NAVIGATING INSURANCE WITH CONFIDENCE

A Guide for the Cleft Community

Created by:
Smile Train's Cleft Community Advisory Council

The purpose of this guide is to empower cleft-affected individuals and families to navigate medical and dental insurance with clarity and confidence...

Because your care is not cosmetic.
Because your story is powerful.
Because you are not alone.

CCAC
CLEFT COMMUNITY ADVISORY COUNCIL

SmileTrain

DISCLAIMER

This packet is intended to provide general guidance and educational resources for individuals and families navigating insurance challenges related to cleft care. The information provided does not constitute legal, medical, or financial advice and should not be used as a substitute for consultation with healthcare providers, insurance representatives, or legal professionals.

While Smile Train is committed to supporting the cleft community, Smile Train cannot guarantee insurance coverage, approval, or reimbursement for any medical or dental service or treatment. Every insurance plan is different, and coverage decisions are ultimately made by individual insurance companies based on their policies and criteria.

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YOU ARE YOUR BEST ADVOCATE

Navigating insurance can feel exhausting, frustrating, and sometimes isolating — but you are not alone. You are part of a strong, resilient community of other cleft-affected individuals and families who have fought — and will continue to fight — for the care they need and deserve.

This guide was created with love, experience, and hard-earned wisdom by others who have walked this path. Our hope is that it empowers you to stand tall in conversations with insurance companies, gives you tools to stay organized, and most importantly, reminds you **that your story and your health matter.**

If you've faced setbacks, remember: A denial is not a final answer. It's just a detour, and you have what it takes to find another route. Every call you make, every letter you write, every record you keep brings you closer to the care you need. At times it will feel as if you are building a plane as you fly it. In those moments, remember to take a break to regroup. To most insurers, this is just a business. They do not see the person or the family on the other side of the patient ID number.

Still, it can be difficult to not take rejections personally. That's why this guide exists. To help you reclaim your power when you feel powerless. To remind you that, yes, this can be an extraordinarily difficult process, but you are not alone. You are doing the best you can with the knowledge you have for the people you love (including yourself!).

Whether you're reading as a parent, a patient, a caregiver, or a supporter, thank you for showing up. Your advocacy is not only making a difference for yourself or your child, it is paving the way for the next person or family who needs it.

We're proud to stand with you.

With love, care, and solidarity,

Smile Train's Cleft Community Advisory Council
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INTRODUCTION

For cleft-affected families and individuals, accessing necessary care is more than just scheduling doctor's appointments; it is a long journey through a complex insurance system that wasn't built with cleft care in mind. From early surgeries to long-term dental work, speech therapy, and follow-up procedures, cleft care can span decades and involve multiple specialists. On top of that, insurance companies frequently deny coverage for cleft-related procedures, misclassifying them as cosmetic or unnecessary. All of it can leave families feeling confused, overwhelmed, and financially burdened. So often, it can feel like falling down a rabbit hole.

This packet is a ladder out.

What You'll Find Inside
This guide offers tools, strategies, and information to help you:
- Understand how insurance works (especially for cleft care)
- Know what is covered and why
- Navigate medical vs. dental benefits
- Advocate for yourself or your child
- Organize communication, documents, and calls
- Appeal denials with confidence
- Access templates and real-life examples
- Connect with support organizations

Who This Packet Is For
- Parents or caregivers of a child with cleft lip and/or palate
- Adults with a cleft navigating follow-up care, surgery, or dental work
- Social workers, case managers, or providers supporting cleft-affected families

In other words, **whether you're brand-new to insurance or deep into a care journey, this packet is for you.**

What Makes Cleft Care Unique
Unlike most conditions, cleft care is multi-disciplinary; it can involve surgeons, orthodontists, ENTs, speech therapists, and more. Insurance plans aren't always set up to handle this type of care, which means denials often happen not because the care isn't needed but because the system doesn't know how to classify it.

How To Use This Packet
You don't need to read everything at once. Jump to the section you need based on where you are in the process:
- **Just getting started? Begin with Section 2**
- **Received a denial? Go straight to Sections 5 and 6**
- **Want to stay organized? Check out the templates in Section 8**

Above all, this guide is a reminder:
You are not alone, and you are your own best advocate.

2. INSURANCE BASICS: WHY IT MATTERS

Insurance terminology can feel like a foreign language. However, understanding your benefits and coverage is crucial to knowing your rights, policies, benefits, limitations, and exclusions — in other words, to getting the care you and/or your child needs. This section breaks down some often confusing terms and concepts so you can navigate claim and pre-authorization approvals with confidence, knowledge, and firmness.

Let's get you fluent in insurance-speak!

Types of Insurance Plans
There are a few main types of health insurance plans. Knowing what kind you have will shape what steps you'll take to get coverage:

- **Private Insurance:** Usually provided through an employer or purchased individually. You pay monthly premiums and share costs through deductibles and co-pays.
- **Medicaid:** A government-funded program for people with limited income. Medicaid often provides comprehensive coverage for cleft care but can vary significantly by state.
- **CHIP (Children's Health Insurance Program):** Covers children whose families earn too much for Medicaid but can't afford private insurance.
- **Marketplace Plans (ACA):** Health plans purchased via Healthcare.gov. Coverage and costs can vary.
- **Military/VA Insurance (TRICARE):** For military families; coverage rules are unique but may offer strong cleft-related benefits.

TERM	DEFINITION
Premium	The amount you pay each month to keep your insurance active.
Deductible	The amount you pay out-of-pocket before insurance starts covering most claims.
Co-pay	A set fee you pay for specific services (ex. $20 for a doctor's visit).
Co-insurance	A percentage of the cost you pay after meeting your deductible.
Out-of-pocket Maximum	The most you'll pay in a year for covered services; once you hit this, insurance covers 100%.

2. INSURANCE BASICS: WHY IT MATTERS

TERM	DEFINITION
In-network	Providers and facilities that have contracts with your insurance company to offer lower rates.
Out-of-network	Providers not contracted with your insurer — typically more expensive and harder to get approved.
Pre-authorization	Approval from your insurance before you receive a procedure or treatment. Often required for surgeries or specialized care.
Explanation of Benefits (EOB)	A statement from your insurance explaining what they paid, what they denied, and what you may owe..

What's Covered?
Every plan is different, so always check your Summary of Benefits, call your insurance company directly, and read through your Evidence of Coverage, which is a more detailed policy document.

Medical Coverage
(provided through your health insurance):
Cleft-related care often includes:
- Surgeries (lip repair*, palate repair, bone grafts, jaw surgeries, nasal revisions)
- Rhinoplasty, revisions (for the lip and/or palate)
- Hospital stays
- Anesthesia
- Audiology
- Speech therapy
- Hearing tests or ear tubes
- Nutrition support
- Genetic counseling

Dental Coverage
(often separate from medical):
- Orthodontics (braces)
- Prosthodontics (dental devices or implants)
- Routine cleanings and dental maintenance

Note: Some dental procedures are medically necessary due to the cleft diagnosis and should be covered under medical insurance. We'll explain how to advocate for this in Section 3.

**While the term "repair" is commonly used in medical settings to describe surgical procedures, community members may prefer terms like "surgery," "treatment," or "care" to emphasize healing rather than correction. When possible, use language that centers the person, not the procedure (e.g., "surgery to address a cleft" instead of "to repair a cleft").*

2. INSURANCE BASICS: WHY IT MATTERS

Understanding Your Benefits Package
Ask your insurance company or HR department for your Benefits Summary.
Look specifically for:
- Covered Services, a section which will include details for terms such as “pre-existing conditions”, “cleft lip and palate” “oral surgery”, “dental appliances or dental prosthesis”, “dental implants”, “therapy”, and “specialist visits”
- If there is a “dental rider” through your medical policy
- Limits (e.g., only 20 therapy visits/year) and age limitations
- Requirements like needing referrals, pre-approvals, or using in-network providers
- Coordination of Benefits, which will explain whether your policy coordinates with other insurance policies if you have more than one plan (e.g., Medicaid + employer insurance).

Helpful Questions To Ask Your Insurance
When speaking with a representative, document the date, time, and name of the person you speak to. Ask:
- Is cleft-related care covered under my plan?
- Is there a case manager, social worker, or patient advocate assigned to my claim?
- What is required for pre-authorization for [procedure]?
- Are both medical and dental coverage included in my plan?
- Can you send me documentation of what’s covered in writing?
- What’s the process for filing an appeal if something is denied?

Real-life Tip — Community Member
“Many times, like I recently experienced with my own son, insurance companies may mislabel coverage, leading to an unnecessary copay or prepayment for services such as speech therapy. Understanding your coverage and contacting your insurance company’s customer service or case manager can help correct these errors. This can save families money they shouldn’t have had to pay in the first place. It’s important to double-check before paying a copay that may not actually be required.”

Takeaway
Understanding your insurance is your first defense against denials, surprise bills, and confusion. You have the right to understand and challenge what your plan does or doesn’t cover. When it comes to insurance, be your own best advocate. Don’t rely on the answer you get from just one representative; most insurance reps are not fully familiar with the complexities of cleft care. Call back and speak with different representatives, ask your HR department about coverage, and request to speak with a supervisor or complex care manager when needed. The more you ask, clarify, and push for answers, the greater your chances of securing the coverage you’re entitled to.

3. MEDICAL VS. DENTAL: NAVIGATING THE DIVIDE

Why It Matters
One of the most frustrating and confusing parts of navigating cleft care is understanding the invisible wall insurance companies build between medical and dental benefits. For cleft-affected individuals, it makes little sense: cleft treatment is both medical and dental, as both aspects are often essential to improving function, development, and quality of life.

Unfortunately, insurers don't always see it that way.

This section explains where procedures typically "fall" (medical vs. dental), what to do when an insurer misclassifies your claim, and how to fight for proper coverage using cleft-specific advocacy tools.

How Insurers Define the Divide
Here's how most insurance companies separate procedures:

COVERED BY MEDICAL INSURANCE	COVERED BY DENTAL INSURANCE
Surgeries (lip/palate repair, jaw, etc.)	Cleanings and checkups
Speech therapy	Fillings and extractions
Hearing exams, ear tubes	Braces (orthodontics)
Bone grafts (in some cases)	Dental implants or prosthetics
Nasal/alveolar reconstruction	Prosthodontics (specialized dental appliances)
Anesthesia & hospital stays	Retainers or cosmetic dental work

But here's the key: **If a dental procedure is required as part of cleft-related care**, it can often be reclassified and covered under medical benefits if you advocate properly.

3. MEDICAL VS. DENTAL: NAVIGATING THE DIVIDE

The Danger of "Cosmetic" Mislabeling
Insurance companies mislabeling cleft-related surgeries or dental work as cosmetic or elective is one of the biggest hurdles families face. Cleft-related procedures are almost always reconstructive or functional, which qualifies them as **medically necessary.**

Key Tip: If a procedure restores function (speech, eating, breathing), it is not cosmetic, even if it also improves appearance.

How To Reclassify a Dental Procedure as Medical
Sometimes the only way to get coverage is to help the insurance company see how a dental procedure is functionally required due to having a cleft.

Note: Make sure that your medical insurance card is on file with the provider's office in lieu of your dental insurance card.

Steps to take:
1. Get a Letter of Medical Necessity from the provider and ensure that they include the following:
- A clear statement of the cleft diagnosis
- Information linking the procedure to health outcomes (eating, speech, jaw growth, breathing, etc.)
- Provider credentials (e.g., "As a craniofacial surgeon...")

2. Submit Medical Records:
- Include surgical history, diagnostic imaging, and past treatment summaries
- Attach supporting letters from specialists if possible (e.g., speech pathologists, orthodontists, ENTs)

3. Use Specific Medical Codes (CPT/ICD) (See Section 6):
- Ensure that your insurer is using cleft-related procedure codes rather than general dental codes
- Work with providers to confirm appropriate coding

4. Request Pre-authorization from Medical Insurance:
- Even if the procedure is "dental," submit it to the medical side with supporting documentation

What If They Still Say It's Dental?
- File an appeal (see Section 6)
- Ask for a medical director review
- If you have both medical and dental plans, ask how coordination of benefits applies — sometimes medical will cover what dental denies
- Some states have cleft mandates (like NY, TX, and CA) that require coverage — look up your state laws

4. PRE-AUTHORIZATION & DOCUMENTATION TIPS

Why Pre-authorization Is Crucial
Imagine showing up for surgery only to be told it's not covered or getting a $10,000 bill weeks later. This can happen if a procedure wasn't pre-authorized by your insurance company. A pre-authorization is a written request from your medical/dental provider to your insurance company asking for a service, treatment, or procedure to be approved prior to it being performed. It is your insurance company's way of saying, "Yes, we agree this procedure is medically necessary, and we will cover it."

Not every service requires pre-authorization, but many cleft-related procedures do. Getting this step right can prevent surprise denials and bills.

This section walks you through exactly how to handle pre-authorizations, what paperwork you need, and how to work with your care team to make the process smooth.

What Is Pre-authorization?
Pre-authorization is when your provider submits a request to your insurance company before a treatment, procedure, or service is performed to confirm it will be covered.

If approved, you'll get a notice in writing. If denied, you'll have a chance to appeal the decision before the procedure happens.

Important: Pre-authorization is **not a guarantee of payment,** but it's an essential step toward coverage.

Procedures That Often Require Pre-authorization
- Lip or palate repair
- Alveolar bone grafts
- Orthognathic (jaw) surgery
- Nasal revisions
- Speech therapy
- Hearing aids
- Ear tube placements (especially for repeat surgeries)
- Dental appliances (e.g., palatal expanders, implants)
- Orthodontic treatment (braces)
- Palatal obturator

4. PRE-AUTHORIZATION & DOCUMENTATION TIPS

How To Get Pre-authorization

Step 1: Confirm Requirements
- Call your insurance provider or log in to your member portal
- Ask: "Does [procedure] require pre-authorization?"
- Document the date, time, and representative's name

Step 2: Coordinate with Your Provider
- Your doctor or care team usually submits the pre-authorization
- Provide them with your insurance card, any secondary insurance, and referral letters if needed

Step 3: Make Sure They Submit These Key Documents:
- CPT and ICD-10 codes for the procedure
- A Letter of Medical Necessity (more on this below)
- Office and treatment notes and cleft diagnosis documentation
- Photos, X-rays, or CT scans if applicable
- The treatment plan and expected outcomes

Step 4: Get It in Writing
- Once approved, request written confirmation, or ask for the approved pre-authorization from your insurance company (not just your provider)
- Save it in your records

What Is a Letter of Medical Necessity (LMN)?
A Letter of Medical Necessity is a critical document that explains why a treatment or procedure is essential for the patient's health. This document is written by your medical/dental provider and needs to include:
- The provider's full name and credentials
- The patient's full name and diagnosis (include the ICD-10 code for cleft)
- A description of the procedure
- The clinical reason why the procedure is medically necessary
- An explanation of how the procedure is related to the cleft
- What could happen if the procedure isn't performed

Pro Tip: The more specific and personalized the letter is, the stronger your case.

Note: Each doctor involved in the procedure should write a letter, i.e., the plastic surgeon and oral surgeon for any dental surgeries.

Sample Excerpt from a Letter of Medical Necessity
"I am writing on behalf of my patient [Name], who was born with a congenital bilateral cleft lip and palate. [Name] is in need of an alveolar bone graft to support tooth eruption and stabilize the upper jaw. This procedure is medically necessary for long-term oral function and proper development. It is not cosmetic and is part of a coordinated treatment plan by our multidisciplinary craniofacial team."

4. PRE-AUTHORIZATION & DOCUMENTATION TIPS

Tips To Avoid Denials
- Double-check with both the provider and insurance that the pre-authorization has been submitted
- Ask for a confirmation or case number
- Follow up regularly until a decision is made
- Keep copies of everything — submissions, letters, emails, and responses
- Make sure the procedure date is covered in the authorization window (some approvals expire after 30-90 days)

Takeaway
Pre-authorization isn't just a formality. It's your best tool to avoid future denials. Work closely with your provider, follow up consistently, and keep everything organized in writing. If something is denied, don't panic. You still have options (coming up in Section 5).

5. DENIED CLAIMS: WHAT NEXT

The Denial Doesn't Mean It's Over
You did everything right: saw an in-network provider, got pre-authorization, and submitted documents. But then you receive that dreaded **Explanation of Benefits (EOB)**, and the service is denied. It's frustrating. It's confusing. And **it's common.** Insurance denials are upsetting and discouraging **but, most importantly, they are not final!**

This section is your action plan when a claim is denied, whether it's a surgery, dental procedure, therapy session, or device. You'll learn how to interpret the denial, correct any errors, and begin the appeal process with confidence.

Common Reasons for Denial
Understanding why a claim was denied is the key to challenging it.
Common reasons include:

REASON GIVEN	WHAT IT MEANS
"Not medically Necessary"	They believe the procedure is cosmetic or optional
"Out of network"	The provider was not contracted with your insurance plan.
"No pre-authorization"	They didn't receive or approve a pre-authorization before the procedure.
"Exceeds coverage limits"	You've used up the maximum benefits allowed for that service (e.g., speech therapy visits).
"Incorrect coding"	The procedure was billed under a code not recognized as cleft-related or covered.
"Dental procedure not covered under medical plan"	They've misclassified it — see Section 3.

Tip: Don't assume their explanation is correct. Many denials happen due to misunderstandings, lack of documentation, or system errors.

5. DENIED CLAIMS: WHAT NEXT

Step-by-Step: What To Do After a Denial
Step 1: Review Your EOB
- Locate the EOB (Explanation of Benefits) from your insurance company
- Look for the denied item and note:
  - The reason for denial
  - The dollar amount denied
  - Any notes or codes listed

Step 2: Call Your Insurance Company
- Ask to speak to a representative or case manager
- Say: "I received a denial for [procedure] on [date], and I need help understand why it was denied."
- Ask them to explain the denial in detail
- Document:
  - The date of the call
  - The representative's name
  - What they said

Step 3: Contact Your Provider
- Let them know about the denial and ask:
  - Did they submit all required documents?
  - Was the correct CPT/ICD-10 code used?
  - Can they provide a more detailed letter of medical necessity or clarification?

Step 4: Start Preparing for an Appeal
- If it's a misunderstanding, your provider may be able to re-submit with corrections
- If it's a full denial, you have the right to file an appeal (see Section 6)
- Some plans allow for an "expedited appeal" if the denied service is time-sensitive (like a surgery scheduled within days or weeks)

Real-life Tip: Cleft Community Member
"In my situation, my insurance company denied coverage for a procedure by an oral surgeon twice. I then went to a craniofacial surgeon who specializes in cleft lip and palate repair. He took photos, wrote a detailed letter explaining the medical necessity, and my procedure was approved right away."

What NOT To Do
- Don't ignore the denial — deadlines matter
- Don't cancel the next procedure or therapy session without checking options
- Don't rely on verbal promises — always get approvals or updates in writing

Timeline To Appeal
You typically have 30 to 180 days from the date of denial to file an appeal, depending on your insurance plan. Check your EOB or call your insurer to confirm the deadline.

5. DENIED CLAIMS: WHAT NEXT

Checklist: After a Denial
- Read and understand your EOB
- Call your insurer to get more details
- Follow up with your insurance company to ensure they received the appeal
- Contact your provider to review what was submitted
- Gather your documents (LMNs, records, corrected codes)
- Mark your appeal deadline
- Prepare to file your formal appeal (Section 6)

Your Response Should Include:
- A new letter of medical necessity from your provider
- Additional supporting records (e.g., clinical photos, progress notes)
- A personal letter or appeal (we'll give you a template in Section 6)
- Clarification of how the service relates to the cleft diagnosis and functionality

Takeaway
A denial is not the end, it's the beginning. You've done nothing wrong. This is a tricky business. Sometimes it's difficult not to take setbacks personally, but this is part of the reason we created this guide. Stay calm, get clarity on the reason for the denial, and build your case. With persistence, strong documentation, and a timely appeal, **many denials are successfully reversed.**

6. APPEALS PROCESS TEMPLATES & GUIDANCE

Turning "No" into "Yes"
If your insurance company has denied a cleft-related procedure or service, **you have the right to appeal**. Many families and individuals have had procedures approved only after filing a strong, well-supported appeal.

This section breaks down how to build a winning appeal and when to escalate it. It also provides a customizable appeal letter template. Fighting a denial may seem intimidating, but with the right documents and a clear message, **you can absolutely change their minds.**

What Is an Appeal?
An appeal is a formal request that your insurance company **review and reconsider** a denied claim. It gives you the chance to submit additional information and clarify why the procedure or service is **medically necessary** — especially in the context of a cleft diagnosis.

Types of Appeals
- **Internal Appeal:** A review conducted by your insurance company. You typically have **30 to 180 days** after the denial to file
- **External Review:** If your internal appeal is denied, you may request an independent medical review. The decision from this review is final and binding
- **Expedited Appeal:** If the denial is urgent (e.g., for surgery scheduled soon or ongoing therapy), you can request a faster review, often within 72 hours

How To File a Strong Appeal
Step 1: Review the Denial Letter
- Identify why the claim was denied (e.g., "not medically necessary," "cosmetic," "missing pre-auth")
- Check your appeal deadline and where to send your materials

Step 2: Collect Your Documents
You'll need:
- A personalized appeal letter (template below)
- A Letter of Medical Necessity from your provider
- Any medical records that support your case (including surgery notes, therapy evaluations, progress reports, diagnostic images)
- Documentation of the cleft diagnosis (ICD-10 code)
- Your original pre-authorization approval, if available
- Provider and specialist letters if multiple care team members are involved
- Photos, X-rays, or functional assessments (when appropriate)

Step 3: Submit the Appeal
- Send your packet by certified mail (or use the insurer's secure portal, if available)
- Keep copies of everything
- Call to confirm receipt a few days after submission

6. APPEALS PROCESS TEMPLATES & GUIDANCE

Sample Appeal Letter Template
Feel free to customize this for your specific situation.

[Your Name]
[Your Address]
[City, State, Zip Code]
[Phone Number]
[Email Address]
[Date]

To:
Appeals Department
[Insurance Company Name]
[Insurance Address or Fax Number]

RE: Appeal for Denial of Coverage – [Procedure Name]
Member ID: [Your Member ID]
Patient: [Your or Your Child's Full Name]
Date of Service: [Date of Procedure or Proposed Service]
Claim #: [If Available]

Dear Appeals Reviewer,

I am writing to formally appeal the denial of coverage for [name of procedure], which was submitted on [date of service or pre-authorization request] and denied on [date of denial].

[My child has/I have] a cleft [lip and/or palate], a congenital condition that requires comprehensive, multidisciplinary care. The requested service is not cosmetic or elective. It is a medically necessary part of cleft-related treatment that directly impacts [speech, nutrition, jaw function, hearing, oral development... insert relevant function].

[Insert 1-2 sentences describing the medical reason for the procedure. Example: "The alveolar bone graft is needed to close the gap in the upper gum line, provide stability for permanent teeth, and allow for proper dental alignment and function."]

Attached you will find the following documents in support of this appeal:
• Letter of Medical Necessity from [provider name and specialty]
• Surgical/dental treatment plan and progress notes
• Cleft diagnosis confirmation and relevant ICD-10 code(s)
• Pre-authorization approval [if applicable]
• Relevant [imaging and/or functional assessments]
• State or federal cleft coverage mandates [if applicable in your area]

The denial reason cited, [insert denial reason from insurance letter], does not take into account the unique and medically complex nature of cleft care. I urge you to reconsider this claim based on the documentation provided.

Thank you for your time and consideration. Please contact me at [your phone/email] if any additional information is required.

I respectfully request that this appeal be reviewed promptly to avoid a delay in this essential care.

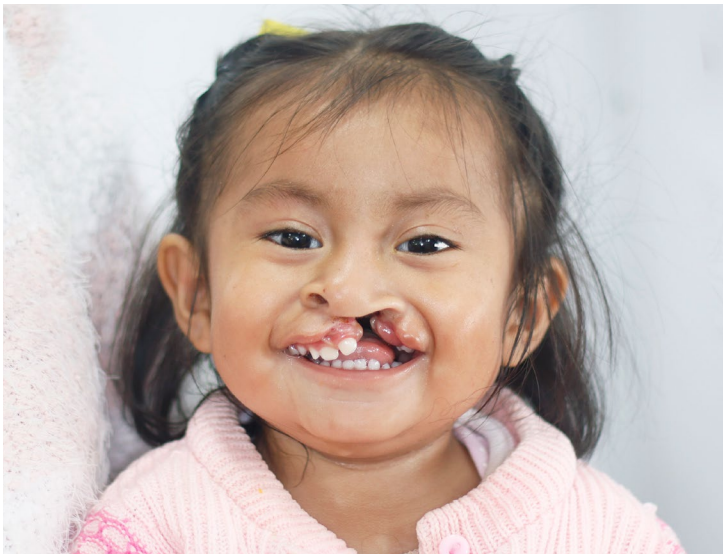
Sincerely,
[Your Full Name]
[Relationship to patient, if applicable]

6. APPEALS PROCESS TEMPLATES & GUIDANCE

Appeal Best Practices
- Be clear and direct in your letter
- Personalize your message — this is about you or your child's health
- Always use the words **"medically necessary"**
- Reference your specific cleft condition directly; include the ICD-10 codes **Q35–Q37**
    - **Q35**
      Cleft palate
    - **Q36**
      Cleft lip
    - **Q37**
      Cleft palate with cleft lip
- Stay polite but firm; advocate with respect
- Track every phone call, submission, and deadline

Escalation Options
If the internal appeal is denied, you can:
- **Request an external review** (check your state laws and insurer policy)
- **Involve a patient advocate or social worker** from your hospital
- **File a complaint** with your state's Department of Insurance or Attorney General
- **Contact advocacy organizations** (see Section 12 for support)

Takeaway
Appeals are not just paperwork; they're a declaration that your care matters. With solid documentation, supportive providers, and a clear, firm letter, you can turn a denial into an approval. **Don't give up.**



7. SENT TO COLLECTIONS: WHAT TO DO

You Still Have Rights and Options
Sometimes, despite your best efforts, a medical bill gets lost in the shuffle. Maybe a claim was denied and no one told you. Maybe you're still appealing a decision, but the provider went ahead and billed you anyway. Suddenly, you get a call — or worse, a letter — from a **collections agency.**

It's scary, stressful, and can feel hopeless. But here's the truth: **You are not powerless.** Being sent to collections doesn't mean the battle is over. This section outlines exactly what to do next to protect your credit, assert your rights, and resolve the debt while still fighting for insurance coverage if needed.

What Does "Sent To Collections" Mean?
If a medical bill goes unpaid for a period of time (usually 90 to 180 days), the hospital or provider may "charge it off" and turn the account over to a third-party **debt collector.** That agency then contacts you to collect payment, sometimes aggressively.

BUT: This doesn't erase your rights as a patient or your ability to fix the situation.

Step 1: Don't Panic or Pay Right Away
- Take a breath. You may still be able to:
  - Reverse the charge
  - Negotiate the amount
  - Get the insurance to pay (if the denial is reversed)

Step 2: Request a Detailed Bill and Review It
- Call the original provider's billing department and ask for:
  - A full itemized bill
  - The date(s) of service
  - Any Explanation of Benefits (EOB) associated with the charges
- Ask why it was sent to collections and whether the claim was submitted to insurance
- Ask if the provider will recall the debt from collections if you agree to settle the insurance or payment dispute

Step 3: Check the Status of Your Insurance Claim
- Contact your insurance company to:
  - Confirm whether a claim was submitted and/or denied
  - Get a copy of the denial reason (if applicable)
  - Confirm whether an appeal is still possible

Tip: If you're appealing a denial, let the billing department and collections agency know. Many will pause the collection process during an active insurance appeal.

7. SENT TO COLLECTIONS: WHAT TO DO

Know Your Rights with Medical Debt

- **You must be notified in writing** before a collections agency can report the debt to credit bureaus
- Under the **No Surprises Act (2022)** and the **Fair Debt Collection Practices Act (FDCPA):**
  - You can dispute the debt in writing within **30 days** of being contacted
  - Collections agencies must **pause efforts** and validate the debt if you dispute it
- Most medical debt **will not be reported to credit bureaus** for **at least 12 months** after the bill is sent to collections
- As of 2023, **unpaid medical debts under $500 no longer appear** on credit reports (Experian, Equifax, TransUnion)

How To Dispute a Medical Debt

Send a certified letter to the collections agency requesting:

- Verification of the debt
- Documentation showing you owe it
- A pause in collection while your dispute is reviewed

Sample Dispute Letter Excerpt:

"I am writing to formally dispute the validity of this medical debt. I request verification of the charges, including the itemized bill, service dates, and related insurance claim. I am currently working with my provider and insurer to resolve the matter. Please cease collection efforts until this is verified."

Negotiation Tips

If the debt is valid and not covered by insurance, you can:

- Request a **payment plan** you can afford (some as low as $25/month)
- Ask for **financial assistance** or **charity care** from the provider (especially for lower-income families)
- Offer a **settlement** (e.g., "I can pay 40% now if the rest is forgiven")

Important: Get any agreements **in writing** before you pay.

Real-life Example

Cleft Community Member

"When I couldn't pay the full amount, I made payments as little as $10 a month to my physician's office, but I was still sent to collections. After that, I continued paying the collection agency $10 a month. If that's all you can do, that's all you can do."

7. SENT TO COLLECTIONS: WHAT TO DO

Checklist: If You're Sent To Collections
- Get a detailed bill and understand the charges
- Contact your insurance and check the claim status
- Contact the provider and ask if they'll recall the debt
- Dispute the debt with the collection agency in writing
- Pause payments while you gather information
- Explore charity care, payment plans, or settlements
- Keep **everything in writing**

When To Seek Help
If you feel overwhelmed or threatened by a collections agency, reach out to:
- A hospital financial counselor
- A patient advocate or social worker
- Legal Aid or a local health law attorney
- The Patient Advocate Foundation **(patientadvocate.org)**

Takeaway
Collections are scary, but they're not the end of the road. You still have time, rights, and tools to fix the problem. Whether you're appealing an insurance denial or negotiating the bill, you can take back control of the situation one step at a time. Remember to breathe and know you don't have to "fight" this all at once.

8. KEEP TRACK OF EVERYTHING

Your Best Defense Is a Strong Paper Trail
When navigating cleft care, you're not just managing medical appointments — you're juggling insurance authorizations, claims, phone calls, bills, letters, appeal deadlines, and provider notes. It's a lot. One missed document or phone call can delay treatment or derail a claim.

That's why **organization is your superpower.** This section shows you how to build a simple system to stay on top of everything, reduce stress, and have all the right documents ready when it's time to appeal or follow up.

Why Keeping Records Matters
- Insurance companies may "lose" documents or say they were never received
- Providers can miscode procedures or forget to send records
- You may need the same documents for multiple procedures
- Appeals often depend on having the right paperwork and being able to prove you did your part

Pro Tip
The more organized you are, the harder it will be for anyone to deny your care or shift blame.

CATEGORY	EXAMPLES
Insurance Info	Policy number, group number, primary/ secondary coverage details
Authorizations	Approval letters, reference numbers, dates of approval/expiration
Claims & EOBs	Explanations of Benefits, claim numbers, amounts approved/denied
Medical Records	Surgery notes, speech evaluations, imaging, diagnosis letters
Letters	Letters of Medical Necessity, appeal letters, provider correspondence
Bills & Payments	Itemized bills, receipts, payment plans, collections notices
Communications	Notes from phone calls, emails, and fax confirmation pages with insurance reps or provider offices
Appeals	Submission confirmation, deadlines, responses, external review notes

8. KEEP TRACK OF EVERYTHING

Create a System That Works for You
Choose a method that matches your style and comfort level:
Option A: Physical Binder or Folder
• Use labeled tabs for each category (e.g., "Authorizations," "EOBs," "Appeals")
• Include a pocket for receipts and bills
• Store everything in one place for easy access at doctor's visits or appeal meetings

Option B: Digital Folder System
• Create a folder on your computer or cloud drive (Google Drive, Dropbox, etc.)
• Use subfolders for each category
• Save documents as PDFs with clear file names (e.g., "2024_Surgery_PreAuth_Aetna.pdf")

Option C: Hybrid System
• Keep physical copies of important letters and bills
• Store backups digitally (scan or photograph key documents)

Phone Call Log Template
When calling insurance companies, always document your conversations under the categories:
Date, Contact Name, Company, Topic, Outcome, Follow-up Needed

Example:
Date: 3/14/25
Contact: Maria, Aetna Rep
Topic: Denial of speech therapy sessions
Outcome: Maria escalated to case manager, follow-up in 3 days
Next Step: Call back on 3/17 if no update

Calendar Tips
Use a digital or paper calendar to track:
• Pre-authorization deadlines
• Appeal due dates
• Upcoming procedures
• Payment plan installments
• Therapy limits (e.g., "20 visits per year")

Apps That Can Help
• **CareZone** – Store insurance info, medications, doctor contacts, and files
• **Evernote/Google Keep** – Take notes and attach files or images
• **Genius Scan/Adobe Scan** – Easily scan paper documents with your phone
• **Google Drive** – Organize everything in one digital place with cloud backup

Takeaway
You don't need a fancy system, just a consistent one. Organization can reduce your stress, help your providers, and give you the evidence you need when challenging a denial.
Keep everything, track everything, and don't delete anything until the dust has fully settled.

9. EDUCATIONAL MATERIALS AND HELPFUL RESOURCES

Knowledge Is Power
One of the best ways to advocate for yourself or your child is to stay informed. Understanding how cleft-related procedures are medically necessary, not cosmetic, can give you the confidence to speak up when insurance companies push back. This section offers explanations of common cleft procedures, answers to frequently asked questions, and a curated list of trusted resources from cleft organizations and advocacy groups.

Frequently Asked Questions (FAQs)
Q: Are cleft-related surgeries considered cosmetic?
A: No. Surgeries like lip and palate repair, alveolar bone grafts, and jaw realignment are reconstructive and often functionally necessary. They help with eating, breathing, speaking, and oral development. While some may result in cosmetic improvements, their primary purpose is to restore function.

Q: Why is orthodontic treatment medically necessary in cleft care?
A: Children and adults with clefts often need orthodontics (braces, palatal expanders, etc.), not for appearance, but to align teeth for speech, proper chewing, and preparation for surgery. In many cases, cleft-affected individuals cannot eat or speak properly without orthodontic treatment.

Q: What if the insurance company says, "We don't cover dental procedures"?
A: If the dental procedure is part of cleft care, it may qualify for medical coverage. Work with your provider to have it reclassified and submit documentation showing how it connects to your cleft diagnosis.

Q: How do I explain this to my insurance company?
A: Use language like:
"This procedure is part of a congenital cleft treatment plan and is necessary for [function: speech, nutrition, breathing, etc.]. It is not cosmetic. Please reclassify under medical necessity." See Section 6 for full templates and appeal letters.

9. EDUCATIONAL MATERIALS AND HELPFUL RESOURCES

PROCEDURE	PURPOSE	COVERED UNDER
Lip/Palate Repair	Closes gaps in the lip and/or roof of mouth to allow feeding, speech, and growth	Medical
Alveolar Bone Graft	Fills the gumline to support permanent teeth and align the jaw	Medical (can be misclassified as dental)
Nasal Reconstruction	Improves breathing and facial symmetry after cleft repair	Medical
Jaw (Orthognathic) Surgery	Realigns jaws to improve chewing, breathing, and speech	Medical
Speech Therapy	Treats cleft-related speech delays and hypernasality	Medical
Ear Tubes	Address the hearing loss and chronic ear infections that are common for people with clefts	Medical
Orthodontics	Align teeth for function and surgery prep	Often misclassified as dental — should be appealed under medical if cleft-related
Dental Implants	Replaces missing teeth caused by a cleft	Often misclassified as dental — can be appealed with proper documentation

9. EDUCATIONAL MATERIALS AND HELPFUL RESOURCES

Other Trusted Resources
American Cleft Palate-Craniofacial Association (ACPA)
• Offers professional standards of cleft care
• Keeps a provider directory for craniofacial teams
• Patient FAQs and cleft care timelines
Website: www.acpa-cpf.org

Patient Advocate Foundation
• Free support for families facing insurance denials, appeals, and medical billing
• Case managers who help with negotiations and paperwork
Website: www.patientadvocate.org

National Association of Dental Plans (NADP)
• Understand dental coverage language
Website: www.nadp.org

State Insurance Departments
Every US state has an insurance regulator that handles complaints, investigates unfair practices, and may enforce cleft coverage mandates.
Search: "[Your state] department of insurance"

Medicaid State Offices
Each state has different rules, but if your child is covered by Medicaid or CHIP, many states offer full cleft coverage under EPSDT (Early Periodic Screening, Diagnosis, and Treatment).
Visit: **www.medicaid.gov**

Takeaway
You don't have to memorize everything, but knowing where to find accurate, cleft-specific information can save you hours of stress and thousands of dollars in bills. **Bookmark key sites, print helpful documents, and use these resources as tools in your insurance journey.**

10. THINGS YOU MIGHT NOT HAVE THOUGHT OF

Small Details That Make a Big Difference
When you're in the thick of navigating insurance for cleft care, it's easy to focus on the big-ticket items such as surgery approvals, denied claims, and appeal letters. But there are often **hidden strategies and overlooked supports** that can help ease the process, save you money, or expand your access to care.

This section highlights practical "extras" that families and individuals in the cleft community may not know they can use to their advantage.

A. Secondary Insurance: Double the Support

If you or your child has **two insurance policies,** you may be able to coordinate them so that one plan covers what the other doesn't. For example:
• A child might have private insurance through a parent and Medicaid as secondary.
• An adult may have coverage through their job and also be eligible for a partner's plan.

This can help with:
• Covering **out-of-pocket expenses**
• Getting access to o**ut-of-network providers**
• Appealing denials from one plan using approval from the other

Ask both insurers: "Do you coordinate benefits, and how do I file claims with both plans?"

B. Medicaid as Backup — Even if You Have Private Insurance

Many people don't realize that you can qualify for Medicaid even with private insurance, especially if your income is moderate and your medical costs are high.
Some families use Medicaid as a secondary payer to:
• Cover costs the private plan won't (like orthodontics or therapy)
• Pay for prescriptions, co-pays, or dental devices
• Access services not included in their main policy

In some states, children with clefts automatically qualify for Medicaid or CHIP based on medical need (regardless of income). Ask your state Medicaid office about "medically needy" or "waiver" programs.

10. THINGS YOU MIGHT NOT HAVE THOUGHT OF

C. Employer-based Advocacy

If you receive your insurance through an employer, HR may be your secret weapon. Here's how:
• Ask your Human Resources (HR) team to **review your plan's cleft coverage policies**
• Request that they advocate directly with the insurer on your behalf
• Ask about **open enrollment options** that offer better cleft-related benefits
• Suggest plan changes for next year if your current coverage is lacking

D. Know Your State Laws

Some states have cleft mandates, laws requiring insurance companies to cover cleft-related care.
Examples of mandates include:
• Orthodontic treatment
• Speech therapy
• Craniofacial team evaluations
• Dental appliances or implants

States like New York, Texas, California, Massachusetts, and others have strong cleft coverage laws. Even if your insurer denies a claim, **state laws may override that denial.**

To find out:
• Search "[Your State] cleft insurance mandate"
• Contact your state's Department of Insurance
• Ask your provider or craniofacial team; they may already know

E. Keep All Providers Informed
Often, cleft care is spread out across multiple providers, surgeons, orthodontists, ENTs, dentists, and therapists, who may not all realize how their services connect to your cleft diagnosis.

To help:
• Bring a **summary of your cleft treatment plan** to new providers
• Remind dental or speech providers that their services may qualify for medical coverage
• Ask every provider to **note the cleft diagnosis** in your file and on insurance claims

Example: If your orthodontist doesn't mention your cleft in the insurance paperwork, it may be denied, even if it's part of your treatment plan.

10. THINGS YOU MIGHT NOT HAVE THOUGHT OF

F. Early Intervention Services

Children under three may be eligible for **free early intervention services** through their state, including:
• Speech therapy
• Occupational therapy
• Developmental evaluations

These services are often offered **regardless of insurance** or income and are designed to catch and treat delays early, often before insurance would even kick in. Referrals to these programs are typically sent when babies are discharged after birth. Parents/guardians often miss this initial call to schedule services because they are in the early-baby stage or overwhelmed by their child's diagnosis. This can lead to delays with beginning feeding and hearing services, speech therapy, etc. Early intervention programs also offer guidance when transitioning into a pre-K program, coordinating IEP (Individualized Education Plan) support, and ensuring children receive the appropriate services in a timely manner.

To find your local program, search "[Your State] early intervention services."

G. Ask for a Case Manager

Some insurance plans offer case managers who can help:
• Guide you through the pre-auth and appeal process
• Coordinate care between multiple providers
• Flag cleft-related codes or exceptions in your plan
• Track claim progress and escalate issues

When calling your insurer, ask:
"Do you offer a pediatric or chronic care case manager for cleft or craniofacial conditions?"

H. Save Your Explanations of Benefits (EOBs)

These statements show how your claims were processed. They're key to:
• Understanding what was paid vs. denied
• Filing appeals
• Disputing incorrect bills
• Tracking how close you are to your deductible or out-of-pocket maximum

Keep every EOB, even if the claim was paid. They are your receipt and protection against billing errors.

10. THINGS YOU MIGHT NOT HAVE THOUGHT OF

I. Consider a Health Savings Account (HSA) or Flexible Spending Account (FSA)

If offered by your employer, these accounts allow you to set aside pre-tax dollars for medical expenses, which can help offset:

- Braces
- Speech therapy
- Co-pays
- Dental implants
- Out-of-network bills

Ask your HR rep about eligibility and covered expenses.

Takeaway
Some of the most helpful tools for managing cleft care costs and coverage aren't obvious — and often go unused. By digging into your state laws, asking the right questions at work, and exploring every benefit available, you may uncover hidden support systems that can make a world of difference.

11. CONTACT SHEET FOR ADVOCACY & SUPPORT

When you're navigating insurance challenges, sometimes the most important thing is knowing where to turn for help. Whether you're appealing a denial, confused about your coverage, or just need a second pair of eyes on a bill, you deserve support.

This contact sheet lists trusted organizations, advocacy groups, and community resources that can offer personalized help, expert guidance, or simply a listening ear.

Smile Train's Cleft Community Advisory Council
- What we do: Offer support, resources, and community-building for cleft-affected individuals and families in the US
- Contact for: Insurance education, emotional support, events, and peer connections
- Email: **cleftcommunity@smiletrain.org**
- Website: **www.smiletrain.org/ccac**

Patient Advocate Foundation
- What they do: Free case management services for patients dealing with insurance denials, medical debt, and access to care
- Contact for: Help with appeals, out-of-pocket cost relief, insurance navigation
- Phone: (800) 532-5274
- Website: **www.patientadvocate.org**

American Cleft Palate-Craniofacial Association (ACPA)
- What they do: The leading professional organization for American cleft and craniofacial providers, they also offer resources and standards of care for patients
- Contact for: Finding cleft/craniofacial teams, treatment guidelines, patient education
- Phone: (919) 933-9044
- Website: **www.acpa-cpf.org**

American Speech-Language and Hearing Association
- What they do: Provide consumers with a list of speech pathologists and audiologists in their area. Providers are all licensed professionals who hold the highest level of credentials in the fields of speech pathology and audiology: The Certificate of Clinical Competence.
- Website: **www.asha.org/public/**

State Department of Insurance (DOI)
- What they do: Regulate insurance companies and handle complaints and appeals
- Contact for: Filing insurance complaints, understanding state coverage mandates, escalation
- Website: **www.naic.org** (Find your state's DOI here)

11. CONTACT SHEET FOR ADVOCACY & SUPPORT

State Medicaid Offices
- What they do: Administer Medicaid and CHIP programs; may also offer secondary insurance or cover cleft services
- Contact for: Enrollment, eligibility, and cleft-related coverage for children and low-income families
- Website: **www.medicaid.gov**

Your Cleft or Craniofacial Team Coordinator
- What they do: Manage treatment plans and communication between providers
- Contact for: Letters of medical necessity, coordinating documentation, tracking claims, insurance coding support
- How to connect: Ask your surgeon or hospital to introduce you to their team coordinator or social worker

Health Insurance Case Managers (Ask Your Insurer)
- What they do: Assigned representatives who can follow your case, help resolve claims, and track appeals
- Contact for: Personalized help with your insurance plan. Ask if your plan offers this service
- How to request: Call your insurance company and say:
  "Can I speak to a case manager or request one be assigned for ongoing cleft-related care?"

Legal Aid/Health Law Services (State-Specific)
- What they do: Provide free or low-cost legal assistance for healthcare access, especially for low-income families
- Contact for: Help with persistent denials, discrimination, or rights under cleft mandates
- How to find: Search "[Your State] legal aid health insurance"

Billing Department or Financial Counselor at Your Hospital
- What they do: Help resolve billing errors, set up payment plans, or apply for financial aid
- Contact for: Payment negotiation, charity care applications, bill corrections
- How to access: Call your hospital's main number and ask for the "billing office" or "financial counselor for cleft care"

Bonus Tip: Create Your Own Support Network

List the names and contact info of you or your child's:
- Surgeon
- Orthodontist
- Speech therapist
- Social worker or case manager
- Insurance rep (get their extension and email, if possible)

CLOSING MESSAGE

We hope this guide leaves you feeling more equipped, more confident, and more seen. Advocacy is rarely easy; it requires courage, persistence, and the willingness to keep asking questions even when the answers don't come right away. Remember: Each time you speak up, appeal a decision, or ask for clarity, you're not just fighting for your care, you're shaping a better path for the many others who will come after you.

Keep using your voice. Keep documenting. Keep learning.

Most importantly, keep believing that you deserve care that honors your story and meets your needs.

If you found this guide helpful, share it with another family, provider, or community member who may be walking a similar road. Together, we can continue to make the system more compassionate, more equitable, and more informed, one conversation at a time.

Never forget:
You are your best advocate, and your advocacy matters.

SmileTrain