The “Why, When and How To” of HIV Disclosure: Perspectives From the North and South

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The "Why, When and How To" of HIV disclosure: Perspectives from the North & South

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Disclosure:

- We have nothing to disclose.

Introduction

- HIV is a potentially life threatening, stigmatised and transmissible illness
- Burden among children, adolescents, and young people remains high esp in sSA
- Access/modalities of treatment have advanced over time
  - Currently “Treat all strategy” (UNAIDS 90 90 90)
- Disclosure of HIV status to children or adults to significant others is a challenge
- Impact of disclosure and nondisclosure; mixed results
- When, how to disclose to children & adolescents crucial to ART outcomes
- HIV disclosure to children/adolescents is a gradual process

AIDS

is a disease, no more, no less.

It is not symbolic of anything.

There are no victims, because there is

no crime. There are no innocents,

because there are no guilty. There is no blame,

because there has bee no intention to cause

harm. There are only sick men, women,

and children, all of whom need our help.

---Douglas Shenson, Feb 28, 1988

New York Times magazine

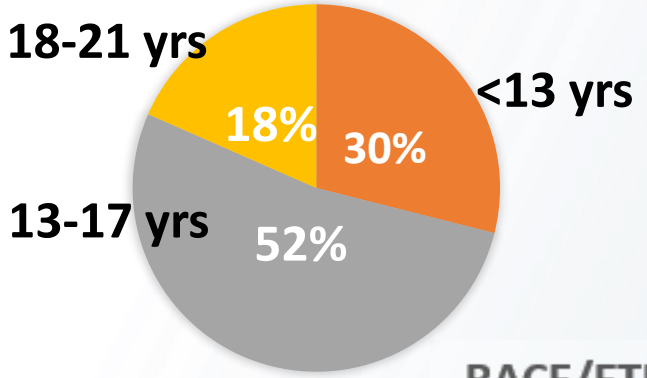
Pediatric HIV Programme Services

- Comprehensive HIV Medical Care
- Case Management
- Mental Health Services
- Transition Education/Planning to adult care
- HIV and Sexual Health Education
- Supportive services
- Child Sexual Assault and Needle stick nPEP

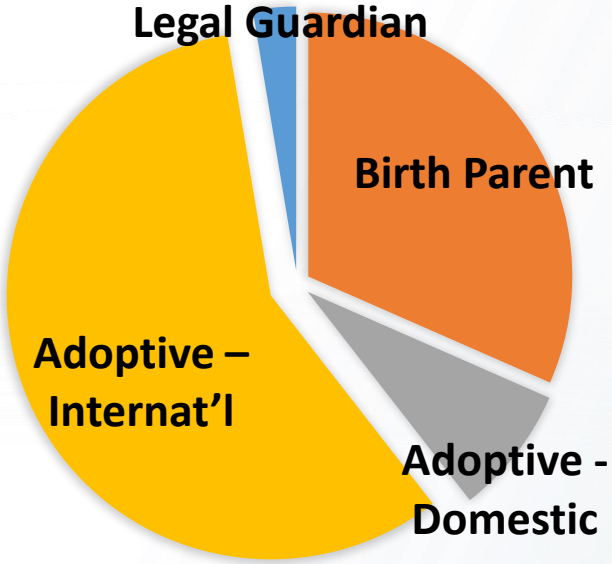
UCSF Benioff Children's Hospital Oakland

Pediatric HIV/AIDS Program

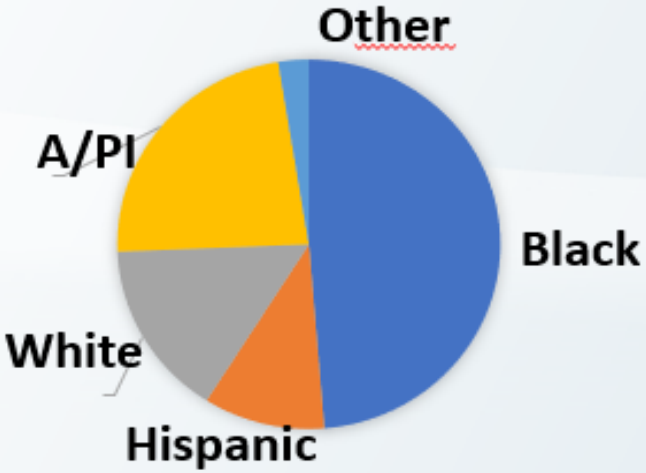
CURRENT PATIENT DEMOGRAPHICS



CAREGIVER



RACE/ETHNICITY



CURRENT PATIENTS SERVED

38 children/youth living with HIV

+10-15 exposed infants/year

+10-12 children/yr for sexual assault or needle stick exposures

OVERALL PATIENTS SERVED 1986-2020

Total: 1019

Infected but inactive: 277

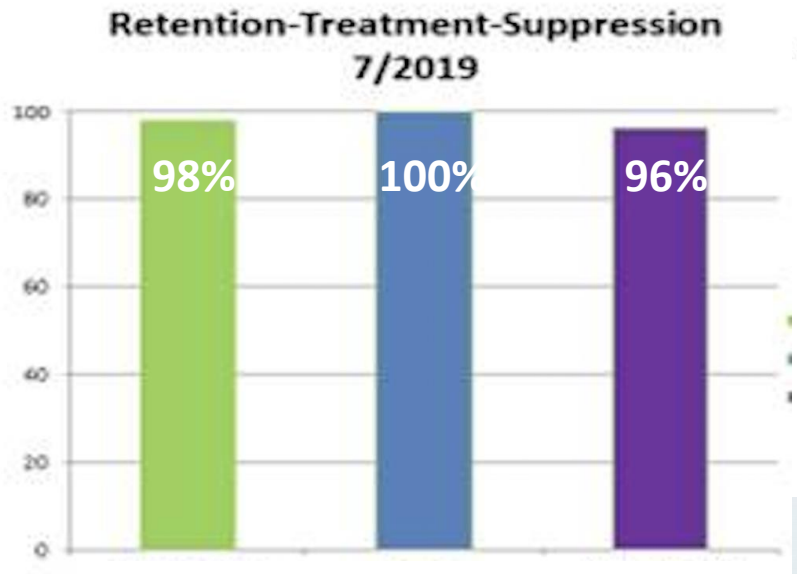
Known to have died: 62

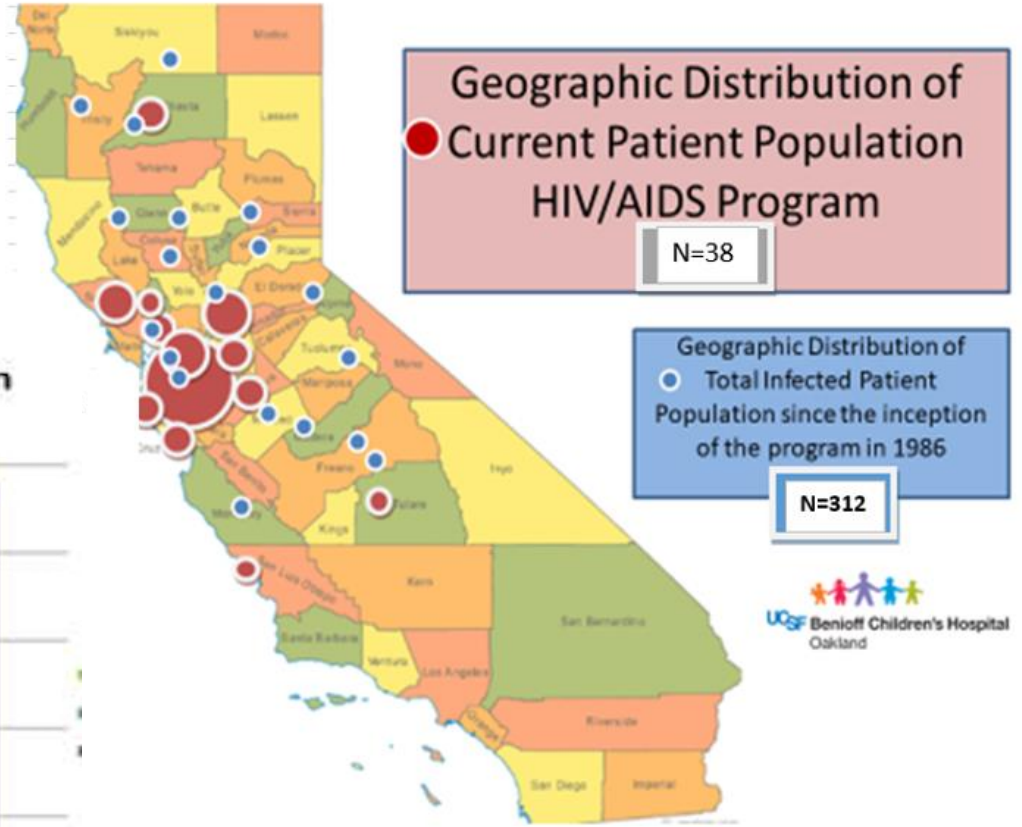
Exposed but uninfected infants: 694

Child Sexual Assaults/Needlesticks: nPEP = 217

CA: Children from 17 counties, up to 200 miles

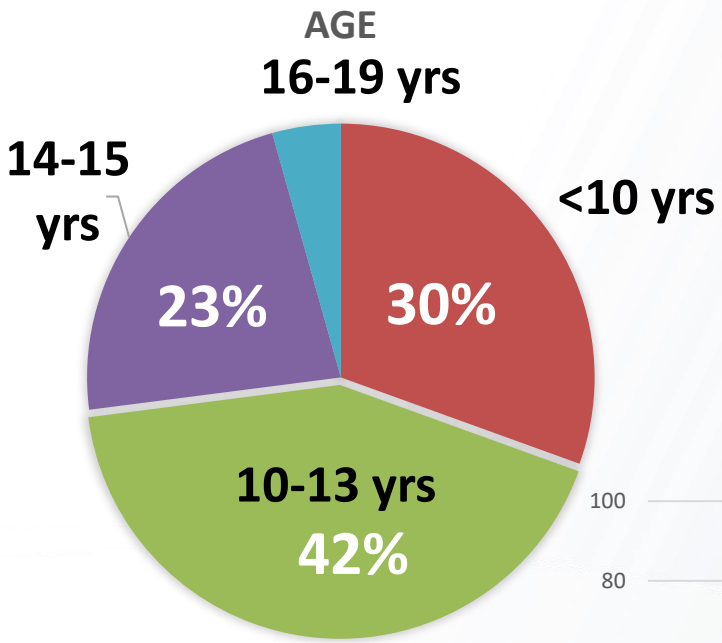
31 Int'l adoptees since 2006
22/38 current patients (58%)



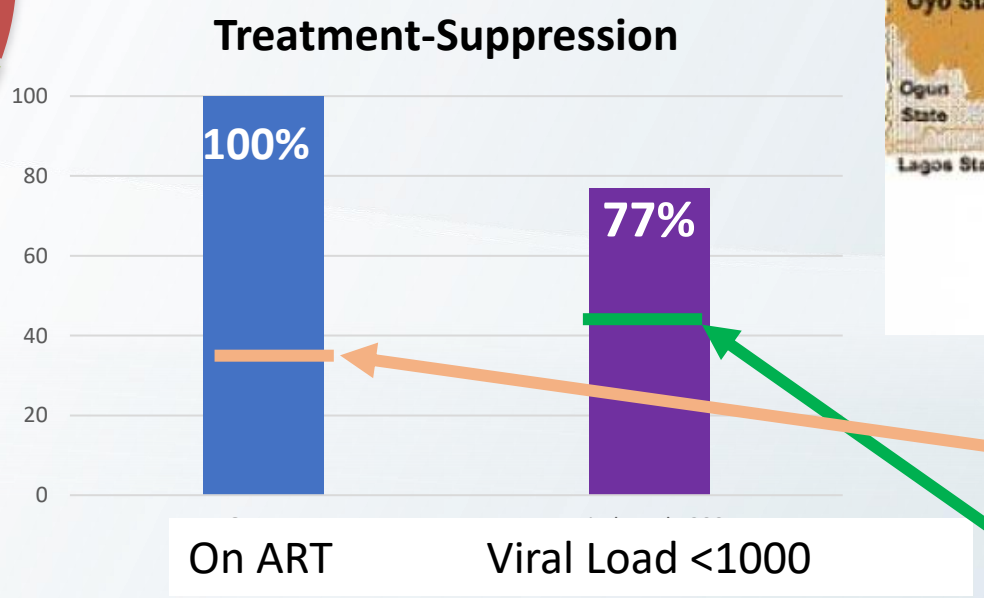


California population 40M

Overview UCH Paediatrics HIV Programme (2006 to date)



Total ever enrolled: **1214**
Total currently in care: **344**
No Transferred out: 289
No died: 119
No Lost to Follow up: 328



But for Nigeria, only 35% of children are on Rx and Only 42% of all are suppressed

Preferred Paediatric HIV ART Regimen

US (clinicalinfo.hiv.gov)

Age	Infants Birth-14 days	14 days to 3 ys	> 3 ys but < 25 kg	> 3 ys but >= 25 kg	> 12 y with SMR 1-3	> 12 y with SMR 4-5
Pref 1	2 NRTIs + NVP if < 2 kg	2 NRTIs + LPV/r if < 2 kg	2 NRTIs + ATV/r or BID DRV/r or RAL	2 NRTIs + DTG or EVG/c	2 NRTIs + BIC	Adult options
Pref 2	2 NRTIs + RAL if >2kg	2 NRTIs + RAL if >2kg				

Nigeria

Age	0- 6 yrs	6-10 yrs	10-19 yrs
Preferred Regimen	ABC/3TC/ LPV/r	ABC/3TC/DTG (if >30 kg) or ABC/3TC/EFV (If <30 kg)	TDF/3TC/ DTG

Big and Small Differences: North vs South

Criteria	South –Ibadan, Nigeria	North – Oakland, CA
Catchment Population	HIV programme decentralized Now within 100km and environs	Localized to largest cities Ethnic, racial diversity Adoptive & biological families
Social Support	Immediate family mainly , some extended family (↑stigma)	Broad, most extended family members 'know' diagnosis
Socio-economic criteria	Across all classes. 1/3 orphans Primary caregivers grandparents	Mixed, adoptive homes better off Most parents work
Health Literacy	Poor for >50%	Excellent for >>50% of parents; poor for ~10%.
Community Education/ Acceptance	High level of stigma	Very knowledgeable, accepting Some big challenges
Government / Community support	Government welfare support poor, Users fees recently abolished for children; ARVs only are free	US Gov't funds; state insurance for the poor; some private insurance. Nothing "free." Some transportation help
Oversight	Fed Govt + partner (APIN-PEPFAR)	Minimal; 'rare' dx in kids; Local collab

HIV Disclosure in Children/Adolescents: Questions to ponder

- There are challenges, barriers, negative & positive consequences of disclosure:
  1. Should parents disclose HIV status to their children/Adolescents?
  2. Should adolescents disclose their HIV status to parents, family members, teachers, friends, sexual partners and others?

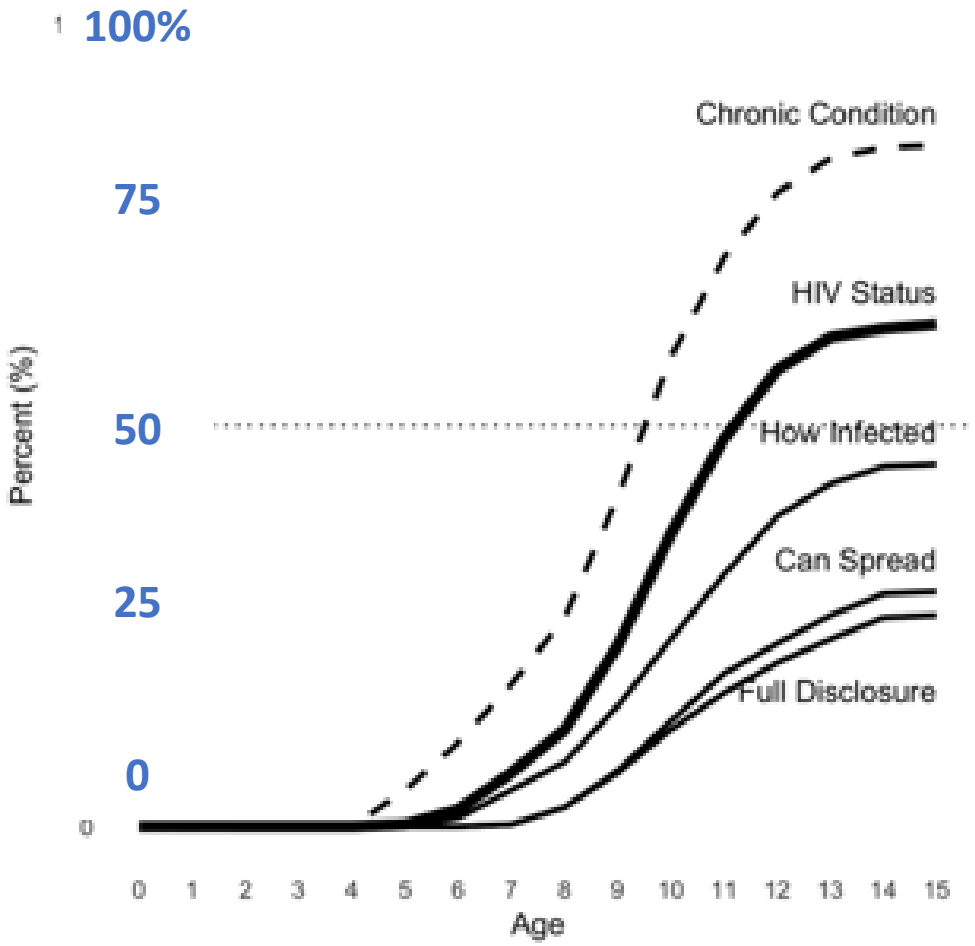
- **Why, When & How?**

Rates of HIV disclosure to children/adolescents:

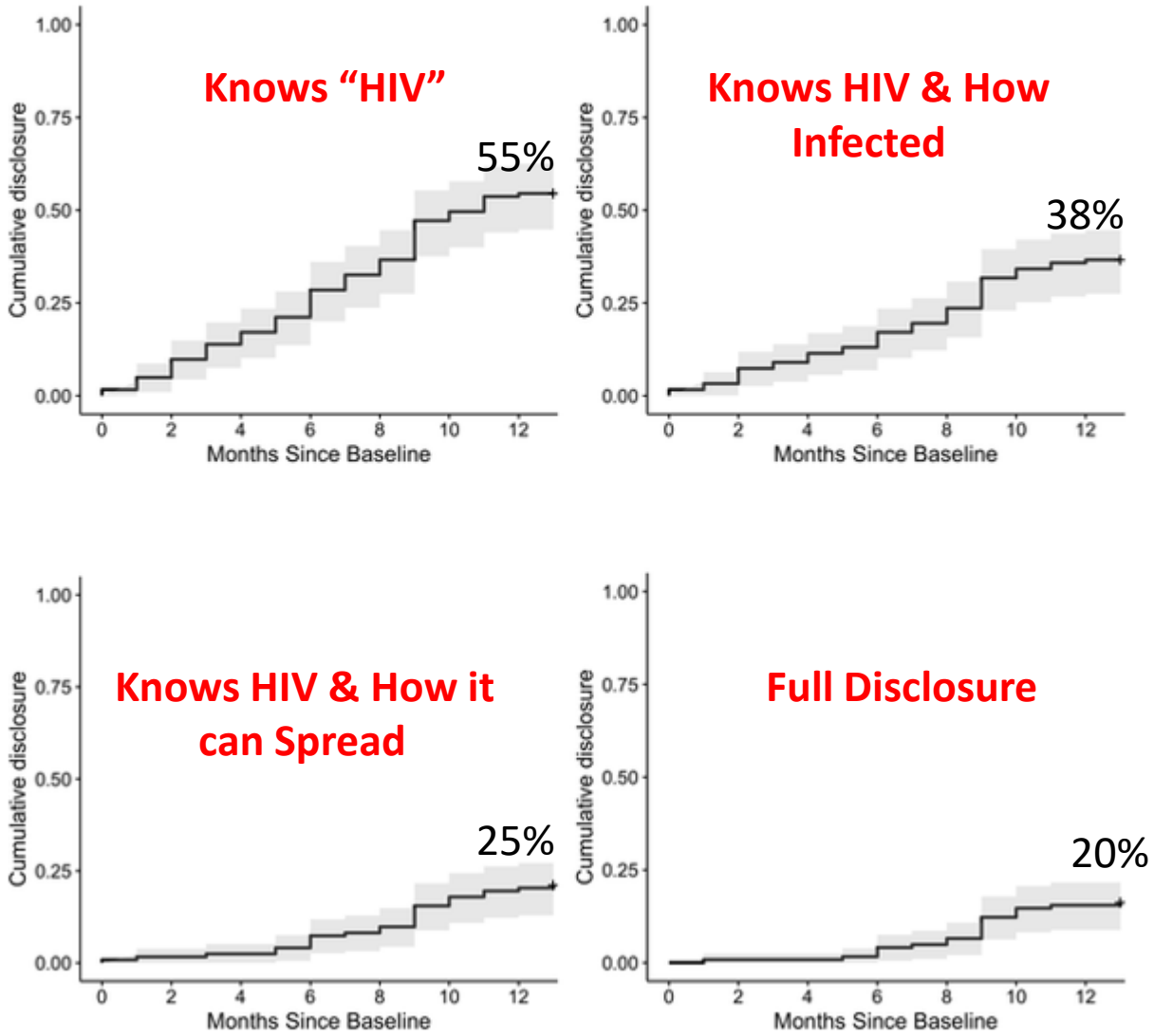
Country (year)	Target population	Disclosure Rate
USA (2002)	6-18 yrs	43%
Zambia (2007)	11-15 yrs	48/127 (37.8%)
Nigeria (2011, UCH)	> 6 yrs	13/96 (13.5%)
Nigeria (2018, UCH)	6-17 ys	54/200 (27%)
Ghana (2018)	6-17 ys	24/103 (23%)
Tanzania (2018)	6-17 ys	102/309 (33%)
Oakland, CA, US (2020)	6-18 ys	26/36 (72%)

Zimbabwe data (2019):

Cumulative distribution of HIV knowledge by age:



During a 12-month period of 'disclosure process'



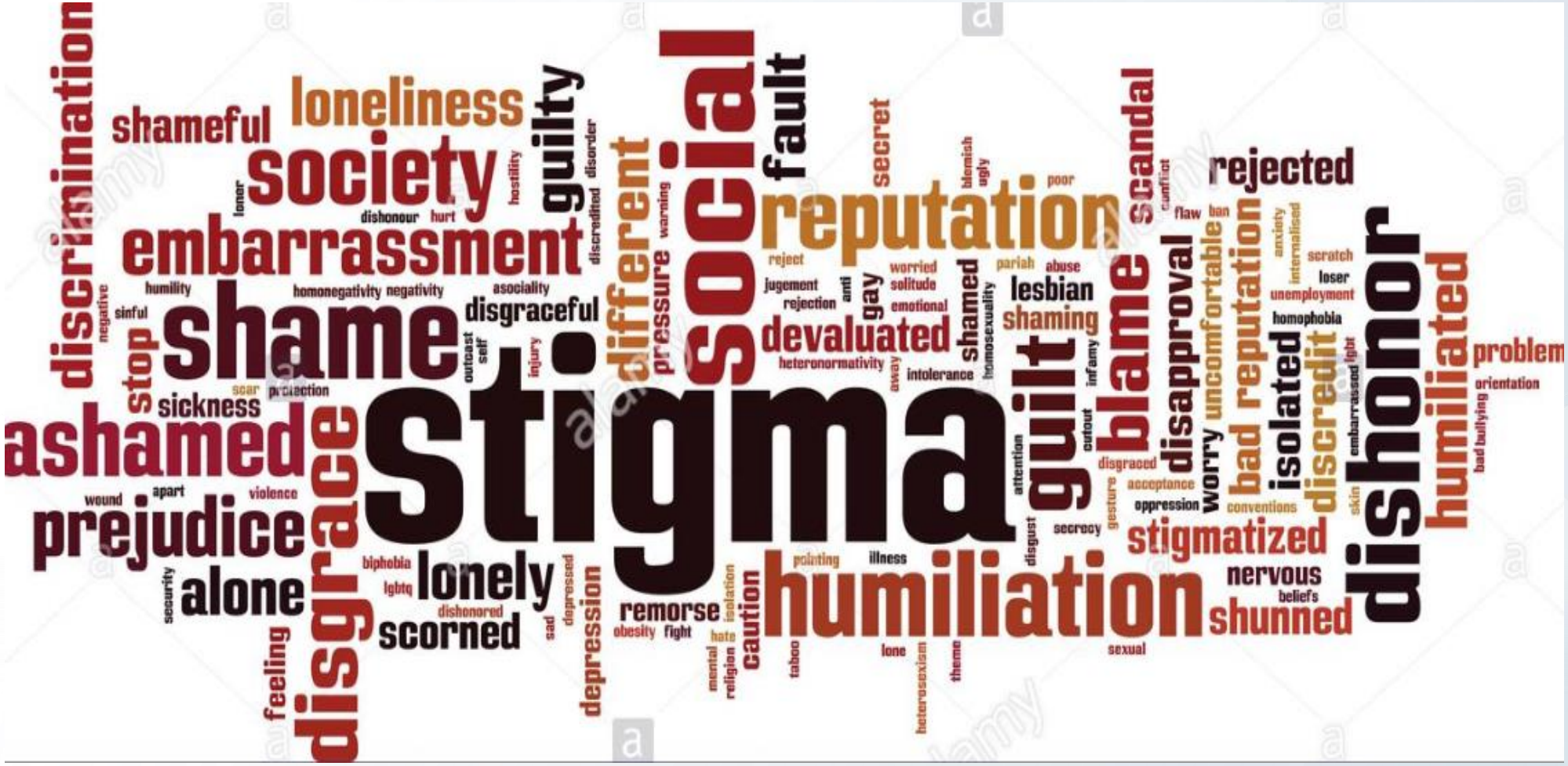
Disclosure of child's HIV status to significant others

- Extended family members in 128/200 (64%)
- Siblings in 33 (21.4 %) of the 154 with siblings
- Family spiritual leaders in 28 (14%)
- Teachers in 3 (1.5%) of 197 children in school

Nwoyeocha et al, *Afr. J. Biomed. Res. 2020*

Disclosure: Why Not?

What stops people from disclosing or delay disclosure?



Reasons for non-disclosure to children by caregivers (Brown et al, 2011)

Reasons*	Number	Percentage
Child too young to understand	53	63.9
Fear of disclosure to other children	34	41.0
Fear of disclosure to family and friends	28	33.7
Fear of psychological disturbance in children	26	31.3
Fear of blaming parents	22	26.5
Fear of refusal of drugs	10	12.0

*Multiple response.

Negative consequences of disclosure to significant others

- Abandonment
  - Parental separation; domestic abuse, father abandoning children and their mother
- Fear of disclosure beyond family circle → Stigmatization
  - In neighborhood, school, church, extended family

- Enabling factors
  - Family function, cultural context
  - Intellectual capacity of both parents and children
  - Support system for parents

Disclosure: Why? Benefits outweigh the risks!

Positive ART outcomes associated with disclosure

- Adults
  - Disclosure was associated with linkage to care and improved ART adherence (Hatcher 2012)
  - Nondisclosure associated with virologic failure at 48 weeks (Chepkurui 2012)
- Children (Wiener et al, 2007, Bulali et al)
  - Promotion of trust, improved adherence, enhanced access to support services, open family communication, and better long-term health and emotional well-being in children
  - Improved QoL

Does disclosure result in improved retention in care, adherence and virological outcomes?

- Adherence
  - HIV status disclosure significantly improved adherence to treatment among children living with HIV/AIDS (Bulali et al, Menon et al)
- Retention in care (Vreeman et al)
- Virologic suppression
  - 79.4% suppressed if disclosed vs 40.6% if undisclosed (Okechukwu et al, 2018)

HIV disclosure: The process…

- When should HIV disclosure take place?
- What factors affect disclosure?
- What is the best way to support caregivers to disclose the HIV status effectively to children & adolescents?
- What is the process of carrying out disclosure in children/adolescents?

Guidelines for HIV disclosure

Guidelines are available for assisting parents and providers to make decisions about disclosure

- WHO: “Guideline on HIV disclosure counselling for children up to 12 years of age” 2011
- Elizabeth Glaser Pediatric AIDS Foundation. *Disclosure of Pediatric and Adolescent HIV Status Toolkit. 2018*
- Visual aids for disclosure: (see Appendix 1)
- Consider some child/adolescent specific and caregiver factors import in HIV disclosure (See Appendix 2)

Disclosure: When?:

- Starts as early as child is asking questions: Partial to full disclosure
- Readiness for disclosure:
  - Child's cognitive ability, developmental stage, HIV clinical status and social circumstances are to be considered
- Age range/cut-off: Variable
  - Disclosure must occur before transition to adult programmes!

Source	Partial disclosure	Full disclosure
WHO	**6-12 yrs**	**12 yrs**
Zambia	**5-7 yrs**	**7+ yrs**
Uganda	**-**	**12 yrs**
AAP (Eliz Glaser PAF)	**School age (6?)**	**10-12 yrs**
USA (Budhwani et al)	**10-12 yrs**	

Disclosure: How?

Practical steps in HIV disclosure

- Children & Adolescents eligible for disclosure to be identified
- Develop/adapt disclosure guide
  - Age, cognitive ability, developmental stage, social circumstances to be considered (See Appendix 1)
  - Disclosure tools adapted (See example in Appendix 2)
- Disclosure committee/focal person identified
- Assess readiness for disclosure
  - Disclosure readiness checklist (e.g Elizabeth Glaser tool kit)

Modalities for disclosure: Who?

- Who discloses to the HIV infected child:
  - Primary caregiver
    - Biological/adoptive mother + Healthcare worker support
  - Healthcare worker
- And the newly diagnosed adolescent?
  - To be guided in disclosing to others

Post disclosure

- Document clients successfully disclosed
- Must monitor & evaluate disclosure and its effects
- Remember to repeat/reinforce the information
- Support newly disclosed children/adolescents and their families
  - Check on family/peer relationships, support, interests, activities, mood, behavior
- For adolescents
  - Separate adolescent/youth clinic days at HIV Clinics, if feasible
  - Work on peer led strategies: Operation Triple Zero (OTZ), Getting To Zero (GTZ)

Appendix 1:
Disclosure tidbits for the Child/Adolescent HIV Healthcare Provider by Dr. Ann Petru

Disclosure is a process, not a moment in time

- Age dependent, “pre-diagnosis”:
  - Most parents don’t intentionally tell children ”HIV” until 8-10 years old or older
  - Others use “HIV” openly, but don’t explain what it means.
  - Young children just need to know that:
    - Taking medication is **required**, it’s not a choice
    - Medications keep children healthy
    - Many people need medications for all sorts of health issues
- Developmental considerations
  - Some children are quite delayed
    - HIV-related disabilities/morbidity
    - Other factors affecting development
      - Maternal alcohol, drug use, infections in pregnancy
      - Malnutrition
      - Concurrent/untreated infections
    - Emotional trauma in early childhood
      - Parental, family losses, death
      - Abandonment
      - Attachment disorders
      - Housing and food insecurities

Disclosure is a process, not a moment in time

- Family dependent
  - Biological Parents
    - Secrecy within the family
    - Guilt or shame about their own HIV
    - Fear of explaining transmission
    - Fear of blame, rejection, withdrawal
    - Thus, often delay disclosure
    - Benefit mainly from help in disclosing
  - Adoptive parents:
    - More comfortable disclosing
    - Less/no guilt or shame; fewer burdens
    - But equal fear about how the child might handle the information
- Private vs 'public' issue within family & community
  - Desire to 'contain' the diagnosis
  - Fear of rejection by siblings & others in the family
  - "Spoiling" the infected child and triggering jealousies within family
  - Fear of community response if the diagnosis is disclosed to friends, neighbors, church, school, employers
  - Child's ability to contain information and remember 'who knows' and 'who doesn't know'

Disclosure is a process, not a moment in time

- School and societal issues
  - How well is community educated?
  - Does school have rules about disclosure, if the teacher finds out?
  - Do meds have to be given at school (which might change everything)?
  - Are teachers educated and kept up-to-date about transmission, prognosis, and reasonable expectations of children with HIV?
- So what triggers parents to choose to disclose to children?
  - Challenges getting children to comply with medications
  - Questions about why they have to take meds, while others don't
  - Time-sensitive events (e.g., prior to going to camp)
  - Inadvertent disclosures by others
  - Prior to adolescence and interest in intimate relations!

What do “HIV” and “AIDS” imply for people?

- For children vs for adults:
  - No meaning or ‘charge’ for some children until it has a name
  - What does it mean to have “HIV”?
  - Others may known “AIDS”=“death”
  - Access to care and to medications?
  - Isolation, abandonment… death?
  - Ability to work, relate, grow?
  - Some only know “take your medications or you will die”
  - Family: ostracization?
- For adopted children from dire circumstances:
  - First abandonment that resulted in living in an orphanage
  - Memories of moving, hiding, keeping diagnosis secret when “HIV Orphanages” had to move abruptly if neighbors found out their diagnoses
  - Children with HIV having to care for other children with HIV because adults were afraid to touch them.
  - Fear of rejection/abandonment (again)

So how do you start telling the story?

- “You’ve been coming to this clinic since you were very little….”
- You’ve been taking medicines and are doing so well.
- You’ve asked why you take your medicines…
- Your parents think you are old enough to understand more…
- Your parent/s were so excited to have a little baby when you were born. You were their perfect baby!
- But when you were a little older, they learned that you had a big problem in your little body… because you (were sick) or (had a blood test that told us there was something wrong).
- So we did more blood tests and discovered what happened and we know how to treat you!
- Do you have any idea what you have?...
- What does that mean to you?
- Are you ready for more?

So, now what? It has a name…

- Help the child understand who in family knows and who doesn't
- Allow the child space to disclose to someone who is 'safe'
- See what comes up for the family between visits
- Always open for new questions
- Build on knowledge each time
- Reinforce/praise good patterns
- Teach to track lab results
- Gradually build independence
- Knowing names of medications
- How many pills?
- When do they take them?
- How do they obtain refills in time, so they never run out?
- Importance of maintaining contact with providers, regular lab tests
- Build towards safe disclosure to partners

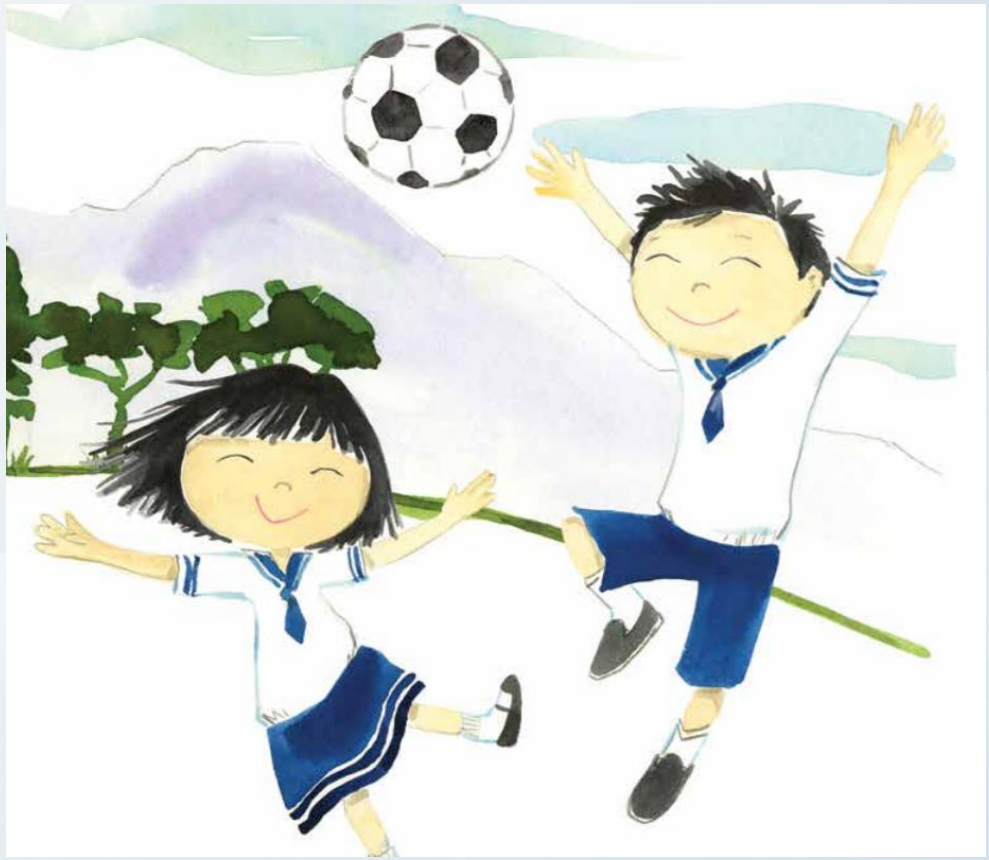
And what about adolescents with new dx?

- Not too different but with a bit more sophisticated discussion
- Provide direct and clear info
- Don’t presume they understand anything accurate about HIV
- Encourage them to disclose to a trusted close relative or friend
- Practice that disclosure before talking to a sexual partner
- Offer to help with disclosure to partners through public health or community health outreach workers, local agencies
- Provide psych support
- Assess readiness for medications
- Frequent follow-up in first few years (every 6-12 weeks)
- Consider group support options

Remember to repeat the information often

- Children will gradually need to build on their knowledge and understanding of HIV.
- As they get older, they may not remember what was said before.
- Developmental stages are critical:
  - One 16 yo boy, 2-3 years after “disclosure”, “You mean I have HIV?”
  - One 16 yo teen, whose parents refused to disclose to him, said to a nurse when she spilled some blood, whispered to her, “Be careful, I have HIV”

Look for resources to help normalize life for children, despite their HIV diagnosis.



Appendix 2

Visual aids for disclosure

(Courtesy of Dr. Ann Petru)

What does HIV stand for?

- H = HUMAN
- I = IMMUNODEFICIENT

  (NOT ENOUGH PROTECTION FROM DISEASES)
- V = VIRUS

  (A GERM)

A - Acquired

I - Immune

D - Deficiency

S - Syndrome

Lots of different germs can make people sick

These are really, really tiny… You can't see them without a special microscope

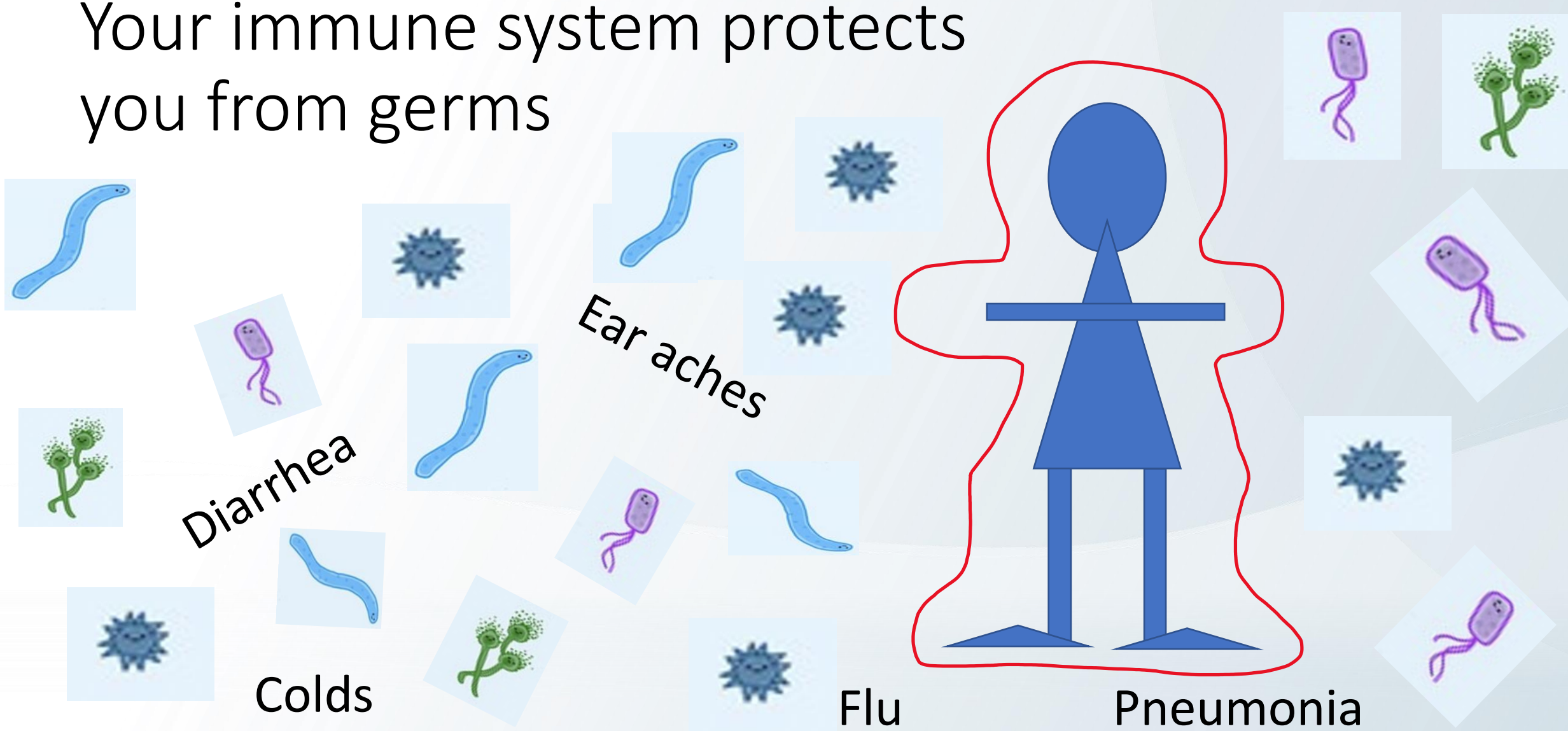
Parasites (worms)

Fungi (rashes)

Bacteria (ear aches)

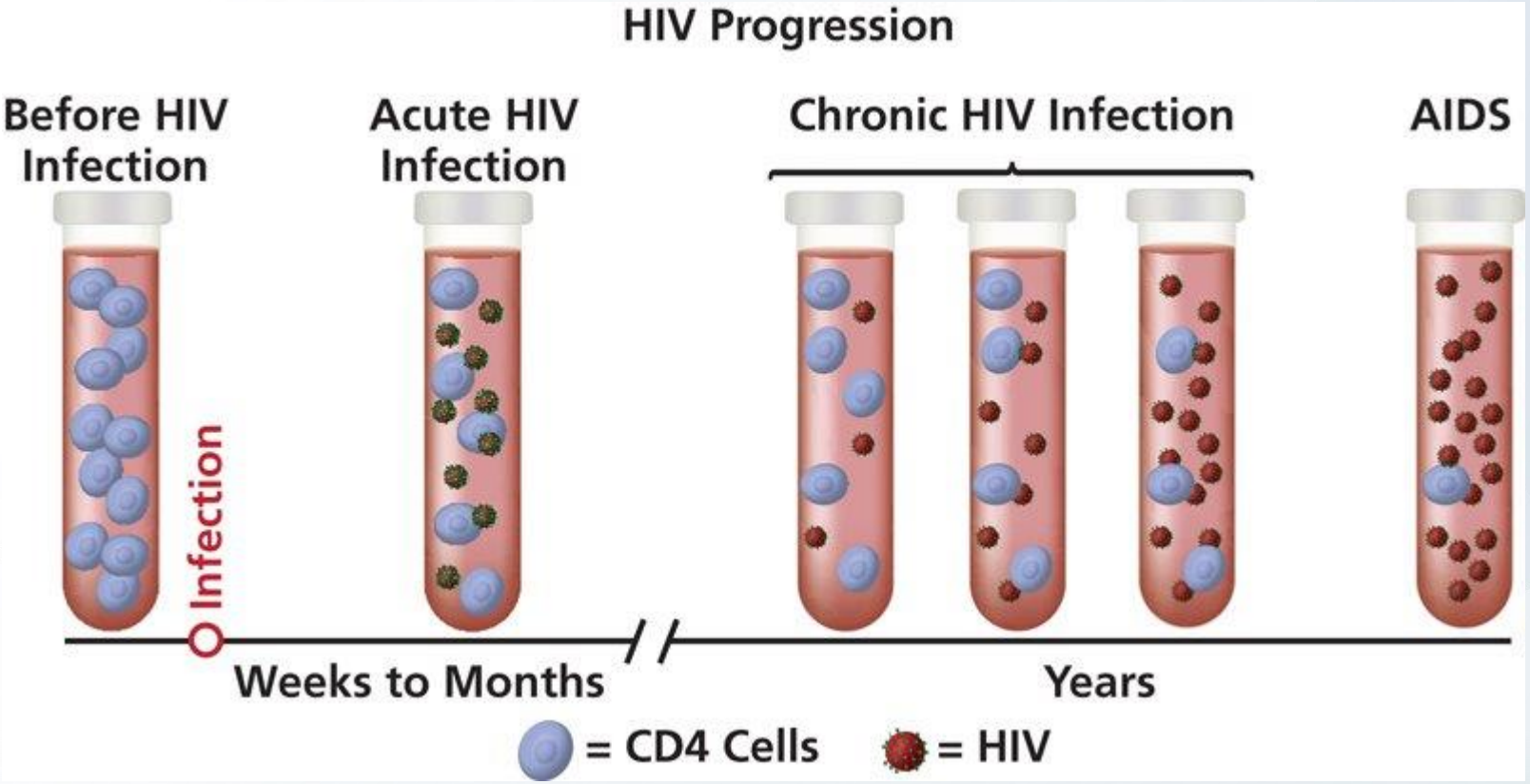
Viruses (colds & flu)

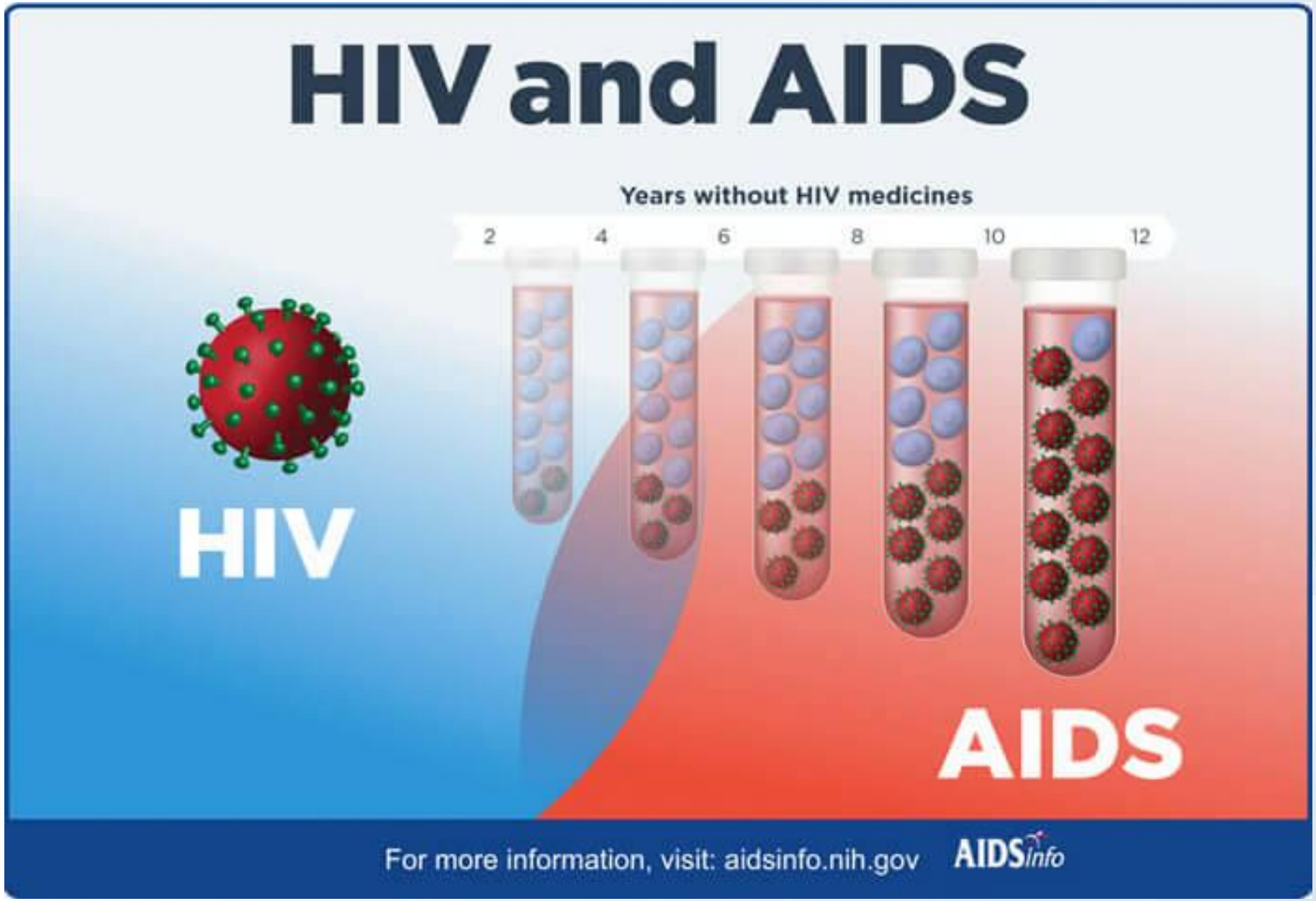
Your immune system protects you from germs



These green “T-cells” or “CD4-cells” are part of the immune system, trying to protect you, but HIV can destroy them.

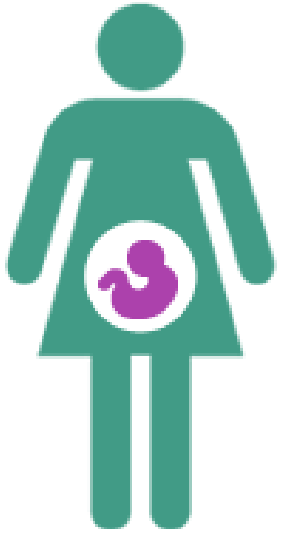
When you take medicines, your T-cells rise and protect you; the virus is better controlled. You want LOTS of T-cells and VERY LITTLE virus (HIV)


HIV Progression
Before HIV Infection
Acute HIV Infection
Chronic HIV Infection
AIDS
Infection
Weeks to Months
Years
= CD4 Cells
= HIV

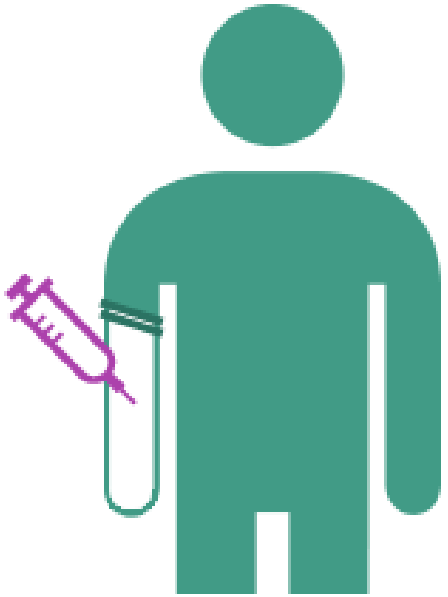

HIV and AIDS
Years without HIV medicines
2
4
6
8
10
12
HIV
AIDS
For more information, visit: aidsinfo.nih.gov
AIDSinfo

YOU CAN GET HIV VIA...

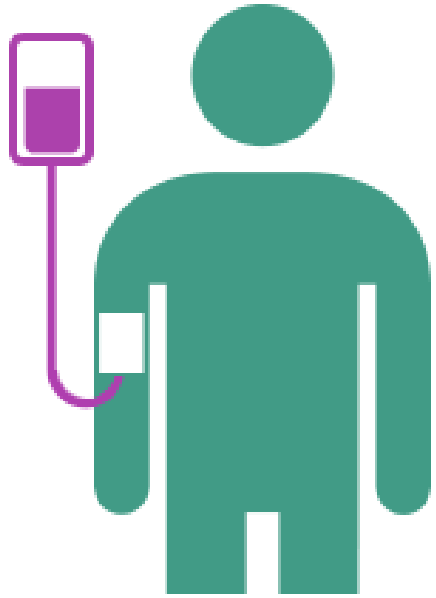
Sex without a condom



Passed from mother to baby



Sharing injecting equipment



Contaminated blood transfusions & organ transplants

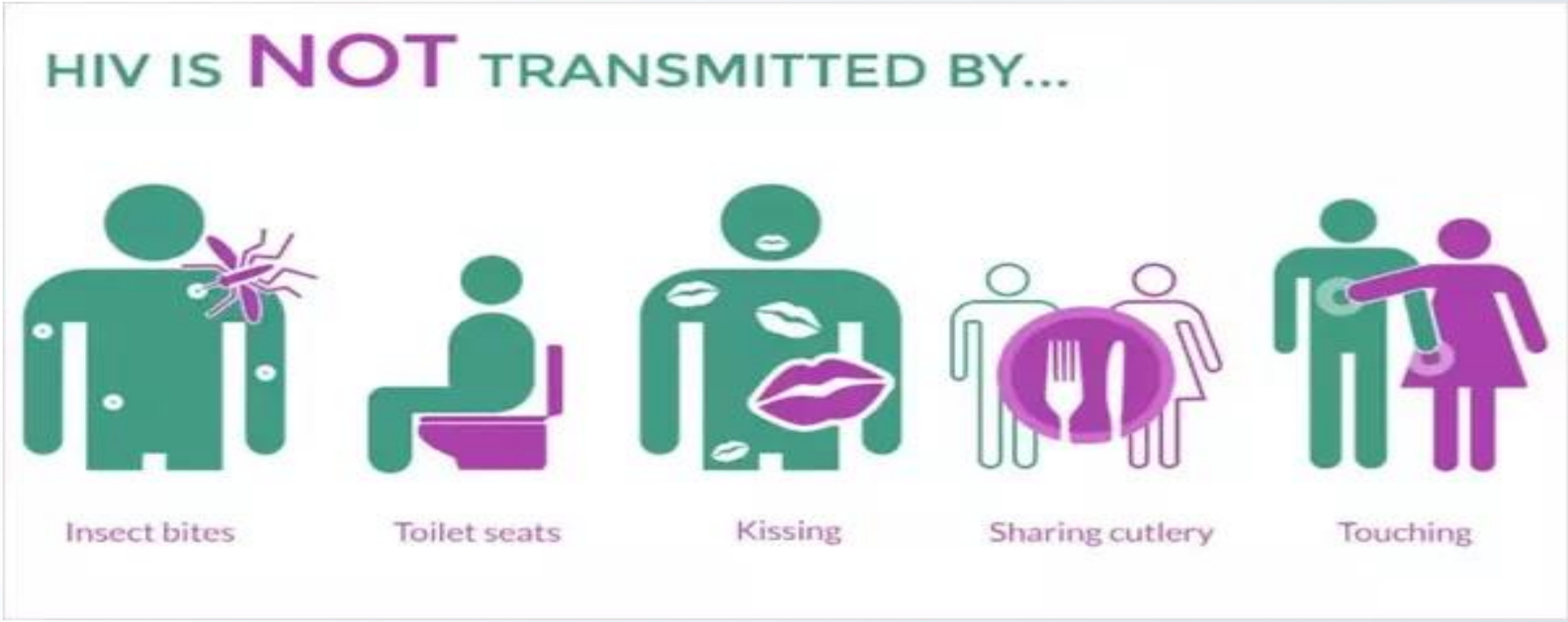
HIV IS NOT TRANSMITTED BY

Air or Water

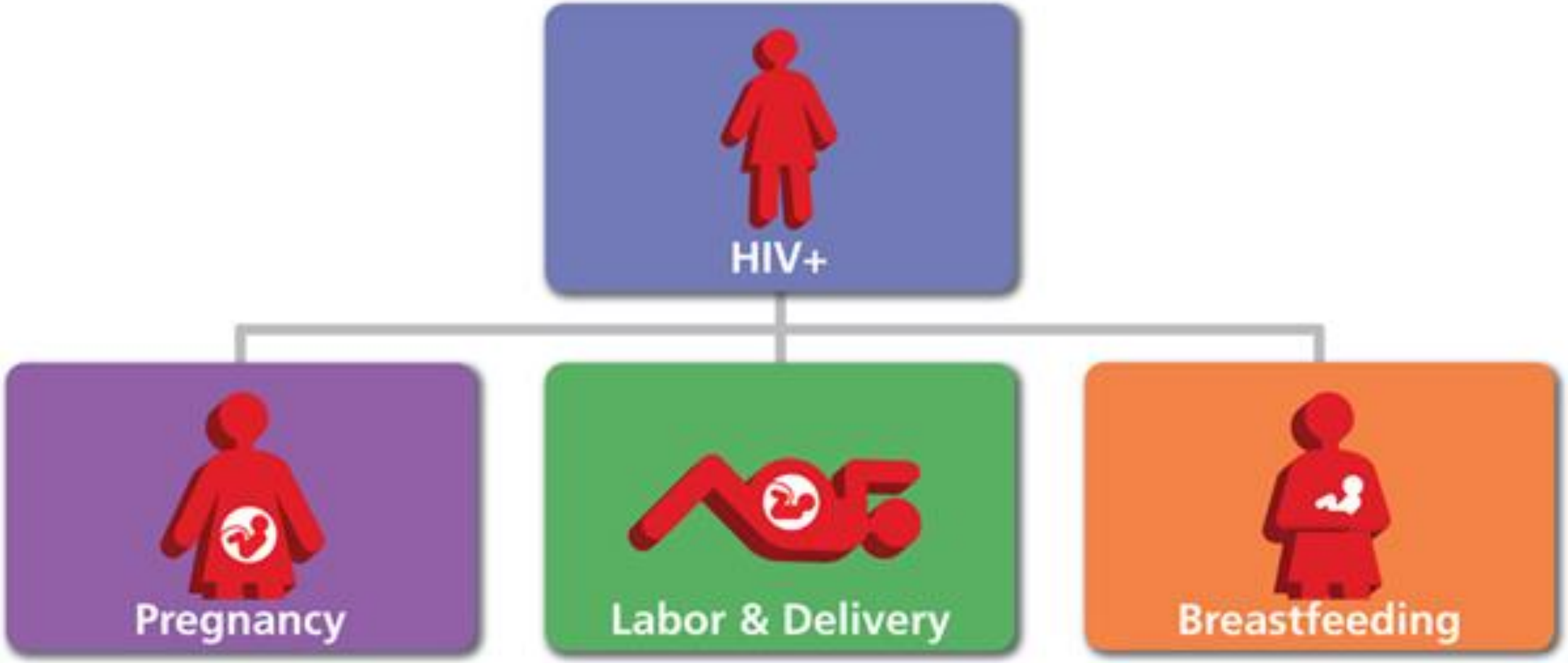
Saliva, Sweat, Tears, or Closed-Mouth Kissing

Insects or Pets

Sharing Toilets, Food, or Drinks



Perinatal Transmission



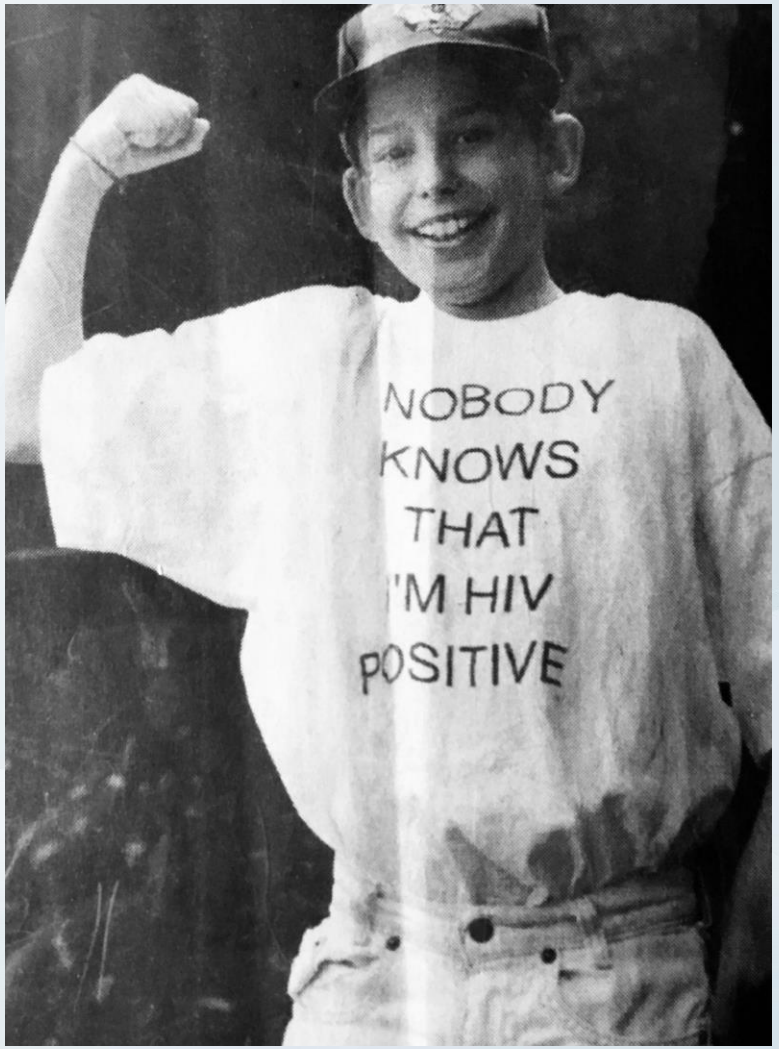
RISK OF PASSING HIV TO BABIES

with treatment	no treatment
1 BABY/100	25 BABIES/100
	
Women begin treatment during pregnancy when viral load is suppresed.	Women without treatment

Conclusion:

Since HIV respects no age, gender or race,
the North and South, uniting in the global village,
have discussed the Why, When and How to disclose.
This is a task that should be accomplished in all clinics
around the world for optimal outcomes
for all children and adolescents living with HIV.

Thank you for your attention!



With appreciation to the teams in our clinics who help the children and families cope with this difficult diagnosis

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UCH Ibadan Team

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- Mrs Lanre Ogunyde
- Mr Lekan Salami
- Mrs Gbemi Olugbade
- Mrs Tomi Babatope

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Video Resources:

- **This is a 9-minute video, “HIV and ME: Marissa's Story” (a 5th grade) video about a child whose mother has HIV:** https://www.youtube.com/watch?v=S2J7bH1JQ40
- **This is the Curriculum Discussion Guide about “HIV and ME” Guide:**
  https://docushare.everett.k12.wa.us/docushare/dsweb/Get/Document-79111/Redefine%20Positive%20Teacher%20Guide.pdf
- **This is a link to a 22-minute HIV and AIDS (6th Grade) video:**
  https://www.youtube.com/watch?v=ZixbZVnvt4E
- **This is a link to a YouTube channel started by a young woman, Diana Koss, infected from birth and followed in Oakland by Dr. Petru for the first 18 years of her life.** *Parents should review content before sharing with younger children or teens:*
  https://www.youtube.com/watch?v=kVPZzHnmgQ8&t=6s