

New NJIT book examines hemophilia and consequences of medical progress

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“Hemophilia as a microcosm of the enterprise of disease management in the United States; that was my goal,” said Pemberton. Credit: New Jersey Institute of Technology

The Bleeding Disease: Hemophilia and the Unintended Consequences of Medical Progress (John Hopkins University Press) is the new book by NJIT Associate Professor Stephen Pemberton. The book recounts the promising and perilous history of medical and social efforts to manage hemophilia in 20th-century America.

Provocatively, the book also uses [hemophilia](#) and its history to shed light on numerous problems of consequence to Americans seeking help for what ails them. "Hemophilia as a [microcosm](#) of the enterprise of [disease management](#) in the United States; that was my goal," said Pemberton.

By the 1970s, a therapeutic revolution, decades in the making, had transformed hemophilia from an obscure hereditary malady into a manageable bleeding disorder. Yet the glory of this achievement was short-lived. The same treatments that delivered some normalcy to the lives of persons with hemophilia brought unexpectedly fatal results in the 1980s when people with the disease contracted HIV-AIDS and [Hepatitis C](#) in staggering numbers.

Pemberton asks, "What does it say about [modern medicine](#) and society that one of our most advanced, technology-intensive efforts to manage disease and promote health actually facilitated the opposite—greater debility and premature death?"

The Bleeding Disease responds to this question by situating hemophilia management as both a success story and a cautionary tale, one built on the emergence in the 1950s and 1960s of an advocacy movement that sought normalcy—rather than social isolation and hyper-protectiveness—for the boys and men who suffered from the severest form of the disease. The book evokes the allure of normalcy as well as the human costs of medical and technological progress in efforts to manage hemophilia. It explains how physicians, advocacy groups, the blood industry, and the government joined patients and families in their unrelenting pursuit of normalcy—and the devastating, unintended consequences that pursuit entailed.

"I thought it was important to show readers the ironies as well as unintended consequences that are inherent to many of our ongoing efforts to manage disease," said Pemberton. "In the case of hemophilia,

there was a collective effort to transform the patients' hopes for a normal life into a purchasable commodity. Ironically, this strategy made it all too easy for key actors and institutions in the United States to ignore the potential dangers of delivering greater health and autonomy to hemophilic boys and men. Thus, in seeking normalcy, our medical experts and their allies produced the opposite of normal; and it was among the most vulnerable groups in America who paid the ultimate price for this mistake."

Pemberton is in the Federated Department of History at NJIT and Rutgers University, Newark. He is coauthor of *The Troubled Dream of Genetic Medicine: Ethnicity and Innovation in Tay-Sachs, Cystic Fibrosis, and Sickle Cell Disease*, also published by Johns Hopkins.

Provided by New Jersey Institute of Technology

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