

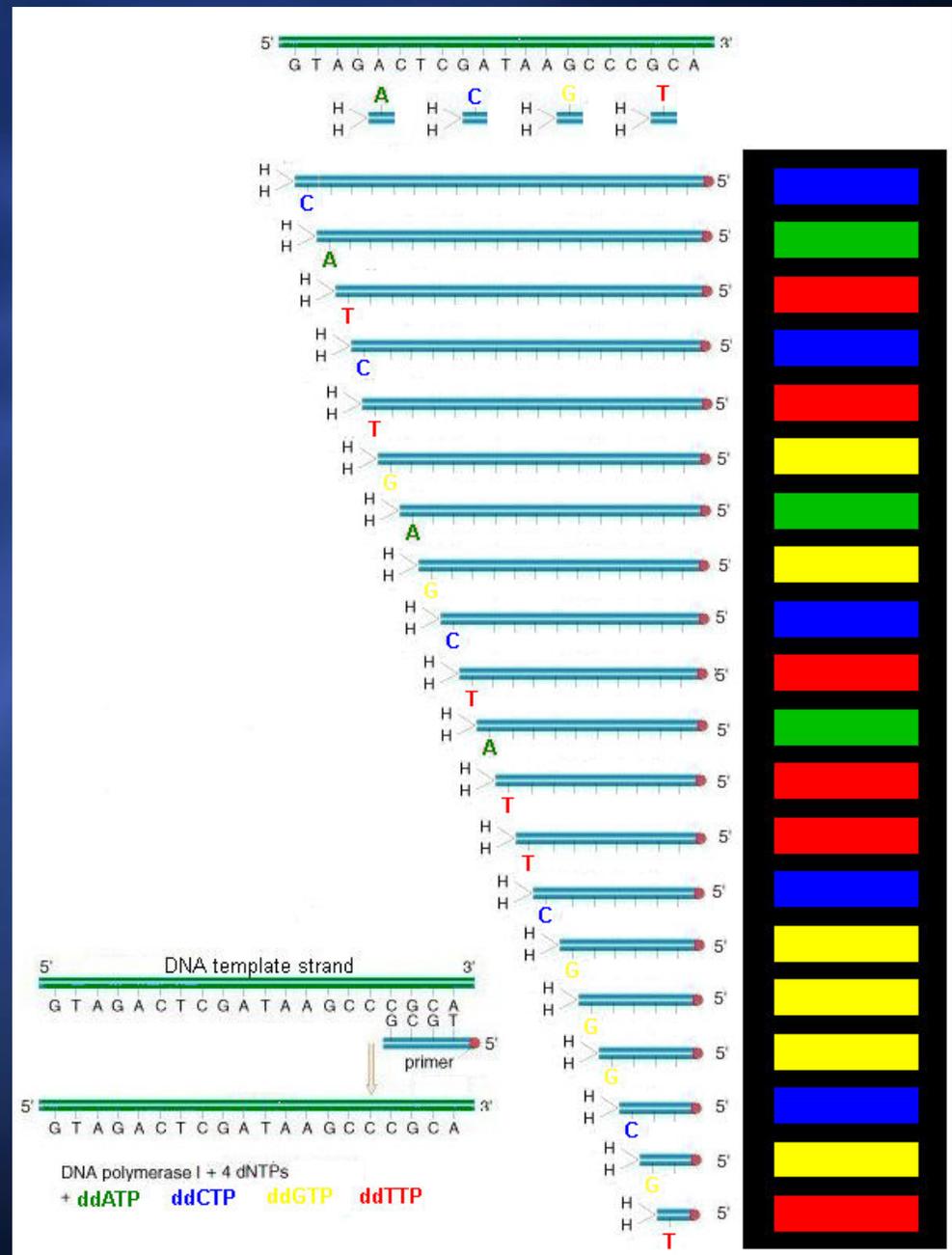
The Human Genome Project

Why scientists and engineers
need to understand how their
knowledge shapes, and is
framed by, culture and society

Brief History

- ⊕ Origins: 1970s and 80s: Charles DeLisi, Robert Sinsheimer, and others desire to sequence the human genome.
- ⊕ Why?
- ⊕ It is the age of gene therapy and pharmacogenomics.

⊕ Wallace Steinberg, chair of the Healthcare Investment Corporation of New Jersey- the largest venture capitalist health-care fund at the time: “By the year 2000, [all] drug companies in the world will use genomic data as their Rosetta stone for the development of new drugs and diagnostic procedures. No science will be more important to the future of medicine than genomic research.” (1989)



Initial Funding for the HGP

- ⊕ Department of Energy (DoE): \$12.8 million in '87. Why the DoE?
- ⊕ National Institutes of Health (NIH): \$17.2 million in '87
- ⊕ Critics of the HGP: Robert Weinberg ('junk' DNA), David Baltimore, and David Botstein
- ⊕ February 1989: the NSF urged Congress to pass a phased, long-term funding plan from 1990 to 2005, \$200 million of new money per annum for 15 years= \$3 billion

ELSI

- ⊕ The Ethical, Legal, and Social Issues/Implications of the HGP
 - ⊕ The specter of eugenics: Robert Wright, New Republic, “Biologists and ethicists have by now expended thousands of words warning about slippery eugenic slopes, reflecting on Nazi Germany, and warning that a government quest for a super race could begin anew if we are not vigilant.”
 - ⊕ U.S. tradition of eugenics
 - ⊕ 3-5% of \$3 billion to ELSI
 - ⊕ James Watson: “We have to be aware of the really terrible past history of eugenics where incomplete knowledge was used in a cavalier and rather awful way. We have to reassure people that their own DNA is private and that no one else can get at it.”
 - ⊕ Genetic privacy and testing issues: Al Gore and Orin Hatch
 - ⊕ Gene Patenting

Where to next? You vote!

- ⊕ genetic essentialism/reduction (i.e.: It is all in our genes.)
- ⊕ eugenics and IVF clinics
- ⊕ gene patenting
- ⊕ genetic testing and privacy (employers and insurance companies having access to your genetic information)
- ⊕ genes and race