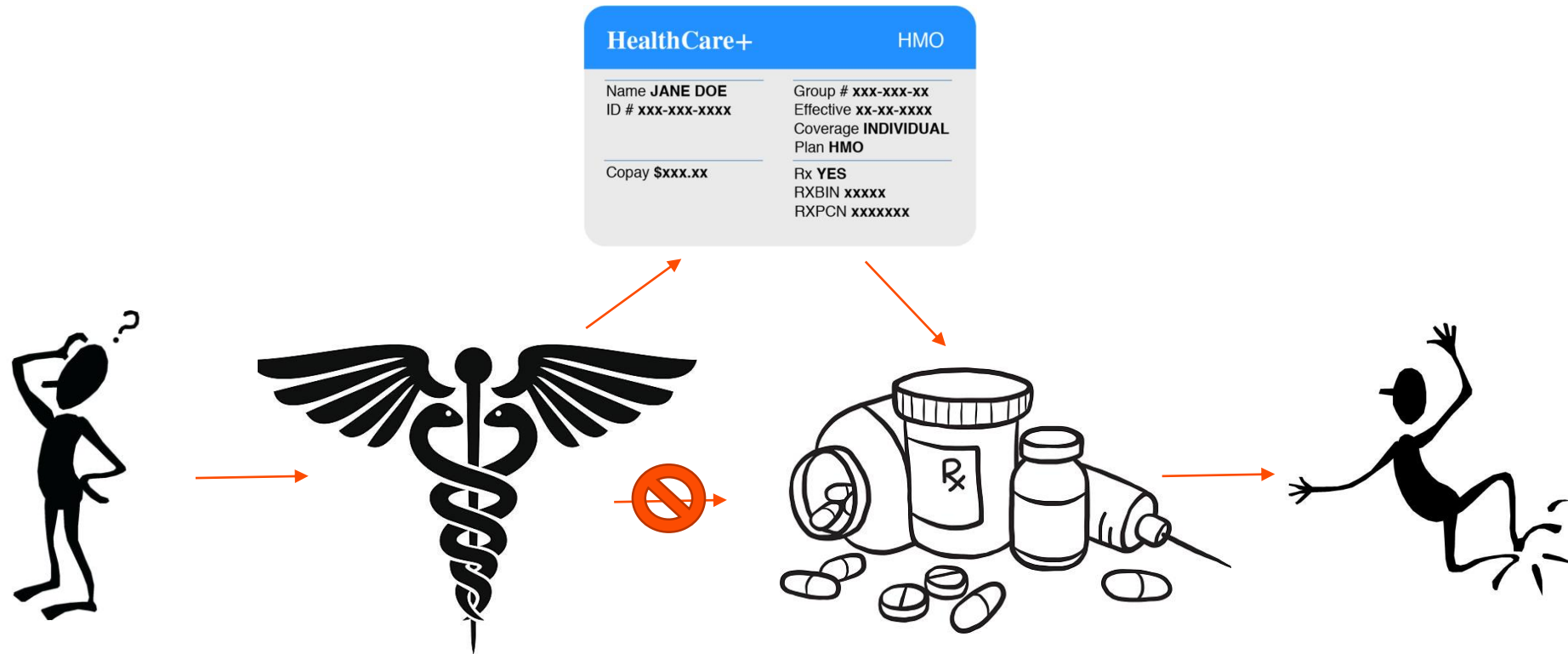
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Navigating Authorization



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Navigating Authorization

- Is the service or medication you're requesting **ever** considered to be in network?
- Who is the in network provider?
 - For some medications, a specific specialty pharmacy is required.
 - Verify that the provider is in network at every step to prevent problems later.
 - This information can be challenging to find, so ask questions at every opportunity.
- If there's any doubt about whether your provider needs an authorization, request that they run a "test claim" to your insurance.



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Navigating Authorization

- Proactive engagement is vital!
 - Who is a part of the approval chain?
 - Write everything down.
- Don't be afraid to pick up the phone
 - If you're wondering what the status of your authorization is, check in.
 - Ask about action steps.
- This process can take anywhere from days to weeks – but it is important to be involved and know where the process is and know what is needed to move forward.
 - Find out where the bottlenecks are.



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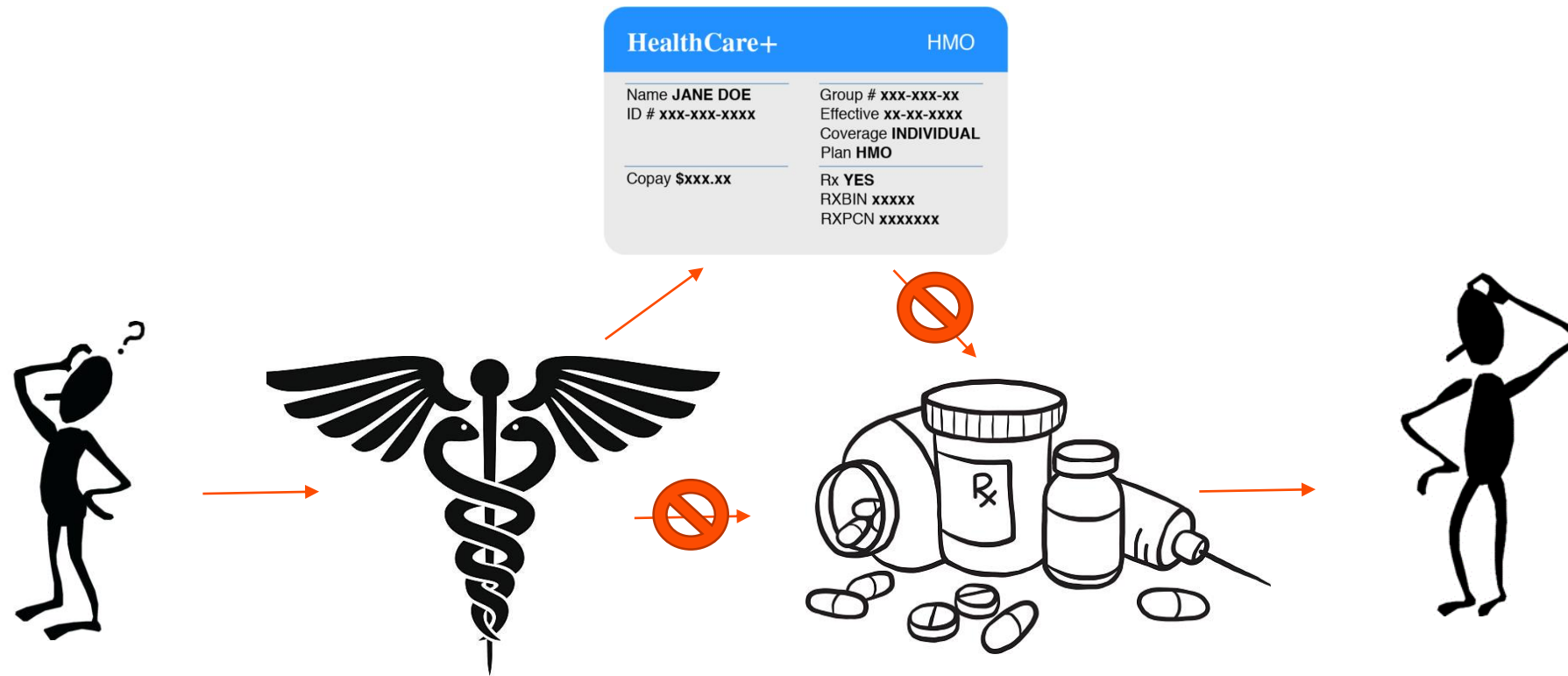
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Appealing Adverse Decisions



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Appealing Adverse Decisions

If your prior authorization, facility stay, test, or treatment is denied you have rights.¹

- Internal review or appeal- You have the right to request an internal review of your case and the insurance is required to review and explain its decision.
- External review or appeal- You have the right to request an external review if your denial involves:²
 - Medical judgement that you or your provider disagree with the health plan.
 - Any determination that a treatment is experimental or investigational.
 - Cancellation of coverage based on your insurer's claim that you gave false or incorrect information when applying.

¹<https://www.hhs.gov/healthcare/about-the-law/cancellations-and-appeals/appealing-health-plan-decisions/index.html>

²<https://www.healthcare.gov/appeal-insurance-company-decision/external-review/>

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Appealing Adverse Decisions

The time allotted to appeal any adverse coverage decision is limited. Making sure you are proactive in the process means that you will know to appeal before the clock even starts.

Before making an appeal, you should ensure that:

- You and/or your provider have provided all of the information requested by your health plan prior to the denial.
- You and/or your provider understands the requirements for the treatment's approval. Often, you can find an insurer's clinical guidelines for treatment online or on your plan's website.

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Appealing Adverse Decisions

Who can initiate these appeals?

- Your provider (Physician, nurse, care manager, pharmacist)
- **YOU**

What should you ask for when requesting an appeal?

- A review from someone in the same specialty as your treating physician. Ask for the name and credentials of the person reviewing your case.
- The reviewing physician speaks with your physician directly.

Depending on the nature of the denial, you may be asking for different things, for example, sometimes, you'll need a formulary waiver for a continuing medication or one that is in shortage.

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Appealing Adverse Decisions

Once your health plan has issued a final denial, you can move to external review. You have at least 60 days to file such a review request *in writing*. The Explanation of Benefits with the final decision from your insurer will have information on how to appeal and the contact information for your plan's review process.

What is an external review?

- Depending on your plan, your case will be reviewed by a state, federal, or independent reviewer.
- This reviewer will take your documentation and your plan's documentation and make a final determination of your coverage.

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Resources

National Association of Insurance Commissioners
(https://www.naic.org/index_members.htm)

HealthCare.gov
(<https://www.healthcare.gov/get-answers/>)

Medicare.gov
(<https://www.medicare.gov/coverage>)

Your own patient organization!

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Making sure you or your loved one get the treatments and services needed matters most to one person: **YOU!**

You can (and should) own this process for yourself.

Your involvement makes a difference!

Questions?



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Question and Answer Session



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Questions?

Submit your questions in the chat box.
Lisa will answer them in the order in which they came in and based on relevance to the discussion.



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