



BD SUMHAC

Bleeding Disorders Substance Use &
Mental Health Access Coalition

Access to Inpatient/Residential Behavioral Health Treatment for People with Bleeding Disorders

Resources for people with bleeding disorders and their loved ones

People with bleeding disorders (BD) deserve equitable access to inpatient/residential substance use disorder and mental health treatment facilities.

If you or a loved one has been denied access to an inpatient/residential mental health or substance use disorder treatment facility because of a BD, don't give up! Bleeding Disorders Substance Use & Mental Health Access Coalition (BD SUMHAC) has tools to help get you the treatment you need and deserve. A denial because of a BD is not the end of the story. It is the beginning of the advocacy.

ABOUT THE BD SUMHAC ACCESS TOOLKIT

The BD SUMHAC Access Toolkit provides resources and tools to help people with BD get access to inpatient/residential mental health and substance use disorder treatment facilities. People with BD are protected from discrimination under the Americans with Disabilities Act, a federal law, and deserve equitable access to care. After a denial, first, contact your BD treatment team and share the BD SUMHAC Toolkit with them. BD SUMHAC is available to support your treatment team as they advocate for your access to treatment. If the BD treatment team does not feel comfortable or able to advocate on your behalf, please contact the BD SUMHAC advocates at the National Hemophilia Foundation or the Hemophilia Federation of America.

Use the QR code to visit the BD SUMHAC website and find the BD SUMHAC Access Toolkit

Contents of the BD SUMHAC Access Toolkit:

- 1. Talking with a provider about the options for addressing your substance use or mental health concerns**
- 2. Preparing for a referral to inpatient/residential substance use or mental health treatment**
- 3. Discussing bleeding disorders with a treatment facility**
- 4. Responding to treatment facility denials**



ISSUE

People with BD are often denied access to inpatient/residential substance use disorder and mental health treatment facilities, despite being medically stable and appropriate for admission. Access to inpatient/residential treatment is a health equity issue. Everyone should have equitable access to inpatient/residential substance use disorder and mental health treatment, regardless of their ability to clot, treatments they use, or state of residence.

A NATIONAL ISSUE

In 2022, BD SUMHAC conducted a national survey of Hemophilia Treatment Center (HTC) providers (social workers, hematologists, nurses, and physical therapists) that showed 83% of those who attempted to place a patient at an inpatient/residential mental health or substance use disorder treatment facility received a denial due to their patient's BD. Both adults and children with BD have been denied access to both substance use disorder and mental health treatment facilities. BD SUMHAC is currently aware of denials in 20 states. BD SUMHAC has launched a multi-pronged approach to addressing this important health equity issue.

REASONS FOR DENIALS

According to interviews with HTC providers, people with BD are denied access for many reasons, such as: concern about use of IV or injection medications, needles, fear about the medical complexity of BD, insurance issues, and access to medication.

HISTORY OF BD SUMHAC

In late 2021, a 20-year-old person with a BD from New England requested that their local HTC assist in finding them a residential facility to treat their substance use disorder. The HTC called many local facilities, but none would take a patient who required intravenous (IV) infusion medications. Without access to appropriate treatment, the person overdosed and died. The New England Hemophilia Association (NEHA), Hemophilia Federation of America, the National Hemophilia Foundation, HTC providers, other chapters, and community members then established BD SUMHAC.

The mission of BD SUMHAC is to advocate for access to appropriate substance use disorder and mental health treatment facilities for all individuals with BD with a focus on inpatient and residential facilities. BD SUMHAC is not a mental health or substance use disorder treatment organization and does not offer behavioral health treatment or recommendations, but it does support providers in getting people with BD the access they need.

If you have any additional questions about the toolkit or would like to help advocate for better access on behalf of the community, please visit www.bdsumhac.org or contact us at info@bdsumhac.org.

If you have been denied access, please contact your BD treatment team or the BD SUMHAC advocates at the national bleeding disorder organizations:

- **BD SUMHAC Advocate at National Hemophilia Foundation:**
Matt Delaney, (212) 328-3780, mdelaney@hemophilia.org.
- **BD SUMHAC Advocate at Hemophilia Federation of America:**
Mark Hobracz, (202) 675-6984, m.hobracz@hemophiliafed.org.

If you have thoughts of self-harm or suicide:

- **Call 911**
- **Go to the closest emergency room**
- **Call/text 988 to contact the National Suicide & Crisis Life Line**
- **Text HOME to 741741 to contact the Crisis Text Line**

Your bleeding disorder should not prevent you from getting the treatment you need.

Talk with your provider about options to address your substance use or mental health concerns.



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