

We are parents, not medical or legal professionals. This reflects our personal experience. Always consult your child's care team before traveling.

Traveling With sJIA

A Practical Guide to Flying With Biologics, Planning Infusions & Staying Prepared

Travel with a medically complex child requires more planning, but it is absolutely doable. We have done it. This guide covers everything we wish someone had told us before our first trip after Corbin's diagnosis.

Before You Go: The Essential Checklist

- Contact your rheumatologist at least 4-6 weeks before travel to discuss medication timing concerns
- Get a letter from your rheumatologist on letterhead stating your child's diagnosis and all current medications, including biologics
- Ensure all prescriptions are filled and you have more than enough medication for the trip plus a buffer for delays
- Check if your destination has a children's hospital or rheumatology center, know the address and phone number before you need it
- Confirm your insurance coverage in your destination (domestic and international)
- Pack the rheumatologist's after-hours emergency number in your phone AND written down
- Carry a one-page medical summary (diagnosis, medications, allergies, emergency contacts) in your wallet and in your child's bag

Flying With Biologics: What You Need to Know

Biologic medications, including injectables like Anakinra, Canakinumab, and others, require special handling when flying.

TSA Rules for Medications

- Medications, including liquid biologics and syringes, are exempt from the 3.1 oz liquid rule, you may carry full quantities

- Inform TSA agents at the beginning of screening that you are carrying medications requiring refrigeration
- Request a manual inspection rather than X-ray if recommended by your medication manufacturer, ask your pharmacist
- Carry medications in your carry-on, never in checked luggage, temperature and handling cannot be controlled in cargo holds

Keeping Biologics Cold

- Use an insulated medication travel case with a cooling insert, many biologic manufacturers provide these free (ask your specialty pharmacy)
- Know your medication's specific room-temperature window (check prescribing information or ask your pharmacist)
- For longer trips, plan how you will access refrigeration at your destination before you leave
- Hotels will almost always provide a refrigerator if you explain it is for medical refrigeration, call ahead to confirm

Documentation to Carry Through Security

- Physician letter on letterhead identifying all medications
- Original pharmacy labels on all medications
- Prescription information printout from pharmacy
- If traveling internationally, have documentation translated if possible

Planning Around Infusions

If your child receives IV biologic infusions (like Tocilizumab), travel timing requires coordination with their infusion schedule.

Option 1: Time Travel Around Infusions

The simplest approach is to plan trips to end within a day or two before the next infusion is due, giving you buffer room if travel is delayed.

Option 2: Arrange an Infusion at Your Destination

For longer trips, it is possible to arrange an infusion at an infusion center near your destination. This requires:

- Your rheumatologist's office to send a referral and current orders to the receiving center
- Insurance pre-authorization for out-of-state or out-of-network infusion (start this 4-6 weeks ahead)
- Pharmacy coordination to ensure medication is available or shipped to the destination center

Finding Infusion Centers: Search "[medication name] infusion center locator" or check childrenshospitals.org, most major cities have a children's hospital with rheumatology infusion capability.

Building a Flare Response Plan for Travel

Before every trip, answer these questions in writing and keep them accessible:

- What are the early warning signs that your child is heading toward a flare?
- What is the first thing you do if those signs appear?
- What is the nearest children's emergency room to your destination?
- What do you say when you arrive at the ER?
- At what point do you cut the trip short and come home?

What to Say at an Unfamiliar ER

"My child has sJIA, Systemic Juvenile Idiopathic Arthritis, which is an autoinflammatory disease. He/she is immunosuppressed due to biologic medication. I am concerned about [specific symptom]. One serious complication of sJIA is Macrophage Activation Syndrome (MAS), which requires immediate evaluation. His/her rheumatologist is [name] at [hospital], reachable at [number]. Here is his/her current medication list."

Print this as a card and keep it in your wallet.

Practical Travel Packing List for sJIA

Medications & Medical Supplies

- All current medications, MORE than enough for trip + 5 extra days
- Biologic in insulated travel case with cooling insert
- Fever-reducing medication (confirm with rheumatologist what to use and dosing)
- Pain medication as prescribed
- Anti-nausea medication if prone to this
- Thermometer (essential)
- Written medication schedule

Documents (Carry-On and Digital Backup)

- Rheumatologist letter for TSA and medical facilities

- Insurance card, front and back photo on your phone
- One-page medical summary
- Emergency contacts including after-hours rheumatology line
- Destination hospital/ER address

Comfort & Flare Management

- Small heating pad or heat patches for joint pain
- Comfortable, easy-on/off shoes (swollen joints and shoelaces are a bad combination)
- Water bottle, always
- Healthy snacks that fit your dietary approach
- Blanket or layers, temperature sensitivity is real

You can do this. We have taken Corbin on trips during remission and during mild flare periods. With preparation, it is possible, and those normal family memories matter enormously. Plan carefully, build in flexibility, and go.