HACA LOOKS BACK

YEARS OF CARING

50

HACA
HEMOPHILIA
ASSOCIATION
of the Capital Area
When a group of parents came together in the early 1960s to help other families like themselves who had children with hemophilia, little did they know how much progress—and how many problems—would affect their community in just 50 years.

The parents’ group was spearheaded by Admiral Gordon Nagler and Margaret Graham. They had children who were “bleeders,” the term common at that time for referring to people (predominantly males) who had hemophilia, a rare blood disorder. They, like other parents of children with hemophilia, often felt isolated from “normal” families, because their “routine” frequently included long stays in hospitals at their sons’ sides while they received life-saving treatments to help their blood clot and their internal injuries heal.

Naturally, these hospital visits brought the parents of “bleeders” together as they worked with the doctors who cared for their children. Realizing that there was strength in numbers, Nagler and Graham decided in 1964 to create the Washington, DC, Chapter of the National Hemophilia Foundation. Graham then served on the Chapter’s board for more than a decade and was instrumental in many of the chapter’s successes during its infancy.

The 50 years that followed were marked by tragedy—and triumph. This is that story.
Early Days

The newly formed chapter — which eventually became known as the Hemophilia Association of the Capital Area (HACA) — got right down to the business of finding members, raising money, and creating a walk-in clinic for people with hemophilia at a local hospital.

Getting the word out about the chapter, so that parents of children with hemophilia could feel less isolated, was one of the most important tasks that the leaders faced. Letters were sent to 28 hospitals in the area and to all the local school districts, asking their assistance in finding families of hemophiliacs. Their efforts were successful: within the first year, according to early meeting minutes, the chapter grew to 62 families, each family containing approximately two people with hemophilia.

Living with Hemophilia

Treatment for hemophilia in the early 1960s was very different from treatment today. Then, children spent weeks in the hospital undergoing transfusions of whole blood or fresh plasma. The idea was that the transfused blood would contain enough of the missing proteins to stop serious internal bleeding. Unfortunately, it was often not possible to raise a patient’s clotting factor levels high enough to do the job, given the volume of whole blood needed. As a result, many people with severe hemophilia, and even some people with mild or moderate forms, died in childhood or early adulthood. The most common causes of death were bleeding in vital organs, especially the brain, and excessive bleeding after minor surgery or trauma. Those who survived were often crippled by the long-term effects of repeated hemorrhages into the joints.

Discovery of cryoprecipitate.

With the discovery of cryoprecipitate in 1964 by Dr. Judith Graham Pool, the outlook for treatment greatly improved. Dr. Pool discovered that the precipitate left from thawing plasma was rich in factor VIII, and this substance — “cryoprecipitate” — could therefore be infused to control serious bleeding. Blood banks began producing and storing cryoprecipitate, making emergency surgery and elective procedures for hemophilia patients more practical. This advancement also ended the need for high-volume whole blood transfusions for people with hemophilia. Subsequently, researchers developed methods to concentrate the factor proteins found in cryoprecipitate. The commercial adaptation of this process led to lyophilized—or freeze-dried— clotting factor concentrates that could be used to quickly raise clotting factor to normal levels.
a one-woman campaign on hemophilia” intent on raising the funds needed to finance a 24-hour walk-in clinic where patients could get treatment, plasma, and counseling.

By 1970, a clinic was established at Suburban Hospital. The clinic featured a blood bank for producing and storing cryoprecipitate. A report in the minutes from a 1971 meeting provided these statistics: “26 Factor VIII youngsters, 4 Factor IX on a demand basis, one Factor XI, 1 von Willebrand, 7 youngsters on prophylaxis, 5 boys who receive cryo three times a week, and one young man on home therapy.”

In 1972, the clinic was still going strong, and the Suburban Hospital hematologists recommended hiring a full-time patient care coordinator. Information on the clinic after the early 1970s is scarce, but it appears that the clinic was eventually moved into the emergency department of the hospital. By the 1990s, recombinant products, which are not made with plasma, became the preferred method of therapy, eliminating the need for a blood bank (the Suburban Hospital clinic’s raison d’etre). The growth of the federally funded hemophilia centers at other hospitals eventually led to the clinic’s closure.

The DC chapter was ahead of the curve in its development of a hemophilia clinic, and there was a subsequent movement underway to make these centers universal throughout the United States.

**Advocacy for Care**

The history of advocacy in the bleeding disorders community can be traced back to the early 1970s, when Sen. Harrison A. Williams, Jr., of New Jersey introduced the Hemophilia Bill of 1973. The bill proposed providing funds for research; creating a comprehensive care model for hemophilia through the establishment of diagnostic and treatment centers that would also train professionals and paraprofessional personnel; establishing regional blood fractionation centers; and forming an advisory board to set national guidelines for diagnosis and treatment of hemophilia.

Ann Walsh, a former HACA board member and parent of a son with hemophilia, was an integral part of the advocacy efforts to get comprehensive care for people with hemophilia. Walsh described the effort to get the bill passed as a “march on Washington.”

The National Hemophilia Foundation led advocacy efforts in the nation’s capital. Walsh did much of the footwork in DC, arranging legislative visits for everyone who attended, setting up room blocks at local hotels, and planning a dinner for the visitors to attend. Chapters were encouraged to bring members to DC and to attend the Senate hearing in November 1973. An impressive list of witnesses spoke at the hearing, including AHF board and staff, well-known physicians, and several boys living with hemophilia.

Despite the success of the DC visit and the hearing, the legislation did not immediately pass. The Hemophilia Act was folded into larger packages of legislation that were vetoed by President Gerald Ford in 1974 and again in 1975. However, Congress overrode that veto in 1975 and passed Public Law 94-63, which included not only the Hemophilia Act provisions but also funding for family planning programs, community mental health centers, a nurse training program, the National Health Services Corps, and other health-care-related items.

When President Ronald Reagan took office in 1980, his administration consolidated a number of disease-related categorical legislative programs into one large block grant, a move that threatened funding for the hemophilia treatment center program. NHF worked with major players such as Senators Harrison Williams, Bob Dole, Orrin Hatch, and Edward Kennedy to make sure that that funding would be preserved. In 1981, the treatment center program became part of Title V Maternal and Child Health Program, where it remains today.

**Local HTCs form.**

Dr. Naomi Luban, a pediatric hematologist at Children’s National Medical System, was heavily involved in the creation of the hemophilia treatment center (HTC) at Children’s and worked with Dr. Sanford Leiken at the hospital to set up the comprehensive care model there. Dr. Luban had trained under Dr. Louis Aledort at Mount Sinai Hospital in New York City and Dr. Margaret Hilgarner at Cornell, both pioneers in hemophilia treatment and care on the East Coast. Dr. Luban came to DC in 1976 to put that training to use.

When the clinic first opened, it set out to demonstrate the difference in treatment that comprehensive care could make. HTC staff included Dr. Luban and a nurse, orthopedist, dentist, physical therapist, and social worker. “When you came to clinic, you would be seen by as many individuals [as] could see you in a half-day time frame,” Dr. Luban said. A report was sent to each Patient’s pediatrician.

Dr. Luban recalled one family who had three affected sons. Their treatment was often used as a benchmark for others.
an example of the benefits of comprehensive care. “[The sons] went from poor, infrequent therapy to people who had a better quality of life,” she said.

The “fly in the ointment” was federal funding. Hemophilia treatment centers have always depended on federal funds to operate, and the amount of funds fluctuated from year to year, depending on the number of patients seen at the center, Dr. Luban said. Over time, staff was whittled down to the core services provided today: a physician, a nurse, a physical therapist, and a social worker. “As therapy improved, you didn’t need to have quite that many people at your beck and call,” she said.

Children’s was an early adapter of transition care. Dr. Luban said, which involved moving a patient’s treatment to the adult treatment center when the time arose. The adult hemophilia treatment center was created at George Washington University in the late 1970s, but moved to Georgetown University Hospital in 1997, where it remains today. There have always been two treatment centers in the DC Metro area — one for children and one for adults.

Relationship with NHF

By the time the DC chapter formed, the National Hemophilia Foundation had undergone more than a few growing pains of its own. The NHF had been created in 1948 by Robert Lee Henry, who later left the board of directors in 1956 over differences about how the organization should function. By 1964, when the DC chapter was formed, NHF had just hired its second executive director.

Chapter co-founder Margaret Graham served on the NHF board in the early 1970s, and Ann Walsh in the 1980s. Both were strong voices for reform from within the organization during their tenures.

Instability at the national level unfortunately continued for many years. Finances were often a problem, and this created rifts in the relationship between chapters and NHF. There were disagreements regarding the assessments paid by chapters to NHF, and many chapter leaders were dissatisfied with how NHF spent the money it received.

Tension between the national organization and the local chapters came to a head during the AIDS crisis, and in the 1990s, HACA chose to be a stand-alone entity with 501(c)(3) status independent of NHF. At the time, NHF was encouraging local chapters to make such a change, believing it could operate more efficiently under the less closely linked structure. Today HACA has chosen to be an affiliate chapter of the NHF, which requires that HACA agrees to a set of chapter standards designed to ensure a high level of service, education, and support to all persons with bleeding disorders. Through this agreement, NHF provides assistance to HACA in meeting the common goals of the national and local organizations.

The national organization has gone to great lengths in the last decade to improve its relationship with chapters, reviving the chapter services arms disassociated with local chapters. NHF has also instituted “chapter tracks” at its own annual meeting, providing leadership training to staff and board members. The Hemophilia Walk, a fundraiser and partnership between NHF and participating chapters, has also helped unify both groups.

Dark Days: The AIDS Crisis

Lyophilized clotting factor had broken away the chains that tethered hemophilia to hospital beds. But there was a dark side to this progress. The demand for plasma rose significantly and the need for volume rather than quality began to drive the plasma industry. Plasma was often obtained from paid donors, including prisoners and others who were high risks for blood-borne diseases; those donations were combined into vast pools, so a lot of factor manufactured from this plasma thus exposed a recipient to tens of thousands of pooled units of blood donated by high-risk populations. Hepatitis (a known risk) and HIV, a new and previously unknown pathogen, tainted almost the entire national supply of clotting factor concentrate.

In early 1982, the first case of AIDS in a person with hemophilia was reported. The Centers for Disease Control rang the alarm, but NHF was slow to respond. There was suddenly a demand for information and action from people in the local bleeding disorders community. Affected individuals and family members came back into the fold for comfort and advice.

HACA response.

In 1983, the chapter was on the verge of shutting down. Hemophilia treatment centers had been established, and injectable clotting factor had stabilized the lives of patients. Interest in chapter activities waned. However, the AIDS crisis brought the chapter back to life in 1984, with Penny DeFilippi serving as executive director. There was suddenly a demand for information and action from people in the local bleeding disorders community. Affected individuals and family members came back into the fold for comfort and advice.
Sandi Qualley takes the reins at HACA for a 21-year tenure

NHF and local chapters begin a campaign to seek assistance, both financial and medical, for individuals who contracted HIV/AIDS through tainted clotting factor

HIV Packet created; later becomes HIV/HCV Today

Annual golf fundraiser begins

HACA members start attending Hole in the Wall Gang Camp

Between 1981 and 1984, more than 50 percent of the population of hemophilia patients in the United States—many of them children—became infected. Many died, though individuals today still live with both HIV and hepatitis C, another blood-borne infection contracted from the tainted blood products.

What had to happen was that people deal with the realities of what was happening,” said Linda Price, a former HACA board member. Chapter members in DC and throughout the country were angry at NHF at what they felt was the organization’s slow response to the reality that blood products were tainted. It took many years for this anger to subside.

Mounting tensions.

“There was significant tension between local chapters and the NHF, which led to the creation of the Hemophilia Federation of America and the Committee of Ten Thousand,” recalled George Price, a former HACA board president. “NHF meetings were filled with bile.” HPFA and COTT were grassroots advocacy groups that formed to help disseminate information and assist people affected with hemophilia and AIDS.

In the world outside these organizations, people—even professionals—were ignorant at best, or patronizing at worst. For example, Linda Price recalls her son’s hematologist patting her on the head and telling her she was overreacting.

“The potential of devastation was such that they couldn’t face it,” she said.

Between 1981 and 1984, more than 50 percent of the population of hemophilia patients in the United States—many of them children—became infected. Many died, though individuals today still live with both HIV and hepatitis C, another blood-borne infection contracted from the tainted blood products.

George Price said it’s a tribute to the chapter’s leadership that it remained intact during this difficult time.

“Lots of chapters split from NHF and floundered after that,” he said. “It was a great accomplishment that we not only advocated for treatment of HIV but better treatment for hemophilia overall, and that we stayed together.”

Families of children affected by hemophilia and AIDS also had to face the stigma that came along with the disease during the first few years of the crisis. A lot of families wanted to go underground, George said, but the chapter pushed hard in the school systems to ensure that HIV-positive students weren’t ostracized. As president of the chapter, George Price spoke before the Fairfax County School Board in 1988 to talk about the district’s proposed policies on AIDS.

“I had spoken in front of a lot of groups before, but it was the first time I spoke before a group where I knew whatever I said would not be accepted,” he said, describing the group as “me and 47 moms who didn’t want their kids exposed to HIV.”

What a crisis it became.

Advocacy continues to play a major role in the bleeding disorders community, on both the state and national level. HACA participates in state advocacy activities with both the Virginia and Maryland chapters each year, as well as in Washington Days with NHF, to protect access to high quality care for individuals affected by bleeding disorders.

Renewal of advocacy efforts: Justice for those infected by HIV

The HIV calamity gave rise to grief, frustration, rage—and activism. Leaders in the hemophilia community mobilized to advocate for a safer blood supply and for compensation for affected individuals and their families.

HACA was deeply involved in these efforts. The Ricky Ray Relief Act, passed in 1998, granted eligible HIV-infected hemophiliacs or their survivors a one-time compassionate payment of $100,000. Former board member Ellis Sahner worked for the Distributive Education Clubs of America (DECA), and the DECA chapter at Robinson Secondary School in Fairfax, VA, threw itself wholly into advocacy for the Act for five years, mobilizing large numbers to lobby on Capitol Hill and contacting lawmakers to persuade them to support the Act. Community advocates also pressed for an investigation into the events that led to the contamination of the U.S. clotting factor supply; these efforts led the U.S. Secretary of Health and Human Services to commission an investigation and ultimately a seminal report by the U.S. Institute of Medicine on “HIV and the Blood Supply: An Analysis of Crisis Decision Making.”

Advocacy continues to play a major role in the bleeding disorders community, on both the state and national level. HACA participates in state advocacy activities with both the Virginia and Maryland chapters each year, as well as in Washington Days with NHF, to protect access to high quality care for individuals affected by bleeding disorders.

Justice for those infected by HIV

The HIV calamity gave rise to grief, frustration, rage—and activism. Leaders in the hemophilia community mobilized to advocate for a safer blood supply and for compensation for affected individuals and their families.

HACA was deeply involved in these efforts. The Ricky Ray Relief Act, passed in 1998, granted eligible HIV-infected hemophiliacs or their survivors a one-time compassionate payment of $100,000. Former board member Ellis Sahner worked for the Distributive Education Clubs of America (DECA), and the DECA chapter at Robinson Secondary School in Fairfax, VA, threw itself wholly into advocacy for the Act for five years, mobilizing large numbers to lobby on Capitol Hill and contacting lawmakers to persuade them to support the Act. Community advocates also pressed for an investigation into the events that led to the contamination of the U.S. clotting factor supply; these efforts led the U.S. Secretary of Health and Human Services to commission an investigation and ultimately a seminal report by the U.S. Institute of Medicine on “HIV and the Blood Supply: An Analysis of Crisis Decision Making.”

Advocacy continues to play a major role in the bleeding disorders community, on both the state and national level. HACA participates in state advocacy activities with both the Virginia and Maryland chapters each year, as well as in Washington Days with NHF, to protect access to high quality care for individuals affected by bleeding disorders.

Renewal of advocacy efforts: Justice for those infected by HIV

The HIV calamity gave rise to grief, frustration, rage—and activism. Leaders in the hemophilia community mobilized to advocate for a safer blood supply and for compensation for affected individuals and their families.

HACA was deeply involved in these efforts. The Ricky Ray Relief Act, passed in 1998, granted eligible HIV-infected hemophiliacs or their survivors a one-time compassionate payment of $100,000. Former board member Ellis Sahner worked for the Distributive Education Clubs of America (DECA), and the DECA chapter at Robinson Secondary School in Fairfax, VA, threw itself wholly into advocacy for the Act for five years, mobilizing large numbers to lobby on Capitol Hill and contacting lawmakers to persuade them to support the Act. Community advocates also pressed for an investigation into the events that led to the contamination of the U.S. clotting factor supply; these efforts led the U.S. Secretary of Health and Human Services to commission an investigation and ultimately a seminal report by the U.S. Institute of Medicine on “HIV and the Blood Supply: An Analysis of Crisis Decision Making.”

Advocacy continues to play a major role in the bleeding disorders community, on both the state and national level. HACA participates in state advocacy activities with both the Virginia and Maryland chapters each year, as well as in Washington Days with NHF, to protect access to high quality care for individuals affected by bleeding disorders.
Surviving the crisis

In 1987, during the devastating AIDS era, Jean Callahan became HACA’s executive director. She ran the organization out of her basement while caring for her son, who was affected with hemophilia, and her daughter.

“All I could do was get information to people in a timely fashion,” she said, a challenge in the pre-Internet and email days. “Folks were still putting their heads in the sand about the risk.”

Socialization, education, and fundraising.

The chapter held monthly gatherings for moms, chapter picnics for families, and summer camps for boys while holding educational sessions about AIDS. Chapter mainstays like the venipuncture camp for boys while holding educational sessions for moms, chapter picnics for families, and summer holidays. Callahan received a $20,000 grant to start Project FINDE, an effort to reach underserved populations.

In 1991, Sandi Qualley became executive director. During her 21-year tenure, Qualley did much to heal the rifts that divided the HIV-traumatized community. “All I could do was get information to people in a timely fashion,” she said, a challenge in the pre-Internet and email days. “Folks were still putting their heads in the sand about the risk.”

Socialization, education, and fundraising.

The chapter held monthly gatherings for moms, chapter picnics for families, and summer camps for boys while holding educational sessions about AIDS. Chapter mainstays like the venipuncture camp for boys while holding educational sessions for moms, chapter picnics for families, and summer holidays. Callahan received a $20,000 grant to start Project FINDE, an effort to reach underserved populations with hemophilia and give them information on comprehensive care and AIDS. Managing these activities was a balancing act for Callahan and chapter board members like the Prices.

Socialization, education, and fundraising.

The chapter held monthly gatherings for moms, chapter picnics for families, and summer camps for boys while holding educational sessions about AIDS. Chapter mainstays like the venipuncture camp for boys while holding educational sessions for moms, chapter picnics for families, and summer holidays. Callahan received a $20,000 grant to start Project FINDE, an effort to reach underserved populations with hemophilia and give them information on comprehensive care and AIDS. Managing these activities was a balancing act for Callahan and chapter board members like the Prices.

Socialization, education, and fundraising.

The chapter held monthly gatherings for moms, chapter picnics for families, and summer camps for boys while holding educational sessions about AIDS. Chapter mainstays like the venipuncture camp for boys while holding educational sessions for moms, chapter picnics for families, and summer holidays. Callahan received a $20,000 grant to start Project FINDE, an effort to reach underserved populations with hemophilia and give them information on comprehensive care and AIDS. Managing these activities was a balancing act for Callahan and chapter board members like the Prices.

Socialization, education, and fundraising.

The chapter held monthly gatherings for moms, chapter picnics for families, and summer camps for boys while holding educational sessions about AIDS. Chapter mainstays like the venipuncture camp for boys while holding educational sessions for moms, chapter picnics for families, and summer holidays. Callahan received a $20,000 grant to start Project FINDE, an effort to reach underserved populations with hemophilia and give them information on comprehensive care and AIDS. Managing these activities was a balancing act for Callahan and chapter board members like the Prices.

Socialization, education, and fundraising.

The chapter held monthly gatherings for moms, chapter picnics for families, and summer camps for boys while holding educational sessions about AIDS. Chapter mainstays like the venipuncture camp for boys while holding educational sessions for moms, chapter picnics for families, and summer holidays. Callahan received a $20,000 grant to start Project FINDE, an effort to reach underserved populations with hemophilia and give them information on comprehensive care and AIDS. Managing these activities was a balancing act for Callahan and chapter board members like the Prices.

Socialization, education, and fundraising.

The chapter held monthly gatherings for moms, chapter picnics for families, and summer camps for boys while holding educational sessions about AIDS. Chapter mainstays like the venipuncture camp for boys while holding educational sessions for moms, chapter picnics for families, and summer holidays. Callahan received a $20,000 grant to start Project FINDE, an effort to reach underserved populations with hemophilia and give them information on comprehensive care and AIDS. Managing these activities was a balancing act for Callahan and chapter board members like the Prices.

Socialization, education, and fundraising.

The chapter held monthly gatherings for moms, chapter picnics for families, and summer camps for boys while holding educational sessions about AIDS. Chapter mainstays like the venipuncture camp for boys while holding educational sessions for moms, chapter picnics for families, and summer holidays. Callahan received a $20,000 grant to start Project FINDE, an effort to reach underserved populations with hemophilia and give them information on comprehensive care and AIDS. Managing these activities was a balancing act for Callahan and chapter board members like the Prices.

Socialization, education, and fundraising.

The chapter held monthly gatherings for moms, chapter picnics for families, and summer camps for boys while holding educational sessions about AIDS. Chapter mainstays like the venipuncture camp for boys while holding educational sessions for moms, chapter picnics for families, and summer holidays. Callahan received a $20,000 grant to start Project FINDE, an effort to reach underserved populations with hemophilia and give them information on comprehensive care and AIDS. Managing these activities was a balancing act for Callahan and chapter board members like the Prices.

Socialization, education, and fundraising.

The chapter held monthly gatherings for moms, chapter picnics for families, and summer camps for boys while holding educational sessions about AIDS. Chapter mainstays like the venipuncture camp for boys while holding educational sessions for moms, chapter picnics for families, and summer holidays. Callahan received a $20,000 grant to start Project FINDE, an effort to reach underserved populations with hemophilia and give them information on comprehensive care and AIDS. Managing these activities was a balancing act for Callahan and chapter board members like the Prices.
Facing the future

Karen Krzmarzick stepped in as executive director when Sandi Qualley retired in 2011. Since Krzmarzick came on board, the chapter has added more educational events to the calendar throughout HACA’s coverage area. In addition, the annual bike ride was retired, and in 2013, the first DC Hemophilia Walk took place at the Lincoln Memorial, bringing in more than $80,000 for the chapter and uniting chapter members at an historic location.

HACA mainstays such as the educational seminar, venipuncture classes, summer camp, support groups, and new family gatherings continue to flourish.

The chapter continues to work with other chapters both locally and regionally, partnering with the hemophilia treatment centers on projects and programs and expanding programs for women with bleeding disorders and people with von Willebrand disease.

Krzmarzick has also turned her attention to raising funds for the chapter outside the pharmaceutical and home healthcare industries through grant writing and other projects. And like the chapter’s founders, HACA continues to reach out to affected individuals and their families in the DC metropolitan area to ensure everyone’s needs are met.

HACA has grown and changed in the last 50 years, but its mission—to support advocacy, education, and awareness efforts that build and sustain community among all people impacted by bleeding disorders—has not wavered since 1964, when that first group of parents united to improve the lives of their children. Today’s staff, board, members, and volunteers are proud to carry on the founders’ legacy.