

BLOOD SAGA

HEMOPHILIA, AIDS, AND THE
SURVIVAL OF A COMMUNITY,
UPDATED EDITION WITH A
NEW PREFACE

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Blood Saga Hemophilia Aids And The Survival Of A Community

**Constance A. Nathanson, Henri
Bergeron**



Blood Saga Hemophilia Aids And The Survival Of A Community:

Blood Saga Susan Resnik, 2023-09-01 For thousands of years boys known as bleeders faced an early painful death from hemophilia Dubbed the Royal Disease because of its identification with Queen Victoria the world's most renowned carrier hemophilia is a genetic disease whose sufferers had little recourse until the mid twentieth century In the first book to chronicle the emergence and transformation of the hemophilia community Susan Resnik sets her story within our national political landscape where the disease is also a social psychological and economic experience Blood Saga includes many players and domains men with hemophilia and their families medical personnel science researchers and the author herself who was Director of Education of the National Hemophilia Foundation in the early 1980s At that time the miracle treatment of freeze dried pooled plasma blood products enabled men with hemophilia to lead full normal lives Then the AIDS virus infiltrated the treatment system and over fifty percent of the hemophilia community became HIV positive But rather than collapsing this community refocused its priorities extended its reach and helped shape blood safety policies to prevent further tragedy The hemophilia community includes people from every socioeconomic and ethnic group and Resnik's narrative and use of oral histories never lose touch with those affected by the disease Her extensive informant interviewing allows much of this social history to be told by participants on all levels parents wives nurses doctors government agency directors health care providers and many others Gene insertion therapy now holds the promise of a cure for hemophilia in the near future Scientific breakthroughs inevitably become intertwined with the industry and academic medical centers that govern the national health care system And in that system says Resnik costs and safety are sometimes contending issues She makes clear that the lessons learned in Blood Saga apply to all of us For thousands of years boys known as bleeders faced an early painful death from hemophilia Dubbed the Royal Disease because of its identification with Queen Victoria the world's most renowned carrier hemophilia is a genetic disease whose sufferers

Blood Saga Susan Resnik, 1999 A stirring history of the blood disease retraces the emergence of a modern hemophiliac community from the identification of Queen Victoria as a carrier of the disease through the AIDS infections of the 1980s and subsequent breakthroughs in gene therapy

Blood Saga Susan Resnik, 2023-09-01 For thousands of years boys known as bleeders faced an early painful death from hemophilia Dubbed the Royal Disease because of its identification with Queen Victoria the world's most renowned carrier hemophilia is a genetic disease whose sufferers had little recourse until the mid twentieth century In the first book to chronicle the emergence and transformation of the hemophilia community Susan Resnik sets her story within our national political landscape where the disease is also a social psychological and economic experience Blood Saga includes many players and domains men with hemophilia and their families medical personnel science researchers and the author herself who was Director of Education of the National Hemophilia Foundation in the early 1980s At that time the miracle treatment of freeze dried pooled plasma blood products enabled men with hemophilia to lead full normal lives Then the AIDS virus infiltrated the

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The Bleeding Disease Stephen

Pemberton, 2011-07-15 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 The Bleeding Disease recounts the promising and perilous history of American medical and social efforts to manage hemophilia in the twentieth century This is 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 Stephen Pemberton evokes the allure of normalcy as well as the human costs of medical and technological progress in efforts to manage hemophilia He 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 Ironically transforming the hope of a normal life into a purchasable commodity for people with bleeding disorders made it all too easy to ignore the potential dangers of delivering greater health and autonomy to hemophilic boys and men

Blood and Steel Ruth D. Reichard, 2021-05-17

Set in the 1980s against a backdrop of the AIDS crisis deindustrialization and the Reagan era this book tells the story of one individual's defiant struggle against his community the city of Kokomo Indiana At the same time as teenage AIDS patient Ryan White bravely fought against the intolerance of his hometown to attend public school one of Kokomo's largest employers Continental Steel filed for bankruptcy significantly raising the stakes of the fight for the city's livelihood and national image This book tells the story of a fearful time in our recent history as people in the heartland endured massive layoffs coped with a lethal new disease and discovered a legacy of toxic waste Now some 30 years after Ryan White's death this book offers a fuller

accounting of the challenges that one city reckoned with during this tumultuous period *A Town without Pity* Jason Vuic, 2025-10-21 This book recounts two stories of small town injustice that rose to national prominence at the end of the Reagan era and forced a reckoning with the staying power of social division and prejudice **Normal** Audrey Elisa Kerr, 2018-07-23 This book chronicles the intersection of chaplaincy, autopathography, illness narratives and stigmatized illness through the observations and stories of a chaplain working at a facility for people with HIV and AIDS Trained as both an ethnographer and a chaplain Audrey Elisa Kerr uses memoir to bridge the relationship between caregiver and patient and allows stories of marginality to frame both her patients' stories and her own **The Politics of Blood** Anne-Maree Farrell, 2012-05-24 How best to manage risk involving multi-valued human biological materials is the overarching theme of this book which draws on the sourcing and supply of blood as a case study Blood has ethical, social, scientific and commercial value This multi-valuing process presents challenges in terms of managing risk therefore making it ultimately a matter for political responsibility This is highlighted through an examination of the circumstances that led to HIV blood contamination episodes in the US, England and France as well as their consequences The roles of scientific expertise and innovation in managing risks to the blood system are also analysed as is the increased use of precautionary and legal strategies in the post-HIV blood contamination era Finally consideration is given to a range of policy and legal strategies that should underpin effective risk governance involving multi-valued human biological materials **Hemophilia** Randall McPartland, 2015-12-15 Hemophilia and other bleeding disorders loom over the lives of people with these conditions and present constant danger This book describes the condition and the genetic causes behind it follows researchers on their path to scientific discovery identifies people who have excelled despite having the problem and tracks the latest treatments and research aimed at helping those living with it Sidebars highlight medical breakthroughs and the people who made them Flesh and Blood Susan E. Lederer, 2008-04-24 Organ transplantation is one of the most dramatic interventions in modern medicine Since the 1950s thousands of people have lived with new hearts, kidneys, lungs, corneas and other organs and tissues transplanted into their bodies From the beginning though there was simply a problem: surgeons often encountered shortages of people willing and able to give their organs and tissues To overcome this problem they often brokered financial arrangements Yet an ethic of gift exchange coexisted with the commodification of the body The same duality characterized the field of blood transfusion which was essential to the development of modern surgery This book will be the first to bring together the histories of blood transfusion and organ transplantation It will show how these two fields redrew the lines between self and non-self, the living and the dead, and humans and animals Drawing on newspapers, magazines, legal cases, films and the papers and correspondence of physicians and surgeons Lederer will challenge the assumptions of some bioethicists and policymakers that popular fears about organ transplantation necessarily reflect timeless human concerns and preoccupations with the body She will show how notions of the body intact in parts living and dead are shaped by the particular culture in which they

are embedded *Doctor Guilt?* Everett Winslow Lovrien,2010-08 Brent admired the chimpanzee he sketched at the zoo He regarded the animal as contemplative He was unaware that similar animals in the wilds of Africa were the source of a virus that would lead to his death from AIDS Brent became infected with HIV from the medicine he infused to treat his hemophilia At six months of age his parents were alarmed when they discovered bruises on his chest which led to the discovery of hemophilia From that moment forward he received frequent intravenous infusions of concentrate to treat recurrent bleeding episodes Infusions of the medicine relieved pain and suffering from bleeding His life seemed normal Unexpectedly Brent's life changed after the discovery of HIV contamination of the medicine The medicine was manufactured from the plasma of paid blood donors Unbeknownst to Brent the plasma was polluted with HIV The SIV in chimpanzees changed to become HIV in humans But the chimpanzees were not the cause of the transfer of SIV in animals to HIV in humans The change from SIV in animals to HIV in humans was the result of human activity The change came about with the production of the hepatitis B vaccine Who was responsible for the pollution of the hemophilia medicine with HIV and hepatitis viruses Was Brent's death preventable

The Life and Death of Ryan White Paul M. Renfro,2024-10-22 In the 1980s as HIV AIDS ravaged queer communities and communities of color in the United States and beyond a straight white teenager named Ryan White emerged as the face of the epidemic Diagnosed with hemophilia at birth Ryan contracted HIV through contaminated blood products In 1985 he became a household name after he was barred from attending his Indiana middle school As Ryan appeared on nightly news broadcasts and graced the covers of popular magazines he was embraced by music icons and well known athletes achieving a curious kind of stardom Analyzing his struggle and celebrity Paul M Renfro's powerful biography grapples with the contested meanings of Ryan's life death and afterlives As Renfro argues Ryan's fight to attend school forced the American public to reckon with prevailing misconceptions about the AIDS epidemic Yet his story also reinforced the hierarchies at the heart of the AIDS crisis Because the innocent Ryan had contracted HIV through no fault of his own as many put it his story was sometimes used to blame presumably guilty populations for spreading the virus Reexamining Ryan's story through this lens Renfro reveals how the consequences of this stigma continue to pervade policy and cultural understandings of HIV AIDS today

The ^ASocial Production of Crisis Constance A. Nathanson, Henri Bergeron,2023-03-10 In *The Social Production of Crisis* Constance A Nathanson and Henri Bergeron focus on the profoundly troubling story of how blood banks and blood products manufacturers and distributors as well as the authorities charged with regulating them in France and the US knowingly allowed blood contaminated with HIV to be distributed to hemophiliacs and others needing transfusions in the early to mid 1980s Based on detailed lively and exciting comparative analysis the book explains why this drama became a political crisis in France and not in the United States The authors use this comparison to advance more general ideas of how political crises are socially produced and to raise questions about disease policy and politics in the two countries

Human Heredity in the Twentieth Century Bernd Gausemeier,2015-10-06 The essays in this

collection examine how human heredity was understood between the end of the First World War and the early 1970s The contributors explore the interaction of science medicine and society in determining how heredity was viewed across the world during the politically turbulent years of the twentieth century *Canary in the Coal Mine* William Cooke,2021 One doctor s courageous fight to save a small town from a silent epidemic that threatened the community s future and exposed a national health crisis When Dr Will Cooke an idealistic young physician just out of medical training set up practice in the small rural community of Austin Indiana he had no idea that much of the town was being torn apart by poverty addiction and life threatening illnesses But he soon found himself at the crossroads of two unprecedented health care disasters a national opioid epidemic and the worst drug fueled HIV outbreak ever seen in rural America Confronted with Austin s hidden secrets Dr Cooke decided he had to do something about them In taking up the fight for Austin s people however he would have to battle some unanticipated foes prejudice political resistance an entrenched bureaucracy and the dark despair that threatened to overwhelm his own soul *Canary in the Coal Mine* is a gripping account of the transformation of a man and his adopted community a compelling and ultimately hopeful read in the vein of *Hillbilly Elegy* *Dreamland* and *Educated*

Authoritarian Absorption Yan Long,2024-11-01 *Authoritarian Absorption* unveils the transformation of China s pandemic response system from 1978 to 2018 through its battle against HIV AIDS Chinese bureaucrats facing pressure from foreign agencies especially those of the US and UK and grassroots social movements developed ways to turn epidemics into opportunities for enhancing domestic control and international stature Drawing on longitudinal ethnographic research Yan Long reveals how Western liberal interventions can simultaneously bolster public health institutions and reinforce authoritarian power a development pivotal to China s subsequent handling of COVID 19 and instrumental in advancing the rights of groups like gay men

Giving Blood Johanne Charbonneau,André Smith,2015-07-24 *Giving Blood* represents a new agenda for blood donation research It explores the diverse historical and contemporary undercurrents that influence how blood donation takes place and the social meanings that people attribute to the act of giving blood Drawing from empirical studies conducted in the United States Canada France Australia China India Latin America and Africa the book s chapters turn our attention to the evolution of blood donation worldwide examining the impact of technology advances on blood collection practices the shifting approaches to donor recruitment and retention the governance and policy issues associated with the establishment of blood clinics the political and legal challenges of regulating blood systems This innovative examination moves the focus from individual explanations of rates of blood donation to a social structural explanation It will appeal to international scholars and students working in the areas of sociology medical anthropology health care public policy socio legal studies comparative politics organizational management health and illness the history of medicine and public health ethics

Hope and Suffering Gretchen Krueger,2020-03-03 Gretchen Krueger s poignant narrative explores how doctors families and the public interpreted the experience of childhood cancer from the 1930s

through the 1970s Pairing the transformation of childhood cancer from killer to curable disease with the personal experiences of young patients and their families Krueger illuminates the twin realities of hope and suffering In this social history each decade follows a family whose experience touches on key themes possible causes means and timing of detection the search for curative treatment the merit of alternative treatments the decisions to pursue or halt therapy the side effects of treatment death and dying and cure Recounting the complex and sometimes contentious interactions among the families of children with cancer medical researchers physicians advocacy organizations the media and policy makers Krueger reveals that personal odyssey and clinical challenge are the simultaneous realities of childhood cancer This engaging study will be of interest to historians medical practitioners and researchers and people whose lives have been altered by cancer

Somaesthetics of Discomfort: Addressing Identity, Normativity, and Alienation M.D. Tschaep, 2024-12-02 This book is about bodies and discomfort Specifically it is about how to recognize discomfort as a motivating source for critical reflection This book is about how people project their discomfort onto others in harmful ways that alienate and it is also about how those who are alienated may use their discomfort to fight against those harms Based in work from pragmatist feminist antiracist queer and disability studies and informed by lessons from personal narratives and philosophical analysis this book develops somaesthetics of discomfort as it examines interrogates and addresses issues concerning identity normativity and alienation

The Quiet Hero Nelson Price, 2015-03-06 In 1985 the eyes of the world turned to the Hoosier State and the attempt by a thirteen year old Kokomo Indiana teenager to do what seemed to be a simple task join his fellow classmates at Western Middle School in Russiaville the school to which his Kokomo neighborhood was assigned The teenager Ryan White however had been diagnosed with Acquired Immune Deficiency Syndrome from contaminated blood based products used to treat his hemophilia It was my decision White said to live a normal life go to school be with friends and enjoying day to day activities It was not going to be easy White s words were an understatement to say the least His wish to return to school was met with panic by parents and some school officials The controversy about White and the quiet courage he and his mother Jeanne displayed in their battle to have him join his classmates is explored in the eleventh volume in the Indiana Historical Society Press s Youth Biography Series A Quiet Hero is written by Nelson Price who wrote about White s odyssey during his days as a reporter and columnist for the Indianapolis News Price goes behind the scenes and brings to light stories and individuals who might have been lost in the media spotlight After a nine month court battle White won the right to return to school but with concessions These were not enough for parents of twenty children who responded by starting their own school At school White became the target of slurs and lies and his locker was vandalized Although the White family received support from citizens and celebrities around the world particularly rock singer Elton John the situation grew so controversial in Kokomo that they moved to Cicero Indiana a community that greeted them much differently In Price s book White who succumbed to his disease in 1990 comes across as a normal teenager who met an impossible situation with uncommon grace

courage and wisdom It was difficult at times to handle but I tried to ignore the injustice because I knew the people were wrong White said My family and I held no hatred for those people because we realized they were victims of their own ignorance

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