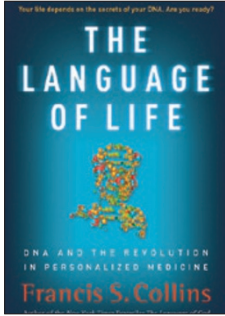


BOOK REVIEW

Personalizing medicine



The Language of Life: DNA and the Revolution in Personalized Medicine

Francis S. Collins

Harper, 2010

368 pp., hardcover, \$26.99

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Reviewed by Edison T Liu

Books about science for the general public have several purposes. They may argue the case for a new idea or expound on a fresh conceptual synthesis of existing knowledge, such as the case with Jared Diamond's *Guns, Germs and Steel*. Then there are books showing the insider's view of a scientific process, such as Craig Venter's *A Life Decoded: My Genome: My Life*. Finally, there are books that seek to explain complex scientific principles to a citizenry that supports science with tax dollars and donations in terms they can appreciate. In this category are works such as Matt Ridley's *Genome: The Autobiography of a Species in 23 Chapters* and Carl Sagan's *Cosmos*. All of this literature collectively serves an important role in modern society by making science accessible to the nonscientist. Far from being just entertainment for the masses, they function as essential tools in the democratic process by intellectually preparing a voting public so that they can participate in major decisions on how science and technology should be used and governed. Thus, *The Language of Life*, the new book by Francis Collins, who is the current director of the US National Institutes of Health, is a welcome addition to this genre and one that comes at a crucial time.

We are at a point in medical knowledge where the root causes of many diseases can now be ascertained and therapeutic solutions can be devised with surprising speed. The key enabler in this success is the knowledge of genomic sequences and the associated advances in computational biology and chemical biology. The speed of discovery, however, often puts us into situations where the legal, social and political structures lag behind the new technologies. And because biology and genetics deal with core principles of humanity, these challenges have religious and ethical implications. In a democratic society, the lay citizen will be called upon to decide on technologies as complex as induced pluripotent stem cells and reproductive cloning. Therefore, popular science publications are important facilitators of democratic governance over science and technology.

To the readers of *Nature Medicine*, Francis Collins is well known as the previous director of the National Human Genome Research Institute in the US where he was a key architect of the Human Genome

Project. But Collins also brings to this very readable book his experience as a physician-geneticist, a basic science researcher, a father and an elder in his church. From this background, Collins explains without condescension—and with clarity and directness—the intricacies of the human genome, what it means to the management of human disease and the possible consequences of these genetic and genomic technologies to society.

The Language of Life is a wonderfully crafted series of scientific stories that explain how researchers discover mutations in genes that cause disease. It goes on to describe the personal toll of these diseases on the individual patients, the conundrums that practicing geneticists face in dealing with disorders that have consequences across generations and the new treatments that have arisen from our genetic knowledge. The book also discusses the challenges society and policy makers face in dealing with this knowledge. It is, indeed, the storytelling that is most compelling. Written in the first person, and often lapsing into the second person, the book gives one the sense of being in a private session with a thoughtful physician who is willing to explain things properly. Thus, the tone of the book comes off as reasoned and honestly expressed rather than didactic.

The introductory chapter tells a story from the point of view of Dr. James, a clinical geneticist who is later revealed to be Dr. Collins himself, as he deals with the personal decisions of some of his patients. Using proper names in his stories, Collins brings closer to the reader the anxiety of “Brad” and his family as they decide to be tested for *BRCA1* mutations and the conflicting emotions of one of his female relatives upon finding that she is negative for the disease mutation only after having already received a bilateral prophylactic mastectomy. Likewise, Collins goes on to describe the personal confusion of “Wayne Joseph,” a black man, who, on a whim, decided to test his genetic ancestry via a direct-to-consumer company only to find out that he has no genetic evidence of being black. It is the depth and breadth of the stories that Collins tells, which can only come from an individual with such unique professional experiences, that make *The Language of Life* a jewel of a book.

There is perhaps one flaw in the book: Collins did not discuss the implications of the Genetic Information Nondiscrimination Act soon to be operational.

Finally, *The Language of Life* left this reviewer with one observation of a current national debate: although medical science in the US is great, the health care system is a bit perverse. For example, many of the patients mentioned in the book had to keep their genetic test results out of their own medical records for fear of losing health insurability. Maybe this book should be required reading for the opponents of American health care reform. But, politics aside, Francis Collins has done a service to society by writing *The Language of Life*. He is educating us by great storytelling and has us smiling and frowning over what could have been very dry scientific facts. He has personalized genetic sciences and made them accessible to all.

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