

Discovering the Truth on Mental Health and Pregnancy for Women living with HIV using Educational Videos

Natalie Sanchez, MPH, Director UCLA Family AIDS Network Shellye Jones, LCSW, Clinical Supervisor Mariela Magaña Ceballos, Data and Quality Analyst

## Presenter Intros





#### Natalie Sanchez, MPH

- Creator/Producer/Writer of the award-winning telenovela webseries "Sin Vergüenza"
- >15 yrs working with Ryan White Programs



#### Shellye Jones, MSW, LCSW

- Social Worker, started 1st support group for women in Los Angeles with >30 yrs working in HIV/AIDS
- Directed/Produced 3 HIV/AIDS and PrEP related PSAs



#### Mariela Magaña Ceballos

- 6 yrs experience on Community Heath and Advocacy
- >5 yrs working with the WICY population



Population-Based Approaches for Improving Access, Engagement/Reengagement, and Health Outcomes

# Learning Objectives



- Identify UCLA Family AIDS Network health education videos as a resource that can be shared with women living with HIV at your agency.
- Describe new approaches to engage women living with HIV into mental health, prenatal, pregnancy and postnatal care.
- Discuss the importance of holistic and women-centered care for women living with HIV.

#### About Us

YEARS VIRTUAL 2020 NATIONAL RYAN WHITE CONFERENCE ON HIV CARE & TREATMENT

The Los Angeles Family AIDS Network (LAFAN) began in 1988 as a CHLA demonstration project with a focus on the needs of infants and children.

Originally called the Los Angeles Pediatric AIDS Network (LAPAN), in 1990, LAPAN received funding as one of the first Ryan White Care Act programs.

Longest existing provider network to be able to provide the medical care and psychosocial support services for women, infants, families and youth (WICY).

In 2015, UCLA acquired the Los Angeles Family AIDS Network and as a result, LAFAN continues to be a pillar in the community and a strong network of service providers.

LAFAN has been a leader in the coordination of family-centered care, providing culturally and linguistically appropriate services.

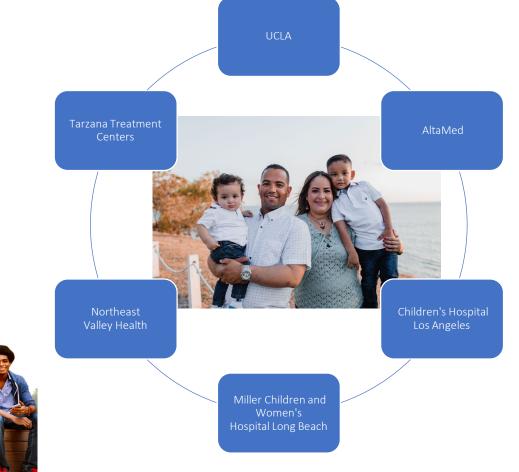


#### LOS ANGELES FAMILY AIDS NETWORK

# The Network











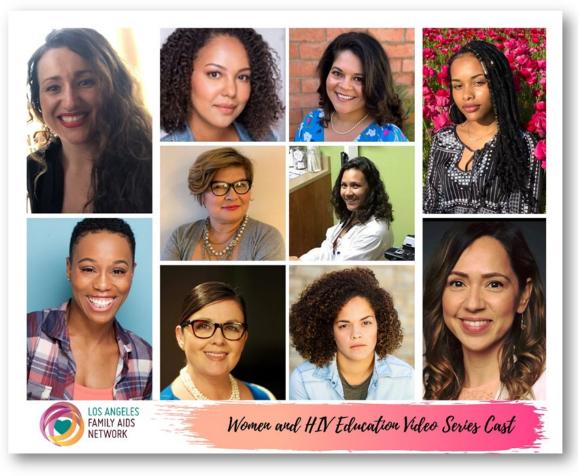
# Women Living with HIV/AIDS



- According to the CDC in 2016, 23% of people living with HIV in the United States were women. Ryan White Part D plays a vital role in the delivery and response to Women, Infant, Children and Youth living with HIV.
- In 2019, UCLA launched its Women and HIV Initiative that included the creation of a Women and HIV bilingual education video series.
- Videos were Funded through HRSA Ryan White Part D Carry Forward under PCN 16-02 Support Services: Health Education Category
- Using visual media to not only address health education, health literacy and treatment adherence, these videos provide an opportunity for women to receive additional medical, support services, and information while also addressing stigma and removing barriers to care.

# Women and HIV Initiative





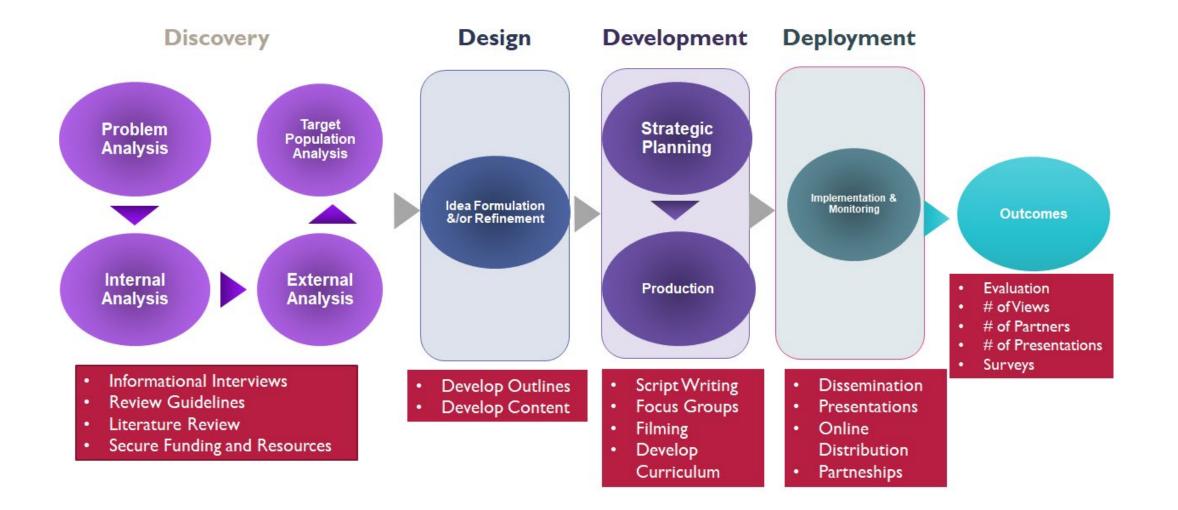
**Representation Matters** 



# Video Development

# Video Development





# **Consumer Engagement**



- Before Writing Video Scripts:
  - Five women were Interviewed
    - Shared their stories and medical journey
- After Writing Video Scripts:
  - Solicited Consumer Advisory Board feedback
- Studio Sneak Peak
  - Invited to filming days
- World AID's Day Videos Were Released
  - Consumers were asked to attend the event

## Focus Groups



Goal: Identify the theme and messaging of the educational video series that would most best illustrate the medical journey stories of our consumers and their provider relationship. Integrating qualitative data is vital to increase the authenticity of the videos story line.

## Focus Group Outcomes



#### • Recurring Themes:

- Providers are providing misleading information to patients
- Providers non-medical background influences the way they practice
- Interviewee's highlighted the need for more education on the intersection between a HIV/AIDS diagnosis, pregnancy and mental health
- The lack of social support throughout the patient's medical journey

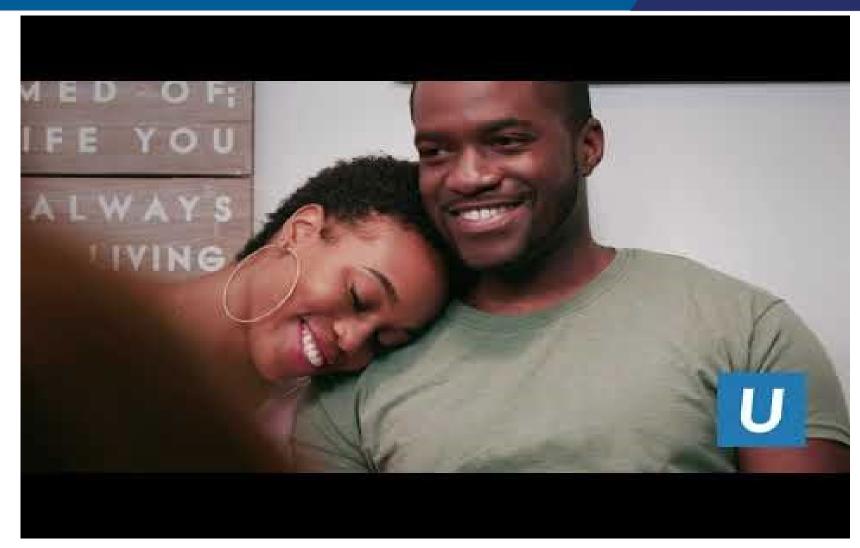
# The Power of Storytelling



- Helped patients through their healing process
- Helped strengthen their social circle
- Identified advocacy topics where they'd like to see change
- Planted a desire to mentor other women living with HIV/AIDS

# *Pregnancy and HIV: Discovering the Truth*





#### 5 Key Facts: Prevent Mother to Child Transmission

#### Pregnancy and HIV: Discovering the Truth presents five key facts

1) Achieving viral suppression is the key to preventing HIV infection to your baby.

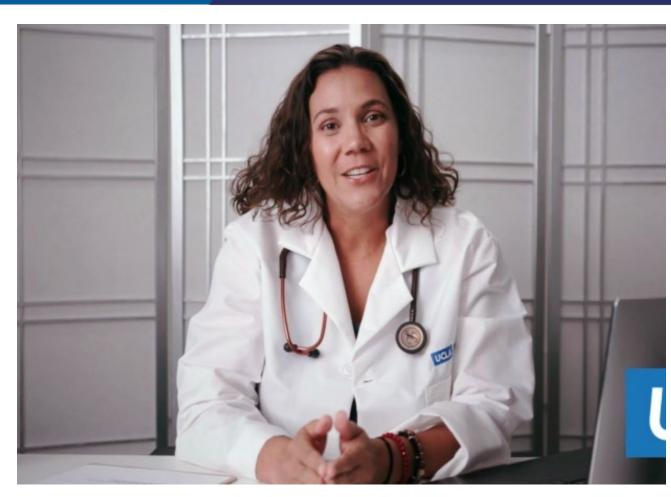
2) Receiving prenatal care with an OB/GYN and Pediatric team who specializes in prenatal care and deliveries for women living with HIV.

3) Communicate any challenges, stressors, or barriers you may experience during your pregnancy

4) Avoid alcohol, narcotics, vaping, other drugs including Marijuana, and non-prescription medications.

5) Breastfeeding is not recommended in the United States

#### **Undetectable = Untransmittable**





# How to use the Pregnancy video

- Contemplating Pregnancy
- Preparation/preconception visit
- As a conversation starter
- After visit summary
- Link to our website (LAFAN.org)

VIRTUAL

### How to Use the Pregnancy Videos (Consumers)

"If I wouldn't have been educated on how to prevent the transmission of HIV to my child, I wouldn't have decided to have a child." – Anonymous

"The social worker instilled in me that medication is like air that I needed to live, without air we can't live. Similar to fish, fish can't live without water."





VIRTUAL

### How to Use the Pregnancy Videos (Providers)



"Doctors don't think about the sentiments of the women, they treat us like if we were an old shoe." Anonymous

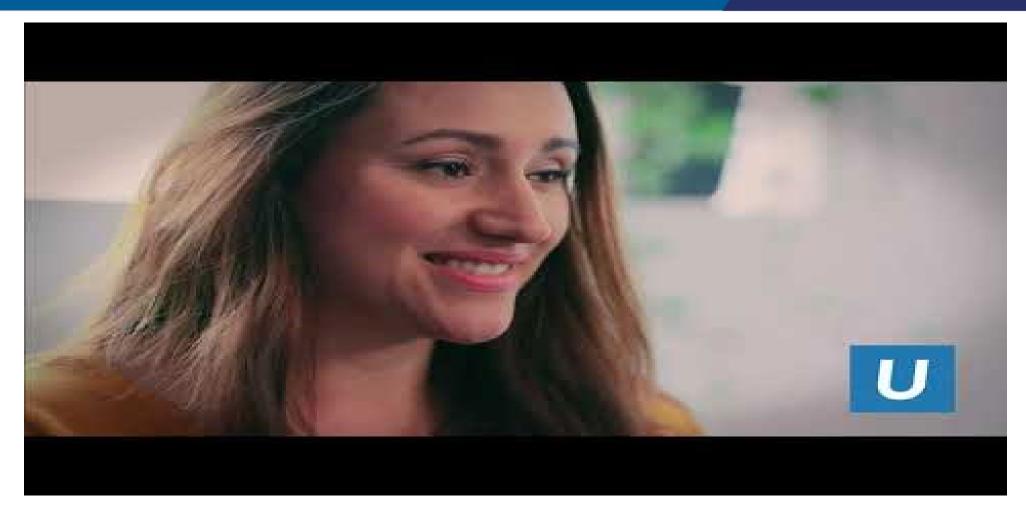
"The doctor suggested I get an abortion because I was HIV positive and was pregnant." – Anonymous

"It could have only been 2 men who transmitted the disease to me. The doctor has no right to label me as promiscuous." – Anonymous



### Breaking the Silence on Mental Health and HIV





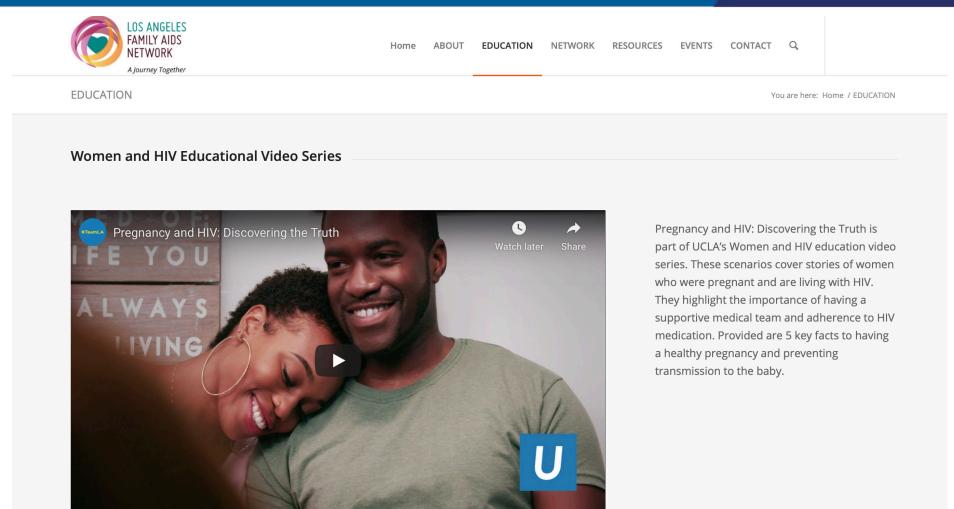
# Mental Health



• The first video, *Breaking the Silence on Mental Health and HIV*, highlights some of the common mental health challenges women living with HIV may encounter. By showing several scenarios depicting women seeking support, the videos seek to help break the silence on mental health by raising awareness and normalizing the process.

### Access English Videos: lafan.org/education/





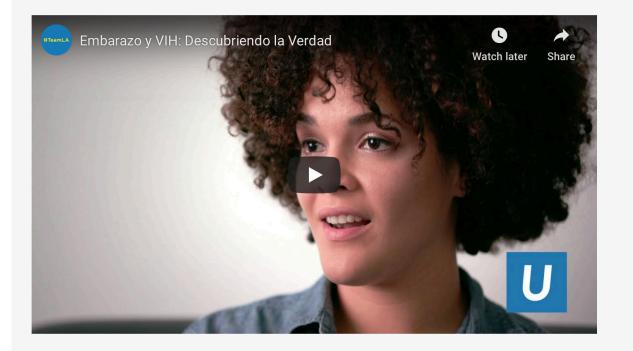
### Access Spanish Videos: lafan.org/education/





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#### SERIE DE VIDEOS EDUCATIVOS SOBRE EL VIH Y LA MUJER



Embarazo y VIH: Descubriendo la Verdad es parte de la serie de videos educativos de UCLA sobre Mujeres y el VIH. Estos escenarios cubren historias de mujeres que estaban embarazadas y que viven con el VIH. Destaca la importancia de contar con un equipo médico de apoyo y la adherencia a los medicamentos contra el VIH. Se proporcionan 5 datos clave para tener un embarazo saludable y prevenir la transmisión al bebé.

## The Use and Benefits of the Mental Health Videos



#### Utilization



- Conversation starter
- Normalize MH treatment and support
- Destigmatize therapy
- Reminder that help is available
- Refer to therapy

- Improve: medication adherence, job/school performance, and self esteem
- Become a better self-advocate
- Communicate more effectively and improve relationships with friends, co-workers, family
- Gift you give to yourself
- FEEL BETTER!!!!

# Possible barriers to accessing Mental Health (MH) Treatment



- Tough to ask for help
- May not know even know they need help
- Stigma around accessing MH services
- Never tried therapy/counseling
- Previous negative experience
- Never offered help
- Appointment wait time
- Insurance coverage/cost
- Getting matched with a culturally/linguistically competent provider
- Provider turn over



# Video Dissemination

## Integrating the MH and Pregnancy Videos

- Educational tool for clients, staff, providers and even yourself
- Played in waiting rooms
- Shared on social media
- Case Management Session
- Support Group
- Case Conference sessions
- Therapy session
- Community events
- Bilingual (English/Spanish)

VIRTUAL

# Video Community Premiere









# Video Community Premiere





### How to Use the Videos (Community)



"In the community there are no billboards, there is none on pregnant women living with HIV. No information in urban areas. That makes me feel like I don't have hope." – Anonymous



# Challenges



#### COVID- Telehealth Visit

#### • Access

- Internet
- Smart Phone
- Computer
- Private space

#### • Watching and Utilizing the Videos

- Provider Comfort
- Client Follow Through
- Projection
- Watching the Videos is not ENOUGH
  - Requires conversation, education, referral



# Thank You

Special Thanks to patients who shared their stories

Content Experts: Dr. Jaime Deville; Vanita Varma, NP; Dr. Aisling Murphy; Hilda Sandoval, PhD; Dr. Jessica Sims, Gabriela Leon

**HRSA Project Officer Nkem Osian** 

**Kavich-Reynolds Productions** 

Cast and Crew

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www.lafan.org

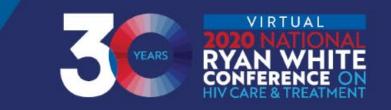




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# **Question and Answers**