

Present Status of EHDI in India

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My Personal Story of EHDI

- I became aware of EHDI 45 years ago when my daughter was born profoundly deaf. In early pregnancy, my wife was infected with Rubella.
- No Rubella vaccine was available at that time

Despite my being a medical doctor it was a challenge to bring up a deaf child

There were no deaf schools in our area
We parents of deaf children researched the best way to teach a deaf child, and opened a deaf school where lip-reading, sign language & speech were used

Special Teachers were hired from Gallaudet University, Washington, DC

Family support to the deaf child was a necessity. All family & friends were taught sign language.

The best way to communicate with a deaf child is speaking slowly and face to face.

Hearing friends of the deaf child were encouraged to learn sign and enjoyed the novelty of a secret language

Psychological support to the
Deaf child and Parents is
essential to alleviate
frustrations and challenges

Adjustment Process

- There is a DENIAL period for the parents; including Grief, Shock, Anger etc.
- Why Me ?
- Depending upon the Culture and Education one either Blames God or Seeks His help.
- Parents need advice from a counselor or other experienced Parents of a deaf child.

Adjustment Process (continued)

- Patience and Persistent efforts result in making the deaf child as well adjusted as their hearing counterpart
- Modern Technology with hearing aids and cochlear implants offer a great hope for normal language development.

Project Deaf India

- Started 1998 with Rotary International
- TWO Major Goals:
 - > EHDI in India
 - > Prevention of Deafness by Nationwide Measles and Rubella vaccination

My Inspiration for Helping Deaf in India



- 1964-Born Deaf, Pregnant Wife exposed to Rubella
- 1969 MR Vaccine, Started First Deaf school using TOTAL Communication in Santa Ana, California
- MA Degree, Gallaudet University
- Married to Deaf Husband, 2 hearing Bi-Lingual Children

Deafness in India

- One of the highest incidences of Deafness in the World
- Exact incidence unknown
- Higher incidence in South India due to consanguinity
- Higher in villages than Urban settings
- Late diagnosis (age 4-6 yrs)-Loss of Language development

Raj Desai Meets President of India



Raj Desai Discussions with the President

- MR vaccine for the entire Nation
(produced locally in Pune)
- Start EHDI countrywide
- Admit deaf students for free education to
all Institutes of Technology in India
- Economical Cochlear implants

Major Breakthrough for Deafness in India

- National Program for the Prevention and Control of Deafness (NPPCD) started 2007
- At present half of India is included in the pilot program
- Begin Training for additional ENT's, Audiologists, and grass root level workers
- Develop training Capacity of Medical Schools and district hospitals
- NPPCD should be complete in 2010, and EHDI implemented throughout India

India is no longer an underdeveloped Country it has had rapid growth in technology.

- India must advance in education and rehabilitation of the Deaf
- India needs new MANDATORY regulations for EHDI
- Aggressive public education on Deafness should be introduced in the Media
- EHDI has been successful in Mysore, Mumbai ,Kerala, Chennai & Goa.

PRACTICAL APPROACH FOR EHDI IN INDIA

- ECONOMICALLY- ONE OAE-AABR MACHINE CAN BE USED BETWEEN SEVERAL HOSPITALS BY ONE AUDIOLOGIST VIA SCOOTER, AS MOTHER AND CHILD ARE KEPT IN HOSPITAL FOR 7 DAYS
- AUDIOLOGISTS CAN ALSO BE SENT TO REMOTE VILLAGES FOR TESTING

EHDI Progress in Goa, India

- Only 1-2 audiologists in State of GOA
- Annual birthrate of 30,000 newborns
- Audiologists from Massachusetts volunteer their expertise to train more health care workers in Goa (100+ trained in one week)
- Newborn screening equipment purchased and donated from Rotary Grant-10 machines & scooters distributed throughout Goa, even home deliveries in villages get tested

State of Goa will be responsible
to carry on the future testing of
newborns









Reality of EHDI in India

- The active involvement and Funding by the Government of India to Prevent and Control Deafness shows promise that EHDI will be achieved by 2010.

“Every Child must be ensured the best start in Life...their future and indeed the future of their communities, Nations and the whole World depends on it”

Unicef

Thank You