

MINUTES OF THE ASIA PACIFIC DOWN SYNDROME FEDERATION AGM 2019

Date

Sunday, December 08, 2019

Venue

Arjawan & Yasmin Room, Shangri- La Hotel – Dubai

Members Present

1. Ms. Salma Kanan
2. Dr. Manal Jaroor
3. Mr. Gamini Galgamuwa
4. Dr. Koralage Dayarathna
5. Ms. Erdene Chultem
6. Mr. Vanchig Ganzorig
7. Mr. Angus Graham
8. Ms. Natalie Graham
9. Dr. Pornswan Wasant
10. Dr. Chaiyan Rajchagool
11. Dr. Bhavani Sriram
12. Ms. Lena. Ye Lei
13. Ms. Mary. Xu Ma Li
14. Dr. Surekha Ramachandran
15. Mr. N. Ramachandran
16. Mr. Shahzeb Shaikh
17. Ms. Mar Lar Phyu
18. Ms. Khant Nay Chi
19. Ms. Aishath Shifa.
20. Ms. Hiroko Kondo
21. Mr. Paul Zanon

Observers:

1. Mrs. Nawal Al Nasser
2. Mrs. Aalya Husain and
3. Ms. Safeya Al Safi
4. Mrs. Rosalina Alexander
5. Mr. Suchart Owatwunasakul
6. Ms. Lily. He Xiang
7. Mr. Dennis Zhou Bo Kai

Agenda

1. Attendance
2. Opening address by the President
3. Confirmation of the minutes of the previous General Meeting
4. Matters arising out of the minutes of the previous General Meeting
5. Financial Report
6. Secretary General's Report
7. Medical Committee Report
8. Any other Business, with the permission of the Chair
9. Mr. Paul Zanon - Vision for APDSF

1. Attendance

Attendance was taken for all members present.

2. Opening address by the President

The President of APDSF, Mr. N. Ramachandran welcomed the gathering by offering condolences on the demise of husband of Vice President Lalita Joshi and Secretary General of APDSF, Mr. S. Krishnan. A one minute silence was observed to pay respect to the departed souls.

He then welcomed China as the latest addition to the APDSF family and solicited their active cooperation in the region.

The following points were discussed:

- APDSF will try and join the CRPD group and apply for funding, however this would take time.
- APDSF is willing to provide assistance to anybody in the region for the betterment of persons with Down syndrome
- He thanked Japan Down Syndrome Society for an excellent Medical Interest Group meeting at Tokyo in November.
- APDSF is trying to reach out to other countries in the region
- He then said that Mr. Angus Graham, Vice President, APDSF would be sharing the discussions and decisions taken during the Executive Committee meetings after the formal agenda items were taken into consideration.
- Each country would be given time after that to discuss their progress.

The committee then got on to the formal agenda.

3. Confirmation of the minutes of the previous General Meeting

- The minutes were passed unanimously with Australia proposing and Japan seconding the motion

4. Matters arising out of the minutes of the previous General Meeting

There were no matters arising out of the minutes of the previous AGM.

5. Financial Report

- The report was passed unanimously by all members present as proposed by Singapore and seconded by Australia.

6. Secretary General's Report

- The report was passed unanimously with Mongolia as the proposer and Myanmar as the seconder of the report.

7. Committee Reports

Executive Committee Report

- Mr. Angus Graham mentioned about the Executive Committee Meeting in the morning and how it was discussed on what the best way forward would be.
- Ideas were circulated during the EC meeting that morning.
- The post lunch session would be able to throw more light on this. In the morning session, the key areas that came out were as follows:
 - Dissemination of information
 - Initiatives that were taken this year
 - Joining the UN CRPD as a member.
 - UAE was one of the first signatories of the UNCRPD.
 - APDSF will look at membership of Conference of State Parties (COSP) in the UNCRPD
 - Each country in the APDSF can become its member.
 - More information can then be made available on Down syndrome to the group
 - Greater chances of availing funding.
 - Australia already a member of COSP.
 - Countries can apply on their own for this.
- **A calendar of Events for APDSF to be created..**
 - All countries can share their events which will be uploaded on the website.
- **Developing the APDSF App**
 - This would provide greater access to information for persons with Down syndrome and their carers.
 - This app should reach out to the maximum number of persons with Down syndrome as possible.
 - Surveys can be shared through the app to get relevant information.

Developing a Database

- Understanding and collecting information for developing a database of persons with Down syndrome. This can help in sending relevant information
- When bodies/individuals subscribe to the APDSF, information would be disseminated to them from APDSF.
- This has not been done before and Australia is developing a database now. The National Body will start doing this
- The criterion is to maintain the privacy of the family and the individual.

Mr. Ramachandran then spoke about how India had their camps across various states in a calendar year and this would also be updated in the calendar being prepared.. Similarly if each country is able to provide the APDSF with their calendar of events, this could be put up on the website

This could benefit neighboring countries in attending events.

Calendar to be ready by END OF JANUARY

Mongolia said that they had reached out to almost 75% of their population

China wanted to know the rules to join CRO

Mr. Ramachandran responded saying that NGOs have the same permission from the government to spread information.

Pakistan delegate said that his government was quite receptive. He expressed a view that anything government support was necessary to support persons with Disabilities. CRPD was considered important in Pakistan too.

Thailand They have a birth defect registry since the best time to deal with this kind of information is at birth. They work along with health personnel and everyone has an ID. This also helps in having details of Persons with Down syndrome across provinces. Estimation is easy but getting accurate data is the key.

Sri Lanka – They do not have any data or statistics separately. Plan is to identify them as a separate disability. They plan to establish clubs across the country to collect data. This was started a couple of months ago. They are trying to form these clubs in rural areas too where access to information is very low. Underprivileged kids still stay at home

Thailand wanted to know the functionalities of the Database collection for which he was informed that the details were yet to be worked out.

Mr. Paul Zanon

- We need to look at the integrity of the Database
- Needs to be accurate from the families that interact with members of APDSF
- We are not looking at a Strike Rate, but rather accurate data

Mr. Ramachandran then assured the delegates present that this activity would be taken forward. He then requested Chair of Medical Committee, Dr. Bhavani Sriram to present the Medical Committee Report.

Medical Committee Report

Dr. Bhavani Sriram

- The report has already been provided to all the delegates as a part of the conference kit.
- It is difficult to decide on what the actual need for each country is
- Last time the delegates wanted to know all about the Medical Interest Group. To take this forward, we need a team of people who can brainstorm and come up with a strategy.
- The Meeting of the Medical Interest Group (MIG) is being planned in August next year (2020)
- Each country to send representatives for the meeting who could be Doctors and allied Health Professionals. In the area of Down syndrome.
- APDSF is planning to host this meeting at Chennai, India
- Plans for the same will be made by January.

DR. BHAVANI SRIRAM TO PROVIDE A ROUGH DRAFT OF THE PROGRAM FOR THE MIG MEETING.

- To start with, each country to use the Medical Passport for Persons with Down syndrome.
- 25 families from each country can fill it. This can be a handheld record for them.
- The families are using this in Singapore and doctors are asked to fill in these records. This helps when someone else is expected to take care of the Person with Down syndrome.
- Passport is a lifelong record for everyone since it is difficult to remember every event in life.
- This is being used in Sri Lanka and India currently.

A REVISED PASSPORT FOR ALL COUNTRIES TO BE SENT OUT BY DR BHAVANI SRIRAM BY END OF JANUARY 2020

- Countries to use the passport and provide feedback to the medical committee along with changes required in the passport format during the MIG meeting in August. Also this would help understand if Generalization of the passport across countries is possible.
- It is understandable if the doctor is reluctant to fill in records, but over time, it would become easier as it would become a routine task.
- **Sri Lanka** has already distributed 500 passports.
 - The Government representatives have not done anything to take this forward.
 - Dr. Sriram wanted to know if there was any association which could take this forward. The response to this was “No”.
 - She then wanted to know if there was any committee like the Indian Association for Pediatricians (IAP). Doctors need to endorse the passport to make it relevant.
- **Mr. Paul Zanon** wanted to know whether the passport could be a useful document even without a Doctor’s endorsement.
 - Dr. Sriram responded that it was but in the affirmative.
 - She needs to add a few addendums and will then circulate it amongst the groups.
- **Maldives** found the passport a good idea for their country.
 - Now a census is being planned in their country where they have asked for a separate identity for persons with Down Syndrome.
 - DS has not been identified by the population yet.
 - She wanted APDSF to send a proposal to the government of each country and this could make the plea stronger.
 - Mr. Ramachandran said that the APDSF was willing to give a letter on behalf of the body, however will the Government accept it?

The proposal to send a letter to Governments on behalf of the APDSF was accepted unanimously by the delegates.

- Organizing medical camps from APDSF not practical at this point. Instead the Passport can be used as the starting point.

Each country spoke on their present situation

Australia

- He would speak to the Government for Financial aid as mentioned in the EC Meeting

China

- It is an honor to attend the meeting
- They have a lot to report to their committee back in china.
- Some of the points are doable back home – including the Passport.
- They will collect the data by going in for Government Support.
- In future they plan to visit Thailand to learn from them
- There is a Government backed Committee on Down syndrome

India

- Healthcare is the basis of the entire program in India.
- The MIG meeting is a good start.
- Only tips regarding healthcare and medication can be given
- Like in India Medical Groups can be created across the region
- APDSF should be able to address 3 major issues –
 1. Awareness
 2. Health
 3. Education

Japan

- They have been members of the APDSF for the past 3 years
- It is a pleasure to have other countries joining the APDSF.
- What we need to do now is to understand how to use time, resources and energy towards the goal of making our region Down syndrome friendly.
- The Database and Passport are wonderful ideas and need to be implemented. If that is done, it would be a good start for the APDSF

Maldives

- She thanked the APDSF for the invitation and said that it was one of the best platforms for sharing information, knowledge and ideas.
- They are happy with Early Intervention programs in their country
- The biggest issue is for Adults with Down syndrome over 18 years of age.
 - They are not schooled nor are they verbal
 - There are no therapists and there is no intervention for them
 - Parents are worried about both their physical and mental wellbeing
 - She requested APDSF to find a solution for them
 - They are planning to start physical fitness activities like Exercise, Gym etc with an instructor. Discussions are also on for Physical Training
- Parents are unwilling to let these young adults go to work

- Suggestions in this area was solicited by the delegate of Maldives

Mongolia

- Mongolian delegate thanked everyone for uniting for the event.
- It was important to raise public awareness and all members should attend such events.
- This time it was a good meeting since a lot of thought sharing happened and new steps taken.
- In Mongolia a new law has been passed so schools have to accept persons with all disabilities including Down syndrome however not enough kids join.
- Countries having resources can provide trainers for these schools
- Health is addressed well by the government
- APDSF can look at a Social Enterprise Model. For e.g. a combination of a Coffee Shop and a Bakery can be started and this can be a Franchise based model for persons with Down syndrome all over the region.
 - Developing countries can look at working on this.
- Independent infrastructure is not available for persons with Down syndrome.
 - Inviting special guests like Dr. Brian Skotko to discuss this.
 - They would like to invite countries like Japan and China to join them and this can help share both learning and costs.
 - During these programs, the Media can be invited and thus help spread awareness.
- The DSAM representative had a query on balancing the various bodies that they are members of – DSi, APDSF etc.

Myanmar

- Disability Certificate is given to persons with Down syndrome in their country
- There is however no separate certificate for persons with Down syndrome and the certificate is for Intellectual Disability alone.
- How can the Disability Certificate be provided in the country? The Myanmar Down Syndrome Association is spearheading this activity
- Qualified Special Needs teachers are not available in Myanmar and they are the most in demand.
- No vocational training is provided for persons with Down syndrome.
- APDSF members were invited to provide support by visiting Myanmar and seeing the situation themselves.
- Medical Passport was shown to Doctors but they refused to fill it in because of lack of time.
- This year, a medical check-up has been planned

Dr. Bhavani Sriram wanted to know how DS is identified separately in their country. Whether Karyotyping was done?

- Myanmar delegate informed the members that only symptom and physical Features were checked for this. No blood tests were done.

Pakistan

- They thought that it was a great learning experience
- He believes that the gathered knowledge should be shared with the local bodies and with the Government
- Their state has an active Smart Disability Card
- Disability Certificate is provided show the category, however the relevant authority needs to have signed it.
- Pakistan will try and implement the Passport for Persons with Down syndrome, however there are financial constraints which have to be taken into consideration.

Sri Lanka

- Their main thought is to deliver services to persons with Down syndrome. But how can they do it.
 - They have started clubs especially for persons with Down syndrome
 - This will enable them to collect data
 - The target is to create at least a 100 such clubs across the island.
 - They have already formed the constitution of the Association.
 - Initially it is self-funded, but they are looking at other sources of funds
 - All these clubs will be affiliated with the central unit of DS Sri Lanka. Therefore information on data can be gathered easily
 - Government is willing to support such initiatives.
 - Also looking at Exchange Programs
 - They wanted information about the Nutrition Booklet.

LINK TO THE NUTRITION BOOKLET SHARED WITH THE DELEGATES

http://downsyndrome.in/NutritionBooklet_DSFI_ND.pdf

Thailand

- Their Educational Act since 1999 has made it compulsory for children to go to school.
- Persons with Disability go to work
- Thailand has come a long way but that is not good enough.
- Once a test proves positive for Down syndrome, the pregnancy is terminated, which is not good.
- Request APDSF to raise awareness to government especially Obstetrician and Gynecologists,
- While we are talking amongst ourselves, the need is to change the attitudes of people towards disability
- Mr. Suchart from DS Thailand then showed some videos about real life experiences of persons with Down syndrome in Thailand. These videos were shown in theatres and were highly appreciated.

UAE

- They initially apologized for being late for the meeting
- There are many positive changes in UAE for persons with Down syndrome.
- Statistics is a big problem and data is not always real since it is a database of overall disability and not DS specific.
- While there is acceptance of persons with Down syndrome, there still needs to be more awareness
- No special therapies or therapists available
- They are trying for Employment opportunities however only traditional jobs like Stewards, Coffee makers etc available.
- A big challenge is people leaving for higher salaries.
- They are keen on medical information since Doctors are always needed.
- Medical insurance does not accept Down syndrome, so persons with DS do not have any insurance
- Down syndrome Clinics have been established all over the Emirates.
- It is important to have the Birth Defect Registry
- They are in touch with the Ministry of Health and Ministry of Communication to put Down syndrome separately in the Identity Cards. However there is no accuracy there.
- The Medical Passport is a good idea and they are trying to use tha.

Conclusion

- The President Mr. N. Ramachandran thanked everyone present for their thoughts and the information sharing
- APDSF invites Self-Advocates for the World Down Syndrome Day Celebrations at the UN at Geneva.
 - It is a platform that the APDSF can provide for the Self-Advocates to speak for themselves.
 - APDSF would be providing the letter for Visa
 - Each country could try and send a self-advocate after deciding since this information has to be passed on the UN also.
 - The countries to raise the necessary resource to send a good candidate
 - The names to be finalized by end of January
 - Sending a sibling as a support would be a good idea since it was a success last year..

The Vision statement of APDSF would be discussed at 2:30 P.M for which all delegates were asked to assemble. The APDSF AGM 2019 was then declared closed by the President.

N. Ramachandran

President – Asia Pacific Down Syndrome Federation