

for all bleeding disorders

MASAC Document # 275 (Replaces Document # 238)

MASAC RECOMMENDATIONS REGARDING PHYSICAL THERAPY MANAGEMENT FOR THE CARE OF PERSONS WITH BLEEDING DISORDERS

The following recommendation was approved by the Medical and Scientific Advisory Council (MASAC) on March 26, 2023, and endorsed by the NHF Board of Directors on May 2, 2023.

Thanks to the contributors of this document: Lora Joyner, Chair Amanda Kilgore, Vice Chair Ryan Rushton, Cindy Bailey, Bruno Steiner, Kim Baumann, Pattye Tobase, and PTWG 2022 members

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.

Copyright 2023 National Hemophilia Foundation. To facilitate the dissemination of these medical recommendations, reproduction of any material in this publication in whole or in part will be permitted provided: 1) a specific reference to the MASAC recommendation number and title is included and 2) the reproduction is not intended for use in connection with the marketing, sale or promotion of any product or service. NHF reserves the right to make the final determination of compliance with this policy. For questions or to obtain a copy of the most recent recommendations, please contact the NHF Senior Vice President for Programs and Medical Information at handi@hemophilia.org or visit the NHF website at www.hemophilia.org.

MASAC RECOMMENDATIONS REGARDING PHYSICAL THERAPY MANAGEMENT FOR THE CARE OF PERSONS WITH CONGENITAL BLEEDING DISORDERS

The Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation (NHF) has recommended that a physical therapist be a core team member of a Hemophilia Treatment Center (HTC) team in order to provide integrated, high quality, patient-centered, and comprehensive care of persons with congenital bleeding disorders. Furthermore, a comprehensive physical therapy evaluation must be conducted at regular intervals, especially for those individuals at risk of musculoskeletal complications from their bleeding disorder. The evaluation and assessment must be adapted to each specific patient and consider their medical or surgical history, activity levels, use of prophylaxis, history of hemarthrosis, and type and severity of bleeding disorder. The evaluation should include anticipatory guidance on activities and physical fitness throughout the lifespan. Additionally, appropriate treatment interventions should be developed and implemented based on evaluation findings. Consultation with community therapists is vital if services cannot be provided at the HTC. The physical therapist should also serve as an educational resource for patients, other providers, and the broader bleeding disorder community.¹

Based on the MASAC recommendation and the ever-expanding role of the physical therapist in the care and management of persons with bleeding disorders, the need has arisen for more detailed and comprehensive guidelines for physical therapy care that can be followed by both HTC and non-HTC physical therapists. Given the integral role of the physical therapist, it is recommended that this be a full-time, supported position.

Recognizing this need, the Physical Therapy Working Group (PTWG) of the NHF has developed the following guidelines and criteria for use by physical therapists in the care and management of persons with bleeding disorders. The group recommends that these practice guidelines are adapted to both scope of practice and local/ institutional guidelines. MASAC recommends adoption of these guidelines by physical therapy services for management of individuals with bleeding disorders, either inpatient or outpatient, both within HTCs and within institutions not affiliated with an HTC. In the latter case, consultation with members of the HTC team is strongly encouraged.

As health care providers, we strive to provide linguistically, developmentally, and culturally appropriate comprehensive care. Background, lived experience, culture, native language, and gender identity or preference must be considered when providing evaluation, treatment, and education services to PWBD as well as their family and support system.

1

¹ Medical and Scientific Advisory Committee. MASAC Document #269: Standards and Criteria for the Care of Persons with Congenital Bleeding Disorders Revised April 2022.

TABLE OF CONTENTS

- 1. The Physical Therapist is a Core Team Member
- 2. Experience and Training
- 3. Assessment of PWBD With Musculoskeletal Complications
 - **a. Appendix A -** Hemophilia Treatment Center Physical Therapy Evaluation Components
 - b. Appendix B Practice Guidelines on Musculoskeletal Ultrasound in the Management of PWBD
- 4. Management of Bleeds
 - **a. Appendix C -** Physical Therapy Practice Guidelines for Persons with Bleeding Disorders: Cryotherapy
 - **b. Appendix D -** Physical Therapy Practice Guidelines for Persons with Bleeding Disorders: Joint Bleeds
 - **c. Appendix E -** Physical Therapy Practice Guidelines for Persons with Bleeding Disorders: Muscle Bleeds
 - **d. Appendix F -** Physical Therapy Practice Guidelines for Persons with Bleeding Disorders: Iliopsoas Bleeds
- 5. Musculoskeletal Complications
- 6. Physical Therapy and Musculoskeletal Surgery
 - **a. Appendix G -** Physical Therapy Practice Guidelines for Persons with Bleeding Disorders: Surgical Synovectomy
 - **b. Appendix H -** Physical Therapy Practice Guidelines for Persons with Bleeding Disorders: Total Knee Replacement
- 7. Physical Therapy for Rehabilitation
- 8. Physical Therapy for Pain Management
- 9. Physical Therapy for Women and Girls with Bleeding Disorders
- 10. Physical Therapy for Rare and Ultra Rare Bleeding Disorders
- 11. Physical Therapy for Bleeding Disorders across the Lifespan
- 12. Adaptive Equipment
 - **a. Appendix I -** Physical Therapy Practice Guidelines for Persons with Bleeding Disorders: Adult Orthoses
 - **b. Appendix J -** Physical Therapy Practice Guidelines for Persons with Bleeding Disorders: Pediatric Orthoses
- 13. Encouraging a Healthy Lifestyle
- 14. List of Appendices

1. The Physical Therapist is a Core Team Member

- a. A physical therapist will provide assessment, treatment, and education on treatment and self-care throughout a Person with a Bleeding Disorder's (PWBD) lifespan as part of the integrated and comprehensive care team.²
- b. Physical therapists will prioritize treatment and care to ensure the best health and quality-of-life outcomes for people with bleeding disorders no matter the diagnosis. However, the chart below summarizes the bleeding disorders most frequently associated with musculoskeletal complications that physical therapists evaluate and treat³.

Frequent	Common	Less Common
Hemophilia A (FVIII Deficiency)	Prothrombin Deficiency	Factor V Deficiency
Hemophilia B (FIX Deficiency)	Factor X Deficiency	Factor VII Deficiency
VWD Type III	Afibrinogenemia	Factor XIII Deficiency

Any bleeding disorder with musculoskeletal complications

Microbleeds and "mild" bleeds with novel therapies and non-factor products

- c. Physical therapists' primary roles on the interdisciplinary team include:
 - i. Joint preservation and optimization
 - ii. Prompt management of bleeding episodes including follow-up of musculoskeletal complications
 - iii. Rehabilitation and management of musculoskeletal complications
 - iv. Consultation/Communication with other team members and health care providers
 - v. Ongoing education for PWBDs and families⁴

2. Experience and Training

a. All physical therapists working with PWBDs in an HTC or non-HTC must practice in accordance with the provisions of their individual state Practice Act and the Scope of their Board Rules.

b. Physical therapy is presumed to include any acts, tests, procedures, modalities, treatments, or interventions that are routinely taught in

² NHF-McMaster Guideline on Care Models for Haemophilia Management. Pai M, Key NS, Skinner M, Curtis R, Feinstein M, Kessler C, Lane SJ, Makris M, Riker E, Santesso N, Soucie JM, Yeung CH, Iorio A, Schünemann HJ. Haemophilia. 2016 Jul;22 Suppl 3:6-16. doi: 10.1111/hae.13008.

³ Canadian Physiotherapist in Hemophilia Care Clinical Practice Guidelines. Revised January 2021

⁴ Srivastava, A, Santagostino, E, Dougall, A, et al. WFH Guidelines for the Management of Hemophilia, 3rd edition. Haemophilia. 2020: 26(Suppl 6): 1- 158. https://doi.org/10.1111/hae.14046

- educational programs, or in continuing education programs for physical therapists and are routinely performed in practice settings.
- c. Additional training is necessary to achieve the advanced level skills required for comprehensive care of PWBDs. This additional training can be obtained via continuing education, self-directed learning, and mentored practice for specific high risk, low volume, or complex care and techniques prior to performing these in clinical practice.
- d. Professional practices should be consistent with guidelines, recommendations, and standards developed by Health Resources and Services Administration (HRSA), the Medical and Scientific Advisory Council of the National Hemophilia Foundation (MASAC), International Society on Hemostasis and Thrombosis (ISTH), World Federation of Hemophilia (WFH), Centers for Disease Control and Preventions, and the US Hemophilia Treatment Center Network.
- e. The physical therapist will maintain clinical competence in the care of PWBDs in an ever changing and advancing field of practice.

3. Assessment of PWBD With Musculoskeletal Complications

- a. The physical therapist will complete an assessment at least annually on each patient with musculoskeletal complications regardless of the type and severity of the bleeding disorder.
- b. The physical therapist will determine if a comprehensive or screening evaluation is more appropriate based on a variety of factors, including but not limited to:
 - i. Patient and Family Concerns
 - ii. Recent joint or muscle bleeds
 - iii. History of joint bleeds, muscle bleeds, or chronic arthropathy
 - iv. Other musculoskeletal complaints
 - v. Comorbidities
 - vi. Type and severity of bleeding disorder
 - vii. Research requirements
 - viii. Baseline/first clinic visit
 - ix. Team request
 - x. Activity level and sports/work participation
- c. The physical therapy evaluation is a vital part of the comprehensive evaluation of a person with a bleeding disorder and is aimed at identifying musculoskeletal limitations and vulnerabilities which impact function and quality of life.
 - i. See Appendix A for the Hemophilia Treatment Center Physical Therapy Evaluation Components
 - ii. The physical therapist will determine the necessary evaluation components to be completed at each visit based on the PWBD's impairment, pain, and functional limitation as well as the type of visit.
- d. Musculoskeletal Ultrasound (MSKUS)/Point-of-Care Ultrasound (POC-US)

- i. Physical therapists can use MSKUS in patients with bleeding disorders to detect the presence or absence of hemarthrosis, synovial or intra-articular soft tissue proliferation with/without inflammation (synovitis), and sequelae of recurrent bleeding episodes including osteochondral derangement.⁵
- ii. The POC-US/MSKUS examination can be a stand-alone evaluation or a valuable adjunct/extension of the physical therapists' exam and/or treatment.
- iii. See **Appendix B** for the practice guidelines on musculoskeletal ultrasound in the management of PWBD.

e. Evaluation Tools

- i. The physical therapist should use standardized and validated assessment tools to measure joint impairment and function, activities and participation, and patient-reported outcomes⁶ ⁷.
 - 1. Hemophilia Joint Health Score (HJHS)
 - 2. Functional Independence Score in Hemophilia (FISH)
 - 3. Haemophiia Activities List (HAL)
 - 4. Haemophilia Activities List Pediatric (PedHAL)
 - 5. EQ-5D-5L or PROMIS
 - 6. Beighton Score for hypermobility⁸
- f. The physical therapist will communicate assessment findings and treatment plan with the other team members.

4. Management of Bleeds

- a. In all cases of musculoskeletal bleeding, adequate treatment generally requires a combination of clotting factor replacement therapy and physical therapy with an experienced physical therapist to achieve complete functional recovery.⁹
- b. The physical therapist has a role in interrupting the bleeding cycle by helping to prevent bleeding episodes and optimizing outcomes once a bleed has occurred. Intervention by a physical therapist is appropriate at any stage of the musculoskeletal bleeding cycle.
- c. The physical therapist must be involved in the early management of joint and muscle bleeds to achieve full recovery, reduce the symptoms of pain and inflammation, optimize functional improvement, and prevent long term complications.

⁵ Kidder, W., et al., Point-of-care musculoskeletal ultrasound is critical for the diagnosis of hemarthrosis, inflammation and soft tissue abnormalities in adult patients with painful haemophilic arthropathy. Haemophilia, 2015. 21(4): 530-7.

⁶ Fischer K, Poonnoose P, Dunn AL, et al. Choosing outcome assessment tools in haemophilia care and research: a multidisciplinary perspective. Hemophilia. 2017; 23(1) 11-24.

⁷ Srivastava, A, Santagostino, E, Dougall, A, et al. WFH Guidelines for the Management of Hemophilia, 3rd edition. Haemophilia. 2020: 26(Suppl 6): 1-158. https://doi.org/10.1111/hae.14046

⁸ https://www.ehlers-danlos.com/assessing-joint-hypermobility/#1667832351239-74ce5479-cdb7

⁹ WFH Guidelines for the Management of Hemophilia, 3rd Edition

- d. The physical therapist should implement and educate the patient and family on **PRICE** principles (protection, rest, ice, compression, and elevation), especially during an acute bleed.
 - i. See **Appendix C** for Physical Therapy Practice Guidelines for Persons with Bleeding Disorders: Cryotherapy
 - ii. "The application of ice has been shown to reduce acute hemarthrosis-related pain; however, it has been suggested that a decrease in intra-articular temperature could interfere with coagulation in the presence of acute tissue lesions" ¹⁰ ¹¹ Therefore, the timing and use of ice is what is important. If factor concentrate is available, then that should be used prior to ice administration to avoid the ice limiting the factor distribution in that local area.
 - iii. Ice is an especially critical modality if factor or non-factor products are not available.
 - iv. The physical therapist should also consider the balance between rest, early mobilization, and weight bearing to prevent unwanted complications associated with immobilization, while minimizing rebleeding, synovitis, and cartilage damage.¹²
 - v. The physical therapist may consider **POLICE** (protection, optimum loading, ice, compression, and elevation), with "optimum loading" replacing "rest", as bleed recovery happens.

e. Joint Bleeds

- The goal of physical therapy in joint bleeds is to assist in the treatment of the bleed, prevent recurrence, limit complications, and restore function to pre-bleed state.
- ii. Physical therapy should be initiated under adequate hemostatic coverage, utilizing factor or non-factor products as indicated. It is vital to monitor the affected joint throughout physical therapy to determine if further hemostatic treatment is needed to prevent recurrence of bleeding.¹³
- iii. Physical therapists must be aware of the potential of inhibitor development and management.
 - The physical therapy treatment plan must be highly individualized in the presence of an inhibitor and is also dependent on if the inhibitor is tolerized, high titer, or low titer. In general, bleeds are harder to control and take longer to heal.
 - 2. The PWBD with an inhibitor has a potentially higher risk of rebleeding especially during physical therapy rehabilitation.

6

¹⁰ Forsyth AL, Zourikian N, Valentino LA, Rivard GE. The effect of cooling on coagulation and haemostasis: should "Ice" be part of treatment of acute haemarthrosis in haemophilia? Haemophilia. 2012; 18 (6): 843 - 850

¹¹ Stephensen D, Bladen M, McLaughlin P. Recent advances in musculoskeletal physiotherapy for hemophilia. Ther Adv Hematol. 2018; 9 (8): 227 - 237.

¹² Stephensen D, Bladen M, McLaughlin P. Recent advances in musculoskeletal physiotherapy for haemophilia . Ther Adv Hematol .2018; 9(8):227-237.

¹³ WFH Guidelines for the Management of Hemophilia, 3rd Edition

- Complete recovery from joint and muscle bleeds is imperative to help prevent rebleeding.
- 3. The physical therapist must be aware of the warning signs of a potential inhibitor to communicate with the team:
 - a. Generally, PWBD have a risk of development of inhibitors during the first 20–50 exposure days.
 - b. Factor prophylaxis not working as it should
 - c. Bleeding out of proportion to prophy, casualty of bleed, or bleeding phenotype
 - d. Delayed rehabilitation progress
- 4. Coordination of care and timing of physical therapy treatment are imperative in management of an inhibitor.
- iv. In PWBD, it is important to differentiate MSK bleeding from other sources of pain, especially chronic arthritic pain¹⁴
- v. See **Appendix D** for specific Physical Therapy Practice Guidelines for Persons with Bleeding Disorders: Joint Bleeds

f. Muscle Bleeds

- i. The goal of the physical therapy assessment in muscle bleeds is to differentiate superficial soft tissue bleeds from deep muscle bleeds and then provide appropriate treatment as needed.
 - 1. Soft tissue hemorrhage can occur in muscles, ligaments, tendons, and subcutaneous spaces.
 - Superficial tissue bleeds will feel warm and tender to touch and may or may not be accompanied by palpable swelling or hematoma.
 - Deep muscle bleeds may be difficult to palpate, but have the potential for compartment syndrome, with paresthesia and distal pallor or pulselessness.
 - 4. Bruises on dark skin develop in the same way as bruises on light or medium skin. However, the colors of a bruise can appear different, depending on the person's skin tone, and bruising may be less apparent on dark skin due to contrast.
- ii. Accurate muscle testing will assist in differential diagnosis of muscle bleeds versus soft tissue injuries.
- iii. Physical therapy recommendations for primary muscle bleeds in bleeding disorders include full history of injury and treatment to date, PRICE, manual and electrical modalities to restore ROM and reduce pain, patient education, a graded exercise program to restore baseline functionality.¹⁵
- iv. See **Appendix E** for Physical Therapy Practice Guidelines for Persons with Bleeding Disorders: Muscle Bleeds

¹⁴ Timmer MA, Posters MF, deKleijn P, et al. How do patients and professionals differentiate between intra-articular joint bleeds and acute flare-ups of arthropathy in patients with haemophilia? Haemophilia. 2016; 22(3):368-373. doi:10.1111/hae.12858

¹⁵ Sorensen B, Benson GM. Management of muscle hematoma in patients with severe hemophilia in an evidence-poor world. Haemophilia. 2012;18(4):598-606

- v. See **Appendix F** for Physical Therapy Practice Guidelines for Persons with Bleeding Disorders: Iliopsoas Bleed
- vi. Insufficient treatment of muscle hematoma or poor response to treatment can lead to serious and debilitating complications, including re-bleeding, infection, compartment syndrome, joint contractures, pseudotumor, myositis ossificans, functional loss and decreased range of motion (ROM). In patients with severe hemophilia and inhibitors, muscle hematomas, such as iliopsoas bleeds, can be life- or limb-threatening.¹¹

5. Musculoskeletal Complications

a. Physical therapy and rehabilitation are particularly important for functional improvement and recovery after repeated musculoskeletal bleeds and for those with chronic hemophilic arthropathy.

b. Target Joint

- The Centers for Disease Control and Prevention (CDC) defines a target joint as a joint that has bled a minimum of three times within a six-month period.¹⁶
- ii. Repeated bleeding leads to destructive changes in the synovium, leading to further bleeding, development of chronic synovitis, and ultimately joint destruction.
- iii. The goal of physical therapy is prevention of further bleeds in the identified target joints. This may occur through activity modification, PRICE, and/or specific individualized exercise programs targeting joint ROM and muscle strengthening.

c. Chronic Synovitis

- i. Acute synovitis often presents with swelling of the joint which is boggy on palpation. Movement of the joint is usually not painful, and the joint may or may not have restricted ROM.
- ii. Recurrent joint bleeding can result in synovial hypertrophy and thickening. Hypertrophic synovial tissue is highly vascular and susceptible to re-bleeding.
- iii. This cycle of re-bleeding leads to chronic synovitis. Patients with chronic synovitis may experience significant musculoskeletal changes such as muscle weakness and atrophy around the affected joint, limited ROM, and joint instability.

d. Chronic Hemophilic Arthropathy

- i. Recurrent hemarthrosis leads to cartilage destruction, bone reabsorption, subchondral cyst formation, osteophyte formation, anatomical instability of the joint, joint space narrowing, and fibrous and bony ankylosis.
- ii. These changes to the anatomical structure of the joint results in limited ROM, pain, contracted or fused joint, joint malalignment deformity, crepitus, arthritic changes, muscle atrophy, and disability.

_

¹⁶ Centers for Disease Control and Prevention

- iii. Physical therapy aimed at preserving muscle strength, joint preservation and optimization, and maximal functional ability is an essential component of the treatment of chronic hemophilic arthropathy.
- iv. Multimodal conservative treatment techniques should be utilized in the management of chronic hemophilic arthropathy. This could include serial casting, bracing and orthotics, assistive devices, adaptations to work, home, or school environments, and many other therapeutic interventions. (See Section 7 for further modalities)
- e. Physical therapy is advised throughout the entire rehabilitation course, with progressive exercises to build up to full weight bearing and complete functional recovery. Functional training may commence based on individualized goals for each patient.
- f. People with moderate and severe hemophilia with more significant arthropathy experienced a lower quality of life, especially in the physical domain. Psychosocial limitations from hemophilic arthropathy may be compounded by gait changes, multiple joints being affected, and chronic pain. ¹⁷
- g. hEDS, Hypermobility, and Joint Pain
 - i. The majority of patients with EDS fall into the hEDS category. A subset of these patients with excessive bleeding may be seen at the HTC. The etiology of bleeding is complicated with potential causes including the inherent pathophysiology of hypermobility and also coagulopathies from factor deficiency, platelet dysfunction, acquired VWD and mast cell activation disease.¹⁸
 - ii. The most common type of EDS, now referred to as hypermobile EDS (hEDS), is defined by joint mobility at the upper end of the spectrum, the presence of relatively objective signs of connective tissue dysfunction, pain that is not the result of inflammation, and the absence of most of the differentiating features of other types.¹⁹
 - iii. Research suggests the contribution of abnormal collagen, which is reflected in symptomatic joint hypermobility, to the expression of bleeding tendency. This highlights the need for a thorough evaluation of collagen disorders/hypermobility as part of an assessment for patients who are being worked up for bleeding

¹⁷ Poon JL, Zhou ZY, Doctor JN, et al. Quality of life in haemophilia A: Hemophilia Utilization Group Study Va (HUGS- Va). Haemophilia. 2012;18(5):699-707.

¹⁸ Tinkle B, Castori M, Berglund B, Cohen H, Grahame R, Kazkaz H, Levy H. 2017. Hypermobile Ehlers–Danlos syndrome (a.k.a. Ehlers–Danlos syndrome Type III and Ehlers–Danlos syndrome hypermobility type): Clinical description and natural history. Am J Med Genet Part C Semin Med Genet 175C:48–69. ¹⁹Castori M, Tinkle B, Levy H, Grahame R, Malfait F, Hakim A. A framework for the classification of joint hypermobility and related conditions. *Am J Med Genet C Semin Med Genet*. 2017; 175(1): 148-157.

- disorders. Physical therapy is a vital component of this assessment.
- iv. The presence of joint hypermobility in patients with bleeding symptoms and normal coagulation profile explains the symptoms of pain, achiness, and other musculoskeletal impairments and also helps direct patients for appropriate care for their known comorbidities.

6. Physical Therapy and Musculoskeletal Surgery

- Surgical interventions may become necessary for musculoskeletal complications if nonsurgical measures fail to provide satisfactory pain relief and improved function.²⁰
- b. During each HTC visit, the physical therapist discusses joint health and will consider surgical consultation and/or procedures with the patient as needed. These discussions are based on multifactorial clinical presentations including pain, functional deficits, bleeding, and quality of life.¹⁴
- c. Preoperative Management, often called Prehabilitation, is the proactive preparation of joints and/or muscles to withstand surgical intervention and improve outcomes of both structure and function. This should be performed prior to surgery.²¹
 - i. Types of Prehabilitation
 - 1. Education on surgical procedure and expectations
 - 2. Functional practice using an assistive device they will use post-op. (i.e., crutch gait, knee scooter, etc.)
 - 3. Muscle lengthening
 - a. Flexibility
 - b. Passive ROM
 - 4. Therapeutic exercise
 - a. Active ROM
 - b. Progressive strengthening
 - c. Resistive work
 - Gait training
 - 6. Neuromuscular Reeducation
 - a. Balance
 - b. Proprioception
 - c. Fall Prevention
- d. Assess patient support systems for surgical success
 - i. Compliance
 - ii. Ability to get to/from all required appointments
 - iii. Assistance at home

²⁰Baduleschu OV, Sirbu PD, Ungureanu C, et al. Orthopedic surgery in hemophilic patients with musculoskeletal disorders: A systematic review. Experimental and Therapeutic Medicine. 2021; 22(3):995 ²¹Escobar MA, Brewer A, Caviglia H, et al. Recommendations on multidisciplinary management of

elective surgery in people with haemophilia. Haemophilia. 2018; 24:693-702.

- e. Postoperative Management begins soon after surgery and depending on the procedure can last weeks to months. Due to the stresses often placed on joints and/or muscles during physical therapy following surgery, it is imperative that the patient's clotting factor is being managed by the hematologist, and that prior to any post-operative physical therapy, the patient is at low risk of bleeding. The physical therapist needs a keen awareness of postoperative bleeding and infection.²²
 - i. Examples of postoperative management:
 - 1. Functional mobility including using specific assistive devices (i.e., crutches, knee scooters, etc.)
 - 2. Progressive Muscle lengthening
 - a. Flexibility
 - b. Passive ROM
 - 3. Progressive Therapeutic exercise
 - a. Active ROM
 - b. Progressive strengthening
 - c. Resistive work
 - 4. Gait training
 - 5. Neuromuscular Reeducation
 - a. Balance
 - b. Proprioception
 - c. Fall Prevention
 - 6. See Physical Therapy for Rehabilitation #7 for other treatment recommendations.
- f. Types of non-surgical and surgical procedures often required by PWBD
 - i. Non-Surgical:
 - 1. Aspiration puncture
 - 2. Intra-articular Corticotherapy
 - 3. Hyaluronic acid injections
 - 4. Non-Surgical synovectomy
 - ii. Surgical:
 - 1. Surgical Synovectomy
 - a. See **Appendix G** for Physical Therapy Practice Guidelines for Persons with Bleeding Disorders: Surgical Synovectomy
 - 2. Arthrotomy and reactionary osteotomy
 - 3. Arthrodesis
 - 4. Endoprosthetic Arthroplasty (i.e., Total Knee Arthroplasty)
 - See Appendix H for Physical Therapy Practice Guidelines for Persons with Bleeding Disorders: Total Knee Replacement
 - iii. Post surgical DVT
 - 1. Although the incidence of symptomatic DVT appears to be slightly lower than the estimated incidence in the general

²²Baduleschu OV, Sirbu PD, Ungureanu C, et al. Orthopedic surgery in hemophilic patients with musculoskeletal disorders: A systematic review. Experimental and Therapeutic Medicine. 2021; 22(3):995

- population without thromboprophylaxis following TKA or THA, physical therapists need to be aware of the signs and symptoms of post-surgical DVTs to communicate to the healthcare team for management.²³
- The most common symptoms are redness, warmth, and swelling. Also, excessive pain and tenderness, beyond expected rehab pain, or a sudden change in how the leg feels.

7. Physical Therapy for Rehabilitation

- a. Physical therapy management of PWBD has been informed largely by the literature pertaining to other populations, such as sports injuries. In PWBD, attention must be paid to ensuring the bleeding has stopped, and to preventing new bleeding during the rehabilitation period.
- During the acute phase, exercise programs should be conducted in limited range, at low velocity and submaximal load, and within patient tolerance, while closely monitoring for signs of new bleeding.²⁴
- c. Progression beyond the acute phase, control of hemorrhage and restoration of range of motion, is an often-ignored component of the rehabilitation process. Functional rehabilitation and return to sport/work levels are vital elements often overlooked in physical therapy treatment programs.
- d. The physical therapist must be familiar with contraindications and safety precautions applicable to treating PWBD.
- e. Therapy Programs may include any of the following treatment modalities based on reason for physical therapy, diagnosis, and current functional status:
 - i. Exercises that have been studied in PWBD, particularly Hemophilia A and Hemophilia B, include exercise in water, active, isometric, and resisted exercise, aerobic exercise, functional (closed chain) exercise, treadmill walking, Tai Chi, Nordic walking, and home exercise programs.²⁵
 - ii. Progressive Muscle lengthening
 - 1. Flexibility
 - 2. Passive ROM
 - iii. Progressive Therapeutic exercise
 - 1. Active ROM
 - 2. Progressive strengthening
 - 3. Resistive work
 - iv. Gait training

_

²³ Prospective, multicenter study of postoperative deep-vein thrombosis in patients with haemophilia undergoing major orthopaedic surgery. Buckner TW, Leavitt AD, Ragni M, Kempton CL, Eyster ME, Cuker A, Lentz SR, Ducore J, Leissinger C, Wang M, Key NS. Thromb Haemost. 2016 Jul 4;116(1):42-9. doi: 10.1160/TH15-10-0802. Epub 2016 Mar 24.

 ²⁴ Canadian Physiotherapist in Hemophilia Care Clinical Practice Guidelines. Revised January 2021
 ²⁵ Strike K, Michael R. Exercise for haemophilia. Cochrane Database Syst Rev. 2016; 12(12):CD011180. Published 2016 Dec 19. doi: 10.1002/14651858.CD011180.pub2

- v. Neuromuscular Reeducation
 - 1. Balance
 - 2. Proprioception
 - 3. Fall Prevention
- vi. Manual Therapy
 - Although there is limited peer reviewed research, preliminary case study articles have shown that manual therapy is effective and safe in reducing frequency of hemarthrosis and activity pain, improving range of motion, limb functionality and quality of life.²⁶
 - Manual techniques that have been studied include joint traction, joint gliding techniques, fascial therapy and manual stretching. These techniques were found to be safe and effective in decreasing pain and minimally increasing range of motion when combined with passive stretching.²⁷
- vii. Splinting
- viii. Kinesiotaping
 - 1. Edema control
 - Muscle facilitation
 - 3. Muscle Inhibition
- ix. Aquatics
 - Aquatics provides a low-risk/low-load environment and is particularly recommended for patients with multiple joint arthropathies, for whom land-based functional strengthening is difficult.²⁸
 - 2. Aquatics has also been suggested as a useful long-term adjunct to reduce muscle stiffness after a bleed.
- x. Other Modalities
 - 1. TENS Transcutaneous Electrical Nerve Stimulation
 - 2. NMES Neuromuscular Electrical Stimulation
 - 3. Therapeutic Ultrasound (MASAC #130)
 - a. Some authors have reported using pulsed ultrasound and/or pulsed short wave diathermy to assist tissue healing and/or hematoma resolution in PWBD. There are no known references that specify parameters for treating acute bleeds in PWBD.²

²⁶ Tat AM, Can F, Tat NM, Sasmaz HI, Antmen AB. The effects of manual therapy and exercises on pain, muscle strength, joint health, functionality and quality of life in haemophilic arthropathy of the elbow joint: a randomized controlled pilot study. Haemophilia. Published online February 24, 2021. doi:10.1111/hae.14281

²⁷ Cuesta-Barriusa R, Gomez-Conesa A, Lopez-Pina JA. Manual and educational therapy in the treatment of hemophilic arthropathy of the elbow: a randomized pilot study. Orphanet J Rare Dis. 2018: 13(1):151.

²⁸Sorensen B, Benson GM. Management of muscle hematoma in patients with severe hemophilia in an evidence-poor world. Haemophilia. 2012;18(4):598-606

- b. Deep heating is not advisable, and pulsed settings should always be used. Heat generating modalities should be applied with caution.²
- c. The use of low-intensity ultrasound is reported to increase calcium ion diffusion across the cell membrane. This can significantly increase the release of wound healing factors. It has been claimed that the use of therapeutic ultrasound can accelerate the inflammatory process, improve scar tissue quality, improve blood flow, and help reduce pain. However, the full validity of these claims remains scientifically unproven. Therapeutic ultrasound is contraindicated over the epiphyseal regions in children.²⁹
- 4. Pulsed High Intensity Laser Therapy³⁰

8. Physical Therapy for Pain Management

- a. Pain, both acute and chronic, is a known complication in people with bleeding disorders. Pain is often the first sign of musculoskeletal bleeding. ³¹ ³² Acute pain occurs as blood puts pressure on nerve endings within joint structures, such as the joint capsule and the synovium. Chronic pain develops secondary to joint arthropathy and is most common in the ankles, knees, and elbows.³³ ³⁴ PWBDs may experience pain that is acute, chronic, or acute-on-chronic.
- b. The physical therapist should assess a patient's pain at their annual comprehensive visit, at their follow up clinic visits, as well as during each bleeding episode. At each of these times, the physical therapist can assist with the management of pain to reduce symptoms, address the impact of pain on daily and work activities, help to improve functional activities and prevent long term complications.
- c. Physical therapy assessment of acute pain should include a subjective history, and an evaluation of current joint status and function, as well as pain specifics of location, quality, intensity, and response to movement.³⁵ Assessment of chronic pain should further include functional tests, and

²⁹ Sorensen B, Benson GM. Management of muscle hematoma in patients with severe hemophilia in an evidence-poor world. Haemophilia. 2012;18(4):598-606

³⁰ Efficacy of pulsed high-intensity laser therapy on pain, functional capacity, and gait in children with haemophilic arthropathy. El-Shamy SM, Abdelaal AAM. Disabil Rehabil. 2018 Feb;40(4):462-468. doi: 10.1080/09638288.2016.1261416. Epub 2016 Dec 15

³¹ Canadian Physiotherapists in Hemophilia Care: Clinical Guidelines for Physiotherapists working with persons with Bleeding Disorders: appendix for CPHC Standards of Physiotherapy Care for Persons with Bleeding Disorders 2018.

³² Witkop M, Lambing A, Divine G, Kachalsky E, Rushlow D, Dinnen J. A national study of pain in the bleeding disorders community: a description of haemophilia pain. Haemophilia. 2012 May;18(3): e115-9.

³³ Gualtierotti, R, Solimeno, LP, Peyvandi, F. Hemophilic arthropathy: Current knowledge and future perspectives. *J Thromb Haemost*. 2021; 19: 2112–2121. https://doi.org/10.1111/jth.15444

Kempton CL, Recht M, Neff A, et al. Impact of pain and functional impairment in US adults with haemophilia: patient-reported outcomes and musculoskeletal evaluation in the pain, functional impairment and quality of life (P-FiQ) study. *Haemophilia*. 2018;24(2):261–270.

³⁵ Canadian Physiotherapist in Hemophilia Care Clinical Practice Guidelines. Revised January 2021

- joint health status. The physical therapist should use standardized and validated assessment tools to measure pain in PWBD.
- d. Physical therapists should employ a variety of treatment techniques to address pain in PWBDs. This should include but not be limited to PRICE, pain education, joint support, and assistive device recommendations, swelling management, ROM, strengthening, stabilization, and balance/proprioception. The physical therapist should also provide education about possible orthopedic interventions and appropriate referrals.
- The physical therapist is often involved in planning for pain management during surgical interventions, which can pose additional challenges in PWBDs.
- f. Physical therapists should be involved along with the pain management team when discussions and plans are being made around opioid use initiation, tapering or discontinuation, to assist with identifying functional goals, and providing additional non-pharmacological interventions to use in conjunction with opioids and to assist with transitions.³⁶ ³⁷

9. Physical Therapy for Women and Girls with Bleeding Disorders

- a. We recognize words are important and the language of "women and girls" is inherently exclusive. The hemostatic challenges described below may be navigated by anyone with the potential to menstruate, become pregnant, deliver a child, and experience menopause. The noted dearth of research extends far beyond those cisgender women and girls to include other marginalized groups as well.³⁸ Education regarding these concerns must incorporate the patient as well as their family and support system, regardless of gender. For the remainder of Standard 9, the term "these individuals" will be used as an all-inclusive term.
- b. These individuals make up a substantial portion of people with inherited and acquired bleeding disorders and their diagnoses range in frequency from common to ultra-rare and in both genotypic and phenotypic severity, from mild to severe. However, discrepancies in the care of male and female patients in the HTC are noted.³⁹ Therefore, some patients may not receive all available services, including visits with a physical therapist.
- c. These individuals with severe bleeding disorders may experience similar musculoskeletal involvement as their male counterparts and the above guidelines should be applied to these patients as well. Additionally, there is a dearth of research regarding the musculoskeletal complications of

3

³⁶ MASAC document 260

³⁷ Newman JR, Durben N, Baumann K, Lambing AY, Nichols CD, Witkop M, Santaella ME, Buckner TW. Physical therapy within US HTCs: A multicentre survey of utilization, practice patterns and pain management approaches. Haemophilia. 2022 Mar;28(2):343-350. doi: 10.1111/hae.14501. Epub 2022 Feb 13. PMID: 35152533.

³⁸ Safer JD. Research gaps in medical treatment of transgender/nonbinary people. J Clin Invest. 2021 Feb 15;131(4): e142029. doi: 10.1172/JCI142029. PMID: 33586675; PMCID: PMC7880308.

³⁹ Miller CH, Soucie JM, Byams VR, et al. Women and girls with haemophilia receiving care at specialized haemophilia treatment centres in the United States. *Haemophilia*. 2021;27(6):1037-1044. doi:10.1111/hae.14403

- patients without severe disease and there are even fewer studies focusing on the musculoskeletal health and pain complaints. For these reasons, these individuals should be screened by a physical therapist as appropriate, regardless of their diagnosis or severity.
- d. These individuals encounter unique hemostatic, musculoskeletal, and neuromuscular challenges including menstruation, pregnancy, delivery, and the postpartum period. The functional limitations due to these situations can be significant and impact the patient greatly. The HTC team may screen patients for specific concerns, including incontinence, pelvic pain, and perinatal concerns. Patients may benefit from referral to a physical therapist specializing in pelvic health. In these situations, the HTC PT will act as a resource for the pelvic health therapist to ensure a general understanding of the patient's bleeding disorder and how it may influence therapy.
- e. It is important to consider the summative effects of bleeding disorders and hormonal changes on bone density, especially in postmenopausal individuals. ⁴¹ Additionally, balance screening, mobility assessments and fall prevention education should be specifically addressed in this population to prevent future morbidity and mortality.

10. Physical Therapy for Rare and Ultra Rare Bleeding Disorders

- a. Clinical symptoms among rare bleeding disorder (RBD) patients vary significantly between disorders, and patients, even when affected with the same disorder. RBD rarity has resulted in limited knowledge with decreased focus on etiologic and pathogenetic research and difficulty describing natural history and variants. Each RBD can have several bleeding symptoms ranging from minor post-traumatic to severe episodes appearing at birth or later in life.⁴²
- b. The most severe bleeding symptoms are found in patients with afibrinogenemia, factor X deficiency, and prothrombin deficiency, with a relatively high frequency of joint and muscle bleeding⁴³
- c. Additionally, there has been a strong association found between residual coagulant activity and clinical bleeding severity for deficiencies of fibrinogen, combined FV + VIII, FX, and FXIII, with a weak association for FV and FVII deficiencies; residual FXI activity did not predict clinical bleeding severity. It was also documented that the minimum level to

⁴⁰ Byams VR, Kouides PA, Kulkarni R, et al. Surveillance of female patients with inherited bleeding disorders in United States Haemophilia Treatment Centres. Haemophilia. 2011;17 Suppl 1(0 1):6-13. doi:10.1111/j.1365-2516.2011. 02558.x

⁴¹ Mansouritorghabeh H, Rezaieyazdi Z. Bleeding disorders and reduced bone density. Rheumatol Int. 2011 Mar;31(3):283-7. doi: 10.1007/s00296-010-1534-y. Epub 2010 May 27. PMID: 20505939.

⁴² Palla R, Pevyandi F, and Shapiro AD. Rare Bleeding Disorders: diagnosis and treatment. Blood. 2015: 123(13): 2052-2061. doi: https://doi.org/10.1182/blood-2014-08-532820

⁴³ Network for Rare Bleeding Disorders

- ensure complete absence of clinical symptoms is different for each disorder.⁴⁴
- d. Persons with rare bleeding disorders may experience similar musculoskeletal involvement as their counterparts with more well-known disorders and the above guidelines should be applied to these patients as well. Additionally, there is insufficient research regarding the musculoskeletal complications of patients without severe disease and there are even fewer studies focusing on the musculoskeletal health and pain complaints of persons with rare bleeding disorders. For these reasons, persons with rare bleeding disorders should be screened by a physical therapist as appropriate, regardless of their diagnosis or severity of disease.

11. Physical Therapy for Bleeding Disorders across the Lifespan

- a. Pediatric Considerations
 - i. The physical therapist will use play activities (distractors) to assess bleed presentation and address impairments through developmentally appropriate interactions. In the care of a child with a bleeding disorder, the physical therapist should facilitate the safest possible participation in play, sports, recreational activities, and family life.
 - ii. Evaluation
 - In addition to the components of the physical therapy examination for PWBD, the following items must be considered for children with BD:
 - a. Development Language, Fine Motor, Social Emotional, Cognitive, and Gross Motor
 - b. Environmental and Cultural Considerations regarding child rearing and parenting
 - c. Caregivers and childcare situation
 - d. Psychosocial issues
 - e. Physiological data and motor control as related to medical and birth history
 - f. Behaviors Stranger anxiety, separation anxiety
 - g. Hands on versus observational exams
 - h. Play strategies and exploration of environment
 - Routine musculoskeletal assessment is essential to the management of children with bleeding disorders to identify deficiencies in muscle strength and flexibility throughout the lifespan. Assessments should be used to promote, advise, and educate on general health and activity, and to individualize exercises for specific sports.⁴⁵

evidence-poor world. Haemophilia. 2012;18(4):598-606

Peyvandi F, Palla R, Menegatti M, et al. European Network of Rare Bleeding Disorders
 GroupCoagulation factor activity and clinical bleeding severity in rare bleeding disorders: results from the European Network of Rare Bleeding Disorders., *J Thromb Haemost*, 2012, vol. 10 4(pg. 615-621)
 Sorensen B, Benson GM. Management of muscle hematoma in patients with severe hemophilia in an

- 3. The physical therapist must utilize age-appropriate evaluation measures to assess the individual's impairments, activities, and participation throughout the lifespan. Validated evaluation tools include:
 - a. PedHAL
 - b. HJHS
 - c. FISH
 - d. Alberta Infant Motor Scale
 - e. Peabody Developmental Motor Scale
 - f. Berg Balance Scale Pediatric
 - g. Other tools with pediatric standards
- 4. Pain Assessment in Children
 - a. The age and cognitive development of the child influences the pain assessment. For younger children, the use of behavioral pain scales is mandatory.⁴⁶
 - EVENDOL Acute or Procedural Pain -0-7 years
 - 2. FLACC 2 months to 7 years with acute pain in different settings
 - PAT Tool (Universal Pain Assessment Tool)
 - 4. Self Reporting Tools
 - a. FACES 3+
 - b. Numeric 8+
 - b. Self-reported pain intensity is the gold standard for children older than age 6 years. There are 8 "wellestablished" self-report pain intensity measures with at least some supportive evidence for children 6 years and older.
 - These include NRS-11, CAS, FPS-R/FPS, Pieces of Hurt (Poker Chip Tool), Oucher photographic and numeric scales, VAS, and FACES scale.⁴⁷
- In newborns and children with severe hemophilia less than 2 years of age, common types of bleeding include: soft tissue and intramuscular bleeding; bleeding associated with a medical procedure (e.g., venipuncture, central line placement, circumcision, neonatal heel prick);

⁴⁷ Birnie KA, Hundert AS, Lalloo C, Nguyen, Stinson JN. Recommendations for selection of self-report pain intensity measures in children and adolescents: a systematic review and quality assessment of measurement properties. Pain. 2019 Jan; 160(1):5-18.

⁴⁶ Beltramini A, Milojevic K, Pateron D. Pain Assessment in Newborns, Infants, and Children, Pediatric Annals. 2017;46(10): e387-e395.

- mucocutaneous bleeding (e.g., oral, nasal); and extracranial bleeding.⁴⁸
- 6. Hallmark bleed presentation signs for children with bleeding disorders, especially younger children, are asymmetrical developmental skills, regression in gross motor, fine motor, or self-help (ADL) skills, and decreased weight bearing.
- 7. Physical therapists should monitor overall development and ensure that children with BDs are able to participate with their peers in school, sport, and leisure activities.

iii. Treatment

- 1. In children, play should be the tool of choice to motivate and progress physical function.
- Exception to PRICE is in young children in whom compression is not advocated due to their inability to give feedback on adverse symptoms such as paresthesia (pins and needles).⁴⁹
- 3. The use of ballistic and aggressive passive techniques as well as more aggressive manual techniques may be needed in young, fit, and athletic PWBD to enable them to return to their pre bleed baseline. Ballistic activity, such as jumping, should be introduced in children late in the restoration stage of treatment to develop muscle strength and normal development.⁵⁰

iv. Other

- The physical therapist must provide ongoing education to PWBD and their families to enable development of selfmanagement skills.
 - Education from the physical therapist should include prevention, identification, and management of MSK bleeding and its sequelae.
 - b. Education should also be specific to the developmental age and situation of the individual.
 - c. Education should consider the caregiver/support system of the PWBD.
 - d. Education should be based on the home, school and or work duties and expectations.
- 2. All people responsible for a child's safety, such as babysitters, teachers, and coaches need to have sufficient information to minimize risk of bleeding and respond appropriately to suspected bleeds.⁵¹ The physical therapist can provide information about:

⁴⁸ WFH Guidelines for the Management of Hemophilia, 3rd Edition

⁴⁹Sorensen B, Benson GM. Management of muscle hematoma in patients with severe hemophilia in an evidence-poor world. Haemophilia. 2012;18(4):598-606
⁵⁰ Ihid

⁵¹ Canadian Physiotherapist in Hemophilia Care Clinical Practice Guidelines. Revised January 2021

- a. Prevention of bleeding including activity selection and modification
- b. Identification of acute bleeding
- c. First aid management of bleeding
- d. Return to activity following a bleed

b. Changes in Elderly

- i. During the lifespan, musculoskeletal bleeding may alter movement patterns and cause pain, which can limit activities and participation in normal social roles. As the life expectancy for people with bleeding disorders increases, issues often associated with "normal aging" may appear such as decreased activity levels, a decline in strength, and balance issues. Impairments are also common in all body systems including hearing and vision loss, chronic pulmonary disease, genitourinary dysfunction, diabetes, hypertension, osteoarthritis, mobility disability, multiple system failures, depression, and dementia.⁵²
- ii. Additionally, the comorbidities may be heightened by the bleeding disorder and be more difficult to medically manage, especially cardiovascular disease.
- iii. Associated with the physical aspects of aging, many persons with bleeding disorders also suffer from psychological symptoms which may be precipitated by changes in work such as early retirement and altered family dynamics.⁵³
- iv. Bone mineral density (BMD) has been shown to be lower in people with bleeding disorders, especially in more severe cases. An increased number of arthropathic joints, loss of joint movement, and muscle atrophy leading to inactivity are associated with a lower BMD⁵⁴
- v. Joint damage progresses with increasing age in a near-linear fashion not only in patients with severe disease but also in moderate cases. Contributing factors include osteoporosis and osteopenia, a sedentary lifestyle, overweight, and obesity. ⁵⁵
- vi. Progressive arthritis and declining fitness may lead to loss of independence which causes great concern for the PWBD.
- vii. The physical therapist needs to be aware of the aging issues in PWBD and develop exercise and wellness programs which are directed to the early identification of disease complications as well as preventative strategies to reduce the physical and psychological impacts of aging.

⁵² Jaul E, Barron J. Age-Related diseases and clinical and public health implications for the 85 years old and over population. Front Public Health. 2017; 5:335

⁵³Shapiro S, Makris M. Haemophilia and ageing. Br J Haematol. 2019;184(5):712-720

⁵⁴ Iorio A, Fabbriciani G, Marcucci M, Brozzetti M, Filipponi P. Bone mineral density in haemophilia patients: a meta-analysis.Thromb Haemost . 2010;103 (3):596-603

⁵⁵ Angelini D, Sood SL. Managing older patients with hemophilia. Hematology Am Soc Hematol Educ Program. 2015; 2015:41-47.

12. Adaptive Equipment

- a. Orthotics
 - i. The physical therapist will work with the provider to prescribe the appropriate orthotics to modify the functional or structural characteristics of the skeletal system.
 - ii. See **Appendix I** for Physical Therapy Practice Guidelines for Persons with Bleeding Disorders: Adult Orthoses
 - iii. See **Appendix J** for Physical Therapy Practice Guidelines for Persons with Bleeding Disorders: Pediatric Orthoses
- b. Joint Support Equipment
 - i. Acute
 - 1. Resting splints
 - 2. ACE wraps
 - 3. Air cast splints/stirrup brace
 - ii. Long-term
 - 1. Ace Wraps
 - 2. Sleeves
 - 3. Soft and lace-up braces
 - 4. Rigid and hinged braces
 - 5. Orthoses: foot/shoe inserts, Arizona Braces
 - iii. Sports
 - 1. Braces
 - 2. Sleeves
 - 3. Orthotics
 - 4. Kinesiology taping
- c. Other
 - i. The physical therapist should recommend mobility aids for PWBD with advancing arthropathy or surgical needs to increase independence, decrease pain, and enhance functional activities and participation.
 - The choice of mobility aids depends on many factors, such as strength, function, and history of bleeding, both in the lower and upper extremities. Length of need of mobility aid (long term versus short term) and patient choice should also be considered.
 - ii. The physical therapist may also recommend modifications to the home, school, or work environment to ensure safety and optimal function.

13. Encouraging a Healthy Lifestyle

- a. The physical therapist will provide education to patients and families regarding healthy living throughout the lifespan.
- b. Fitness and Physical Activity
 - i. The physical therapist should make physical activity recommendations to encourage an active, healthy lifestyle to promote cardiovascular fitness, healthy body weight, psychological well-being, and ability to maintain independence.

ii. Sport Choice and Safe Participation

- The physical therapist should work with the HTC team, the patient, and the family prior to the patient engaging in new sports or physical activities. The sport or activity decision should be based on a variety of factors as well as the physical therapist's clinical exam.
- 2. The choice of activities should reflect the individual's preferences, interests, physical condition and ability, local contexts, and available resources.
- 3. Vulnerability of the individual to injury, type of BD, severity of BD, bleeding history (especially the presence of target joints), and physical characteristics must be considered.⁵⁶
- The physical therapist should be involved in a program focused on preparation of the required physical skills for the sport or activity.
- The physical therapist should work with the patient and family in a joint decision-making process to determine the implications of any given activity in relation to their bleeding disorder.
 - a. NHF Playing it Safe
 - b. Activity Intensity Risk⁵⁷
 - c. Organized versus Unstructured
 - d. Age of patient at time of participation
 - e. Use of prophylaxis

6. Equipment

- a. Appropriate for sport, age, and intensity of activity
- b. Custom made dental mouth guards may be required to prevent trauma and bleeding to teeth and oral soft tissues.⁵⁸
- c. Additional braces or splints related to bleeding disorder.

c. Nutrition and Weight Management

i. Obesity impacts physical activity in both children and adults.

Although few studies have assessed the effects of obesity on hemophilia-specific outcomes, there is evidence that excess weight has a significant impact on lower extremity joint range of motion and functional ability, as well as on joint pain, with potentially significant effects on overall quality of life. Overweight and obesity

⁵⁶ Sorensen B, Benson GM. Management of muscle hematoma in patients with severe hemophilia in an evidence-poor world. Haemophilia. 2012;18(4):598-606

⁵⁷ Hernandez G, Baumann K, Knight S, Purrington H, Gilgannon M, Newman J, Tobase T, Mathew S, Cooper D. Ranges and drivers of risk associated with sports and recreational activities in people with haemophilia: results of the Activity-Intensity-Risk Consensus Survey of US Physical Therapists. Haemophilia. 2018;24(57):5-26

⁵⁸ American Dental Association Council on Access, Prevention and Interprofessional Relations, American Dental Association Council on Scientific Affairs. Using mouthguards to reduce the incidence and severity of sports- related oral injuries. J Am Dent Assoc. 2006;137(12):1712-1720.

can affect frequency of bleeding in different ways: some overweight/obese patients have reduced bleeding rates, but this may be due to lower levels of physical activity; conversely, obese patients with hemophilia tend to have more joint bleeds, compared to non-obese patients with hemophilia.⁵⁹

- ii. Weight management should be offered as part of health promotion within hemophilia treatment centers for all patients. This should include:
 - 1. nutritional education for parents of children as well as for adults with bleeding disorders
 - 2. weight management programs.
 - 3. psychological support.
 - 4. exercise programs (preferably monitored by the center's physical therapist).
 - 5. pharmacological therapy
 - 6. collaboration with/referral to obesity medical/surgical teams⁶⁰

d. Bone Health

- i. Weight bearing activities that promote development and maintenance of good bone density should be encouraged to the extent that joint health permits.⁶¹
- ii. Physical therapists should recommend weight-bearing activities and suitable sports that promote development and maintenance of good bone density for younger patients, if their joint health permits, to build bone mass and reduce the risk of osteoporosis development
- e. Work/Career Considerations
 - i. Job Selection
 - 1. Risks versus Benefits
 - 2. Physical Preparedness
 - 3. Short Term Job versus Long Term Career
 - ii. Work Ergonomics
 - 1. Physical Requirements of the Job
 - 2. Workplace or Workspace Environment
 - iii. Modifications
 - 1. Physical Requirements
 - 2. Workplace or Workspace
 - 3. Schedule
 - iv. Return to Work
 - 1. Planning with HTC
 - 2. Planning with Employer

⁵⁹ Kahan S, Cuker A, Kushner RF, et al. Prevalence and impact of obesity in people with haemophilia: review of literature and expert discussion around implementing weight management guidelines. Haemophilia. 2017;23(6):812-820.

⁶⁰ WFH Guidelines for the Management of Hemophilia, 3rd edition.

⁶¹ Kempton CL, Antoniucci DM, Rodriguez-Merchan EC. Bone health in persons with haemophilia . Haemophilia. 2015; 21 (5): 568 - 577.

Appendix A:

HEMOPHILIA TREATMENT CENTER PHYSICAL THERAPY EVALUATION COMPONENTS

Appendix B:

PRACTICE GUIDELINES FOR IMPLEMENTATION AND USE OF MUSCULOSKELETAL ULTRASOUND IN THE MANAGEMENT OF INDIVIDUALS WITH HEMOPHILIA AND OTHER BLEEDING DISORDERS

Appendix C:

PHYSICAL THERAPY PRACTICE GUIDELINES FOR PERSONS WITH BLEEDING DISORDERS: CRYOTHERAPY

Appendix D:

PHYSICAL THERAPY PRACTICE GUIDELINES FOR PERSONS WITH BLEEDING DISORDERS: JOINT BLEEDS

Appendix E:

PHYSICAL THERAPY PRACTICE GUIDELINES FOR PERSONS WITH BLEEDING DISORDERS: MUSCLES BLEEDS

Appendix F:

PHYSICAL THERAPY PRACTICE GUIDELINES FOR PERSONS WITH BLEEDING DISORDERS: ILIOPSOAS BLEEDS

Appendix G:

PHYSICAL THERAPY PRACTICE GUIDELINES FOR PERSONS WITH BLEEDING DISORDERS: SURGICAL SYNOVECTOMY

Appendix H:

PHYSICAL THERAPY PRACTICE GUIDELINES FOR PERSONS WITH BLEEDING DISORDERS: TOTAL KNEE REPLACEMENT

Appendix I:

PHYSICAL THERAPY PRACTICE GUIDELINES FOR PERSONS WITH BLEEDING DISORDERS: ADULT ORTHOTICS

Appendix J:

PHYSICAL THERAPY PRACTICE GUIDELINES FOR PERSONS WITH BLEEDING DISORDERS: PEDIATRIC ORTHOTICS