

For More Information

- Sign-Up for The Buddy Buzz, our community-based newsletter
 - Send an email to: info@cthemophilia.org
 - Subject: Buddy Buzz
- Like us on Facebook
 - <https://www.facebook.com/cthemophilia/>
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HTCs – Hemophilia Treatment Centers

- Comprehensive care centers, created 1973, specifically to care for people with bleeding disorders.
- Centers not only provide specialty care but can also act as a resource to regular family physician or dentist.
- Members of care team include:
 - Hematologists
 - Pediatricians
 - Nurses
 - Social Workers
 - Physical Therapists
 - Orthopedists
 - Dentists
 - Patients and Their Families
- Bleeding disorders is the only disease state that uses a treatment center model for comprehensive care.
- There are approximately 141 treatment centers across the country.



CT Hemophilia Society – Mission & Events

- Mission Statement:

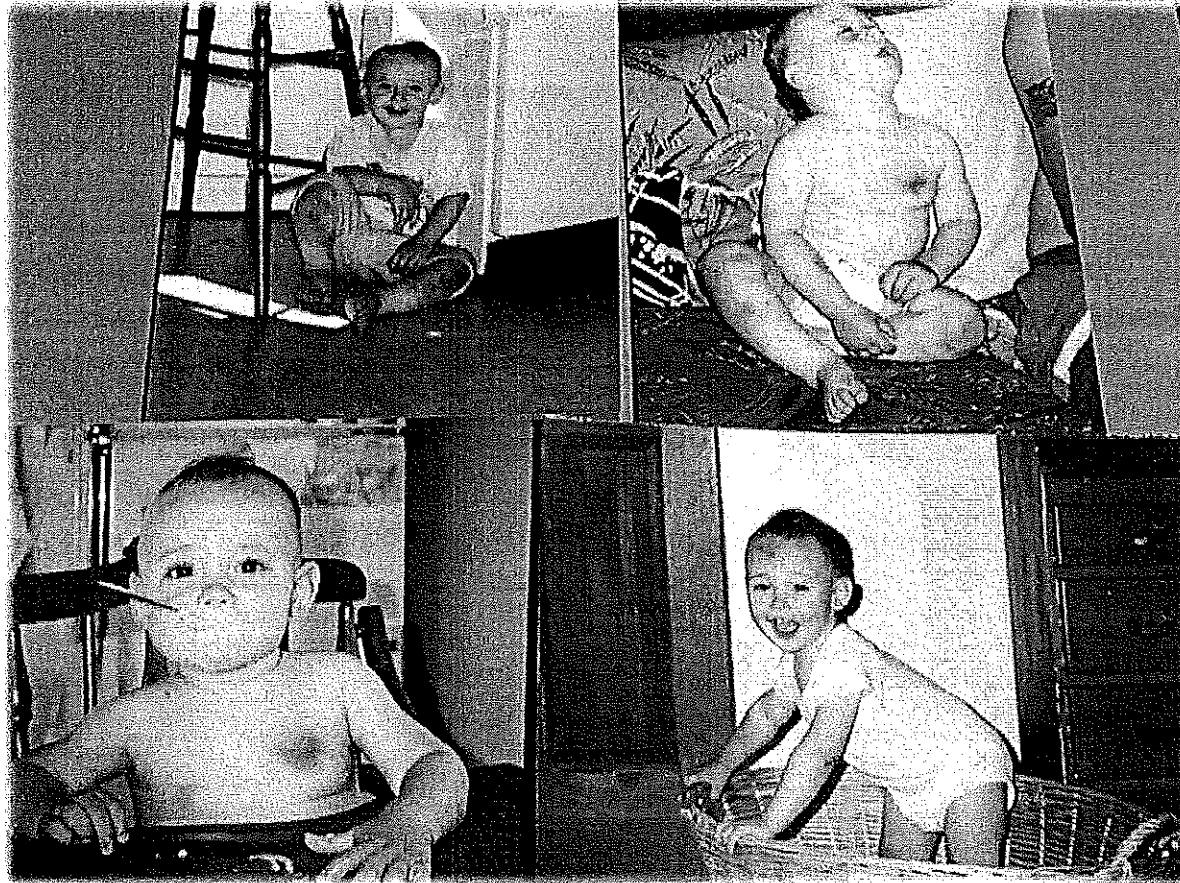
- Founded on February 17, 2010, the Connecticut Hemophilia Society, Inc., or CHS, is a non-profit corporation that is dedicated to improving the quality of life of persons with bleeding disorders and their families through education and financial support, and by supporting scientific research that is aimed at finding a cure for hemophilia. Although our goals are noteworthy, we plan on having lots of fun while striving to achieve them.

- Events:

- Spring Social
- Annual Meeting
- Infusion classes,
- Strike Out Hemophilia Tailgate Party & Baseball Game
- Lake Compounce Family Fun Day
- Events combined with NEHA and the Hemophilia Alliance of Maine



What it looks like



Hemophilia

- According to the US Centers for Disease Control and Prevention:
 - Hemophilia occurs in approximately 1 in 5,000 live births.
 - There are about 20,000 people with Hemophilia in the United States
 - All races and ethnic groups are affected
 - Hemophilia A is four times as common as Hemophilia B
 - Hemophilia A = Missing Factor VIII protein
 - Hemophilia B = Missing Factor IX protein
 - More than half of patients with Hemophilia A have the severe form of Hemophilia
 - Approximately 2/3 have family history
 - Approximately 1/3 are a spontaneous mutation
 - Hemophilia mostly affects males, with less than 1% females.
 - Women who were once considered symptomatic carriers are considered to have mild Hemophilia
- Approximate number of people in CT with Hemophilia = 329
 - This is an approximation as not all affected individuals are seen at treatment centers



Overview

- A brief overview of bleeding disorders
- Hemophilia
- von Willebrand disease
- What it looks like
- CT Hemophilia Society – Mission & Events
- CT Hemophilia Society – Benefits
- HTC's – Hemophilia Treatment Centers
- NEBDAC - New England Bleeding Disorders Advocacy Coalition
- For More Information

