



CEES SMIT

Surviving hemophilia

A road trip through the world of healthcare

2020

meeting would produce some action to arrest the threat the new syndrome posed to the nation's blood supply'."

Some vocal members of the MASAC did not change their opinion on AIDS. Stakeholders within the US hemophilia community denied the problem or refused to think about lowering consumption of plasma products. They did not want to lose the freedom the products had given them. In a compromise, the NHF recommended the larger group of hemophiliacs to continue their use of clotting factor concentrates unless advised otherwise by their personal physician. Between 1981 and mid-October 1984, 52 AIDS cases among persons with a clotting disease were reported, 48 of them people with hemophilia A. At CDC there was no doubt about Factor VIII preparations being the potential vehicles of AIDS transmission.

Action in the Netherlands

It was not just CLB, the producer of plasma Factor VIII in the Netherlands, that was concerned about the information coming from the USA, but also the public health sector of the municipality of Amsterdam with its large community of homosexual men. At the end of the year, on Wednesday, December 29, 1982, CLB organized a meeting with the NVHP. They informed us about an article that would appear in the *New England Journal of Medicine* early 1983, addressing AIDS and the use of blood products by hemophiliacs. The impact of AIDS for the hemophilia community became quite clear. In the next meeting on January 4, 1983, the hemophiliac doctors were informed. At that meeting, the NVHP decided to send letters with information to all hemophiliacs and their family members. We wanted to avoid that they would be alarmed by newspaper articles with maybe the wrong content. The first letter, warning our members for a new potential threat in their medicines, was mailed on January 5, a second one on February 27. In the first issue of *Faktor*, March 1983, an overview of the available knowledge was provided (Figure 24). The NVHP Board announced the Assembly of Members on May 14, where more information would be shared.

Bloody Sunday

Sunday, January 30, 1983, got the name of "Bloody Sunday". On that day a large meeting took place at CLB in Amsterdam with representatives of the GG&GDs [= Public Health Municipality Groups] of Amsterdam and Rotterdam, the State Health Inspectorate, the Central Medical Blood Transfusion Committee (CMBC), the regional blood banks, some virologists, NVHB doctors and the NVHP to discuss potential safety measures. One of these was the withdrawal of promiscuous homosexual men as blood donors. Unfortunately, a high percentage of them was blood donor, because of a trial running on a hepatitis B vaccine by GG&GD and CLB. The