

# *An Interview with Marilyn Ness*

By Susan Moore

# Bad Blood

**B**ad Blood, *A Cautionary Tale* is a feature-length film documenting the HIV/AIDS disaster in the bleeding disorder community. Adding a face to this medical tragedy, **Bad Blood** shares the memories of six families affected by hemophilia and HIV as well as members of the medical profession who provided care for patients with hemophilia. We are reminded to continue our vigilance in advocating for our community and to never forget those we have lost.

*Producer of Bad Blood, “Marilyn Ness is a two-time Emmy Award-winning documentary producer. She founded Necessary Films in 2005, directing short films for non-profits and developing documentaries including Bad Blood and Genome: The Future Is Now. Prior to that, Ness spent four years as a producer for director Ric Burns, collaborating on four award-winning PBS films...other credits include films for TLC, Court TV and National Geographic... She lives in New York City with her husband and two sons.”\**

**Bad Blood** has been created with utmost care given to show the world what happened, how it happened and to bring to light the lessons that cannot be forgotten. Marilyn’s intent was not to incite anger or ill will, but to open everyone’s eyes to the dangers that are still possible, and to keep the world attentive in order to safeguard against history repeating itself.

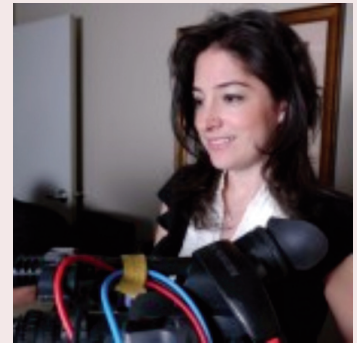
This film impresses on us the need for everyone to be alert to the necessity of oversight and accountability that is so vital to extinguish future tragedies before they occur. Government agencies, blood collection centers, drug manufacturers, research and development

companies, even our physicians must be held accountable for informing and educating when there is danger involved.

After viewing the film and meeting Marilyn Ness, I had many questions. The filmmaker was gracious enough to share her responses to some of my questions, and allowed me to share them with you:

**Susan Moore:** What was your personal motivation for taking on the **Bad Blood** documentary project?

**Marilyn Ness:** *Growing up with Mathew Kleiner in Brooklyn, we drifted apart as kids often do, but our parents stayed friends. Coincidentally, my sister wound up on the same dorm floor as Matt their freshman year at Cornell and they reconnected. During those years Matt came out publicly that he was HIV positive. Years later, Matt was living in New York working as an assistant District Attorney. I was living in New York working on documentary films. Knowing the lessons from this tragedy had never fully been understood by the general public, he asked if I knew how he was HIV infected. He thought perhaps I’d want to make a film about it. When he unraveled what had happened in the hemophilia community through the 1970s and 1980s, I was completely astonished and knew – as did Matt – that this story needed to be told.*



Producer, Marilyn Ness

**SM:** You are open to sharing that Matt Kleiner is your personal connection to our community. When you learned of his medical travesty, obviously you did not abandon him or judge him. Did you find others in your community who did?

**MN:** *By the time I came to this story much of the general public had long since lost sight of how the hemophilia community had been so decimated by the AIDS crisis. So there were not strong feelings of discrimination by then (in 1999). However, I know Matt's family hid Matt's HIV status throughout the late 1980s and early 1990s fearing stories like Ryan White's and Ricky Ray's. Matt was moved to go public about his HIV status after watching so many college students make unsafe sex choices – but it was not*

*without consequence. Matt also worked in his dining hall at Cornell and after giving safe sex talks he'd watch kids he had spoken to the night before move to another food line – still too afraid to accept food from his ladle. I think Matt can be credited with educating many of the students in the Northeast about HIV and safe sex at a time when discrimination and a lack of understanding still pervaded much of society.*

**SM:** How long did it take you to complete the film, from the first action you took until you said, “That’s a wrap!”?

**MN:** *Filming began with Matt in 1999, shortly after he told me his story and in time for his first court appearances in his litigation against the pharmaceutical companies. I filmed with Matt and his wife Jenny over the course of three days following him to doctors' appointments, the courthouse, infusing factor, and in conversations with his family. I also filmed an interview with Matt's attorney Eric Weinberg in those three days.*

*I put the film down from 1999 until 2006 for lack of funds. During that time I was working as a producer for Ric Burns, learning my craft. In 2006 I decided I wanted to finish BAD BLOOD – it was always the project that called to me. So I picked it back up in earnest in late 2006 until we finished the theatrical length version (touring the community now) in 2010. We just completed the shorter, broadcast version in early 2011. Now, it's a wrap!*



**SM:** Your film documents the lives of six families affected by hemophilia and the HIV holocaust. Choosing the Kleiner family, of course, would be a given, considering your history with Matt. How did you choose the other five families?

**MN:** *As Matt's story evolved through the years I realized I needed to expand the story, both for practical reasons, and because there would be more power for an audience if they understood this happened to 10,000 families and was not just one family's bad luck. I made an outline of all of the kinds of stories I wanted to include and my team and I then went on to cast different people who could help flesh out those aspects of the story. For instance, we wanted someone who was an activist, someone from NHF, someone*

*whose story would show the impact on spouses and children. We wanted stories where people weren't given the choice to go back to cryo or where they were too late to benefit from voluntary recalls. And then we figured out how to use all of these stories to tell one coherent whole.*

**SM:** What was the most difficult aspect of completing the documentary?

**MN:** *Fundraising was the most challenging. It was hard to convince traditional film funders that this story was important (though now that it is done audiences seem to understand the current relevance). While fundraising is never easy, BAD BLOOD was particularly daunting. I am proud of the film we made despite the hard road and thank my husband every day for the sacrifices he made so I could see this film through!*

**SM:** Was the bureaucracy overwhelming to cut through? How complex was it for you to gain access to the investigative findings, to the photographs, memos and footage that you obtained?

**MN:** *It took me a very long time to gain the trust of the community -- which at first surprised me -- but I now completely understand. This is a community that felt betrayed by those they trusted most – the government, their doctors, the drug companies working to protect them. I know over the years the media would pop in*

and out of the community as did various attorneys and politicians. So people did not warm up instantly. My team and I did quite a bit of “proving ourselves.” I think we had shown to all parties we had thoroughly done our research and were looking for the truth as told by the people themselves – from every perspective in this tragic story. Once we proved our intentions were honest and driven by integrity the doors opened wider and the materials came.

**SM:** Do you have any thoughts about whether it was the pharmaceutical industry or the government that was the biggest offender?

**MN:** I will leave it to the audience to determine how they feel about this “perfect storm of failure.” This was a collective tragedy and one that was incredibly complex. I don’t think there are any black and white answers and I think the lessons for future generations lies in carefully parsing the shades of grey.

**SM:** Given your connection with Matt, was it challenging for you not to play the blame-game? Did you find it difficult to remain objective?

**MN:** First and foremost I am a documentary filmmaker and Matt understood, even when he first approached me to make the film that I was going to do this with journalistic integrity. (And he knew it might also mean I’d come away with opinions different than his own – and that my editorial opinion would be the overriding opinion.) I spent much of my career making films for American Experience, the premiere historical documentary series on PBS. There is a responsibility that comes with making the seminal film on an historic subject – you have to get it right because it becomes the historical record. With that burden, objectivity was a must and “blame” was never part of my mission.

**SM:** What were the criteria used in choosing the treaters and researchers that appear in your film – Regina Butler, RN, Dr. Shelby Dietrich, Glenn Pierce and Dr. Bruce Evatt?

**MN:** As with casting the families, we were focusing on people who could contribute to various aspects of the story through first person accounts.

We cast Regina Butler because her clinic did offer patients the choice to go back to cryoprecipitate.

We cast Shelby Dietrich because of her commitment to

her patients from establishing comprehensive care in the hemophilia community, to traveling to the Jan. 4, 1983 CDC meeting to learn anything she could about this emerging epidemic, and because she was reflective and thoughtful on her failures and accomplishments in this community.

Bruce Evatt was the only choice for the CDC interview as far as I was concerned and it was fortuitous that I approached him just as he retired! Dr. Evatt received the first phone call about the first case of AIDS in the hemophilia community and stuck by this community throughout the crisis making key decisions.

Glenn Pierce was actually interviewed for his role as a patient leader within NHF and to try to shed light on the actions of NHF, particularly those decisions made by those affected by hemophilia whether personally or in their families.

Again, each person was chosen for the part of the story they could tell from their own perspective that would help shed light on the collective experience.

**SM:** How arduous was it for you to secure the participation of government regulators and pharmaceutical companies in the making of this film?

**MN:** Those were, by far, the most challenging interviews to obtain. I found David Castaldi, former president of Hyland Baxter who had since left hemophilia therapeutics, and he agreed to sit for an interview. I offered every company the chance to provide an interview. The only stipulation: it had to be someone in a leadership position making decisions at the time. (No PR people.)



In the end, industry asked me to interview Jan Bult, President of the PPTA, which I did despite the fact he was not making decision for industry during the crisis and was, in fact, living in The Netherlands at the time. Given the lack of first-person perspective we could never make his interview work with our storytelling approach. We will include his interview on the [BadBloodDocumentary.com](http://BadBloodDocumentary.com) website in the coming months.

**SM:** You were able to conduct interviews with actual government regulators and decision makers, and corporate giants during your ten-year process. How comfortable are



you that the magnitude of our community's tragedy has strengthened and improved the system, and that greed of pharmaceutical companies will not place the safety of our nation's blood supply at risk?

**MN:** *It is my belief that the hemophilia community did manage to safeguard the nation's blood supply and improve the safety of their therapeutics in significant ways. It is one of the things I admire most about this community and one of the most important take aways from the film: your voice **can** make a difference.*



*However, I do not believe the lessons from this tragedy have been learned by other pharmaceutical giants or even within other divisions of the FDA. I sincerely hope that with the PBS broadcast and our efforts to distribute the film in medical schools, business schools and public health schools, that the cautionary tale chronicled in **BAD BLOOD** can help safeguard the drug industry for all Americans.*

**SM:** What has been the overall reaction to your film? Has anyone from the government or the pharmaceuticals given you any disparagement? Any appreciation?

**MN:** *Industry reps have sent me many thank you notes saying they felt the film was accurate and incredibly informative. Even for those who have been in this community for a long time, they felt the way we interwove the public policies with the personal stories shed new light on this tragedy and how they understand it. **BAD BLOOD** is being used by at least four of the companies in training for all new employees. That is an incredibly satisfying response and one I know Matt would be proud of.*

**SM:** Are there any plans for a sequel, perhaps documenting the hepatitis dilemma and the refusal of the manufactures to own up to the ten years of infecting our guys?

**MN:** *I have been speaking with activists in the hepatitis C community – not just within the bleeding disorders community – about a film that sheds light on that story. It's always hard to say where these projects will go. But I enjoy making films about science and ethics and I will reflect back on my career with pride if I can continue to*

*make important films like **BAD BLOOD**.*

**SM:** You have been commissioned to complete a 50th Anniversary film for the World Federation of Hemophilia (WFH) in 2012; can you share anything about it? A sneak preview, perhaps?


**MN:** *I am creating a series of 12 short films to celebrate the history and accomplishments of the World Federation of Hemophilia over the 50 years they have been in existence. They are such an impressive organization – small but extraordinarily effective – I have been*

*telling everyone I know that if every disease group had an organization like the WFH advocating for them, there would be much less suffering in the world. It has also been a gift, after working on a film as sad as **BAD BLOOD**, to work on a film where people are performing the most amazing acts of kindness for their fellow human beings. It has restored my faith in people and only further strengthened my admiration for this unique community.*

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Perhaps by now you have been fortunate enough to view **Bad Blood, A Cautionary Tale**. The haunting tale is both heart wrenching and deeply inspirational as it demonstrates our community's ability to stand together in times of trouble. This film finally captures the gravity of what our community endured. Though the truth may be hard to bear, **Bad Blood** is already having a positive impact. The film has been screened for legislators, and has been delivered to several health care committees in the House and Senate.

In honor of World Hemophilia Day, April 17th, the WFH named Marilyn Ness an "*Inspirational Individual*" and has commissioned her to do a 50th Anniversary film for the WFH in 2012. (*Congratulations, Marilyn!*)

For the latest on future viewings, PBS television broadcasts, or to order a copy of the DVD **Bad Blood, A Cautionary Tale**, please visit the website: <http://badblooddokumentary.com> 

\* <http://badblooddokumentary.com/about/the-filmmaker>