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# Blood Feuds: AIDS, Blood, and the Politics of Medical Disaster

*From Eric Feldman*

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## B L O O D F E U D S

AIDS, Blood, and  
the Politics of Medical Disaster



*Edited by*

**Eric A. Feldman ▲ Ronald Bayer**

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**From Eric Feldman : Blood Feuds: AIDS, Blood, and the Politics of Medical Disaster** before purchasing it in order to gauge whether or not it would be worth my time, and all praised Blood Feuds: AIDS, Blood, and the Politics of Medical Disaster:

11 of 11 people found the following review helpful. A fascinating comparative analysis of a tragic set of events By Jacob S. Hacker This trenchant edited volume dissects a series of critical events that, while prominent in the public

realm, have yet to receive adequate attention from students of social and political affairs -- the explosive scandals that rocked many nations after public health officials became aware of HIV contamination of domestic and international blood supplies. These events represent not only a fascinating and tragic historical episode in their own right, but also provide a revealing window into the response of national leaders to symbolically and politically potent crises under conditions of uncertainty, anxiety, and fear. The essays in this volume, all written by country experts and notable social scientists, examine the comparative response to the tainted blood crisis in eight advanced industrial democracies: Australia, Canada, Denmark, France, Germany, Italy, Japan, and the United States. The questions asked in the case studies, in the fine opening chapter by Bayer and Feldman, and in the excellent concluding chapter by Marmor, Dillon, and Scher include: \* Should national leaders have responded more quickly to the evidence that hemophiliacs and other blood transfusion recipients were becoming infected with HIV? \* What accounts for the differences and similarities among nations in the speed and character of the eventual response? \* Why did the tainted blood crisis become high political scandal in some nations -- such as France -- and not others, especially since the severity of the scandals does not seem to correlate directly with the speed and effectiveness of national leaders' responses? \* What does this historical episode tell us about the influence of political institutions on policy outcomes? And what does it say about the relative performance of different national blood products regimes? Did it matter, for example, whether donors were paid or not, or whether nations were self-sufficient with regard to blood products rather than importing them from abroad? \* What was the process through which hemophiliac groups and other affected parties came to see their grievances as legal and political claims against their governments and, at times, against the very organizations that had once represented them? \* How can such tragedies be prevented in the future? This is, in short, a vital book for all those interested in this important chapter in the history of the AIDS tragedy, as well as for those who wish to learn more about how nations with very different cultures and political institutions respond to a common medical disaster.

In the mid-1980s public health officials in North America, Europe, Japan, and Australia discovered that almost half of the hemophiliac population, as well as tens of thousands of blood transfusion recipients, had been infected with HIV-tainted blood. This book provides a comparative perspective on the political, legal, and social struggles that emerged in response to the HIV contamination of the blood supply of the industrialized world. It describes how eight nations responded to the first signs that AIDS might be transmitted through blood, how early efforts to secure the blood supply faltered, and what measures were ultimately implemented to resolve the contamination. The authors detail the remarkable mobilization of hemophiliacs who challenged the state, the medical establishment, and their own caregivers to seek recompense and justice. In the end, the blood establishments in almost all the advanced industrial nations were shaken. In Canada, the Red Cross was forced to withdraw from blood collection and distribution. In Japan, pharmaceutical firms that manufactured clotting factor agreed to massive compensation -- \$500,000 per hemophiliac infected. In France, blood officials went to prison. Even in Denmark, where the number of infected hemophiliacs was relatively small, the struggle and litigation surrounding blood has resulted in the most protracted legal and administrative conflict in modern Danish history. *Blood Feuds* brings together chapters on the experiences of the United States, Japan, France, Canada, Germany, Denmark, Italy, and Australia with four comparative essays that shed light on the cultural, institutional, and economic dimensions of the HIV/blood disaster.

From *The New England Journal of Medicine* On July 16, 1982, the Centers for Disease Control reported the occurrence of *Pneumocystis carinii* pneumonia in three male patients with severe hemophilia A and no other underlying disease. The clinical and immunologic features -- which were those of the syndrome soon to be known as AIDS -- were strikingly similar to those in previously reported cases in homosexual men, heterosexuals who had used injected drugs, and Haitians who had recently migrated to the United States. All three of the patients with hemophilia had received frequent injections of factor VIII concentrate. The editorial note in *Morbidity and Mortality Weekly Report* concluded: "Although the cause of the severe immune dysfunction [in these patients] is unknown, the occurrence among the three hemophiliac cases suggests the possible transmission of an agent through blood products." This seminal report, which was soon followed by other reports of cases associated with transfusions of blood or blood products, produced profound changes in perceptions of AIDS and of the safety of blood. Scientists as well as the public became convinced of the transmissibility of an "AIDS agent," and focused efforts soon resulted in the discovery of the causative virus (later named the human immunodeficiency virus, or HIV). But the public perception of the safety of blood was altered, and AIDS changed forever the rules for those operating and regulating blood systems. This history and its lessons are thoroughly reviewed in *Blood Feuds: AIDS, Blood, and the Politics of Medical Disaster*. This fascinating book is uniformly well written and easy to read, especially for an edited book with several authors. It contains 11 chapters in addition to an introduction and conclusion. Part I comprises eight chapters, each of which gives a summary analysis of the national responses to the crisis caused by the presence of HIV in the blood supply in a particular country -- the United States, Japan, France, Canada, Denmark, Germany, Italy, and Australia. As the authors state, "Because the unfolding of conflicts over contaminated blood occurred almost simultaneously in different nations, blood became the vantage point from which to analyze the way in which countries with distinctive

historical legacies managed a common crisis." The chapters on the individual countries have been written by thoughtful and knowledgeable experts and deal less with technical issues than with public concern and the response of the government and the private sector in each country. The descriptions of the differences as well as the similarities in national responses to a nearly identical crisis make fascinating reading. The authors evaluate the part played by such factors as the extent to which the government is responsible for directly providing blood and blood products, the dependency of the country on imported blood or plasma, the visibility of the HIV epidemic in the country, and various cultural differences. Particularly intriguing are the comparisons of how different countries encountered liability and approached the issue of compensating patients with hemophilia. Unlike other battles in the AIDS epidemic, which ebbed in the late 1980s, Bayer and Feldman note, "the controversy surrounding blood persisted. Indeed, the intensity of the controversy over blood and AIDS underwent a process of amplification in the early 1990s," after the beginnings of activism among patients with hemophilia and their families. In many industrialized nations, patients with hemophilia had been liberated by the liberal use of factor VIII concentrates in the 1970s. The increase in life expectancy and the decrease in morbidity that resulted from treatment with products pooled from the plasma of thousands of donors (who were usually paid) was inadvertently accompanied by a tragic risk of a new disease, AIDS. In a poignant chapter on the activism of patients with hemophilia and their families, Kirp details how "the victims ultimately regarded what happened as no accident but rather as the inevitable result of decisions driven by corporate greed." Following the example of ACT UP (the AIDS Coalition to Unleash Power) years earlier, patients with hemophilia organized, demonstrated, and lobbied, seeking compensation through the courts and legislative processes. The "blood scandals" and their personal and institutional ramifications are richly described in the book. In the concluding chapter, Marmor and colleagues analyze the comparative politics and note that the intensity of the scandal in a given country was not a good measure of the wrongdoing in that nation. Of course, although concern about the safety of blood was indelibly changed by the experience with AIDS, more recent questions involve hepatitis C and even bovine spongiform encephalopathy (mad cow disease). By providing a cogent and thorough description of the AIDS saga, *Blood Feuds* provides insight into coping with these current and future threats to public health. This excellent book is well worth reading. ed by James W. Curran, M.D., M.P.H. Copyright 1999 Massachusetts Medical Society. All rights reserved. The New England Journal of Medicine is a registered trademark of the MMS. " ... an informative book ... provides a comprehensive review of the evolution of the crisis in Canada and of the belated response that resulted in [the Krever Inquiry] ... this book is an invaluable contribution to our understanding of the many issues raised by the contamination of blood and the "feuds" to which this tragic event gave rise." *Clinical and Investigative Medicine* (Dec 1999) "Blood Feuds is a much-needed contribution to our historical and comparative understanding of AIDS. The expanding globalization of AIDS and all that it entails makes this volume an important step in what will undoubtedly have to be a long and ever-widening research agenda." --*Law and Politics* Book "Blood Feuds: AIDS, Blood, and the Politics of Medical Disaster, a thorough history of the epidemiologic, political, and legal events.... this history provides a basis for beginning to understand and address a dignificant healthcare policy issue."--*MedGenMed* "...this book is an invaluable contribution to our understanding of the many issues raised by the contamination of blood and the 'fueds' to which this tragic event gave rise."--*Clinical and Investigative Medicine* "...the contributions are essentially cool and pragmatic views of the impact of AIDS on the several countries represented. Statements are well referenced, and assessments have been made of the adequacy of the public response, and ways in which this could be improved in any future similarsituation.... This book should be of great interest to the transfusion community..."--*Transfusion Today* "A fascinating comparative analysis of a tragic set of events.... This is, in short, a vital book for all those interested in this important chapter in the history of the AIDS tragedy, as well as for those who wish to learn more about how nations with very different cultures and political institutions respond to a common medical disaster."--Jacob S. Hacker, Fellow, The New America Foundation "A profound analysis of contaminated blood scandals in eight countries (US, France, Japan, Germany, Canada, Italy, Denmark, Australia)."--*Le Nouvel Observateur* "This book is a welcome addition to the library of anyone concerned about AIDS/HIV, the contamination of the blood supply, and the lessons that we can learn from this specific aspect of this world-wide epidemic. The contributors provide us with the opportunity to learn from the story of the way the developments were handled in our own country as well as those of the other countries covered. This is a unique contribution to the AIDS/HIV literature."--*Doody's Journal* noted in *Lancet* "This fascinating book is uniformly well written and easy to read, especially for an edited book with several authors.... The chapters on the individual countries have been written by thoughtful and knowledgeable experts.... By providing a cogent and thorough description of the AIDS saga, *Blood Feuds* provides insight into coping with these current and future threats to public health. This excellent book is well worth reading."--*New England Journal of Medicine* "A major contribution of *Blood Feuds* is that its comparative analysis of national experiences should puncture any complacency that may exist about the absolute safety of Canada's blood supply, or about the likelihood that our public health and political systems will respond more effectively to future health threats. This book will raise serious questions about the appropriateness of the resulting changes that have been made in many national blood systems." -- Jan Skirrow, *Canadian HIV/AIDS Policy and Law Newsletter*, Vol 5, No. 2/3, Spring/Summer 2000 About the Author Eric A. Feldman is at New York University. Ronald Bayer is at Columbia

University.