

# Lessons Learnt From 10 Years of Linking

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# Collaborators

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# Outline: Lessons Learnt

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1. Program approach: Hope for the best, prepare for the worst
  - Prepare: Information & resources
2. Donor identity requests
  - Donor (& origins he represents) holds significance for donor-conceived adults
3. Donor-linked peer contact can be invaluable

# Linking at *One* US Open-Identity Program

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- Limited (25-65%) disclosure among heterosexual couple parents
- Limited ART regulation
- Voluntary: Program-dependent (>50%, dual-track)
  - Exception
    - The Sperm Bank of California (TSBC): all open-identity (recent)

# Open-Identity Donation: Different Origins

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1982 TSBC (nonprofit health collective)

- Same-sex female couples (60%) & singles (20-25%)

## DI for Different Needs

- Known donors not always available – info is impt
- Risks to parental rights (when no genetic ties)

Solution: Access to info, maybe the donor,  
Access for DC adults only

# Approach to Open-Identity Donation

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Hope for the best, prepare for the worst

- Provide donors & parents, later DC adults
  - Benefits & limits of future identifiability
  - Resources: info, community, Family Contact List (30%)

Expectations of stakeholders:

Release identity -----Add'l info -- Contact ----- Form relationship

# Identity Requests – TSBC Donors

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## In Program

- Implications of identity & contact info release

## Post-Program

- Contact & medical update
- Info: How to talk with family

## **1 Year Prior to Identity Requests**

- *Info, MHP consult & Request Update*
  - Personal & medical update
  - Contact openness & preferences

# Identity Requests – DC Adults

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Multi-step process (~1 month)

- Request in writing
- Review process w/ Alice Ruby (TSBC ED)
- Submit forms
- 2<sup>nd</sup> meeting
  - Donor update & openness to contact
  - Resources – info, FCL, MHP consult

To date: 185 releases completed



# DC Adult Interest – 1<sup>st</sup> Ten Years of Releases

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Requests from 33-40% families with a DC adult

- 68% of donors' identities released
- Most at age 18-19
- Motivated by access to origins, explore meaning of the link
- Family type differences: Gender
  - 70-75% of eligible women: 25-30% of eligible men from single mother or mother-father families
  - 49% of eligible women: 51% of eligible from two-mother families

# Releases by Family Type

- Fewer requests than expected, but

Parents	% of eligible adults who requested	Adolescents: % request at age 18
LBQ couples	37	58
Singles	58	73
Heterosexual couples	23	17

- Most intended to request some point
  - 25-30 year old requests begin
    - DNA testing impacting requests

# Plans to Contact Donor?

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- 75% planned to contact donor
  - Kept expectations low
  - Timing unclear

*Exploratory, conditional on Update*

“I think it will depend on how I feel at each stage. It will depend as it happens. [My] intention is to have at least one conversation...”

# Donor Openness

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- 91% donors open to contact from DC adults
  - Provided Updates
- 4 against contact or not reached
  - 2 provided contact prefs

## DC adult response

Considerable upset, disappointment

- Donor's significance
- Support: MHP & donor-linked peers

# DC Adult Feedback: Releases 2002 - 2014

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## 47 Interviews

- Release process
- Contacting donor
- Contacting donor-linked peers
- Outcomes

# Summary

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Open-identity donation is working

- DC adult & donor outcomes
  - Donors provide update, contact preferences
  - DC Adults
    - Experiences with donor
    - Experiences of release
    - Experiences with donor-linked peers
- Converging solutions from 2 different (regulated vs. unregulated) systems