# One Voice



International Stuttering

Association

**Issue 27 - January 2010** 

Downloadable from <u>www.stutterisa.org</u>

Incorporating The Voice of ELSA, the newsletter of

**European League of Stuttering Associations** 



## Faces of Stuttering



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A Disclaim: In keeping with our mission of providing an open forum for the exchange of extensive and thought-provoking information about stuttering, the ISA Newsletter presents a wide range of views. The ISA does not necessarily endorse the opinions of the writers of Newsletter articles.

Edited by Jianliang (Albert) Zhang (email: al\_zhang@hotmail.com

## **Message from ISA Chair**

#### By Michael Sugarman, USA

I sincerely hope that 2010 can bring us all peace, hope, health and spiritual attainment---an organization such as ISA will benefit many people who stutter and their loved ones if and only if we as members of this community can strive for coordination and a shared belief that we/people who stutter are not alone.

At the end of 2009 the ISA Board of Directors created working committees and chairs to help facilitate change not only for people who stutter around the world but also to spread general awareness to the public about stuttering.

Advisory Board Members have been requested to pick one or more committees and e-mail the chair(s) to work out how they can best serve.

In June 2010 the ISA Board of Directors will reassess committees:

(Some of the committees are already closed due to desire to keep the committee manageable. However, the closed committees are open to feedback by Board and Advisory Board Members.)

Everyone is requested to be respectful of their words. Anyone can email the ISA Chair directly about concerns or joys

- ♣ Keith will Chair, Outreach, One Voice and ISA internal Face-book.
- **♣** Suzana will Chair, ISA World Congress.
- **♣** Thomas will Chair, Ten Recommendations
- Masuhiko will Chair, Constitution (Committee is closed)
- Michael and Mel will Co-Chair, Finance (Committee is closed)
- ♣ Benny will Chair, Website---Judy Kuster will serve as a consultant (Committee is closed)

Many of you know that the end of 2009 was a transition time for ISA. Please let me know how I can improve my communication. Please send me feedback on my position as Chair. For example, areas in which I can improve.

Please feel free to contact any of the Chairs, with your thoughts. We are here to serve you.

Thank you for your time, and remember to tell us what you want.

Michael Sugarman ISA Chair msugarman1@sbcglobal.net

## **Message from ELSA**

#### By Anita Blom, Sweden, and Edwin J Farr, England, UK

ELSA was successful in applying for funds from the European Youth Foundation part of the European Council in Strasbourg, and was able to once more organize a European Youth Meeting 24-31 July 2009, the 7<sup>th</sup>. For six days 40 young people who stutter (PWS) came from all over Europe to a lovely boarding school/conference centre in Giggleswick, UK, for a week of workshops, lectures, presentations, social outings and many other activities. The theme was "THE RIGHT TO SPEAK - Human Rights Education and Intercultural Dialogue", very important for PWS.

The event was aimed at PWS between 18 and 26 to introduce the delegates to Human Rights policy and how it is linked to stuttering, to discuss the situation for PWS, the workings of their National Stuttering Associations, to network and to actively take charge in changing their situation. It is hoped that the meeting will inspire the delegates to participate in the work of their own association and importantly provide for personal development.

After the energizing experience of presenting ourselves the pressure was gone and we could all enjoy the week, realizing we are all in the same situation. The drama and performing art workshops showed us alternative ways of communicating and the amazing fakir stunts made us realize anything is possible if you only believe in yourself. Human Rights was the main topic and the delegates were given presentations and documents that they can use back in their own country. Also discussed were the workings of the national stuttering associations resulting in a project for the delegates to carry out "what they could achieve if they were to get a certain amount of money to spend on stuttering awareness". This enabled them to focus on the core essentials. They also shared life stories and discussed human rights and gender equality and showed their drama talents during self-directed performances on the last evening.

The leaders were not just board members but also previous delegates, for example Irina Papencheva who was successful in her work as a policy officer for the European Disability Forum and the Deputy Major of Sofia and Guðbjörg Ása Jónsdóttir an actress. Another role model was one of the first delegates, Daniel Hunter, today a highly regarded Speech & Language Therapist. This shows the success of the Youth meetings.

But the week also consisted of leisure activities such as a trip to the amazing nearby caves, a football match, a visit to the indoor pool and of course relaxing, dancing and talking, making new friends for life. Today there is both a Yahoo group for this year's group, but also a Facebook group for delegates from all ELSA Youth Meetings.

And it didn't even end there. One of the delegates has now received the member of the year award in his home country, Iceland and a slide show with pictures from this year's delegates is to be found on this year's ISAD online conference! Needless to say we are all very proud!

<u>ELSA website</u> - We now have a new enthusiastic webmaster, Richard Bourgondiën from the Netherlands.

<u>Campaigning</u> - ELSA continues its relationship with the European Disability Forum, a Brussels based disability organisation that is now 10 years old. ELSA was one of the founding members and Edwin J Farr is on the EDF's General Council.

ELSA also supports the ECSF, The European Symposium of Fluency Disorders, and Richard Bourgondiën recently gave a presentation at one of their meetings

## **Message from Chair of ISA Outreach**

#### By Keith Boss, England, UK

It is an honor and privilege to be working on the ISA Board and in Outreach again. I appreciate the confidence placed in me by the Board of the ISA when they voted to welcome me back to the Board and to the position of Outreach Chair. During the remaining term of this Board, I will direct the work in Outreach to help as many people who stutter in as many countries as possible.

Other articles in this issue give a better idea of what we have been doing recently. I would like to talk about two things: My visit to TISA (The Indian Stammering Association) in February 2010, and my future plans for Outreach work.

#### **Visit to TISA in February**

I first floated the idea of TISA in 2006. Towards the end of 2009, TISA made history. They completed the paper work and became a registered Indian Charity. Because of this milestone I wanted

to visit them. I approached Dr Satyendra Srivastava (Sachin). We first looked at October 2009, but shortly changed that to February 2010. I suggested a start and finish date and said I would like to visit as many TISA friends as possible. Sachin collected a small team of people and developed the following plan.

- ❖ 11<sup>th</sup> Feb Thur Arrive in Delhi in the early morning;
- ❖ 15<sup>th</sup> Feb Mon Arrive Pune in the evening;
- ❖ 18<sup>th</sup> Feb Fri Arrive Chennai in the evening;
- ❖ 22<sup>nd</sup> Feb Mon Arrive in Dehradun in the morning;
- ❖ 25<sup>th</sup> Feb Thur Arrive in Delhi late evening for flight home on the 26<sup>th</sup>.

Flight times, and more information, are available from the TISA websites (<a href="http://stammer.in">http://stammer.in</a>; <a href="http://stammer.in">http:/

In Delhi, Pune and Chennai there will be conference(s), and a range of meetings with SHGs (Self Help Groups); People Who Stammer; Families; and hopefully media / schools / employers / therapists / local health staff and whoever else is interested. I am in the hands of Sachin's team

My visit to Dehradun will include time in Herbertpur at to see Sachin to talk about many things. This will be a very fitting spiritual end to a long-standing wish to meet TISA friends.

I also plan to attend a Toastmasters meeting in Chennai and maybe Delhi, as well as chatting with some Toastmasters in Pune and to see where there is a natural affinity of the Toastmasters work to improve communication and leadership skills and a SHGs requirement to help any PWS to communicate more easily without any negative emotions.

#### **Future plans for Outreach**

Ever since the ISA was formed, Outreach has been one of the main ways we used to achieve 'more understanding around the world' (ISAD, the online conference, and the ISA World Congresses and Regional Congresses are three other ways).

In the past we have achieved much in Outreach. Look at the work of Mark; Stefan; Moussa and Joseph, to name but 4 members of our ISA community as well as the ISP S teams.

I think that we can achieve more and I welcome any thoughts and suggestions about how I can improve the work done in this area of the ISA. Constructive suggestions will **always** be welcome. I will take Outreach forward on the lines that more hands make light work.

I would like to 'split' the world to 5 regions

1. Africa

- 2. Asia
- 3. Europe
- 4. Latin America
- 5. Northern America and Oceania

I want to build up a team of ISA members and people from ISA Member Associations. (This means all of you reading this message.)

I need 5 Regional Coordinators and several helpers to work in each of the 5 regions.

Initially the work will be on your computer. Working in one or more countries (I worked in India and Pakistan from 2006 and 2007) to build up teams of local people who stammer who want to start Self Help Groups all over their Country, one City at a time. We have the expertise on how to do this, we can advise them. Also in time they will want to arrange conferences and start a charitable Association. We can advise them. They may want visits from us to help them on their way. If so, we need to raise funds to pay for travel and some board and lodging.

But first we need volunteers to work in regions and countries.

- Have you a little free time?
- Are you interested in helping others?
- Have you a computer, or access to one?
- Would you like to help the ISA Outreach vision?

Please get in touch.

Have a very good 2010,

Keith

**Keith Boss** 

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## We Can Make Our Voices Heard by Associating with Other Disability Movements

#### By Joseph Lukong, Cameroon

Speak Clear Association of Cameroon and Bamenda Coordinating Centre for Studies in Disability and Rehabilitation Email: Joseph.Lukong@stutterisa.org

The questions of whether stuttering can be considered as a disability has always been very controversial. While some persons who stutter (PWS) and their families, speech language pathologists and speech professionals consider stuttering to be a real disability, others do not have this view. To some of us who consider stuttering to be a disability, we think it is proper for persons who stutter to join other persons with disabilities for our voices to be heard. To this effect, the SPEAK CLEAR ASSOCIATION OF CAMEROON, which is the primary the stuttering association in Cameroon, has been joining with other disability movements in Cameroon to observe the International Day of Persons with Disabilities, recognized and observed on 3rd of December the world over.

Our Involvement started in 2008 when we were invited to make a presentation on stuttering as a disability at one conference organized here in Cameroon to mark that day. Since then our involvement, networking and working with other disability associations in Cameroon has been going on and in this direction.

The annual observance of the International Day of Persons with Disabilities on 3 December aims to promote an understanding of disability issues, the rights of persons with disabilities and gains to be derived from the integration of persons with disabilities in every aspect of the political, social, economic and cultural life of their communities. The Day provides an opportunity to mobilize action to achieve the goal of full and equal enjoyment of human rights and participation in society by persons with disabilities, established by the World Programme of Action concerning Disabled Persons, adopted by the United Nations General Assembly in 1982.

The theme of the 2009 International Day of Persons with Disabilities was "Making the Millennium Development Goals (MDGs) disability-inclusive: Empowerment of persons with disabilities and their communities around the world."

To mark this day in Cameroon, the Bamenda Coordinating Centre for Studies in Disability and Rehabilitation (BCCSDR) organizes an annual conference on Disability and Rehabilitation. This year's conference brought together persons with disabilities, disability activists, speech language therapists, occupational therapists, physiotherapists, and other health and rehabilitation professionals for two days coming principally from Cameroon, Canada, and the US to discuss issues touching on disability and rehabilitation in Cameroon.

The Bamenda Coordinating Centre For studies in Disability and Research BCCSDR works in to support education and research in the areas of disabilities and rehabilitation. Some of the activities include running a self help group for people who stutter, and public education workshops. The centre hopes to offer some speech therapy sessions in collaboration with local and International SLPs. It is presently carrying on a research project on the prevalence of disabilities and impairments in the North West Region of Cameroon and their impact on the quality of life for persons with disabilities. I had the honor to have been hired as the Research Project Coordinator for this project.

As persons who stutter, and in order to make our voices heard locally and international, it is high time we consider associating our self help groups with other groups for persons with disabilities.

## **Message from Burkina Faso**

#### By Moussa Dao, Burkina Faso

#### **Partners coming from France**

From September 16 to November 2, we received 12 students from France. They come from the Speech Language Pathology (SLP) department of the medical school of Montpellier (France). Within the framework of their final training courses they decided to come and support us in our activities.

The team of Orthofaso: Moussa and his harem

Dioulasso (second big city of the country). There, they took care of children, adolescent and adults that stutter. For children, we met their parents and gave them advice and we let the team of Orthofaso to act directly with children.



Self help meeting: French adolescents and burkinabe

In fact, three years ago, from the department of SLP of this university, an association called Orthofaso was set up. It's aimed to send yearly a team of SLP student in Burkina Faso in order to help people with speech impairment.

The 12 students were located in the two major cities of Burkina Faso. 6 were in Ouagadougou (capital of the country) and 6 others in Bobo

From October 21 to November 3, we received 2 SLP and 4 adolescents that stutter. They are members of an association called Solidarité Faso bégaiement (SFB). The therapists put their 4 patients in contact with some adolescents from our association. During one year, the adolescents from France and Burkina Faso exchanged through internet. It was a kind of self help group across the borders.

#### **International Stuttering Awareness Day (ISAD)**



Radio brodcasting with Orthofaso members at Ouaga

This year, face to the imperative need expressed by the population of Bobo Dioulasso since several years, we decided for the first time to celebrate ISAD out of Ouagadougou on October 31.

For the ISAD, I wrote an article that was published on October 22 in the newspapers of Burkina Faso. In this message I talked about stuttering, the importance of ISAD and its theme for the year 2009. I received several positive reactions from people.

We also had one live radio broadcasting with the team of students in Ouagadougou.

Two day before October 31, a team of our association (ACB) and I left Ouagadougou with my car. I drove the car over 365 km and arrived at 17h: 30 after 5 hours (we have no highways). Just at the moment where we were entering at the city of Bobo a journalist called me and told that he wanted urgently to meet us just for few minutes in order to prepare the ISAD. We drove directly to the national radio station where the journalist was waiting for us. We followed him through the lanes of the radio station house and much to our surprise, we found ourselves in the live broadcasting room. Despite my efforts to try to postpone this improvisation due to driving tiredness, he explained: "No time to discuss, please do it". Finally, it was good and just after that, I received some calls for congratulations.



Moussa with the journalist at the national radio

The day before October 31, we were very very busy. We had several meetings and were obliged to cancel some appointments. We had two other live radio broadcastings.



Moussa and Sourabie in the radio with loudspeakers

Due to tiredness, I stuttered a lot in one radio station but in other I was very fluent. I was surprised by this. For one hour live radio broadcasting during which people called, I was fluent. When I looked around inside the room and saw loudspeakers. Immediately I understood what happened and thought about Benny and his ear device. To hear your voice when you talk can be really helpful.

On October 31, we organized a conference, and its theme was: what stuttering is? And what can be done?



The members of ACB with their banner

We were so happy to notice that the conference room of the French cultural center was full. There were more than 150 participants.



Moussa interviewed by the media after opening ceremony

There were three presentations:

Our partners from France (Orthofaso and SFB) did presentation on the generalities about stuttering; definition, causes, treatments.

- ➤ Then I did a presentation on what is done in Burkina Faso; why have we set up an association and how a person who stutters can undertake its self therapy.
- Finally, one member of our association did a presentation on self help group of Ouagadougou



**Participants** 



**Participants** 

We had many questions and interesting comments and testimonies.

All the participants were very touched by the moving testimony of one member of our association in Bobo (Charles). Many of them were surprised to notice that Charles stuttered severely when he was talking while he was fluent when he sang sweet music during the opening ceremony. Charles said: "I left school when I was at 4 years of elementary school. Every time when I went to the blackboard I could not read and cry, because of that I told to my mother that I will no longer go to school and I abandoned."



The presenters replying to the questions of the participants



Charles sings

This year our Godmother was the chair of the representative of ADD (Action on disability and development) in West Africa. ADD is a British NGO helping disabled persons. During her speech, she said: "I am happy and honored to be involved



Moussa giving his blood after the opening ceremony

at this celebration. I promised to do my best to support the theme of stuttering."

Being in a country where yearly malaria causes numerous deaths particularly among children and also being aware that this situation is greatly due by the lack of blood in hospitals, we decided to join the theme of stuttering at the blood. Our slogan was: "Blood give life and Speech valorizes the life." Therefore our members and participants gave blood.



Members of ACB and Orthofaso preparing to give their blood

#### International forum of partners on the disability

After ISAD at Bobo Dioulasso, we drove back to Ouagadougou in order to participate at a forum on disabilities from November 3<sup>rd</sup> to 6<sup>th</sup>. The theme was about how partners could increase their support for inclusive education. The main objective was to gather the representatives of governments, partners acting on disabilities and associations and NGOs from Burkina and some countries. There were about 400 participants. There was UNICEF, WHO, French speaking countries organization (Francophonie), Handicap International, different ministers related to education and disabilities and several other national and international NGOs.



Participants at the forum (conference room of Ouaga 2000)

The speakers from United nation agencies told that formerly it was difficult to mobilize fund for the

purpose of disabilities but with the convention on the right of disabled persons adopted in 2007 by UNO surely thing will change positively.

I had to do a presentation on stuttering and explain the difficult situation of Children who stutter in school and the importance to do something to help them.

For my first time since I have involved in volunteer work on behalf of people who stutter, I was scared to do a presentation. It was a big challenge for me. I was tired by the preparation of ISAD in Bobo. How can I attract participants' attention? What can I say that can touch people, what can I say to show to partners that the theme of stuttering is also important and need their support like the situation of children living with deafness, blindness, mental disability and physical disability?

I was afraid to be ridiculous.



Moussa doing his presentation



Moussa replying to questions

My personal situation is particular; living with two handicaps (physical and stuttering) obviously I

know that stuttering is not ridiculous thing, but I had to transmit my feeling to participants. I had thought that when I would be walking to go front for my presentation, many participants may think that: "this person will talk about physical handicap and probably another person will come and talk about stuttering."

Finally I think that my personal testimony was the best way to attract their attention.

During my presentation I told them: "When my stuttering was severe, if by magic someone proposed to eliminate one handicap be sure I would choose stuttering. Physical handicap didn't prevent me from doing what I want and the reaction of people was no so bad like in the case of stuttering..."

I noticed that people was very surprised by what I told. And I was at ease to develop it. I'm so proud to notice that I successfully transmit my feeling to them.

One representative of a NGO told me: "Thanks a lot for talking about this Hidden handicap. You deeply touch us. We should also think about the theme of stuttering."

That encourages me to pursue what I have started. I have been writing a book related to the view and attitude of people about my stuttering and physical disability. It would be my testimony to tell that viewing someone, what attracts the attention of people is not always the main problem for this person. I hope by this to be helpful for the cause of stuttering. Maybe you will read it during next world congress.

## The Faces Of Stuttering

by Michael Sugarman with music by Scatman John, from California, USA

This 2-minute video features the faces of many people around the world who live with stuttering. The idea for the video was envisioned by Michael Sugarman who contacted several organizations to send pictures and put together this video with the help of his daughter, Rebekah. All individuals in the video have given permission for their pictures

to be included. The background music, "I'm the Scatman" by John "Scatman" Larkin is part of the video with permission of John's widow, Judy.

The video is here:

http://www.mnsu.edu/comdis/isad12/papers/faces.mp4.

## **Message from Mali**

#### By Zan, Mali

Association vaincre le bégaiement du Mali AVB-Mali Centre de Référence de Santé de la Commune III (PMI Central) Email:avbmali@hotmail.com/zanjunior@yahoo.fr

Like many International communities, Mali's Stuttering Association celebrated its 12<sup>th</sup> world day of stuttering (ISAD) in the room "Wa Kamissoko" at the International Conference Center of Bamako, on Saturday 24<sup>th</sup> October 2009. We celebrate 22th October each year. This year the day had a theme "To stutter is more than stuttering".

In Mali, every October is devoted to solidarity and the fight against exclusion. This 15<sup>th</sup> edition of solidarity and fight against exclusion has a theme "Solidarity is not a word, it is a behavior".

It is within this framework that the national social development office; children's foundation; ministry responsible for institution relations; government representatives; the united club of wives of ambassadors and Dr Aliou Sylla honorable president and other partners joined us in commemorating this day.

The Stuttering Association, which is in its 3<sup>rd</sup> year, organized a conference and a means to request donations from the association for the development of commune III of Bamako district.

The objectives were to inform and to sensitize the public on the handicap of stuttering in order to change people's vision about it, so that in the future they take it into consideration.

The conference began with the speech of Miss Diallo Oumou Sidibé, president of the Stuttering Association followed with speeches by Miss Timbo Oumou Bah god mother of weak handicapped persons, the president of the Association for the development of commune III and the representative of Malian Federation of Handicap, Mrs Idrissa Diakité.

In her introduction, the president of the Stuttering Association welcomed all the guests. After her welcome words, she summarized the organization's history regarding the world day of stuttering (ISAD) and defined the objectives of International Stuttering Association through the organization of the said day. Concerning the choice of the theme of this day, the leader of the Stuttering Association explained to participants the

reasons for the theme the International Stuttering Association (ISA) set for this year.

It springs from the comments that stuttering doesn't mean only repetitions of syllables, words, groups of words, blockages (grimaces, tic etc). This visible part of stuttering in the less important part of stuttering because the stutterer, in this situation, will attempt to hide the stutter, to keep it secret, to reduce painful shame.



After these different speeches, Olivia LEFEBVRE, Orthophonist (Speech Language Therapist) did a presentation on another topic. Entitled: Role of environment and attitudes advocated.

The different points developed through this presentation:

- Definition of stuttering;
- Why stutter, factors of stuttering(3P);
- How to help people to stop stuttering?
- Stuttering: a communication trouble;
- Attitudes to avoid; then what to do.

The organization of the day was a total success. It helped to spread the message on stuttering to generate more awareness among public.

We wish strongly that the Malian authorities take in account the necessity to create a learning center for people who stutter to ease the burden of stuttering by giving them opportunities to find more fluent speech.

#### **Partnerships**

For a few years Lille 2 University in collaboration with "Ortho Go" have sent students in internship in certain African countries specially Mali. This year the internship held from April 15<sup>th</sup> to June 18<sup>th</sup>. This present team named "orthomalille2009" is composed of six young students in speech who are: Marie, Marion, Morgane, Bertille, Julie and Katheleen.



Because of this stuttering in Mali is supported by a few specialized therapist and unqualified students.

The Stuttering Association, an organisation created by people who stutter, benefited from the assistance of "Ortho Go" because of the support for children who stutter.

Despite their lack of experience, the students reached out to help and support children who stutter. The children and theirs parent took part in many activities, using advice and different techniques developed by therapists to help people who stutter.

We complement our six students who did their very best to ensure good coaching for these children through training meetings in groups and with individuals at home. They have shown love, courage and responsibility to the children. The children and theirs parents were very enthusiastic and satisfied with their efforts.

Finally, all the members of the Stuttering Association, especially the president Miss Diallo Oumou Sidibé, wish them a good, safe return to their respective families and hope to see them when they become professional Speech Therapists.



### **Voices Across Borders**

#### By Josh Denault, USA

Voices Across Borders Administrator East Bay, California NSA Co-Chapter Leader www.bayareansa.com

Voices Across Borders was founded in October of 2009 as a collaborative effort between the East Bay Chapter of the National Stuttering Association and the International Stuttering Association. The original purpose of this endeavor was to get young PWS adults in their 20's together from around the world to discuss all issues related to stuttering. The premise was young adults just entering the workforce, family life and issues that arose and challenges it presented with their speech.

Through careful thought and consideration it was agreed that a Facebook page was the way to go for this project. Facebook is currently known as the #1 social networking site between young adults that exists on the internet. We figured it was a

good place to start VAB. Although we found it difficult to keep it in the "20something" age range, it has turned out to be a great meeting ground for PWS regardless of age. Since October, the "Facebook Fans" of VAB has risen to 120 to date, comprising of PWS from 19 countries and 11 different native languages spoken. More data can be found here:

http://bayareansa.com/Site/VAB.html

We hope in 2010 that VAB will grow even more and perhaps branch off into other forms of networking as it has been seen as a valuable asset to not only "young adults", but PWS in general from around the world. Please help spread the word.

## ISAD 2009 San Francisco, CA

#### By Mike Garcia, USA

Originally published at www.bayareansa.com

I was very impressed with the way things came together for the presentation tonight. Though a lot of planning had lead up to this day, the concept of an online conference was still pretty vague to me until it finally came together. Our challenge was to keep the presentation consistent and in the spirit of what International Stuttering Awareness Day (ISAD) is all about...reaching out and including PWS in the discussion no matter how far they may live from where the discussion is taking place. Which actually puts the discussion in every person's home...or Blackberry, or laptop, etc. To include those who have felt so unincluded.

14 physically gathered in the telecon room at Alliant International University in San Francisco tonight, and we were also joined by 2 conference callers, Gary from Pennsylvania and John from San Ramon. The conference call lines were open to anybody who wanted to call in and listen to and/or participate in the presentations. Five presentations were given tonight....

- 1. Michael Sugarman- "Introduction and ISAD Explanation"...Introduction to the presentation and ISAD. He illustrated that we as PWS are not alone by showing a slideshow of the many faces of stuttering, played to music of "The Scatman" who was an advocate for PWS as a PWS himself.
- 2. Nina Ghiselli- "Reframing the Iceberg"...
  Nina's alternative to Joe Sheehan's analogy
  of the iceberg, which compares the stutter
  to the tip of the iceberg. Below the tip is
  the base, which is much larger in
  comparison. The base is compared to the
  feelings of fear, shame, guilt, anxiety,

hopelessness, isolation, and denial which can perpetuate the stutter. In contrast to Sheehan's analogy, Nina offered her own-the base of the iceberg might include courage, authenticity, pride, forgiveness, peace, hope, community, and acceptance. This shift in thinking comes from the self-help movement and finding community.

- 3. Josh Denault- "Methods of Outreach"...
  Different community outreach approaches for our 3 events, as well as the support group in general, were discussed. His presentation showed the way we linked our group/website to other organizations/people in the Bay Area. A recap of the Hayward bi-lingual event and the Teen Open House event were given at the end.
- 4. Mike Garcia- "The Word is Mightier than the Sword"... Arguments and confrontations are unavoidable in life and can be especially troublesome for PWS since we tend to become more disfluent when we argue. By using a recent, personal experience, I talked about how you don't have to be fluent to succeed in an argument. Preparation and personal conviction are more powerful.
- 5. Vanna Nicks- "Communication Over Fluency"... Fluency is not a component of successful social interaction. Instead of trying to increase fluency, PWS could

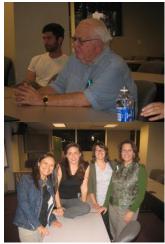
focus on aspects of effective communication to achieve success. Communication strategies and tools were discussed in the presentation.

After the oral presentations, we moved to the computer lab so that we could explore <a href="SutteringHomePage.com">SutteringHomePage.com</a>. This is an online forum for discussions, research papers, and personal experiences to be shared with anyone from around the world. If you haven't checked this out, I strongly encourage you to. The evening concluded with dinner at a nearby restaurant for those who could stay.

The "International" theme hit home for me later when I learned that the powerpoint presentations, complete with audio, will be posted online on <a href="StutteringHomePage.com">StutteringHomePage.com</a> for all to view at a convenience of their own, no matter where they live. We're also going to post this on our Bay Area NSA website.

We'd like to thank Mr. Mel Hoffman for attending tonight. Mel is a big reason why the NSA is here today, and we enjoyed being in his company tonight. I'd also like to send a heartful thank you to Vanna Nicks. Vanna is a recent addition to the East Bay Chapter, and she hasn't wasted any time in getting involved. She gave a great presentation tonight and brings a contagious energy to the group. I hope she continues to be as involved.

Thanks to all that came tonight.









### From the Editor

#### By Jianliang (Albert) Zhang, China

Thomas Lauren Friedman, an American journalist, once titled his bestselling book "The World Is Flat." True, the world is never like before and it is getting flatter and flatter. When you see that every stuttering help group and institution is online, approachable day and night without a physical boundary, that you can make friends with others who stutter and interact with them online, in facebook.com or myspace.com, that you can get whatever information about stuttering, e.g., treatment options, scientific research, and critiques and stories from other stutterers, with a few strokes on the keyboard and a few clicks of the mouse, you realize this is a new era, an era that is revealing itself to you on the 2-D LCD monitor. The infinite connections via internet pose both challenges and potentials for the stuttering help groups.

For example, recently we have seen the fast development of stuttering self-help groups in China, and its failure to host the 2010 World Congress For People Who Stutter. With my previous involvement with the Chinese stuttering self-help groups, I believe that this is because the Chinese stuttering association is a looselyconnected organization mainly based on the electronic Bulletin Board System. Unlike those with longer histories and physical existences (e.g., the National Stuttering Association was founded in 1977 and has a headquarter office in New York), stuttering associations like that in China would not have been born without the midwife named internet. People share their stories in the bulletin boards, convene in the internet chat rooms, and meet face-to-face only if they happen to live in the same city with a few enthusiasts who call for the activities online. These newborn associations, I assume, are more frequently seen in developing countries, simply because, usually, the developed countries have had the stuttering help groups before the internet became popular.

The internet also changes the already established stuttering help groups. Not only they are online, but new groups, new projects have been started for facebook users. In this issue of One Voice, it is introduced that Voices Across Borders, a project with the concerted effort from International Stuttering Association and the bay area chapter of National Stuttering Association, is based on

facebook.com for it is aimed to attract young adults who stutter from every corner of the world. So, there is no doubt that this world is becoming flat, and people are connected in a manner unbelievable decades ago.

I have some concerns about the cultural variation. The fast growing internet provides opportunities for people who stutter to meet on line, get help online, and it also helps to reveal the great differences between cultural groups, e.g., the language, the knowledge of stuttering, the attitude toward stuttering, the treatment options for stuttering, etc. For groups like the International Stuttering Association and individuals with a noble ambition to help people who stutter around the world, cultural variation is an imminent consideration, yet it is rarely investigated systematically, especially in Asian and African regions. Partly it is because there is a lack of research about stuttering in Asian and African countries, partly, I believe, this is a reflection of cultural variation per se.

Cultural variation in how people perceive and understand stuttering, and treat people who stutter, is an interesting issue to consider. Through anecdotes and a limited number of studies, we know that Africans are more likely to believe in mythical etiology of stuttering, Asians tend to blame people who stutter for not being able to speak normally, whereas Caucasians will consult speech language pathologists for stuttering.

I have a strong interest in cultural variations about interesting, probably because I have had the chance to experience the "cultural shock" related to stuttering between East and West. Growing up in China, I learned from early age that I'd better hide my stuttering - pretend to be unknowledgeable, or have a bad memory, but never make abnormal utterances, or show the struggles, because people will laugh at me. Therefore, in 2004, when I went abroad for the first time and saw hundreds of Western people who stutter at Perth, Australia, I was totally unprepared to see that there are places where one can stutter openly and freely, without worrying about being interrupted, mocked, mimicked, scolded, and stigmatized. I could not stop thinking that, for many people who stutter that live in

China, how their lives could be changed had the society have a better understanding and tolerance of stuttering. I know my life would have been much easier. However, China might be a safer place to live than Uganda, where, reportedly, children could be killed because of stuttering (Irwin, 2005).

But there are things that have intrigued me. For example, in America, it is evident that autism and attention deficit have received more discussions in public media than stuttering. At least I know autism affects 1 child in 150, a chance much smaller than that of stuttering, which affects 1 in 20 children. Also, when looking for stuttering videos on youtube.com, I found a number of stuttering prank phone calls. To my amaze, a lot of people commented that these pranksters are very funny. I have seen that American people are generally nice and usually don't criticize or respond negatively to others, so how come people who stutter are still publically humiliated? And this is America. I know things are worse in China, and probably not any better in some other countries.

Because of the omnipresence of the internet, discriminations against people who stutter in youtube.com need to be fought back with people who stutter from everywhere. We may be divided by oceans, but we are united on the web. We may

have specific goals to conquer in our own society, but there are universal goals that will be achieved only by working together. Writing in English may not be the preferred expressions for many of us, yet still it can be powerful in delivering ideas and emotions, just like our tangled tongue. We are seeking universal acceptance of stuttering, we are working to make this world "a world that understands stuttering." In this sense, the various voices from us, though separated physically, culturally, and linguistically, are actually just one voice.

Therefore, there is One Voice. It is the semiannual newsletter of the International Stuttering Association. It is published online with the incorporation of the ELSA (European League of Stuttering Association) newsletter. Its previous issues can be retrieved at the websites of ISA and ELSA. The unique feature of One Voice is that its contributors are from various countries. The topics cover recent activities of national self-help groups, international affairs, and personal experiences and ideas about stuttering.

#### Reference

Irwin, M. (2005). African conference and international speech project. *One Voice*, 20, 1-2.

## Photos from ISAD 2009, Croatia

