

A MODEL OF CARE

HTCs BRING A 'DIFFERENT LEVEL
OF SOPHISTICATION'

BY LISETTE HILTON

To understand the value that hemophilia treatment centers (HTCs) offer, you need only hear one of *many* success stories.

Leonard A. Valentino, MD, associate professor of pediatrics and internal medicine and director, Rush Hemophilia and Thrombophilia Center, Rush University Medical Center, Chicago, talks about his experience with a boy who has severe hemophilia B and an inhibitor, and who first hobbled on crutches into an HTC when he was in the fourth grade.



HTC CARE IS TIME-CONSUMING AND EDUCATION-INTENSIVE, SAY THE BLEEDING AND CLOTTING DISORDER EXPERTS WHO WORK AT THE CENTERS

ing into a knee and an elbow,” Valentino says. “We then removed the synovial tissue in two different surgical procedures. That allowed us to bring his joints back to baseline... Over the course of the next 10 months or so, we aggressively rehabilitated him with physical therapy and splinting.”

“He had been on crutches for two years and had been cared for in a general pediatric hematology/oncology practice, which did not have particular experience or expertise in managing complicated patients with hemophilia,” Valentino says.

The quality of care convinced the boy’s family to start receiving hemophilia care at the HTC, rather than in the general community setting.

“One of the first things we did was put the patient on a prophylaxis regimen to stop the joint bleeding. He had chronic bleed-

says the Rush HTC started in November 1993 with four patients and today has more than 200, as well as a large patient base made up of people with platelet disorders, von Willebrand disease (VWD), rare factor deficiencies and thrombophilia.

“The HTC brings a different level of sophistication to the care of patients with hemophilia. Because the HTC is used to dealing with this type of population patients and their complications, I think that HTCs tend to be more proactive, rather than reactive,” Valentino says. “The other benefit is that because there is a team assembled in one place, the care that is provided is usually much more comprehensive and involved.”

HTC ABCS

Nearly 30 years ago, the National Hemophilia Foundation (NHF), in partnership with physicians who treated hemophilia patients, launched its campaign to create a nationwide network of hemophilia diagnostic and treatment centers.

Today, with 134 HTCs in the US, the concept remains the same: to provide a range of comprehensive services for patients and families within one treatment center. The Maternal and Child Health Bureau (MCHB) of the Health Resources Service Administration and Centers for Disease Control and Prevention (CDC) fund HTCs through grants and a cooperative agreement with 12 regional grantees. And now, as part of its National Prevention Program, NHF’s *Do the 5* health campaign urges people living

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with bleeding disorders to get an annual comprehensive checkup at an HTC as part of five steps to live longer and healthier.

HTC care is time-consuming and education-intensive, say the bleeding and clotting disorder experts who work at the centers. It is aimed not only at preventing bleeds and other complications—so that people with bleeding and clotting disorders can live better-quality lives—but also aims to enable patients and their families to care largely for themselves.

Staff members at HTCs are devoted to keeping up with how best to care for people with bleeding disorders. They usually include onsite or consultant hematologists who are specialists in bleeding and clotting disorders, pediatricians, nurse specialists, social workers (who help with emotional issues and also locating insurance and other financial resources), physical therapists, orthopedists and dentists.

To get their MCHB and CDC funding, HTCs in the network are responsible for achieving federal goals and objectives, and to provide care according to standards set by the CDC, says Judith Baker, MHSA, regional coordinator, Federal Hemophilia Treatment Centers/Region IX, Children's Hospital Los Angeles.

Baker also says there is an important public health component of the national network. Each region designates a regional director and coordinator. Guided by a regional executive committee, these individuals—as patient advocates—provide leadership and public health oversight to help identify and address regional needs. They monitor care provision at the centers, provide technical assistance and training and help educate new clinicians who are joining HTCs. They also work with the state health departments and local hemophilia organizations and address national and state policies that ensure or threaten access to the centers.

“For example, with Hurricane Katrina, because there was a national network of HTCs, there was a coordinated response to help affected bleeding disorder patients and families,” Baker says.

A CONCEPT THAT WORKS

When it comes to hemophilia care success, HTCs have *more* than just stories of happier, healthier patients. There are large-scale scientific studies that put meat behind their worth.

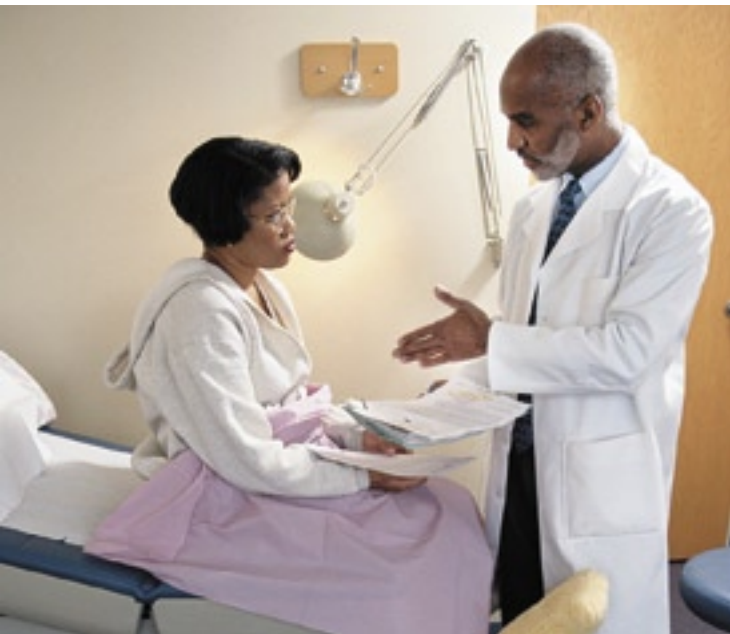
According to Sally Crudder, acting director, division of Hereditary Blood Disorders, National Center for Birth Defects and Developmental Disabilities, CDC, “HTCs have been shown to save lives and reduce cost because of reduced hospitalizations.”

Among those studies is one by J. Michael Soucie, PhD, and colleagues in 2000 and 2001, which found that death rates and hospitalizations related to hemophilia plummeted 40% when people got their care at an HTC versus by a hematologist, internist, primary care doctor, pediatrician or emergency room in the general community (see box).

“Frankly, we were surprised to find the results of that study because the more severe patients are the ones seen by HTCs,” Crudder says. “The dramatic difference makes a strong case for the HTC model of care.”

Mary Anne Schall, RN, MS, regional coordinator at Federal Hemophilia Treatment Centers/Region V-West, Great Lakes Hemophilia Foundation, Milwaukee, worked as a nurse in oncology before moving into hemophilia care.

“It may be hard to understand the difference between going to a hematologist in the community or seeing a hematologist at a treatment center,” she says. “It is more



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than just the *type* of doctor. A hematologist practicing [in the general community] might spend most of their time with oncology patients and only occasionally see patients with hemophilia; whereas physicians at treatment centers specialize in bleeding disorders and because of their experience and expertise can provide their patients with more options and insights.”

THE CHALLENGES

Unfortunately, all the good news about HTCs has not increased their funding. In fact, government funding of HTCs has been flat, while the costs of delivering care have risen.

“The federal dollars put into this program were meant to be seed money,” Crudder says. “The idea was that they would be demonstrated to be effective and, then, local healthcare systems would pick up the cost, but, in effect, that really has not happened.”

NHF has taken on the challenge of HTC funding. During NHF’s recent Washington Days conference in March, more than 200 community members visited Capitol Hill to advocate for members of Congress to approve an additional \$3 million in funding for the CDC to support HTCs around the country.

However, in the meantime, HTCs are left to seek alternative funding sources. One source of funding for about half of HTCs in the US is the 340b program, a government initiative allowing certain hospitals to purchase outpatient factor and other drugs for bleeding disorder patients at a significantly reduced rate.

The Rush HTC uses profits from its 340b program to help fund outreach efforts. Valentino says that he, a

nurse, a physical therapist and a social worker travel to satellite sites to see as few as five or six patients.

Not all HTCs participate in the 340b program. Wing-yen Wong, MD, director of the Hemostasis Thrombosis Center at Children’s Hospital Los Angeles, and associate professor of pediatrics at University of Southern California Keck School of Medicine, says the HTC she directs is among the oldest and largest, with more than 900 patients.

“People don’t realize how underfunded HTCs are ... and we try and basically make do with funding from as many different sources as we can, including clinical trials and grants,” Wong says. “Patients are so used to the service, they do not see the efforts to sustain this service.”

The comprehensiveness of HTC care is also at risk, says Baker. Sometimes, HMOs allow hemophilia patients to get their annual evaluations at HTCs, but these insurers often require that these patients get their lab work at the HMO.

This is a problem, Baker says, “because very few labs have enough experience to properly conduct the specialized tests to give someone a correct diagnosis. An HMO can also delay, deny or modify the treatment center’s plan, further jeopardizing the health of the patient.”

Another challenge: to make sure that we train the next generation of hemophilia care providers—in particular physicians—but also to provide specialized training in areas such as nursing, social work, physical therapy, genetic counseling and dental care, says W. Keith Hoots, MD, professor of pediatrics and internal

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Find an HTC

To locate the HTC nearest your community, visit the National Hemophilia Foundation Web site at www.hemophilia.org or call NHF’s Information Resource Center at 800-42-HANDI.



medicine and medical director at the Gulf States Hemophilia and Thrombophilia Center, Houston, Texas.

“It is a must for HTC to participate in training, so that we continue and expand the network into the future. If that doesn’t happen, even with funding, you will get a gap in terms of capacity to provide the kind of specialized care that is important to enhance survival in hemophilia,” Hoots says.

According to Hoots, a hematologist might go through training with almost no experience with hemophilia. “The training programs are combined hematology and oncology and it is very difficult to do just hematology and make a living. By contrast, oncology generates a lot of revenue. So there is a disequilibrium. Only by having academic and patient resources available to attract hematologists and special training programs to prepare them, are we likely to continue to be able to get the brightest and most energetic people to go into the field.”

TACKLING THE MYTHS

Doctors in the community might be hesitant to send their patients to HTCs for fear of completely losing the care of those patients. But that’s a misconception.

“Most people are seen by a treatment center team and then go home to their local providers, where they are followed,” Crudder says.

Insurance and payment are other issues keeping some from HTC care. The fact is, according to Schall, HTC staff is skilled at helping people get coverage or receive help for indigent care.

While today’s HTCs capture about 70% to 80% of all patients with hemophilia, 3,400 to 5,000 of the estimated 17,000 people in the US with hemophilia go elsewhere for their care, according to the Soucie study. Crudder and others believe that many of those who do not seek HTC care have milder forms of hemophilia and do not believe they need the comprehensive care. Studies, however, suggest that people with milder forms of the disease are putting themselves at higher risk for death and complications by not going to HTCs.

Some also cite the distance from home to the nearest

HTC as a hurdle to receiving HTC care. But distance to and from an HTC does not have to preclude this specialty care. According to Schall, many HTCs hold outreach clinics or help patients who qualify with funding for transportation—even an overnight stay.

RICH INFORMATION SOURCE

HTCs provide the hemophilia community with a wealth of information about hemophilia that would not otherwise be available. HTC care made possible the Universal Data Collection System (UDC), a blood bank surveillance launched in 1998 to monitor blood safety against HIV and other infections. Today, the CDC surveillance also monitors primary complications of hemophilia, including joint damage and blood-borne viruses.

“We have been able to utilize that bank for things like West Nile virus and determined that it was not being transmitted through hemophilia products,” Crudder says. “In addition, we are collecting routine clinical data. One outcome that we have been able to show is that young men with hemophilia have twice the rate of overweight as the general population. And researchers have reported that overweight kids with hemophilia have more decreased range of motion than kids with hemophilia who are not overweight.”

HTCs offer free testing for hepatitis A, B and C and HIV through the UDC, according to Baker. “If there is a threat to the blood supply, HTCs are poised to very quickly take actions based on data. Not only are HTC patients getting the most expert clinical care, but they can participate in groundbreaking research for optimum care and better products not only for themselves but also for future generations of people with hemophilia.” ●

READ MORE

To read more research articles on HTCs, see:

Baker JR, Crudder SO, Riske B, et al. A model for a regional system of care to promote the health and well-being of people with rare chronic genetic disorders. *Am Journal Public Health* 2005;95:1910–1916.

Soucie JM, Nuss R, Evatt B, et al. and the Hemophilia Surveillance System Project Investigators. Mortality among males with hemophilia: relations with source of medical care. *Blood* 2000;96:437–442.

Soucie JM, Nuss R, Evatt B, et al. and the Hemophilia Surveillance System Project Investigators. Home based factor infusion therapy and hospitalization for bleeding complications among males with hemophilia. *Haemophilia* 2001;7:198–206.