First National Conference

of Indian People Who Stammer



28th December 2011 – 1st January 2012

At Institute of Health Sciences, Bhubaneshwar, Orissa.



The Indian Stammering Association



"Stuttering is fun"

- Sumit Nagpal, a participant



"We can either celebrate our stammering or be unhappy about it. We have choices"

- Mohit Jaiswal, a participant

Acknowledgement



Dr. Satya Mahapatra, Director, IHS

We thank IHS for giving us their beautiful campus. We are very grateful to Dr Satya Mahapatra and his staff for their hospitality and warmth shown to all the TISA members as well as their continuous and tireless efforts in making this a successful event. We also wish to thank each and every participant for travelling all the way to Bhubaneswar, many of them for the first time and participating with great courage, enthusiasm and energy



The Beautiful IHS Campus

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Objective

The event was organized to celebrate who we are and meet fellow TISA members from all over the country (and if possible from other countries as well). The event would also help us in openly talking about stammering and hence reduce the stigma attached to it.

Participants

All the participants were male adults who stammer other than Elaine Robin, a practicing SLP from Seattle, Washington (USA). Presently in China, Elaine (who also stammers) is trying to interact with Chinese people who stutter and trying to understand the situation and initiate a self-help movement in the country, travelled to Bhubaneshwar to witness the first National Conference in India. Two participants had come with their wives and one participant had come with his father. Director of IHS, Dr Satya Mahapatra also attended all the days of the event. One of the participant, Mr Pawas Anand, a senior HR professional from a leading MNC also participated for two days. Total strength was 26.

Following is the list of participants:

#	Name	Location
1	Dr. Satya Mahapatra	Bhubaneshwar, Orissa
2	Pramendra Singh Bundela	Indore, Madhya Pradesh
3	Rakesh Jaiswal	Faizabad, UP
4	Harpreet Singh Arora (Romi)	Mumbai, Maharashtra
5	Sanket Jaiswal	Akola, Maharashtra
6	Vivek Singh	Pune, Maharashtra
7	Pawas Anand	New Delhi
8	Lalit Pandey	New Delhi
9	Nitin Ahuja	New Delhi
10	Harshveer Singh	New Delhi
11	Dhruva Kathuria	Chandigarh, Punjab
12	Sumit Nagpal	Chandigarh, Punjab
13	Jai Prakash Sunda	Chandigarh, Punjab
14	Mitesh Thakker	Surat, Gujrat
15	Gorav Datta	Yamuna Nagar, Haryana
16	Deepak Datta (Gorav's Father)	Yamuna Nagar, Haryana
17	Dr. Satyendra Srivastava	Dehradun, Uttarakhand

18	Mohit Kumar	Patna, Bihar
19	Umesh Rawat	Faridabad, Haryana
20	Harish Usgaonker	Margao, Goa
21	Mohit Jaiswal	Kharagpur, Kolkata
22	Raja Bhattacharjee	Chennai, Tamil Nadu
23	Rajesri Bhattacharjee (Raja's wife)	Chennai, Tamil Nadu
24	Manimaran Vellan	Chennai, Tamil Nadu
25	Usha Manimaran (Manimaran's wife)	Chennai, Tamil Nadu
26	Elaine Robin	Seattle, USA / China

Content

2-Day Communication Workshop (28th and 29th December 2011)

The first two days were scheduled for communication workshop where we focused on introducing the participants to various speech tools like bouncing, prolongation, voluntary stuttering, pausing with input/help from two SLPs: Ms Elaine Robin and Dr Satya Mahapatra. Elaine also demonstrated pullouts and made some of the participants practice it. There was lot of experience sharing on the topic of acceptance and how some of us may need just this to be at peace with our own self!



Dr. Satyendra Srivastava introducing participants to speech techniques during the workshop

Dr. Satya Mahapatra answered queries coming from each and every participants clearing the myths about stuttering and therapies. Dr. Mahapatra also introduced the participants to his approach of speech therapy and while he did this, he shared some of his personal childhood experiences and difficulties he himself faced due to speech dis-fluency, thus inspiring the participants.



Dr. Satya Mahapatra answering queries coming from the participants

During this 2-day workshop, Elaine Robin also interacted with the speech therapy students of the IHS, Bhubaneshwar briefing them with certain aspects about stuttering, stuttering therapy approaches in USA, et al.



Elaine Robin interacting with the speech therapy students at IHS

The workshop also proved to be a good warm-up and build up to the main event, as the participants got an opportunity to gel together, know each other and share their stories.

The Event (30th December 2011 to 1st January 2012)

Day 1



Lighting of lamp by Mrs Manimaran as Elaine and Rajeshree wait for their turn

The National Conference was formally started on 30th December 2011 with lighting of the lamp by our three lady participants, Mrs. Usha Manimaran, Elaine Robin and Mrs. Rajshri Battacharjee.

Keynote Addresses (Elaine Robin and Dr. Satya Mahapatra)



Elaine Robin explains the iceberg analogy of stuttering during her keynote speech

The event kicked off with the keynote addresses by Elaine Robin, followed by Dr. Mahapatra. Elaine shared experiences of her personal journey of dealing with stuttering, how coming in contact with NSA was a life-changing

experience, initiating a dialogue with her father and also shared a few examples of a few of her stuttering patients and how she tried to involve parents to help the stutterer.

Elaine also stressed on the ice-berg analogy of stuttering and the need to cater to the un-seen cognitive aspects of stuttering along with the speech techniques.



Dr. Satya Mahapatra addresses participants with his keynote speech

<u>Dr. Mahapatra's keynote address</u> was full of inspirational personal experiences and wonderful anecdotes and analogies which taught the lesson of acceptance. He briefed on why most of the speech therapies fail due to lack of implementation and emotional reactions.

Dr. Mahapatra emphasized that techniques taught by the therapist may not seem natural, but if you practice it over a long period of time, it does become natural and helpful in the long run. After all, whatever we have learned after birth- writing, walking, talking- must have seemed quite "un-natural" in the beginning! He also highlighted the fact that neuro-plasticity does work even in adult life and constant, determined practice can change the wiring in the brain. So, there is no need to give up hope. He stressed on keeping a check on the way we react to stammering situations, and also the significance of doing the things along with knowing.

Employer's Perspective in Job Interviews (Pawas Anand)



Pawas Anand conducting a session on the Employer's Perspective

Job interviews could be seen as a herculean task by people who stammer. Often it brings lot of apprehensions and questions in PWS who are on the verge of starting a career. Will I be rejected due to my stutter? Should I talk about my stutter? Will my stutter affect my chances in the interview? Pawas Anand, Director of Human Resources Department with a leading MNC and also a PWS, answered all these questions.

In a detailed presentation, Pawas put some light on what qualities the employers are looking for in a prospective candidates and what areas should the aspiring professional look to prepare to crack that interview and come out a winner.

A mock interview followed the presentation, in which Gorav Datta, a graduate on the verge of starting his career volunteered, and other participants could witness how the HR conduct an interview with a candidate who stammers.



Gorav volunteers for a mock interview

Pawas then answered questions and cleared a few doubts coming from the participants.

Acceptance: What and Why? (Manimaran Vellan)



Mr. Manimaran tells the participants why to accept

Acceptance of stammering can be a difficult path for a majority of PWS. For many, it is a total U-turn approach of dealing with stammering. Manimaran Vellan, who has been coordinating SHG successfully for years and spreading the message of acceptance, gave some deeper insights about acceptance and it's role in recovery, followed by a step-by-step approach of how to take the path to acceptance.

The session was followed by a question and answer session.

Role of SHGs (Vivek Singh)



Vivek sharing the challenges faced while coordinating SHG meetings

Vivek Singh from Pune, who with his grit and determination took an initiative of educating people at his workplace about stuttering, and even went on to initiate a corporate self-help group in his company, talked about the Role of SHGs and how it can help PWS to come out of their shell.

During his session, he shared his own experiences while trying to initiate a SHG in his company and how coordinating an SHG helped him with his social skills.

Vivek also discussed about challenges which a coordinator has to face, especially keeping the group alive and encouraging participation, and gave a few tips.

Can stutterers tell joke?



Many of us have difficulty with punch line, but Raja Bhattacharjee, on being given the NSA button, quipped:

"I totally agree. I don't stammer, when I am alone!"

The NSA button said: If you stutter, you are not alone!

Day 2



A race on the beach on Bay of Bengal.

Day 2 of National Conference was planned as a day out to explore Bhubaneswar with sessions in the bus and on the beach. Dr Mahapatra acted as our expert "guide" throughout the day taking us to places like Udayagiri and Khandagiri Caves, Buddha Temple at Dhauligiri, shopping spree at Pipali famous for it's appliqué works and the historic Sun temple at Konark. The day culminated with watching the last sunset of the year, on the Chandrabaga beach on Bay of Bengal and then a New Year party going on till 2 am.



Participants posing in front of the Udayagiri and Khandagiri Caves



A session in the bus by Deepak



At the Buddha Temple in Dauligiri



Welcoming the new year with cake-cutting ceremony

Day 3

Role of Writing (Journal / Blog) in Recovery (Harish Usgaonkar and Dhruva Kathuria)



Harish and Dhruva give a session on role of writing in recovery from stammering

The final day of conference began with presentation on role of writing / blogging in recovery by Mr. Harish Usgaonkar (Editor, TISA newsletter) and Mr. Dhruva Kathuria. During the session, Harish introduced participants to some of the studies conducted on the writing therapy, and then shared his personal experiences of how he switched to writing and how it helped in his recovery.

Dhruva introduced the concept of blogging and the challenges one might face to keep the blog active. Dhruva also shared how blogging has helped him and how he tries to produce content on his blog and make sure that the readers have something interesting to read.

At the end of the session Harish gave some tips on getting started with writing, and it's significance into the path to acceptance. Dhruva also added tips on how to start with blogging.

The session was concluded with a question and answer session and a healthy discussion.

Open Mike Session



Mohit Kumar, a participant from Patna, Bihar talks about gaining confidence during the open mike session

Post lunch, we had an open mike session facilitated by Elaine Robin. During this session, each and every participant got an opportunity to speak in front of the audience and share anything that runs in their mind. All the participants grabbed the opportunity and shared their stories, about the ups and downs of life dealing with stammering, challenges faced in school, colleges and jobs and even at home.

Many of the participants discovered a sense of confidence in them while sharing their stories which showed in their speech.

We formally concluded the whole event by thanking everyone who made this event possible along with discussing the venue for the next National conference (which may be Goa!). There were many moist eyes and warm hugs as the evening progressed.

Follow-up of the Conference

We plan to be in continuous touch with the participants through phone, email and online social networking. Most of the participants have been given author rights to TISA blog.

Conclusion

Meeting other people who stammer and being with them for 5 days can be a very liberating, therapeutic and empowering experience as one participant said -"Now I know who I am".

Read More...

Here are some of the links to the daily reports and videos of the event which were posted on TISA blog while the event was held:

http://t-tisa.blogspot.in/2011/12/well-begun.html

http://t-tisa.blogspot.in/2011/12/nc-day-1.html

http://t-tisa.blogspot.in/2011/12/beautiful-campus.html

http://t-tisa.blogspot.in/2011/12/day-2.html

http://t-tisa.blogspot.in/2011/12/day-3.html

http://t-tisa.blogspot.in/2012/01/descriptions.html

http://t-tisa.blogspot.in/2012/01/nc-day-4.html

http://t-tisa.blogspot.in/2012/01/tisa-thanks-everyone.html

http://t-tisa.blogspot.in/2012/01/some-nc-videos.html

Web Album:

https://picasaweb.google.com/117465129517612405511/FirstNationalConferenceOnStammeringSel fHelpBhubaneshwarOrissa?authkey=Gv1sRgCKOsxLXkgK3kFw#

Appendix

What is TISA?

TISA is a self help association of Indian people who stammer (IPWS). It is active since 2008.

Its purpose is to collect and disseminate relevant, correct and unbiased information for people who stammer and their families, friends and society in general. It is promoting a self help group movement, where PWS learn to help each other and themselves in the ancient Indian spirit: "This Self is to be achieved through self effort!"

Studies have shown that self help groups (SHGs) provide most consistent and long-lasting support structure; more than any speech therapy or other technique/device. TISA co-ordinates city-wise SHGs in India; currently there are SHGs being run in Delhi, Mumbai, Chennai, Bangalore, Pune, Surat, Hyderabad and Dehradun.

If you stammer, or know somebody who does, have a look at TISA SHGs. These SHGs are open to all and are absolutely free. To know more about SHG activities, check the left-hand side menu - Self Help Groups. If there is no SHG in your city, start one. You need just two PWS to start a group. It could be a physical group or even a web or phone based group. TISA will help you in every way it can. Drop a mail to JP or Harish and we will take it forward. "People who stammer (PWS)" nomenclature is based on the principle of "people first, then disability". It is also based on the concept that stammering is something we do, not who we are. And we do many more things besides stammering!

Vision statement: TISA endeavors to assist PWS in acceptance of their stammering and overcoming the associated behaviors and mindset, through self-help movement. Our vision is a society where stammering is understood both as a significant source of suffering and disability.

Values

- 1. "Self help" is not just a means but a goal as well. People who learn to rely on themselves, are more empowered and have better self-esteem.
- 2. Stammering is a long term problem of social presentation of 'Self'. Hence any attempt to deal with stammering should be embedded in social processes like self help groups. Speech therapy is accepted if it is affordable, transparent, based on sound science, clinical evidence and ethics of healing profession.
- 3. We accept stammering but try to work on communication. Communication transcends fluency. We accept PWS with both overt and covert symptoms, and the entire spectrum in between, as source of significant suffering.
- 4. In the context of self-help, serving others is same as serving yourself and requires no special qualification except a willingness to serve. Selfless service to people in need, is a spiritual goal by itself, in our traditions.
- 5. Family, employers, teachers, media- all have a role and responsibility towards children and adults who stammer.

Objectives

- 1. To start/ promote/ support Self help groups or initiatives in cities and villages, whether physical, phone or web based.
- 2. To promote availability of self help material (text, video, audio, electronic, web based) in various Indian languages.
- 3. To promote networking among IPWS and their groups.
- 4. Work with state actors, policy makers, employers and therapists, in as much as self-help requires a suitable policy environment and specialist interventions.

Acceptance

Acceptance in the case of a stutterer, has often been misunderstood. It is the first step towards change. It does not mean accepting the problem and staying put. It also does not mean denying the problem we face or trivializing it. We reproduce here -with some minor changes, a very balanced understanding of what acceptance would mean in our case, from Tom Weidig:

- 1. I have a neuro-biological abnormality affecting my speech systems leading to a propensity to stutter.
- 2. I have to live with my abnormality for the rest of my life. (as far as we know today).
- 3. I have to work on myself if I want to improve my communication.
- 4. I have to work on myself if I want to minimize the psychological and social consequences of stuttering.
- 5. Shame, negative beliefs and most fears I held or experienced were completely unnecessary and harmful.
- 6. Stuttering had some positive effect in that I was forced to take a deeper look at myself.
- 7. Moderate to severe stuttering can be a burden to others who listen to me that I should minimize.
- 8. Some jobs that strongly focus on fluent verbal expression are not for moderate or severe stutterers.