

Zumbro Lutheran Church
Adult Forum
The ELCA Social Statement on
Genetics

Bob Jenkins
Karen Schowalter
January 30, 2011

Ecclesiastes 1:12-18

What Is Wisdom?

¹² I, the Teacher, was king over Israel in Jerusalem. ¹³ I applied my mind to study and to explore by wisdom all that is done under the heavens. What a heavy burden God has laid on mankind! ¹⁴ I have seen all the things that are done under the sun; all of them are meaningless, a chasing after the wind.

¹⁵ What is crooked cannot be straightened;
what is lacking cannot be counted.

¹⁶ I said to myself, “Look, I have increased in wisdom more than anyone who has ruled over Jerusalem before me; I have experienced much of wisdom and knowledge.” ¹⁷ Then I applied myself to the understanding of wisdom, and also of madness and folly, but I learned that this, too, is a chasing after the wind.

¹⁸ For with much wisdom comes much sorrow;
the more knowledge, the more grief.

Outline

- The history of the draft social statement
- Introduction to the draft social statement
- The pace of modern genetics and Illustrative examples
- Draft social statement recommendations
- Conclusions
- Questions/discussion

The Draft ELCA Social Statement on Genetics

A Brief History

- In 2005 the ELCA Assembly requested the development of a Social Statement on Genetics
- A task force was formed
- They issued a genetics study guide in 2008
- The draft social statement was issued in early 2010
- Comments were accepted until October 2010
- A revised draft will be circulated.
- It will be discussed at the 2011 ELCA General Assembly



The Draft ELCA Social Statement on Genetics

6 Sections

I. Introduction

II. Faith Affirmations

III. Social Context

IV. An Ethical Framework

V. Challenges for a Community of Christ

VI. Power, Choice and Responsibility

I. Introduction

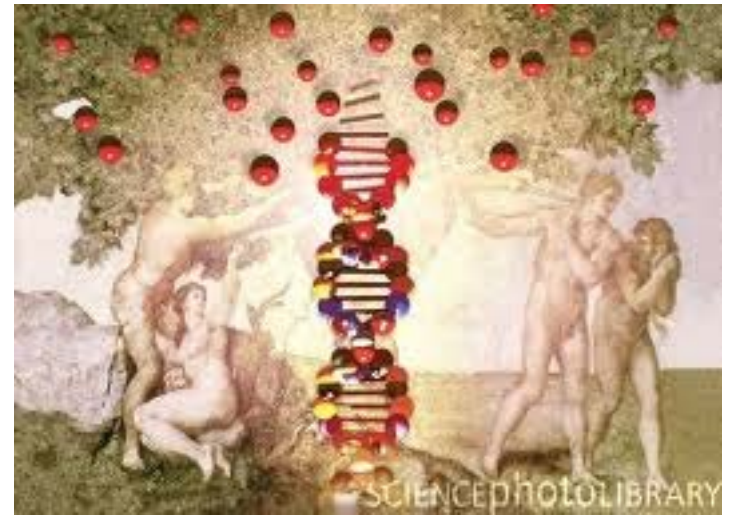
“This church trusts that this gracious God who creates, redeems and will fulfill creation has also granted human beings access to discernment and insight and entrusted us with the vocation to respect and promote the good of creation with justice and wisdom.”

II. Faith Affirmations

- The word genetics is not in scripture, but we have the Law and Gospel.
- Genesis provides insight – transforming barren emptiness into abundance that can sustain the web of life, to multiply and fill the earth.....
- Dominion implies that humans have the vocation to understand and manage the natural world
- Promised *already*, but present *not yet*

Tree of Knowledge

Pride in having divine knowledge of good and evil.



One way Sin manifests is as *exalted pride*, a misplaced trust in human knowledge, will and ability rather than in God.

Sin is also manifest as *negligence or complacency*, neglecting responsibility for love and action and despairing over our failures and limitations

Romans 8:18-25 The Spirit helps us in our weakness.



Wow... They've
CRACKED THE
HUMAN GENETIC
CODE!

Yep!

THIS RAISES
SOME 'BIG'
QUESTIONS...

REALLY
BIG...

Yessir...
BIG, BIG, BIG,
BIG, BIG...

THE
BIGGEST...

LIKE...
SHOULD WE
ADD BIOTECHS
TO OUR 401(K)'S?

NO, SIR...
NO
EASY
ANSWERS...

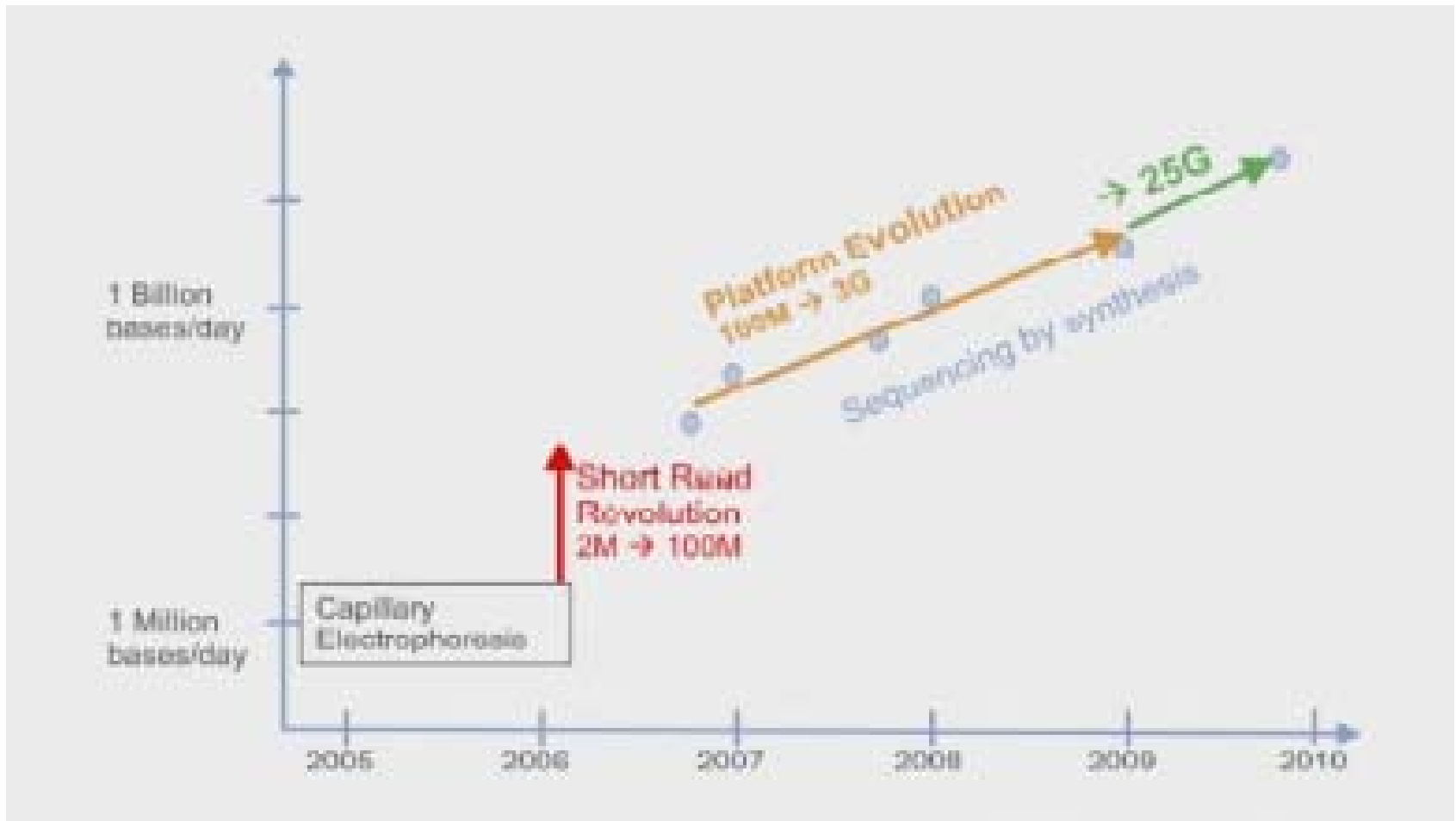
JOHN COOPER

The Draft ELCA Social Statement on Genetics

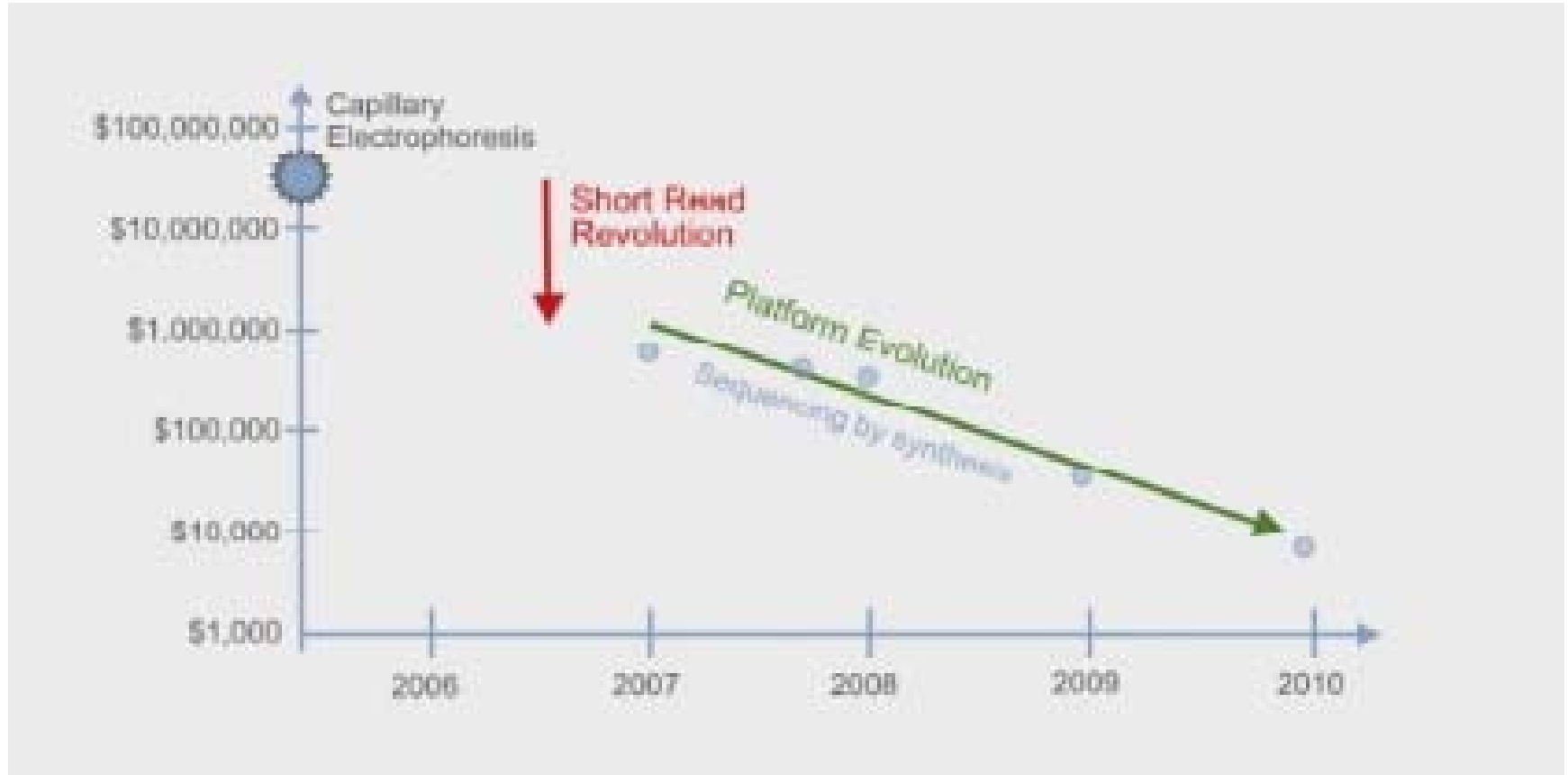
Underlying Principles

- The Committee and the document recognizes that the pace of genetics is changing so rapidly that it would be difficult to make highly specific recommendations
- Thus, it is focused on developing a framework that can be adapted to the rapidly changing environment
- It is also focused on supporting the vocations of doctor, scientist (geneticist)
- (It does made a few specific recommendations)

Recent History of Whole Genome Sequencing Speed



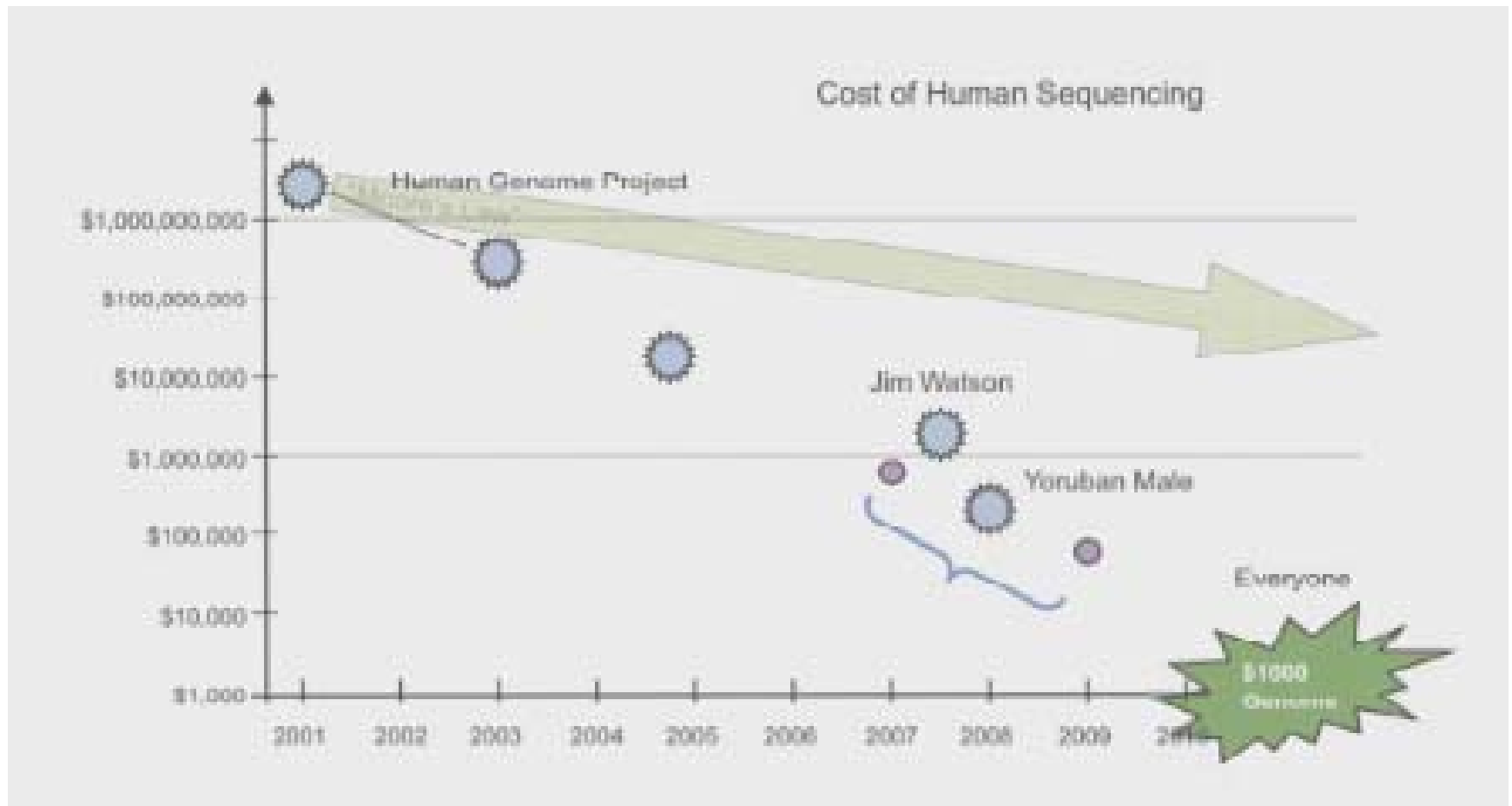
Recent History of Whole Genome Sequencing Cost



Short read sequencing is based on a mean coverage of 30x

Susan Wakelin, Illumina <http://www.aip.org/industry/ipf/2010/wakelin.html>

A Decade of DNA Sequencing



Delivering on the Scalability of HiSeq

Significantly scaled output, lower priced genome and highest data quality

EXPECT PERFORMANCE OF 1.14Tb (1.14×10^{12}) PER RUN

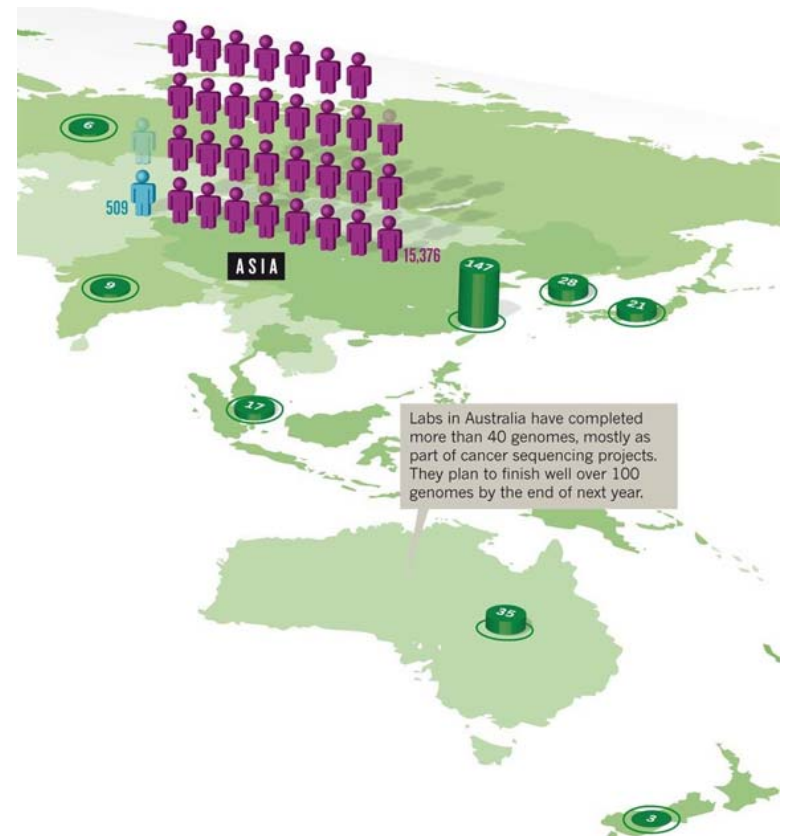
- To be released this Spring
- 2 x 150bp reads
- New reagents and software; No hardware changes
- 2 – 2.5x Reduction in price per genome
 - Reagent list price <\$5000 USD per HG



HiSeq 2000

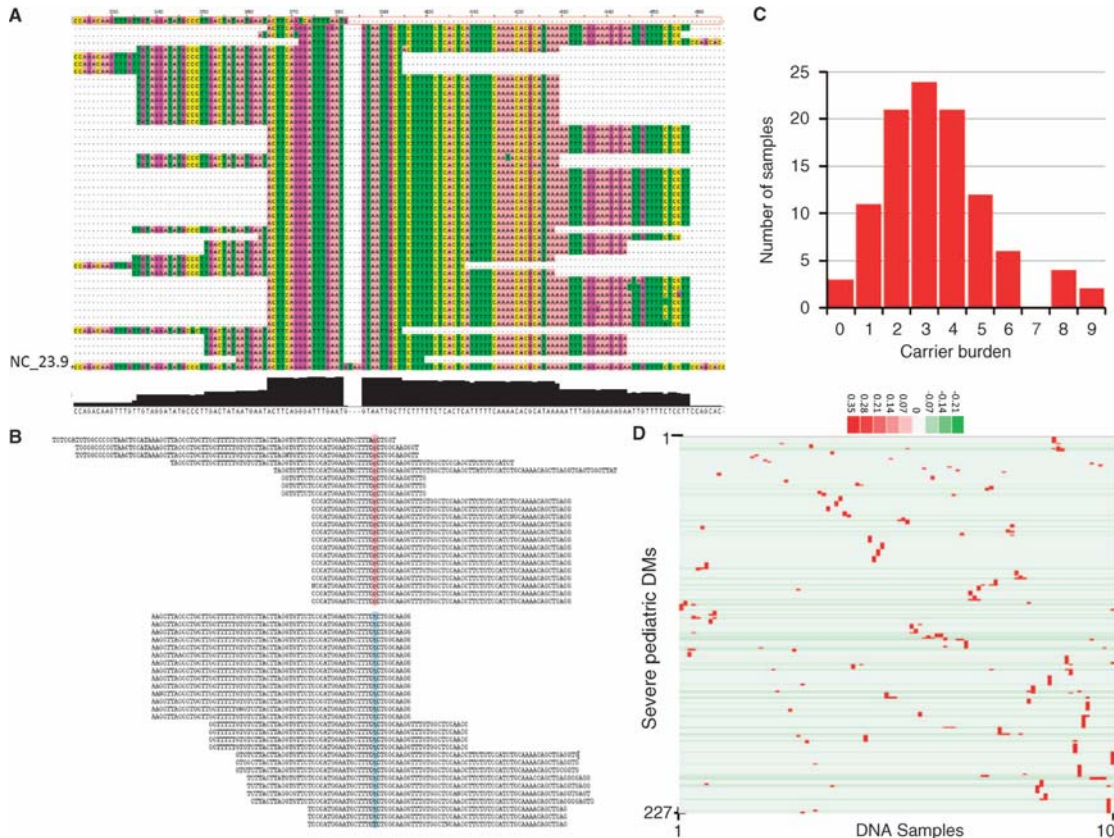
- $30 \text{ fold coverage} \times 3 \times 10^9 \text{ bp per haploid genome} = 9 \times 10^{10} \text{ bp needed per person}$
- $1.14 \times 10^{12} / 9 \times 10^{10} = \sim 12 \text{ people multiplexed per run}$
- For $\sim \$20,000$

Genomes by the 1000s



Carrier Testing for Severe Childhood Recessive Diseases by Next-Generation Sequencing

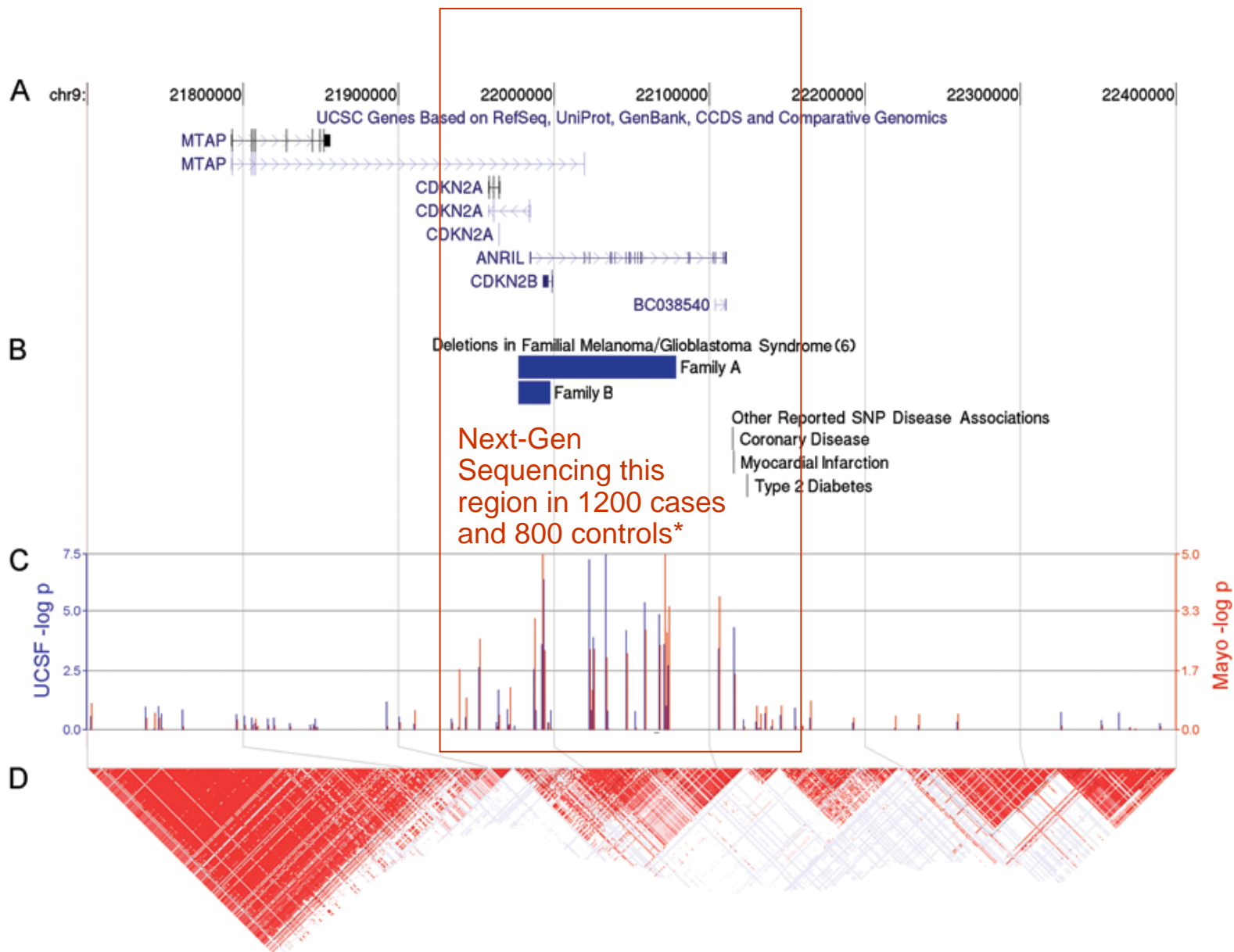
Callum J. Bell,^{1*} Darrell L. Dinwiddie,^{1,2*} Neil A. Miller,^{1,2} Shannon L. Hateley,¹ Elena E. Ganusova,¹ Joann Mudge,¹ Ray J. Langley,¹ Lu Zhang,³ Clarence C. Lee,⁴ Faye D. Schilkey,¹ Vrunda Sheth,⁴ Jimmy E. Woodward,¹ Heather E. Peckham,⁴ Gary P. Schroth,³ Ryan W. Kim,¹ Stephen F. Kingsmore^{1,2†}



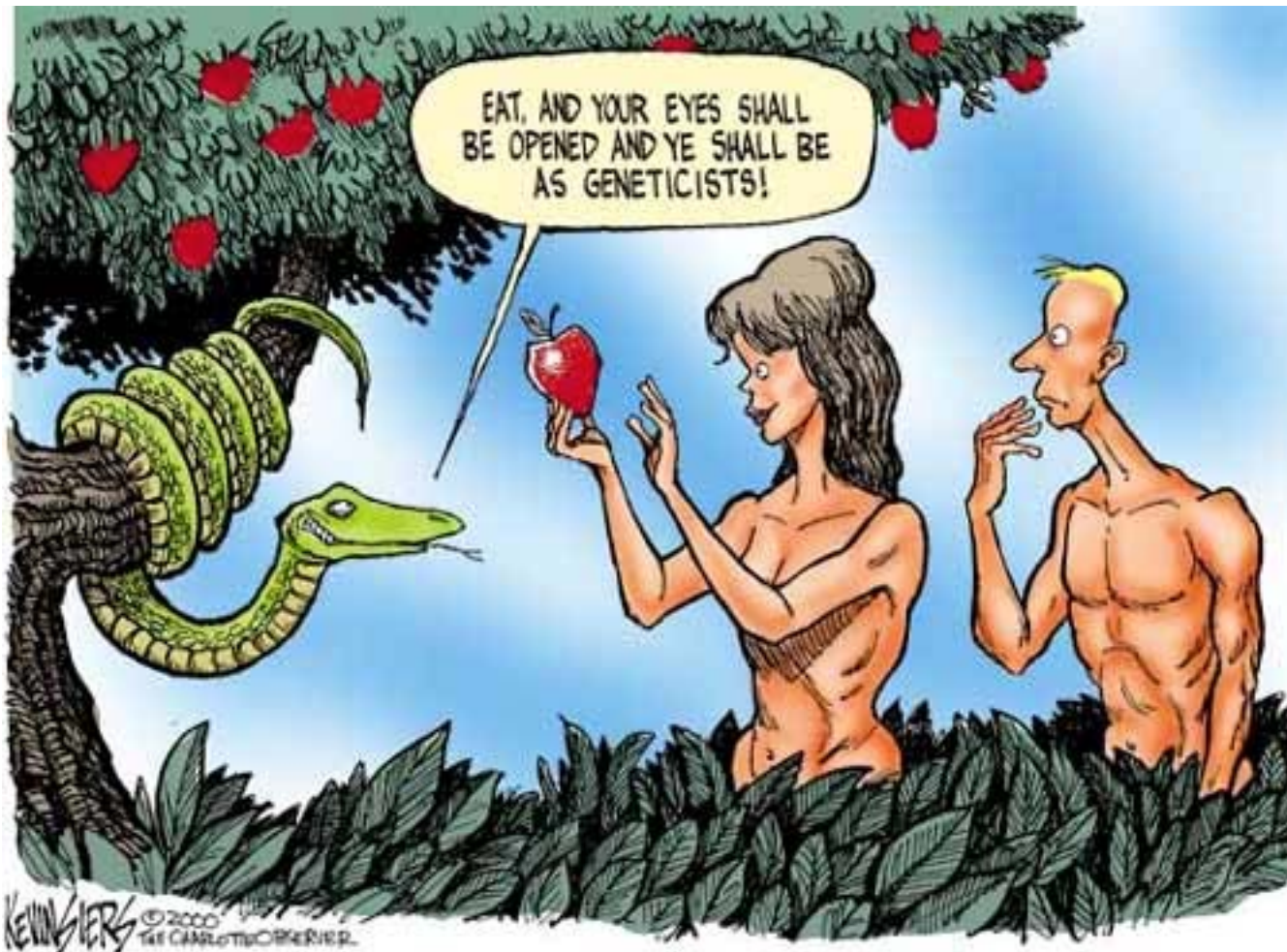
448 genes for severe recessive childhood diseases

~1.5Gb/run
8-fold multiplexed

Each person tested carried ~3 severe recessive mutations



* Sequencing a total of 658kb over 5p15, 7p12, 8q24, 9p21 and 20q13 in 1200 cases and 800 controls



KEVIN KERS © 2000 THE CHARLOTTE OBSERVER

The Draft ELCA Social Statement on Genetics

Five Directions in the Development of Genetic Technology (Draft p. 12)

- Genetic engineering in agriculture (biotechnology), including practices such as genetically engineering seeds or cloning plants and animals, and pharming.
- Molecular medicine, including practices involving stem cell research, genetic therapy, personal genomics and SNP mapping, as well as efforts to extend the longevity of human life to as much as three times today's average.
- Procreative activities, including prenatal testing and screening, genetically aided assisted reproductive technologies (ART), pre-implantation genetic diagnoses (PGD), and the artificial creation of new life forms (synthetic biology).
- Commercial delivery, including DNA testing for employment and health insurance, trade policies, patenting of genetic material and research processes.
- Social use or implications, such as in criminology and DNA evidence; potential implications include discrimination based on genetic profiling, the practice of eugenics and belief in genetic determinism.

Scenario #1: GM Agriculture

Frank and Jody are farmers in SE Minnesota. The farm has been in their family for over 100 years. Every year they save back some of their soybean and corn seeds. The seeds are cleaned by an itinerant seed cleaner, Max. Max and his father have cleaned seed for Frank and Jody's family for many years.

Several of the farms around Frank and Jody have been planting GM soybeans and corn that are resistant to Roundup. These farmers buy their seeds and herbicide from a large seed company.

The seed company has sent representatives to randomly sample Frank and Jody's soybeans. They find evidence that some of the grain is actually GM. The company's lawyers ask Frank and Jody to pay the royalties that the neighboring farmers have paid to use GM seed. They are also told that they must not use Max's seed cleaning services.

Frank and Jody have never bought GM seed.

What should they do?



Scenario #2: IVF and PGD

A couple in Minnesota gave birth to their first child, Molly, in 1996. Molly was diagnosed with Fanconi anemia, a rare blood condition with no known human cure. People with Fanconi anemia usually die before age 10.

Molly's parents used in vitro fertilization (IVF) to conceive their next child. Once IVF had produced several embryos, pre-implantation genetic diagnosis (PGD) was used to screen them for both the absence of Fanconi anemia and also as a suitable bone marrow donor for Molly. Molly's younger brother, Adam, was born in 2001, and his umbilical cord blood was used for an infusion that cured Molly.

Adam was the first report case of an embryo selected to be a transplant donor.

Was it ethical for Molly's parents to use PGD to produce a sibling donor for Molly?

Telomerase reactivation reverses tissue degeneration in aged telomerase-deficient mice

Mariela Jaskelioff¹, Florian L. Muller¹, Ji-Hye Paik¹, Emily Thomas¹, Shan Jiang¹, Andrew C. Adams², Ergun Sahin¹, Maria Kost-Alimova¹, Alexei Protopopov¹, Juan Cadiñanos¹, James W. Horner¹, Eleftheria Maratos-Flier² & Ronald A. DePinho¹

.....In conclusion, this unprecedented reversal of age-related decline in the central nervous system and other organs vital to adult mammalian health justify exploration of telomere rejuvenation strategies for age-associated diseases, particularly those driven by accumulating genotoxic stress.

Last week Dr. DePinho was on both NPR's Science Friday as well as Comedy Central's Colbert Report

Extinct Woolly Mammoth May Be Resurrected by Scientists

ABC News Jan 20, 2011



"It's amazing days isn't it?" American Museum of Natural History mammal curator Ross McPhee said. "The idea that you might be able to reach back into the past and pull out the genetic code of an extinct mammal like a woolly mammoth and somehow with modern technology recreate it."

The scientists plan to extract cell nuclei from a frozen mammoth they dug up in Siberia and implant them in egg cells of the mammoth's closest living relative, the elephant. They are hoping that the elephant will give birth to a real-live woolly mammoth.

Plans to resurrect the mammoth have been in place since 1997. During three separate studies, a research team from Kinki University in Japan obtained mammoth skin and muscle tissue excavated in good condition from the permafrost in Siberia.

But they soon discovered that most nuclei in the cells were damaged by ice crystals and were unusable. So the project was abandoned

Japanese researchers said in 2008 that they successfully cloned a mouse from a body that had been frozen for 16 years, which they claimed theoretically opened the door to preserving endangered animals and resurrecting extinct animals such as the woolly mammoth. An expert in cryopreservation has joined the project. He has petitioned zoos to donate elephant egg cells when their female elephants die so more research can be done. If all goes according to plan, an elephant will be giving birth to a woolly mammoth in the next five to six years, the Japanese paper Yomiuri Shimbun reported.

Some people think bringing this mammoth back to life is a great idea.

"It's the most adorable kind of cloning, because anything that's woolly [is] adorable," one supporter said.

Others prefer to leave the past alone and let the furry beasts rest in peace.

"It sounds to me like you're a little bit messing with the laws of nature," a skeptic told ABC News.

What do you think?

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An Ethical Framework (Draft p. 16-32)

- The ethical imperative in an age of unprecedented power is to respect and promote the community of life with justice and wisdom—each term arising from the theology and basic ethical commitments already set forth in the statement; in one sense this imperative is simply a contemporary restatement of the golden rule to “do until to others as you would have them do unto you.”
- The good of the **community of life** is the value which all research and application should seek to advance; this registers a concern not only for human good but, in some measure, a concern for the biosphere and future generations;
- The principle **respect** has priority over the principle **promote**; this ethical framework offers a cautious approach that respects the priority of species and natural processes as they currently exist, but does not in principle object to imagination and innovation when science, commerce or public policy can demonstrate a contribution to the good of all;
- The meaning of **justice** is specified through four principles: *sufficient, sustainable, solidarity and participation*; the best uses of genetic knowledge will be those that can demonstrate how they contribute to the growth of sufficiency, sustainability, solidarity and participation in human society and within the wider order of all of creation;
- The meaning of **wisdom** in the contemporary context invokes duty to use “expert knowledge” for the good of all, to exercise *humility* and, on occasion, the need to invoke the *precautionary principle*.

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Frank and Jody have never bought GM seed.

What should they do?

Scenario #1

- The U.S. District Court in Lafayette, Indiana issued a permanent injunction against Mr. _____ prohibiting him from cleaning Roundup Ready soybeans
- “Monsanto has agreed not to collect the damages awarded against Mr. _____ as long as Mr. _____ honors the terms of the court order.”

The Draft ELCA Social Statement on Genetics

Convictions (Draft p. 32-33)

- The ELCA calls upon individuals, agencies, organizations, corporations and governments *to pursue goals and to set policies that will:*
 - advocate for genetic research and discovery for the good of all; affirm the good of genetic technologies and economic enterprise that enables the community of life to flourish;
 - encourage varieties of research aimed at improving human health and well-being, while registering caution about enhancements that might lead beyond the baseline of what constitutes human personhood;
 - give priority to global health issues and needs, particularly those which may benefit by genetic research even when the economic return is small;
 - maximize the use of medical genetic information to improve care without succumbing to discrimination or the abuse of privacy;
 - affirm quality of human life improvement with reasonable life extension without expecting or seeking near perfection or immortality, insofar as such research does not lead to unjust use of limited human and financial resources;
 - encourage the development of genetic means to aid reversal of past human misuse of the environment;
 - encourage the development of means to enable marginalized voices of those most affected to be heard in public policy debates; and
 - promote these goals through effective and judicious regulatory protocols and systems.

The Draft ELCA Social Statement on Genetics

Convictions (Draft p. 32-33)

- Likewise, this church *rejects goals and policies that will:*
 - use any form of genetic knowledge or technology to create supposed states of near perfection or near-immortality;
 - expand genetic research or technology that endangers human bodies in the service of economic and social power arrangements. This danger is especially acute for marginalized racial and ethnic communities.

- Likewise, the ELCA *will raise vigorous questions about goals and policies that will:*
 - expand genetic research or technology while knowingly and unduly endangering plant and animal species, micro flora or fauna, or the existence of biodiversity;
 - *impact negatively on individual livelihoods, especially those related to agriculture.*
 - direct genetic knowledge and technology toward benefits for the interests of the few at the expense of the many;
 - foster greater inequities in access and benefits.

Scenario #2: IVF and PGD

A couple in Minnesota gave birth to their first child, Molly, in 1996. Molly was diagnosed with Fanconi anemia, a rare blood condition with no known human cure. People with Fanconi anemia usually die before age 10.

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Scenario #2



Molly is now 15 and Adam is now 9

"Parents are coming to us from all over the world with many kinds of rare genetic diseases," says Oleg Verlinsky of the Reproductive Genetics Institute in Chicago, which did the immune system screening on Adam Nash before his birth. Since then, RGI has performed more than 250 such screenings, Verlinsky says, for children whose birth led to the treatment of an older sibling.

"Molly Nash is a wonderful story," Verlinsky says. "We worked so hard on her assay. The little girl was dying. Most patients come to us just for screening, but cases where parents come to you with an already-sick child are very hard."

Some bioethicists, such as former bioethics council chief Leon Kass of the American Enterprise Institute, raised worries that children born from such procedures would feel unloved, if they see themselves as exploited. [At that time] the council also asked the public to weigh concerns about an era of "designer babies" [and the past history of eugenics in the US].

"People are certainly entitled to their opinions. But we were doing what was best for our family," says Lisa Nash. She has become an advocate for cord-blood banking from newborns as a result of her experience. "I'd urge people to really think about it early in their pregnancy."

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Other Statements: Use of Embryos

- This church's respect for the "value, worth, and dignity" of human embryonic life precludes the creation of embryos expressly for research purposes. Commercial development ("embryo farming") is incompatible with this church's understanding of the value of life.
- At the same time, this church cannot be indifferent to the suffering of patients who await the therapeutic potential of regenerative medicine. It welcomes scientific research aimed at finding alternative sources of pluripotent stem cells that do not involve the use of embryonic human life.
- In the meantime, it accepts the use of surplus frozen embryos that were created for infertility treatment but are no longer needed. Since they are unlikely to be implanted and will ultimately be discarded, it seems preferable that they be used in research that may be beneficial to millions of humans and future generations.

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Other Statements: Human Cloning

- This church rejects the “technological imperative,” that is, it rejects the prevalent practice or belief that we are free to use any knowledge that becomes available to create any technological application if the market will support it.
- Likewise, the reproductive cloning of human individuals is rejected. Currently, attempts to clone a human being represent unacceptable experimentation.
- Violating the principle of respect

What Next?

- A revised draft will be circulated before the 2011 ELCA Assembly
 - Share/Talk
 - Bible study/classes
 - Dialogue with other cultures/faiths
 - Investments
 - Choices - Costs - Consequences
-

<http://www.elca.org/What-We-Believe/Social-Issues/Social-Statements-in-Process/Genetics/Draft-Social-Statement.aspx>

Or “Google” “ELCA Genetics Statement”

Professional Genetics Resources at Zumbro Lutheran Church

- Daniel Van Dyke
- Rhett Ketterling
- Bob Jenkins
- Karin Wain
- Karen Schowalter
- Jamie Randolph
- Nearly every Mayo physician!!

“Justice is what love looks like in public, just like
tenderness is what love feels like in private. “

– Cornell West, Colbert Report 1-18-2011

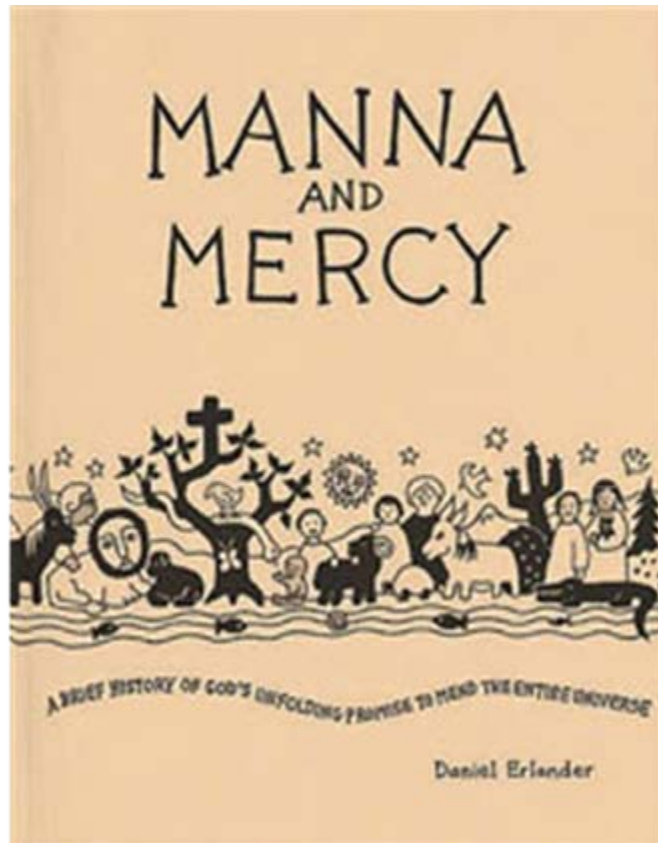
“Love is a steadfast commitment to the well
being of other people.”

– Steven Colbert, Colbert Report 1-18-2011

“He has showed you, people, what is good. And
what does the LORD require of you? To love
justice and walk humbly with your God.”

– Micah 6:8

Alan Storey Manna and Mercy Retreat Feb 26/27 Assisi Heights



Manna is our daily bread

Mercy for all