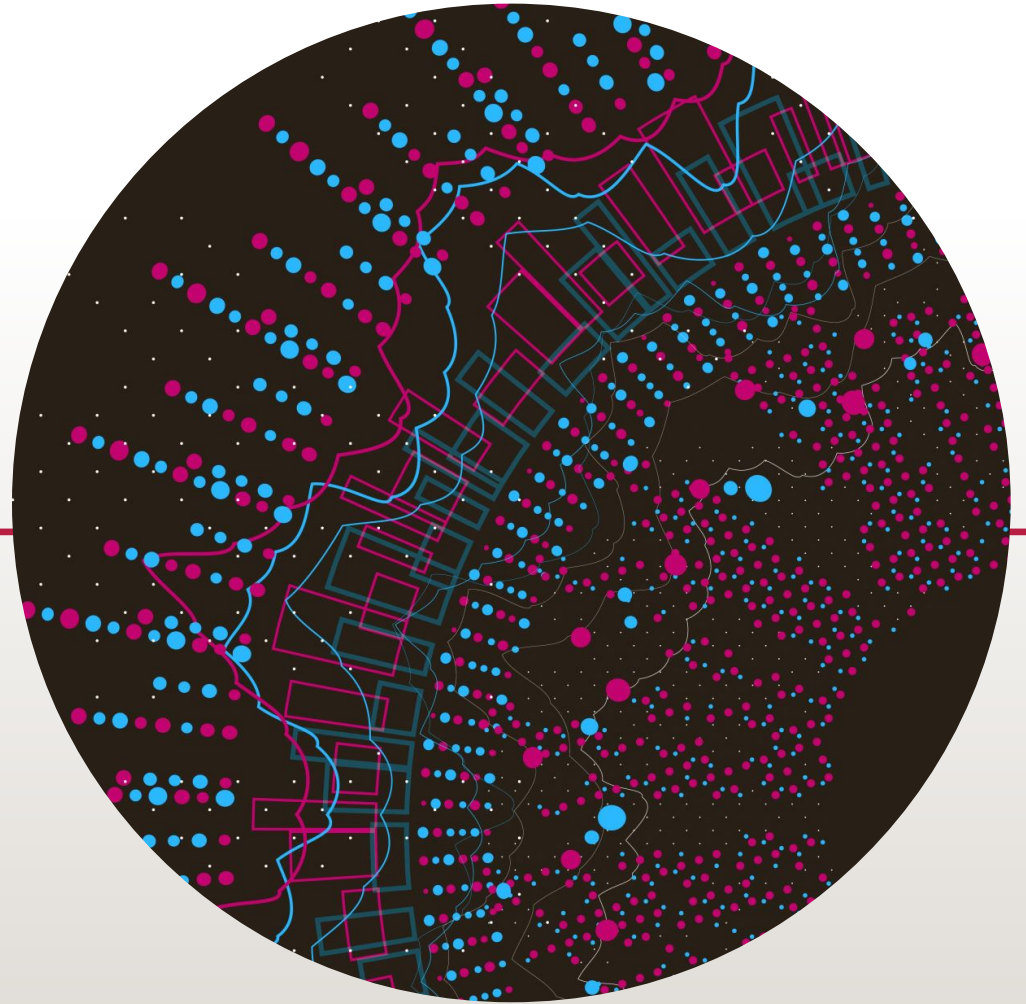


GENETICS, ETHICS, AND A CHRISTIAN RESPONSE

DEVELOPMENT OF THE MASTER OF
SCIENCE AND FAITH IN GENETIC
COUNSELING



THE BASIC PREMISE (I)

- I've been working discussing, learning about, and investigating these particular ideas for over 6 years
- I've been involved in molecular biology/biotechnology teaching (35) and research (40) for years
- I still find all of this overwhelming, and I don't have all of the answers! I'm still on the journey as well
- Clarification questions



THE BASIC PREMISE (II)

- In thinking about questions of genetics and ethics, the most important premise is to determine when human personhood begins.
 - It is clear scientifically that human life begins at conception
 - Recombination during gametogenesis (meiosis)
 - Each gamete is genetically unique
 - Arguments are regarding when that human life has the right to life, as is true for other persons.
 - For this purposes of this presentation, the premise is that **personhood also begins at conception**, which is the position of Union University.



The background of the slide is a blue-toned microscopic image of an in vitro fertilization (IVF) procedure. It shows a large, spherical oocyte being manipulated by a glass needle. A thin stream of fluid is being introduced into the oocyte, likely for micromanipulation or fertilization. The scene is set against a light blue background with several smaller, out-of-focus spherical cells visible.

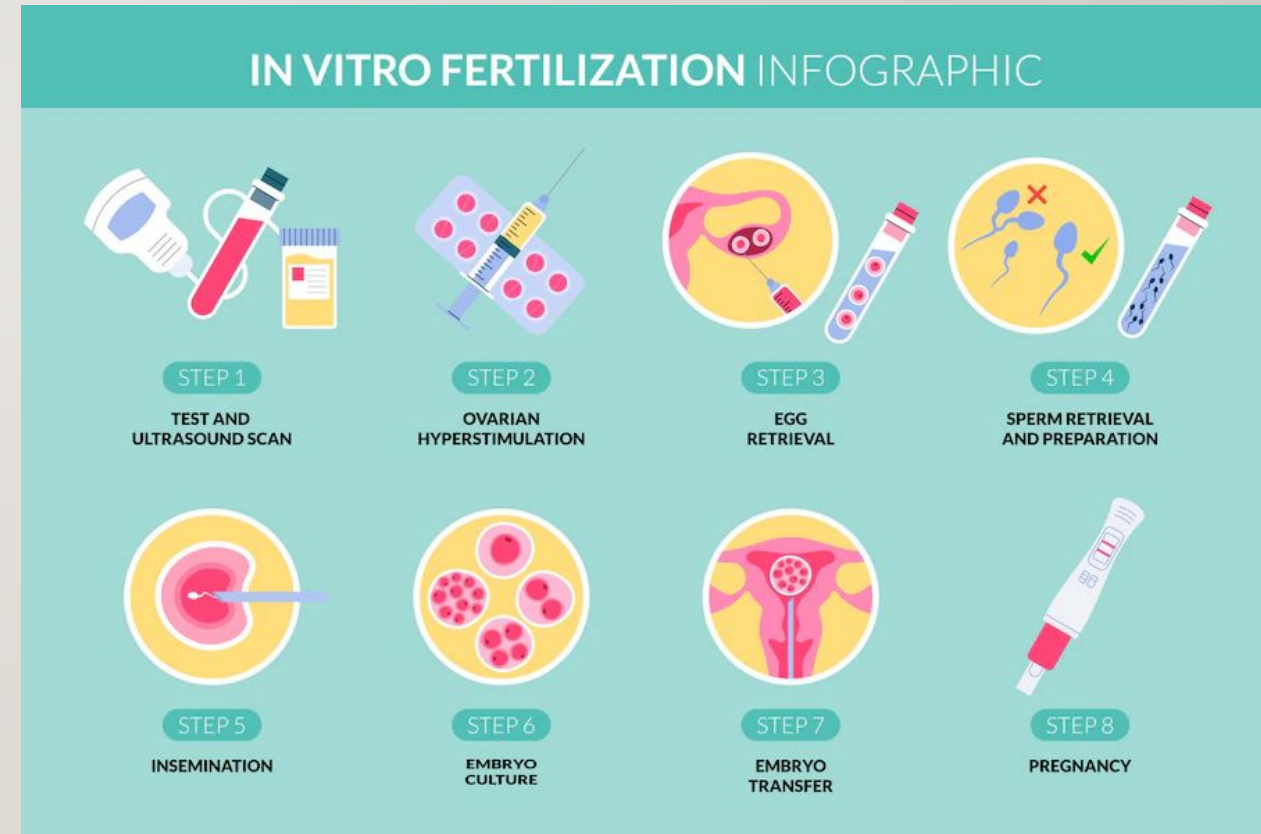
SECTION I: IN VITRO FERTILIZATION, PAST – PRESENT - FUTURE

IN VITRO FERTILIZATION ... OR NOT

- I would argue that there are a variety of Christian approaches to in vitro fertilization.
- One accepts in vitro fertilization as a valuable tool in helping infertile couples give birth to a much-wanted child
- A second sees in vitro fertilization as a technological tool to create babies in a way that is another part of our technological society. Babies are “made” in the way that everything else is made.
- Maybe babies should be “begotten, not made”
- In Oliver O'Donovan's book *“Begotten or Made?”* (2022, 2nd ed.), he makes these two distinctions:
 - Begetting: “is to speak of...the possibility that one may form another being who will share one's own nature, and with whom one will enjoy a fellowship based on radical equality.”
 - Made: “A being who is the ‘maker’ of any other being is alienated from that which he as made, transcending it by his will and acting as the law of its being.” (also, C.S. Lewis, *Abolition of Man*)
- So, there are certainly arguments for rejecting in vitro fertilization (and associated human-making technologies) altogether
- There are a number of things that we shouldn't be doing but that we are doing

WHAT ARE SOME CURRENT AND FUTURE GENETIC/BIOTECHNOLOGICAL ISSUES FOR CHRISTIANS?

- One of the earliest developments in modern human reproductive technology was *in vitro* fertilization (1978)
 - The use of in vitro fertilization has been widely accepted, but should it be?
 - There are several different elements of the overall process that can be discussed separately
 - Is the foundation for lots of other technological “advancements”
 - Ovarian hyperstimulation can be dangerous
- The biggest challenge is embryo storage, the results of producing more embryos than are needed
 - Step 6.5a No one knows for certain, but the estimate is that there are over 6 million frozen embryos (“persons”) in the US, and this storage comes at a financial cost
 - This will be explored in more detail later!
 - Step 6.5b Prenatal Genetic Diagnosis; becoming more

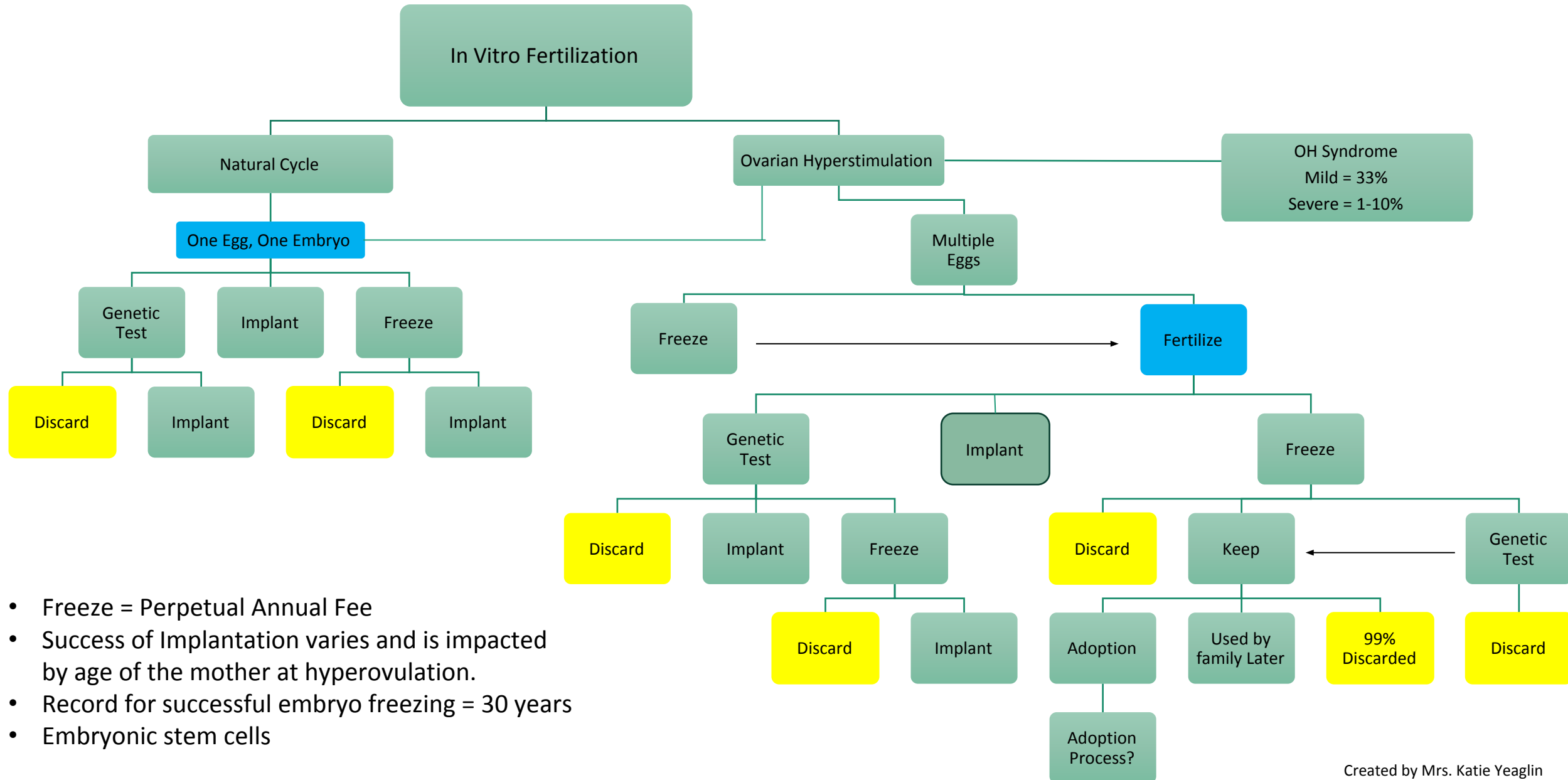


WHAT ARE THE COSTS FOR THIS?

- These are some of the costs that are incurred for pre-natal genetic testing
- Additional tests can be performed for additional costs, such as whole exome sequencing for about \$3000
- Requires the detection of an anomaly, or of a family history of a particular disease
- Eventually, we will be able to screen for traits that are independent of health outcomes

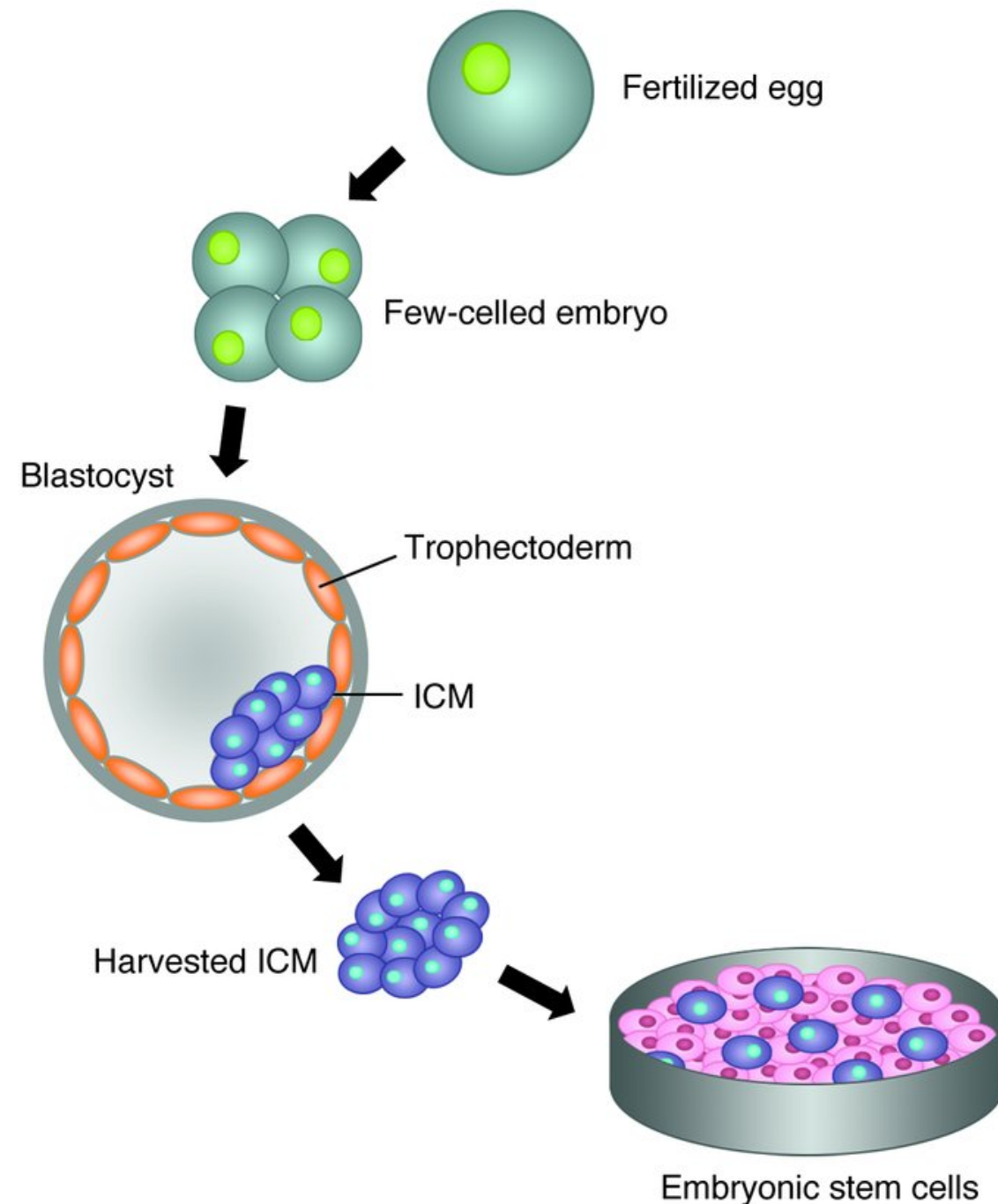
IVF-ICSI with fresh transfer cost (without PGS) Intracytoplasmic sperm injection	\$12,000
IVF medication costs Medications for generating multiple eggs	About \$3500 or more
Embryo biopsy cost Removing one cell from an embryo	\$1500
Embryo freezing cost	\$800
PGT-A test cost Genetic test for chromosomal abnormalities	\$3500
FET cycle cost Frozen embryo transfer	\$3000-\$5000
IVF PGT-A cycle with one FET included package cost	\$20,000 + meds

Crossing the line in the sand: Evaluating in vitro fertilization (and offshoots) in more depth

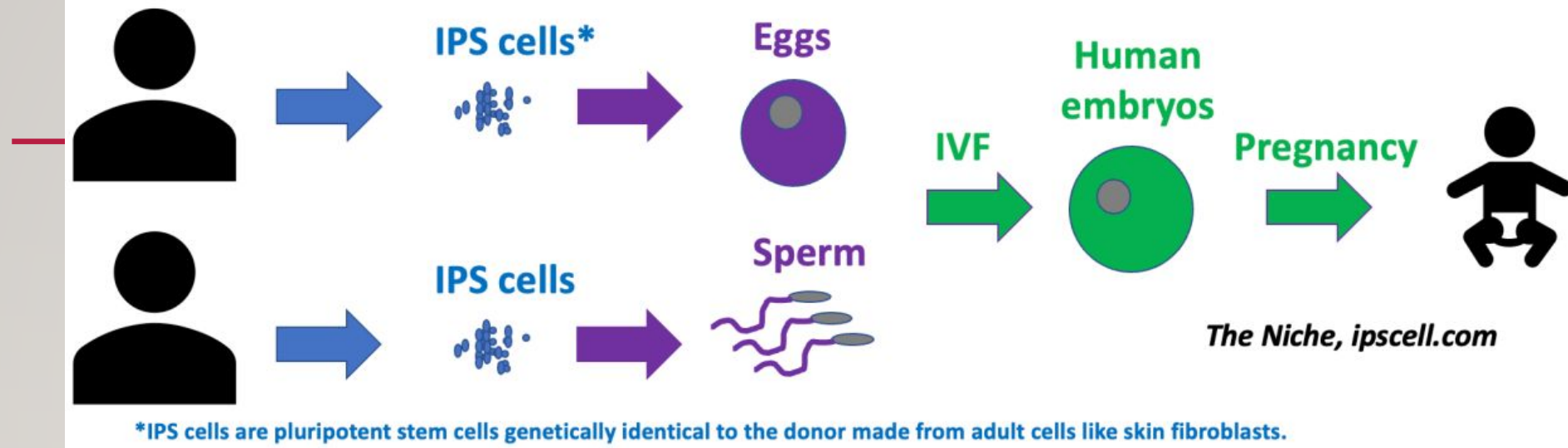


STEM CELL TREATMENTS: ARE ALL STEM CELLS THE SAME?

- The use of adult stem cells as treatments for disease has been used for decades (first successful bone marrow transplant was conducted in 1968). This is not controversial.
- The use of embryonic stem (ES) cells as a potential treatment for disease is more controversial and to this point not successful in humans (first cultured in 1998, first treatment in 2011)
 - Because personhood begins at conception, this involves dismantling a person
- Induced pluripotent stem cells (2006) are a great alternative to embryonic stem cells and are being used more frequently
 - Involves genetically engineering somatic (body) cells to behave like embryonic stem cells (will be unpacked next)
 - Is gradually eliminating the need for ES cells



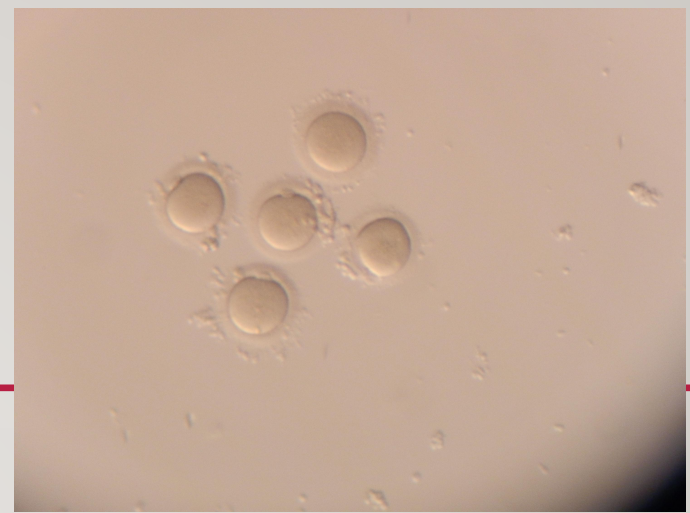
In vitro gametogenesis (IVG)



LAYER

- This is a process that is not available yet for human reproduction yet, but Induced Pluripotent Stem Cells (IPS) are becoming more widely used for the development of stem cells when stem cells are needed. **The great value is that they are replacing embryonic stem cells.** These cells are produced by genetically engineering normal body cells.
- The challenge is that the same process is being used to produce gametes in rodents, which may someday be used for in vitro fertilization in humans. The weird(est) thing is that both gametes can come from the same person!

IN VITRO FERTILIZATION IN ALABAMA



- The Alabama Supreme Court ruled that all children, born or pre-born, in utero or in vitro, were in fact “persons”, entitled to legal protection
 - Legislation has subsequently provided immunity
- The Southern Baptist Convention recently voted to “reaffirm the unconditional value and right to life of every human being, including those in an embryonic stage” in relation to IVF
 - Hot topic!
- This impacts the freezing, discarding, and use of embryos for research
 - Production of embryonic stem cells
- Two alternatives have been suggested to generating and freezing unused embryos
 - First, fertilizing only the number of embryos that are going to be implanted
 - Second, freezing eggs instead of embryos
 - Each of these reduce the likelihood of success, and could increase the cost, but eliminate the discarding of embryos
 - Financial support could be provided for these two approaches as an offset to discouraging traditional IVF
 - There are a number of other legislative considerations regarding issues that we have just discussed, including:
 - In vitro gametogenesis
 - Partial ectogenesis (or ectogestation)

THE DEVELOPMENT OF A HUMAN ARTIFICIAL WOMB WILL CHANGE LOTS OF THINGS (PARTIAL ECTOGENESIS)

- Scientists have succeeded in producing an artificial womb to grow baby sheep for the last trimester of development (2017)
- Work will be approved soon (if not already) for something similar for humans
 - Ideally to continue development for babies under 23 weeks that need to be removed from their mothers prematurely (why?); clinical trials being considered
 - Not sure how early they will be able to start, but probably no earlier than the development of the umbilical cord, about week 7
- Total ectogenesis would be having the entire process, from conception, be in vitro

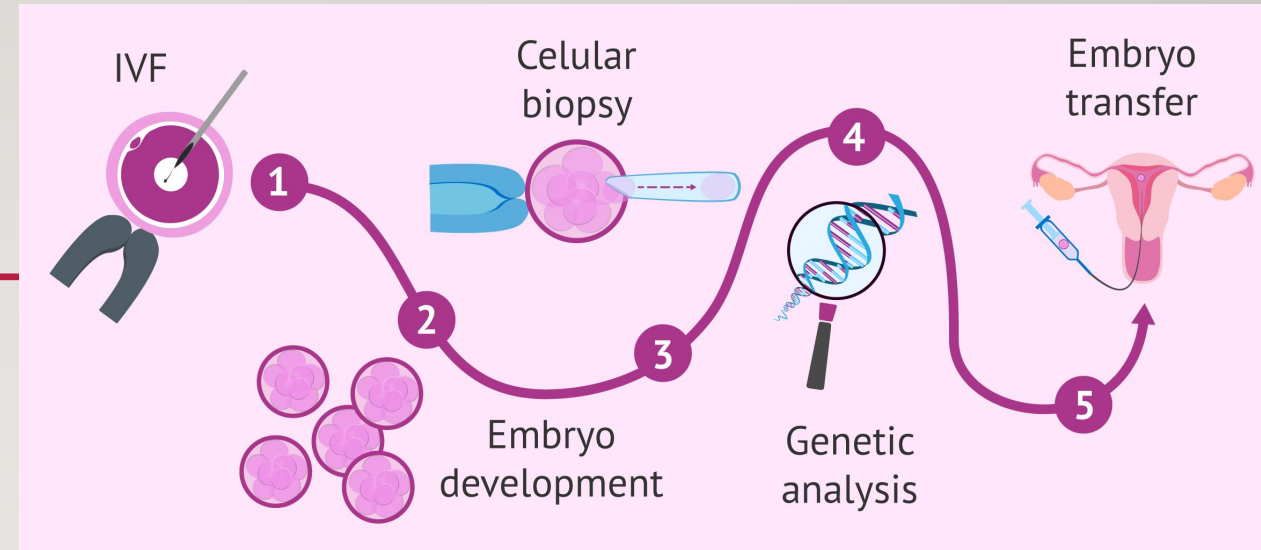


SECTION II: GENETIC TESTING AND SEQUENCING

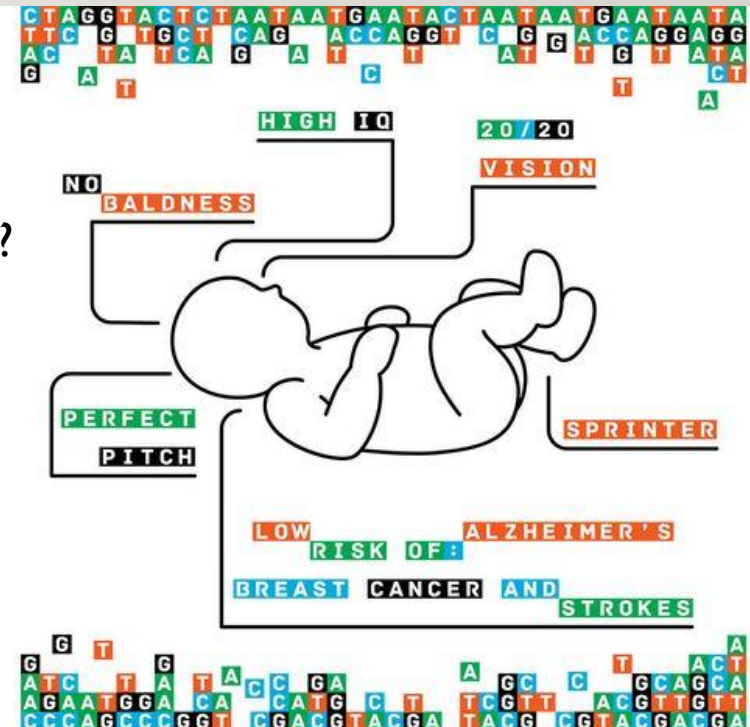


HOW MUCH DO WE WANT TO KNOW ABOUT OUR PRE-BORN BABIES?

- **Embryo selection, or pre-implantation genetic diagnosis, is the ability to generate embryos from IVF, then select embryos with “healthy genomes” for implantation into the mother**
 - More and more things that we can select for!
- **Pre-natal genetic testing is something that Christians with a family history of a genetic disease might find tempting; can be done at different developmental stages**
- **Some “routine” genetic tests, say, for gender, can reveal much more, sometimes more than parents are prepared for**



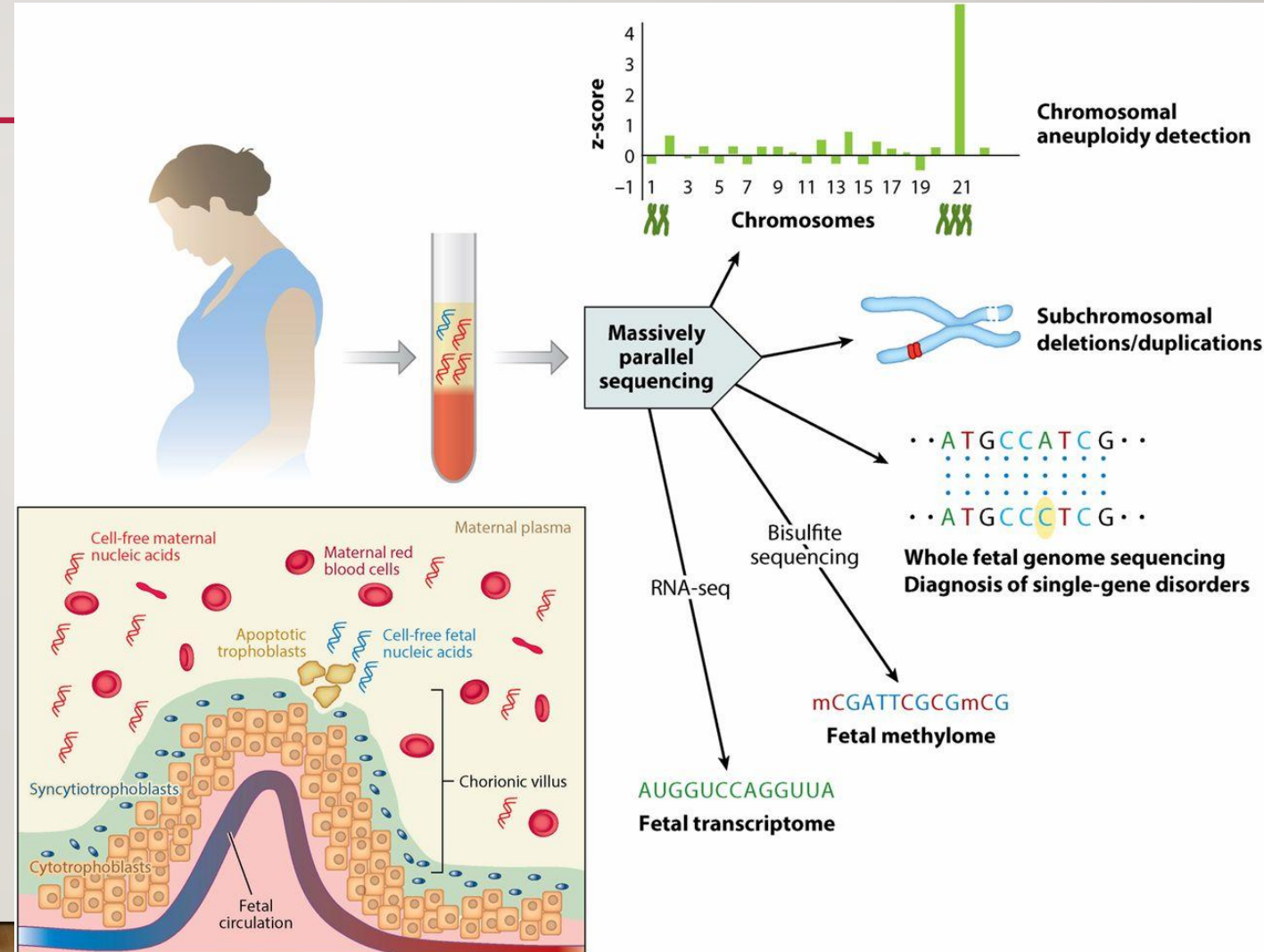
The Future?



- **Receiving “a diagnosis” can be**
<https://www.invitra.com/en/about-the-pgd-process/>
<https://science.howstuffworks.com/life/genetic/sequence-genome-newborns-news.htm>

NON-INVASIVE PRENATAL TESTING USING CELL-FREE FETAL DNA

- If parents are interested in genetic testing but not embryo selection, NIPT is a newer option
- These tests postpone the “big needle” tests (chorionic villus sampling and amniocentesis), and so have no risk of miscarriage, but are fairly new; **all tests are predictive, not determinative** (false positives and negatives)
- Even if a parent would never consider terminating a pregnancy based on the results of a test, the results can still provide information to help prepare parents for what may be coming
- Huge mental and emotional differences between terminating a pregnancy and allowing the process to continue naturally



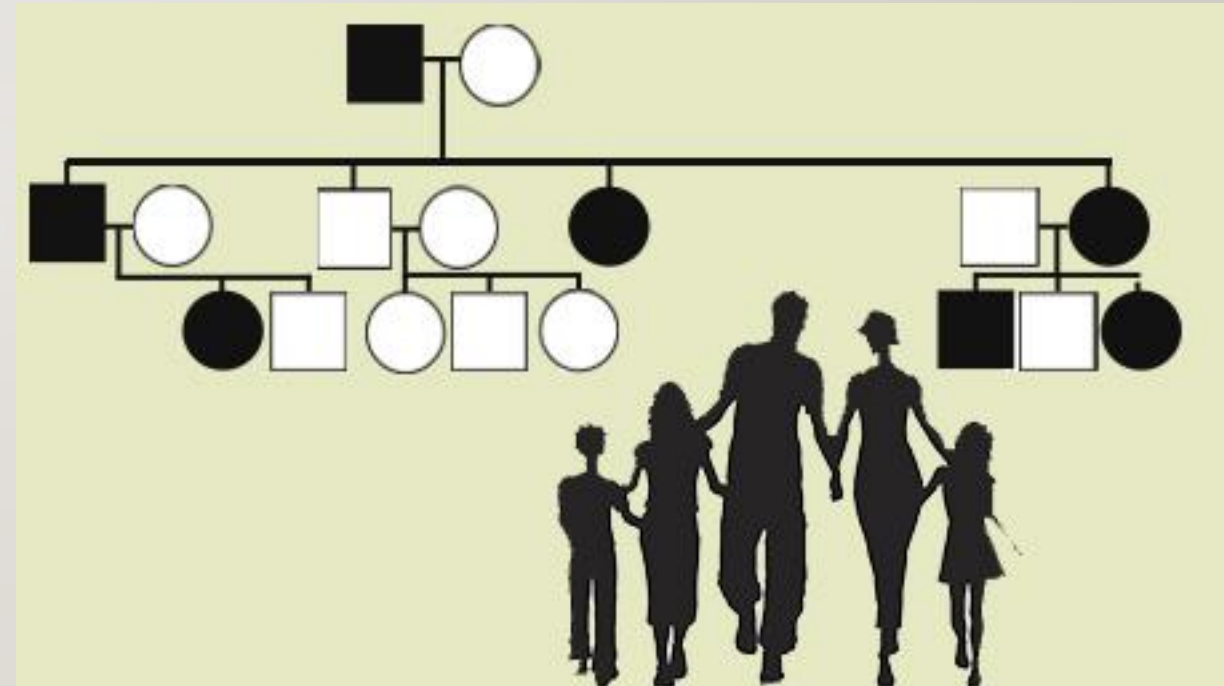
MAKING DECISIONS IN THE FACE OF LOTS OF CONFLICTING INFORMATION: FULLY INFORMED CONSENT



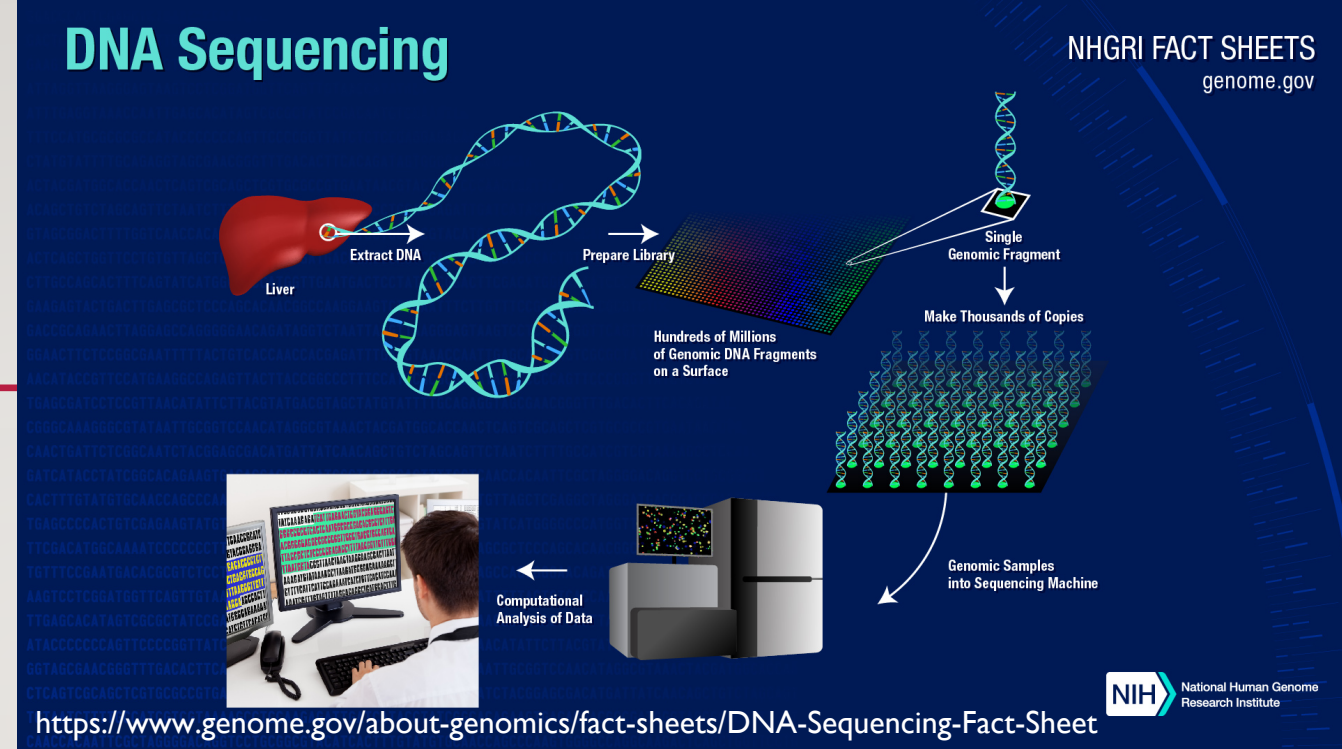
- Based on the results of these tests, physicians sometimes make recommendations regarding the trajectory of a pregnancy based on out-dated data on what are "life-limiting conditions"
 - Sometimes perinatal hospice is warranted, in that the condition is truly "incompatible with life"
 - Sometimes a pre-natal diagnosis is a death sentence and self-fulfilling prophecy, in that children are born and then not cared for (not provided nutrition or water), whereas children born with the same condition without a diagnosis are "fought for" by the health care team
- There are a number of organizations who are working to provide accurate information to physicians, families, and others, including:
 - Them Before Us: "centers the child in every conversation about marriage and family including divorce, same-sex parenting, reproductive technologies, surrogacy, adoption, cohabitation"
 - Be Not Afraid: "We believe that every baby is a gift, and we support parents not only in advocating for basic care, but also in obtaining the treatment they deem appropriate for their child after birth no matter the diagnosis."

HOW MUCH DO WE WANT TO KNOW ABOUT OURSELVES?

- Genetic testing is not limited to the pre-natal world!
 - There are currently over 175,000 genetic tests
- The impact of the results of genetic testing for one person can have a major impact on other family members
- There are challenges regarding whether to share genetic information
- This information leads to decisions
 - To ignore the information
 - To take action in response
 - Physically (such as a mastectomy)
 - Genetically (such as genome editing)
 - Life-style (such as diet and exercise)



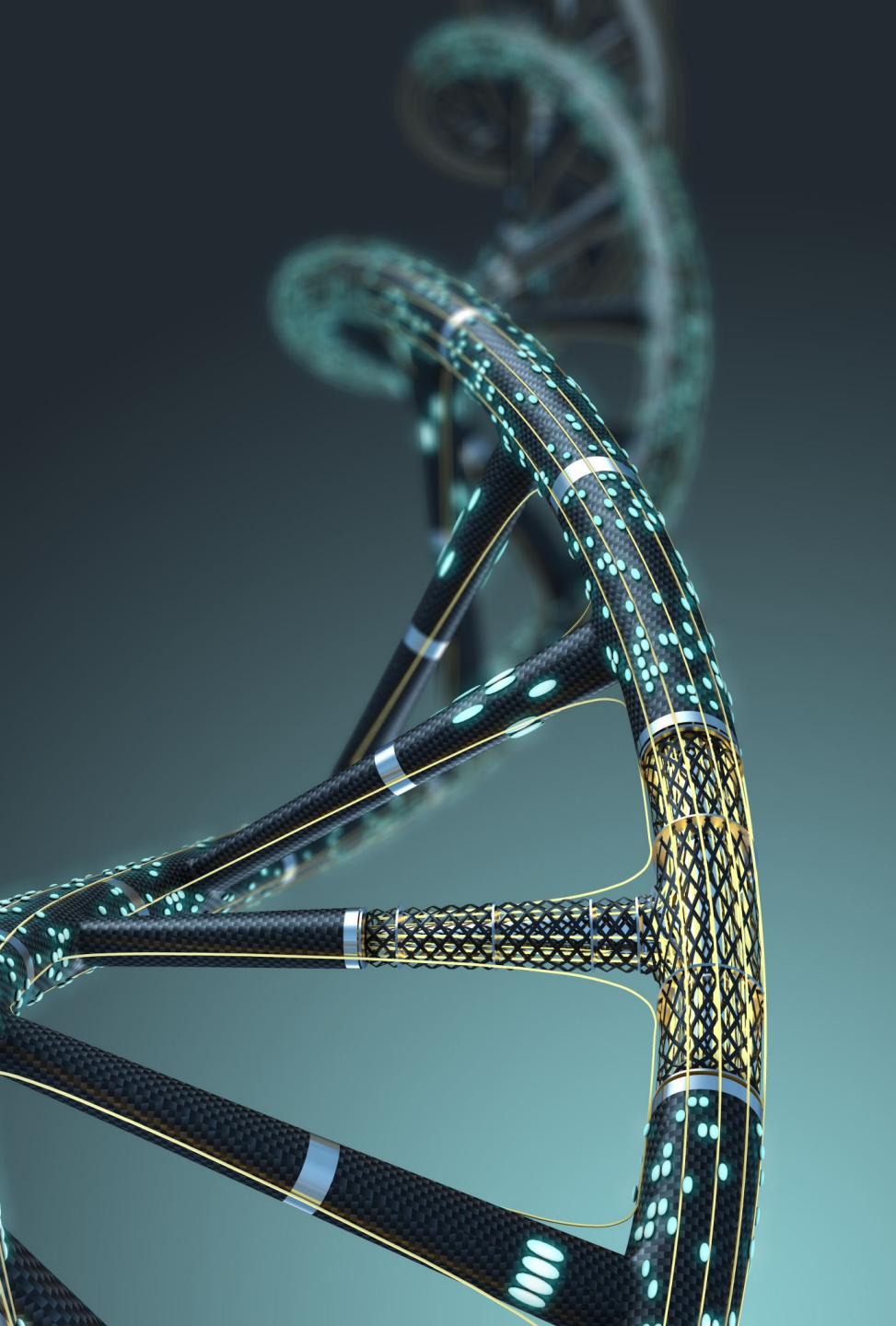
GENOME SEQUENCING: HOW MUCH DO WE WANT TO KNOW (part II)? HOW MUCH DO YOU WANT OTHERS TO KNOW? WHO ELSE MIGHT BE INTERESTED?



- Since the completion of the first draft of the Human Genome was completed in 2003 at a cost of \$3B, the cost of whole genome sequencing has dropped dramatically, to about \$600, with the target of \$200.
- The more we know about our genome, the more things we can look for, in ourselves and in others, sometimes without their permission (UK newborn genome project).
- Would you like to have your genome sequenced?

BROAD IMPACT OF GENETIC TESTING

- **What are the ramifications of these kinds of genetic tests, for us and for our families?**
(mentioned earlier)
- **Who else might be interested in our genomic information, and why?**
- **What if you were compelled to share your genetic information?**
 - **Genetic Information Non-Discrimination Act (GINA; 2009):** part of the Human Genome Project
 - **HR 1313 (March, 2017)** “would allow companies to require employees to undergo genetic testing or risk paying a penalty of thousands of dollars and would let employers see ... genetic and other health information.” Died in congress, but was passed out of a committee
 - **Single payer insurance (Government as legislators and providers of health care)**
 - **Military and businesses of under 15 employees are exempt from GINA**
- **GATTACA (1997):** We are getting closer all the time



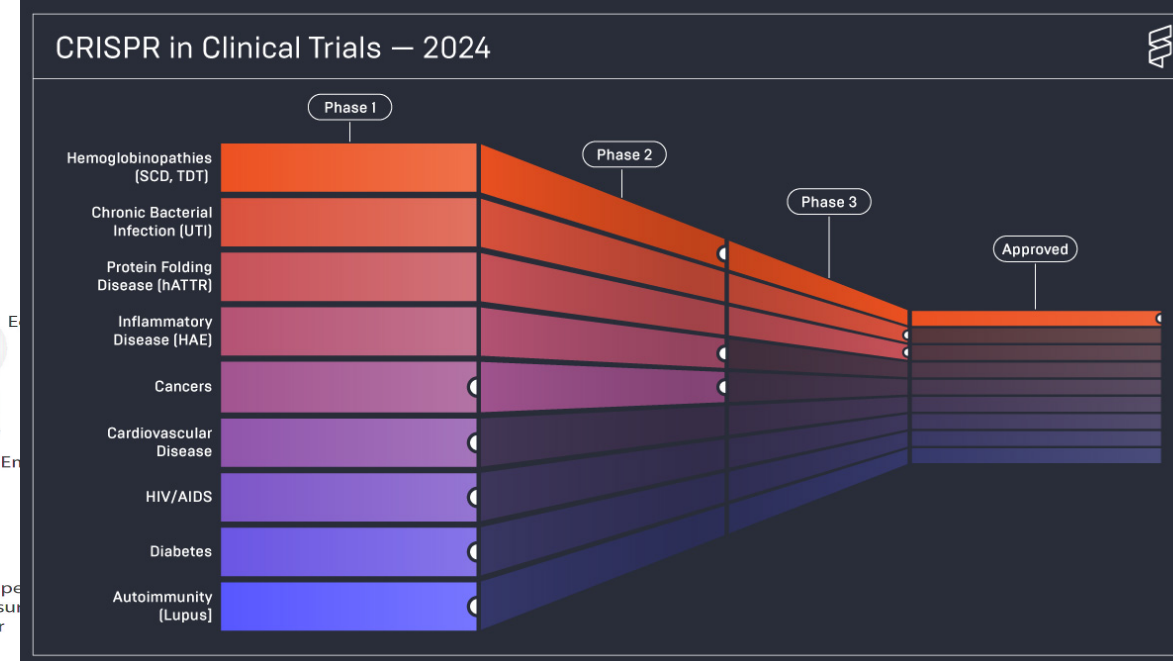
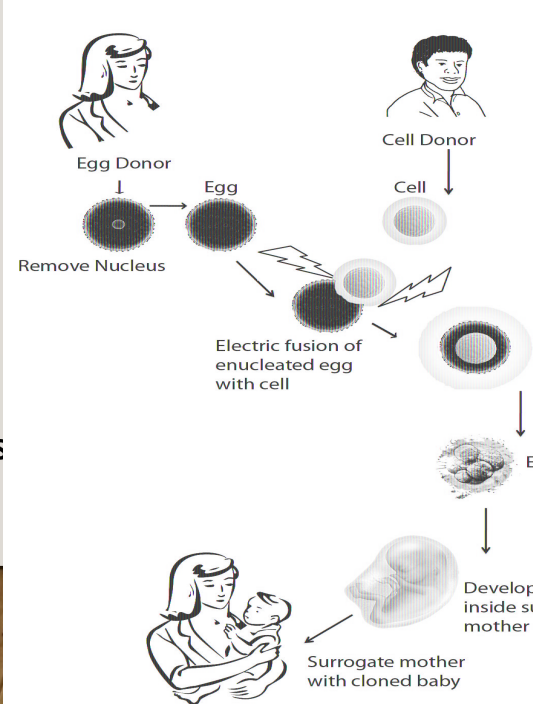
SECTION III: GENETIC TREATMENTS AND OTHER THERAPIES



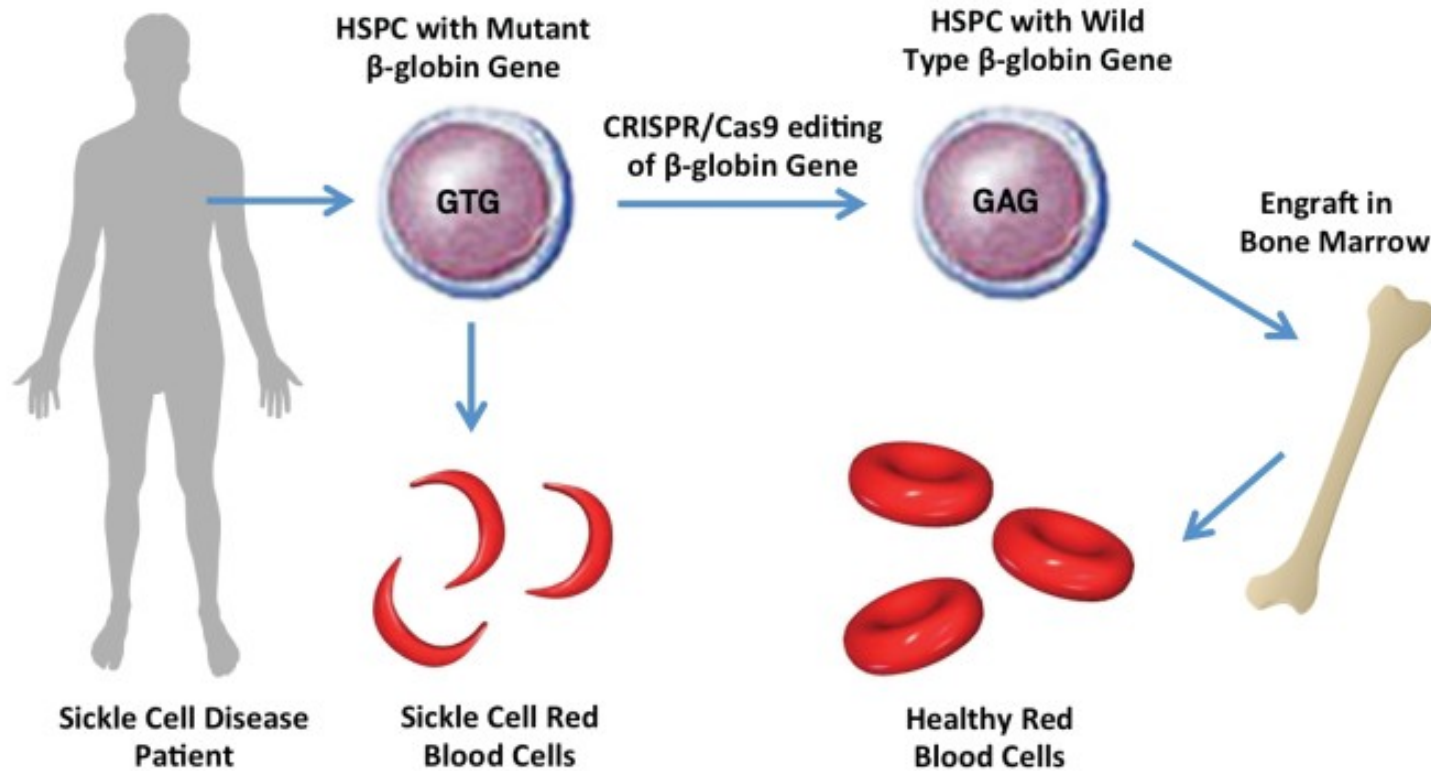
GENOME EDITING: SHORT-TERM AND LONG-TERM

- Somatic Cell therapy and editing
 - This kind of treatment involves changing the DNA of an individual in a way that is not passed down to future generations
 - Gene therapy involves adding or knocking out a gene in the human genome (1991)
 - **Gene editing** involves making minor edits to existing genes
 - Sickle cell disease (SCD),
Thalassemia (TDT): blood disorders
 - *Ex vivo* vs *in situ*

- Germ line therapy, editing, and cloning
 - These are processes that are made before fertilization of a human egg takes place so that every cell of the new individual is modified, and those modifications can be passed to future generations
 - **Reproductive Cloning** vs Therapeutic cloning: not yet in humans
 - How many states have banned reproductive cloning (as of 2015)?
 - Therapeutic cloning (as of 2024)?
 - Gene therapy involves adding or knocking out genes to gametes, or cells used in cloning: not yet successful in humans
 - Genome editing: One successful, and condemned, birth in 2019 (China)



WHAT IF WE CAN NOT ONLY KNOW WHAT IS IN OUR GENOME, BUT WE CAN CHANGE IT?

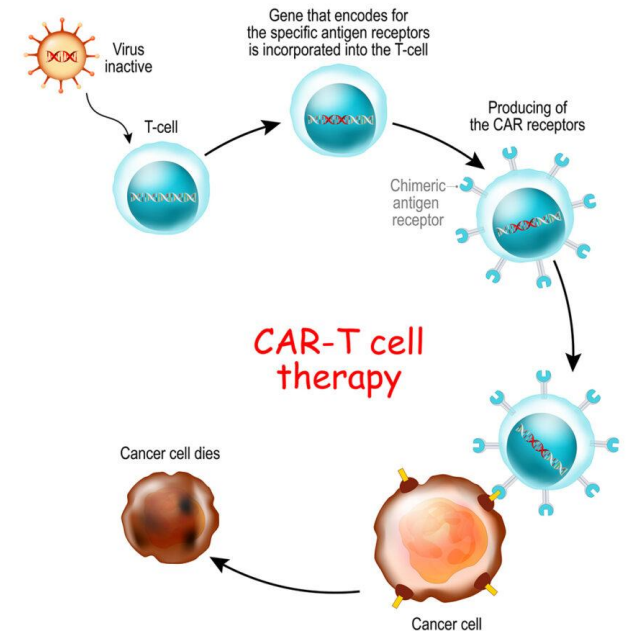


HSPC = Human Pluripotent Stem Cells (blood stem cells)

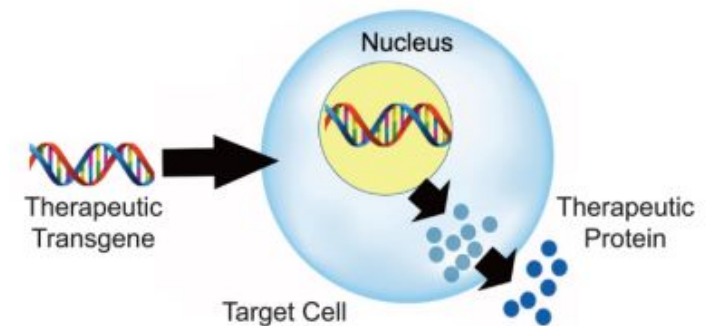
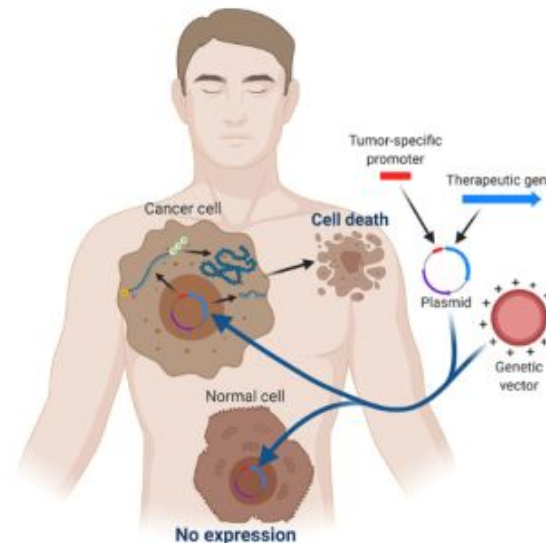
- With advances in genome editing, scientists have been able to not only understand what the genome means, but to identify problems and correct them
 - Sickle Cell Disease (>\$2M)
- It may be that in the future people will be encouraged to have their damaged genes repaired to save on health care costs
- In addition to fixing problems, in the future we will be able to enhance or improve things that are not a problem
- Lots of different applications of genome editing and gene therapy (adding or inactivating genes)

HOW IS GENE THERAPY BEING USED TO TREAT CANCER?

- In vitro: CAR-T cells are the individual's own white blood cells that can be engineered outside of the body, then be reintroduced to recognize and destroy cancer cells. So far this is very effective, but very expensive (\$500K - \$1M), because the treatment is tailored to each person; some side effects
- In vivo: Gene therapy can be used to introduce genes that only work in cancer cells, and will produce toxins that will kill the cancers, but no other cells
- Some of the challenges with gene therapy are that cells that are engineered become cancer cells themselves
- Pharmacogenomics (the use of one's genome to create personalized treatments) is also becoming more prevalent, but can also provide more information than desired



HOW GENE THERAPY CAN HELP AGAINST CANCER



<https://acgtfoundation.org/news/gene-therapy-for-cancer/>

<https://www.biocode.org.uk/2022/12/15/how-gene-therapy-can-help-against-cancer-2/>

WHO IS TASKED WITH MAKING SENSE OF ALL OF THIS: GENETIC COUNSELORS

- The health care professionals who are trained to deal with questions of genetics and family histories are called Genetic Counselors:
 - Genetic counseling is the process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease. The process integrates:
 - Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence
 - Education about inheritance, testing, management, prevention, resources
 - Counseling to promote informed choices and adaptation to the risk or condition
- The challenge is the idea of “directiveness” vs “non-directiveness”; the extent to which the counselor interjects their own worldview
- Are there genetic counselors who are Christians? Yes, but we need more!

WHAT IF WE WERE ABLE TO DEVELOP FAITH-BASED EXPERTS IN THESE AREAS TO SERVE AS A RESOURCE TO THE CHRISTIAN COMMUNITY (AND OTHERS)?

- How much do Christian parents, pastors, pregnancy care center directors, and other Christian leaders know about genetic issues?
- These and other biological tests and treatments are coming faster than we can keep up with them
- I am working with Baptist Memorial Hospital in Memphis to develop the Master of Science and Faith in Genetic Counseling to train pro-life Christians to be salt and light as Genetic Counselors, and to be resources for the Christian community



SO, WHAT'S THE OTHER SIDE OF THE STORY

- Data indicates that conservative Christians tend to not use genetic testing and counseling
- With regard to pre-natal genetic testing, there is a sense of “I’m not going to have an abortion, why would I want to have genetic tests/counseling?”
- There is also a sense that the genetic counselor will be antagonistic toward faith-based worldviews.
- However, there can be great benefit to genetic tests/counseling in terms of understanding what is coming; there are often things that can be done!
- Genetic Counseling is an area in which pro-life Christians are not openly represented, although there are genetic counselors who are pro-life.
- **Christian Medical and Dental Association:** 97% indicated that having access to pro-life genetic counselors would be positive. 32% had patients with negative experiences with genetic counselors based on different worldviews.
- **American Association of Pro-Life OB/Gyns:** 100% were in favor of having access to pro-life genetic counselors, and 82% had patients with negative experiences with genetic counselors based on different worldviews.

THIS NEW WORLD CAN BE VERY CONFUSING! HOW CAN CHRISTIANS CONNECT WITH FAITH-BASED GENETIC COUNSELORS?

- It is our hope that more and more Christian physicians and other health care providers will become more aware of graduates of our program, and refer patients to them
- We also hope that our graduates are employed by medically-based pregnancy care centers
- In connection with that, we plan to institute telemedicine options for pregnancy care centers and others with questions
- We plan to provide resources for Christians that will help address a lot of the questions that are raised by these types of new technologies, in part based on research that our students conduct
- We anticipate that faith-based hospital systems will seek out our graduates as well
- We see our graduates as being salt and light throughout the health care field



Andrew Bell

PROGRESS SO FAR?

- This idea germinated in early 2019, and has gone through several steps:
- 1. Is there even a need for faith-based genetic counselors? My research indicated that there is!
- 2. We then developed a curriculum that was passed overwhelmingly by the Union Faculty.
- 3. We have had communications with Accreditors, and the communication has been positive so far.
- 4. We have a good relationship with the pro-life geneticist at Baptist Hospital in Memphis with regard to a partnership for the clinical training for students in this program

WHAT'S NEXT?

- There are a number of things that need to happen to get this program off the ground:
- 1. Working on raising start-up funding for the program, which will be used to:
 - A. Hire a Program Director (who must be a genetic counselor), and a Geneticist
 - B. Pay fees for Accreditation, recruiting students, and developing markets for future graduates
- 2. Develop an Advisory Council and expand the awareness of the program once the infrastructure is developed
- But there is much more than most of the Christian community is aware of!

VIDEO

PLEASE VISIT OUR WEBPAGE AT UU.EDU/MSFGC

WE CAN USE ALL THE SUPPORT WE CAN GET!

YOUR QUESTIONS:

- “The only things that are not permitted are the things that are not yet possible” Ben Hurlbut, Bioethicist, Arizona State
- Special thanks to Pastor Waddell!
- I’m happy to take your questions at this point!



GENETIC COUNSELING

WHAT'S IT ALL ABOUT?

WHAT GENETIC COUNSELORS **DO**

Make complex genetic topics and tests easier to understand

Take time to explore your fears, questions, and concerns

Provide information about testing options

Identify the most cost-efficient approach in your situation

Help you navigate care, arrange referrals, and connect for support

WHAT GENETIC COUNSELORS **DON'T DO**

Make decisions for you about testing or having children

Pactice as licensed therapists or psychologists

Prescribe medications or diagnose your disease or condition

Replace other healthcare team members like physicians