PERSPECTIVES ON PARTICIPATION & RECRUITMENT IN HIV CURE-RELATED TRIALS

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A LOOK BACK ON LOST TIME…

1986-1996
"STAYING ALIVE"
SURVIVAL

TREATMENT-NAÏVE

1996-2014
"YOU GOTTA HAVE HAART"
ACCESS

2014 - present
"MISSION IMPOSSIBLE"

PERSONAL URGENT NEED

OTHERWISE HEALTHY

ALTRUISM

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ALTRUISM

Urgent Survival

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SELECTING PARTICIPANTS

PEOPLE LIVING WITH HIV WHO ARE INTERESTED IN CLINICAL TRIALS

People living with HIV who are interested in clinical trials.

I'm happy taking one pill every day, thank you very much! I have no need to get involved with cure research.

**PEOPLE LIVING WITH HIV WHO ARE INTERESTED IN CLINICAL TRIALS**

- Healthy on cART
- Those who stop cART

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PEOPLE LIVING WITH HIV WHO ARE INTERESTED IN CLINICAL TRIALS

healthy on cART

those who stop cART

on cART fail to suppress HIV

on cART incomplete immune recovery


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Inadequate engagement & education

Small #s of people

Limited time and resources

Misleading media

No consensus on ethical issues

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HOW WILL WE IDENTIFY OUR POZMONAUGHTS?
What Risks *Won’t* Be Taken?

**Personal Clinical Risks**
- Activation of genes that could cause cancer
- The possibility of drug resistance
- Toxicities/side effects

**Procedures**
- Spinal taps
- Bone marrow biopsies

**Side effects**
- Hair loss
- Vomiting

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Managing Expectations?

“I BEGAN TO BELIEVE I WAS CURED”

“JOHN’S STORY”

“I COULD DIE CURED”

“GARY’S STORY”

Watch the video of Gary’s story CURED / NOT CURED on defeatHIV’s YouTube channel

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...WHAT CAN WE DO?

- Fund Community Engagement
- Plan for early involvement & future access
- Document evidence-based approaches
- Reduce disparities in power
- Support effective community responses to HIV