

# Seeking medical treatment out of state

*Guide for persons with scleroderma on how to travel out of state to  
obtain medical treatment*



# Things to consider before traveling out of state for medical treatment

Some people living with scleroderma may decide to seek medical treatment outside of their own state because they want to consult with a physician who has a specific expertise. Others may receive a referral to seek treatment from a physician who is outside of their state because their own medical team is unable to provide the care that is needed. Whether it is a referral or a personal choice that is driving the decision for you and your loved one to travel, there are some common things to consider before traveling.

## ❑ **Does your insurance cover the expense?**

Many insurance plans have in-network coverage and out-of-network coverage and based on your specific plan, the amount that the insurance carrier will cover out of state could vary. The first step before deciding to travel out of state for medical treatment is to talk directly to your insurance carrier and have them outline your coverage plan, out-of-pocket expenses, deductibles and any other necessary information. Make sure you obtain the name of whom you are speaking to and document this conversation for reference if needed.

## ❑ **Travel costs**

Calculating your travel costs before making the decision to seek out of state treatment is always advisable. These costs include but are not limited to travel expenses to and from the destination, food, lodging, incidentals while out of state such as Uber rides, cabs, bus or parking fees.

## ❑ **What are the health risks of traveling?**

Every person who is considering travel outside of their own state must consider the benefits versus the risks. Having an open-ended conversation with your medical team regarding any potential risks to your medical health is a good start to making the best decision for you. Being an educated advocate means being more successful during your travels.

# Difference between in-network and out-of-network

When a doctor, hospital or other provider accepts your health insurance plan they're **in network**. They can also be called **participating providers**.

When you go to a doctor or provider who doesn't take your plan, it is known as being **out of network**.

The two main differences between them are cost and whether your plan helps pay for the care you get from out-of-network providers.



**REJECTED**  
**INSURANCE**  
**CLAIM**

# Planning for an out of state visit

Seeking medical treatment out of state requires advance planning. If your desire is to obtain a consult and potentially receive medical care from physicians outside of your own state, you might be concerned about the costs associated with the care.

No one wants to travel and find out afterward that they are unable to afford treatment and then return home empty handed. Conversely, it would be regrettable to travel, receive medical services, and then return home to overwhelming financial burdens from the medical bills.

Doing as much preparation in advance as you can will provide you with a clear picture of the costs associated with out of state medical treatment for you or a loved one. Consider the following:

- ❑ Contact the medical team in advance to determine out-of-network costs.
- ❑ Ask about seeking services on a cash basis and if there is a reduced fee structure for this.
- ❑ Clearly define payment plan options prior to travel.
- ❑ Discuss the ability to have a consult and then to seek follow up treatment from your in-network medical providers. This includes the ability to do imaging and other testing in-network and to have the results sent to out-of-network for evaluation to maintain lower costs.



# How to pack for medical travel

## What to pack

- Temperature appropriate clothing. Loose fitting if you are planning on having testing done.
- Toiletries
- Reading materials
- Comfort items
- Snacks
- List of medication, contacts, medical history for the medical team.

## Practice the 1-2-3-4-5-6 Rule

- Here's a simple suitcase-packing tip. For a week-long trip, pack:
- 1 hat
- 2 pairs of shoes
- 3 pairs of pants or skirts
- 4 shirts
- 5 pairs of socks
- 6 sets of underwear
- <https://www.allianztravelinsurance.com/travel/planning/luggage-packing-tips.htm>

# Medication and TSA: Know the Rules

## Get educated before you fly

- One of the more popular questions TSA gets from travelers is: “Can I travel with my medication.” The answer is yes, with some qualifiers. Here are a few tips that you might find helpful.
- It is not necessary to present your medication to or notify an officer about any medication you are traveling with unless it is in liquid form (See next bullet).
- Medication in liquid form is allowed in carry-on bags in excess of 3.4 ounces in reasonable quantities for the flight. It is not necessary to place medically required liquids in a zip-top bag. However, you must tell the officer that you have medically necessary liquids at the start of the screening checkpoint process. Medically required liquids will be subjected to additional screening that could include being asked to open the container.
- You can bring your medication in pill or solid form in unlimited amounts as long as it is screened.
- You can travel with your medication in both carry-on and checked baggage. It’s highly recommended you place these items in your carry-on in the event that you need immediate access.

<https://www.tsa.gov/blog/2014/09/05/tsa-travel-tips-traveling-medication>

## How to contact the TSA

- TSA does not require passengers to have medications in prescription bottles, but states have individual laws regarding the labeling of prescription medication with which passengers need to comply.
- Medication is usually screened by X-ray; however, if a passenger does not want a medication X-rayed, he or she may ask for an inspection instead. This request must be made before any items are sent through the X-ray tunnel.
- Nitroglycerin tablets and spray (used to treat episodes of angina in people who have coronary artery disease) are permitted and have never been prohibited.
- **For more information, you can contact:**
- **TSA Contact Center** - The TSA Contact Center is available to help travelers prepare for upcoming flights. The hours are Monday - Friday, 8 a.m. - 11 p.m., Eastern Time; weekends and federal holidays, 9 a.m. - 8 p.m., Eastern time.
- The TCC can be reached at 866-289-9673.
- Passengers can also reach out to the TSA Contact Center (TCC) with questions about TSA procedures, upcoming travel or to provide feedback or voice concerns.

# Rules for Taking Prescription Drugs Through US Airport Security

In US airports, the Transportation Security Administration (TSA) allows passengers to bring prescription drugs and other medically required substances, such as water or juice, with them onto the airplane. You may place medications in 3.4 ounce (100 milliliters) or smaller containers in a one-quart size clear zip-top plastic bag along with your other personal liquid and gel items. If your prescription medications come in larger containers or bottles, you will need to pack them separately in your carry-on bag.

You must declare each medication to the security officer when you arrive at the airport security checkpoint. Permitted items include:

- Prescription and over-the-counter medications and supplies, such as saline solution for contact lenses
- Water, juice, "liquid nutrition" (such as Boost), and gels that are necessary for a passenger with a medical condition or disability to consume during the flight
- Bone marrow, transplant organs, and other life-sustaining materials
- Mastectomy products and other cosmetic or medical augmentation items that contain gel or liquid
- Breast milk and baby formula
- Frozen gels or liquids (ice packs) required to cool medications, life-sustaining materials, or disability-related items
- When you arrive at the security checkpoint, you, your travel companion or a family member must declare your medically necessary liquid and gel items to a security screening officer if these items are in bottles or containers larger 3.4 ounces. You can tell the screening officer about your prescription drugs or present a written list. You may wish to bring doctor's notes, original prescription bottles or containers, and other documentation to make the screening process go more quickly.



# Over the counter items to travel with

- Pain reliever
- Antidiarrheal
- Motion sickness medication
- Cold remedies
- Laxative
- Antibiotic ointment
- Band-aids
- Cough drops
- Antacid medication
- Eye drops



# Keeping your medication cold while traveling

Scleroderma related medications often require refrigeration, and whether you are flying, taking a train, a bus, or driving in an automobile, your medication will need to be kept at a specific temperature during your trip.

The best way to ensure that your medication is kept at the correct temperature is to check with your pharmacist in order to obtain accurate information about the requirements of the medication(s) you are on.

Using gel packs or ice packs that you can purchase online or at the local drug store will assure that your traveling experience is not more stressful due to ice melting during layovers or unplanned delays.

You can purchase an insulated carrying case for your medication and these can be found online. Be mindful when traveling that the placement of your medication is important since heat in a car, direct sunlight or other elements will effect the temperature of your medication.

Once you arrive at your destination, immediately secure refrigeration for your medication and refreeze the gel packs or ice packs.

When looking for temporary housing for your trip, do not forget to seek out locations that have refrigeration available in your room.



# Airlines and medical baggage

Check with each of the following airlines regarding their updated policies on medical bags as an additional carry on. They do not charge for your medical baggage.

Delta

American Airlines

United

Southwest

- When you are traveling outside of your state seeking medical treatment it is wise to check with your airlines to determine whether they have a policy on not charging for an additional medical bag. These extra savings can add up!
- When packing your medical bag, it is critical that only medical items be included in order to be considered for an additional medical carry-on at no charge. This means you are unable to add anything into the bag other than medical items that you need.
- If you do not locate an airline carrier on the left-hand side of this slide, it is advisable to contact your carrier and to ask about their policies
- When traveling it is wise to keep all your medications and supplies in your carry-on.



# Medical Notification Card

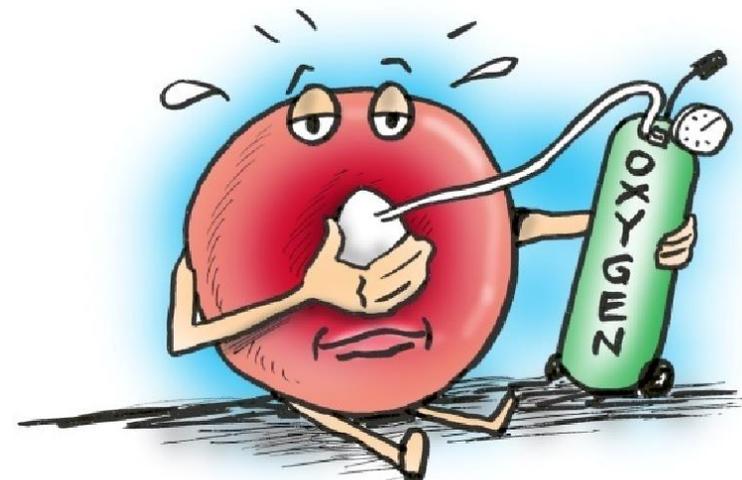
All persons traveling by air are subjected to a TSA screening at a checkpoint in the airport. If you have a disability or concern about this screening process, contact TSA in advance of your travel date to seek a TSA notification card. This card alerts the TSA Personnel to your specific medical concerns prior to being subjected to a screening and can save you and your travel companion time and obstacles the day of your flight. It is important to always travel with any medical documentation that can accurately describe your medical condition(s) and to supply this information to a TSA officer. If you need additional information, contact passenger support.



# Traveling with oxygen

For some people living with scleroderma traveling with oxygen is a necessity. Here are some tips to help your travel experience.

- ❑ Contact your airline carrier to determine what their specific rules are for traveling with oxygen. If you have questions, call and speak to someone in person to obtain the accurate and current information and do not rely on website searches.
- ❑ Check your oxygen unit to learn whether it is approved for in-flight use. If you have any concerns, contact the manufacturer of the unit.
- ❑ When entering the TSA checkpoint, if you can, disconnect your portable oxygen and check the equipment as you would a carry-on bag, following all the same rules. This will make your screening experience move quicker and be less problematic.
- ❑ Know in advance whether your equipment can or cannot undergo X-ray screening. If your equipment is unable to be screened with the use of x-ray, then it will require a manual inspection.
- ❑ For those people who are unable to disconnect from their oxygen, you will be screened by a TSA professional using a pat-down procedure. This is done with dignity and respect in mind and will protect your equipment.
- ❑ Discuss your travel plans with your medical team so you can obtain the best advice for you prior to your travel date. If you are unable to disconnect and someone continually requests this of you, ask to speak to a manager for a consultation. Having medical documentation will prevent any miscommunication and will help you have a positive travel experience.



# Finding affordable lodging

When traveling out of state most persons with scleroderma have a strong desire to maintain a low budget line for lodging costs. One solution might be to research availability through the, "Healthcare Hospitality Network."

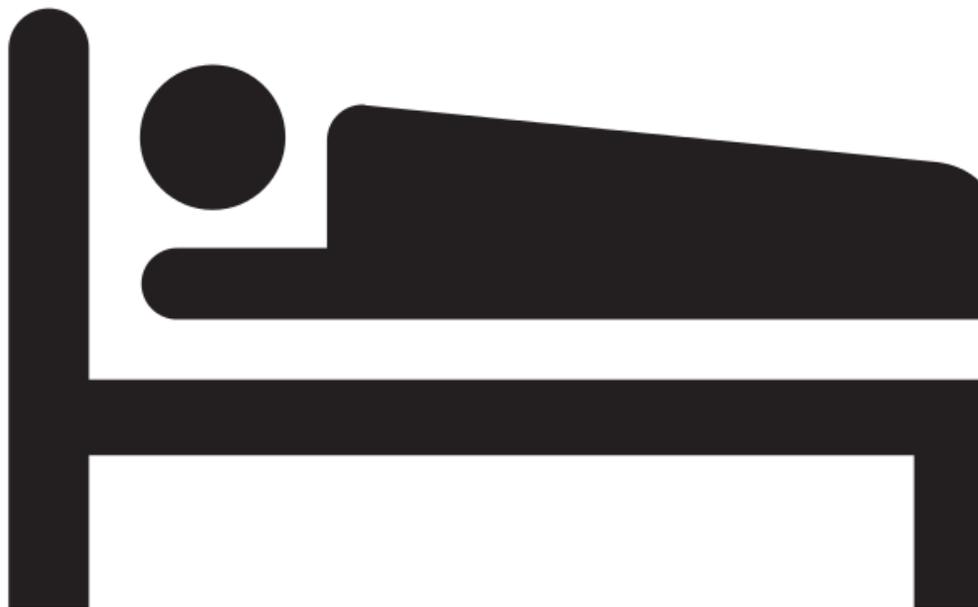
Use this link to locate affordable lodging in states where you may be traveling.

<https://www.hhnetwork.org/find-lodging#/>

Here is a map of the member's housing options. This is updated as more lodging becomes available so check back.

<https://www.hhnetwork.org/map>

**These are hospitality homes that are often near the larger hospitals and medical centers.**



# Hosts for Hospitals

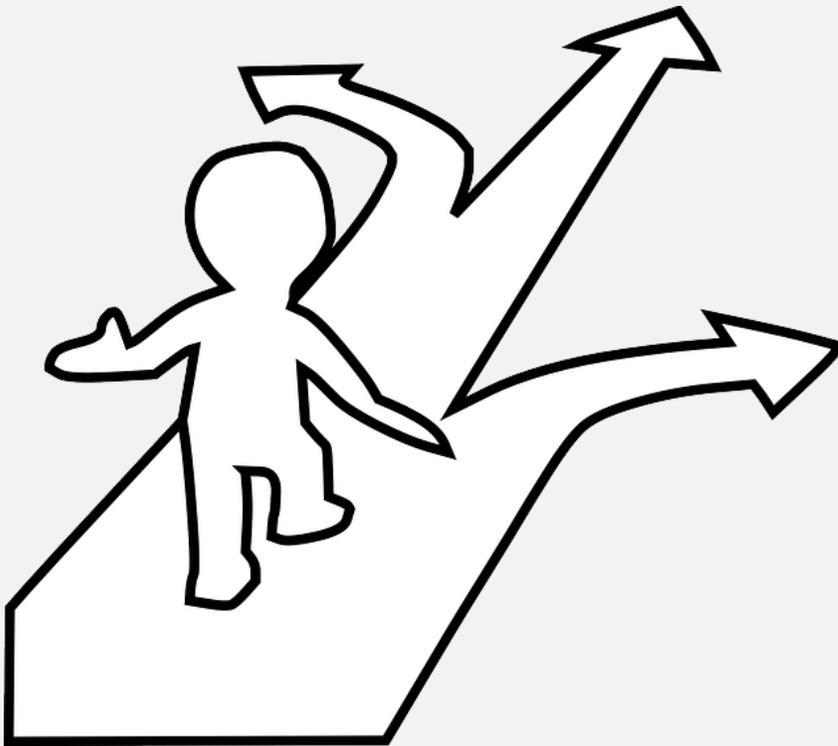
Hosts for Hospitals strives to provide every family in need of lodging when coming from out-of-town to a city for medical care the option of staying at a locally administered volunteer host-home or group facility suitable to meeting that patient-family's specific lodging needs.

Host-homes programs may be created as:

- Part of a hospital, enabling more patients from further distances to come there to receive medical care.
- Part of any local Ronald McDonald or other hospitality house to increase the number of patient-families for whom that facility may provide lodging; or,
- A collective activity for members of community groups or places of worship as an easy way for people to give back.
- The fee of \$20 per night/per family is charged. Food is not covered under this fee. Guests must bring their own toiletries.
- To complete an application use this link. <http://www.hostsforhospitals.org/becoming-a-guest/>

*Be Our*  
**GUEST**

# Working with a patient navigator



- When you are considering traveling outside of your network, consider asking about working with a patient navigator.
- A patient navigator help patients "navigate" the maze of clinics, administrative systems and patient support services.
- Navigators reduce barriers that keep patients from getting timely treatment by identifying patient needs and directing them to sources of emotional, financial, administrative, or cultural support.
- Patient navigators are often knowledgeable about diseases and medical conditions and can assist patients and their family members in obtaining information.
- Navigators work with members of the health care team to facilitate patient healthcare.
- They promote patient health and comfort.
- Patient navigators help patients to become advocates for themselves.
- Ask your medical team or medical institute about their Patient Navigators today to see if this is an option for you.

# Patient Advocate Foundation

- Patient Advocate Foundation is *A national 501 (c)(3) non-profit charity that provides direct services to patients with chronic, life threatening and debilitating diseases to help access care and treatment recommended by their doctor.*
- Their website is: <https://www.patientadvocate.org/>
- The services they provide include:
  - [Case Management Services & MedCareLines](#)
  - [Co-Pay Relief Program](#)
  - [Financial Aid Funds](#)
  - [Apply for a Scholarship](#)
- They have several educational topics that could provide those persons living with scleroderma and their loved ones with education and resources.



# HealthWell Foundation

- HealthWell Foundation assists those patients who are struggling to afford the cost of medical treatments.
- They help with copays, premiums, deductibles and out-of-pocket expenses for supplies, supplements, surgeries and more.
- They offer financial assistance through a number of Disease Funds, with new funds opening every year, so patients can get the care that is needed.
- Scleroderma is not currently covered but you can apply to have it covered on their website.
- They also have other resources you may want to research to see if they are a good fit for you.
- HealthWell Foundation does cover several disease so review the list carefully and often to determine if any of those that are covered can benefit you.
- Share the information with your network of family and friends.
- Go to their website for more information.
- <https://www.healthwellfoundation.org/patients/>



# Preparing for the visit

- ❑ Preparation for your visit to a new or return medical facility will help make a smoother experience for all involved.
- ❑ **Buy a good notebook for notetaking. Take notes on everything, your vitals, blood work, testing and the conversation you have with the medical team.**
- ❑ Secure a family member, friend or someone that can accompany you on the trip to take notes and actively listen during the visit.



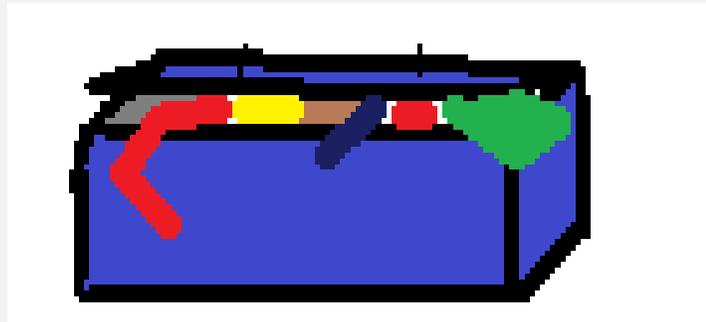
# Food and your travel plans

- Travel for persons with scleroderma requires advance planning and if you have GI symptoms it can complicate any traveling experience.
- Think ahead and buy snacks and food items that will provide nourishment for you during your travel and stay.
- If you are traveling with a younger person who has scleroderma, pack items that your child can enjoy in the airplane such as dried fruit, oatmeal cups, (ask the stewardess to give you hot water) and other healthy food items that do not have liquid so you can carry them onto the airplane.
- If your food items require liquids, have your medical team provide you with proper documentation so TSA will approve you bringing these items onto the airplane and you will not be left without any food options you can enjoy.
- Create a food list on your phone so during your stay you can easily reference it when shopping.
- Research the medical facility and surrounding area prior to your travel date to learn about eating choices and plan your stay. Check on-line for menus to make sure that each place you choose has something to offer you that will meet your dietary needs.

# Packing an entertainment/carry-on bag for your travel

- Electronics
- Phone charger
- Valuables
- Toothbrush
- Toothpaste
- Facial wipes
- Blanket
- Head rest
- Pillow
- Comfort items
- Earphones
- Insurance cards
- Cash

Here are some items to remember when packing for your trip. These will help entertain you during your travel and in between your medical visits.



- ID
- Itineraries
- Videos
- Computer/laptop
- Crafts
- Toys for children
- Small games for children
- Gum for ear pressure
- Sweater
- First aid items
- Motion sickness medication
- Pain reliever
- Snacks

# Uber to and from the medical facility

To use Uber for your traveling needs here are the steps.

- Go to their app and create an account. To do this you will need an email address and phone number. Do this in advance of your travel plans to save time and difficulty with internet connections not being available. You can request a ride from the Uber app. You can download this on the [App Store](#) or [Google Play](#).
- Enter your destination once you open the Uber app. State exactly where you want to go and confirm the location. Confirm again to be matched with a driver.
- Meet your driver. Uber makes it easy to track your driver within the app. This allows you to see the car as it is approaching your location.
- Check your ride. Confirm you are in the right car by checking that the driver matches the app and the car does also. You will have the license plate, car make and model, and driver photo all provided in your app.
- Paying for the trip. When you arrive at your destination, payment is easy. Depending on your region, you have options. Use cash or a payment method like a credit card or [Uber Cash](#) balance.



# Lyft travel made easy for you

- ❑ **To request a Lyft ride**, download the Lyft app and create an account. Then: Open the Lyft app. Tap 'search destination' and enter your destination. You can enter an address or search for a location. Select your ride mode. Swipe left for economy, luxury, or extra seating options. Tap “Select” to request a ride. **The pickup location** will automatically set to your current GPS location.
- ❑ To change the pickup location: Tap “Current location” at the top of the screen
- ❑ Enter an address or drag the location pin to the right spot. Tap, “Set pickup”.
- ❑ If there's an easier pickup location nearby, you'll have the option to meet your driver at the new location to save time. Pickup suggestions are always optional and are only a short walk away.
- ❑ **Change your payment method** before requesting a ride by tapping the payment method shown on the ride mode selection screen. On the 'Payment' screen you can change or add payment methods, view any active promos, and switch between personal or business accounts. You'll see the price of your ride on the ride mode selection screen before you tap “Select.” Learn more about how to estimate a Lyft ride's cost.

**To schedule a ride** for a later time:

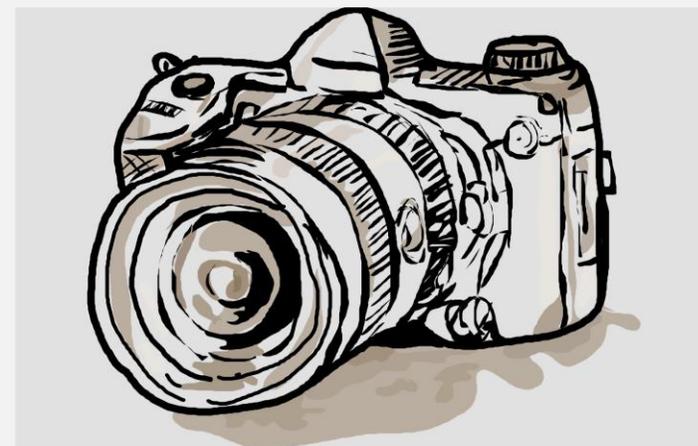
- ❑ Set your destination. Tap “Schedule” on the ride mode selection screen. Choose a date and time and tap 'Set pick up time. Confirm your pickup and drop-off location, then tap “Schedule.”



# How to fill your time in between medical visits

When out of state for medical treatment, you may find you have extra time on your hands. Here are some fun things you can consider to keep yourself entertained in between your medical visits, testing and assuring you are getting plenty of rest.

- Eat where the locals eat. Ask at your place of stay where their favorite eating locations are and try out a new destination.
- Check out the local parks and enjoy a restful stroll, people-watching or just the beauty.
- Visit the local zoo.
- Visit the local museum or any monuments.
- Read a book in a local coffee shop.
- Take a tour of the city on your own and look at the houses, buildings and cityscape.
- Visit the churches.
- Photograph your trip and special memories.
- Explore your surroundings and enjoy the new area.



# What to do when you return back home

When you return home from your out of state medical visit, there are a few things you will want to do. Here are some tips to remember.

- Forward all documentation from your medical visits to your home-based medical team to keep them updated on your out of state treatment and care.
- Manage your insurance claims and out of state invoicing.
- Organize your medical records.
- Schedule follow up appointments as needed.
- Make future travel plans as needed.

