

The impending medical revolution in haemophilia care: one patient's view

Adam R Jones

The history of haemophilia care has been fraught with extreme successes and epic failures. The development of plasma-derived concentrates made prophylactic treatment and home care possible, but the unintended consequences were devastating for a generation and only abated with the emergence of recombinant products. Now with the arrival of longer-acting factor concentrates and the potential offered by gene therapy, further improvements in medical and social outcomes are possible. But these new treatment approaches raise challenging ethical and moral issues that society must be prepared to confront.

Key words: haemophilia, haemophilia B, Christmas disease, gene therapy, long-acting clotting factor

I was born in April 1972. Six months later I was diagnosed with severe haemophilia B, which at that time was more commonly known as Christmas disease, being so named after Stephen Christmas, the first patient in whom it was described as being different from classical haemophilia (which is now known as haemophilia A) [1]. During the ensuing years I have witnessed much of the evolution of care and treatment for haemophilia in the United Kingdom.

I can recall the days when hospital admission seemed, for me at least, to be the norm rather than the exception. Many times I was placed in traction for joint bleeds – especially knee bleeds, a practice that, as far as I am aware, has long been abandoned. As a child I remember when it was necessary to travel to hospital for treatment each time I had a bleed, and hoping that I would get there before the haemophilia unit closed so that my parents and I would not have to wait hours for the doctor on call to arrive. It made an incredible difference when I was allowed to begin home treatment and my mother was trained to prepare and administer my clotting factor.

I also remember the isolation I felt at school for being different to everyone else; this difference being most evident during physical education lessons where all the other boys in my class were learning how to play football, rugby, hockey, or cricket. In those years these were all games in which I was never allowed to participate for fear of injury.

The 1980s and 1990s ushered in the beginning of a



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purge among the haemophilia community, with lives being lost or affected by HIV/AIDS and hepatitis C [2] through no fault of their own. Not a day goes by that I don't think of my dear friends who are still struggling with, or were unable to win the battle against these dreadful diseases, which contaminated the UK supply of blood and blood products [3]. I am one of the lucky few to come through this period of devastation relatively unscathed. I don't know how, but to this day I remain HIV negative. Maybe I am CCR5 $\Delta 32$ homozygous [4]? Even so, I have contracted both hepatitis B and hepatitis C through treatment with infected clotting factor IX (FIX), but on both occasions my immune system has managed to clear these viruses without the need for medical intervention (other than a liver biopsy).

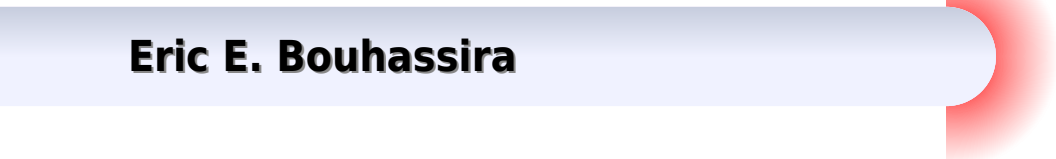
Enter the recombinants

Some years later I was elated to learn that there was a new treatment, recombinant FIX (rFIX) [5], being made available.

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The Impending Medical Revolution

Eric E. Bouhassira



The Impending Medical Revolution:

The Impending Medical Revolution Deryck Taverner, 1968 21st-Century Miracle Medicine Alexandra Wyke, 2013-11-11 The future of healthcare may be very simple You will sit in your living room chair and drink your tea coffee and beer As you sip the chair will absorb an encyclopedia of knowledge about your physical state of affairs A life management computer in your kitchen will integrate the data and then display it for you on your watch face A daily physical work up precisely tailored to your body will pop up on the display showing you what you have to do over the next 24 hours to avoid all the major disease processes currently plaguing the world This comprehensive data bank will draw on all the world's medical databases which have been integrated to help you prevent disease You will rise from your chair and undertake an exact modicum of exercise tailored to your requirements performing proscribed activities that will build your stamina precisely based on your chair data The health status monitoring sweatshirt that you wear during exercise will continue its analysis throughout the day Your diet will be calibrated from your medical database which vii viii 21st CENTURY MIRACLE MEDICINE will be stored in a now common bathroom appliance the special preventive care server In fact clothed in your own domestic decor the home will become the most sophisticated medical center in the world All you have to do is keep going as medicine becomes an invisible service and your life will be effortlessly extended ten to twenty years The Cybernetic Revolution and the Forthcoming Epoch of Self-Regulating Systems Grinin, Leonid, Grinin, Anton L., 2016-01-01 The monograph presents the ideas about the main changes that occurred in the development of technologies from the emergence of Homo sapiens till present time and outlines the prospects of their development in the next 30 60 years and in some respect until the end of the twenty first century What determines the transition of a society from one level of development to another One of the most fundamental causes is the global technological transformations Among all major technological breakthroughs in history the most important are three production revolutions 1 the Agrarian Revolution 2 the Industrial Revolution and 3 the Cybernetic one The book introduces the theory of production revolutions which is a new valuable explanatory paradigm that analyzes causes and trends of dramatic shifts in historical process The authors describe the course of technological transformations in history and demonstrate a possible application of the theory to explain the present and forthcoming technological changes They analyze the technological shifts which took place in the second half of the twentieth and early twenty first centuries and forecast the main shifts in the next half a century On this basis the authors present a detailed analysis of the latest production revolution which is denoted as cybernetic They make some predictions about its development in the nearest five decades and up to the end of the twenty first century and show that the development of various self regulating systems will be the main trend of this revolution The authors argue that the transition to the starting final phase of the Cybernetic Revolution in the 2030 2040s will first occur in the field of medicine in some of its innovative branches In future we will deal with the started convergence of innovative technologies which will form the

system of MANBRIC technologies i e the technological paradigm based on medicine additive nano and bio technologies robotics IT and cognitive technologies The monograph gives an outline of the future breakthroughs in medicine and some other technologies between the 2010s and 2070s *Our Schools of Medicine, and the Coming Medical Struggle. By an Allopathic Practitioner* ,1858 **Revolutionary Medicine** Jeanne E Abrams,2013-09-13 An engaging history of the role that George Washington Thomas Jefferson and Benjamin Franklin played in the origins of public health in America Before the advent of modern antibiotics one s life could be abruptly shattered by contagion and death and debility from infectious diseases and epidemics was commonplace for early Americans regardless of social status Concerns over health affected the Founding Fathers and their families as it did slaves merchants immigrants and everyone else in North America As both victims of illness and national leaders the Founders occupied a unique position regarding the development of public health in America Historian Jeanne E Abrams s Revolutionary Medicine refocuses the study of the lives of George and Martha Washington Benjamin Franklin Thomas Jefferson John and Abigail Adams and James and Dolley Madison away from politics to the perspective of sickness health and medicine For the Founders republican ideals fostered a reciprocal connection between individual health and the health of the nation Studying the encounters of these American Founders with illness and disease as well as their viewpoints about good health not only provides a richer and more nuanced insight into their lives but also opens a window into the practice of medicine in the eighteenth century which is at once intimate personal and first hand Today s American public health initiatives have their roots in the work of America s Founders for they recognized early on that government had compelling reasons to shoulder some new responsibilities with respect to ensuring the health and well being of its citizenry beginning the conversation about the country s state of medicine and public healthcare that continues to be a work in progress **Technology and the Welfare State** Stephen Uttley,2025-11-21 Technology and the Welfare State 1991 explores the relationship between technological innovation welfare and levels of economic activity Drawing on a wide literature spanning many disciplines it explores the influence of technological change upon the development of health service production in America and Britain since the mid nineteenth century The analysis is based upon a broad perspective on technological innovation which embraces changes in social organization Particular attention is paid to the relationship between government action long term changes in economic activity and the course of innovation in health care The case study of health care forms the basis for demonstrating the potential contribution that an analysis of technological change can make to constructing theoretical explanations for the development of welfare states These insights cast light on the contemporary debate about crisis and future viability of the welfare state **Curing America's Ill-Health by Reversing Our Widespread Magnesium Deficiency** Kindig,2012-02 **Miraculous Power Overcoming Hopeless Adversity** George Kuttickal Chacko,George Kuttickal Chacko, Dr, PhD,Dr George Kuttickal Chacko Ph D,2012-11 Confounding Medical Consensus an 81 year old hatha yoga master whom a surgical error rendered a quasi quadriplegic and who was told

independently by three doctors that he would never walk again WALKS in 8 Months A Triumph of Therapy A Triumph of Faith Until I directly confronted the Health Care Provider Medical Director at the Hebrew Home for 10 weeks I was flailing against lengthening shadows of ignorance of my truly hopeless condition because my surgeon chose to violate his legal requirement to tell me my physical condition Is this affliction a punishment from God Can I who have delivered many Prophetic Messages to meet many concrete needs of many people at four different churches in Asia and America over 60 years ask God for a Prophecy of Healing Will God find me Faithless if I don t take literally Prophecy I Or II regarding my healing In the second week of my stay at Hebrew Home of Greater Washington D C the Health Care Provider Medical Director decided to discharge me around September 30 Two fundamental miracles had to occur to void the imminent discharge I sketch the Herculean efforts to re create 23 functionalities beginning with the likes of crawling 1 Crawl 2 Kneel 3 Scoot 4 Stand 5 Transfer 6 Walk The re creation of functionalities takes place within the certainty of the date of my death known since 1979 at age 49 which assures me that the quadriplegia is not unto death I have confounded medical consensus that I will never walk again thanks to the faith of several communities continually praying for my recovery the faith creating and consummating the miracle of a quasi quadriplegic walking in 8 months rapidly progressing to walking 3 miles a day unassisted *For the Good of Mankind?* Vicki Oransky Wittenstein, 2013-10-01 Experiment A child is deliberately infected with the deadly smallpox disease without his parents informed consent Result The world s first vaccine Experiment A slave woman is forced to undergo more than thirty operations without anesthesia Result The beginnings of modern gynecology Incidents like these paved the way for crucial lifesaving medical discoveries But they also harmed and humiliated their test subjects many of whom did not agree to the experiments in the first place How do doctors balance the need to test new medicines and procedures with their ethical duty to protect the rights of human subjects Take a harrowing journey through some of history s greatest medical advances and its most horrifying medical atrocities to discover how human suffering has gone hand in hand with medical advancement The SAGE Encyclopedia of Stem Cell Research Eric E. Bouhassira, 2015-06-15 The SAGE Encyclopedia of Stem Cell Research Second Edition is filled with new procedures and exciting medical breakthroughs including executive orders from the Obama administration reversing barriers to research imposed under the Bush administration court rulings impacting NIH funding of research based on human embryonic stem cells edicts by the Papacy and other religious leaders and the first success in cloning human stem cells Stem cell biology is clearly fueling excitement and potential in traditional areas of developmental biology and in the field of regenerative medicine where they are believed to hold much promise in addressing any number of intractable medical conditions This updated second edition encyclopedia will expand on information that was given in the first edition and present more than 270 new and updated articles that explore major topics in ways accessible to nonscientists thus bringing readers up to date with where stem cell biology stands today including new and evolving ethical religious legal social and political perspectives This

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