

HTC History of Growing Needs and Financial Challenges

Why preserving HTC funding is critical

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Ronnie Nelson, of Tennessee, advocates on Capitol Hill during NHF's 2011 Washington Days.

[Read about advocacy efforts for the hemophilia treatment center network.](#)

Hemophilia treatment centers (HTCs) have become victims of their own success, says Marion Koerper, MD, medical advisor to the National Hemophilia Foundation (NHF). "The government sees no more patients in hospitals, no new joint disease, no new infections, and asks, 'Why do we need HTCs anymore?'" says Koerper, director emerita of the HTC at the University of California, San Francisco. "But the reason hemophilia patients are doing so well is because of the HTCs." In addition to providing high-quality care, HTCs conduct research that has greatly contributed to advancements in management and improved treatment outcomes in patients with bleeding disorders.

In the 36 years since the HTC network was created, federal funding has decreased even as the patient population has grown. People with von Willebrand disease (VWD) and rare factor deficiencies could benefit from the comprehensive care provided at HTCs. Further, more people with hemophilia are surviving into adulthood than ever before, because of the reduced risk of HIV and hepatitis C from contaminated blood products, effective HIV treatment and at-home prophylaxis, says Judith Baker, MHSA, administrative director of the network's Region IX, which represents 14 HTCs in California, Guam, Hawaii and Nevada.

Hemophilia Treatment Centers' Growth

In 1973, NHF launched a campaign to establish a nationwide network of HTCs. Two years later, Congress authorized it. In the beginning, there were 25 centers around the country. Grants from the Maternal and Child Health Bureau of the US Health Resources and Services Administration (HRSA) helped fund case management, social work and other services that are essential to the comprehensive care model but are not covered by insurance. In 1987, the Centers for Disease Control and

Prevention (CDC) responded to the AIDS crisis by adding support for HIV surveillance, education and prevention.

“Because the comprehensive care model was so successful, the number of centers was increasing,” Koerper says. The number eventually reached 140 around 2000. Traveling clinics helped fill the gaps, Baker says. But there are still plenty of underserved areas, and not just in rural parts of the country. “Urban areas like Los Angeles, where there’s very limited public transportation, can also be underserved,” Baker says.

Hemophilia Treatment Center Funding Challenges

Ensuring that plasma-derived factor products would eventually become safer from viral contamination was an achievement for the bleeding disorders community, but it also threatened the CDC funding. “By 1995, CDC administrators were saying that HIV was a non-issue, so why should it continue to fund HTC?” Koerper says. Fortunately, the CDC ultimately decided to continue HTC funding. It redirected its focus to surveillance of joint disease and other secondary complications, and safeguarding the blood supply from potential threats.

While this was welcome news, federal funding represents only a small part of HTC budgets. Most funding comes from billing insurers—both public and private—for services. That reimbursement isn’t enough to cover the extensive education and care HTCs provide, says Koerper, particularly as hospitals’ income from insurance reimbursement began to drop once prophylactic treatment decreased the frequency of joint bleeds and, thus, the number of HTC visits.

Between 2000 and 2010, some hospitals began regarding HTCs as losses, with some saying their centers had to close, Koerper says. In addition, many of the original HTC directors were retiring, and there weren’t enough young physicians to replace them. By 2010, the number of HTCs had dropped to 130, says Koerper.

One hopeful funding development is HTCs’ growing participation in the federal government’s “340B” pharmacy program. This allows HTCs to purchase factor at a reduced price, sell it to patients and reinvest the modest revenues back into the centers. About 85 HTCs now have such programs.

Koerper is confident that advocacy by NHF and the rest of the bleeding disorders community can also help preserve HTC funding. “When a doctor goes to Congress and says, ‘I want you to keep giving me money,’ it’s seen as self-serving,” she says. “When patients say, ‘Our lives are better because of treatment from HTCs,’ that’s a very powerful voice to persuade Congress to continue funding.”