



HEALTH INSURANCE 101 TOOLKIT

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WELCOME!

We are so glad you are here. This toolkit is designed for people living with narcolepsy and their loved ones to offer new tools, tips, and perspectives on navigating health insurance with a chronic condition. Project Sleep created this toolkit as part of the **Narcolepsy Nerd Alert** series.

Narcolepsy Nerd Alert is an educational series diving deeper into specific topics relevant to narcolepsy. Each month, Project Sleep broadcasts a live event via Facebook, hosted by Julie Flygare, JD, Project Sleep's President & CEO.

After each live broadcast, we create a corresponding toolkit (like this one!) to capture our collective knowledge to help others down the road. Quotes featured throughout the toolkit are from panelists and audience members who joined us for the live broadcast.

PLEASE NOTE

The **Narcolepsy Nerd Alert** series is intended for educational and awareness purposes and is not a substitute for medical attention. If anything in this toolkit sparks questions for you about your medical management, please bring those questions to your sleep doctor or narcolepsy specialist.



MEET OUR GUEST



Megan Donnell is a passionate advocate for those living with rare disorders, primarily children's growth and narcolepsy/idiopathic hypersomnia. She is the Division Consultant for Small for Gestational Age for the MAGIC Foundation and ICOSEP and has provided benefit education and advocacy webinars for MAGIC and Ascendis Pharmaceuticals.

Megan holds a BA from The University of Richmond and an MBA from the University of Phoenix. With over 20 years of client service and account management experience, she works closely with clients as Vice President and Account Executive at Eastern Benefits Group. She lives on the South Shore of Massachusetts with her husband Jerry and has two children in college, one of whom is living with idiopathic hypersomnia.

“ I'm a parent of a young adult who has several different diagnoses. Her most recent diagnosis was idiopathic hypersomnia. - Megan

MEET THE HOST



Julie Flygare, JD, currently serves as President & CEO of Project Sleep. She was diagnosed with narcolepsy with cataplexy in 2007 while in law school. Julie is an internationally recognized patient-perspective leader, an accomplished advocate, and the award-winning author of *Wide Awake and Dreaming: A Memoir of Narcolepsy*.



HEALTH INSURANCE 101

Ever feel like navigating health insurance is a full-time job?

On February 23, 2022, special guest Megan Donnell joined host Julie Flygare to discuss the basics of healthcare coverage.

If you are comparing health insurance options or have a new diagnosis and treatment plan to consider, you may have questions like, "How do I know my medications and procedures will be covered?" or "What can I do if a prescription is not approved by my insurance?" With lengthy documents, unfamiliar terms, and crucial deadlines, it can feel overwhelming. That's why Megan is sharing her expertise, tips for success, and where to find help if you need it.

“ When my daughter was very young, I spent so much time working through her health insurance. Because of that, I realized I wanted to help others.

- Megan

- Watch the [Health Insurance 101 Video](#)
- Learn more about the [Narcolepsy Nerd Alert Series](#)



Stumped on a term? See the glossary at the end of the toolkit or visit [CMS.gov's Glossary of Health Coverage and Medical Terms](#).



TYPES OF INSURANCE

Understanding which kinds of plans are available to you and the amount of coverage provided when choosing a plan are the first steps to success. The information in this toolkit focuses on **group** health insurance, but much of it can be applied to other types of plans.

What types of health insurance coverage are available in the USA?

- Group sponsored health insurance is usually offered through your employer or sometimes your spouse or domestic partner's employer.
- Private direct pay health insurance can be purchased from the carrier.
- Individual/family coverage via the Exchange ("Marketplace")
 - State or Federal policies are purchased through the Exchange/Marketplace.
 - Can be subsidized or unsubsidized depending on your income and family size.
- Medicare
 - Typically for age 65+.
 - Younger individuals with qualifying disabilities/conditions may qualify.
- Medicaid and/or CHIP
 - Eligibility can vary state to state.
 - Income and family size affect eligibility.



COMPARING OPTIONS

Usually an insurance provider will offer multiple plans or types of plans at different price points. Your out-of-pocket costs, flexibility in choosing providers, and other considerations will vary according to the type of plan you choose.

TYPES OF GROUP INSURANCE PLANS

Health Maintenance Organization (HMO)	Preferred Provider Organization (PPO)	Point of Service (POS)	High Deductible Health Plan (HDHP)
<p>Limits choice of providers to local network</p> <p>Lower premium & co-pay</p> <p>Usually requires a Primary Care Physician (PCP) to make referrals for specialists</p>	<p>Medium flexibility: reduced rates if you choose a provider in the network</p> <p>Usually does NOT require a PCP to refer specialists</p>	<p>A product sometimes offered in an HMO plan</p> <p>Gives more flexibility to see non-network providers</p> <p>Usually higher deductibles & coinsurances</p>	<p>Combines a Health Savings Account (HSA) or a Health Reimbursement Arrangement (HRA), traditional medical coverage, and a tax-advantaged way to save for future medical expenses</p>

SOURCES:

[Healthcare and Health Insurance: Plan Types](#) from OPM.gov

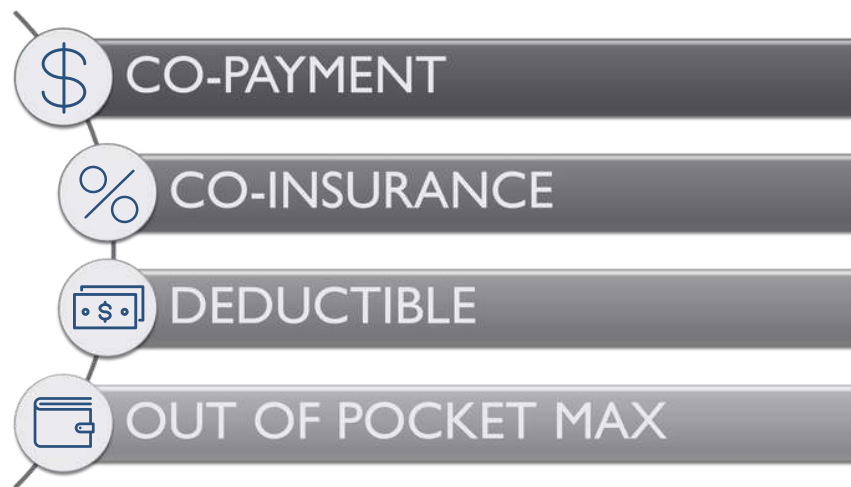
[Health Insurance Plan Types and Definitions](#) from NCSL.org

[Fast Facts: High Deductible Health Plan](#) from OPM.gov



BENEFITS & COVERAGE

Take time to carefully review the information given in the **Summary of Benefits and Coverage** provided by the insurance carrier. By comparing the costs in these areas across various plans that are offered, you can determine the best choice for your situation.



- Sometimes a deductible is more cost effective than a co-pay based plan, depending on how much you expect to spend on medical care.
 - What is the deductible & is the deductible capped per person and per family?
 - Keep in mind a lower monthly premium may mean a higher deductible.
 - Understand which services and medications are covered before the deductible is met.
 - Once the deductible is met, your plan will often cover 100% of many expenses.
- Consider the out-of-pocket maximum.
- Will you stay in network or will you have out-of-network expenses?
 - Take the time to find out whether your current healthcare providers are in network for your specific plan so you don't incur unexpected expenses.
- Look back at last year to review services.

While it seems logical that a more expensive plan would probably cover more, this is not necessarily true. Be sure to read carefully, understand your options, and ASK if you have questions!



UNDERSTANDING YOUR PLAN

How do I know what my plan will cover?

- Your Summary of Benefits and Coverage is a good place to start.
 - Produced by the insurance company
 - Required to be provided by the employer to the employees
 - Basic information - co-pays, deductible, out-of-pocket maximum, etc.
 - **Does not state what exact medications/procedures may be covered.**
- Each year the insurance company should provide a Certificate of Coverage with more in depth information.
 - This may be called "Health Plan Coverage" or something similar.
- For certain procedures and medications there is typically a Medical Policy. It could also be called something else such as a "Coverage Policy" or "Pharmacy Policy."

“ Keep in mind that coverage is dependent on your plan alone – you could have the same carrier and same type of plan as your neighbor but coverage can vary!

- Megan

How can I find out if a specific prescription or procedure is covered?

Insurance companies typically have Medical Policies for procedures and medications that need prior authorization. A Medical Policy will describe in which situations insurance will help pay for certain procedures and medicines.

- BEFORE your doctor applies for any prescription, you want to know the Medical Policy of your particular insurance company and plan.
- Pay attention to which diagnoses are covered – and any that are not ("exclusions").
- Also pay attention to which brands are covered – for which condition – and which brands may simply not be covered at all.



Where do I find the Medical Policy?

- Search when logged in to your own account on the insurance company's website.
- Go to the website for your insurance company; use the search bar & type in "medical policy xyz."

If you cannot find it using the above tools, try the insurance company's webpage for health care providers. Sometimes you can search for a Medical Policy there. You could also call member services and ask for the Medical Policy to be provided to you or ask your employer's Human Resources staff to help you get the policy.

Sometimes, you can search online, and ask, and still have difficulty obtaining this! Once you find the document, you **know the rules** and can **use them to your advantage!**

“ It's like finding Waldo sometimes -- trying to locate the information you need among all the documentation from the insurance company. - Megan

Common terminology with prescription approvals

"Prior authorization" - requires the doctor ordering a procedure or prescribing a drug to provide evidence for medical necessity under the insurance company's guidelines. The insurance company approves the procedure or prescription before it can be released to the member

"Step therapy" - requires the member to try a "lower tier"/lower cost prescription before the higher cost/brand is approved

"Dispensing limitation" - insurance company may limit certain drugs to a number of doses in a month



DENIALS AND APPEALS

It's not uncommon to be denied coverage for a medication or other medical claim. If this happens to you, make sure to follow the appeal protocol carefully.

- The **doctor initiates the coverage request** with the insurance company.
 - Phone call or fax
 - ASK your doctor how they will be contacting the insurance company - FAX often requires follow up and the doctor's office may not respond quickly enough - this prompts a denial.
- The doctor is typically responsible for the **first round of appeals**.
 - Submits more medical evidence
 - If any medical information was missing, the doctor will submit it at this point.
- **If the doctor's appeal is denied**, the member should get a **notification in the mail with instructions** on how to file a second-level appeal.
 - It's important that you DO NOT miss the deadline and keep copies of the information.
 - Example appeal letters are available on the Hypersomnia Foundation's page, [Insurance Denials and Appeals](#).
- You can request a "Summary of Plan Document" from your employer that may detail the appeal process.
- You could ask your employer if their Insurance Broker of the medical insurance will help.
- Final appeal after internal appeal is typically external and will be binding.

“ I have gone through more prior authorization denial appeal procedures than I care to count. Hopefully by having the information they need up front, people can avoid this situation. - Megan

*** See the Resources section at the end of the toolkit for organizations and programs that may be able to help with medication access and/or appeals.**



STEPS TO SUCCESS

While your schedule may be full and energy may be limited, Megan emphasized that taking ownership over your health insurance will help you avoid more challenges down the road.

- Always open EVERY piece of mail from your insurance company or the pharmacy benefit manager.
- Be engaged & ASK questions.
- If you have insurance at work go to any open enrollment or educational events.
- NEVER assume benefits are the same each year – always check to be sure your current prescriptions continue to be covered in the same way even if you're told that "there are no changes."
- If offered a case manager – accept! Take their calls and if they don't work well for you, ask for a new one.
- If you are told you need to participate in a program, ask if it is mandatory. If it is, ask what happens if you refuse (typically you can be denied access to the plan and lose your coverage, or you may be charged a lot more).
- **Set yourself up for success before you or your doctor start any processes**
 - Know your coverage BEFORE you apply for certain services – share the medical policy for your own plan with your doctors before they apply for any prior authorizations.
 - If your policy does not meet your needs, you may want to research other policies and benefits.
- **Document any communication with the insurance company/doctor's office – name, date, what they said, next steps, how to get back in touch.**
- **Keep copies of your appeal documents & follow the deadlines and appeal instructions.**



RESOURCES

Here are some of our favorite resources. We look forward to hearing what our fellow #NarcolepsyNerds find most useful for navigating health insurance!

NARCOLEPSY & HYPERSOMNIA RESOURCES

- **Hypersomnia Foundation - Disability & Health Insurance**
www.hypersomniafoundation.org/insurance-and-disability/
 - Resources for understanding health insurance, prescription drug insurance, disability, and other benefit programs
- **NeedyMeds.org** www.needymeds.org
 - Education and educational webinars
 - Ways to save on medications
 - Locate patient assistance programs
- **Jazz Cares** www.jazzcares.com
 - Patient assistance program for Xyrem and Xywav
 - 1-833-533-JAZZ
- **WAKIX for You** www.wakix.com/wakix-for-you
 - Patient assistance program for WAKIX
 - 1-855-WAKIX4U

PATIENT ORGANIZATIONS

- Major US Organizations:
 - [Hypersomnia Foundation](#)
 - [Narcolepsy Network](#)
 - [Project Sleep](#)
 - [Wake Up Narcolepsy](#)
- International Organizations:
 - Listed on Project Sleep's [World Narcolepsy Day webpage](#)



ADVOCACY & HELP WITH APPEALS

- **Patient Advocate Foundation**
www.patientadvocate.org/
- **Health Law Advocates - Guide to an Appeal**
www.healthlawadvocates.org/get-legal-help/resources/hla-guide-to-appeals
- In each state:
 - Your state representative/senator
 - Attorney General's office
 - Division of Insurance

UNDERSTANDING HEALTH INSURANCE

- **Glossary of Health Coverage and Medical Terms**
www.cms.gov/ccio/resources/files/downloads/dwnlds/uniform-glossary-final.pdf
- **Healthcare and Health Insurance: Plan Types**
www.opm.gov/healthcare-insurance/healthcare/plan-information/plan-types
- **Fast Facts: High Deductible Health Plan**
www.opm.gov/healthcare-insurance/fastfacts/high-deductible-health-plans.pdf
- **Health Insurance Plan Types and Definitions**
www.ncsl.org/research/health/health-insurance-plan-types-and-definitions.aspx



GLOSSARY

appeal - A request for your health insurer or plan to review a decision or a grievance again.

co-insurance - Your share of the costs of a covered health care service, calculated as a percent (for example, 20%) of the allowed amount for the service. You pay co-insurance plus any deductibles you owe. For example, if the health insurance plan's allowed amount for an office visit is \$100 and you've met your deductible, your co-insurance payment of 20% would be \$20. The plan pays the rest of the allowed amount.

co-payment or co-pay - A fixed amount (for example, \$15) you pay for a covered health care service, usually when you receive the service. The amount can vary by the type of covered health care service.

deductible - The amount you owe for health care services your health insurance plan covers before your plan begins to pay. For example, if your deductible is \$1000, your plan won't pay anything until you've met your \$1000 deductible for covered health care services subject to the deductible. Many plans do not apply the deductible to primary care, mental health care, preventive care, and other routine services. This means you will only be responsible for the copay or coinsurance your plan specifies for these services.

dispensing limitation - Your insurance company may limit certain drugs to a number of doses in a month.

network - The facilities, providers, and suppliers your health insurer or plan has contracted with to provide health care services.

out-of-pocket maximum (or out-of-pocket limit) - The most you pay during a policy period (usually a year) before your health insurance or plan begins to pay 100% of the allowed amount. This limit never includes your premium, balance-billed charges or health care your health insurance plan doesn't cover. Some plans don't count all of your copayments, deductibles, coinsurance payments, out-of-network payments or other expenses toward this limit.

premium - The amount that must be paid for your health insurance plan. You and/or your employer usually pay it monthly, quarterly, or yearly.

prior authorization - Requires the doctor ordering a procedure or prescribing a drug to provide evidence for medical necessity under the insurance company's guidelines and the insurance company's approval before it can be released to the member.

step therapy - Requires the member to try a "lower tier"/lower cost prescription before the higher cost/brand is approved.

Find more terms & definitions on CMS.gov's website:

www.cms.gov/cciiio/resources/files/downloads/dwnlds/uniform-glossary-final.pdf



THANK YOU!

We are so grateful that you took the time to check out this toolkit!

Project Sleep is a 501(c)(3) nonprofit organization dedicated to raising awareness about sleep health and sleep disorders.

More resources at: www.project-sleep.com

