

Away We Go!



TRAVEL TIPS FOR THE BLEEDING DISORDERS COMMUNITY

Sure, travel can pose some extra challenges for individuals and families who manage a chronic illness like hemophilia, vonWillebrands, and other rare bleeding disorders. But with a little planning there's no reason you can't set off on adventures near and far... relax and have a great time!

BEFORE YOU GO

1. QUESTIONS FOR YOUR TREATMENT TEAM

- Should you take a dose of factor before you leave?
- Should you change your prophylaxis schedule or temporarily adopt a prophylaxis regime?
- How many doses of factor should you bring with you? Ask about other medications that are part of your treatment plan (Amicar, DDAVP).
- How should you pack and store medications?
- Do you need to carry prescriptions for your medications?

2. CARRYING PROPER IDENTIFICATION/ DOCUMENTATION

- Medical identification jewelry – it is always important to wear some kind of medical identification, but never more so than when you're traveling. Paper documentation can get lost or destroyed – this could save your life.
- Travel letter – provided by your Hemophilia Treatment Center (HTC) or Hematologist, this letter should describe your diagnosis, how you treat, what kind of medication and supplies you are traveling with, why it's important that your factor bag stay with you at all times, and contact information for your treatment team in case of an emergency. This letter should be dated within the last 12 months. Find a sample Travel Letter in HFA's Be Prepared Tool Kit at www.hemophilia.org
- Carry several copies of emergency contact info – if you can't speak up for yourself, make sure medical providers know how to contact your HTC or Hematologist and a designated friend or family member back home. Also leave important contact info with that person at home so they can help in an emergency.

3. PACKING YOUR FACTOR

- Most factor products can be stored at room temperature, but each product has different requirements so check the package insert or the manufacturer's website under "Prescribing Information."
- NEVER pack factor in checked baggage. Pack factor and supplies in their own carry-on bag to simplify the inspection process.
- Don't forget a small Sharps disposal container – you should be able to get one from your factor provider.
- While not always required, it is recommended that factor boxes have a prescription label including provider's name and contact info.

4. DO YOUR HOMEWORK

- Insurance coverage on the road – ask your health insurer about benefits outside of your area and what their definition of an emergency is. Some policies require that you seek care at the closest ER – what happens if you want to go a further distance to a recognized Hemophilia Treatment Center? This is even more important if you have Medicare or Medicaid as there are very specific rules for out-of-state coverage.
- Know where to find hemophilia specialists – research which HTC's are near your destination and along the way. A U.S. Hemophilia Treatment Center Directory can be found at www.cdc.gov/nbddd/hemophilia/HTC.html. You may want to call ahead and tell them you'll be in the area; ask if they carry your brand of factor, and whether they'll let you bring in your own factor if you go to their ER. If you don't self-infuse, ask what support might be

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available for infusions. The World Federation of Hemophilia (www.wfh.org) provides a list of HTC's in over 100 countries.

- Find out if your factor provider will ship to your destination – if you're going to be away for an extended period of time it might be easier to travel with a small amount of factor and supplies and have the rest shipped to your destination (be prepared to ship home or travel with whatever's left). Knowing that you can get more factor in a pinch can also reduce stress while traveling.
- Don't be caught by surprise at the airport – check out The Transportation Security Administration (TSA) website: <http://www.tsa.gov/traveler-information/travelers-disabilities-and-medical-conditions>. The guidelines for persons with diabetes also apply to people with bleeding disorders.

- Mobility assistance – if you expect to need assistance at any airport on your itinerary, contact your airline at least 24 hours in advance. You may be able to request special seating on the plane by contacting your airline's Customer Service or Disability Service Dept. Be prepared for varying levels of service and accommodations.
- Hotel rooms – consider asking for a room on a lower level in case there's an emergency, power failure or maintenance issue that takes elevators out of service. Make sure your room has a refrigerator if cold storage is required for factor.

DURING YOUR TRIP

1. Airport Security – while you should be prepared for all possibilities, most people with bleeding disorders will tell you that they have no problems carrying factor and supplies through security.

- At the screening checkpoint, notify the Security Officer that you have a bleeding disorder and are carrying your medication and supplies with you.
- You can request that TSA officers visually inspect your medication and supplies instead of putting them through the x-ray.
- The limit of one carry-on and one personal item (purse, briefcase, computer case) does not apply to medical supplies.
- Let them know if you have any implants (i.e., port-a-cath, joint replacement) that might set off security alarms.

2. NEVER leave factor in a hot or freezing car!

3. Keep infusion records while traveling

4. International Travel

- If you're traveling to a country in which English is not commonly spoken, try to bring a Travel Letter written in a second language.
- Most private health insurance policies provide some coverage for emergencies abroad, but the only way to know for sure is to ask. Be prepared to pay upfront; get itemized receipts from all medical providers so you can submit a claim when you get home.
- Medicare or Medicaid pays only for services in the 50 states, Washington DC, and U.S. Territories such as Puerto Rico.