



NATIONAL HEMOPHILIA FOUNDATION

for all bleeding disorders

TOOLKIT FOR YOU

Health Equity Through HTC's



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ABOUT THIS RESOURCE

ABOUT NHF

The **National Hemophilia Foundation (NHF)** is dedicated to finding cures for inheritable blood disorders and to addressing and preventing the complications of these disorders through research, education, and advocacy enabling people and families to thrive. This mission to address and prevent complications of all bleeding disorders drives NHF's work to better understand health disparities and develop interventions that can begin to address those differences and promote health equity.

THIS RESOURCE WAS DEVELOPED AS PART OF A PROGRAM THAT



Gathered insight from Black and African-American patients and caregivers about their experiences, as well as from their healthcare providers teams. NHF found that the community feels HTC's provide consistent, high quality support, but challenges arose in Emergency Departments and with transportation to care. More opportunities to connect and support each other was also desired.



Provided training and resources to strengthen Hemophilia Treatment Centers (HTCs) to reduce health disparities, and increase quality of care.



Created tools for patients and caregivers to improve the ability to manage their health and make their voice heard at their local HTC or other provider settings.

NHF CONTACT

For more NHF resources visit hemophilia.org or contact HANDI, NHF's Information Resource Center at 800.424.2634 (extension 2), 9am-5pm Eastern, Monday to Friday or email handi@hemophilia.org

RESOURCES NEAR YOU

NHF Would like to express its appreciation to the Rush Hemophilia and Thrombophilia Center, the Louisiana Center for Bleeding and Clotting Disorders at Tulane University for the participation in this initiative, to Kelly Macías, Ph.D. for overall consultation for this project, and to Marlee Whetten and Kate Nammacher, MPH for content development.

This publication was supported by a grant from Genentech. This is intended for informational purposes only. It is not intended to be used to make healthcare coverage or treatment determinations. NHF's Medical and Scientific Advisory Council (MASAC) recommends that the product and corresponding treatment regimen used by an individual should remain a decision between patient and physician.



EMERGENCY DEPARTMENT VISITS

Emergency department visits can be a challenge. You may encounter doctors or nurses who don't have as much training in bleeding disorders or compassionate, culturally responsive care. Emergency departments can often feel more chaotic, with many patients across a broad range of health conditions. While you can't control the environment you are going into, or the training or unconscious biases of the healthcare providers assigned to you, you can use the following resources to be as prepared as possible and to advocate for your best care.



PREPARE

You can save time and avoid stress by preparing a few items in advance and keeping all together in a go-bag just for these situations.



DO YOU HAVE AN EMERGENCY CARE PLAN FROM YOUR HTC?

You can ask them for an updated plan and review the sample on the next page to make sure it includes all the important details.



DO YOU HAVE UPDATED PERSONAL EMERGENCY INFORMATION READY IN ONE SPOT?

Consider having it all in Notes in your phone or use the template on one of the following pages to print.



DO YOU HAVE A GO-BAG FILLED WITH NECESSARY ITEMS:

- Your medication (treatment product vials, needles or other supplies, etc)
- Your health insurance card
- An ice pack for your time in the waiting room
- Extra clothes
- Reading materials



HAVE YOU UPDATED YOUR GO-BAG TO ENSURE ALL INFORMATION IS UP TO DATE AND MEDICATION IS NOT EXPIRED EACH YEAR?



CALL AHEAD

Contacting your HTC before you go to the emergency department will best set you up for successful personal advocacy, and a more positive experience. Your HTC can call the emergency department in advance to let them know you are coming and how to proceed with care.

EMERGENCY DEPARTMENT VISITS



CONNECT YOUR CARE PROVIDERS

Provide your HTC's contact information to the emergency department staff and ask that they call your HTC to coordinate care. Use the Emergency Department Go Cards below to hand to emergency department staff and keep a few extras in your go-bag and wallet. If you continue to face challenges from the emergency department team, reach back out to your HTC for support. Don't wait, as getting treatment as quickly as possible is priority #1 when you have a bleed.



CONNECT YOUR CARE PROVIDERS

Be prepared for navigating the emergency department by reviewing the MASAC for You on this topic (on one of the following pages) and even keeping in your go-bag.

You may need to educate the doctors, nurses, and other members of the emergency department health care team. You can share the Bleeding Disorders Emergency Management Guideline pocket guide with the healthcare provider as it was created to provide guidance to emergency department personnel who may encounter patients presenting with a bleeding disorder.

<http://eguideline.guidelinecentral.com/i/1206765-emergency-management-of-bleeding-disorders/O>
Advocate for your best care by asking lots of questions and preparing a list in advance or while you wait. Feel free to use the Questions to Ask in the Emergency Department on one of the following pages to get you started.

EMERGENCY CARE PLAN

Your HTC likely has something similar to this sample plan below that you can use to give to the emergency department staff, that gets updated each year at your Comprehensive Care Visit. You can always reach back out to ask for an updated one.

EMERGENCY MEDICAL MANAGEMENT TEMPLATE

_____ is a current patient at the _____ Hemophilia Treatment Center. They have been advised that emergency medical care should be sought for significant bleeding and/or after trauma. They have been trained in self-administration of their treatment and have received extensive disease education by their nurse. They/their caregiver have been provided with an emergency guide for treatment of bleeding disorders which they have been instructed to bring with them to the ER. Kindly use it as a reference in _____'s treatment.

You can also find it here:

<http://eguideline.guidelinecentral.com/i/1206765-emergency-management-of-bleeding-disorders/0?>

A head CT or x-ray may be indicated for head, major limb or any life-threatening injury. Due to the risk of inter-joint bleeding, we ask that the patient be given an infusion of clotting factor prior to obtaining any lab tests or x-ray.

If there is a concern that _____ has suffered a head or other kind of traumatic injury, please do not delay treatment with clotting factor which should be given as soon as possible. Prompt, aggressive, preventive treatment can play a major role in minimizing what would be a potentially dangerous bleeding situation.

While it may seem unusual, please listen to what they/their parents are saying when they present to the ER. They are not physicians or nurses however are knowledgeable consumers. Given that few people in the general population are familiar with bleeding disorders and its treatment, we do educate patients and caregivers thoroughly and you may find their comments very helpful in their care.

Thank you so much for your assistance with this patient, should they be brought to your emergency room. If you have any questions about _____, please contact the Hemophilia Treatment Center at _____. In an emergency, please request that the hematologist on-call be paged.

EMERGENCY CARE PLAN

As part of your Emergency Care Plan, you can also ask your HTC for a letter like this to address concerns from staff at an Emergency Department around bruising and child abuse.

FREQUENT BRUISING LOOKS LIKE ABUSE TEMPLATE

Re:
DOB:
Diagnosis:

To Whom It May Concern:

Please be aware that _____ has been diagnosed with an inherited bleeding disorder, _____. _____ is a chronic, lifelong disease that is the result of a deficiency of a protein that clots the blood. This deficiency results in bleeding and in _____ case can be spontaneous (i.e. without provocation) and severe or even life-threatening.

Please know that bruising can be very prominent and evoke staring from the general public. In fact, it is not uncommon for parents of children with a bleeding disorder to be reported to the state's Children' & Family Services for suspected abuse due to dark, frequent bruising. Though well-intended, this can be upsetting for the parents; information typically resolves this misunderstanding. Thankfully, bruising and nosebleeds are rarely life threatening or dangerous. Please know that bleeding into the abdomen, throat and muscles may be severe or if bleeding is in the head, severely debilitating or even fatal. These are rare but require immediate attention.

Bleeding disorders can make life a bit more complicated for children and families but advances in medicine have offered children with bleeding disorders more opportunities to be more active and to enjoy satisfying lives at home with their families. At our HTC, our nurses teach the parents of children how to identify injuries and in many cases to treat their children with treatment products at home. They are also often advised to when it is necessary to take their children to the emergency room or hospital for care. Our goal is the help families minimize the many demands bleeding disorders brings to their lives. If you have any questions, please call me at _____. Thank you.

Sincerely,

PERSONAL EMERGENCY INFORMATION



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NAME _____

Address _____

Date of Birth _____ Weight _____

Primary Insurance _____ ID# _____ Insurance Phone _____

Secondary Insurance _____ ID# _____ Insurance Phone _____

Emergency Contact _____

Phone _____ Relationship _____



Bleeding Disorder (type/severity) _____

Hematologist/Hemophilia Treatment Center _____

Phone _____

Preferred Emergency Department _____

Past Bleeds _____

Self/Home Treatment Yes No

Type & Location of port/PICC _____

Possible Bleeding Disorder Medication _____

Allergies _____

Past Surgeries _____

Other Medical Conditions _____

Medications to Avoid & Reasons _____



EMERGENCY DEPARTMENT GO CARDS

Fill these out each year and have them in available in a few places (your go bag, your wallet, etc) so when at the emergency department you give one to your healthcare provider so they can easily call the HTC as well as have the QR code to pull up the latest Guideline for Emergency Management of Bleeding Disorders.



Patient Name _____

HTC Name and Phone Number _____

Bleeding Disorder _____

Bleeding Disorder Medication & Dose _____

Scan the QR Code to Access the Guideline Central Bleeding Disorders Emergency Management Pocket Guide



Patient Name _____

HTC Name and Phone Number _____

Bleeding Disorder _____

Bleeding Disorder Medication & Dose _____

Scan the QR Code to Access the Guideline Central Bleeding Disorders Emergency Management Pocket Guide



Patient Name _____

HTC Name and Phone Number _____

Bleeding Disorder _____

Bleeding Disorder Medication & Dose _____

Scan the QR Code to Access the Guideline Central Bleeding Disorders Emergency Management Pocket Guide



Patient Name _____

HTC Name and Phone Number _____

Bleeding Disorder _____

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Patient Name _____

HTC Name and Phone Number _____

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Patient Name _____

HTC Name and Phone Number _____

Bleeding Disorder _____

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Patient Name _____

HTC Name and Phone Number _____

Bleeding Disorder _____

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Patient Name _____

HTC Name and Phone Number _____

Bleeding Disorder _____

Bleeding Disorder Medication & Dose _____

Scan the QR Code to Access the Guideline Central Bleeding Disorders Emergency Management Pocket Guide



MASAC FOR YOU

GUIDELINES FOR EMERGENCY DEPARTMENT MANAGEMENT OF HEMOPHILIA AND OTHER BLEEDING DISORDERS



SELF-ADVOCACY

No one knows your health and your body better than you.

These guidelines can help you and the people who care for you speak up for what you need when you visit an emergency department for medical care.

ADMISSION

- **ALERT** staff that you have a bleeding disorder as soon as you arrive.
- **PROVIDE** your hematologist or primary care physician's contact information and ask that they call and speak with them.
- **ADVOCATE** for staff to give you the medication you use to treat your bleeding disorder as soon as you're admitted, rather than waiting to meet with the doctor or to have tests like lab work or X rays.



ASSESSMENT

- **SHARE** a copy of the medication dosing guidelines from your hematologist with the emergency department. Some Hemophilia Treatment Centers call this a "travel letter".
- **EXPLAIN** that treatment decisions should be made based on a suspected bleeding-related problem and should not wait for test results.





DIAGNOSIS

- **ADVOCATE** for getting the medication you use to treat your bleeding disorder before any tests to find the cause of the problem (X-rays, CT scans, etc.), especially in the case of head injury or suspected bleeding in the brain.
- **REMIN**D the provider that imaging is **NOT** recommended for routine joint bleeding.
- **PRETREAT** before surgery or invasive procedures to get your factor levels to 100% with the medication you use to treat your bleeding disorder.
- **REMIN**D the emergency department provider that routine lab tests are not needed to treat a common bleeding episode unless asked for by your hematologist.

TREATMENT

Signs for when you should use your medication for treating bleeds include:

- Suspected bleeding into a joint or muscle.
- Any serious injury to the head, neck, mouth or eyes or sign of bleeding in these areas.
- Any new or unusual headache, particularly one following injury.
- Severe pain or swelling at any site.
- An open wound needing stitches, adhesive, or steri-strips.
- History of an accident or trauma that might result in internal bleeding.
- Any invasive procedure or surgery.
- Heavy or continuous bleeding from any site.
- Stomach bleeding leading to moderate or severely low iron levels.
- Broken bones, dislocations, and sprains.
- Heavy menstrual bleeding leading to moderate to severely low iron levels or low blood volume...



MASAC Guidelines for Reference

MASAC Document 257 - Guidelines for Emergency Department Management of Individuals with Hemophilia and Other Bleeding Disorders

MASAC Document 258 - Recommendation on the Use and Management of Emicizumab-icxvh (Hemlibra®) for Hemophilia A with and without Inhibitors

MASAC Document 260 - Management of Chronic Pain in Persons with Bleeding Disorders: Guidance for Practical Application of The Centers for Disease Control's Opioid Prescribing Guidelines

MASAC Document 263 - MASAC Recommendations Concerning Products Licensed for the Treatment of Hemophilia and Other Bleeding Disorders

MASAC Document 264 - MASAC Recommendations Regarding Diagnosis and Management of Inherited Bleeding Disorders in Girls and Women with Personal and Family History of Bleeding

MASAC Document 265 - MASAC Guidelines for Pregnancy and Perinatal Management of Women with Inherited Bleeding Disorders and Carriers of Hemophilia A or B

MASAC Document 266 - MASAC Recommendations Regarding the Treatment of von Willebrand Disease



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QUESTIONS TO ASK IN THE EMERGENCY DEPARTMENT

THE QUESTIONS BELOW CAN GET YOU STARTED

- 1** HAVE YOU SPOKEN WITH MY HEMOPHILIA TREATMENT CENTER?
- 2** WHEN WILL I GET TREATMENT FOR MY BLEED?
I WAS ADVISED IT MUST BE BEFORE ANY OTHER ASSESSMENT OR DIAGNOSTIC TESTS TO PREVENT BLEEDING COMPLICATIONS.
- 3** WHAT IS THE TEST FOR?
- 4** WHEN WILL I GET THE RESULTS?
- 5** HOW DO YOU SPELL THE NAME OF THAT DRUG?
- 6** ARE THERE ANY SIDE EFFECTS?
- 7** WILL THIS MEDICINE INTERACT WITH MEDICINES THAT I'M ALREADY TAKING?
- 8** WHY DO I NEED THIS TREATMENT?
- 9** ARE THERE ANY ALTERNATIVES?
- 10** WHAT ARE THE POSSIBLE COMPLICATIONS?
- 11** HOW MANY TIMES HAVE YOU DONE THIS PROCEDURE?
- 12** WHO DO I FOLLOW UP WITH IF I HAVE ANY MORE ISSUES?



FINDING YOUR COMMUNITY



CONNECT ONLINE

NHF's Bleeding Disorders and Black Communities is a space for black people with bleeding disorders to gather together, exchange ideas and access educational resources in a safe and private space, define and work toward meaningful solutions within our realm of influence, and unify our voices through empowered collective action. **To join email mwhetten@hemophilia.org.**



NHF'S BLEEDING DISORDERS CONFERENCE INTERSECTIONS TRACK

Join us at NHF! (<https://www.hemophilia.org/events>) While there is a lot of educational content, NHF also is committed to creating spaces for communities within the broader bleeding disorders community to connect and learn together. NHF's Intersections track offers opportunities to explore the various dimensions of personal identity and culture that may impact life with a bleeding disorder. Watch previous year's sessions, including sessions such as Intersections: Black Communities and Their Voices at <https://www.hemophilia.org/educational-programs/education/online-education>



CONNECT AT LOCAL CHAPTER OR HTC EVENTS

Find local resources and events at your nearest chapter of HTC.
<https://www.hemophilia.org/community-resources/resources-near-you>

If your chapter or HTC doesn't currently offer any sessions or events specifically for Black and African-American community members, put your advocacy skills to use in a new way and ask if they would be willing to host one. Perhaps you may even offer to volunteer to help get it off the ground and going in the right direction.



TACKLING TRANSPORTATION & PATIENT ASSISTANCE PROGRAMS



TRANSPORTATION SUPPORT

- 1 - TALK TO THE SOCIAL WORKER AT YOUR HTC ABOUT WHAT TRANSPORTATION SUPPORT OPTIONS ARE AVAILABLE**
- 2 - REACH OUT TO YOUR LOCAL CHAPTER TO SEE IF THEY OFFER ANY TRANSPORTATION SUPPORT PROGRAMS**
- 3 - CHECK THESE ORGANIZATIONS THAT OFFER SUPPORT FOR VARIOUS COSTS INCLUDING OUT OF POCKET COSTS FOR INCIDENTAL MEDICAL EXPENSES LIKE TRAVEL**

A. The Assistance Fund (TAF)

<https://tafcares.org/>

B. Colburn Keenan Foundation Individual Grant Program

<http://colkeen.org/individual-financial-assistance-grants/>

C. Accessia Health (formerly Patient Services, Inc) Patient Assistance Programs

<https://www.patientservicesinc.org/patients/>



CONSIDER TELEHEALTH

Telehealth — sometimes called telemedicine — lets your doctor provide care for you without an in-person office visit. Telehealth is done primarily online with wifi access on your computer, tablet, or smartphone. A telehealth visit may sound really complicated, but may be as simple as a zoom call or facetime with your doctor

Talk to your HTC about what visits might make sense via telehealth if you have long distances or other barriers for travel.

Don't have internet access or not sure how to use telehealth? You aren't alone. While many had to learn quickly during the COVID-19 pandemic when that may have been the only option to see a doctor, many still have questions or concerns about using telehealth. Here are some additional resources that can help:

<https://telehealth.hhs.gov/patients/getting-help/>

<https://www.cms.gov/files/document/c2c-telehealth-patient-toolkitdigital508c.pdf>

