

While Traveling Be Prepared for All Possibilities!

- 1 Let your HTC medical team know you will be traveling out-of-state or country in order to set up an appropriate plan.
- 2 Review with them the number of doses you will need while on your vacation and, if necessary, contact Cascade well before your trip to ensure timely delivery of your meds. Keep in Mind: Extra doses may require more approval time from your insurance company.
- 3 Familiarize yourself with your insurance plan rules regarding out-of-state travel, or particularly when traveling internationally. Be sure to carry your current insurance information with you at all times.
- 4 Ask your nurse to supply you with an **Emergency Department or Travel Letter** explaining your disorder and how to treat. The HTC writes many of these letters and may also call an HTC near your vacation destination, if necessary. As applicable, have all letters written in English or in the language of the country you are visiting.



Planning Ahead for Unexpected Occurrences will Help You Relax and Enjoy Your Trip

- 5 Review a list of treatment centers in the state/s or countries that you will be visiting to determine availability of adult and/or pediatric care centers in the area. Remember some HTCs only treat adults or pediatric patients. **Visit:** hemophilia.org for a complete list of U.S. treatment centers and wfh.org for centers outside of the U.S.
- 6 If flying, carry all factor products, medications and supplies (in their original containers) along with the treatment center letters in your carry-on to ensure they arrive with you at your destination and maintain their required temperature. Place them in a clear plastic bag for ease during screening. **Visit:** your airline's website for more information and requirements, or tsa.gov/travel/special-procedures.
- 7 Don't forget to wear your up-to-date medical ID bracelet at all times.

And Have Fun!

Excerpts taken from: Hunter, Susan, RN, BSN. Nursing Working Group-Nurses' Guide to Bleeding Disorders. National Hemophilia Foundation. 2013
World Federation of Hemophilia website wfh.org/en/page.aspx?pid=902 December 7, 2016



Language assistance services are available free of charge. Call: 1-800-996-2575.

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-800-996-2575.

يلااتلا مقرلاب لاصتالاء اجرلا. أناجم كل عرفوتم ةيوغلللا ةدعاسملاو ةمجرتللا تامدخ نإف ،ةيبرعللا م لكنتت تنك اذا :ةظحالم (1-800-996-2575)



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A Message from Cascade's Colleen Joiner, Social Worker

Dear Readers,

With Spring upon us and Summer arriving soon, many of us look forward to taking a well-deserved vacation. There's really nothing more exciting than finding the perfect location to wind down, relax, and enjoy family and friends.

We hope you take a moment to read about the Jafri family's international travel experience in this month's newsletter and review some helpful travel tips to make your vacation safe and enjoyable! Have a wonderful time wherever you may go. Enjoy!

Colleen



Hemophilia Treatment Center staff enjoying a pre-conference side-trip

Cascade Hemophilia Consortium Mission

To enhance the system of care for people with bleeding disorders and related complications, by assuring the lowest possible price for the full range of treatments, HIV and hepatitis related therapies and other medications available to treat their disease; to provide access to these medications for those without insurance or inadequate insurance coverage; to support the comprehensive hemophilia treatment centers in treating and educating consumers and their families so they may become knowledgeable and proactive in managing their own care; to fund research.

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International Travel with the Jafri Family

In 2016, Fiza Jafri came with her family to the United States from Pakistan. They came to be with family, but more than anything, they wanted to be sure that Fiza and her brother, Wajid, received adequate care for their bleeding disorders. Both Fiza and Wajid were diagnosed in Pakistan with a rare Factor X deficiency, and care for their bleeding disorder at the time was not ideal.

Fiza and Wajid are the only two in the extended family to be diagnosed with a bleeding disorder. Fiza explained that they received the “gene jackpot” because both of her parents must have had a recessive gene.

Fiza, her parents, and her three siblings visit Pakistan as a family once each year for a period of up to 45 days. They have several family members who remained in Pakistan, and they enjoy the extended stay, visiting with their grandmother, aunts, and cousins.

It can be overwhelming for any family of five to plan such a trip. But when you have a bleeding disorder, you have more to consider than which flights to take or what to pack. When you add travel to a country in which many people do not have access to factor products or other medicine, it can become much more complicated.

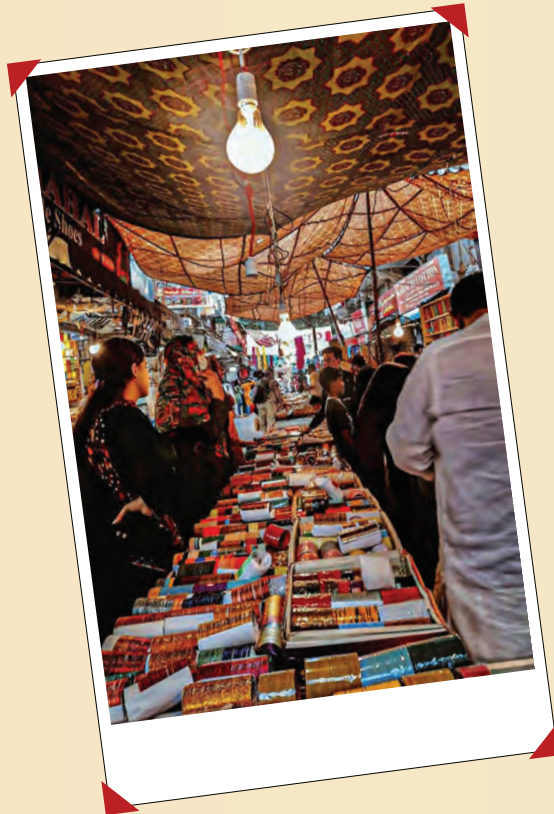
Identify the Nearest Medical Facility

Most hemophilia treatment center (HTC) teams advise families to identify the nearest HTC at your vacation destination before leaving home. Bring the address and phone number with you on the trip, and if traveling to more than one state or country, bring multiple contacts. Your HTC can help you find where these clinics are located.

Visit: hemophilia.org for a complete list of U.S. treatment centers and wfh.org for centers outside of the U.S

In Fiza’s case, she is fortunate that her Pakistani family lives in Lahore, as it’s close to one of the free clinics funded through the World Health Organization. Factor products and other medicines are donated to the facility, and the medical services are provided free of cost. The Jafri’s factor product is not always available there and that’s why it’s critical they take their own. The family is happy with the hematologist in Pakistan, Dr. Shahla Sohail, and they feel they receive excellent care as she is also a prominent bleeding disorders activist.

Fiza recommends that **regardless of where you travel, “You should plan ahead and locate where a treatment center is nearby.** You may even want to go to the center if you’re out of the country. To me, nothing is spontaneous. I try to be prepared for all outcomes.” Fiza, who is a student at the University of Michigan, Dearborn, arranges most, if not all, of the travel arrangements for the family. And she certainly has experience!



Plan Ahead

When asked how the family plans for their annual trip, Fiza says she starts by talking to her HTC staff **two months** before the visit. She states, “I understand that I’m not the only patient the clinic is working with, and I want to give them time.”

One month to two weeks before the trip, Fiza reminds her HTC nurse, and they start talking about the amount of factor they might need for their stay. They also review the travel letter the family will need to take with them. The HTC then notifies Cascade, and our insurance specialists check to see if the insurance plan will approve any additional doses needed for the trip. This is sometimes referred to as a “vacation fill.” Finally, Fiza requests the delivery to her home three days before the trip so that she doesn’t need to worry at the last minute.

Traveling With and Storing Your Medication

Most HTC staff recommend bringing your factor, Hemlibra, or other medication with you on the plane in case your luggage is lost. However, if you are planning an extended trip or have more medication than can be carried, there are some creative ways to keep it safe.

Airlines to Pakistan limit luggage for each passenger. Because Fiza and her brother treat twice per week, their factor and supplies are extensive and count as two full pieces of luggage. Their factor product doesn’t require refrigeration but the Jafri’s like to be sure it doesn’t get too warm during the 16-hour flight and prefer to refrigerate it.

To do this, they have a creative plan. Fiza states, “Once we receive the medication for our trip, we unload the factor into the refrigerator. Then we take the cold packs out of the box

and put those in the freezer until the morning of the trip. We packed everything back into the box that morning, including the ice packs and a copy of the travel letter. The medication and supplies are the last to go into the car, and they are always in their original packaging.” They even purchased a refrigerator in Pakistan to keep at a family member’s home to store their medications while they are there.

Sage Advice

Fiza’s advice to plan ahead is key. It’s important to work with your treatment center and pharmacy to get everything in place including your medication and supplies. If you plan ahead, you’ll be ready for anything and have more time to enjoy your vacation!

