

Family Focused Care

Why Attend Comprehensive Clinic?

Though the IHTC and health care providers in the bleeding disorder community at large have been stressing the importance of attending an annual Comprehensive Clinic for quite some time, it remains a difficult task for many patients to complete.

Outlined below are some important points to consider when deciding whether to schedule a Comprehensive Clinic visit at IHTC.

What is the cost of this visit?

Your comprehensive clinic visit at the IHTC is free. You will not be charged by the IHTC for your medical and other healthcare provider evaluations. *Your insurance carrier will be billed for laboratory tests or radiological evaluations that are ordered by the physician.* Laboratory tests that are part of a research study such as the Universal Data Collection Study are provided at no charge.

What type of report will I receive from this visit?

You will receive written documentation of your comprehensive clinic evaluation that includes recommendations from each healthcare provider who sees you. This report may take several weeks to complete. It will be mailed to you and to your primary care physician. This report is very helpful when applying for disability, or as a resource you can provide to your insurance provider to justify your medical needs, or to other healthcare providers to document and discuss your diagnosis and treatment.

Does my insurance require an Annual Evaluation?

In many respects, especially in regards to reimbursement for clotting factor replacement, yes! Virtually all insurance companies require documentation of a Comprehensive Clinic visit before they will reimburse for factor.



Who will I see during the visit?

The IHTC multidisciplinary team consists of healthcare professionals with experience in the care of persons with bleeding disorders.

- **Hematologist — Physician**

- Responsible for medical management of the bleeding disorder

- **Hemophilia Nurse**

- Nursing assessment of general health and bleeding-related problems
- Patient and family education
- Coordination and evaluation of home therapy programs
- Development and coordination of patient plan of care
- Participation in quality assurance activities

- **Research Nurse**

- Facilitation of data collection and documentation
- Presentation of available research studies

- **Social Worker**

- Psychosocial assessments, supportive counseling, health education, counseling resource referral, assistance with employment or insurance problems, loss and grief work.
- Candid supportive communication, identify obstacles to optimal patient care (e.g., institutional rules, communication or personality styles, social circumstances, etc.), and facilitate effective problem solving and conflict resolution
- Bridge to community-based organizations serving persons diagnosed with bleeding disorders, their families, and sexual partners
- Assess insurance coverage for hemophilia-related needs

- **Physical Therapist**

- Assess musculoskeletal and functional status
- Develop educational and exercise programs appropriate for home use
- Assist in the development of a healthy approach to exercise
- Discuss importance of regular physical activity
- Maximize independent functional status of all persons seen at comprehensive clinic



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Why Attend Comprehensive Clinic, cont.

- **Genetic Counselor**

- Obtain and record detailed family history
- Educate and discuss mode of inheritance, carrier testing, and reproductive decision-making options in a confidential, sensitive, age-appropriate and culturally competent manner

- **Career Counselor**

- Assess current academic performance and identify areas of strength and areas of improvement
- Review educational requirements to meet specific career objectives
- Review strategies and life skills necessary for improving performance in areas of concern
- Assessment of personality types, learning styles and career interests



- **Dental Hygienist**

- Education on oral hygiene and potential oral complications of bleeding disorders
- Age appropriate educational material and presumptive counseling
- Identification of resources available for dental care
- Coordination of required dental interventions

- **Dietitian**

- Nutritional intake
- Assessment of current eating habits, physical activity, laboratory values, nutritional and herbal supplements
- Adequacy of nutritional intake
- Attention to special needs such as HIV, hepatitis
- Growth and development
- Calculation of Body Mass Index (BMI)
- Methods to optimize BMI
- Educate and reinforce general nutritional health and intake for preventative care and healthy living



- **Pharmacist**

- Review medications for possible interactions
- Review homecare needs as appropriate
- Update insurance when indicated

- **Risk Reduction Coordinator**

- Hepatitis Risk Reduction
- Annual Screening including liver function tests and basic viral hepatitis serologies including hepatitis A, B, C, and D
- Hepatitis A and B vaccination as indicated
- Hepatitis B and/or C infection follow-up as appropriate
 - > Screening for liver damage including cirrhosis, hepatocellular carcinoma
 - > Viral genotype and viral load assays as indicated
 - > Counseling about additional risk factors for chronic liver disease such as alcohol and Tylenol®
 - > Referral to a liver specialist (Hepatologist), when indicated, for diagnosis and treatment of liver disease
- HIV infection testing and follow-up as appropriate
 - > Assessment of HIV knowledge, attitudes, beliefs and behavior of patients, partners and families
 - > HIV testing for at-risk persons and sexual partners, with pre- and post-test counseling by trained HIV risk-reduction specialist, ensuring confidentiality consistent with Federal and State legislation
 - > HIV treatment referral or care
 - > Resource or referral for psychosocial assessment and intervention, as well as stress reduction, for patients and their families regarding HIV infection
- Safe Sex Education as appropriate
 - > Education on transmission of sexually transmitted disease
 - > Includes risk behavior assessment and counseling regarding options, including abstinence and barrier protection, condom use in a confidential, age appropriate, sensitive and culturally competent manner