

WORLD DOWN SYNDROME
CONGRESS 2015
CHENNAI, INDIA
AUG. 19 – 21ST



- ▶ 500 delegates attended the conference from 40 countries
- ▶ 110 research papers submitted
- ▶ 1.6 million persons with Down syndrome in India
- ▶ 1.3 billion people total population
- ▶ 1 billion people in the world with a disability

STATISTICS





KEY POINTS FROM THE CONFERENCE

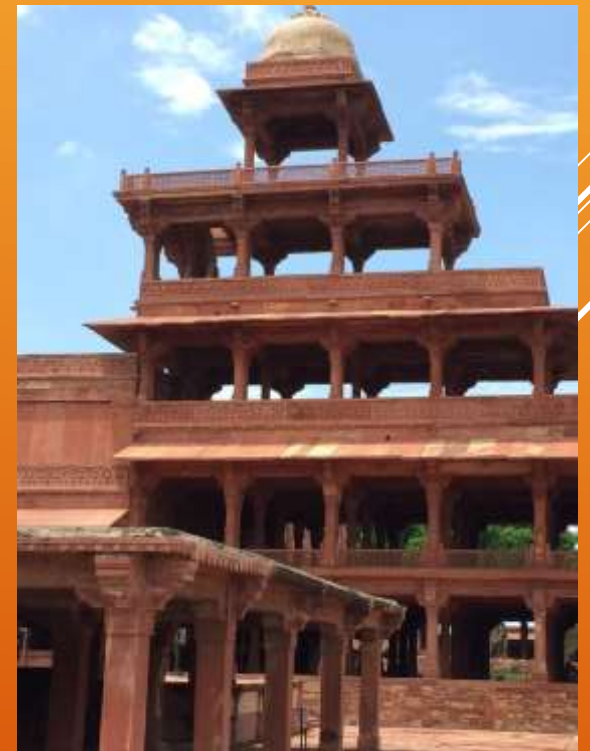
- ▶ Research on people with Down syndrome will benefit everyone, not just people with Ds, yet most underfunded 'genetic condition'
- ▶ Ds research links to: heart conditions, cancer, dementia, Alzheimer's, and diabetes.

CUTTING-EDGE RESEARCH



- ▶ The twenty-first chromosome has been mapped out
- ▶ Scientist have the ability to study human chromosomes in mice
- ▶ Shut a chromosome down (aka Gene Silencing)
- ▶ Ability to take genes and turn them into any cell type (stem cell research)
- ▶ Trisomy 21 to Mosaic Down syndrome *paper just released

CUTTING-EDGE RESEARCH



- ▶ Primary care physicians need to read the healthcare guidelines, and understand the reasoning behind each point and why it is in place.
- ▶ www.healthychildren.org click on health issues → conditions → developmental disabilities → Children with Down Syndrome: health care information for families

QUALITY HEALTHCARE



- ▶ “Be the keeper of your child’s story; hold the narrative of their life.”
- ▶ Emphasis on: thyroid status (check yearly with blood test), hearing and vision assessments, sleep studies and obstructive sleep apnea
- ▶ Personal safety: ignorance is not bliss. Information is much safer.

HEALTH



- ▶ The United Nation's Convention on the Rights of Persons with Disabilities (UNCRPD) is an important document that every family should read.

HUMAN RIGHTS



Why bother teaching kids with Ds math?

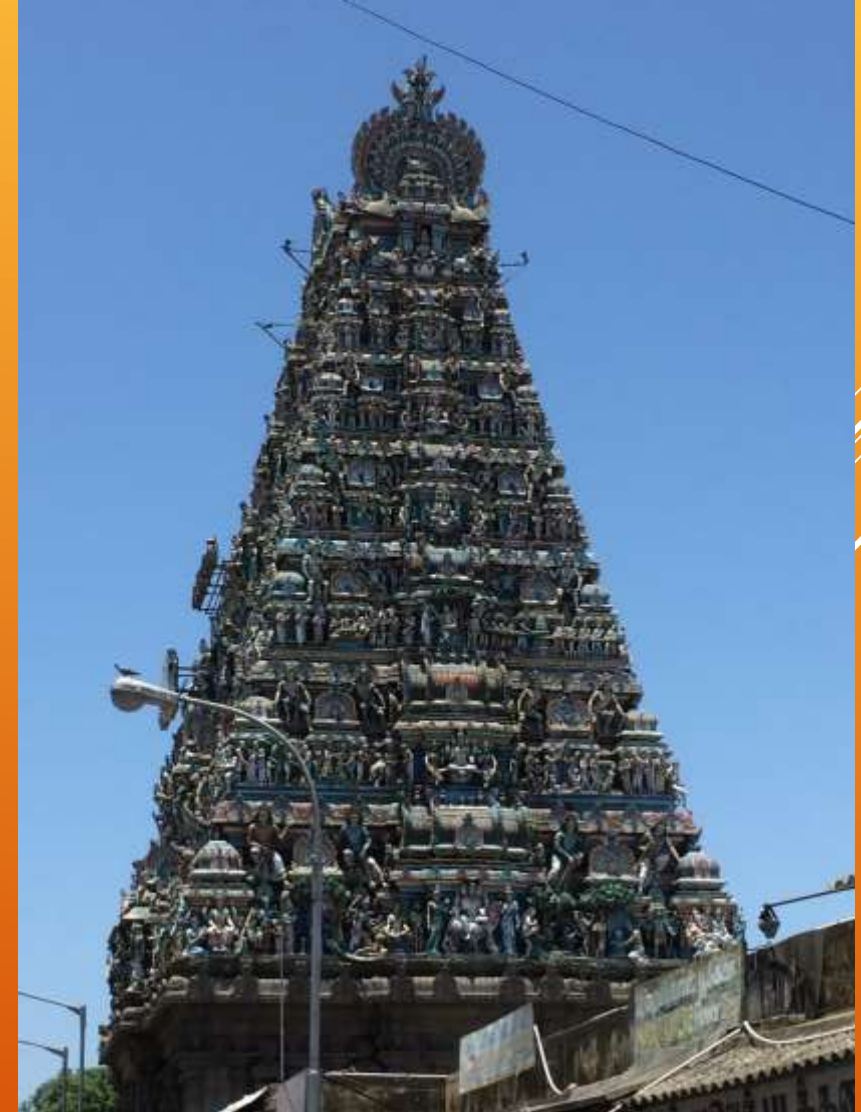
- ▶ You need math in everyday life: e.g., waking up, cooking, managing finances
- ▶ The more math you can do, the more contexts you can engage in
- ▶ Not being able to do math will cost you your independence
- ▶ Math is a human right! Use age-level curriculum, and modify as needed! (e.g. giving more time and less questions)



EDUCATION – MATH

- ▶ “There’s no such thing as a child who doesn’t know how to read, only a child who hasn’t found the right book.”
- ▶ “There is no glass ceiling.”
- ▶ If you increase motivation, you will increase success
- ▶ Modify books
- ▶ Make personalized books
 - ▶ FREE APP called ‘Story Creator’

EDUCATION - LITERACY



What's wrong in the U.K? (similar to Canada)

- ▶ Struggles with housing
- ▶ Lack of employment opportunities
- ▶ Isolation of adults with Ds
- ▶ Health inadequacies
- ▶ Community support, lacking



University of Sydney,
Program for students with ID

Benefits:

- ▶ Individuals became more independent
- ▶ Learned a lot
- ▶ Became more assertive
- ▶ Had mentors/friends (person who assisted them with note-taking in lecture)

SUPPORT SYSTEMS

- ▶ “Families are the true experts.” Dr. Balbir Singh
- ▶ Importance of the family and creating a network of support, i.e. Champions – “makes me feel strong.”
- ▶ Brian G. Skotko –
www.massgeneral.org/downsyndromeresearch.com
- ▶ Importance of sibling relationships, which are the longest lasting
- ▶ Great suggestion: Discuss an emergency plan for your loved one with Down syndrome once a year.

FAMILY



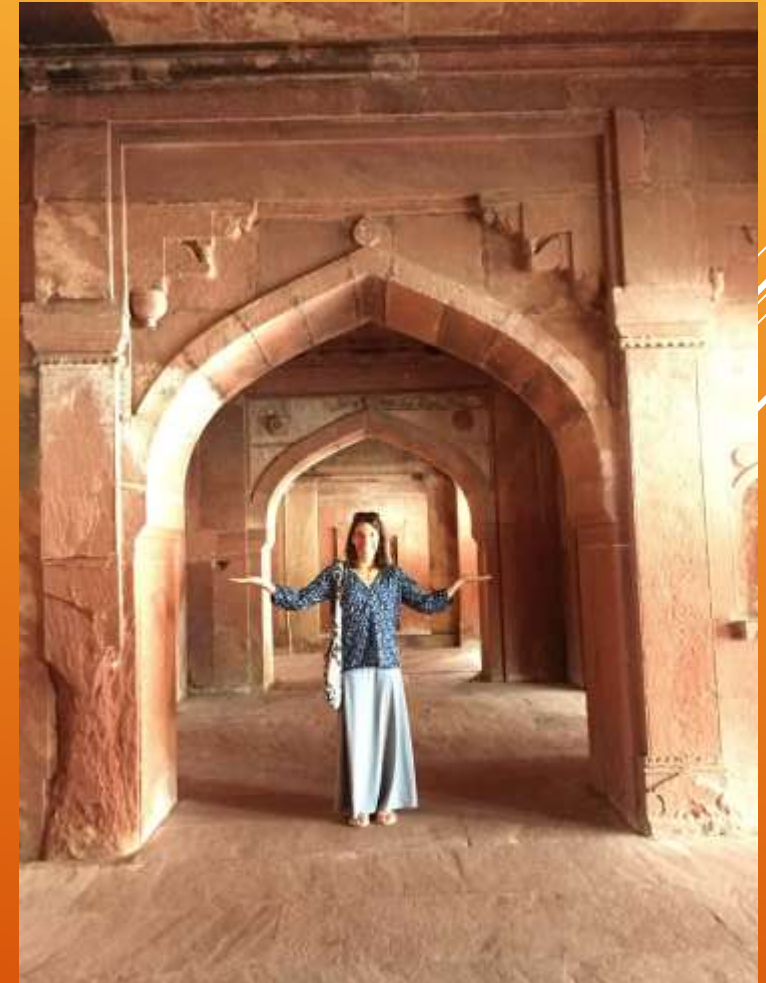
- ▶ Right of the person with Ds or any ID to choose their own future
- ▶ All of our children can think and make their own decisions
- ▶ A parent also has the right to **influence** their child

SELF-DETERMINATION



- ▶ Keep your child in speech therapy until a stranger can understand what they are saying
- ▶ General stimulation vs. specific muscle groups
- ▶ Potty training – looking for a **minimum degree of compliance**
- ▶ Importance of building a positive self-image and self-esteem
- ▶ Set your expectations high

GOOD ADVICE & A WORD ON
THERAPY...



- ▶ Attending Sheri Brynard's speech, a young woman from South Africa who is the only qualified teacher with Ds in the world.
- ▶ "I was awarded South Africa's Woman of The Year Award. Me, a person with a condition that causes people to abort."
- ▶ "We deserve to live!"



CONFERENCE HIGHLIGHT

- ▶ “Addressing the needs and taking care of those with Down syndrome strengthens the person, the family, the community, the workforce, the nation, and connects us all with what is best about our shared humanity.” Dr. George Capone, USA
- ▶ “The inability to see ability is the only disability.”
- ▶ “I know that my soul is not disabled.” Self-Advocate, Alex Sneddon (Scotland)
- ▶ “There is no such thing as a false note.”
(end of Sheri Brynard’s talk)



QUOTATIONS



FUTURE CONFERENCES

Future Conferences to be held:

WDSC in Glasgow, Scotland - 2018

Also of interest: European Down Syndrome Congress (EDSC) to be held August 5th to 7th, 2016 in Istanbul, Turkey