THE BLEEDING DISORDERS COMMUNITY needs your help TO PRESERVE OUR HISTORY BEFORE IT’S LOST.
Our community’s legacy must be preserved for future generations.

With your help, it can be.
The Smithsonian Institution’s National Museum of American History in Washington, D.C., has committed to archiving a selection of artifacts and oral histories we have collected from the bleeding disorders community.

Our history has been set. But, preserving it for the future lies with you.
For most of the 20th century, people living with hemophilia struggled with severe health problems. Up until the late 1960s, treatment was limited to whole-blood transfusions and icing joints, a procedure that required days in the hospital to recover from a bleed. After a faster and more effective treatment for bleeding episodes, cryoprecipitate, was developed in 1964 life expectancy rose to just over 39 years, a vast improvement from the 27-year median during the decades that preceded.

The success with treatment brought new challenges that few in the community could have envisioned. As life expectancy grew, it brought with it new side effects, questions and concerns for psychiatrists, social workers and community members as they dealt with the social complications that go along with having a crippling illness. Suicide was, in fact, the most common cause of death among adolescents who suffered from hemophilia.
It’s hard for those who didn’t live through the ’60s to imagine the impact the first plasma-based clotting factor product had on the community when it was administered to a hemophilia patient for the first time in 1967. This, along with a growing national focus on people living with hemophilia, led to a sharp increase in positive outcomes for hemophilia patients, as life expectancy rose to 60 years old.

During the late 1970s through the mid-1980s, much of America’s blood supply, particularly the stores of antihemophilic clotting factor, was contaminated with two deadly viruses: HIV and hepatitis C. These viruses are devastating and continue to evoke a terrible calamity in our community.

At first, both the pharmaceutical industry and certain government offices insisted the adulteration of clotting factors was an unforeseen and unavoidable accident. Persistent questioning and investigation by our community and its supporters, including the effective efforts of the then newly-formed Hemophilia Federation of America, strongly supports the position that appropriate diligence on the part of industry during those times would have substantially reduced, if not prevented, the incursion of these viruses into the medicines that otherwise promised our community a relatively normal, active and productive life.

Organizations professing to advocate on behalf of our community, along with leaders of the medical profession treating bleeding disorders, failed to aggressively and appropriately protect the health and safety of those whose care they had been entrusted. Many felt this breach of duty resulted, in large part, because those persons and entities did not wish to challenge or provoke the industry that was their major source of funding.

Much of our community believes that the failure of the pharmaceutical industry, certain government offices, advocacy groups and members of the medical profession to avert the HIV and hepatitis C crisis resulted from complacency and disregard for the safety of our community.

“Tthis is a story that could repeat itself, affecting far larger numbers of people than the community of hemophiliacs.”
-Donna Shaw
A RESPONSE TO CATASTROPHE

From the devastation of the blood supply crisis, Hemophilia Federation of America was founded to provide the patient population with a voice and to improve the care and quality of life for all people with bleeding disorders. With this voice, a community was invigorated.

As a leader in rare disease, we strive to remove barriers to diagnosis, treatment and cure. For the past 25 years, we’ve worked tirelessly with our community to assist, educate and advocate for people living with bleeding disorders.

We have always believed that paying tribute to and preserving the bleeding disorders community’s legacy of advocacy, sacrifice and treatment advancements is imperative. For years, we’ve proudly played a role in preserving our shared history with the Honoring Our Past, Building Our Future project, where we collected significant stories and artifacts which best represent our community. In tandem with a celebration of our 25th anniversary, we have invested significant resources into launching the History Archive Project.
“When we founded HFA, we all had aspirations and dreams of what we wanted to accomplish with no money. The fact that HFA’s story will be preserved in the Smithsonian is just overwhelming. I’m so proud of the 25 years of growth.”

- Jan Hamilton, HFA Founding Member
WORK REMAINS
While we have built a comprehensive timeline of the community’s history, recorded personal stories and oral histories, and made an initial donation of artifacts to the Smithsonian Institution’s National Museum of American History in Washington, D.C., there is much work left to be done. HFA can be the catalyst for this monumental project, but we can’t preserve the community’s history on our own. It’s not HFA’s story to tell, it’s all of ours!

We must preserve the history of the bleeding disorders community for future generations to ensure the community’s legacy of advocacy, sacrifice and scientific advancements will be not forgotten.

WHY NOW?
While time and generational changes have brought our community scientific advancements and improved quality of life, it also brings the unavoidable ability for moments in history to be forgotten. The reality is that the generation who lived through the crisis of the blood supply’s contamination of HIV and hepatitis C, and the family members of individuals who were lost, are growing old. The people who worked tirelessly to protect the nation’s blood supply and bring justice to the bleeding disorders community have stories to tell.

Their voices, their stories, their struggles and triumphs, have had a profound impact on the community and the nation. Now is the time to ensure that we preserve our community’s unique history for the future.

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**OUR PLAN**

HFA has made an initial donation of artifacts related to the history of the bleeding disorders community to the Smithsonian Institution's National Museum of American History in Washington, D.C. This donation, which consists of items generously given by community members, is a huge step in formally preserving the history of the bleeding disorders community for future generations.

An effort to collect additional artifacts from the community is currently underway and a second donation of these items to the Smithsonian is slated for 2020. HFA will continue to record the oral histories and personal stories of community members to include in the donation of artifacts and make these available to the public on its website.

All of these items will be recorded and cataloged in compliance with the Smithsonian's archiving process, and they will be accessible via a custom-built webpage hosted within the museum's site and accessible from HFA's site.

**POTENTIAL COSTS**

We estimate the total cost of this project will be $200,000.

- Archiving of oral histories and personal stories .......................................................... $50,000
- Initial donation of artifacts to Smithsonian Institution .................................................. $25,000
- Second donation of artifacts to Smithsonian Institution ............................................... $25,000
- Building-out of Smithsonian Institution website ......................................................... $70,000
- Smithsonian Institution's archiving process ............................................................... $15,000
- Dedication Ceremony at Smithsonian Institution ........................................................ $15,000

More than 1,000 hours of HFA's staff time will be invested into seeing this project through to completion.
WE NEED YOUR HELP
Support from individuals, families, industry professionals, nonprofit organizations and corporations is needed to ensure this project is accomplished and thrives.

Being born today with a bleeding disorder still has its challenges, but children are growing up with a quality of life unparalleled by the generations before them. It’s imperative they don’t lose the sense of community that ushered in a new era for people living with bleeding disorders.

Opportunities like this are extremely rare: very few people have the chance to archive their history in the Smithsonian.

WITH YOUR SUPPORT, we can make it happen.