

# Ethics of Pediatric Fertility Preservation

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# Talk objectives

Identify and discuss ethical considerations for different pediatric fertility preservation (FP) populations

*No disclosures*

# General ethical considerations



- Autonomy: developing/future autonomy vs. best interest
- Beneficence: preserve potential for genetic children
- Nonmaleficence: minimize risks and harms
- Justice
  - Access and cost
  - FP vs. other medical treatments
  - Fair treatment for DSD and trans youth

# Case based approach

- Examine the unique ethical considerations for:
  - Cancer patients
  - Youth with disorders (differences) of sex development (DSD)
  - Transgender youth

# Collaborative publications

Volume 29, Number 4 *The Journal of Clinical Ethics* 261

Gwendolyn P. Quinn, Amani Sampson, and Lisa Campo-Engelstein. "Familial Discordance Regarding Fertility Preservation for a Transgender Teen: An Ethical Case Study." *The Journal of Clinical Ethics* 29, no. 4 (Winter 2018): 261-5.

## Features

### Familial Discordance Regarding Fertility Preservation for a Transgender Teen: An Ethical Case Study

Gwendolyn P. Quinn, Amani Sampson,  
and Lisa Campo-Engelstein

### Fertility Preservation for a Transgender Teenager

Leena Nahata, MD,<sup>a,b</sup> Lisa T. Campo-Engelstein, PhD,<sup>c</sup> Amy Tishelman, PhD,<sup>d,e</sup> Gwendolyn P. Quinn, PhD,<sup>f</sup> John D. Lantos, MD<sup>g</sup>

*The American Journal of Bioethics*, 12(6): 38-43, 2012  
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DOI: 10.1080/15265161.2012.673688

## Target Article

### Preserving the Right to Future Children: An Ethical Case Analysis

**Gwendolyn P. Quinn**, Moffitt Cancer Center, Health Outcomes and Behavior Program, and University of South Florida  
**Daniel K. Stearsman**, University of South Florida, College of Medicine  
**Lisa Campo-Engelstein**, Alden March Bioethics Institute, Albany Medical College  
**nevin Murphy**, Jonathan Jaques Children's Cancer Center, Miller Children's Hospital, HARBOR-UCLA

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Volume 4, Number 3, 2015  
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DOI: 10.1089/jayao.2014.0047

## Perspective

### Tough Talk: Discussing Fertility Preservation with Adolescents and Young Adults with Cancer

Angel Petropanagos, PhD,<sup>1</sup> and Lisa Campo-Engelstein, PhD<sup>2</sup>

### The Ethics of Fertility Preservation for Pediatric Patients With Differences (Disorders) of Sex Development


Lisa Campo-Engelstein,<sup>1</sup> Diane Chen,<sup>2,3</sup> Arlene B. Baratz,<sup>4</sup> Emilie K. Johnson,<sup>5,6</sup>  
and Courtney Finlayson<sup>7,8</sup>



*Pediatric and Adolescent Oncofertility*, pp 259-267 | [Cite as](#)

### Ethical Issues in Pediatric and Adolescent Fertility Preservation

Authors [Authors and affiliations](#)

Lisa Campo-Engelstein , Diane Chen

# 4 box method

**Medical Indications** - diagnosis, prognosis, treatment options, and goals of care

**Patient Preferences** - patient's values or best interests of patient

**Quality of Life** - improve, or at least address, quality of life for the patient

**Contextual Features** - social context including family, culture, religion, SES, hospital policy, law, finances, etc.

# Case 1: Oncofertility

# Case overview

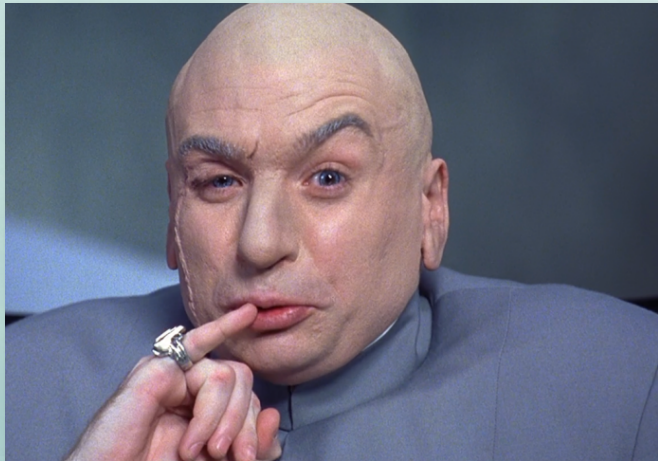
- Ben is 4 years old
- Brain tumor with poor prognosis
- Parents want FP
  - Testicular tissue





# Who decides?

- Ben can't consent, assent limited
- Parental paternalism justified



# Reasons for FP

- Open future
- Forgoing FP = sterilization?
  - Adoption difficult for cancer survivors
- Frozen hope



# Concerns with FP

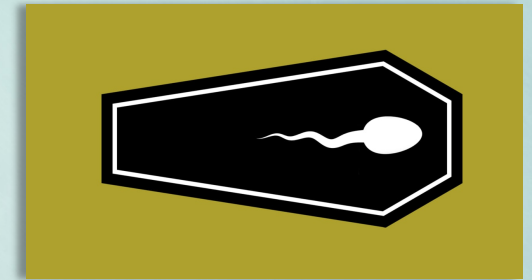


- Physical
- Psychological
- Experimental procedure
  - False hope
  - Conflict of interest



# Parental role and influence

- Gonadal tissue “belongs” to Ben
  - Destroyed or donated if he dies
- FP means genetic grandchildren expected
  - Parents devote time and money to expectations



# Prognosis

- When is the prognosis too poor for FP?
  - Discussing vs. providing FP



# Finances



Covered through clinical trial



Insurance coverage

# Moving forward

- Risk of infertility and prognosis
- Untangle Ben's and parents' interests
- Recognize family unit as “patient”



# Case 2: DSD fertility



# Case overview

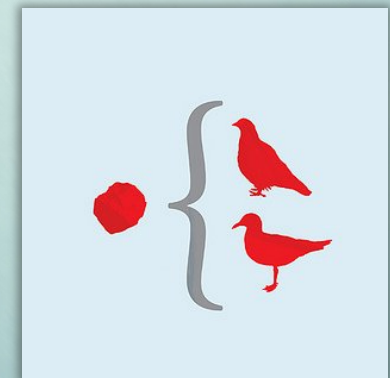
- Zoli is 13 years old and just began menarche
- Turner Syndrome
  - Diminished fertility
  - FP more likely successful at younger age
    - Egg freezing or ovarian tissue cryopreservation
- Her parents want FP
- Zoli is refusing FP



# Gonadectomy

## Reasons for

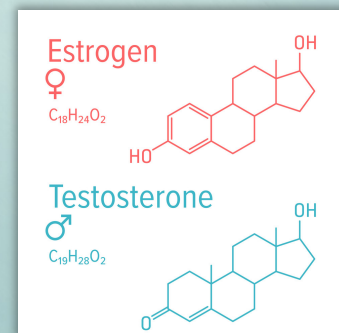
- Increased cancer risk
  - Difficult to monitor gonads
- Gonads lacking “purpose”
  - Not traditional hormone production and fertility
- Combine gonadectomy and FP



# Gonadectomy

## Medical reasons against

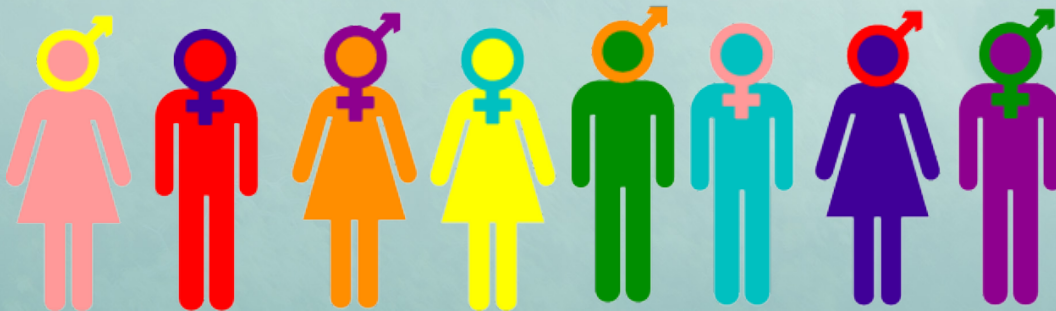
- Cancer risk varies among DSDs
- Surgery involves risk
- Preference for endogenous hormones



# Gonadectomy

## Ethical and psychosocial reasons against

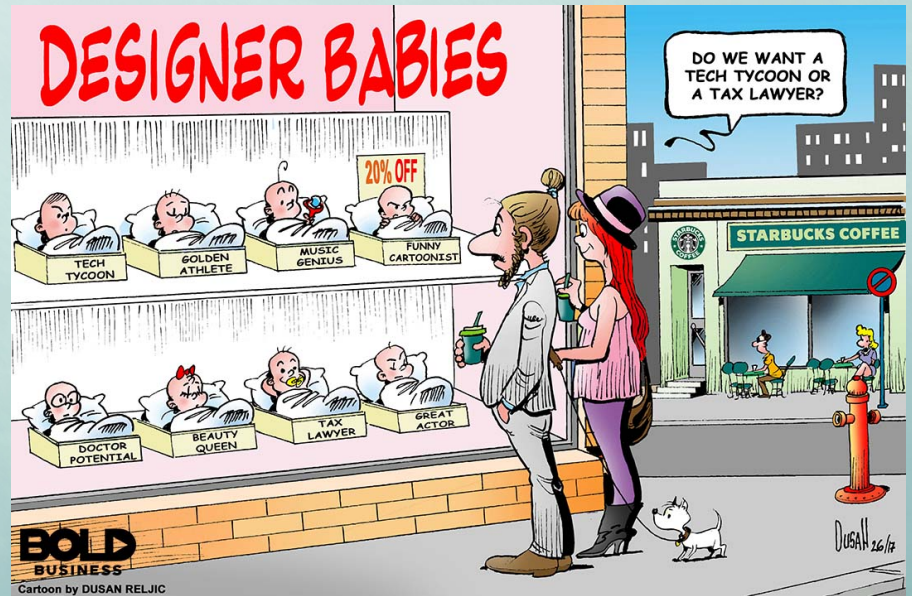
- Violation of autonomy
  - “Normalizing” surgeries for DSD
  - WHO and UN human rights violations
- Damage to gendered identity



# Passing condition onto children

## Concerns for future children

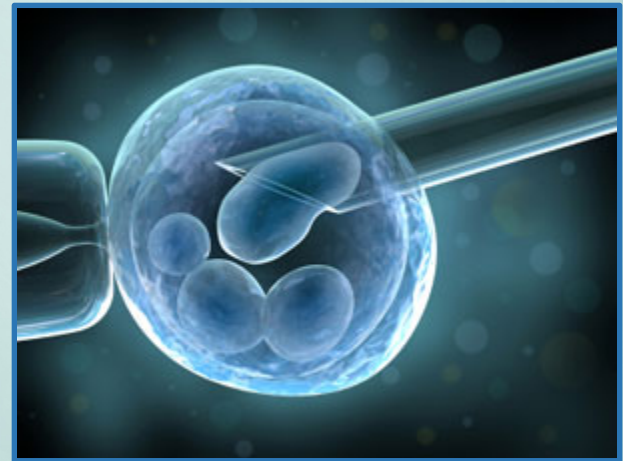
- Obligation to minimize harm and promote good
- Duty to have the “best” children



# Passing condition onto children

## Treatments

- Treatments for some medical conditions associated with DSDs
- Preimplantation genetic diagnosis



# Passing condition onto children

## Valuing DSD lives



- Devaluing disabled lives
- Adults with DSD reject label of disordered, diseased, or disabled

# Disagreement about FP

Who decides?

Parents' paternalistic beneficence

vs.

Zoli's reproductive autonomy





# Assent

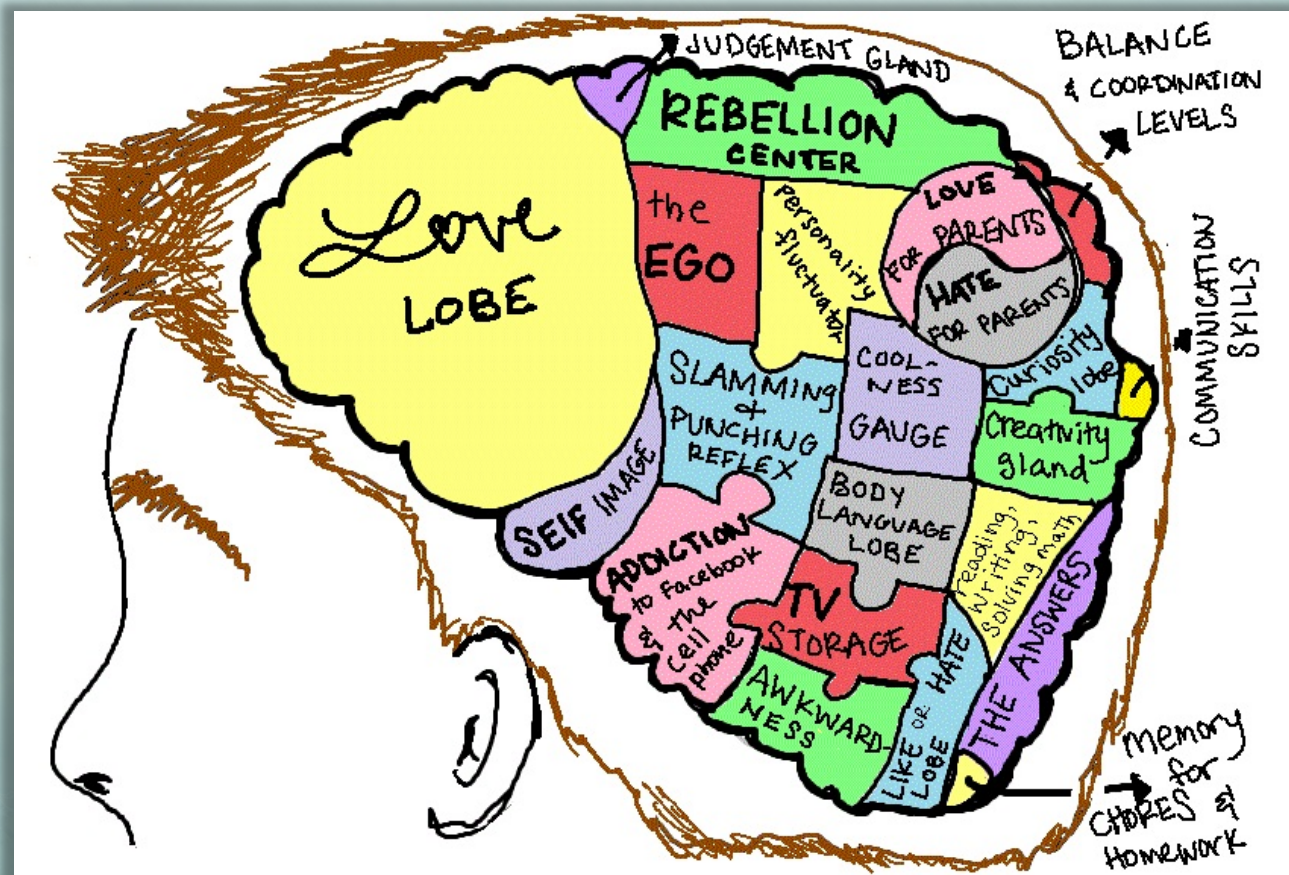
## Importance of involving Zoli

- Zoli cannot consent, but can assent
- Subjectivity of treatment
  - Reproduction as deeply personal



# Assent

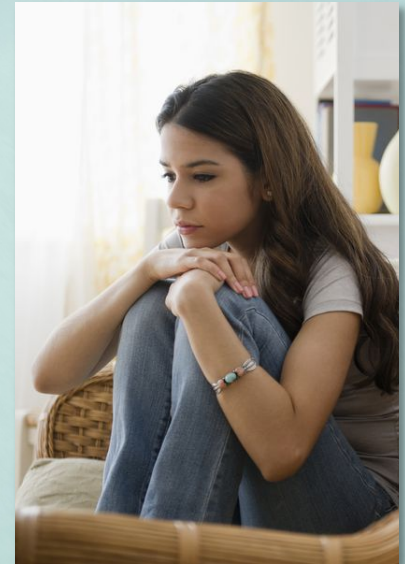
## Concerns with Zoli deciding



# Assent

## Concerns with Zoli deciding

- Reasons for refusal
  - Fear
  - Discomfort
- Not be able to predict her future wishes
- Not recognizing the potential significance of genetic reproduction
  - Most teens focused on pregnancy prevention



# Negative rights

- Right to bodily integrity
  - Almost absolute in medicine
- Logistics of forcing her



# Moving forward

- Conversations and even mediation
- If still refuses, don't force
  - Non-lifesaving treatment
  - Future opportunities for FP
  - Alternative family building



# Case 3: Trans fertility

# Case overview

- Jackie is 16 years old
- Assigned male at birth, identifies as female
- Has been on puberty blockers since age 9
- Eager to start hormones
  - Hormones will affect fertility



# Future parenthood

- Jackie is interested in FP
- Jackie is attracted to people who identify as female
- Jackie wants to have a genetic child with a future partner





# Jackie's parents

- Jackie's parents, Jane and John, are divorced
- Jane supports Jackie's choices
- John is concerned about Jackie going on hormones
- John believes FP is a waste of money



# Who decides?



- Jackie may be able to consent
- Jackie should be involved in gender affirming care and FP
  - Both decisions very personal
- Legal and logistical barriers to FP

# Positive rights



- Positive right to something
  - Entails duties from others
  - Limited in medicine
- There isn't a positive right to FP



# Parental consent

- In most states, minors need parental consent for hormones and FP
- Other reproductive services don't require parental consent



# Cost as a barrier

- FP expensive and is often not covered by insurance
  - Even supportive parents cannot afford FP
- No charity programs for FP for transgender individuals



# Paths to genetic parenthood

- Delay hormones until 18
  - Psychosocial cost of delaying puberty
- Seek emancipated minor status
- Go off hormone therapy as an adult
  - Effects of cross sex hormones on Jackie's future fertility



# Alternative family building

- High costs
- Discriminatory laws and policies



# How to move forward

- Providers want to be supportive of Jackie
- Providers may not want to encourage FP over John's objections
  - Minor, financial support, parental consent
- Ideally uphold Jackie's wishes





# Legal solutions for parental discord

- Mediation
- Neutral third party
- Divorce agreement
  - Jane may have the ultimate legal authority
  - Jane can appeal for final decision-making authority



# Final thoughts

- Various ethical considerations regarding FP for different pediatric populations
- Let's continue to explore them together!

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