

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

Alexandra Wyke



The Impending Medical Revolution:

The Impending Medical Revolution Deryck Taverner, 1968 **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

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 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

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

Our Schools of Medicine, and the Coming Medical Struggle. By an Allopathic Practitioner ,1858

Curing America's Ill-Health by Reversing Our Widespread Magnesium Deficiency Kindig,2012-02

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 second edition reference work will serve as a universal resource for all public and academic libraries It is an excellent foundation for anyone who is interested in the subject area of stem cell

biology Key Features Reader s Guide Further Readings Cross References Chronology Resource Guide Index A Glossary will elucidate stem cell terminology for the nonscientist Statistics and selected reprints of major journal articles that pertain to milestones achieved in stem cell research Documents from Congressional Hearings on stem cells and cloning Reports to the President s Council on Bioethics and more Healers Abroad Institute of Medicine,Board on Global Health,Committee on the Options for Overseas Placement of U.S. Health Professionals,2005-07-27 Healers Abroad Americans Responding to the Human Resource Crisis in HIV AIDS calls for the federal government to create and fund the United States Global Health Service GHS to mobilize the nation s best health care professionals and other highly skilled experts to help combat HIV AIDS in hard hit African Caribbean and Southeast Asian countries The dearth of qualified health care workers in many lowincome nations is often the biggest roadblock to mounting effective responses to public health needs The proposal s goal is to build the capacity of targeted countries to fight the HIV AIDS pandemic over the long run The GHS would be comprised of six multifaceted components Full time salaried professionals would make up the organization s pivotal service corps working side by side with other colleagues already on the ground to provide medical care and drug therapy to affected populations while offering local counterparts training and assistance in clinical technical and managerial areas **Embracing**

Uncertainty: The Revolutionary Science of Stress-Free Living Through Probabilistic Thinking Gaurav Garg, In a world obsessed with certainty this book dares to embrace the unknown Dancing with Uncertainty isn t just a catchy title it s a revolutionary approach to navigating the complexities of modern life Within these pages you ll discover how to harness the power of probabilistic thinking to make better decisions manage risks and find opportunities where others see only chaos From the boardroom to the bedroom from financial investments to personal relationships this book will transform the way you view the world Key concepts you ll explore include The Probabilistic Mindset Learn to see life as a series of probabilities rather than absolutes The 60 40 Rule A practical guide to decision making in uncertain situations Expected Value Calculations Maximize your life ROI by understanding the true value of your choices The Monte Carlo Method Simulate multiple futures to prepare for any outcome Bayesian Thinking Update your beliefs intelligently as new information comes to light But this isn t just a dry textbook It s filled with real life examples practical exercises and even a dash of humor You ll learn from poker players stock traders meteorologists and everyday people who ve used probabilistic thinking to achieve extraordinary results In an uncertain world the only mistake is to be unprepared This book is your guide to turning uncertainty into your greatest advantage Whether you re a CEO making high stakes decisions a student planning your future or simply someone looking to navigate life with more confidence Dancing with Uncertainty offers a new lens through which to view the world So are you ready to embrace the power of probability To see opportunities where others see only risk To dance with uncertainty and lead a richer more calculated life Open this book and take your first step into a larger more probabilistic world **National Library of Medicine Current Catalog** National Library of Medicine (U.S.),1969 First

multi year cumulation covers six years 1965 70 *The Anti-Aging Triad* Stephen Holt,2011-04-01 This book is a groundbreaking review of the three most important scientific areas of anti aging medicine Stephen Holt MD has navigated areas of conventional and integrative medicine to produce a book that is valuable for both a layperson and biomedical experts

Toxic Mix? Herbert N. Foerstel,2009-12-09 This book presents a comprehensive analysis of the contentious relationship between the White House and the scientific community from the FDR administration to the Obama administration *Toxic Mix A Handbook of Science and Politics* takes a topic very much in the center of public debate in the last decade and places it in a revealing historical context It follows the often contentious relationship of science and politics from the FDR era to the current Obama administration highlighting the many highly charged moments when the two were in conflict *Toxic Mix* ranges across the major areas of scientific inquiry with public policy implications including atomic energy space science public health stem cells sexual reproduction environmental science global warming and evolution to examine important events where political imperatives and scientific research were at odds In addition the book looks at another important area where politics and science are at cross purposes immigration as many of our most accomplished degree earners are foreign born and are unable to stay and work in the United States A final chapter analyzes the attempts by the early Obama administration to build public policy that embraces science rather than manipulates it **Biotechnology and**

Communication Sandra Braman,2004-04-26 This volume examines the convergence of biotechnology and communication systems and explores how this convergence directly influences our understanding of the nature of communication Editor Sandra Braman brings together scholars to examine this convergence in three areas genetic information and facticity social issues and implications and the economic and legal issues raised by the production and ownership of information The work highlights the sophisticated processes taking place as biotechnology and information technology systems continue to evolve The chapters in this book approach the complex history of this topic and the issues it raises from a number of directions It begins by examining the shared features and spaces of biotechnology and digital information technologies as meta technologies qualitatively distinct from both the tools first used in the premodern era and the industrial technologies that characterized modernity Next the book explores what is and is not useful in treating the types of information processed by the two meta technologies through a shared conceptual lens and looks at issues raised by the ownership of genetic and digital information The final chapters are concerned with relationships between information and power Defining a future research agenda for communication scholarship this work is beneficial to scholars and students in science communication cultural studies information technologies and sociology **The 100-Year Life** Lynda Gratton,Andrew J. Scott,2020-05-28

What will your 100 year life look like A new edition of the international bestseller featuring a new preface Brilliant timely original well written and utterly terrifying Niall Ferguson Does the thought of working for 60 or 70 years fill you with dread Or can you see the potential for a more stimulating future as a result of having so much extra time Many of us have been

raised on the traditional notion of a three stage approach to our working lives education followed by work and then retirement But this well established pathway is already beginning to collapse life expectancy is rising final salary pensions are vanishing and increasing numbers of people are juggling multiple careers Whether you are 18 45 or 60 you will need to do things very differently from previous generations and learn to structure your life in completely new ways The 100 Year Life is here to help Drawing on the unique pairing of their experience in psychology and economics Lynda Gratton and Andrew J Scott offer a broad ranging analysis as well as a raft of solutions showing how to rethink your finances your education your career and your relationships and create a fulfilling 100 year life How can you fashion a career and life path that defines you and your values and creates a shifting balance between work and leisure What are the most effective ways of boosting your physical and mental health over a longer and more dynamic lifespan How can you make the most of your intangible assets such as family and friends as you build a productive longer life In a multiple stage life how can you learn to make the transitions that will be so crucial and experiment with new ways of living working and learning Shortlisted for the FT McKinsey Business Book of the Year Award and featuring a new preface The 100 Year Life is a wake up call that describes what to expect and considers the choices and options that you will face It is also fundamentally a call to action for individuals politicians firms and governments and offers the clearest demonstration that a 100 year life can be a wonderful and inspiring one

Medical Record ,1918 *Bookseller and the Stationery Trades' Journal* ,1874 *The American Journal of Clinical Medicine* ,1911 **A Physician Explains Ellen White's Counsel on Drugs, Herbs, and Natural Remedies** Mervyn G. Hardinge,2001 *A History of the Brain* Andrew P. Wickens,2014-12-08 A History of the Brain tells the full story of neuroscience from antiquity to the present day It describes how we have come to understand the biological nature of the brain beginning in prehistoric times and progressing to the twentieth century with the development of Modern Neuroscience This is the first time a history of the brain has been written in a narrative way emphasizing how our understanding of the brain and nervous system has developed over time with the development of the disciplines of anatomy pharmacology physiology psychology and neurosurgery The book covers beliefs about the brain in ancient Egypt Greece and Rome the Medieval period Renaissance and Enlightenment the nineteenth century the most important advances in the twentieth century and future directions in neuroscience The discoveries leading to the development of modern neuroscience gave rise to one of the most exciting and fascinating stories in the whole of science Written for readers with no prior knowledge of the brain or history the book will delight students and will also be of great interest to researchers and lecturers with an interest in understanding how we have arrived at our present knowledge of the brain *Medical Care in Australia* R. B. Scotton,1974

Embracing the Tune of Phrase: An Emotional Symphony within **The Impending Medical Revolution**

In a world eaten by displays and the ceaseless chatter of instant conversation, the melodic beauty and mental symphony produced by the published word usually disappear into the backdrop, eclipsed by the constant sound and interruptions that permeate our lives. But, set within the pages of **The Impending Medical Revolution** a stunning fictional prize overflowing with fresh thoughts, lies an immersive symphony waiting to be embraced. Constructed by a masterful musician of language, that interesting masterpiece conducts viewers on a mental journey, skillfully unraveling the hidden songs and profound influence resonating within each carefully crafted phrase. Within the depths of this moving assessment, we can examine the book's key harmonies, analyze their enthralling writing design, and submit ourselves to the profound resonance that echoes in the depths of readers' souls.

https://archive.kdd.org/files/Resources/default.aspx/The_Official_Parents_Sourcebook_On_Childhood_Nephrotic_Syndrome.pdf

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