



Travel and Vacation Planning

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Travel is a normal part of life. This chapter addresses aspects of travel to be considered in order to decrease worry and allow for happy and healthy travel for individuals with a bleeding disorder and their families. Planning and preparation will provide the most efficient plan of care, should trauma or other unexpected events occur.

Though the focus of this chapter is vacation and trip planning, it is important for the HTC staff to discuss with patients that any time they are away from home or using vehicles such as the car, bus, boat or bike, they should follow some basic safety measures. Please see the attached MASAC document #201 recommendation (Attachment A) for usage of medical alert tags and the resources listed at the end of this chapter. Patients should be reminded to always wear an up-to-date medical alert tag and carry a medical emergency card in their wallet. These medical alert tags generally can be obtained by mail order, web site, local pharmacy or hemophilia chapters.

Note also that the CDC website <http://emergency.cdc.gov> has a Family Emergency Kit Checklist which includes tips for people with bleeding disorders and general vehicle safety.

PREPARATIONS FOR TRAVEL

Hemophilia Treatment Centers (HTCs), many of which have undergone a name change to reflect care for hemostasis and thrombosis patients, play an important role in preparing their patients for travel. They also serve as valuable resources for families travelling to their location because of the assured expertise in managing bleeding disorders and the ease of networking with each other. When searching for HTCs to serve as a resource, it is important to note that some centers serve only pediatric or adult patients, while others can accommodate both populations.

HTC staff should discuss the importance of planning for travel at the annual comprehensive evaluations and during other routine contacts with the family. The hemophilia nurse assists by helping the family exercise responsibility in making preparations to insure safe, enjoyable travel.

Families should consider each member's ability to participate in the activities of the trip and discuss any concerns with the HTC staff ahead of time.

Patients must have a thorough knowledge of their therapy and its purposes. They should understand the plan in case of trauma and or bleeding events. Of course, this plan must be individualized for each patient.



LOCATING A HEMOPHILIA TREATMENT CENTER

An essential step in planning a trip is locating HTC's in the cities, states, or countries that the family will be visiting.

To locate HTC's in the US:

Anyone can access the Centers for Disease Control and Prevention (CDC) website at www.cdc.gov/ncbddd/hemophilia/treatment.html for the HTC directory. This list includes only federally funded HTC's in the United States. There may be other medical facilities not listed on this website that can serve the patient with a bleeding disorder. Access to this same directory is also available through the National Hemophilia Foundation at www.hemophilia.org

Contact information for National Hemophilia Foundation (NHF):

National Hemophilia Foundation
116 West 32nd Street, 11th Floor
New York, NY 10001
Phone: (212) 328-3700
Fax: (212) 328-3777

HANDI, NHF's free, confidential information resource center, answers questions, makes referrals, provides literature and maintains an extensive library collection on bleeding and clotting disorders. Phone 800-424-2634, e-mail: handi@hemophilia.org.

To locate HTC's in other countries:

The World Federation of Hemophilia (WFH) web site is www.wfh.org. This site contains a listing of the names, addresses and telephone numbers of HTC's in countries around the world. Go to the web site and click on the 'Resources' tab for the drop-down option to Find a Treatment Centre.

The contact information for WFH is:

World Federation of Hemophilia
1425 Rene Levesque Blvd. West, Suite 1010
Montreal, Quebec, Canada H3G 1T7
Telephone: (514) 875-7944
Fax: (514) 875-8916
E-mail: wfh@wfh.org
Web site: www.wfh.org

Once the patient/family has identified the HTC of choice near their destination, they should confirm that the listed contact information is correct and request that the HTC send a medical information travel letter. It is always worthwhile for the family to call the identified HTC and verify their ability to serve the patient. It is also helpful to discuss specific concerns or requirements the individual may have in their treatment plan. The patient should also have a



copy of the medical information travel letter to carry with him in the event travel plans or destination changes occur.

FACTOR CONCENTRATE, STIMATE, AMICAR and OTHER MEDICATIONS

SUPPLY AND ADMINISTRATION

The HTC nurse can help determine the quantity of factor, infusion supplies and other treatment products that may be necessary to take along for travel. Considerations as to the length of stay, self infusion capability, plan for on demand or prophylaxis treatment, and the availability of the product at the proposed location must be used to determine a reasonable amount to transport. Possible sources of treatment products should be explored. If a local HTC or the patient's homecare company can provide medications, supplies or nursing support at the travel destination, this may reduce the need to transport large amounts of factor and supplies or to visit a hospital for infusions.

Biohazard containers for sharps and contaminated materials must be included, and arrangements for disposal should be planned. The nurse should help coordinate a medication schedule for routine treatments, keeping in mind the change in time zones.

STORAGE

Storage of factor products, medications and supplies while in transit and upon arrival should be addressed. The HTC nurse should review with families the concerns regarding light exposure and temperatures for medications as well as storage of medications and supplies in a safe and secure location. This will be individualized, and it should be noted that not all factor products have the same storage requirements.

AIR TRAVEL

Patients should keep medicine and supplies with them and not check medications through as luggage.

US commercial airlines have increased security measures since September 11, 2001, and the restrictions are subject to change. Air travelers should check with their airline at least several days prior to departure to learn the specific regulations regarding the transport of medications and supplies. NHF recommends that when traveling with clotting factor, an individual should bring a prescription from his/her physician with contact information, as well as a letter from the physician/HTC that provides a brief explanation of the condition and the need for the medication. In addition, when needles are brought onto an airplane in carry-on luggage, the traveler must have clotting factor with him/her as well. See the full recommendations at www.hemophilia.org: click on News and then click on Travel Advisory. See attachment C for sample travel letter templates that you can individualize for each patient.

INSURANCE



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The patient and family should carry current insurance information at all times, making sure it includes the number of their service representative should it become necessary for providers to contact the company. It is important to determine whether there are restrictions in coverage for travel outside their area, especially for international travel.

ACCESSIBILITY

If a wheelchair will be required, it should be determined if all locations to be visited are wheelchair accessible. If traveling by airline, train or bus, call ahead to make arrangements if a wheelchair is necessary.

ADDITIONAL CONSIDERATIONS FOR INTERNATIONAL TRAVEL

The Centers for Disease Control and Prevention (CDC) Web site www.cdc.gov/travel/ contains recommendations for immunizations when traveling abroad. Also see attachment B for General Preparation: Practical Considerations which is also available at the CDC website.

Providers of medical alert tags, such as MedicAlert, also provide assistance for travel, such as locating physicians and translation services through their special services found under Travel Plus program. See www.medicalert.org or call 888- 633-4298. This resource is provided as a sample of available information and is not meant as a recommendation of any particular service organization.

Encourage patients to bring a letter summarizing their care in the language of the country they are visiting. Medical services may need to be paid for in cash. Problems beyond simple language barriers may involve the transport of drugs, particularly for pain, and transport of syringes and needles. A note written on the prescription indicating their necessity may be helpful.

THE IMMUNOCOMPROMISED TRAVELER

The nurse should remind the patient to contact his/her infectious disease healthcare provider well in advance of travel. A physical exam including blood work, prescriptions for medications, and recommendations for vaccinations all need to be addressed.

Preventative measures regarding exposure to respiratory infections and vector-borne illness should be reviewed.

For more information, visit the CDC website at www.cdc.gov/travel/ and click on Travelers with Special Needs..

TRAVEL LETTERS

A letter explaining the patient's condition and required treatment is an essential component of ensuring safe travel. Travel letters should be customized to express the specific needs and



concerns for each patient. Here is a general outline of information to be provided in most travel letters:

1. Demographic information: Name, address, telephone, date and place of birth.
2. Type and severity of bleeding disorder.
3. Treatment required: product, dosage, frequency, method of administration and reason (emergency, routine bleeding, prophylaxis).
4. Special considerations: inhibitor, target joints, sensitivities or allergic reactions, and past experience.
5. Self-infusion or assisted infusion capacity.
6. Authorization to carry factor concentrates, needles, syringes and other supplies
7. Prior medical and social history
8. Name and contact information, including phone number with 24 hour availability of hemophilia provider or HTC.

See attachment C for basic sample letter templates.



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Resources:

1. National Hemophilia Foundation. Nurses' Guide to Bleeding Disorders 2002. Chapter 15 Travel and Vacation Planning by Marilyn Ford, RN.
2. National Hemophilia Foundation. Traveling With Factor Supplies and New Airline Safety Precautions.
3. World Federation of Hemophilia. Passport. 2000
4. Gorlin JB, Hooke MC. Use of emergency medical identification in the paediatric haemophilia population: a national study. Haemophilia 2011; 17: 215-22.

Contact information:

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2. World Federation of Hemophilia
1425 Rene Levesque Blvd. West, Suite 1010
Montreal, Quebec, Canada H3G 1T7
Telephone: (514) 875-7944
Fax: (514) 875-8916
E-mail: wfh@wfh.org
Web site: www.wfh.org

3. Office of Health Communication
National Center for Infectious Diseases
Centers for Disease Control and Prevention (CDC)
Mailstop C-14
1600 Clifton Road
Atlanta, GA 30333
<http://emergency.cdc.gov>
CDC HTC directory: www.cdc.gov/ncbddd/hemophilia/treatment.html
CDC Travelers' Information website: www.cdc.gov/travel/

4. MedicAlert Foundation
888-633-4298.
www.MedicAlert.org



**Attachment A
Masac Document #201**

MASAC Document #201

The following recommendations were approved by the Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation on November 13, 2010, and adopted by the NHF Board of Directors on November 14, 2010.

**MASAC RECOMMENDATION ON USE OF
EMERGENCY MEDICAL IDENTIFICATION DEVICES FOR CHILDREN**

The Nursing Working Group (NWG) conducted a survey of use of Emergency Medical Identification (EMI) devices available for children and found that there are no devices appropriate for infants and young children under 3 years of age. In addition, the number of children wearing these devices is low in all age groups. Based on their study, the NWG has established the following guidelines for use of EMI devices in children:

- For all age groups, EMI should be worn on the body instead of externally such as in a wallet, on a car seat, or in a caregiver's purse or diaper bag. An emergency medical identification card placed in one of those locations can accompany the child, but this should not replace EMI on the child.
- The EMI should be identified with a medical symbol (i.e. Caduceus) and look like an EMI so it will not be mistaken for a piece of jewelry.
- The EMI should be fastened securely but not tightly and should be assessed frequently to insure that the fit is snug but not tight.
- Presently there is no ideal EMI for infants under 1 year of age.
- All EMIs placed on a child <3 years old which have emblems or clasps <1 3/4 inches should carry the warning: "Not intended for children < 3 years old due to choking hazard."
- These are general guideline to be adapted to meet the needs of each child.

NHF does not endorse any specific brand of EMI, however being affiliated with a 24- hour on-call nonprofit program is encouraged.



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Emergency Medical Identification (EMI) Options by Age

Infant (<1 year old)*	Toddler and Preschooler (1-5 years old)*	School age and Adolescents (6-13 years old)
MedicAlert® Petite/Child metal emblem with chain bracelet placed on ankle. Starts at size 4 1/2 inches*	MedicAlert® petite/child metal emblem with chain bracelet or metal emblem with sport strap placed on ankle/ wrist. *	MedicAlert® small metal emblem with chain bracelet or sport strap on wrist. Pendant Necklace, dog tag or beaded bracelet for children >8 yrs old.
StickyJ® metal emblem on sport strap placed on ankle. Size 4-6 inches*	StickyJ® metal emblem with sport strap placed on ankle/wrist. *	StickyJ® metal emblem with chain bracelet or sport strap placed on wrist. Pendant necklace or beaded bracelet for children >8 years old.
	Tagmykid® no metal emblem, cloth and velcro band placed on ankle/wrist. Starts at 5 inches*	Tagmykid® no metal emblem cloth velcro band placed on wrist.

MedicAlert® is MedicAlert.com (includes on-call program)

StickyJ® is StickyJewelry.com (on-call program not included)

Tagmykid® is Tagmykid.com (on-call program not included)

*All EMIs placed on a child <3 years old which have emblems or clasps <1 3/4 inches should carry the warning: “Not intended for children <3 years old due to choking hazard.”

This material is provided for your general information only. NHF does not give medical advice or engage in the practice of medicine. NHF under no circumstances recommends particular treatment for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

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Attachment B

General Preparation: Practical Considerations (www.cdc.gov/travel/)

Although traveling abroad can be relaxing and rewarding, the physical demands of travel (e.g., maneuvering through a crowded terminal, rushing to catch a flight) can be stressful, particularly for travelers with underlying chronic medical illnesses. However, with adequate preparation, these individuals can have safe and enjoyable trips.

The following is a list of recommendations to help those with chronic medical illnesses:

- **Ensure that any chronic illnesses are stable.** Persons with underlying medical illness should see their physicians to ensure that the management of their illness is optimized.
- **Recommend seeking pre-travel consultation early, at least 4–6 weeks prior to departure.** This is to ensure that there is adequate time to respond to immunizations and, in some circumstances, to try medications prior to travel.
- **Provide a physician’s letter.** The letter should be on office letterhead stationery, outlining existing medical conditions, medications prescribed (including generic names), and any equipment required to manage the condition.
- **Advise travelers to pack medications in carry-on luggage in their original containers.** Ensure sufficient quantities of medications for the entire trip, plus extra in case of unexpected delays. When crossing time zones, medications should be taken based on elapsed time, not time of day.
- **Educate regarding important drug interactions.** Medications used to treat chronic medical illnesses may interact with medications prescribed for self-treatment of travelers’ diarrhea or for malaria chemoprophylaxis. Discuss all medications to be used, either daily or on an as-needed basis.
- **Recommend consideration of supplemental insurance.** Consideration should be given for three types of insurance policies: 1) trip cancellation in the event of illness prior to travel; 2) supplemental insurance so that money paid for health care abroad may be reimbursed, since most medical insurance policies do not cover health care in other countries; and 3) medical evacuation insurance (see the [Travel Insurance and Evacuation Insurance](#) section in Chapter 2).
- **Help devise a health plan.** This plan should give instructions for managing minor problems or exacerbations of underlying illnesses and should include information about medical facilities available in the destination country (see the [Obtaining Health Care Abroad for the Ill Traveler](#) section in Chapter 2).
- **Recommend that the traveler wear a medical alert bracelet.**
- **Always advise the traveler about packing a health kit** (see [Travel Health Kits](#) section in Chapter 2).



Attachment C

Examples of travel letters

Letter for Severe hemophilia A or B

Date:

Regarding: *(name, address, phone)*

DOB: *(place of birth may also be helpful for some travel)*

To Whom It May Concern:

(The patient listed above) has severe hemophilia A/B/von Willebrand disease.

When he/she requires treatment, he/she receives approximately (dose/units) of (product). For most routine bleeding episodes, he/she needs one dose mixed and infused as an intravenous push. For invasive procedures or more serious bleeding, such as trauma to the head, neck or abdomen, this patient may need to begin treatment with a higher dose and then continue with medical follow up. He/She or His/Her parent will bring the clotting factor he/she uses. He/she is/is not trained in venipuncture for home/self infusion.

(Name) is followed by *(Physician name)*, a hematologist at *(Institution name)*. Please call (phone number) at any time day or night for hemophilia treatment information or concerns regarding the care of *(name)*.

Sincerely,

Name

Title

Letter for Mild Hemophilia A

Date:

Regarding: *(Name, address, phone)*

DOB: *(place of birth may also be helpful to include)*

To Whom It May Concern:

(Patient name) has mild hemophilia A. He/She could have prolonged bleeding resulting from injury, surgery or invasive procedures. For concerns of prolonged bleeding, we recommend using desmopressin acetate (DDAVP) (include form of DDAVP and dose). Our testing demonstrated that this dose will result in a doubling of his/her factor VIII activity as it releases stored factor into the bloodstream.



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For severe trauma, treatment with a factor concentrate may be indicated. If you have any questions about hemophilia treatment for this patient, please contact the hemophilia treatment center at (*institution name*) by calling (*phone number*).

Sincerely,
Name, Title

Letter to a Physician:

Date:
Regarding: (*name*)
DOB:
To Whom It May Concern:

(Patient name) is followed by the Hemophilia Treatment Center (HTC) at (institution name) and has been diagnosed as having von Willebrand disease (type)/hemophilia (factor deficiency %). He /she and/or a family member have been trained to administer his/her clotting factor intravenously. Therefore, they are in possession of syringes, needles, and appropriate supplies for the infusions. This patient and the family are knowledgeable about this disease and its treatment; please listen to them. On occasion it may be necessary for this patient to seek the aid of physicians or nurses at a hospital or emergency room.

In the event of a bleeding episode, the patient will need clotting factor therapy with (product). The dosage range is (units/kg). Recommendations are as follows:

Never prescribe aspirin or aspirin-containing drugs or those medications that inhibit clotting. Higher doses of clotting factor are used for major injuries such as a head injury than for routine trauma. Always infuse immediately when bleeding is suspected or documented.

If you have questions or need assistance in the care of this patient, contact the HTC at (phone number).

Sincerely,

Name
Title and institution

Letter to an Emergency Physician (1)

Date:
Regarding: (*name, address, phone*)
DOB: (*place of birth may also be helpful to note*)

Dear Emergency Room Physician:



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Please be advised that (*name*) is a person with hemophilia A/B or von Willebrand disease. His/Her percent of factor ____ is ____%. We treat him/her with (product name) approximately (units/kg) for routine bleeding episodes. For a serious bleed or invasive procedure, he/she should receive approximately (units/kg) as his/her dose.

(*Name*) is approved by us to carry the factor and ancillary supplies with him/her. If you have concerns or questions regarding this treatment, please do not hesitate to contact our office at (*phone number*).

Your participation in the care of this patient is greatly appreciated.

Sincerely,

Name

Title

Letter to an Emergency Physician (2)

Date

Dear Emergency Care Provider,

My patient, _____ DOB _____ has mild Hemophilia B with a Factor IX (nine) level of ____%. Hemophilia is a rare, genetic blood clotting disorder. The bleeding may follow trauma or may occur spontaneously. Since the bleeding may be serious and protracted, the patient needs treatment instituted urgently.

In the early stages of the bleed there may be no visible physical abnormalities. Patients/families are taught to recognize an early bleed via the symptoms of tingling, pain, warmth and stiffness. If a bleed is suspected, please treat immediately. It is imperative that you listen to the patient or his parent.

In the case of trauma, such as head injury or MVA, it is prudent to administer recombinant factor IX concentrate, prophylactically rather than waiting for any signs of a bleed. Also, it is crucial that recombinant factor IX concentrate be administered prior to any invasive procedures such as an ABG, LP, NG tube insertion, etc. In addition, there is no clinical indication to perform x-rays of the extremities in the absence of trauma, as they will not change the management course.

IM injections should be avoided if at all possible. Aspirin and most non-steroidal anti-inflammatory agents (NSAID's) inhibit platelet function and therefore are contraindicated for



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persons with bleeding disorders. Acetaminophen products are safe as are opiates as long as they are not combined with ASA-containing medications.

_____ will travel with his own supply of recombinant factor IX, brand name. He needs a venipuncture with a small gauge Butterfly needle to administer his dose of factor nine. His dose of recombinant Factor IX concentrate is _____Units. His parent, _____, will be carrying the product he needs.

If you have any questions or problems, please do not hesitate to call. The HTC nurse, _____, can be reached during business hours at (phone). My office or the on-call hematologist can be reached 24-hours a day at (phone).

Sincerely,

_____, M.D.
Title