

PRESS RELEASE

Assisting and advocating for the bleeding disorders community.

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ABC's Secrets and Lies Dishonors Thousands of Americans Living with Hemophilia

Calls manageable hereditary condition "nasty byproduct of incest."

WASHINGTON, DC—<u>The Hemophilia Federation of America (HFA)</u> was appalled to learn that the American Broadcasting Company (ABC) show *Secrets and Lies* last night referred to hemophilia as a "nasty byproduct of incest" in the episode "The Sister" (S01, E04). **HFA formally requests that ABC issue a public apology for drawing this connection, which stigmatizes hemophilia and, by extension, the 20,000 known Americans living with this condition.**

"This kind of thoughtless inaccuracy by ABC—linking hemophilia to incest—is insulting. I cannot imagine what ABC was thinking when airing this scenario, especially against the backdrop of Hemophilia Awareness Month. If ever there was a time for network television to promote a more comprehensive view of hemophilia and the Americans living with this and similar conditions, it would be now. We cannot understate our disappointment with ABC today," said Kimberly Haugstad, HFA Executive Director. "ABC's attempt to manufacture drama has now inappropriately linked 20,000 known Americans living with hemophilia to an ugly taboo."

Hemophilia is inherited by way of the X-chromosome. As such, males—like the one referenced in the show—receive none of the hemophilia genes from their father, rendering ABC's fabrication grossly unfounded. Mothers carrying the genes have a 50% chance of passing it to their children. As carriers, many of these mothers display symptoms of the condition themselves and can even have hemophilia if their clotting levels are below 50%. In addition, approximately 1/3 of individuals who have hemophilia are spontaneous genetic mutations, with no family history whatsoever.

This event comes in the middle of <u>Hemophilia Awareness Month</u>, which every March recognizes the strengths of the bleeding disorders community and the unfathomable challenges that we have overcome. Less than 75 years ago, the median life expectancy for someone with hemophilia was only 27 years, and a person with severe hemophilia would likely spend much of that time suffering from excruciatingly painful bleeding episodes. Revolutionary treatments like clotting factor concentrates provided an opportunity to reduce bleeding episodes and greatly improve the quality of life and life expectancy for those with hemophilia, but evolved at a terrible cost. We live in the wake of the tragic decimation of thousands of our population to co-infections from the human immunodeficiency virus (HIV) and hepatitis-C (HCV) when blood products were tainted in the 1980s. Despite these tremendous obstacles, families with hemophilia are one of the strongest patient networks advocating nationwide today.

We invite ABC to attend <u>our upcoming national patient meeting</u> next week in St. Louis, to obtain valuable education on what living with hemophilia is really about.

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The Hemophilia Federation of America is a national community-based organization that assists and advocates for people with bleeding disorders and their families. This month, HFA is celebrating Hemophilia Awareness Month, culminating in our annual Symposium event, taking place March 26-28 in St. Louis, Missouri. This event will bring together over 800 patients, caregivers, family members, clinicians, and other providers from the bleeding disorders community to educate and support each other while honoring those we've lost.