How Stigma & Lack of Disclosure Fuel this Cruel Disease

Suniti Solomon, MD
Director, YRG CARE
The First Evidence...

“Expect the Unexpected!”

“Evidence for HTLV-III Infection in prostitutes in Tamil Nadu (India)”
YRGCARE – VCT Trend

22680 clients have accessed VCT services
“Marriage, monogamy and HIV: a profile of HIV-infected women in south India”

Lack of Disclosure to Spouse

Most Memorable Day

April 14, 1996…….

Diyas Birthday!
Discrimination Health Care Settings

Hospital turns away HIV-positive woman

Chennai: An HIV-positive woman who has been receiving anti-retroviral therapy since 2002 was refused entry to a hospital in Chennai. The woman, who had been referred to a specialist hospital for treatment, was turned away by the staff of the hospital.

AIDS patient finds all doors shut

Kendrapara, Jan 10: At a time when celebrities go out of their way to interact with AIDS patients to promote awareness, the fate of an AIDS patient hangs in the balance as he and his family have been ostracized by the village committee.

Man forced to deliver baby of HIV+ wife

Mcrut, June 28: In a shocking incident, a man was forced to deliver the baby of his HIV-positive wife in a government hospital when doctors allegedly refused to help the woman after getting to know about her status.
Evolution of YRG CARE
Ashok Pillai: President INP+
Murasoli Maran Surgical Suite
Lack of Disclosure to Family

- Malar........
- Girls in Tamil Nadu are culturally bound to marry their uncle (mother’s brother)
YRG CARE Matrimonial Service
Marriages are Made in Heaven but Initiated On Earth

- Murthy, an engineer, was pressured to get married by his parents
- Turned to the support services of YRG CARE
- His CV along with photo circulated to a network NGO in Maharashtra
- Murthy flew to Mumbai & met Bhavna
- Their love blossomed and they got married 2 months later
- Today, they are the proud parents of Akash
Barren Women – even more stigmatized!
Fertility Issues

- Revathy was married to her uncle (mother’s brother)
- She was aware of his HIV+ status but agreed as it is the custom
- Two years later, they were pressured by the family for a child
- Revathy travelled 400 miles to Chennai
- She underwent AI which only the couple were aware of
- Today, they are the proud parents of Aarthi
Stigma in the workplace

- I am a widow at 18 with a little girl
- I was denied employment which I was entitled to
- I am not wanted by my in-laws or parents
Interventions at Workplace

Ford India, Maraimalai Magar
Park Sheraton Hotels, Chennai
Vaas Industries, Chennai
Brakes India, Chennai
TVS Srichakra Tyres, Chennai
Thirumalai Chemicals, Ranipet
ISEX Fashions, Chennai
Neyveli Lignite Corporation
Onkyo, Chennai
The Hindu, Chennai
Autolec Industries, Chennai
Audco India Limited, Chennai
M K Electric
FORCE 1 SECURITIES

Simpson & Co, Chennai.
Larsen & Tubro McNeil, Chennai
Sundaram Fasteners, Chennai
Ucal Fuel Systems Ltd, Chennai
Chennai Petroleum Corporation Ltd,
Carborundum Universal, Chennai
FITSI, Chennai
ONGC, Chennai
SRF Ltd, Gummudipoondi
Visteon India Ltd, Chennai
Kodai International, Kodaikanal
Hosak Industries, Chennai
Southern Sulphates and Chemicals
SHRI RAM CHIT Funds

Overall more than 5000 individuals were provided workplace intervention
Discrimination at School

Indian school throws out HIV boy

A four-year-old boy has been thrown out of nursery school in India because he has been found to be HIV-positive.

The government-run school in Alwal, near the southern city of Hyderabad, sent the child home after parents of other children protested.

These children in Kerala fought for two years to get back to school.

'HIV stigma' drives India suicide

A 19-year-old Indian boy whose parents had HIV was driven to suicide by the stigma associated with the virus, police say.

Santosh Baniya died of burn injuries after setting himself on fire in the western city of Ahmedabad last week.

Despite efforts to raise awareness, stigma about HIV persists.

Both his parents were diagnosed with HIV two years ago. They are among more than five million people infected with the virus in India.

Before he died the boy had expressed fears about surviving his parents.
Children and Disclosure

Story of Bala and Mahesh
How to disclose with so much stigma fueling the cruel disease?

Do it with ........
It makes a difference

As the old man walked along the beach at dawn, he noticed a young woman ahead of him picking up a starfish and flinging it into the sea. Catching up with the youth, he asked her why was she doing this. The answer was that the stranded starfish would die if left to the morning sun.

“But the beach goes on for miles and there are millions of starfish” countered the old man. “How can your efforts make any difference”?

The young woman looked at the starfish in her hand and threw it to the safety of the seas. “It makes a difference to this one,” she said.

-Adpated from “unexpected Universe” by Loren Eiseley
“I live in a hope of world that will be, if not free from disease, free from stigma and discrimination”

Dominic D’Souza
THANK YOU