

LIVING WITH **THALASSAEMIA,**
SICKLE CELL DISEASE
& OTHER **RARE ANAEMIAS**

TRAVEL
GUIDANCE
FOR PATIENTS
AND FAMILIES



Most patients with thalassaemia, sickle cell disease (SCD) and other rare anaemias can travel abroad provided they take appropriate precautions and they are well aware in advance of these, which may vary between countries and especially across regions of the world.

It is important thus to consult with your treating physician **before** making any travel plans.

This booklet aims to only complement national recommendations for specific destinations or to just provide a general overview of considerations and guidance for patients with thalassaemia, sickle cell disease (SCD) and other rare anaemias who intend to travel abroad. Separated into three sections, travelling for leisure (vacations / holidays), studying away from home (in another city or country) and relocating (for work or other reasons), the information provided here is general in nature, and it is essential to consult your treating physician for personalized advice based on your specific medical condition and travel plans. They can provide you with the most accurate and up-to-date information to ensure your safety and well-being during your travels.

Those parts indicated in orange are specific for sickle cell disease patients.

Access to healthcare services may differ from country to country.

The Thalassaemia International Federation (TIF), upon request, can help you identify local assistance in the country / city you intend to visit. Specifically, TIF can provide guidance on:

1. The National Thalassaemia Association, including a focal point of contact in case of an emergency
2. Healthcare Providers (doctor, treating centre or centre of expertise), including a focal point of contact in case of an emergency (if available)

For longer stays and/or relocations, TIF can request from official sources, obtain and offer information to patients/parents regarding costs of blood transfusion, iron chelation and other medicines and whether these are financially covered by the national health system, out-of-pocket or private insurance. In addition, TIF can provide guidance on the procedures necessary in order to obtain coverage for your healthcare requirements.





Travelling for Leisure

► **Medical Consultation:** Prior to travelling, consult with your treating physician who is familiar with your health condition as early as possible (at least six weeks before travel). They can assess your overall health, provide necessary medical advice, and guide you regarding the suitability of travel.

If you have SCD and have had a severe crises within 2 weeks of a planned trip, you should NOT travel.

If you are unwell, and particularly if you have fever (high temperature) the day before or on the day of travel, consult with your doctor to advise if it is safe for you to travel or postpone your trip.

► **Destination Selection:** Consider the healthcare facilities available at your destination. It is recommended to choose destinations that have adequate medical facilities, resources and expertise to address any potential medical emergencies or complications related to your medical condition. It may be beneficial to travel for example to places with well-developed healthcare systems.

► **Medication and Medical Records:** Ensure that you have an adequate supply of necessary medications for the duration of your trip, including any backup medications in case of loss or delays. Carry your medical records (including your most recent in-patient medical information), pharmaceutical drug prescriptions, and contact details of your doctor(s), in case you need to seek medical assistance while travelling.

► **Vaccinations:** Stay up to date with routine vaccinations recommended for patients with thalassaemia, SCD and other rare anaemias, including those for Hepatitis B and A. Consult with



your healthcare provider to determine if there are any specific additional vaccinations related to the prevalence of particular infections at your destination. Your treating doctor will also advise if there are any contraindicated vaccinations or pharmaceutical drugs that you must not take based on your medical records and the medications you are currently taking.

► **Travel Insurance:** Consider obtaining travel insurance (wherever possible) that covers at least medical emergencies. Thalassaemia, SCD or other rare anaemia patients may have specific requirements, so review the policy carefully and ensure it covers any potential complications or hospitalizations related to your condition. **It is a known fact that insurers do not or are very reluctant to insure patients with these disorders and TIF is making strong efforts to alter this.**



EU citizens travelling through the European Union should ensure their EU Health Card is renewed and valid. This can be used to access healthcare facilities and services in an emergency.

► **Hydration and Diet:** Stay well-hydrated during travel to prevent dehydration, which can also occur due to diarrhoea (common among travellers abroad). Dehydration can exacerbate thalassaemia-related symptoms and trigger crises in SCD patients. Carry water and hydrating beverages with you. Additionally, maintain a balanced diet to support your overall health. Exercise caution with food whose ingredients you are not familiar with; adventures in exploring new food tastes may not be very safe as your digestive system may have an unwanted reaction.

SCD patients in particular should carry oral rehydration salt sachets to avoid triggering a crisis.

► **Blood Transfusions:** If you require regular blood transfusions as part of your management, ask your doctor to create a transfusion schedule that can help avoid emergencies during your trip. This includes the transfusion upon your return, not just the transfusion before departure.

If you plan to be abroad on vacation for a longer period of time then it is necessary to arrange for transfusion facilities at your destination well in advance, acknowledging the variable experience of the available / nearby transfusion facility and possible costs that may be incurred. Your doctor and TIF can help you with referrals or contacts for transfusion centres in the city you are visiting, if needed.

Bear in mind that blood transfusion practices, supplies and safety vary across the world.

Therefore it is important to identify the best possible transfusion centre in order to safeguard the safety and effectiveness of your transfusion.

► **Air Travel Considerations:** Thalassaemia and SCD patients may have an increased risk of developing deep vein thrombosis (DVT) due to prolonged periods of inactivity during air travel. To minimize this risk, stay hydrated, move around and stretch your legs regularly during the flight, and consider (upon your doctors' advice) wearing compression stockings.

Inform relevant authorities (e.g. airline etc) if you need to travel with prescribed medications, which may include antibiotics and strong painkillers such as opiates, or that may require refrigeration.

SCD patients who will require oxygen during their flight, should inform the airline to make necessary arrangements.

It is prudent to carry packed snacks for the flight as provision of on-board food and refreshments vary among airlines.

2. Studying Away from Home

Careful planning and consideration is needed to ensure your health and well-being while pursuing your studies away from home. In addition to the factors listed under the previous section (Travelling for Leisure) and given that you will likely be away from home for a longer period of time, it is worth considering the following:

► **Medical Records:** Carry your medical records (including your most recent in-patient medical information), pharmaceutical drug prescriptions, and contact details of your doctor(s), in case you need to seek medical assistance.



► **Educational Institutions:** Look for educational institutions that have a good support system in place for students with chronic and complex medical conditions. Consider universities or colleges that have healthcare facilities on campus or are located near quality healthcare providers with expertise in the clinical management of thalassaemia, SCD and other rare anaemias. It is essential to find out before you embark on your studies, whether the prospective educational institution has a medical / health office or service.

► **Medical Support:** Ensure that you will have access to medical support and specialists in your new location. Research and identify (where and if possible) local healthcare facilities, haematologists, and other specialists who can provide the necessary care and treatment for your condition well before you arrive. TIF can be of great help in such cases.

► **Student Health Services:** Familiarize yourself with the student health services offered by the (prospective) educational institution. Find out if they have any specific provisions for students with chronic medical conditions and the process for accessing healthcare services. Inform these services about your medical condition from your first day.

► **Medication and Treatment Continuity:** Plan ahead to ensure a seamless transition for your medication and treatment. Consult with your current doctor to determine the logistics of continuing your treatment plan in the new location. Make arrangements for an adequate supply of medications and understand how to refill prescriptions at your new location.

► **Insurance Coverage:** Review your health insurance coverage (if you have one) and ensure that it will still be valid in your new location or make any amendments needed. Understand the coverage for medical services and treatments related to your medical condition and make adjustments to your insurance plan if necessary.

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► **Healthcare Access:** Familiarize yourself with the healthcare system and its provisions for chronic and complex diseases, such as thalassaemia, SCD and other rare anaemias to ensure that you know your rights and you will have access to healthcare facilities and specialists appropriate for your medical condition in your new location. Thalassaemia, SCD or other rare anaemias require ongoing and specialized medical management, so it is important to have doctors who are knowledgeable and expert, and can continue (and even improve) your treatment plan, wherever possible. It may be necessary to connect with a Reference Centre in the city / country for more specialized consultation in case your new doctor has confined experience in managing your medical condition.

It is imperative to investigate and understand the procedures and processes for accessing treatment in your new location well in advance, including the costs of blood transfusion, iron chelation and other medicines and whether these are financially covered by the national health system, out-of-pocket or private insurance.

If you are an EU citizen planning to study in another EU country, consult with the national focal point for cross-border healthcare in your home country to find out this information. More information about patient rights in cross-border healthcare is found on TIF's factsheet here. In addition, make sure your EU Health Card is valid and carry it with you at all times.

Communicate with Educators: Inform the (prospective) educational institution about your condition. Communicate with your professors, advisors, and any relevant staff members (or at least one focal person) about your needs and any potential accommodations required. They can provide support and help you navigate any challenges that may arise during your studies.

▶ **Support Network:** Build a support network in your new location. Reach out to fellow students, student organizations, or local patient associations (ask TIF to help) to connect with others who can provide guidance, share experiences, and offer support.

▶ **Self-Care and Stress Management:** Prioritize self-care and stress management while balancing your academic responsibilities and disease management. Maintain a healthy lifestyle, get enough rest, and practice stress reduction techniques such as meditation or exercise.

▶ **Emergency Preparedness:** Familiarize yourself with emergency procedures and contact information at your new educational institution. Make sure you have emergency contact numbers readily available, including those of healthcare providers and support network.

Remember to consult with your treating physician throughout the process. They can provide personalized advice, address any concerns, and ensure a smooth transition in managing your disease while pursuing your education.

3. Relocation

Relocating for work or other reasons as a thalassaemia, SCD or other rare anaemia patient requires careful advance planning and consideration to ensure your health and well-being are ensured. In addition to the considerations listed under the previous sections (Travelling for Leisure, Studying away from home), below are some additional aspects to take into account:

▶ **Migration:** It is of the utmost importance to complete all documents and procedures so your relocation is legally recognised by the authorities in the destination country. Legal migration / immigration will mean that you are entitled to services offered by the country's health and social care system to meet your needs as a thalassaemia, SCD and other rare anaemias patient.

▶ **Healthcare Access:** Familiarize yourself with the healthcare system and its provisions for chronic and complex diseases, such as thalassaemia, SCD and other rare anaemias to ensure that you know your rights and you will have access to healthcare facilities and specialists appropriate for your medical condition in your new location. Thalassaemia, SCD or other rare anaemias require ongoing and specialized medical management, so it is important to have doctors who are knowledgeable and expert, and can continue (and even improve) your treatment plan, wherever possible.



It is imperative to investigate and understand the procedures and processes for accessing treatment in your new location well in advance, including the costs of blood transfusion, iron chelation and other medicines and whether these are financially covered by the national health system, out-of-pocket or private insurance.

If you are an EU citizen planning to relocate to another EU country, consult with the national focal point for cross-border healthcare in your home country to find out this information. More information about patient rights in cross-border healthcare is found on TIF's factsheet here. In addition, make sure your EU Health Card is valid and carry it with you at all times.

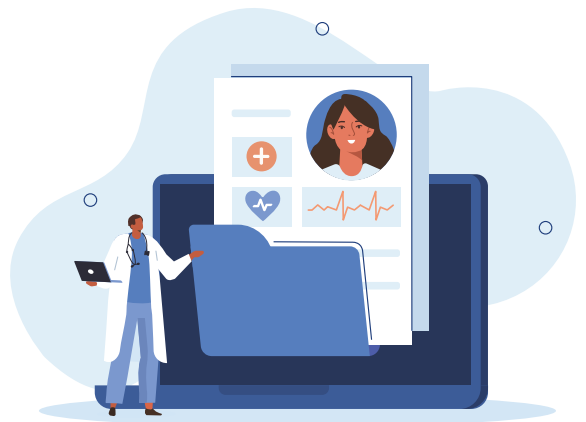
► **Insurance Coverage:** Review your health insurance coverage (if you have one) and ensure that it will still be valid in your new location or make any amendments needed. Understand the coverage for medical services and treatments related to your medical condition and make adjustments to your insurance plan if necessary.

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► **Medication and Treatment Continuity:**

Ensure a seamless transition for your medication and treatment plan. Before relocating, consult with your current doctor to ensure you have an adequate supply of medications for the short-term until you have settled down. Determine the logistics of continuing your treatment plan in the new location.

► **Medical Records Transfer:** Arrange for the timely transfer of your medical records from your current healthcare providers to the new ones. This will help the new healthcare team understand your medical history and make arrangements for the continuation of your care. Availability in electronic form is a great added-value.

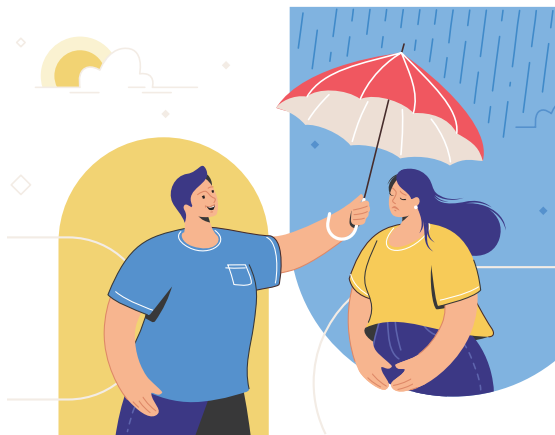


► **Support System:** Relocating to a new place can be emotionally challenging. Establish a support system in your new location, to help cope with the stress and emotional aspects of the relocation process. Connect with local patient associations (ask TIF to help) to find others who can provide guidance, but most importantly to share experiences, and offer support.

► **Lifestyle Considerations:** Take into account lifestyle factors that may impact the management of your disease. Consider factors such as climate, air pollution, and lifestyle habits like diet and exercise in your new location. Adapt your lifestyle accordingly to support your overall health.

► **Planning Ahead:** Give yourself plenty of time to plan and prepare for the relocation. This includes apart from organizing your medical supplies (as recommended above), finding appropriate housing that suits your needs, and understanding transportation options to healthcare facilities.

Remember to work closely with your healthcare provider throughout the relocation process. They can provide personalized advice, address any concerns, and ensure a smooth transition in managing your disease in your new location.



40 Tips for parents of children with thalassaemia, SCD and other rare anaemias

Travelling with a child who has thalassaemia, SCD or another rare anaemia requires extra planning and preparation to ensure their health and safety. Here are some tips (this is not an exhaustive list) for parents travelling with children with thalassaemia, SCD or another rare anaemia:

► **Consult with Treating Physicians:** Before travelling, consult with your child's doctor who is familiar with their thalassaemia, SCD or other rare anaemia needs. Discuss the travel plans and seek their advice on any special precautions or recommendations specific to your child's needs. Ensure that their condition is stable and that they are fit for travel, particularly if the trip will take many hours.

► **Medication and Medical Supplies:** Pack a sufficient supply of your child's medications, including any backups in case of delays or losses. Carry a complete list of their medications, dosages, and any specific instructions. If travelling by air, keep medications in your carry-on bag to ensure they are easily accessible. Pack any other necessary medical supplies, such as needles, syringes, or infusion equipment.

For customs, it is prudent to carry an official confirmation of your child's diagnosis and medical condition as well as treatment needs, signed by your child's doctor. This will provide justification / documentation for carrying needles, medications and other necessary medical equipment.

► **Insurance Coverage:** Consider purchasing travel insurance for you and your child (if and when possible) that will cover medical emergencies and other specific needs. Keep a copy of the insurance details easily accessible during the trip.

EU citizens travelling through the European Union should ensure their EU Health Card is renewed and valid. This can be used to access healthcare facilities and services in an emergency.

► **Access to Medical Care:** Identify healthcare facilities, hospitals, or specialists at your destination who are familiar with thalassaemia, SCD or other rare anaemia. Ensure (if possible) that their contact information is readily available in case of emergencies or if medical assistance is needed during the trip.

► **Hydration and Nutrition:** Thalassaemia and SCD patients, especially children, need to stay well-hydrated. Encourage your child to drink plenty of fluids during the trip. Carry a water bottle and hydrating beverages with you. Also, pack nutritious snacks and meals to maintain a balanced diet during travel.

It is prudent to carry packed snacks for the flight as provision of on-board food and refreshments vary among airlines.

► **Weather and Climate Considerations:** Be mindful of the weather and climate at your destination, as extreme temperatures or certain weather conditions may impact your child's well-being. Take necessary precautions, such as dressing appropriately, using sunscreen, or staying hydrated to ensure their comfort and health.

► **Transportation Considerations:** If travelling by air, inform the airline in advance about your child's medical condition. They may be able to provide assistance or accommodations, such as pre-boarding or seat selection to ensure your child's comfort during the flight. For long journeys, consider frequent breaks and movement to prevent any risk of deep vein thrombosis (DVT).

► **Emergency Preparedness:** Keep a list of emergency numbers, including local emergency services, your child's doctor, and any local support networks you may have (e.g. local doctor, patient support group etc). You may choose to consult TIF in these issues.

► **Enjoyment and Rest:** While taking necessary precautions, remember to create opportunities for your child to enjoy the trip and engage in age-appropriate activities. Find a balance between exploration and rest to ensure they have an enjoyable travel experience.



The following checklist we hope will help you in your travel plans!

Travel Checklist

BEFORE TRAVELLING

- Inform your doctor about travel plans as early as possible (at least six weeks before travel).
- Ask your doctor to create a transfusion schedule that can help avoid emergencies during your trip. This includes the transfusion upon your return, not just the transfusion before departure.
- Make sure you are up-to-date with routine vaccinations and the hepatitis B vaccine. See TIF Guidelines for more information.
- Confirm if there are specific vaccines (or boosters) that are recommended for your destination (your doctor will be able to advise on these) and make necessary arrangements well before travelling.
- Contact relevant authorities (e.g. airline etc) to inform them if you need to travel with prescribed medications, which may include antibiotics and strong painkillers such as opiates.
- Arrange with the airline if you will need oxygen during the flight.
- Take malaria prevention medication ahead of your trip (if you are travelling / transit in a country where malaria occurs).
- Consider purchasing travel insurance to cover any emergency medical expenses and repatriation if necessary.
- Before departure, make sure you book your next transfusion appointment!

Occurrences during the trip (e.g. weather, delayed flights, stress levels etc) can affect anaemia levels. It is best to avoid “urgent” transfusions upon returning home.

Don't forget to pack:

- Iron chelation and other medicines (including extra quantities just in case they are needed)
- Medical report from your doctor stating your diagnosis and treatment plan. This should include your usual haemoglobin level, medications, drug allergies and emergency contact and any haematological and other tests results for at least the last 6 months
- Mosquito net and insect repellent (especially if travelling to a malaria endemic area)
- Malaria treatment medicine (especially if travelling to a malaria endemic area and staying far from medical care)
- Oral rehydration salt sachets (for SCD patients)
- Current vaccination record

ALL MEDICINES SHOULD BE PACKED IN YOUR HAND-LUGGAGE

DURING THE TRIP

On long flights (more than 6 hours) make sure that you:

- Walk around at least every 30 minutes
- Stay well-hydrated (drink water and avoid alcohol)
- Wear warm clothing / use a blanket to avoid chilling
- Wear flight socks to reduce the risk of thrombosis

- ▶ Get treatment urgently if you develop fever or notice blood in the stools or if you are bitten (by insects or other animals).
- ▶ Wear protective clothing (e.g long trousers), especially if trekking or camping and use mosquito nets.

AFTER RETURNING HOME

- Make sure you book your next transfusion appointment before departure as occurrences during the trip (e.g. weather, delayed flights, stress levels etc) can affect anaemia levels. It is best to avoid “urgent” transfusions upon returning home.

The Thalassaemia International Federation (TIF) remains committed to ensure that children and adults with thalassaemia, SCD and other rare anaemias remain safe while travelling and obtain appropriate for their needs health and other care at their destination by providing any requested information on available health-care services and providers as well as the processes necessary for healthcare coverage (for longer stays).

Contact us today with your request at
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