



Learn. Grow. Shine.

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# “Denied Due to Lack of Medical Necessity”: Preventing & Responding to Insurance Denials for PANS/PANDAS Treatments

*The information provided herein does not, and is not intended to, constitute legal or medical advice.  
All information and content is for general informational purposes only.*

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- Private Practice Therapist
- Adjunct Graduate Psychology professor at Pepperdine University
- A PANS parent



*Not an attorney nor a doctor: Today's presentation is not legal or medical advice*

# What The Presentation Will Discuss

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- Defining 'Medical Necessity'
- UR-Related Laws
- Insurance UR/UM Systems
- Advocacy Strategies

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# The Way I See It

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- This is deeply personal
- Care access issues in a flawed system
- Utilization Review = Patient Advocacy
- The best interest of patients and families
- Making it stick... a little humor

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# Learning The System

# Be Mindful of Different Goals

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Your goal: Treat and heal your patient

Insurance goal: Monitor appropriateness  
of care and reduce costs

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# Your Notes: Setting The Tone For The Case

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# The Term 'Medical Necessity'

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# Ever Made This Face When Talking With An Insurance Reviewer?

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You're not the only one.  
Let's talk through it.

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# The Term Itself

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From *Treatment Planning for Person Centered Care* by Adams and Grieder (2014):

“Simply stated, the demonstration of Medical Necessity requires that there is a legitimate clinical need and that services provided are an appropriate response.”

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# Underlying Clinical Records

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**WHO**

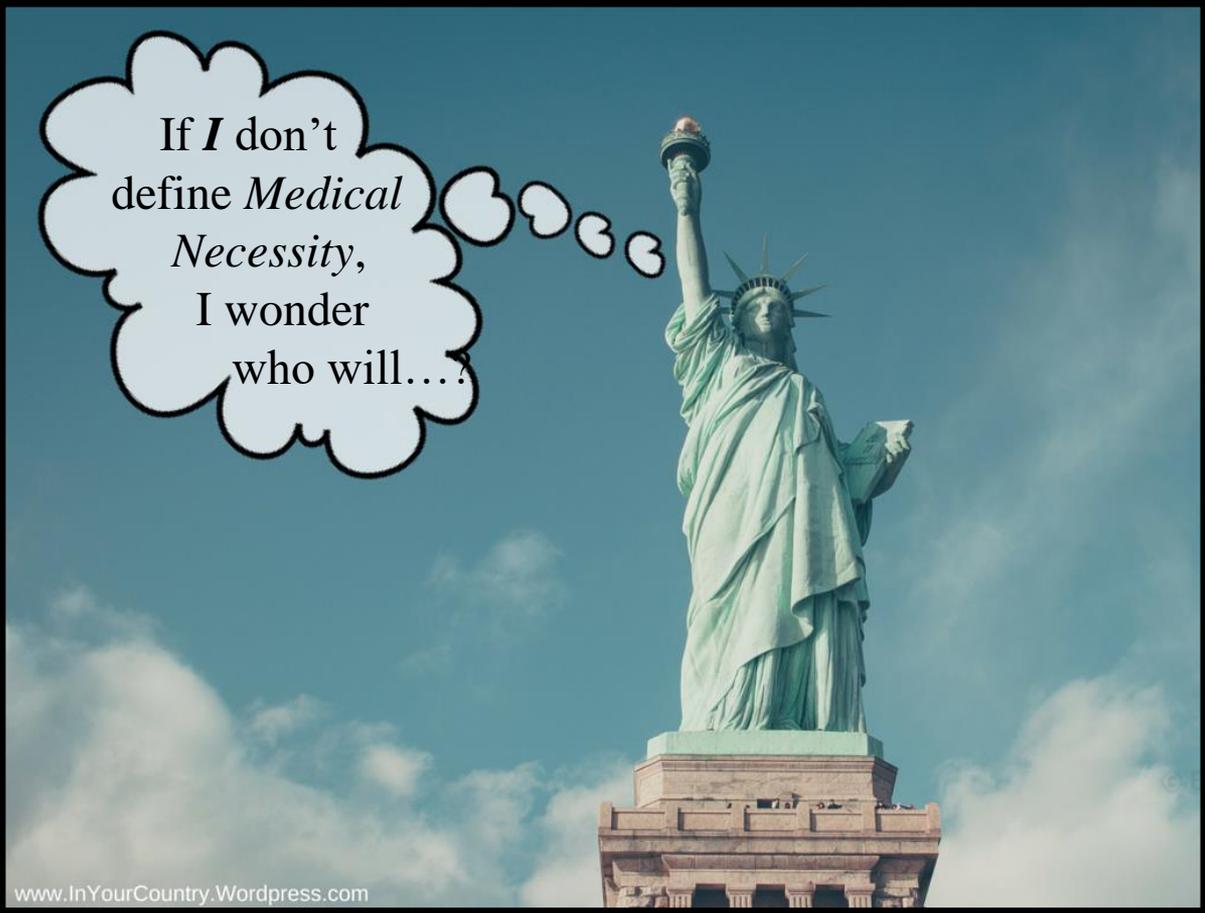
**WHAT**

**WHERE**

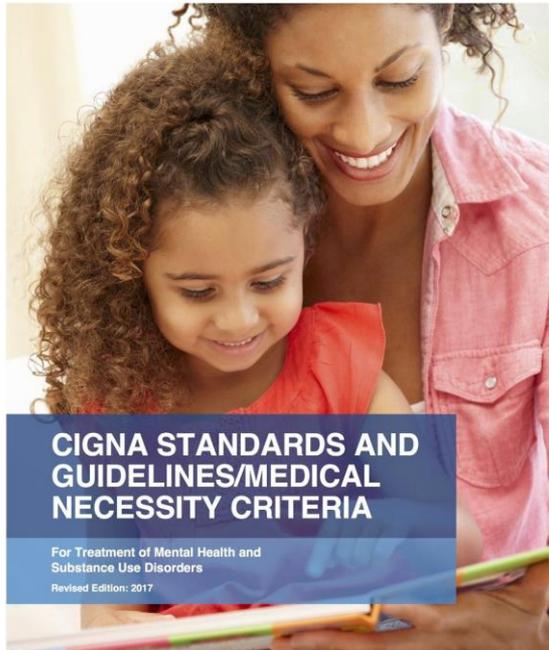
**WHY**

**WHEN**

1

A photograph of the Statue of Liberty against a blue sky with light clouds. A white thought bubble with a black outline is positioned to the left of the statue's head. The text inside the bubble is in a serif font. The statue is shown from the waist up, holding a torch in her right hand and a tablet in her left. The base of the statue is visible at the bottom.

If *I* don't  
define *Medical*  
*Necessity*,  
I wonder  
who will...?



## **CIGNA STANDARDS AND GUIDELINES/MEDICAL NECESSITY CRITERIA**

For Treatment of Mental Health and  
Substance Use Disorders

Revised Edition: 2017

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# Breaking Down Denials

# Insurance Company Denial Letter for Ruxience

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Excerpt from an actual letter:

“Your request for a drug (Ruxience 70 units) for the inflammation in your brain (autoimmune encephalitis) cannot be approved for payment. The reason is that Ruxience is not medically necessary for you. **There are no Food and Drug Administration (FDA) approved or Off Label Uses for Ruxience for your condition. We cannot approve a drug for a use that is not approved by the FDA.**

This decision is based upon the [Insurance Company] Policy Rituximab-pvvr (Ruxience). Your appeal was also reviewed by an expert (Pediatric Rheumatologist) who agrees with this denial, stating that **Ruxience is considered not medically necessary for the treatment of your child’s condition (pediatric autoimmune neuropsychiatric disorders associated with Streptococcal infections).**

Member’s appeal was reviewed by an independent Pediatric Rheumatologist who agrees with this denial.”

# California Welfare And Institutions Code §14059.5

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California Welfare and Institutions Code §14059.5 states, “[A] service is ‘medically necessary’ or a ‘medical necessity’ when it is **reasonable and necessary to protect life, to prevent significant illness or significant disability, or to alleviate severe pain.**”

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# California Health & Safety Code §1374.33, Et Seq.

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Per California Health & Safety Code §1374.33, et seq., codified in 2015, relating to Independent Medical Review applications:

*(b) Following its review, the reviewer or reviewers shall determine whether the disputed health care service was medically necessary based on the specific medical needs of the enrollee and any of the following:*

- (1) **Peer-reviewed scientific and medical evidence** regarding the effectiveness of the disputed service.*
- (2) **Nationally recognized professional standards.***
- (3) **Expert opinion.***
- (4) Generally accepted **standards of medical practice.***
- (5) Treatments that are likely to provide a benefit to a patient for conditions for which other treatments are not clinically efficacious.*

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# What These Laws **DON'T** Say...

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- There is no requirement in the state of CA that a service or treatment be approved by the FDA in order to be considered 'medically necessary'

Moreover...

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# Pulling From Case Law

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On February 11, 2022, the U.S. Court of Appeals for the 11th Circuit reversed a lower-court decision and found that Medicare must provide coverage for a beneficiary's off-label use of a medication in *Dobson v. Secretary of Health & Human Services*, No. 20-11996, 2022 WL 424813 (11th Cir. Feb. 11, 2022)

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# How To Use This Information

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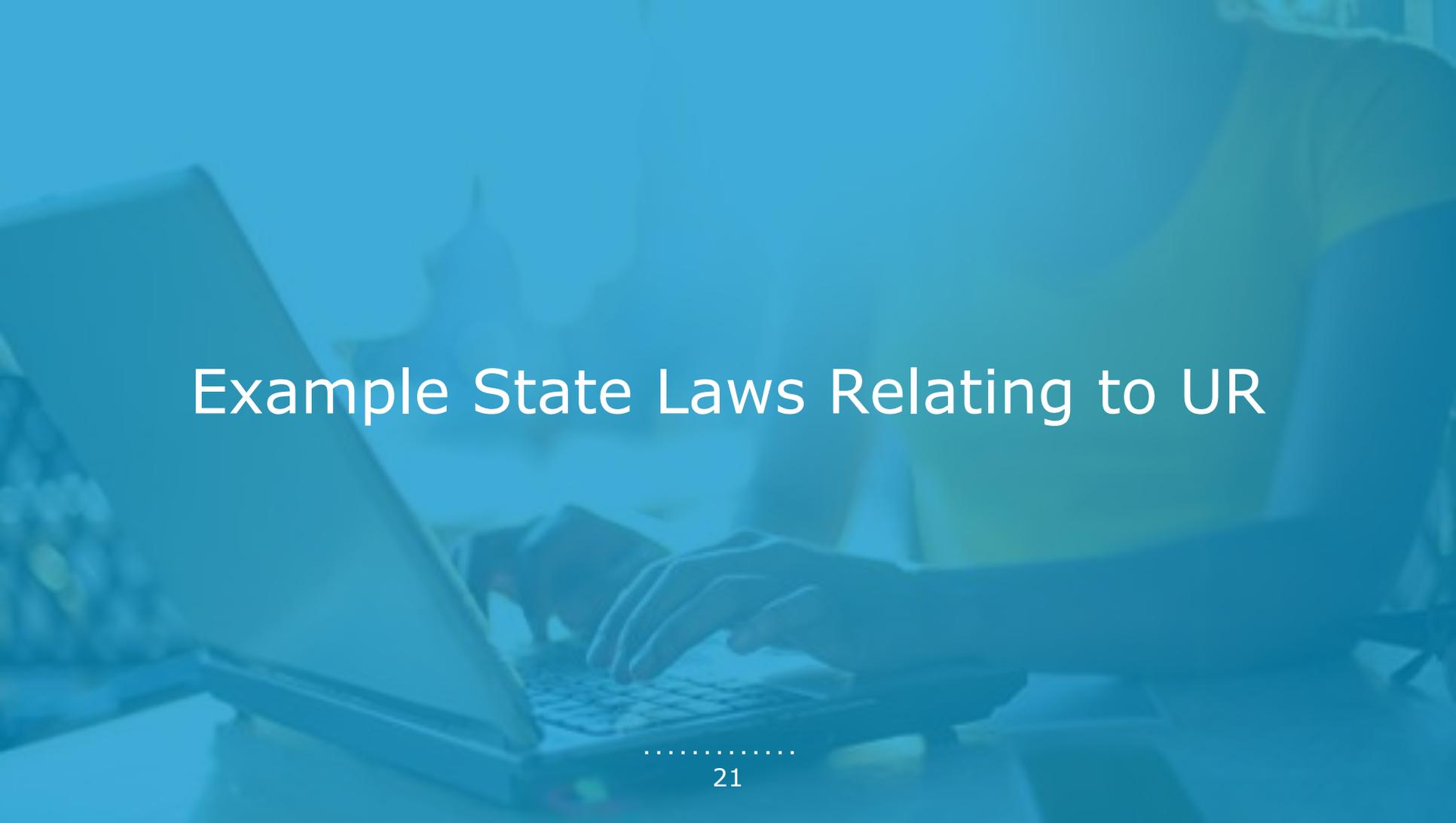
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Know your state's medical necessity laws. Do some googling and ask your professional association.

Have these laws handy when doing peer-to-peer calls and when writing appeals... quote them directly.

Compare/contrast with the insurance company's own published medical necessity criteria.

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# Example State Laws Relating to UR

# CA Corporate Practice of Medicine Doctrine

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“The rationale underlying CPOM is that physicians, as **the only persons licensed to practice medicine, should control clinical decisions**; the concern is that, if business entities owned by non-physicians are permitted to control the rendering of care, they will subordinate clinical care to commercial considerations and profits. The objective, therefore, is to prevent non-physicians and non-physician-owned business entities from influencing treatment decisions.”

Note: Roughly 30 US States have some version of a CPOM... find out if yours does

# Florida Social Welfare Code §409.9131 (Medicaid)

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“‘Medical necessity’ or ‘medically necessary’ means any goods or services necessary to palliate the effects of a terminal condition or **to prevent, diagnose, correct, cure, alleviate, or preclude deterioration of a condition that threatens life, causes pain or suffering, or results in illness or infirmity**, which goods or services are provided in accordance with generally accepted standards of medical practice.”

# New York Social Services Law - SOS § 365-a. (Public Services)

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“Standard coverage’ shall mean payment of part or all of the cost of medically necessary medical, dental and remedial care, services and supplies... which are **necessary to prevent, diagnose, correct or cure conditions in the person that cause acute suffering, endanger life, result in illness or infirmity, interfere with such person's capacity for normal activity, or threaten some significant handicap** and which are furnished an eligible person in accordance with this title and the regulations of the department.”

# Texas Administrative Code

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*The Texas Administrative Code has separate definitions of medical necessity for different age groups and services. For example, for Texas Medicaid members under the age of 20:*

“...other health care services [...] that are **necessary to correct or ameliorate a defect or physical or mental illness or condition...**”

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# Why This Matters

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There are discrepancies between what the insurance companies are considering ‘medically-necessary treatment’, and how various states view it.

**In other words: The insurance company’s definition of Medical Necessity is NOT the law of the land**

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# Insurance Systems

# Insurance Company 'Scripts'



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# That Last Page in the Denial Letter

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SAVE IT!

# Odds of Denial Reversal Internally

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95%+ of denials are upheld in subsequent review

REMEMBER:

This does not mean the service is not 'Medically Necessary' per your state laws

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# Insurance Review Considerations

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- In order for an appeal to go to a higher regulatory body, it must go through **all levels** of internal appeal
- Reviewing nurses and doctors are not always specialized in this condition. Ask directly during review calls and document the response in a case note

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# Always Request Expedited Processing

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## **Standard turnaround is 30 days**

In order to justify an expedited review, there must be a clear illustration of imminent risk without the requested treatment

**MAKE THIS CLEAR IN YOUR NOTES**

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# Watchdog Organizations

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Every state has its own regulatory board(s)



# Watchdog Agencies = Final Say

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California Department of Managed  
Healthcare has a denial overturn rate of  
60%+

These external appeals are not a waste of  
time (yours nor the family's)

# Structure of an External Appeal, Slide 1

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1. Support letters from colleagues (regardless of whether they've actually treated the patient)
2. Overview of history of the patient's symptoms, treatments, and functional impairments
3. Published research (literally quoting the studies in a letter to the payor or watchdog agency)
4. State or federal laws relating to medical necessity, with explanation about how the requested service(s) satisfies medical necessity
5. Payor's own published medical necessity standards

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If the payor says, "We only pay for a certain service when the xyz factors are met," literally quote their criteria in the letter and break down how the service meets medical necessity in relation to each factor

# Structure of an External Appeal, Slide 2

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6. Reiteration of the patient's functional impairment and probable consequences associated with the payor blocking payment for the requested service
  - Specifically name it: Anorexia, self-harm, harm to others, permanent brain damage, failure to meet age-appropriate social norms, etc.)
  - Overt 'the blood is on your hands'
7. Consequences if they do not authorize the service

Involvement of media outlets (with family's consent), company-wide health insurance plan shift (coordinated with patient's HR), legal proceedings, etc.
8. Attorney letterhead, if possible
  - Can your practice/organization retain a healthcare attorney?
  - Does the family have an attorney friend who can put this letter on their letterhead?

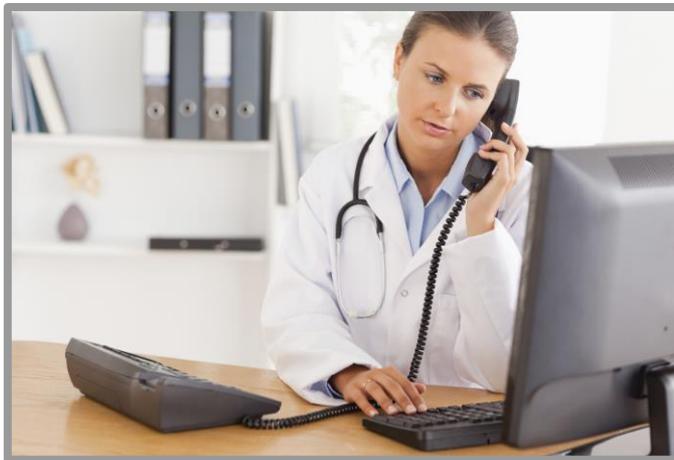
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# UR Call & Appeal Strategies

# Support From Other Providers

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Ask your colleagues for support letters. There's strength in numbers.

Does your organization have boilerplate letters you can supply to colleagues/programs for support?

# Planning Case Shaping/P2P Calls

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1. Insurance reviewers are required to read all documents you send over prior to calls. Ask directly if they've done this (and document it if they say they haven't... chances are that they haven't read the documents...)
2. Insurance reviewers may try to limit the information you provide (the 'script')... they can't do this
3. Ask them to read their notes back to you on calls

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# Minding The Clock & Handling Delays

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- If an insurance company exceeds defined timelines, it can sometimes result in an automatic denial reversal by regulatory bodies
- Document WHAT you did and WHEN you did it, in case you need to illustrate bad faith

# Be Prepared

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- Stay abreast of legal updates relating to PANS patients and specific treatments
- Keep copies of relevant laws within reach during calls

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# Focus On Patient Safety & Quality Of Life

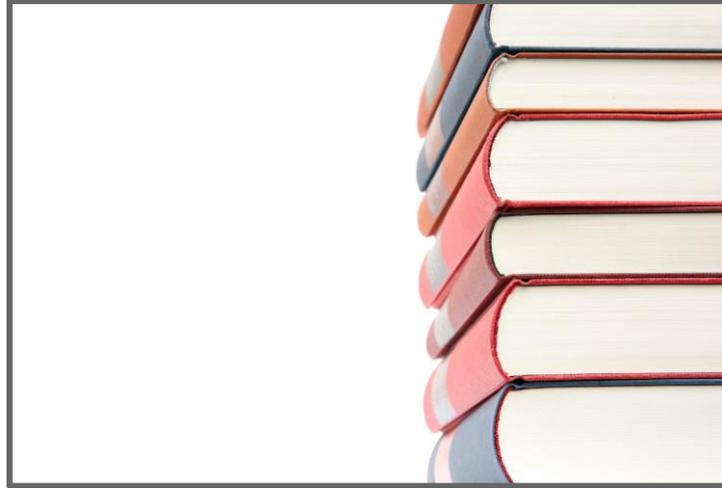
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# Reference Clinical Studies & Level of Care Guidelines

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You're an expert in this patient and this treatment.

The reviewer is not. Educate them.

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# 'The Squeaky Wheel Gets The Oil'

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Don't be afraid to go up the chain of command or ask for a different reviewer. Document everything in a case note.

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# Recap

# How To Use This Information To Your Advantage

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- Keep updated copies of your state's Medical Necessity laws & the insurance company's care criteria. Quote them!
- Follow through with denials: Appeal, appeal, appeal
- In all notes, illustrate how the patient's functional impairments indicate medical necessity

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# The Way I See It

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Go forth and  
advocate.

# Contact Information



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