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PACIFIC WAVES - EXPLORING SCIENTIFIC FRONTIERS IN AN EVOLVING SOCIETY
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It doesn't stop at conception: Long-term genetic and psychological implications of gamete donation

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Disclosure Slide

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Employee: CooperSurgical

Stock Shareholder: CooperSurgical

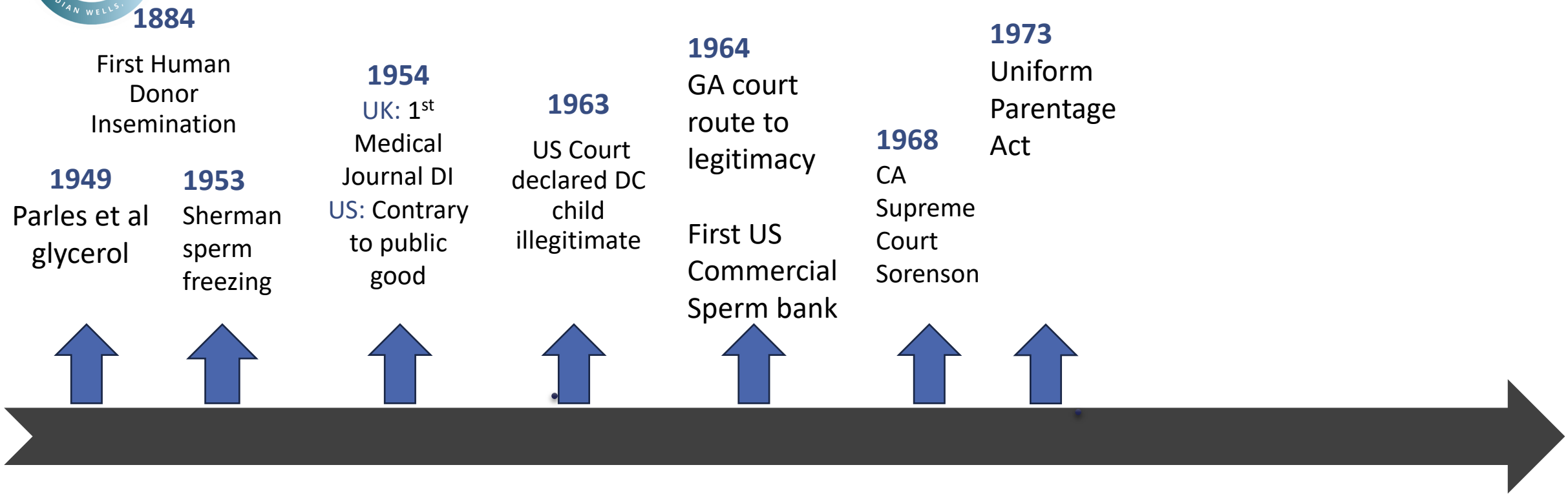
Lauren Berman: Nothing to Disclose

Danny Shapiro: Nothing to Disclose

Josh McLaurin: Nothing to Disclose

Expected Learning Outcomes

- Describe the impact of gamete donation on the donors themselves and donor-conceived persons over a lifetime.
- Summarize the ways in which the long-term impact of gamete donation can inform the initial genetic and psychological counseling that donors undergo.
- Identify some challenges to informed consent around the lifetime impact of gamete donation.


1884
First Human Donor Insemination
1949
Parles et al glycerol
1953
Sherman sperm freezing
1954
UK: 1st Medical Journal DI
US: Contrary to public good
1963
US Court declared DC child illegitimate
1964
GA court route to legitimacy
First US Commercial Sperm bank
1968
CA Supreme Court Sorenson
1973
Uniform Parentage Act
1979
First IVF baby born
1984
First baby born using oocyte donor
1990's
Oocyte donation programs established in IVF clinics
1986-2000
Published reports of pregnancy from cryopreserved oocytes
2006 Vitrification
2007 Beginning of commercial egg backs

History of Disclosure/Anonymity

- THEN:
  - Historically, few records (if any) were kept on sperm donors
  - Disclosure of an individual's donor conception was not commonplace
  - Physicians often selected the recipient's donor
  - Regulations on donor anonymity began to evolve in the mid-1980s in some countries

- NOW:
  - Evolving practices related to 'donor anonymity' especially outside the U.S.
  - Bigger push from gamete recipients/offspring for less anonymity
  - More socially acceptable to disclose to offspring
    - However, disclosure practices are still variable
  - Current donors better understand anonymity is never guaranteed
    - Adult photos, donors have now grown up with social media, etc.

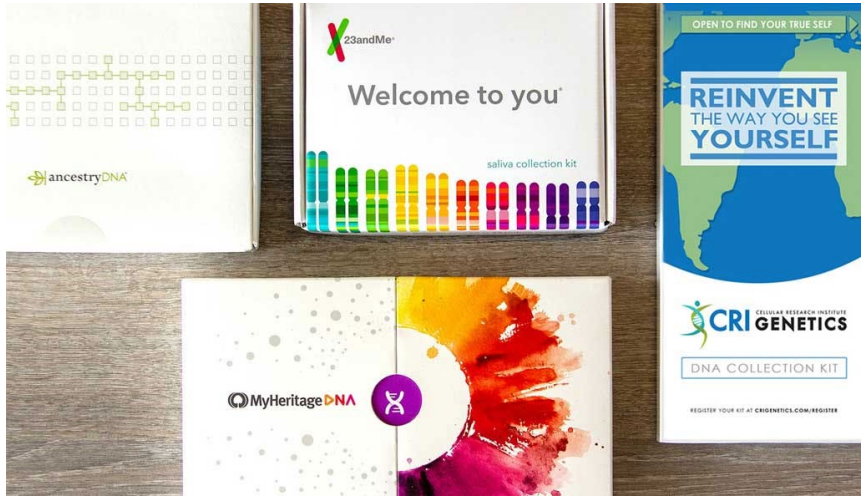
Impact of secrecy on donor-conceived

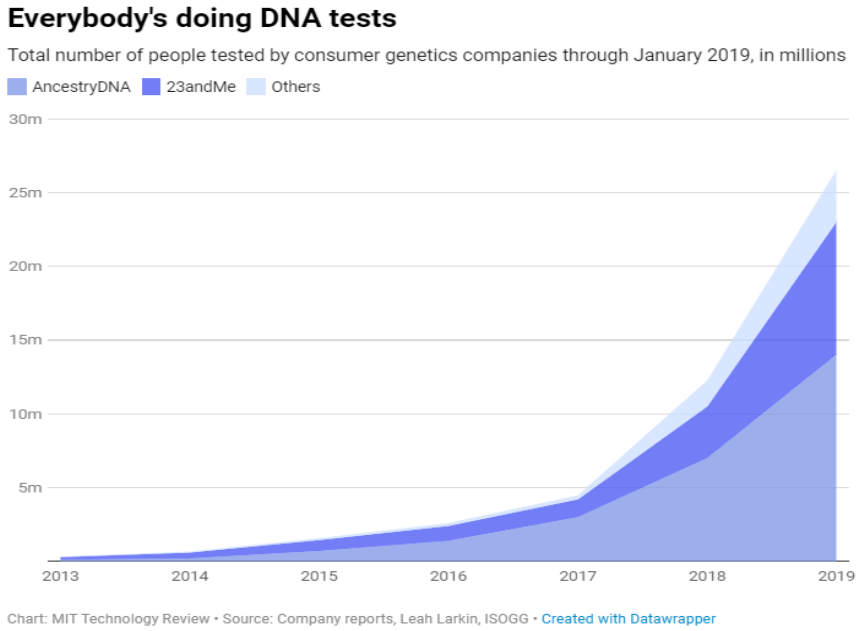
- The discovery of hidden donor-conception can create an identity crisis
  - Loss of connection to family legacy and, possibly, ethnicity & religious
  - Loss of sense of self
  - Need for new narrative of self in relation to family
  - New definition of family
  - Many experience betrayal, anger, stigma, shame, fear, anxiety, shock
  - Worry about the implications for their relationships and their children
  - Worry about rejection by family they grew up with

Grethel et al 2024

Direct-To-Consumer Genetic Testing (DTC-GT)

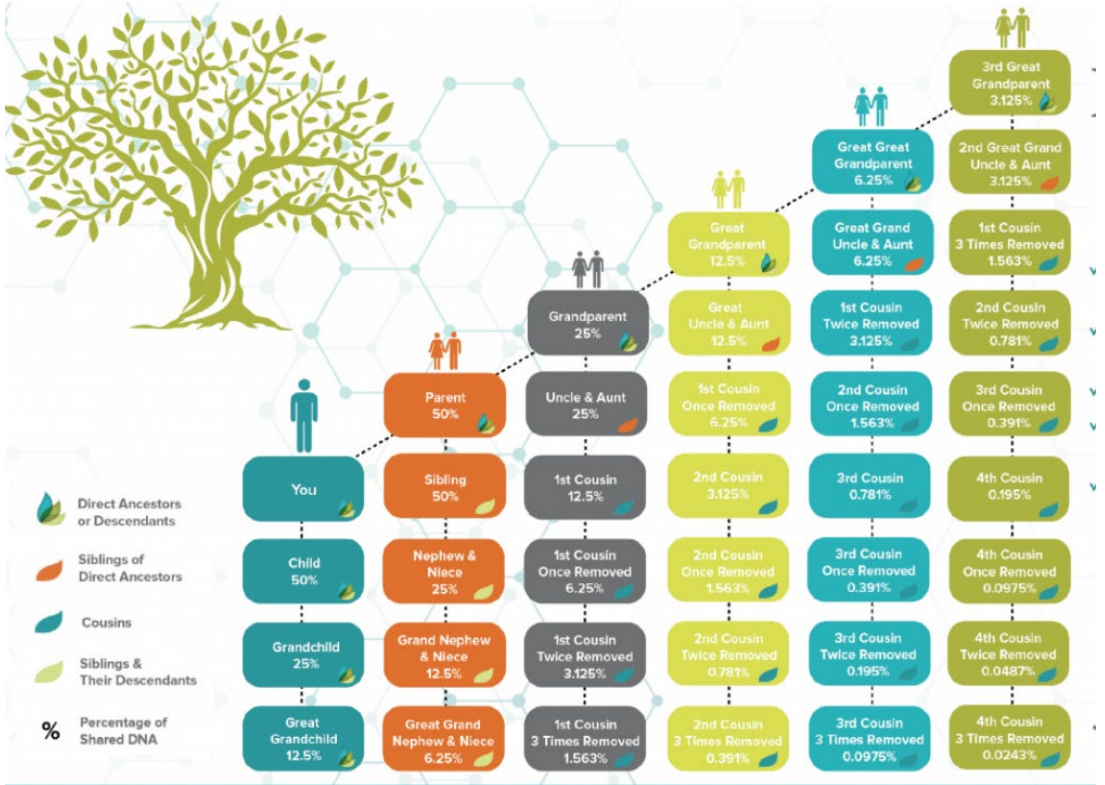
- 100 million individuals are expected to take a DTC test by 2021
- DTC DNA tests are increasingly being used to solve unknown parentage cases for adoptees, foundlings and donor-conceived persons





DTC-GT and Relatedness

- Determines how much DNA is shared between the tested individual and others in that DTC-GT's company's database
- Often reported in "centimorgans" and/or percentage of shared DNA
  - Centimorgan: a unit used to measure the probability that a section of DNA will be passed on to a descendant intact
  - i.e. parent/child have >3,330 centimorgans shared; full siblings have 2,200 – 3,300 centimorgans shared
- May also show degrees of separation and possible relationships



https://www.legacytree.com/dna-relationship-chart

The Impact of DTC-GT

Most individuals who take a DTC-GT learn something new about themselves or their relatives (Guerrini 2022)

- Surveyed ~23,000 who had participated in genetic relative finder services via DTC-GT
- 82% learned the identity of at least one genetic relative
- 61% learned something new about themselves or their relatives (see table)
- A minority of respondents learned new information about their first-degree or second-degree relatives
  - Person they believed to be their biological parent is not their biological parent (5%)
  - Had a full or half sibling they had not known about (8%)
- Those who learned that they were donor conceived reported the highest decisional regret and represented the largest proportion reporting net-negative consequences for themselves

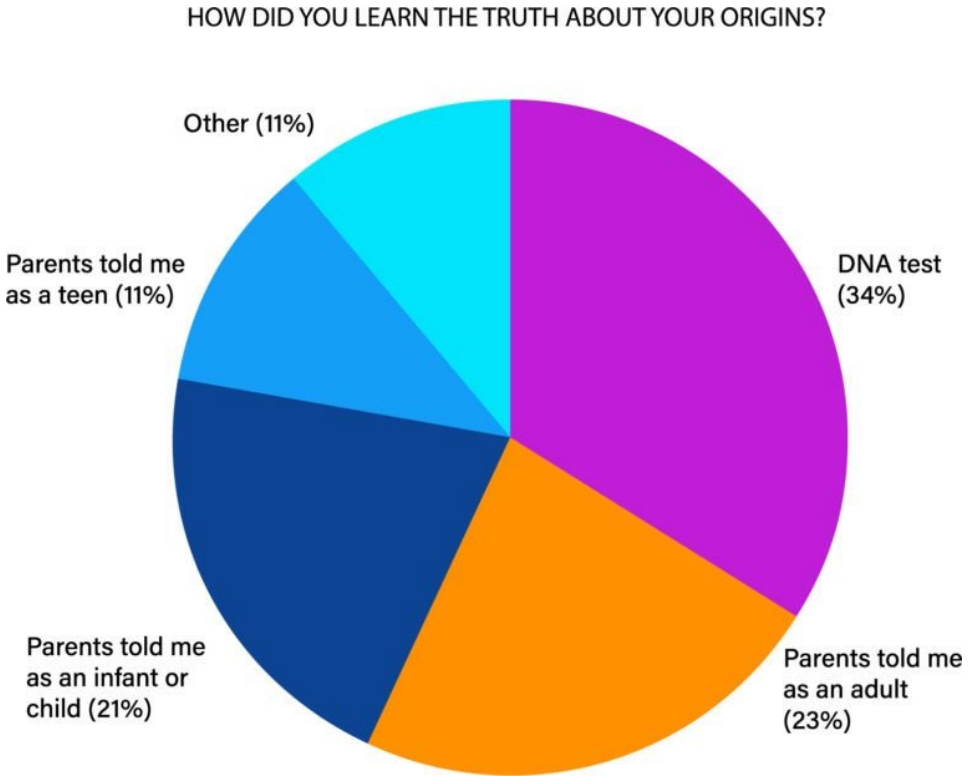
Self and/or relative information discoveries and outcomes

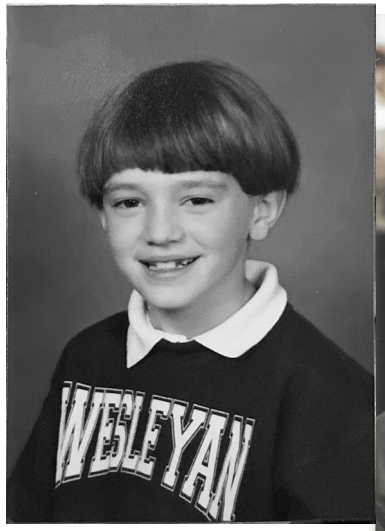
Information discoveries	Discovery	Consequences for self, n (%)[a]			
		Negative	Positive	Neutral	None
Any discovery, N = 23,196	14,134 (61)	352 (2)	9,305 (66)	1,120 (8)	3,357 (24)
Specific discovery,[d] N = 14,134					
Parent not bio parent	646 (5)	108 (17)	336 (52)	126 (20)	76 (12)
Bio parent had +children	1,171 (8)	63 (5)	855 (73)	123 (11)	130 (11)
GR parent not bio parent	1,012 (7)	55 (5)	670 (66)	104 (10)	183 (18)
Unexpected family health	1,745 (12)	51 (3)	1,275 (73)	142 (8)	277 (16)
Unexpected race/ethnicity	4,098 (29)	99 (2)	2,579 (63)	328 (8)	1,092 (27)
Other[e]	8,132 (58)	121 (1)	5,539 (68)	562 (7)	1,910 (23)
Self donor-conceived	59 (0.4)	10 (17)	28 (47)	14 (24)	7 (12)
Self adopted	244 (2)	22 (9)	159 (65)	34 (14)	29 (12)
GR donor-conceived	27 (0.2)	1 (4)	18 (67)	5 (19)	3 (11)
GR adopted	274 (2)	7 (3)	206 (75)	25 (9)	36 (13)

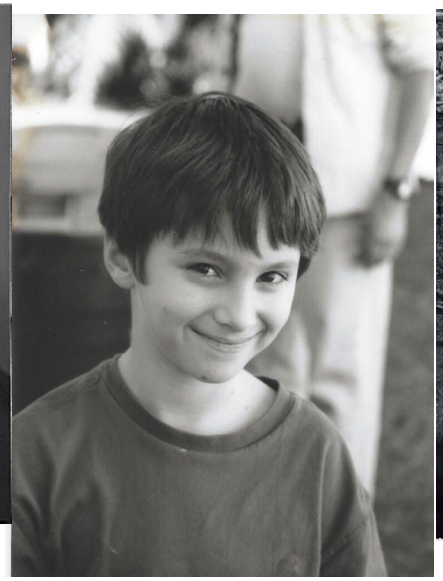
DTC-GT and Inadvertent Disclosure

One-third of individuals discover their nature of conception via DNA tests (2020 study from We Are Donor Conceived)

- Donor and donor-conceived person may match as relatives
- DCP may show non-paternity with presumed biological father
- DCP may have less of a genetic relationship than expected with relatives
- DCP may match with other half-siblings







How Important is DNA?

Q&A

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