

We are parents, not medical or legal professionals. This reflects our personal experience. For complex or ongoing cases, consider working with a patient advocate or healthcare attorney.

Fighting for the Medicine Your Child Needs

A Step-by-Step Guide to Insurance Escalation for sJIA Biologics

You are more powerful than you know. A denial is not a final answer. It is the opening of a negotiation. Insurance companies count on families giving up. Don't give up.

Our Story (and Why We Wrote This)

When Corbin's rheumatologist prescribed a biologic, a medication that we were told could put his disease into remission and protect his organs, our insurance denied it. Not once. Three times.

We were devastated, furious, and completely lost. We didn't know we had rights. We didn't know there was a process. We didn't know that the denial letter was the beginning of a fight we could actually win.

We want every sJIA family to know what we eventually learned, because the medicine your child needs is worth fighting for.

Understanding Why Biologics Get Denied

Insurance companies frequently deny biologic medications for sJIA on first submission. Common denial reasons include:

- **"Step therapy" or "fail first" requirements** — insurance wants to see that less expensive medications were tried first
- **"Not medically necessary"** — often used as a catch-all denial
- **"Experimental or investigational"** — sometimes used for newer biologics
- **Prior authorization not completed correctly**
- **Missing clinical documentation**

Step 1: Understand the Denial Letter Completely

Before you do anything else, read the denial letter word for word. Make note of:

- The specific reason for denial (the medical/clinical language used)
- The insurance plan's internal appeal deadline (usually 30-180 days, missing this forfeits your rights)
- The reference to the specific plan document or policy that supports the denial
- The name of the medical reviewer who made the decision
- The instructions for filing an internal appeal

Call your insurance company and ask them to explain the denial in plain language. Ask specifically:

"What clinical criteria must be met for this medication to be approved?"

"What documentation is missing from the original prior authorization?"

"Is there a specific step therapy protocol I need to complete?"

Step 2: Arm Your Doctor

Your rheumatologist is your most important ally. They need to be willing to fight alongside you. Schedule a call or appointment specifically to discuss the denial and your plan to appeal.

What to Ask Your Doctor to Document

A strong Letter of Medical Necessity (LMN) is the foundation of your appeal. Ask your rheumatologist to include:

- Specific diagnosis with ICD-10 code (M08.20 for sJIA, or the relevant code for your child)
- Disease severity documentation: lab values (ferritin, CRP, ESR, CBC), joint counts, fever documentation, physician notes
- Documentation of all prior treatments tried and why they failed or are inappropriate (the "step therapy" evidence)
- Medical literature supporting the prescribed biologic as standard of care for sJIA
- Statement that denial puts the child at risk of serious complications, including MAS, organ damage, and permanent joint damage
- Urgency if applicable: "Delayed treatment poses immediate risk" is powerful language

Tip: Ask your rheumatologist to cite the ACR guidelines for sJIA treatment. Insurance companies are required to consider clinical guidelines when making coverage decisions.

Step 3: File the Internal Appeal

Every insurance plan is required by law to offer at least one internal appeal. This is your first formal step.

What to Include in Your Internal Appeal Packet

- A cover letter from you as the parent
- Your doctor's Letter of Medical Necessity
- Copies of relevant medical records (office visit notes, lab results, imaging)
- The denial letter itself
- Published medical guidelines supporting the treatment (ACR, CARRA)
- Any peer-reviewed research supporting the medication for sJIA
- Manufacturer prescribing information showing FDA approval for this indication

How to Write Your Parent Cover Letter

This letter is more powerful than you might think. Insurance reviewers are human beings. Your story matters.

1. **Who your child is.** Name (first name only for privacy), age, diagnosis, when diagnosed.
2. **What their disease looks like.** Describe a flare in real terms. What did it look like? What did it cost your family? What school did they miss?
3. **Why this specific medication.** What has your doctor told you about why this is the right medication? What alternatives have been tried?
4. **What the denial means.** In plain terms, explain what happens if your child does not get this medication.
5. **What you are asking for.** A clear request for approval, and a statement that you will continue to escalate through every available channel if denied.

Step 4: Request a Peer-to-Peer Review

While your internal appeal is pending, or if it is denied, ask your rheumatologist to request a peer-to-peer (P2P) review with the insurance company's medical reviewer.

In a P2P review, your child's doctor speaks directly with the insurance company's physician. A pediatric rheumatologist speaking specialist-to-specialist is very different from a form letter.

- Ask your rheumatologist's office if they are willing to do this, most will if asked
- This typically happens by phone, and the rheumatologist can make the case for medical necessity directly
- P2P reviews result in approval a significant percentage of the time

Step 5: File an External Independent Review

If your insurance company upholds the denial after an internal appeal, you have the right to request an External Independent Review (EIR), also called an Independent Medical Review (IMR).

- An EIR is conducted by an independent organization with no relationship to your insurance company
- The reviewer must be qualified to evaluate your child's condition
- Most states require the insurance company to comply with the EIR decision if it is in your favor
- **Filing an EIR is free**

How to request: The appeal denial letter should include instructions. If not, contact your state insurance commissioner's office, they regulate insurance companies in your state and can help.

Step 6: Escalate Through Additional Channels

These additional channels can be used simultaneously or if the EIR is unsuccessful:

State Insurance Commissioner

File a complaint with your state insurance commissioner. This is free and creates a formal record. Insurance companies take these complaints seriously.

Your Employer's HR / Benefits Team

If your insurance is employer-provided, your HR department has leverage you don't. Contact them, explain the situation, and ask them to escalate with the insurance carrier on your behalf.

The Biologic Manufacturer's Patient Support Program

Most biologic manufacturers have patient assistance and advocacy teams. Call the manufacturer's patient support line and ask for help with prior authorization support. Ask about bridge supply, many manufacturers will provide free medication while the appeal is pending.

Patient Advocate Foundation

Free case management services from professionals who navigate insurance issues for a living. They can help review denial letters, advise on appeals, and in some cases directly advocate on your behalf.

Medicaid / CHIP

If the cost or insurance battle is becoming untenable, explore whether your child might qualify for supplemental coverage through Medicaid or CHIP. These programs sometimes cover medications that private insurance won't.

While You Fight: Bridge Programs

The wait during an insurance appeal can be agonizing when your child needs medication now. Ask about these options:

- Manufacturer patient assistance programs, many provide free medication while appeal is pending
- 340B programs at qualifying hospitals or clinics
- State pharmaceutical assistance programs
- Nonprofit programs like the HealthWell Foundation, Patient Access Network Foundation, or the Assistance Fund

Your Documentation System

From day one, keep a binder or digital folder. Insurance fights can take months, and you will need a paper trail.

- Every phone call: date, time, representative name, and what was said
- Every denial letter: date received and deadline for appeal
- Every letter or document submitted: keep copies of everything
- Every email sent or received
- Every peer-to-peer review request and outcome
- Every prescription, infusion, and associated cost during the fight

Always ask for everything in writing. When you call insurance, say "Can you please send me a confirmation of that in writing?" A verbal promise is not a guarantee.

A Note on Step Therapy / "Fail First" Laws

Many states have passed Step Therapy Reform laws that protect patients from being forced to "fail first" on inferior medications. These laws typically allow doctors to request an exception to step therapy requirements when:

- The required medication is contraindicated
- Your child has already tried the required medications
- The treating physician believes the required medication would cause harm

Quick Reference: Who to Call

Who	When to Call	How to Find
Your Rheumatologist's Office	First denial; need LMN; peer-to-peer review	Your existing contact
Insurance Member Services	Understand denial; appeal instructions	Back of your insurance card
Biologic Manufacturer	Bridge supply; PA support; appeal assistance	Drug website patient support page
Patient Advocate Foundation	Complex cases; case management	patientadvocate.org
State Insurance Commissioner	File complaint after internal appeal	naic.org
Employer HR / Benefits	Employer-sponsored plans; escalation	Your company HR department

We spent four months fighting before Corbin got his biologic approved. It was exhausting and frightening, and we wish we had found this information on month one instead of month three. You can win this fight. Document everything, be persistent, and never let a denial be the last word.