EQUITABLE HEALTH CARE FOR CHILDREN WITH DOWN SYNDROME IN INDIA

The challenges....

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Challenge 1 – The population

• 1.2 Billion and counting..
• 27 million births/yr
• 27,000 Born every year with DS
  • 19 / minute
• Spread over a vast expanse of geography
The Health Care Delivery system

• A combination of Government, Private & NGO, both urban and rural India
• Primary health centers/ District Head quarter hospitals and Teaching Institutions
• States decide their health policy
• Some policies by the Union health Ministry.
• The Indian Academy of Pediatrics lays guidelines for pediatric care
CHALLENGE - 2

Ensuring clinical recognition & confirmation of DS at birth.

- Intensive training for health workers / doctors for recognition & understanding implications
- Availability of confirmatory testing
CHALLENGE - 3

Setting up a National registry

- Leveraging the IT strengths of India
- National registry can be set up
- Registered families can have access to uniform health care practices
- Neighborhood experts can be connected
Communicating the (correct) information to the parents & help prepare them for providing optimal care

• Identifying champions in each district
• Training counselors
• NGO’s
• Social media
Social media..

Nawab Sameer
my son is 1.5 year old he is suffering from dwnsyndrm... he cant walk cant speak... i m crying a lot... why it happens with me? he is our first child pls help me i dont know more about it...

Like · Comment · October 3, 2013 at 1:50pm

Recent Posts by Others

Santosh Upadhyay
my son ansh is a ds baby bt i dont know what is ds... but doctors will be say he is abnormal baby..... pls tel me what i do 4him ..... i have nt suffecent monny for dis baby for his treatment ..........so plse advise me what can i do????

Like · Comment · March 14 at 11:02am via mobile

• Responses?
• Reaching out?
CHALLENGE - 5

Evolving a health care plan & implementation

- Role of The Indian Academy of Pediatrics
- Sensitizing the Government
- Partnering with experts
- Epilepsy
- Emotional & Psychological
- Sleep disorders
- Hearing loss

- Hypotonia
- Increased risk for spinal problems

- Pneumonia
- Need for vaccination

- Reproductive health

- Recurrent infections

- Structural
- Digestion
- Milk protein allergy

- Growth problems
- Overweight
- Underweight

- 50% heart defects

- Hypothyroidism

Access to specialised care
CHALLENGE - 6

Addressing the cost of health care

- Government funding to set up specialized departments
- Health insurance
  - Relatively young in India
  - Individuals with DS not covered under insurance
- Advocacy for health insurance
CHALLENGE -6

Federal Law
The Federal Health Insurance Portability and Accountability Act, otherwise known as HIPAA, prevents insurance companies from denying coverage to a person with Down syndrome. The law applies to group health insurance plans.

• According to the NDSC
  “People with Down syndrome have been and continue to be discriminated against with regard to access to health insurance, solely on the basis of the diagnosis of Down syndrome and without consideration of their individual health status or health histories.”
Addressing the Cost Challenge

• “Corporate Social Responsibility” of the companies?
• In India 2% of profits must be spent for social causes..
Messages..

• Tremendous challenges in India to address Universal health care for DS in India
• Logistics, information dissemination essential
• Creation of “champions” from the community essential
• A public-Private partnership is a good way forward
Have a nice day

Welcome to the 12th World Down Syndrome Congress

12th World Down Syndrome Congress

2015

Chennai, India

It is with pride that we invite you to visit India in 2015 and enjoy a bit of India and understand our major role in creating a world of respect for all those people with Down Syndrome.

The Theme will be Panch Tatvas - Revealing the FIVE TRUTHS about people with Down Syndrome

- Social Awareness & Self determination - Health - Education & Employment - Support System - Rights and the Law