Hemophilia Treatment Centers

Program Justification

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Hemophilia Treatment Centers

- Our history
- Our support
- Our activity
- Our staff
- Our outcomes
- Our stories
- Our threats and opportunities
Our History

- Most HTCs have 3 parallel histories
  - Center, Regional, Federal Designation
- 1956: HFM begins as an all-volunteer chapter of NHF
- 1969: Hemophilia camp begins
- 1971: UM begins Hemophilia Treatment Center
- 1973: NHF in partnership with hemophilia treaters launches a campaign to create a nationwide network of hemophilia diagnostic and treatment centers
- 1975: HFM becomes the regional core center for MI, OH and IN
- 1986: CDC AIDS Risk Reduction funding begins
- 1996: NHF amends bylaws changing relationship with chapters
- 1997: HFM granted independent 503(c)(3) status
Our Support

- Institutional support:
  - Staff, space

- Funding has been a moving target
  - Hemophilia Homecare (for-profit) Clinical Care Management
  - Federal: MCHB, CDC
  - State: CMS?
  - 340B: Institutional, regional (Cascade)
  - Foundations: ATHN
  - Research: Pharma trials, investigator-initiated studies
Our Activity

- High quality multidisciplinary care
- Cost-containment
- Family-centered
- Specialized diagnostic services
- Research
- Advocacy and education
- Downstream impacts in our health systems
Our Staff
Our Outcomes

- Baker JR et al. A model for a regional system of care to promote the health and well-being of people with rare chronic genetic disorders.

- Grosse SD et al. Models of comprehensive multidisciplinary care for individuals in the United States with genetic disorders.
  - *Pediatrics* 2009;123:407-12


  - *Haemophilia* 2001;7:198–206

- Kulkarni R et al. Sites of initial bleeding episodes, mode of delivery and age at diagnosis in babies with haemophilia diagnosed before age 2 years: a report from The Centers for Disease control and Prevention’s (CDC) Universal Data Collection (UDC) project.
Our Outcomes

- Smith PS, Levine PH. The benefits of comprehensive care of hemophilia: a five-year study of outcomes.

  - *Transfusion* 2004;44:1179-85


- Soucie JM et al. Joint range of motion limitations among young males with hemophilia: prevalence and risk factors.
  - *Blood* 2004;103:2467-2473

- Ashrani et al. Septic arthritis in males with hemophilia.
  - *Haemophilia* 2008;14:494-503

  - *Haemophilia* 2009;15:918-25
Our Stories
Our Threats and Opportunities

- MCHB funding has been flat or declining for years
- CDC funding remains pinched
  - HIV care has become less of a priority
  - Shift from focus on seroconversion to longitudinal outcomes
  - Dilution of hemophilia within broader hematology objectives
- Challenges to 340B
- Insurance restrictions
  - Inexperienced home care delivery, prior auths, uninsured, locked out of HTC network
- Health reform?
- Thrombophilia - friend or foe?
- Rare bleeding disorders
- National focus on disaster preparedness
- ATHN, HTRS and other federal research networks