

# Steps to STOP AIDS in children - pitfalls along the road

KARL TECHNAU

26<sup>TH</sup> JUNE 2025



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EYE OPENING CASES



# Objectives for today's talk

- ▶ Highlighting existing resources
- ▶ Discussing diagnostic pitfalls that can ultimately lead to Paediatric AIDS (Dilemmas and Delays)
  - ▶ Mothers
  - ▶ Infants
- ▶ Identifying severe illness and acting appropriately – clinical struggles
- ▶ Pitfalls for mothers/families along the pathway of care – how can we avoid problems
- ▶ Pitfalls for clinicians – our relationship with each other and our patients – how can we improve our impact and avoid harm



# Existing Resources

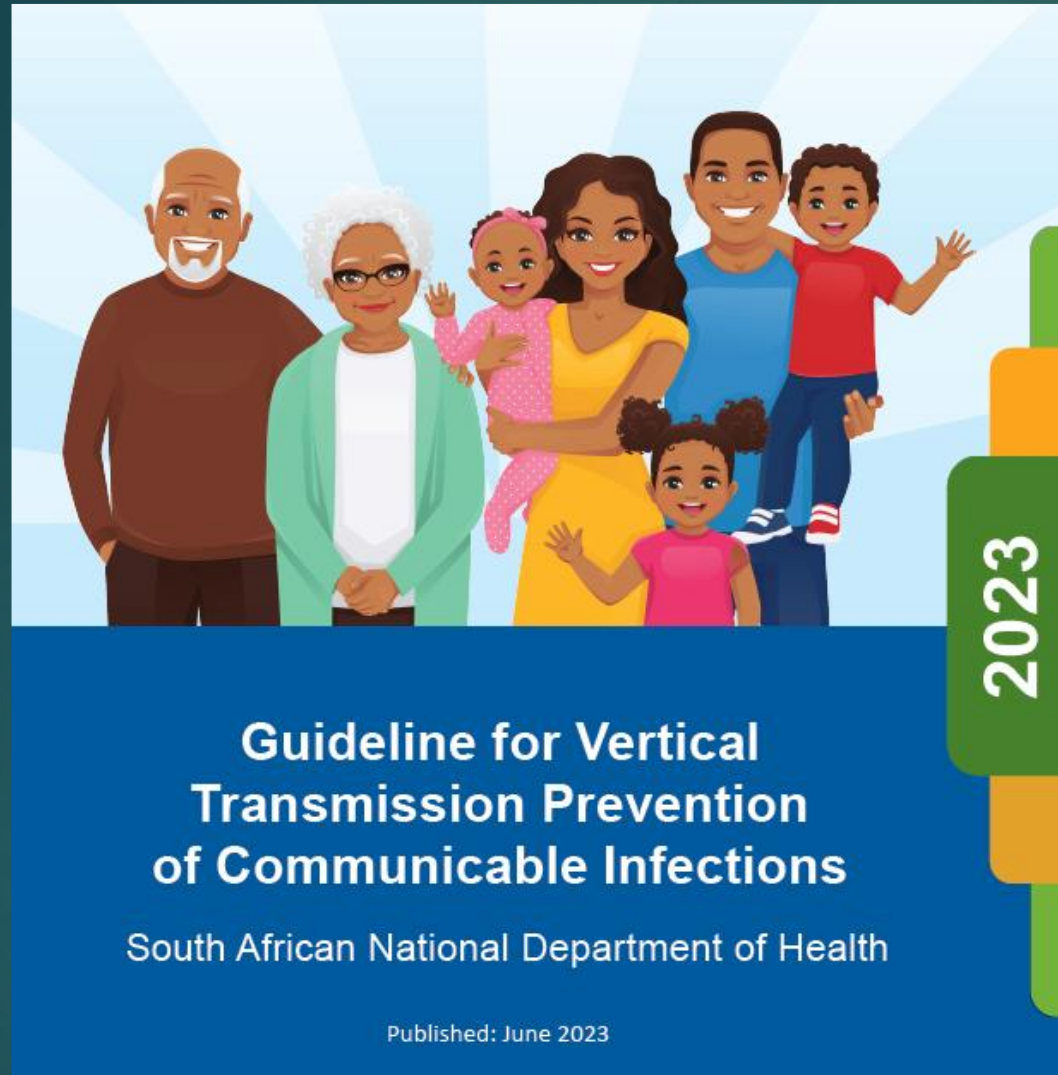
- ▶ Package of care for children and adolescents with advanced HIV disease: stop AIDS
- ▶ ADH Presentation 8 Feb 2024 Dr Frigati.pdf



TECHNICAL BRIEF — JULY 2020

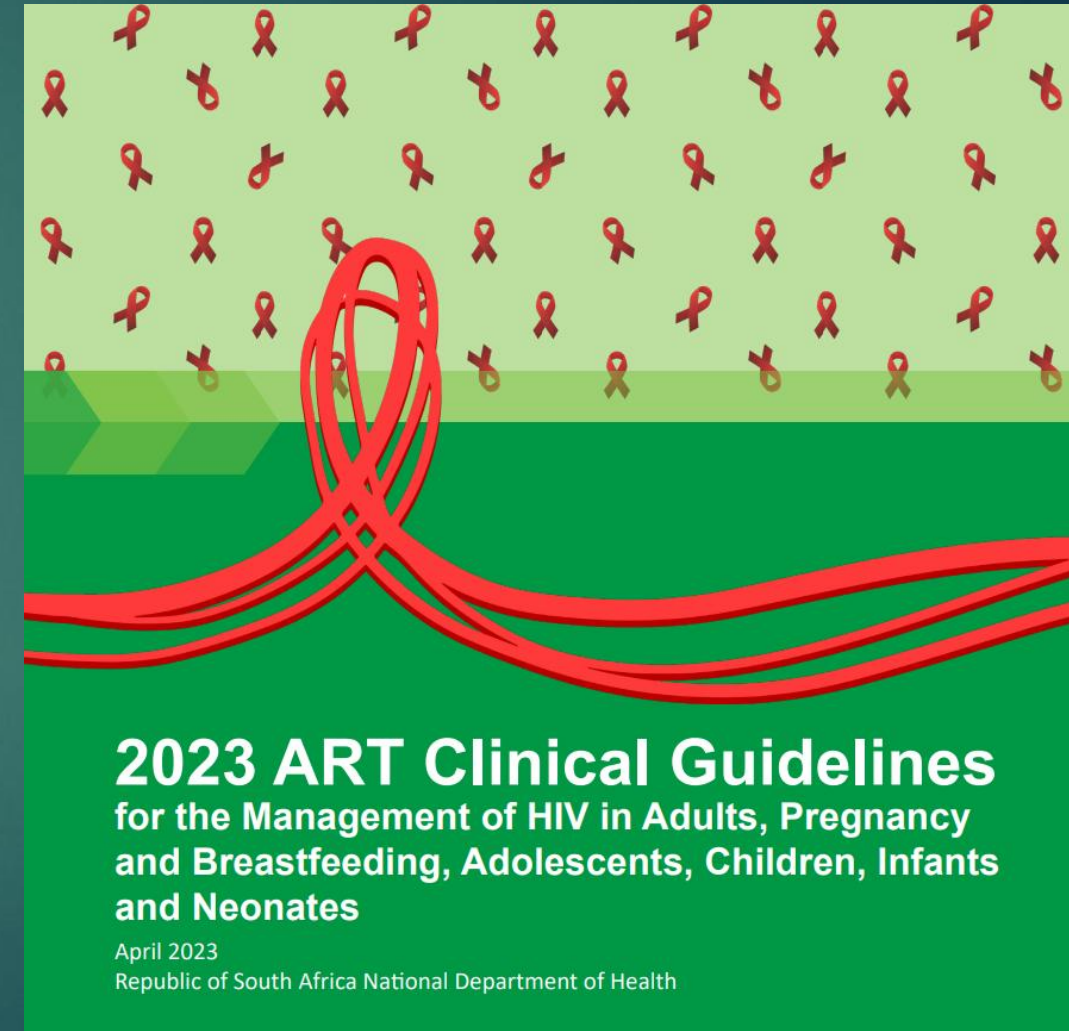
PACKAGE OF CARE FOR CHILDREN  
AND ADOLESCENTS WITH ADVANCED  
HIV DISEASE: **STOP AIDS**

# Guidelines



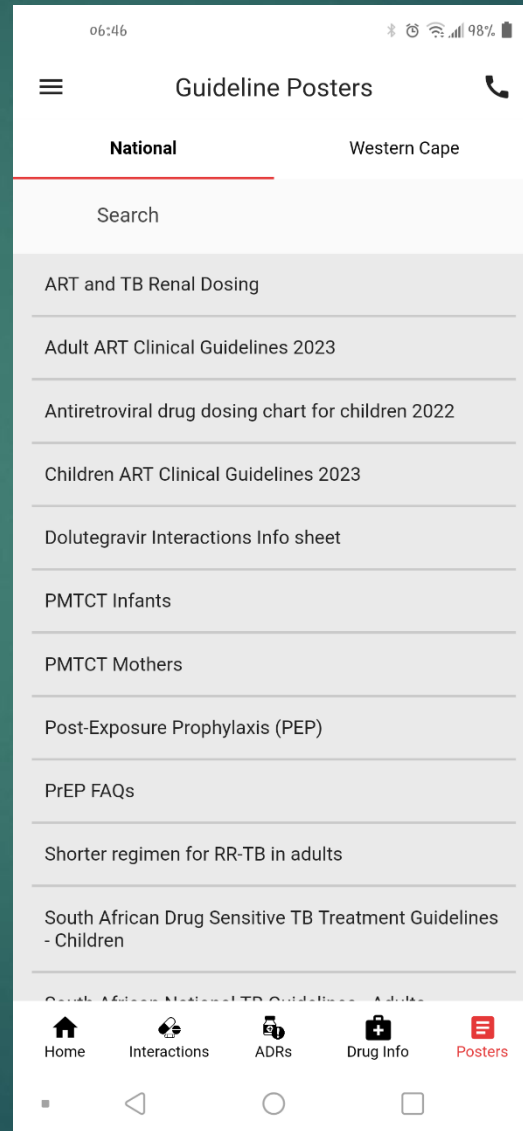
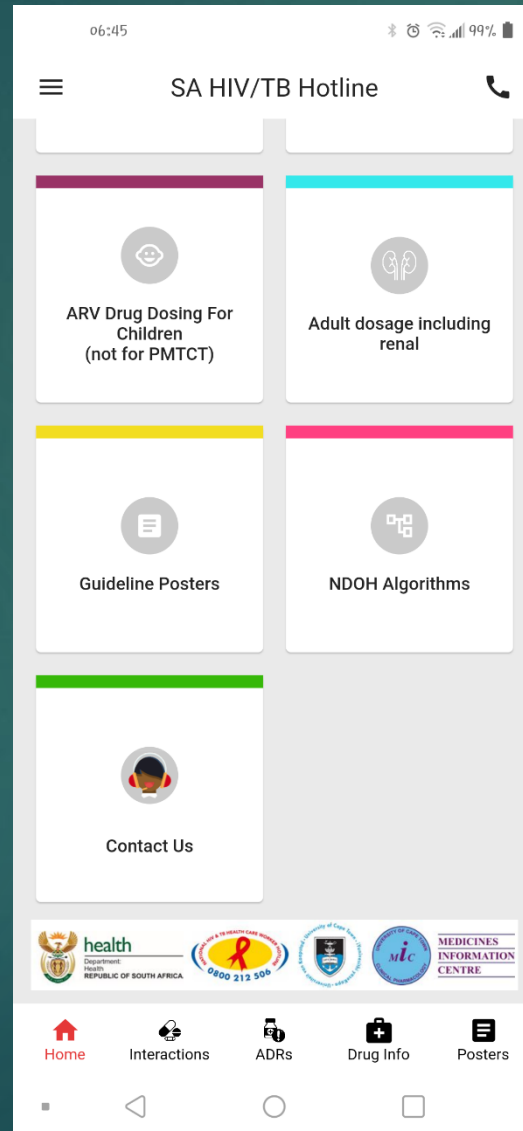
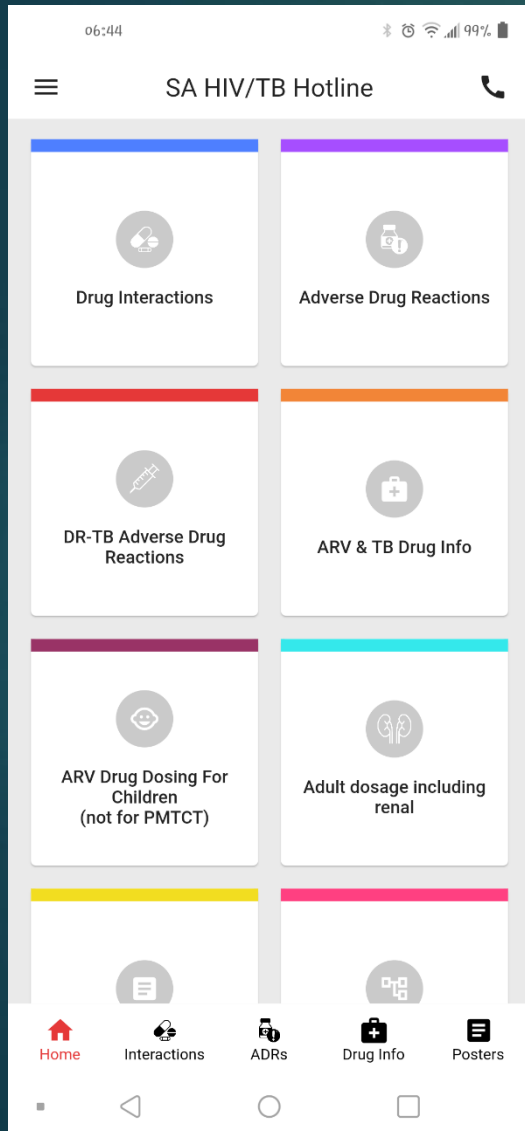
[2023 Vertical Transmission Prevention Guideline  
04092023 signed WEB\\_1.pdf](#)

[National ART Clinical Guideline 2023 04 28  
signed 0.pdf](#)



# Very useful APP

## SA HIV/TB Hotline App | Medicines Information Centre






# Comments on guidelines

- ▶ Excellent resources
- ▶ Difficulties:
  - ▶ A long history of guidelines – our journey has been long – many changes – implementation and training
  - ▶ Some colleagues and patients have lived through different eras
  - ▶ Examples
    - ▶ Feeding methods
    - ▶ VTP prophylaxis
    - ▶ Timing of meds






# Diagnostic pitfalls – the mother and family

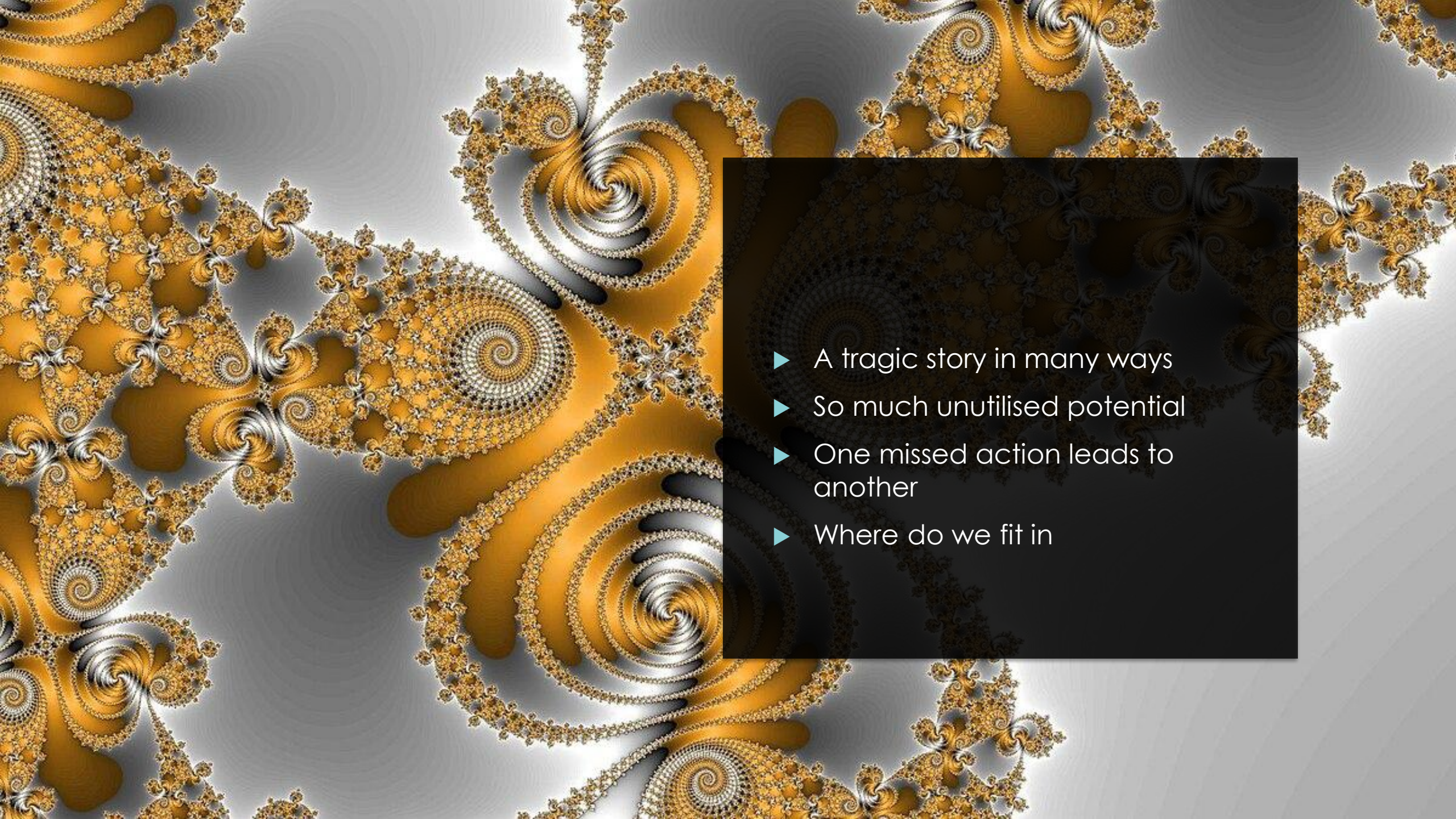


# A story

- ▶ Mary is 24 and found out recently that she is pregnant
- ▶ She is excited though she is not sure how supportive her partner will be
- ▶ She wants to book early but is just too late to enter the clinic and is told to come back next week
- ▶ Unfortunately there is a death in the family and she travels home for the funeral
- ▶ She misses the chance to book
- ▶ She starts feeling unwell and experiences a miscarriage at 18 weeks
- ▶ Bloods are done but she is discharged over the weekend before results are checked, anyway it is hard to communicate, she does not speak English well
- ▶ She leaves the hospital an ELISA result comes back as HIV positive and RPR is positive but treatment is not started

- 
- ▶ A year later she returns, pregnant and now books at her local clinic
  - ▶ She has struggled a lot with depression since the miscarriage but the new pregnancy is a promise of better things to come
  - ▶ Syphilis and HIV are diagnosed on her booking visit
  - ▶ She is very upset about this and does not know what to do, she delays starting ART
  - ▶ She is counselled about the need to start ART and she agrees to start at 28 weeks,
  - ▶ Her VL at the time is 48000, CD4 458
  - ▶ By the time she delivers her VL is 86 and she had completed her treatment for syphilis
  - ▶ The Baby's PCR is .....





- ▶ A tragic story in many ways
- ▶ So much unutilised potential
- ▶ One missed action leads to another
- ▶ Where do we fit in



# Diagnosis of the mother

- ▶ From the initial story – a clear example of missed diagnosis
  - ▶ Patients navigating services
  - ▶ Patient not returning in time
  - ▶ Not following protocols (ELISA, rapid) – importance of tracking
  - ▶ Insufficient counselling
  - ▶ Importance of gynae/obstetric collaboration, diagnosis during pregnancy loss/termination



#### PILLAR 1

Primary prevention of transmittable diseases, especially among women of childbearing age



#### PILLAR 2

Preventing unintended pregnancies among women diagnosed with transmittable infections



#### PILLAR 3

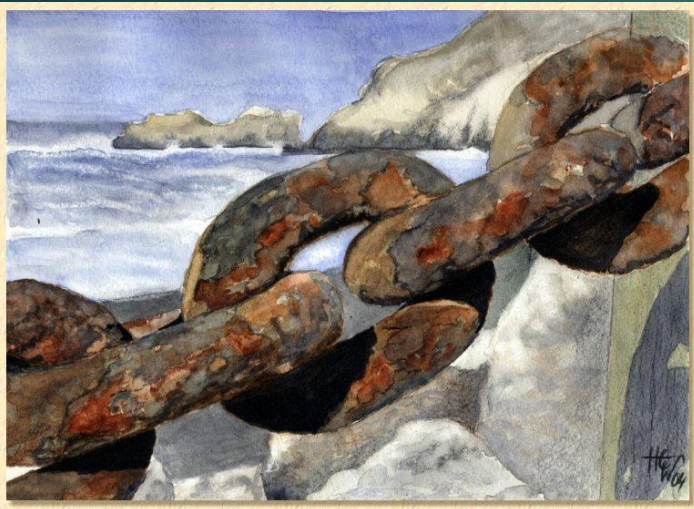
Preventing vertical transmission from a woman living with a transmittable infection to her infant



#### PILLAR 4

Providing appropriate treatment, care, and support to women, their children, partners and families

**Figure 1** *The four pillars of prevention of vertical infections*



**Preventing  
Paediatric AIDS  
starts long before  
the pregnancy**

**CHAIN OF  
SURVIVAL**



# Case

- ▶ 20 yr old mother
  - ▶ Repeatedly HIV negative during pregnancy
  - ▶ Rapid tests discordant at delivery



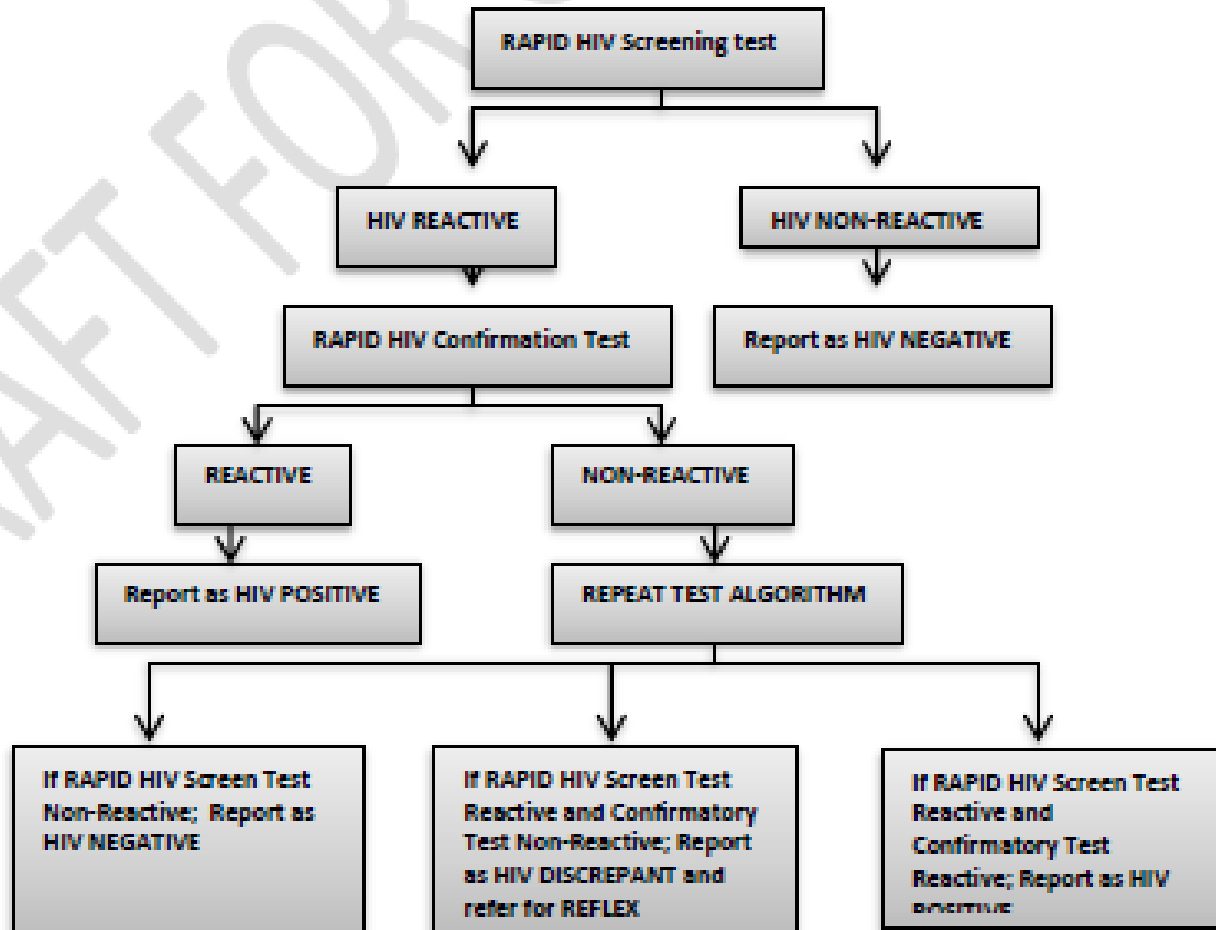
# Take a moment ask yourself:

- ▶ What are the likely causes?
- ▶ What is the correct algorithm for HIV testing in adults
- ▶ How would you counsel her – at delivery



# MCQ

- ▶ What should you do next in this case?
  - ▶ 1) Wait for the 6 weeks window period to pass and repeat the rapid test
  - ▶ 2) Repeat the rapid test algorithm now
  - ▶ 3) Send off a HIV PCR test and base your next steps on that result
  - ▶ 4) Do an HIV ELISA test and base your next steps on that result
  - ▶ 5) Treat the mother as HIV positive



# HIV Testing Protocol for adults



What next?



# HIV TESTS

- ▶ Indirect tests  
→ **Antibody tests**

- ▶ Tests:

- ▶ Rapid (always x 2)
  - ▶ ELISA

- ▶ Use to:

- ▶ Check exposure to HIV in infants
  - ▶ HIV diagnosis in > 24m

- ▶ Direct tests → **viral material**

- ▶ Tests:

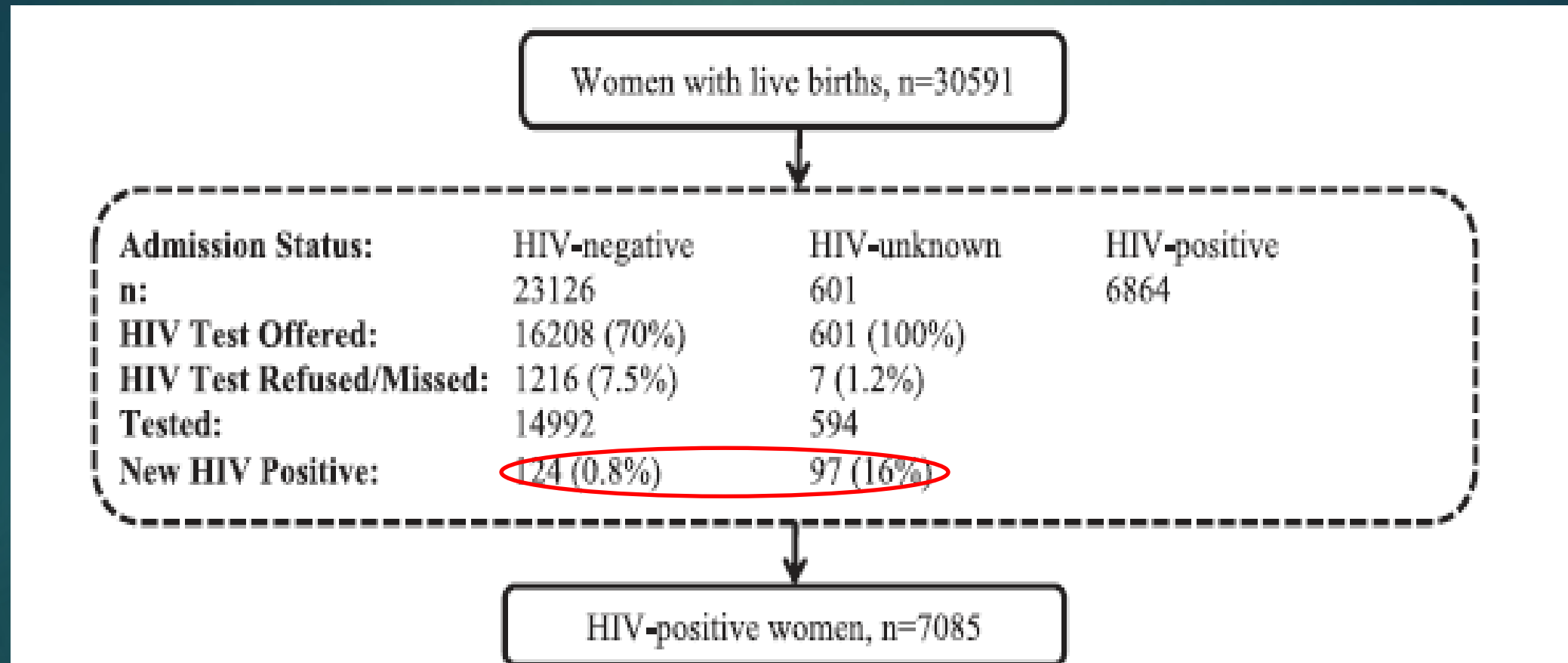
- ▶ **TNA** PCR
  - ▶ RNA PCR (VL)

- ▶ Use to:

- ▶ Dx HIV in < 24m exposed
  - ▶ Confirm HIV infx in infants
  - ▶ Monitor response to ART

# Testing – Identifying who is exposed

19



Technau K-G et al. *Journal of the International AIDS Society* 2017, **20**:21436  
<http://www.jiasociety.org/index.php/jias/article/view/21436> | <http://dx.doi.org/10.7448/IAS.20.1.21436>

221 (3% of Pos) women  
newly diagnosed  
at delivery

# Testing – Identifying who is exposed

20

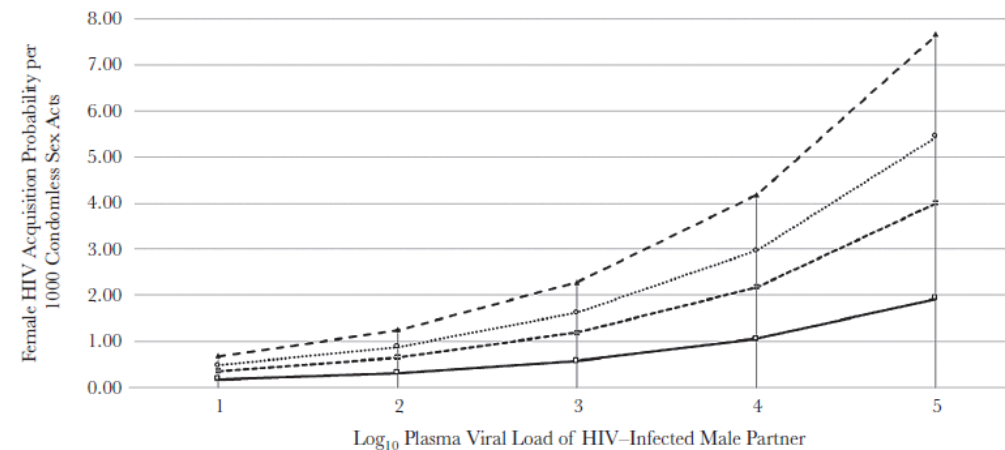
- ▶ Maternal testing at delivery facility important
  - ▶ 16 (16%) of 99 infected neonates identified at birth were born to 221 women newly diagnosed as part of the postnatal maternal testing programme of 7085 women







# Increased Risk of HIV Acquisition Among Women Throughout Pregnancy and During the Postpartum Period: A Prospective Per-Coital-Act Analysis Among Women With HIV-Infected Partners

Kerry A. Thomson,<sup>1</sup> James Hughes,<sup>2</sup> Jared M. Baeten,<sup>1,3,4</sup> Grace John-Stewart,<sup>1,3,4,5</sup> Connie Celum,<sup>1,3,4,5</sup> Craig R. Cohen,<sup>6</sup> Kenneth Ngunjiri,<sup>3,7</sup>

**Conclusion.** The HIV acquisition probability per condomless sex act steadily increased during pregnancy and was highest during the postpartum period, suggesting that biological changes during pregnancy and the postpartum period increase HIV susceptibility among women.



	Nonpregnant	0.17	0.31	0.58	1.05	1.93
	Early pregnancy	0.36	0.65	1.19	2.19	4.00
	Late pregnancy	0.48	0.89	1.62	2.97	5.44
	Postpartum	0.68	1.25	2.29	4.18	7.65

**Figure 1.** Adjusted absolute female human immunodeficiency virus type 1 (HIV) acquisition probabilities represent infectivity estimates per 1000 condomless sex acts for a 25-year-old woman not taking preexposure prophylaxis (PrEP) at varying levels of plasma HIV viral load for a male HIV-infected partner.

# Discordant results

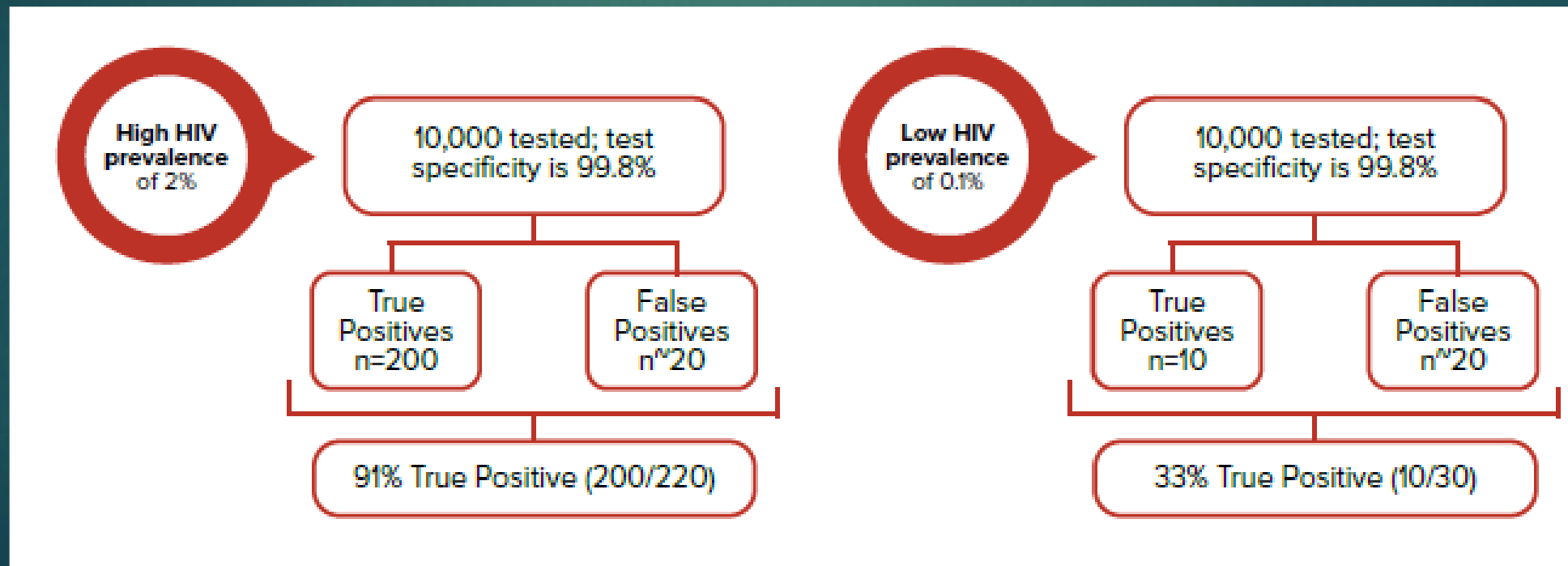
22

- ▶ Large numbers of tests required to identify the new cases
- ▶ Low yield population
- ▶ PPV drops
  - ▶ False positives crop up more amongst the non-negatives

# Effect of prevalence

23

- Note that the prevalence amongst previously tested individuals is <1%



# False Positive and False Negative Ab Tests

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- ▶ False negative
  - ▶ Technical Issues
    - ▶ Mix up
    - ▶ Mislabelling
    - ▶ Improper handling
    - ▶ Misinterpretation
  - ▶ Biological Issues
    - ▶ New/recent infection
    - ▶ Elite controllers, post-treatment controllers
    - ▶ Disease progression with low antibodies or antibodies in disarray
    - ▶ On ART and known infected and not disclosing this

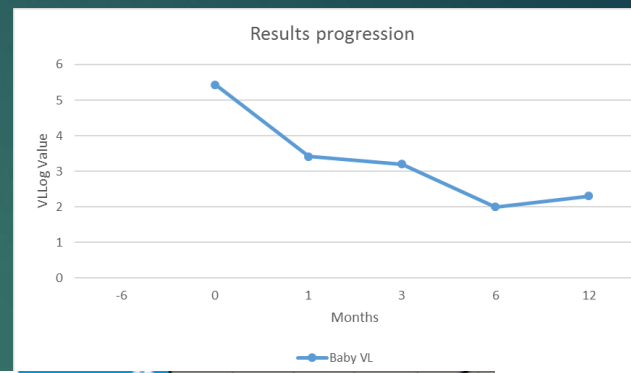
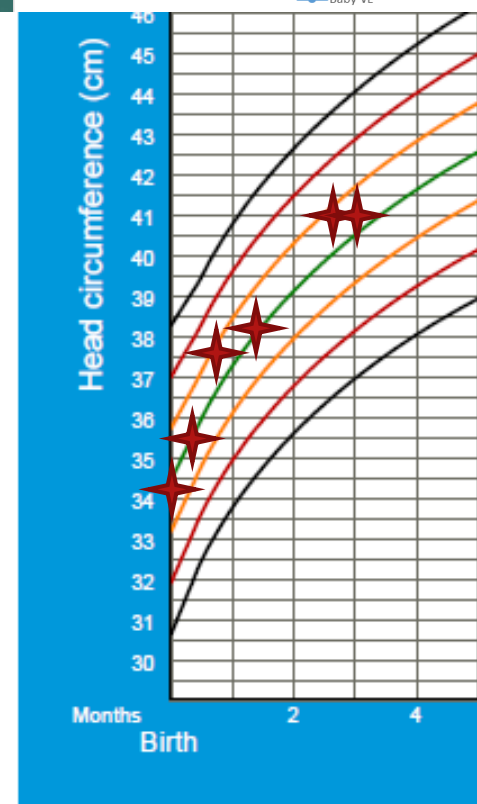
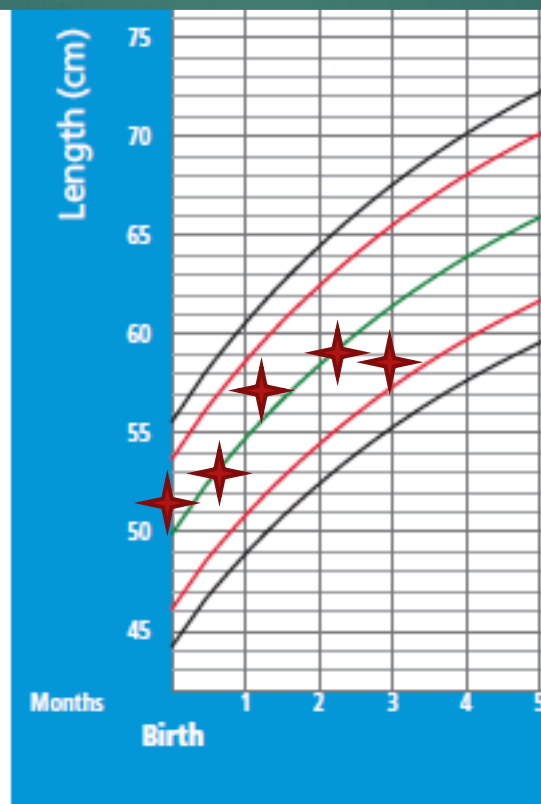
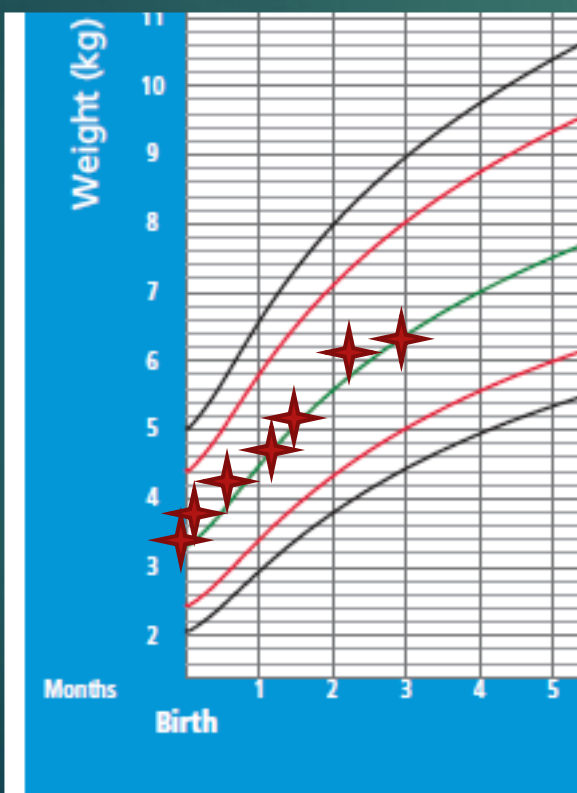


## The case carries on

- ▶ 20 yr old mother
  - ▶ HIV negative during pregnancy
  - ▶ Rapid tests discordant at delivery
  - ▶ ELISA equivocal
  - ▶ VL 40000 CD4:500
  - ▶ Baby infected
- ▶ Case demonstrates the risks in the context of discordant rapid results/equivocal Elisa results

- ▶ BW 3.14, BL 48 BHC 34cm, breastfeeding
- ▶ Baby did well
  - ▶ No admissions,
  - ▶ no advanced disease

Baby



## Stages of the Grief Cycle

"NORMAL"  
FUNCTIONING



Shock  
and Denial

- Avoidance
- Confusion
- Fear
- Numbness
- Blame

**GUILT**

**FEAR**

Anger

- Frustration
- Anxiety
- Irritation
- Embarrassment
- Shame

Depression and  
Detachment

- Overwhelmed
- Blihs
- Lack of energy
- Helplessness

**DEPRESSION**

RETURN TO  
MEANINGFUL LIFE



Acceptance

- Exploring options
- A new plan in place

Dialogue and  
Bargaining

- Reaching out to others
- Desire to tell one's story
- Struggle to find meaning for what has happened

Adapted from Kübler-Ross, 1969

# Summary

- ▶ Using every testing opportunity possible – it may be hard to find every case but it will be worth spending the extra time
- ▶ Repeat testing – especially during pregnancy and pregnancy related admissions but any persons
- ▶ Individual counselling and care needed for new diagnoses
- ▶ Managing diagnostic dilemmas correctly
- ▶ Following clinical concerns and repeating testing if needed



# Diagnostic pitfalls – the baby

# A further case

- ▶ Mother is pregnant and adherent on ART
- ▶ She travels to another province for a family emergency
- ▶ She runs out of ART and approaches the local clinic
- ▶ They say that they cannot help her without a transfer letter
- ▶ She interrupts ART
- ▶ Her baby is born, PCRs are done and two separate PCRs confirm that the baby is living with HIV
- ▶ The baby starts ART
- ▶ She returns to JHB and attends immunisation clinic at ten weeks where the baby is retested – PCR is negative
- ▶ ART is stopped and baby is referred to our clinic



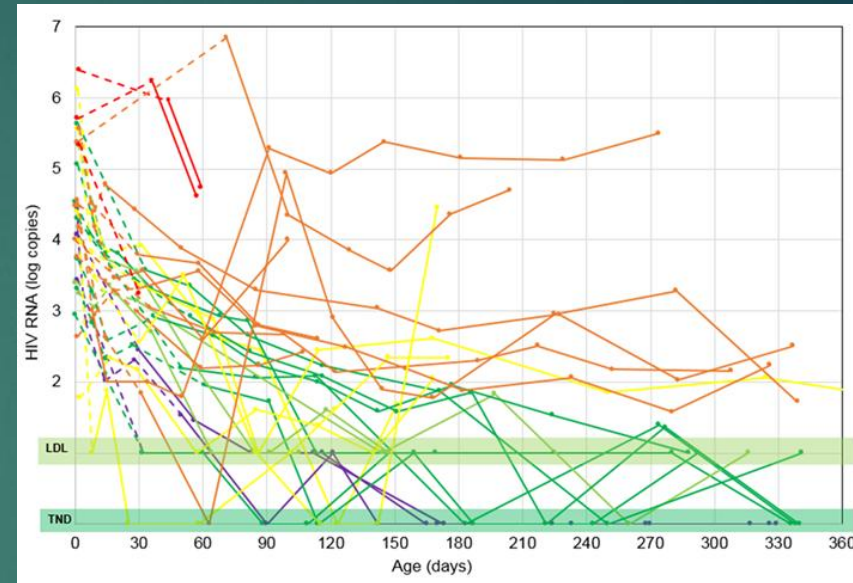
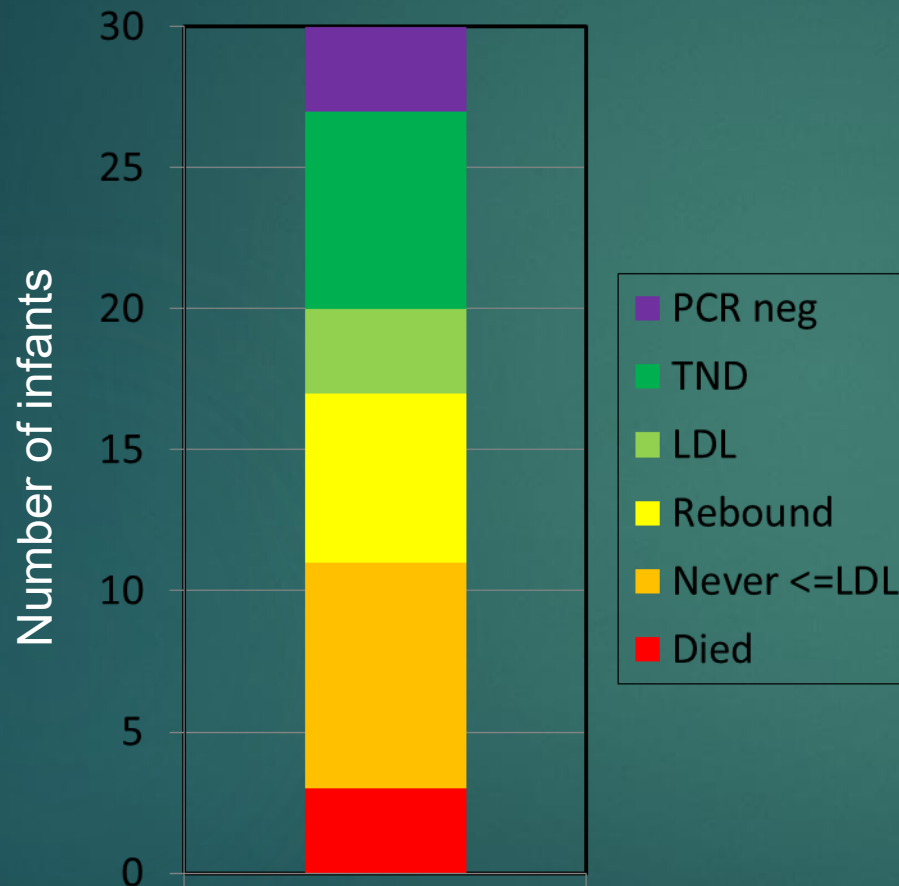
A lot of issues once again

# Some issues

- ▶ Travels and is not able to access ART
  - ▶ Should have brought extra?
  - ▶ Should have known?
  - ▶ Did she approach the clinic in time?
  - ▶ What caused the inability to help?
- ▶ Retesting of infants who have already been diagnosed
  - ▶ Documentation in RTHB
  - ▶ Checking for previous results
  - ▶ Risk of negative or indeterminate PCR result upon retest
  - ▶ Treatment interruption - risk for advanced disease



# Patterns of virologic response to early treatment over the first year of life



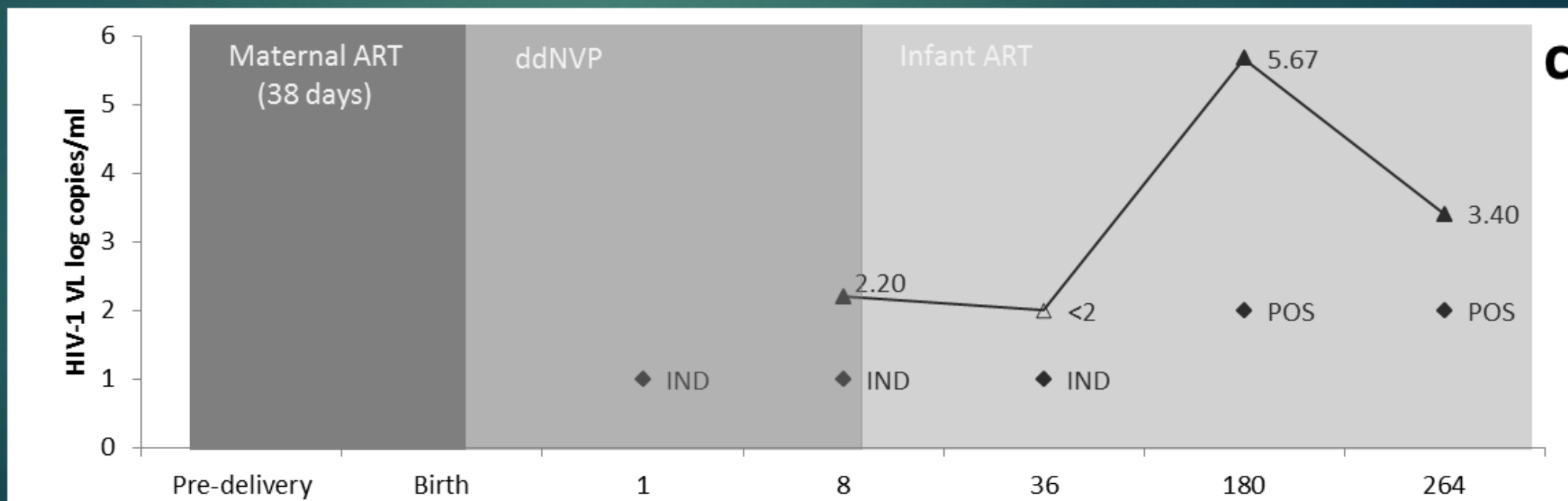
From: Prof L Kuhn et al: Treatment of acute HIV infection in neonates. Presented at CROI 2017.

# Example Case 1

35

Technau K-G et al. *Journal of the International AIDS Society* 2017, **20**(Suppl 6):21761  
<http://www.jiasociety.org/index.php/jias/article/view/21761> | <http://dx.doi.org/10.7448/IAS.20.7.21761>

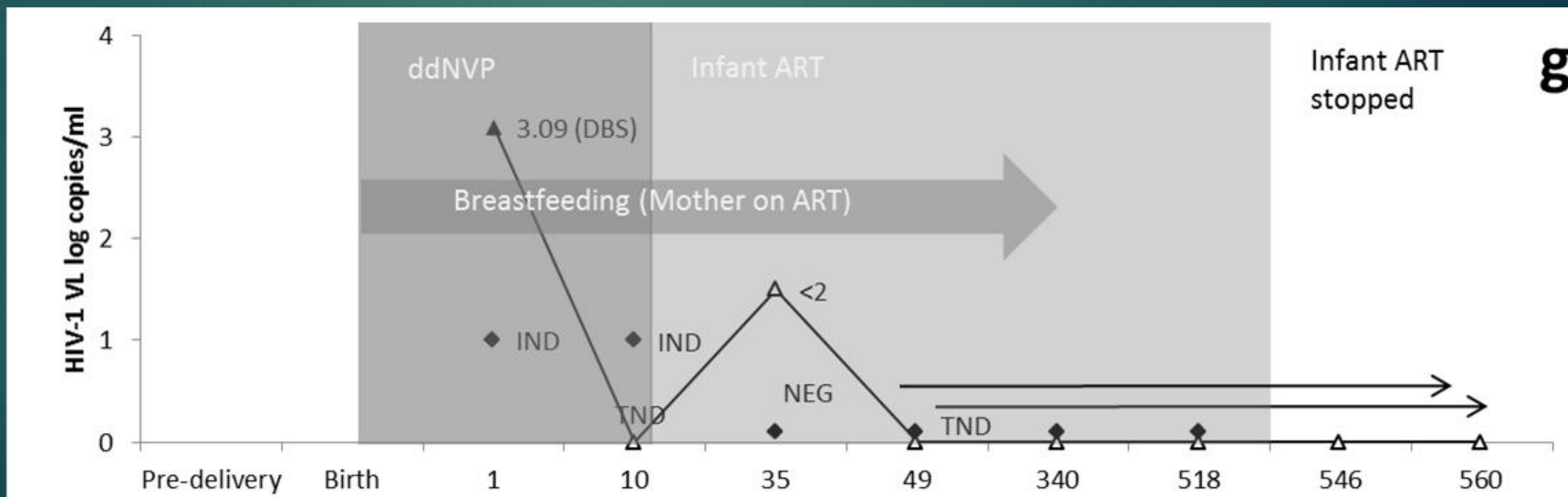
- ▶ Initial indeterminate results
- ▶ Low grade VL 158
- ▶ Later clear positive results



# Example Case 2

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- ▶ Clear VL on one sample only
- ▶ Subsequent negative or indeterminate results
- ▶ Case remains uncertain



# Example Case 3

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- ▶ Birth HIV PCR done at age 2 days: POSITIVE
- ▶ NVP/AZT given, high risk exposure & abandoned
- ▶ Confirmatory VL on day 7 of life <100 (=indeterminate)
- ▶ Further confirmatory HIV PCR on day 11 NEGATIVE
- ▶ Further testing done at one month (age 32 days), results Viral Load 54 copies/ml.
- ▶ Child is HIV infected



# MCQ

- ▶ Which of these sequences of results in 2 month old infants definitely shows an HIV infection present in the infant
  - ▶ 1) Infant 1: HIV PCR NEGATIVE then HIV ELISA POSITIVE
  - ▶ 2) Infant 2: HIV PCR NEGATIVE then HIV PCR POSITIVE then HIV PCR NEGATIVE
  - ▶ 3) Infant 3: HIV PCR POSITIVE, then HIV PCR NEGATIVE with HIV VL 124 copies/ml
  - ▶ 4) Infant 4: HIV Rapid positive, HIV ELISA Positive, HIV VL Lower than detectable

# Timing of Testing

- ▶ Critically important to confirm the diagnosis
- ▶ Follow-up on discordant results
- ▶ Check with the lab
- ▶ Investigate the documents and barcodes
  - ▶ Maternal/infant sample swaps
  - ▶ Lab errors

## HIV TESTING SCHEDULE

Birth HIV-PCR

HIV-PCR at age 10 weeks

HIV-PCR at **6 months** for all HIV-exposed infants

- Aligned with 6-month maternal HIV VL

**Universal 18 month rapid/ELISA** for all children

- Whether exposed or un-exposed
- Aligned with 18-month maternal HIV VL

Age-appropriate test at **6 weeks post-cessation of BF**

Age-appropriate test at any time if the baby is unwell

AGE OF CHILD	HIV SCREENING TEST	HIV CONFIRMATORY TEST
Less than 18 months	PCR	PCR
18 months to 2 years	Rapid	PCR
More than 2 years	Rapid	Rapid

# The older child

- ▶ Beware of false negative rapid tests, rare but does happen and delays the process
- ▶ What is the diagnostic sensitivity of your clinical exam?
- ▶ It may help to be a safety net
- ▶ Caution:
  - ▶ Ill presentation
    - ▶ Not exposed
      - ▶ Mother says she is negative and is not tested
      - ▶ Mother not available
      - ▶ Mother herself has false negative result
    - ▶ Exposed but rapid negative
      - ▶ E.g. advanced HIV



# Key Message

- ▶ **Up to a ¼ of cases require more than one confirmatory test**
- ▶ **in a small minority the diagnosis may remain uncertain – careful follow-up critical**
- ▶ **Following the age related testing guidelines**
- ▶ **Not retesting cases unnecessarily if confirmed already**
- ▶ **Ensure distinction between maternal and infant samples**



# Advanced disease in infants


# Case

- ▶ 3 month old infant presents with known HIV diagnosis – two confirmed PCR tests
- ▶ Started ART 2 weeks ago (ABC/3TC/DTG)
- ▶ Presents with diarrhoea and mild cough
- ▶ Baby's anthropometry is within normal range
- ▶ On admission: tachypnoea RR 45-50, fever and oral thrush, saturation is 91-92% on room air, well hydrated
- ▶ Overnight, baby does not sleep well and is restless, saturation starts to drop to 85% on room air

# MCQ

- ▶ Which of these statements are correct
  - ▶ 1) The infant is unlikely to have PJP pneumonia since he is already on ART
  - ▶ 2) The main problem in this infant is gastroenteritis and likely imminent dehydration
  - ▶ 3) This infant should be treated for oral thrush
  - ▶ 4) The infant is at risk for multiple infections including TB, CMV, PJP and bacterial pneumonia



- 
- ▶ Baby is admitted to ICU by the evening requiring high frequency oscillator ventilation
  - ▶ PJP PCR is positive
  - ▶ TB investigations are negative TBNAAT
  - ▶ CD4: 10%
  - ▶ Baby spends many days in ICU slowly improving
  - ▶ Ultimately able to be extubated
  - ▶ Develops sudden decompensation, pneumothorax
  - ▶ Reintubated but does not manage to wean
  - ▶ Demise after >20 days in ICU

# Important conditions

- ▶ PJP – early treatment with high dose co-trimoxazole and prednisone
- ▶ CMV – treatment with ganciclovir/valgancyclovir
- ▶ TB – investigation, low index of suspicion – family investigations
- ▶ Candida – oral/oesophageal/laryngeal

# Definition of advanced disease in children: further articulated in 2020 technical brief



TECHNICAL BRIEF – JULY 2020

PACKAGE OF CARE FOR CHILDREN  
AND ADOLESCENTS WITH ADVANCED  
HIV DISEASE: **STOP AIDS**



## Children > 5 years:

- WHO stage 3 or 4 or a CD4 cell count <200 cells/mm<sup>3</sup>

## Children < 5 years:

- have advanced HIV disease
- “Although children younger than five years are defined as having advanced disease at presentation, those who have been receiving ART > 1 year and who are clinically stable should not be considered to have advanced disease and should be eligible for multi-month dispensing”

### Box 1. Screen, Treat, Optimize and Prevent AIDS

#### Screen\*

##### TB

- Screen for TB using a clinical algorithm<sup>a</sup> followed by X-ray when indicated and if available
- Use the following diagnostic tests to confirm TB as applicable:<sup>c</sup>
  - Rapid molecular diagnostic (Xpert® MTB/RIF or Ultra) on (induced) sputum, stool, gastric aspirate or nasopharyngeal aspirate or other extrapulmonary samples if relevant
  - Lateral flow urine lipoarabinomannan (LF-LAM) assay<sup>d</sup>

##### Cryptococcal infection among adolescents

- Serum or plasma or blood cryptococcal antigen screening followed by lumbar puncture if positive or symptomatic

##### Malnutrition

- Weight-for-height
- Height-for-age
- Mid-upper arm circumference among children 2–5 years old

#### Treat

TB, severe pneumonia, severe bacterial infections, cryptococcal meningitis and severe acute malnutrition according to WHO guidelines

#### Optimize

Rapid antiretroviral therapy start – within seven days with optimal regimens\*

Antiretroviral therapy counselling

#### Prevent

Bacterial infections and *Pneumocystis pneumonia*

- Co-trimoxazole prophylaxis

##### TB

- TB preventive treatment

Cryptococcal meningitis among adolescents

- Fluconazole pre-emptive therapy

##### Vaccinations

- Pneumococcal vaccine
- Human papillomavirus
- Measles
- BCG



\* Screening refers to screening and diagnostics throughout this publication.

<sup>a</sup> See Fig. 3 in *Guidance for national tuberculosis programmes on the management of tuberculosis in children* (9).

<sup>c</sup> A negative test result does not exclude TB in children living with HIV in whom there is a strong clinical suspicion of TB.

<sup>d</sup> See Table 2 and the text for recommendations.

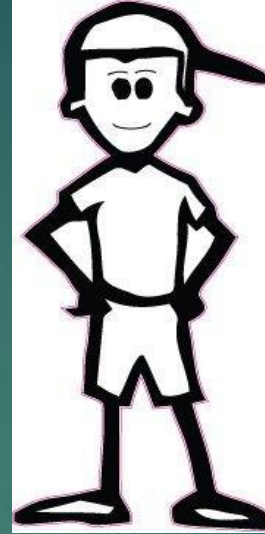
\* Unless TB or cryptococcal disease is diagnosed (10).



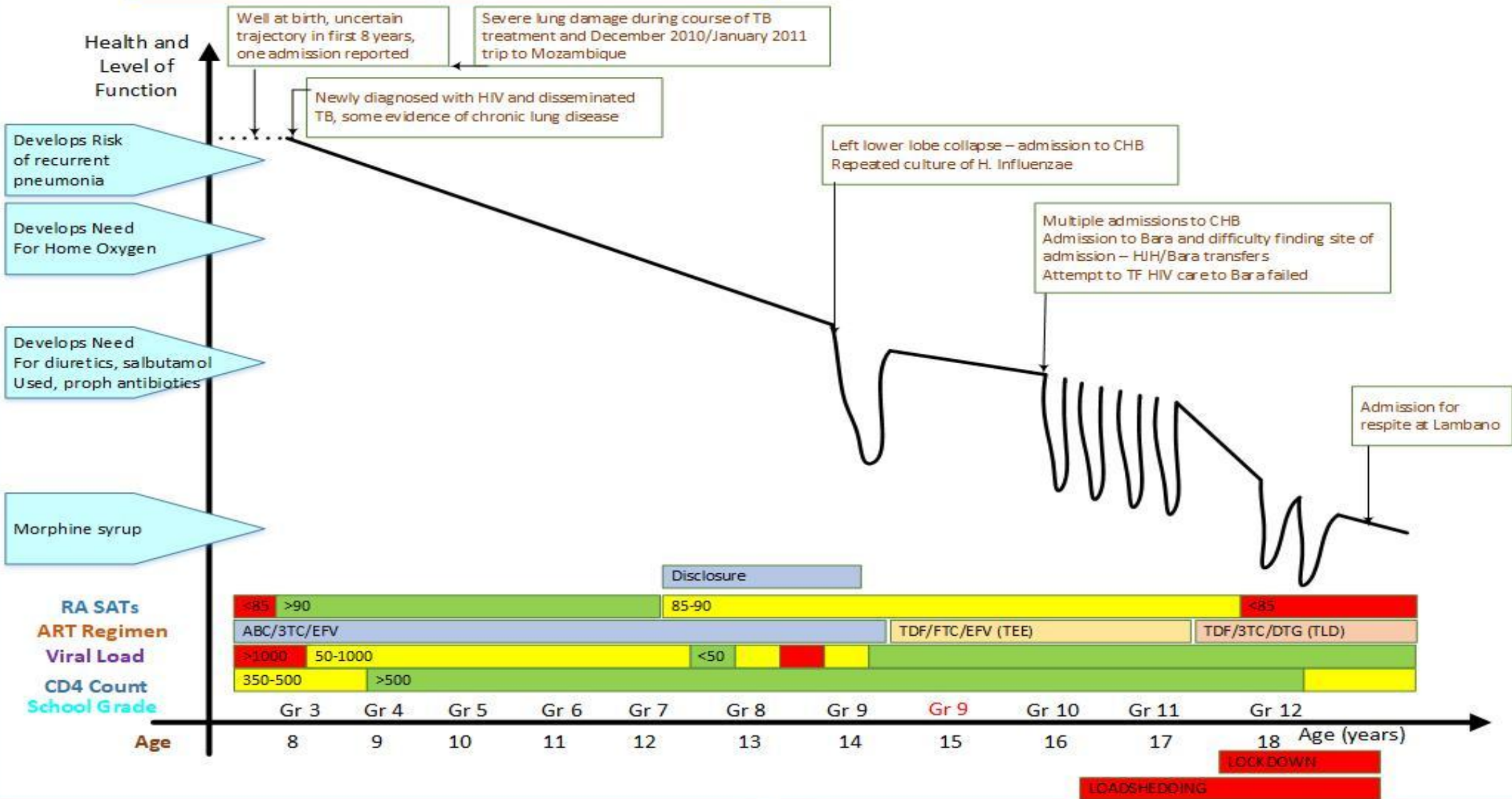
# A young man from our clinic

49

- ▶ Male
- ▶ Born at the end of 2002
- ▶ We met in 2008 at Empilweni
- ▶ He lives in a township  
in the north of Johannesburg
- ▶ He has both his parents, they live with him and  
2 younger brothers
- ▶ His older sister lives in another city



**Figure 2: Disease Trajectory of an 18 year old boy**





# Problem List

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Chronic lung disease (bronchiectasis post-TB) with type 1 respiratory failure (New York Heart Association Class III dyspnoea) – mild stress foecal incontinence

Cor pulmonale complicated by congestive cardiac failure (New York Heart Association Class III cardiac failure)

Vertically acquired HIV (WHO Stage III [Chronic lung disease], virologically suppressed, immune reconstituted)

Reduced bone mineral density (Z-score and T-score < -5)

Mild depression

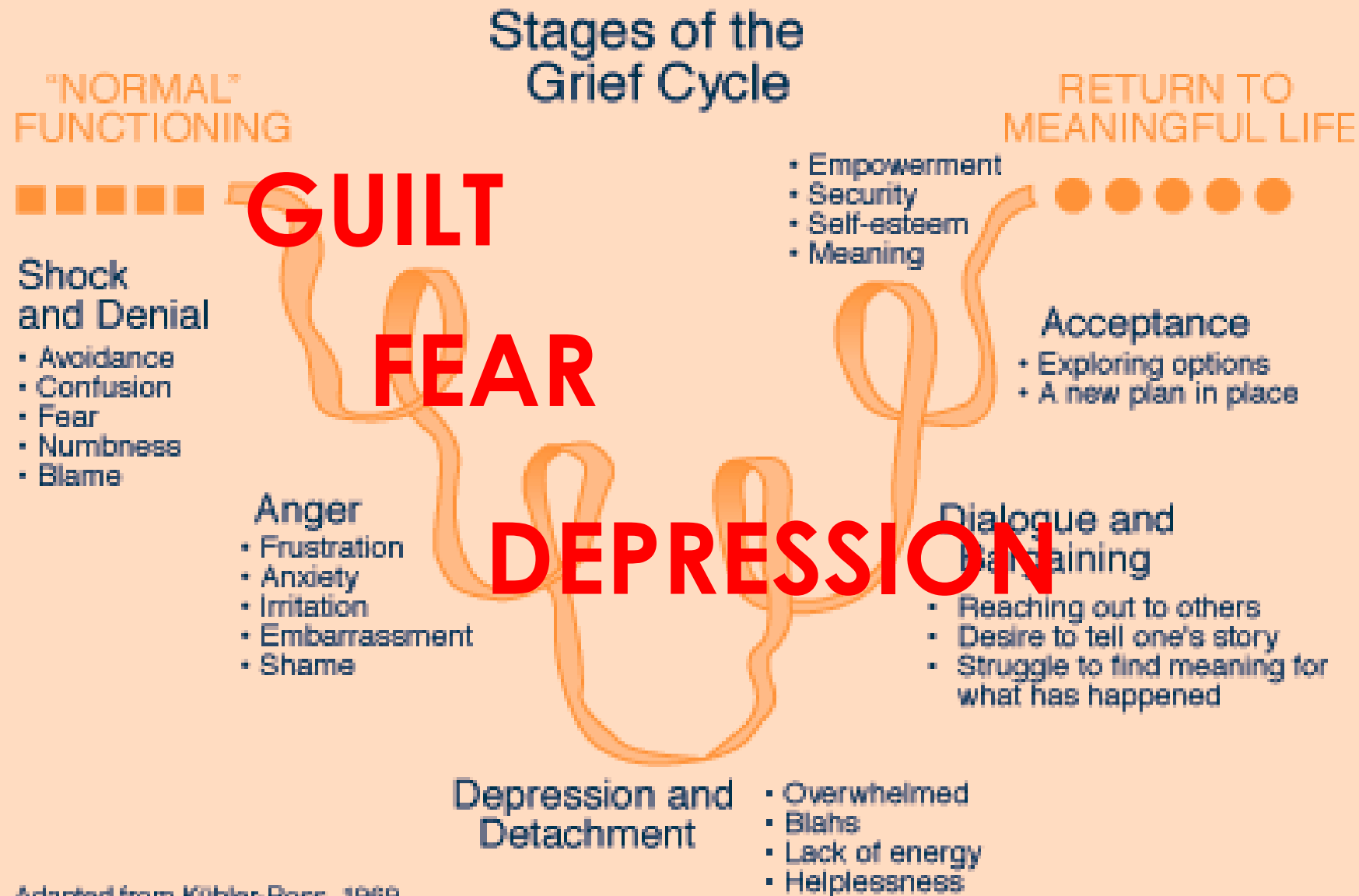
Familial conflict (parental conflict / verbal/physical abuse Father -> Mother)

# Chronic lung disease

- ▶ A devastating condition with severe impairment
- ▶ This case as well as another recent case at our hospital
  - ▶ Difficulties of late ART initiation and ART interruptions
  - ▶ Palliative needs for managing the children and their families
- ▶ Severe lung and ultimately heart disease with early death



# Pitfalls for mothers



# Results return and ART start for infants at birth

55

- ▶ Different settings must be anticipated:
  - ▶ Majority (~80% of cases) generally well out-patient setting
  - ▶ 3-5% are born to mothers who are sick/incapacitated
  - ▶ 2% of mothers are <20 years old
  - ▶ 15-20% neonates are admitted (e.g. prematurity, congenital infections, etc) and possibly very ill





# Adherence and follow-up

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- ▶ Both maternal and neonatal adherence critical
- ▶ Neonatal adherence
  - ▶ Who is available to help? Is the mother alone?
  - ▶ Teaching a family member other than mother
  - ▶ What are the mother's mobility and work plans?
  - ▶ Has a caregiver been identified if the mother plans to return to work?
- ▶ Maternal adherence
  - ▶ Ideally at same location
  - ▶ Emphasis of maternal wellbeing and support critical
  - ▶ Support with disclosure
  - ▶ Mothers who silence themselves – phenomena assoc. with trauma around caring for a “sick” child

# Other Common problems

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- ▶ Maternal documentation
  - ▶ High rate of foreign patients (asylum seekers, illegal immigrants) – poor documentation
- ▶ Mobility and foreign language
  - ▶ Some unable to communicate without a specific translator
  - ▶ May required travelling between countries
- ▶ Post-ICU syndrome

- ▶ Consideration post acute illness
- ▶ Trauma reveals itself years later
- ▶ Often only really noted by clinicians at times of later adherence difficulties or disclosure

#### CONCISE DEFINITIVE REVIEW

## Family response to critical illness Postintensive care syndrome–family

Davidson, Judy E. DNP, RN, FCCM; Jones, Christina RN, PhD, MBACP, MBPsS, CSci, DipH; Bienvenu, O. Joseph MD, PhD

Author Information📄

*Critical Care Medicine* 40(2):p 618-624, February 2012. | DOI: 10.1097/CCM.0b013e318236ebf9

#### SPECIAL ARTICLE OPEN

Check for updates

## Psychological distress in the neonatal intensive care unit: a meta-review

Lizelle van Wyk<sup>1,3</sup>, Athenkosi P. Majiza<sup>1</sup>, Cordelia S. E. Ely<sup>1</sup> and Lynn T. Singer<sup>2,3</sup>

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**INTRODUCTION:** Parental psychological distress (PD) (anxiety, depression, stress and post-traumatic stress syndrome) can adversely affect parents' own physical and mental health as well as their children's long-term health and development. Numerous studies have addressed PD in mothers of infants admitted to NICU, with interventions proposed, but few have addressed the impact on fathers or other family members. The present review examined systematic reviews that addressed PD in NICU and potential interventions.

**METHODS:** A meta-review was performed by searching various databases between 2000 and May 2024.

**RESULTS:** Fifty-four studies were included. The incidence of maternal PD varied depending on the screening tool used (13–93%), as did paternal PD (0.08–46%). The incidence of PD in sexual, racial and gender minorities, siblings, grandparents and those in lower-middle income countries is not known. Numerous screening tools were used with a wide variety of cut-off values. Various intervention programmes were evaluated and showed contradictory evidence regarding their effect on PD.

**DISCUSSION:** Routine screening should be implemented together with a combination of interventional programmes, specifically family-centred interventions. More research is required for PD in siblings, sexual and gender minority parents as well as parents living in low middle income countries.

*Pediatric Research* (2024) 96:1510–1518; <https://doi.org/10.1038/s41390-024-03599-1>

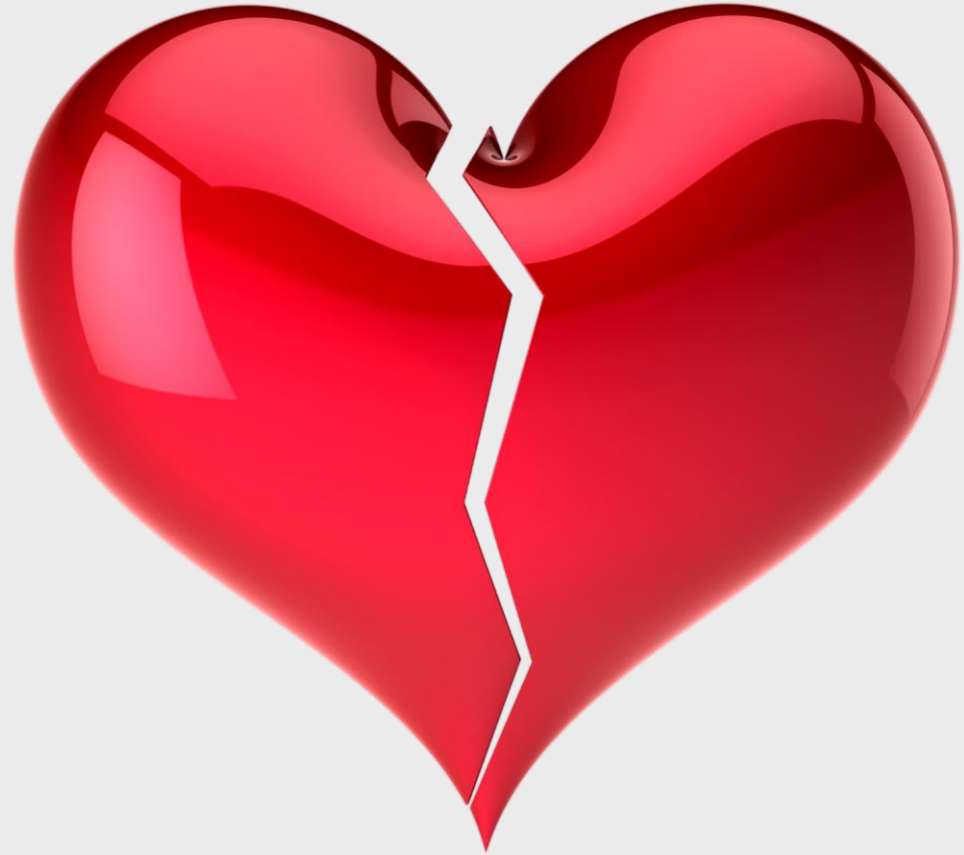
#### IMPACT STATEMENT:

- Psychological distress is high in NICU, affecting parents and siblings.
- Maternal psychological distress may have long lasting effects on infant health and differs from that of fathers, who require as much attention as mothers
- Little is known about emotional stress in siblings and sex and gender minority group peoples
- Few interventions showed conclusive effectiveness in reducing psychological distress with combination interventions showing more effectiveness than single interventions



- ▶ **Why do you have HIV, my child?**
- ▶ **Severe spiritual suffering**
  - ▶ **Guilt**
  - ▶ **Anger**
  - ▶ **Frustration**
  - ▶ **Fear**

The hardest  
part of  
treating a  
baby with HIV  
is treating the  
mother's  
broken heart





# Considerations

- ▶ Careful communication
- ▶ Support post diagnosis of the child
- ▶ Maternal care/Family care
- ▶ Prevent maternal illness and family disintegration
- ▶ Mindful of bereavement
- ▶ Cervical cancer and HPV awareness



## Care for the Caregiver: How Caregiver Mortality Affects Treatment Outcomes—An Observational Cohort Study

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**Table 1** Ages of caregiver and children and relation to clinic entry in cases with caregiver death

	All	Mother	Father	Other
Total	119	100	18	1
Median age of child (years) at time of death (IQR)	6.9 (3.5–11.7) N=95	6.1 (3.1–10.3) N=81	10.6 (5.1–13.5) N=13	12.7 N=1
Median age of caregiver (years) at time of death (IQR)	35.3 (30.2–41.7) N=77	35.2 (29.9–39.2) N=66	43.2 (32.7–52.1) N=10	65.4 N=1
Death in relation to entry into clinic N (%)				
After entry	66 (69)	57 (70)	8 (62)	1 (100%)
Same year as entry	10 (11)	8 (10)	2 (15)	0
Before entry	19 (20)	16 (20)	3 (23)	0
Unknown	24 (20)	19 (20)	5 (28)	0
Year of death N (%)				
2005 and earlier	2 (2)	2 (2)	0	0
2006–2010	13 (11)	13 (13)	0	0
2011–2015	23 (19)	19 (19)	4 (22)	0
2016–2021	54 (45)	44 (44)	9 (50)	1 (100)
Unknown	27 (23)	22 (22)	5 (28)	0

IQR Inter-quartile range

A hand holding a syringe against a teal background. The syringe is held vertically, with the needle pointing upwards. The hand is positioned in the lower right quadrant of the frame. The syringe has markings on its barrel, including 0.5, 1, 1.5, and 2.5. The text "Clinician pitfalls" is overlaid in a large, yellow, sans-serif font across the center of the image.

# Clinician pitfalls

# MCQ

- ▶ You admit Michael, a 13 year old boy and diagnose advanced HIV disease. You find out that his mother already knew about his HIV status but did not tell you. She is scared to tell Michael, his father and wants to delay ART. What is the most appropriate immediate response?
  - ▶ 1 You have to tell Michael his HIV status immediately since he is 13 years old and has a right to know his HIV status.
  - ▶ 2 We have to start antiretroviral treatment right now. His life is at stake and we don't have time for family problems.
  - ▶ 3 Report Michael's mother to the social worker for lying to you and neglecting Michael
  - ▶ 4 None of the above

# Many interactions are problematic

- ▶ Patient centred care is an opportunity to improve things
- ▶ How do we address attitudes, communication and behaviour
- ▶ Structural changes are often put forward to improve things
  - ▶ Decentralised Care
  - ▶ Training programmes
  - ▶ Mobile technology
  - ▶ Task shifting
- ▶ Too little focus on interpersonal relationships
- ▶ Where are we struggling?



# What do we experience every day?



► **Our experience is not virtual**

► <https://medium.com/@theostowell/a-complete-guide-to-minimising-digital-distractions-67889b5e48dc>



# Who am I?

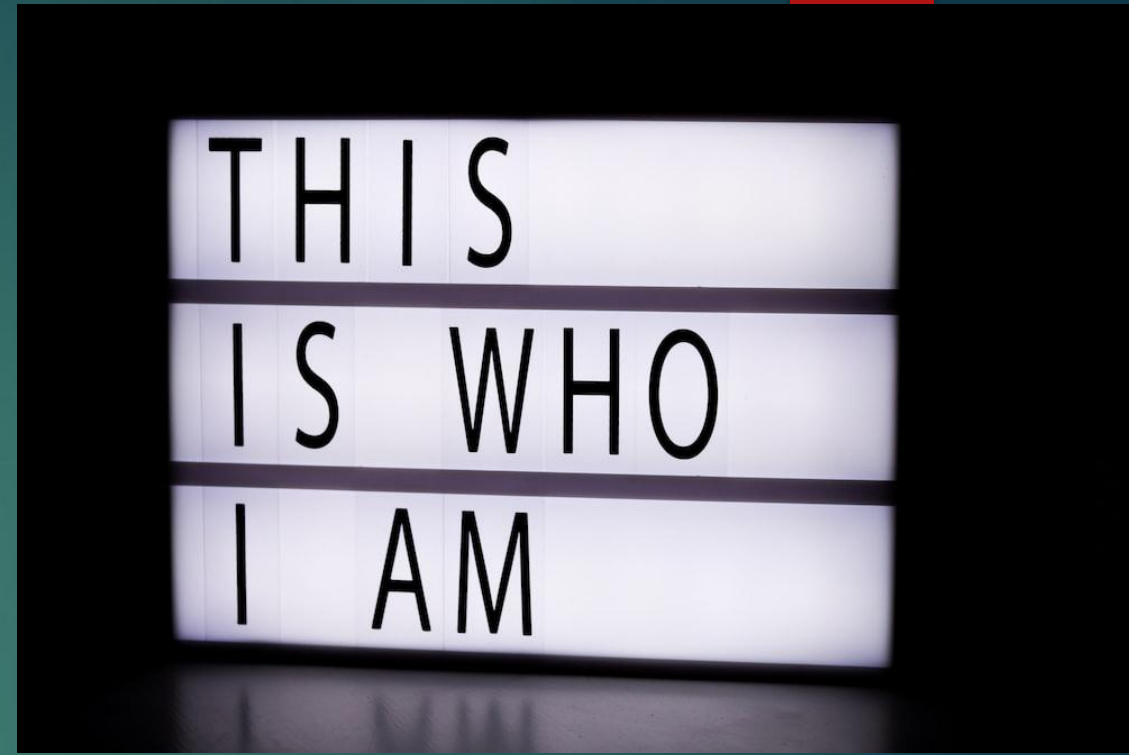
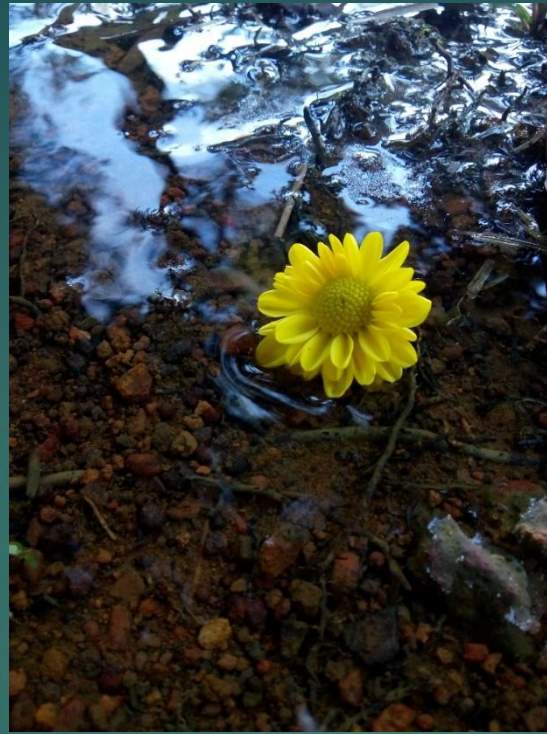


Photo by [Schayane Feitoza](#) on [Unsplash](#)

- ▶ A person willing to relate to and help other people
- ▶ Engaging fully in depth with a new person every few minutes
- ▶ At the coalface of some of the most difficult things
- ▶ Inequality
- ▶ Extreme suffering and deprivation
- ▶ Inadequate resources
- ▶ All life's other stressors
- ▶ Yet every day
  - ▶ You show up
  - ▶ Often silencing your needs
  - ▶ Working extreme hours

# Do you have time to recharge and get support?

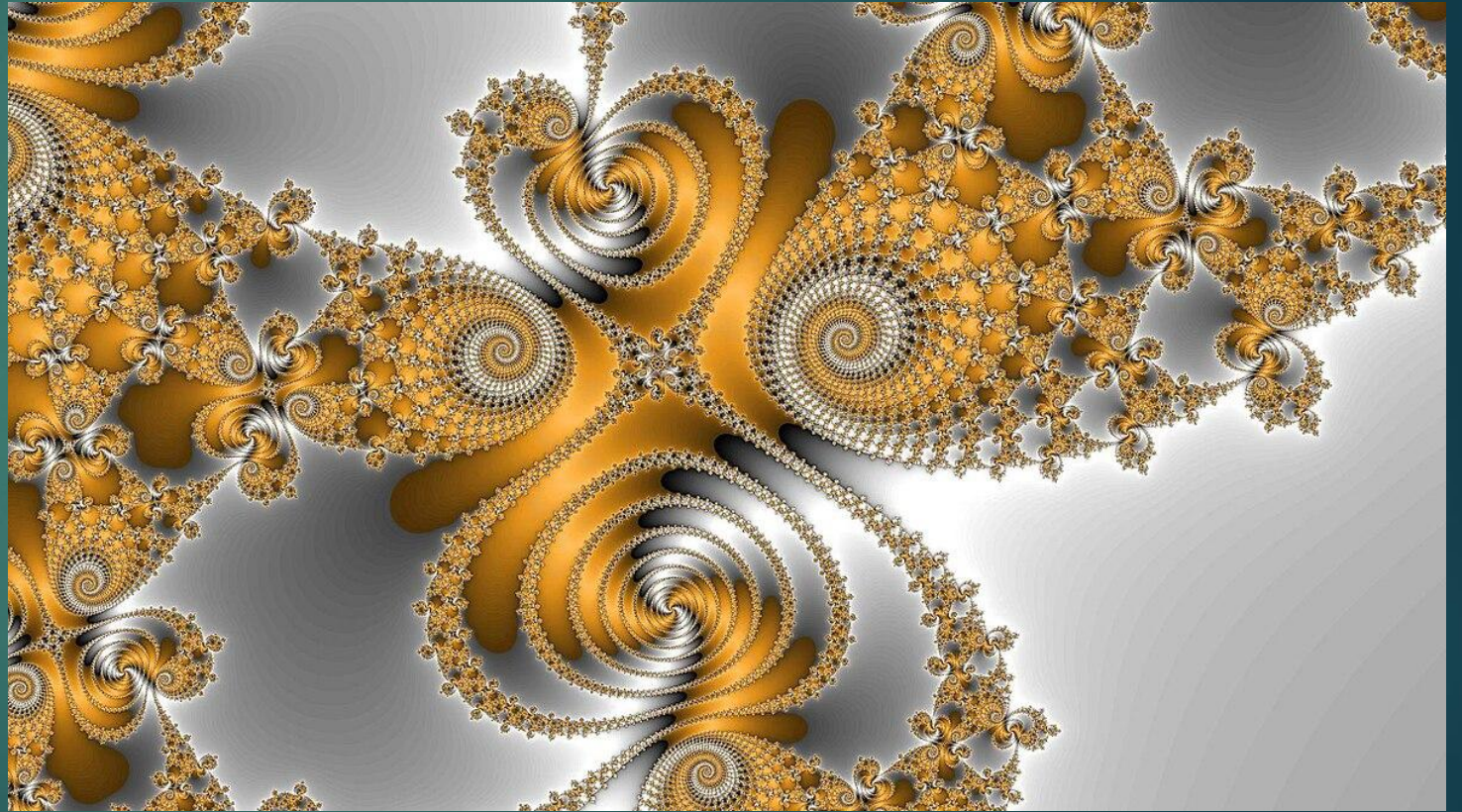
- ▶ Or are we left alone, to cry alone or process things without help
- ▶ When do we mourn our patients
- ▶ When do we process our feelings or frustrations





# You as the Clinician/Researcher

- ▶ You have immeasurable effects on the world around you
- ▶ In our context: on the lives of Families, mothers, infants
- ▶ How many lives have you touched
- ▶ How many families exist because of you, how much suffering has been averted?
- ▶ Do you stop to recognize that occasionally
- ▶ Maybe now would be a good time





# The consultation room

- ▶ We have covered a lot of potential stress the mother may be under
- ▶ We have not covered what stress the clinician is under?
- ▶ Is this leading to us butting heads in the consultation room?
- ▶ Our experience in high risk HIV ANC clinic – needing to be heard



<https://www.everypixel.com> Benjamin Melville



# Pointers about Patient Interaction

IT IS **CURIOSITY** THAT  
TRANSFORMS STRANGERS  
INTO PEOPLE WE CAN  
EMPATHIZE WITH

FAITH FITZGERALD ADAPTED FROM PROF NEIL PROSE



# Patient Centeredness

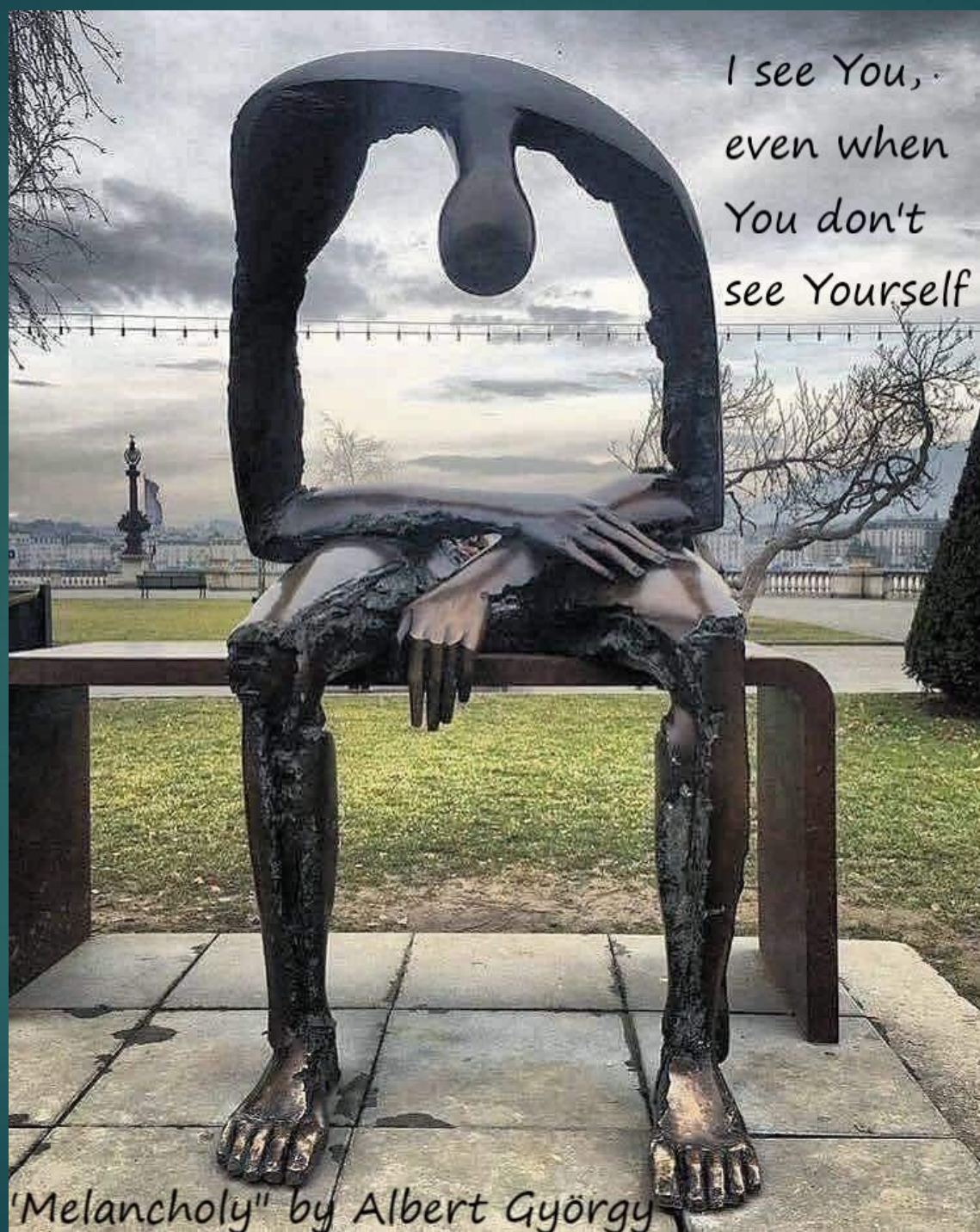
- ▶ Calm down before interaction, conscious decision to pay attention
- ▶ Sit
- ▶ Appropriate eye contact
- ▶ Listen to opening statement fully
- ▶ Open-ended questions and continuers
- ▶ If need to interrupt, ask for permission
- ▶ Consider asking permission to give advice
- ▶ Consider asking permission before explaining
- ▶ Reflective listening
- ▶ Joint decision making
- ▶ “Is there anything else...”

# Addressing emotions

- ▶ We are empathic
  - ▶ Name the emotion
  - ▶ Understand and legitimize the feeling
  - ▶ Respect and praise
  - ▶ Support – we will sort this out together
- ▶ Self-awareness
  - ▶ What makes you angry
  - ▶ How do you feel about the situation
  - ▶ Defensiveness

# Key Messages

- ▶ **Preventing AIDS in children requires comprehensive family care and support**
- ▶ **Using all opportunities to Screen, test, optimise and prevent, HIV itself as well as other associated conditions**
- ▶ **Diagnostic dilemmas can cause significant problems**
- ▶ **Advanced disease requires urgent action**
- ▶ **The journey of a child having HIV may be the hardest thing a mother will ever face**
- ▶ **You are the instrument – you require care, self-compassion, forgiveness and willingness to start afresh every day**



I see You,  
even when  
You don't  
see Yourself

'Melancholy' by Albert György





Dedicated to the families and beautiful children we accompanied last week







# Thank you for your attention

QUESTIONS AND DISCUSSION

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