



**Minutes of the APDSF AGM**

**Date** – 8 September 2017

**Venue** – Villa Medici Hall, Taj Mahal Hotel

**Members Present:**

President

Mr. N. Ramachandran

Vice Presidents

Dr. Bhavani Sriram

Dr. Lalita Joshi

Mr. Angus Graham

Executive Committee Members

Ms. Erdenechuluun Chultem

Ms. Hiroko Kondo

Secretary General

Mr. S. Krishnan

Treasurer

Mr. K. Rajendiran

Chair of the Awards Committee

Dr. S. Suresh

Independent observer

Mr. Paul Zanon

Special Invitee

Dr. Surekha Ramachandran, President - Down Syndrome Federation of India

Country Representatives

Australia

Ms. Ellen Skladzien

Bangladesh

Mr. Sarder Razzak

Prof. Hakim Arif

Bhutan

Ms. Beda Giri

Kinga Wangmao

India

Dr. Surekha Ramachandran

Dr. S. Suresh

Dr. Shaji John Thomas

Dr. Priya Chandrasekhar

Dr. D. K. Chopade

Mr. Amarjit Singh Anand

Indonesia

Mrs Sri Rejeki Ekasasi

Mrs. Olivia Duhita

Mongolia

Mr. Ganzorig Vanchig

Myanmar

Mar Lar Phyu

Nway Nway Eaint

Nepal

Mr Ram Kishore Singh

Mrs. Dr Prabha Sayami (Mainali)



New Zealand

Ms. Zandra Vaccarino – could not make it but report sent and read out

Sri Lanka

Mr.G.A.W.G.Galgamuwa

Dr. Koralage Dayarathna

### **Proposed Agenda**

Introduction by President

APDSF Annual Report

APDSF Treasurer Report

Address by Vice Presidents

Country Reports

### **Minutes**

#### **Agenda Item - Introduction by President**

Mr. N. Ramachandran, President APDSF welcomed the delegates and a round of introduction of all members was done. He then thanked members for attending the AGM and gave a brief gist of why the body was formed and what it hoped to achieve. **He also gave a summary of the discussion at the Executive committee meeting.** He mentioned about the formation of the various committees and the AGM unanimously approved the formation of the 3 committees – The Finance Committee, the Medical Committee and the Research Committee

He also said that the award winners had been selected. However since time was short, the criteria next time would be different and enough time given for both nominations and selection of winners by the awards committee.

He welcomed everyone again and gave the assurance that the finances of APDSF would be strong and the money put to good use for APDSF members. It should be endeavored to raise US \$ 50000 to be held as a reserve for the APDSF to be available at any point in time.

#### **Agenda Item - APDSF Annual Report**

The annual report of the APDSF for the years 2016-17 and 2017-18 (so far) was read out and unanimously approved.

#### **Agenda Item - APDSF Treasurer Report**

The Financial report was read out and unanimously approved.

#### **Agenda Item - Address by Vice Presidents**

Dr. Bhavani Sriram explained what was discussed for the Research and medical committees at the EC meeting

Mr. Angus Graham thanked the gathering and spoke about how the APDSF had so many countries coming together as one. The group, he felt, had the capability to become a powerful body that can negotiate with the regional governments. He also mentioned that it was necessary for the website to become a tool for information dissemination.



Dr. Lalita Joshi hoped that with the APDSF better results would follow for Down syndrome in Nepal. Spreading awareness and Inclusive education was the need of the hour for countries like Nepal and others in the Asian region.

### **Agenda Item – Country Reports**

This was followed by the country reports from various countries.

#### **Australia – Dr. Ellen Skladzien**

- Focus on advocacy, information and community awareness
- Disability grant for persons with Down syndrome
- NPIT screening free for moms-to-be
- NDIS – National Disability Insurance Scheme
  - Government funds persons with Down syndrome
  - Package depends on the needs of the individual
  - Not everybody gets the same amount

The President requested for a copy to be given to all APDSF countries for them to discuss with their respective governments.

Mr. Graham, mentioned that this was probably the biggest social reform worth approximately AUD \$ 20 billion

- Earlier it was done state wise
- It was at the discretion of the person with down syndrome
- Service providers can be changed
- The amount works out to anywhere between AUD 5000 – AUD 12,000.

A question was asked as to how it went to an individual. The response was that:

The money went to the person with disability

- Need based packages available
- Annual review for evaluation
- Funding done through tax paid by every individual tax payer
- Changes to visa laws are required since persons with Down syndrome are not given visas easily.

Does termination occur because of free screening in Australia? Yes 70%-90% people chose to terminate the pregnancy on getting positive result.

What are the assessments done for the insurance? The outcome measures?

- Planners are recruited who meet the persons with disability
- They take information from the teachers, physicians etc before recommending to the government
- The outcomes of this is employment, social and economic independence

#### **Bangladesh**

- Focus areas Education, medical programs recognizing potential
- Mission – raising awareness to and by parent support groups, formation of self advocate groups, DS sibling groups, DS education group
- 1<sup>st</sup> edition of their Newsletter released in March 2017, second edition in October.
- 2 resource centers established where Early intervention and inclusive education is taught.
- Many parents not interested in allowing their children play with persons with Down syndrome.
- Outreach programs in villages launched
  - 30 new members joined the Bangladesh group from the rural areas due to the outreach program



- Government of Bangladesh observed WSDS this year
- Media coverage for WSDS and interviews of persons with Down syndrome aired on local Bangladesh channels
- Non medical research work being conducted.
- Funding the main problem for DS in Bangladesh

### **Bhutan**

- The king and queen of Bhutan very positive and supportive
- During the annual festival a person with Down syndrome (one particular child) takes a picture with the king and queen and this has become a ritual.
- From 2014 - WSDS celebrations began in Bhutan. From 2015, it was Cerebral Palsy. 2013 - Autism
- Gross Happiness - the index of the country
- Being Buddhists, diagnostics not practices in Bhutan
- Screening for neo-natal done.
- Parents allowed to express views on any aspect of the disability policy
- Education curriculum depends on the special educators
- Inclusion encouraged by means of media - TV, newspaper, radio and all national media
- During WSDS government officials all encouraged to be part of the programs.
- How is the Gross Happiness Index measured?
  - During taking of national index, disability is measured in a bottom up approach where each individual under the various local governments is measured for the same.

### **Japan**

- Japanese Down Syndrome Society (JDSS) has over 1000 + members
- Independent bodies at local levels organize their own events.
- Interest rising amongst the citizens regarding disabilities
- Currently 5% employment reservation for persons with disability in any company. Bodies like JDSS fighting for up to 7%.
  - If persons with disability are removed from employment, the organization needs to pay a penalty.
    - Education options for persons with disability provided in schools and colleges
  - Parents can choose either a special school or a public school
  - Systems are different in different schools
  - Both local and national governments offer support for Persons with disabilities
- Parents' voices are being heard now. Awareness campaigns through social media have led to success of events like Buddy Walk
- JDSS held the 1<sup>st</sup> conference on social and medical changes in the month of October. The aim of the conference was to discuss advancements for persons with Down syndrome

### **Issues**

- Promotion and push for the various movements being launched for persons with Down syndrome
- Choices to be expanded post education and during employment phase
- Seamless medical care
- Wages for Persons with Disability to be fixed.

How is disability defined in Japan?

- The government identifies and certifies a person as someone with disability.

### **Indonesia**



- Parents are not embarrassed to be associated with a child with Down syndrome.
- Fees are subsidized.
- Teachers understand the need of persons with Down syndrome
- Today society is clearer about DS
- Celebrated WDSO
- Every school needs to accept children with disability
- However for persons with Down syndrome this has not been very successful
- In every company 1% of workforce to be person with disability
- In universities, medical faculty, psychology students who know DS work as volunteers
- Overall Indonesian society is aware of Down syndrome

### **India**

- After WDSO 2015, awareness about Down syndrome much higher
- 2 children with Down syndrome adopted from orphanages
- A few families have opted to continue with a pregnancy even after knowing that the child was a person with Down syndrome
- Fighting on with the government to make Down syndrome a better understood condition
- Medical research on early intervention happening and diet modifications being offered to make them healthy children
- Promotion of sports for children with Down syndrome by means of special Olympics
- Self advocacy centers being opened in the north
- Inclusive education though a law has not yet been implemented.
- Change in attitude following WDSO
- Awareness about DS is partial in most of the areas in India
- Testing and screening available yet people not utilizing it due to lack of knowledge
- Insurance companies not willing to provide insurance to persons with DS.

### **Mongolia**

- Government subsidizes medical insurance but that is not enough.
- Ministers more into paper work than looking at ground realities
- DSAM does not get anything from the government
- There are special schools and there are mainstream schools - there is no concept of inclusion
- Special educators in mainstream schools are not willing to take in persons with special needs
- Education is compulsory. However there is no penalty if the child is not educated
- No proper methodology to detect Down syndrome
- Healthcare is a weak point in Mongolia
- Young adults with DS in Cambodia need to be provided with Vocational training, employment, sex education and inclusion.
  - The main challenge for these people is there is no concept of independent living and no place to go.
  - An institution can be set up however the idea needs to be worked upon
- According to law 5% of the employees can be disabled, but companies prefer paying penalty
- Cambodia is looking for support in the form of best practices from other countries
- Currently research work is happening on shutting down the extra chromosome
- The aim of the APDSF should be to set a benchmark for the world in the area of Down syndrome



- The federation should get to a position where they can advise governments on matters related to DS in the region
- The government should be our ambassadors
- A synergy can be brought about by working with like minded organizations like Special Olympics.
- SPONSORSHIP can be obtained from the corporate who already sponsor these events
  - Each country can look at global sponsors who would be glad to associate with us for the cause.
- Subjects like research in dementia in persons with DS that is happening in Australia can be shared with Mongolia.
- Indian medical tourism can be shared with other APDSF countries

### **Myanmar**

- Teachers not sure on how to address persons with Down syndrome
- Early intervention is vital
- For addressing dental healthcare issues, they have tied up with the University of Dental medicine where 150 people were tested for dental health as well as hearing.
- Training is happening to include people to contribute to society by being volunteers
- They are also a part of a local talk show which shows persons with Down syndrome and their families.

### **Nepal**

- They have a 10 year plan
- Dr. Lalita Joshi was elected member of the Special Olympics
- 2 children have been moved to mainstream school
- Many health camps organized. Walkathon also organized to spread the word
- Economic status of persons with disability and their parents need to be raised.
- As an inclusive measure, children with DS were taken to the zoo and other social events
- Counselling is being done on a regular basis even to persons from remote areas
- APDSF is an umbrella organization with which all countries should work together
- A pilot health insurance policy was undertaken last year and an amount of Nepali Rs. 2500 given in insurance
- There is no support except for family

New Zealand report read by Mr. Paul Zanon in absentia.

The President then said that all the reports would be made available on the website. Only the important points would be sent out as minutes.

### **Sri Lanka**

- A brief history of the organization was provided
- 6Lakh disabled people in a 1.2 billion population. There is no statistics for Down syndrome
- Disability grant provided for all children - Rs. 2500/- per month
- Most schools have special educators with a department specially for that in the government
  - The teachers however need to be motivated through training etc
  - A proposal was passed to provide special allowances for these teachers
  - A training session was undertaken for teachers to be able to identify Down syndrome
- A new program has been introduced where professionals will help persons with DS and school children also motivated to help persons with Down syndrome become more inclusive



- A travel program - a kind of exchange program where people from other countries can become guests of parents with DS in another country. This can be done with other disabilities also
- Tour packages can be organized
- Exposure needs to be created for persons with Down syndrome

A Federation in the name of Sri Lanka cannot be registered as there are a lot of legal issues connected with it. But the members are trying for it.

### **Agenda Point - The Way Ahead**

The President thanked all members for reposing their confidence in him. The next plan of action as discussed was as follows:

- Collation of best practices and dissemination of the same
- Information sharing using the website/other social media
- 2 discussions between members using skype and 1 AGM every year
- Raising funds for APDSF
- Website to be provided information on advances in research
- Countries interested in hosting the next AGM to send a mail to the secretariat with information on what they can do and what assistance they would be needing from the secretariat.
- The APDSF awards have been finalized.
- APDSF members should identify multinationals who can provide sponsorship for APDSF as a whole
- There will be a 1 currency account for sponsorship and it was unanimously agreed that it would be a Dollar account.
- Committee members to be suggested for the Medical and Research committees from their countries by respective country representatives

The president reemphasized that the APDSF was an independent body, beholden to none and willing to collaborate with anyone for attracting best practices. However the goals should be clear - working together for a common cause. . He also mentioned that the APDSF can be rebranded subsequently if the need arises. As a body nomenclature was not important, but the work going on into it so that persons with Down syndrome can lead better lives.

The meeting was brought to a close with the Vote of Thanks by the Secretary General.

The above minutes have been prepared and edited by the Secretary General, Mr. S. Krishnan, IAS (Retd.) and sent on his behalf.