Best Practices

For Accessing Residential Substance Use Disorder Treatment For Individuals With Bleeding Disorders

BD SUMHAC

Bleeding Disorders Substance Use & Mental Health Access Coalition

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Providers at hemophilia treatment centers (HTCs) should be aware that individuals with bleeding disorders (BD) are often denied access to residential substance use disorder (SUD) treatment, sometimes with significant consequences. The information in this document is based on interviews with HTC providers (physicians, nurses, and social workers) who have been successful in securing residential placements for their patients. This document offers best practices and resources for HTC providers to consider before making referrals, during the referral process, and in the event of a denial.

In late 2021, a 20-year-old individual from New England with BD requested that their HTC assist in finding a residential treatment facility for their substance use disorder. Although the HTC nurse called many local residential addiction treatment facilities, none of them would take a patient with BD who required intravenous (IV) infusion medications during their stay. Without access to appropriate treatment, the patient overdosed and died.

Unfortunately, this tragedy is not unique to New England. In a recent national survey of HTC providers (social workers, hematologists, nurses, and physical therapists) 78% of those that had attempted to secure placement for their patient with BD at an addiction treatment facility or at a mental health facility failed. Other patients with a BD have also died as a result of their inability to access necessary addiction treatment.

The New England Hemophilia Association (NEHA) has partnered with the Hemophilia Federation of American (HFA), the National Hemophilia Foundation (NHF), HTC providers, and BD community members to establish the Bleeding Disorders Substance Use and Mental Health Access Coalition (the Coalition) to address this critical access issue for the bleeding disorders community. The mission of the Coalition is to advocate for access to appropriate SUD and mental health (MH) treatment facilities for all individuals with BD. While this document is focused on strategies to facilitate access to residential SUD treatment facilities, the Coalition plans to develop a similar document that focuses on access to MH facilities in the future.

In surveying the landscape, the Coalition found that patients with BD generally have access to both acute, hospital-based, inpatient treatment programs (level 4) and various outpatient programs (level 2). Therefore, the Coalition's focus is on facilitating access to residential addiction treatment facilities (level 3). The Coalition recognizes that some states use the terms "inpatient" and "residential" interchangeably when describing longer, live-in treatment facilities that may not have medical staff or medical oversight. For these documents, the Coalition will use the term "residential" to describe level 3 programs, so as not to confuse them with level 4 acute, hospital-based programs.

In addition to the resources provided, know that the Coalition is available to support you and your BD patient in the event of a denial. Please do not hesitate to contact Kate Bazinsky at BDSUMHAC@gmail.com, Marla Feinstein, Senior Policy and Healthcare Analyst at National Hemophilia Foundation (mfeinstein@hemophilia.org or 212-328-3734) and Mark Hobraczk: Senior Manager for Policy, Hemophilia Federation of America (m.hobraczk@hemophiliafed.org or cell: 813-965-2127) to share your experience.

Considering the Options for Substance Use Disorder (SUD) Treatment

Research conducted by the Coalition suggests individuals with bleeding disorders (BD) can access outpatient and hospital-based substance use disorder (SUD) treatment programs, equally with other patient populations. However, patients with BD experience a much higher rate of denials for residential treatment.

Overview of Treatment Options*

Outpatient treatment

- Therapy, medication-assisted treatment (MAT), or group
- Intensive Outpatient Program (IOP): usually 3-5 days a week for 2-4 hours a day
- Partial Hospitalization Program (PHP): usually 5 days a week for 4-8 hours a day

Inpatient treatment

- Residential (where the denials are higher for patients with BD)
- Hospital based setting (where bed availability is very limited)

**States use different terminology. Please see your state's Department of Insurance, Department of Health and Human Services, Department of Substance Use/Addiction for the terminology for your state.*

Considerations before referring to a residential SUD treatment program

- Does the patient really need inpatient/residential treatment, or could they be successful in an outpatient program?
  - People with BD do not typically have difficulties accessing outpatient treatment, so you might consider a referral to a partial hospitalization program (PHP) or an intensive outpatient program (IOP).
- Is the patient stable enough from a bleeding disorders perspective to live in a residential SUD facility without medical oversight?
  - If not, please consider referring the patient to a hospital-based, inpatient treatment program. Although hospital-based programs have limited availability, people with BD do not typically have difficulties accessing treatment in these facilities.
- If the patient requires residential treatment, is there another provider (primary care provider or a non-hemophilia treatment center (HTC) social worker) who could make the initial referral?
  - Through interviews with HTC providers who have had success and failure with referring patients to residential treatment, the Coalition found that patients with BD have more success accessing residential treatment programs when a non-HTC provider makes the initial referral, and the HTC is available for support. When an HTC provider makes the initial referral, it highlights the patient's bleeding disorder and may make it harder for the patient to access needed care.

Best Practices for Referring Patients with Bleeding Disorders (BD) to Substance Use Disorder (SUD) Treatment

Standard Process for Referrals to SUD Treatment

1. **Determine level of care:** The provider (at hemophilia treatment center (HTC) or other) determines the patient is ready for the appropriate level of care (hospital-based, residential, or outpatient) and their insurance will cover it.

2. **Initial outreach/ referral call:** The provider prepares and collaborates with the patient to make the initial outreach call to the treatment facility to determine bed availability and request an intake call. If necessary, the patient's primary care provider, emergency department provider, HTC, or other provider makes the initial referral call to the appropriate facility.

3. **Facility responds:** The facility sends over the admissions paperwork or denies admission.

4. **Submit paperwork:** The provider completes and submits the admissions paperwork to the facility.

5. **Intake call:** The patient does an intake call with the facility with provider support.

6. **Facility decides:** The facility accepts the patient or denies the patient admission.

Preparing the patient with a BD for the initial outreach or intake call with the residential SUD facility

1. Encourage the patient to focus on their problems with substance use and why they are seeking treatment, not the bleeding disorder. Advise the patient not to bring up the bleeding disorder or medications until the facility asks about it.

2. Once the facility has asked about the bleeding disorder, encourage the patient to answer any questions as directly as possible, stressing their independence in managing their condition, but also the support that the HTC provides. Suggested language:

- I have [insert name of bleeding disorder], which is a well-controlled medical condition.
- I have had this chronic issue my whole life and have learned to manage my condition with the support of my hemophilia treatment center.
- I independently give myself my medication, which will be taken in private and stored at the facility.
- I regularly give myself my medication as directed by my physician without any medical supervision or assistance.
- My hemophilia treatment center is available to support me while I am in treatment at your facility. I am happy to put you in touch with them. Would you like me to have them call you? Is there any other information you want from my doctor at this time?

3. To maximize the likelihood of success, also ensure that the patient is prepared to:

   • Discuss readiness for change and willingness to engage in treatment.

   • Discuss the treatments they have tried in the past and what makes this time different.

   • Discuss their goals, strengths, and supports.

   • Call the facility daily to check on bed availability.

Considerations during initial provider call to a residential SUD treatment facility

If the HTC provider is in the best position to make the initial referral, please consider the following best practices for the initial call (HTC provider to facility):

• When discussing bleeding disorders **do**:

   - Keep it brief.

   - Refer to the patient's bleeding disorder honestly, but with terms like "well-controlled" or "stable."

   - Assume intake workers have no medical knowledge (minimal training). Limit use of medical terminology.

   - Answer any questions as directly as possible and avoid offering additional information.

   - If asked about the patient's medical conditions be direct without elaboration. Suggested language:

      • Patient has a well-controlled medical condition and self-administers medication that will be taken in private and stored at the facility.

      • Patient has a chronic health condition that they manage independently.

   - Offer to send a letter from the hematologist to assure the facility the patient is stable from a BD perspective and appropriate for admission.

• When discussing bleeding disorders **do not**:

   - Bring up medications right away.

   - Make the bleeding disorder the focus of the call.

   - Use the terms "IV drug" or "works" in reference to medications or medical supplies (sounds scary to non-medical workers at a SUD treatment facility).

   - Use big medical terminology, or label bleeding disorders as "complex" or "requiring close monitoring."

Best Practices in the Event of a Denial

When a substance use disorder (SUD) treatment facility denies a patient with a bleeding disorder (BD) access, it is important to get more information from the facility as to the reason(s) for the denial. If the denial was due to the patient's BD, providing additional education to the facility staff about BD may encourage them to reconsider their decision. Regardless of the facility's final decision, please share the denial experience with the Bleeding Disorders Substance Use and Mental Health Access Coalition. The information you share about your denial experiences will help us refine these best practices and support other people with BD in getting access to the SUD treatment they need.

Responding to a Denial

• Call the substance use disorder (SUD) facility that made the denial and ask them to explain why the patient was denied.

• If the denial is related to the bleeding disorder (BD), try to get a better understanding of their concerns. Suggested language:

- What is it about the bleeding disorder that makes you feel you cannot provide treatment for this patient?

- Do you accept patients with other chronic conditions such as diabetes, cardiac disease, etc.? If so, what makes BD different?

• Provide them with basic education about bleeding disorders and offer to send them the Bleeding Disorder Basics for Residential Substance Use Disorder (SUD) Treatment Facility Staff education sheet. Suggested language:

- Inherited bleeding disorders are lifelong genetic conditions with no known cure. Recent medical advances and the development of medications to treat bleeding disorders have allowed patients to prevent or control bleeding and lead healthy lives.

- We believe that the current medications that [insert patient name] is taking, significantly decreases their risk of spontaneous bleeding and bleeding related to routine activities of daily living.

- There are no restrictions for activities except participation in activities that could result in significant physical injury, i.e.,: football, wrestling, hockey, contact martial arts, etc.

- Would it be helpful if I sent you a letter from the patient's hematologist regarding the patient's appropriateness for admission?

- Would your facility's [medical director/nurse/director] like to have a conversation with the patient's hematologist?

• Assure the facility staff that the patient with BD does not require medical supervision, the patient's BD is stable, and from the hemophilia treatment center (HTC) perspective, the patient is appropriate for admission. Suggested language:

- BD are chronic health conditions that the patient has learned to manage independently.

- With access to medication in the stable environment that your facility provides, we are confident that the patient's BD will be sufficiently controlled for admission to your facility.

• Assure them that the patient does not require medical staff to support the administration of the injection or infusion. Suggested language:

- The patient does not require any medical supervision at your facility but may need to self-administer their BD medication while there.

- This medication is routinely self-administered either subcutaneously or intravenously. [Insert patient name] is fully competent to self-administer their medication.

- All of the patient's medication can be given at your facility either self-administered by the patient, or by nurses that we can arrange.

- The medication does not require special monitoring, laboratory work, or frequent visits to offsite providers that could interrupt treatment.

- Would you like more information about infusions?

• Assure them that you are willing to collaborate to confirm the bleeding disorders care is planned and provided. Stress the value of the HTC treatment team and the support system the patient has in place. Suggested language:

- We are available and will assist with the patient's bleeding disorder management plan while they receive treatment at your facility.

- Here are our emergency and on-call phone numbers for the HTC: [insert phone numbers]

• If the facility refuses to reconsider the admission, request that the facility send you a letter denying the patient's access to treatment.

Please contact the following members of the Coalition to share your denial experience:

Marla Feinstein, Senior Policy and Healthcare Analyst, National Hemophilia Foundation: (212) 328-3734, mfeinstein@hemophilia.org

Mark Hobraczk, Senior Manager for Policy, Hemophilia Federation of America: (813) 965-2127, m.hobraczk@hemophiliafed.org

Kate Bazinsky, Chair, Bleeding Disorders Substance Use and Mental Health Access Coalition: BDSUMHAC@gmail.com

Draft Letter from the Hemophilia Treatment Center (HTC) to the Substance Use Disorder (SUD) Treatment Facility Regarding the Stability of a Bleeding Disorder (BD) Patient

Patient Name: [*insert patient name*]

This patient has [*insert diagnosis*]

Maintained on [*insert medication*]

Inherited bleeding disorders are lifelong genetic conditions with no known cure. Recent medical advances and the development of medications to treat bleeding disorders have allowed providers to make strides in the care of patients. These medications can be used prophylactically to prevent bleeding or to treat bleeding. We believe that the current medications that [*insert patient name*] is taking, significantly decreases their risk of spontaneous bleeding and bleeding related to routine activities of daily living.

There are no restrictions for activities except participation in activities that could result in significant physical injury (ex: football, wrestling, hockey, contact martial arts, etc.)

The patient does not require any medical supervision at your facility but may need to self-administer their bleeding disorder medication while there. This medication is routinely self-administered either subcutaneously or intravenously. [*insert patient name*] is fully competent to self-administer their medication.

[ ] With access to medication in the stable environment that your facility provides, we are confident that the patient's bleeding disorder will be sufficiently controlled for admission to [*insert facility name*]. We are available and will assist with the patient's bleeding disorder management plan while they receive treatment at [*insert facility name*].

Thank you for your time and collaboration,

[*insert signature of provider*]

[*insert date*]

[*insert clinic/day phone number*]

[*insert emergency/ on-call phone number*]

Bleeding Disorder Basics for Residential Substance Use Disorder (SUD) Treatment Facility Staff

About Bleeding Disorders (BD): Bleeding disorders are life-long, genetic conditions that make it harder for a person's blood to clot. Bleeding can occur under the skin, and into muscles, joints, or elsewhere. People with BD work with their medical teams and are trained to recognize the early signs of bleeding, which are often not visible. It is important to listen when someone with a bleeding disorder says that they are having a bleed whether or not you see any visible signs of a problem.

Medications: Many people with BD take medicine intravenously or by injection to prevent bleeding, or to control acute bleeding that may occur despite preventive treatment. Treating with these medications requires the use of needles or some other form of intravenous access, such as a butterfly needle. Some individuals with milder bleeding disorders may use oral medication (such as aminocaproic acid (Amicar) or tranexamic acid (Lysteda)) or nasal sprays for treatment of bleeding episodes. Lysteda, in particular, is frequently used to treat heavy menstrual bleeding. In most situations, the individual with a bleeding disorder is able to self-administer their medication. Most medications for BD cannot be dispensed by a retail pharmacy and require the use of a specialty pharmacy. Most patients have pre-existing relationships with specialty pharmacies that can provide access to their bleeding disorder medications.

Internal bleeding causes pain. Clotting medication is not a pain reliever but is taken to stop the bleeding and allow the blood to clot. Treating bleeds early avoids complications and long-term disability and gets people back to their regular activities. People with BD do not require laboratory work on a consistent basis.

Manufacturers typically recommend storing products in the refrigerator, although many are stable at room temperature for a limited time. Products should never be frozen. Medications requiring refrigeration should be kept in a refrigerator in the same area where other medications are stored. Do not let a refrigerated product come to room temperature and then refrigerate it again.

Key points to remember:

- **Most bleeds are not emergencies:** Most accidents, even without visible injury, should be addressed with first aid, rest and ice. Consult the patient's emergency plan and call the hematology team if you need help.
- **You have time to figure it out:** People with bleeding disorders do not bleed faster than others, just longer. You have time to check the treatment plan, or call the hematology team, if necessary.
- **Trust the patient's self-assessment:** When a person says that they are in pain or have a bleed, trust them. People with bleeding disorders are experts in their condition. Ask the individual if they need to get a dose of their medication.
- **Use acetaminophen to treat pain.** Never give someone with a bleeding disorder aspirin, ibuprofen or naproxen (Advil, Aleve, Motrin). These medications make the bleeding worse. Only use acetaminophen (Tempra, Tylenol). When acetaminophen is inadequate, the selective COX-2 inhibitor celecoxib (Celebrex) may be another option for pain control, provided that it is prescribed for the patient by a healthcare provider.
- **Emergencies:** Some bleeds require prompt, emergency care; emergency treatment recommendations may be sent with a patient to the treatment facility. Call the patient's hematology team and 911 immediately, if the person injures their:
  - Head
  - Throat
  - Abdomen
  - Eyes

About the ASAM Criteria

The American Society for Addiction Medicine (ASAM) establishes levels of substance use disorder (SUD) treatment/care in their national criteria. However, ASAM is not an accreditation organization and does not regulate SUD programs. While most states rely on the ASAM criteria to establish the regulations for SUD treatment, they may or may not adopt ASAM's language and classification schema. For more detailed information about the ASAM Criteria, please visit the ASAM website: https://www.asam.org.

• **Level 0.5 early intervention:** The first described level of treatment is designed for those who are at known risk for developing a substance use disorder (i.e.: DUI program).

• **Level 1 outpatient:** Where patients maintain their daily lives but regularly meet with addiction specialists and treatment professionals for evaluation, treatment and follow-up for a SUD.

• **Level 2 intensive outpatient/partial hospitalization services:**

- Level 2.1 intensive outpatient program (IOP): Patients receive treatment for 9 to 20 hours per week and have frequent contact with physicians, psychiatrists and therapists. Treatment is provided during the day or on evenings and weekends. Patients can continue working, going to school or carrying out other responsibilities while attending.

- Level 2.5 partial hospitalization program (PHP): The most rigorous of outpatient programs. Services lasts for at least 20 hours per week. Individual, group and family therapy are major components of treatment, as is psychoeducation. Frequent contact with medical and therapeutic staff is expected and integrated into the treatment.

• **Level 3 residential services:** Residential treatment programs, or inpatient drug treatment programs, are for patients whose addictions have created significant functional impairments. It is also for patients who require more stability than they can achieve at home. At this level, patients live on-site or in close proximity to their treatment. Treatment is offered around the clock — 24 hours per day, seven days per week. Level 3 care escalates based on the amount and depth of a patient's interactions with clinicians.

- Level 3.1 clinically managed low-intensity residential: 24 hour living support (halfway/ recovery house) with at least 5 hours clinical services/week (may be provided on-site or in an outpatient services program). Treatment at this level focuses on teaching recovery skills, such as relapse prevention and emotion management. At this level, treatment must be capable of treating co-occurring disorders.

- Level 3.3 clinically managed population specific high-intensity residential: Adults only. There are two distinctive features of Level 3.3 treatment. First, treatment at this level can proceed at a slower pace but with more reinforcement to accommodate those who may be experiencing cognitive or other impairments. Second, clinicians at this level of treatment must be capable of managing "multidimensional imminent danger" such as acute dangers of conditions like alcohol withdrawal or when a patient is at imminent risk for self-harm.

- Level 3.5 clinically managed residential – high intensity for adults, medium intensity for adolescents: 24 hour care with clinical staff including addiction counselors, social workers, or licensed professional counselors and allied health professionals. No on-site physician, but nursing staff. Treatment takes place at a regular pace but is directed toward those who have

multiple active needs. These needs can include a co-occurring disorder, severe functional impairment or difficulty adjusting to healthy routines.

- Level 3.7 medically monitored residential – intensive for adults, high-intensity for adolescents: Highly structured 24 hour services. Physician available on-site 24 hours daily, along with nurses, addiction counselors, and other clinical staff. Patients in a residential setting are at risk for withdrawal or have medical needs that require careful observation, treatment or follow-up. This is the highest intensity service that Level 3 offers.

• **Level 4 medically managed intensive inpatient:** Daily direct care from a physician. Hospital-based setting. The highest overall level of treatment which includes 24 hour treatment and high-level medical and clinical monitoring. Services include medical detoxification and medication-assisted treatment. Co-occurring disorders are readily treated. This service level is similar to the care a patient would receive at an acute care medical or psychiatric hospital, and the facility will have many of the same available resources as those institutions.

About the Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC)

Mission Statement

The mission of the coalition is to advocate for access to appropriate substance use and mental health treatment facilities for all individuals with bleeding disorders.

Coalition members:

- **Kate Bazinsky:** *Board Member, New England Hemophilia Association (NEHA); Chair, Bleeding Disorders Substance Use and Mental Health Access Coalition*
- **Jacqueline Bottacari:** *Licensed Clinical Social Worker, Yale Hemophilia Treatment Center*
- **Marla Feinstein:** *Senior Policy and Healthcare Analyst, National Hemophilia Foundation*
- **Jen Feldman:** *Nurse Coordinator, University of Massachusetts Memorial Hemophilia Treatment Center*
- **Miriam Goldstein:** *Director of Policy, Hemophilia Federation of America*
- **Mark Hobraczk:** *Senior Manager for Policy, Hemophilia Federation of America*
- **Ziva Mann:** *Massachusetts State Lead, the New England Bleeding Disorders Advocacy Coalition; Board Member, National Hemophilia Foundation*
- **Nick McRae:** *Board Member of Hemophilia Alliance of Maine, Maine State Lead with the New England Bleeding Disorders Advocacy Coalition*
- **Ann Marie Minichiello:** *Massachusetts State Lead, New England Bleeding Disorders Advocacy Coalition*
- **Lucy Ramirez:** *Social Worker, Rush University Medical Center Hemophilia Treatment Center*
- **Gillian Schultz:** *Director of Programs, Bleeding Disorders Foundation of North Carolina*
- **Joanne Fadale Wagner:** *Social Work Care Manager, Dartmouth Health Hemophilia Treatment Center*
- **Joe Zamboni:** *Advocacy Coordinator, New England Bleeding Disorders Advocacy Coalition*

Sponsoring organizations:

- **National Hemophilia Foundation**
- **New England Hemophilia Association**
- **Rush University Medical Center Hemophilia Treatment Center**