One Voice

Tears in my eyes ....of Joy

I am 58 ½ years old. I co-founded National Stuttering Association in 1977. I 'pushed the envelope' for International Stuttering Awareness Day in 1998. I was elected Chair, International Stuttering Association in 2011. I have had so many memorable moments with the stuttering community--- I can not share what other "old timers" must feel. I can only share my thoughts.

I was sitting on the steps in front of the building where World Congress 2011 was being held, Buenos Aires, Argentina. And in front of me were eight teens who stuttered...sharing their stories with laughter; or in the early 1990's at the National Stuttering Association conference welcoming parents and their children who stuttered into the stuttering community; meeting young children who stutter at conferences; sitting and sharing with members from the professional community; or in 1978 with members from Oakland, California support group going to a local deli and six of us who stuttered using a bull horn stuttering in front of the store---because the owner/ counter person made fun of one of our members stuttering; and witnessing the mass distribution of "The King's Speech".

This summer around the globe people who stutter are meeting: Canada, Chile, Finland, Germany, United Kingdom, USA---Very Awesome.

I feel extremely blessed to know that a new generation of people who stutter are changing their attitudes about their stuttering , a new wave of speech language professionals are listening to 'our' wants and how both people who stutter and professionals are changing the attitudes of the general public toward stuttering.

Thank you for welcoming me into your heart....And I feel very blessed to experience a new wave of people who stutter who can lead the "stuttering self help movement".

Hugs and Love

Michael,

Chair ISA 2011 - 2013

MESSAGE FROM ELSA

The European League of Stuttering Associations (ELSA) reporting from our Youth Meeting at Giggleswick in England.

28 young delegates, pws, are here in England to participate in ELSA's 8th Youth meeting. The Theme is "The Right to be heard - Social Inclusion and Human Rights starts on line"

The Meeting is part funded by the Council of Europe and has attracted young delegates, 18-27, from all over Europe, from Iceland to Spain, from Ireland to Lithuania.

Presenters and organisers Edwin Farr, Anita Blom and Richard Bourgondien have been joined by world famous film producer Erik Lamens, famous for the short film "To Speak" and Harry Dhillon, former chair of the London Toastmasters.

ELSA's main objectives in holding this Youth Meeting are twofold a) to promote the understanding that Human Rights education is the key to change and 2) encourage and teach young people who stutter to make the most out of the new media and internet in order to combat social exclusion. ELSA's aim is to ensure that social inclusion starts online.

The delegates have been split into 4 groups and each group is making a film under the direction of Erik incorporating elements of Human Rights and raising awareness of stuttering and promoting stuttering and their stuttering association. At the end of the week the intention is to use social media to upload the film onto the internet and to use the social media to raise their voices and educate on stuttering.

During the week the delegates will be joined by BSA members Leys Geddes (BSA Chair), Daniel Hunter (graduate of the 1st ELSA Youth meeting in

1995 and now a SLT) and Bob Adams (former board member of the BSA and a leader of a performance group on stuttering topics)

Edwin Farr MBE, Anita Blom and Richard Bourgondien

MESSAGE FROM ISA OUTREACH

In One Voice 28 (http://www.isastutter.org/news/one-voice-newsletter) I talked about the Danish 'Ambassadors at Large' program. In One voice 29, I asked you to start such a program, if one did not exist in your Country, and to tell us about it in this One Voice. No one has sent any information. Our Danish Association (http://www.isastutter.org/who-we-are/member-associations/denmark) has demonstrated further examples of this approach. They have linked with Nepal (http://www.isastutter.org/who-we-are/member-associations/nepal) and helped them in so many ways, as 'Mentors'. They have spent time in Nepal helping; they have supplied materials, and some money and financially helped Sanjay (The President of the Nepal Stutters Association) to go to Argentina for the 9th World Congress. This 'Mentoring' of a new, less experienced Association, is a special kind of Outreach / fundraising which combines a lot of action with much verbal support. One member from each Association gave a very interesting presentation at the World Congress in May. It was well attended, well received and many questions were asked. This is another superb initiative and should be welcomed and expanded. One of the American Chapters has embarked on this path with another Self Help Group in the World.

The ISA is expecting a few more Associations from more Countries to join our membership over the next few months. Can you and your Association Mentor one of the new Associations? Can one of your Self Help Groups help another one? If so, please let me know.

We often talk about the ISA Family. While at the World Congress in Buenos Aires I had that very special feeling of meeting family members, either for the first time or for the second or third time. In other articles below, Clara, from Argentina, and others talk about that very special atmosphere. Thanks must go to our hosts for creating this very special warmth. I will not talk much about the 9th World Congress, because so many people have written about it. What I will say is that some very kind helpful people on both ISA Boards bought me a plane ticket so that I could attend the Congress. Thank you very much. I really enjoyed myself: I learned a lot; I met many new friends; and I talked, and talked..... One very important thing was highlighted. We need to work out how we can cross the language barrier and link up with more people who do not speak English. One of the best things that happened for me at the Congress was when Michael and I, on many occasions, said we want your help in the ISA and many of you put your hands up and said, I will help if I can. The ISA Boards will be able to do so much more useful work with your help. Thank you all.

If you are interested in the work we want to do, visit http://www.isastutter.org/initiatives. More offers of help are always welcome. We will try to keep you up to date with progress in Michael's monthly e-newsflash. (For past copies see http://www.isastutter.org/news/e-newsflash) Please contact us if you have queries, or see some item of work we could do for you.

Some questions for you. When you receive an e-newsflash or the latest One Voice, do you pass it around all your members? Does it go on your website? Do you alert your members when you hear from the ISA? **Several people attending the members meeting in Buenos Aires said they did not see either the monthly e-newsflashes or the six-monthly One Voice.** Can you help to ensure your membership sees what we try to do for them.

One of our projects will be Fundraising. This will not be limited to raising money, but will include various other ways of asking people for special kinds of help (e.g. Mentoring other Associations or Self Help Groups / Chapters;) . Watch the progress in e-newsflash.

As often, I will close my contribution by reminding all of us that the ISA exists to help People Who Stutter in any Country of the World. For the ISA to succeed, we need

-volunteers with time;

-we need volunteers to help with translation between other languages; and

-we need money.

If you can give the ISA some of your valuable skills / time / money, contact either myself at keithmaxkb@yahoo.com or Michael, our Chair, at msugarman1@sbcglobal.net.

One last big thank you to our hosts of the 9th World Congress , and I look forward to working with more of you over the next 2 year until the 10th World Congress for People Who Stutter in Holland in 2013 (http://www.demosthenes.nl/wc2013.html).

Please pass this to all your members.

Keith Boss
ISA Chair of Outreach
Vice Chair and Treasurer
keithmaxkb@yahoo.com

BIGGEST CONFERENCE EVER FOR THE NATIONAL STUTTERING ASSOCIATION

The National Stuttering Association's 28th national conference, held July 6-10 in Fort Worth, Texas, was the U.S. organization's largest with 871 attendees. As in past years, the conference included a family program with activities for children and teens who stutter and their parents, workshops for adults and continuing education sessions for speech-language pathologists.

What made this conference different was its sheer size – 200 more attendees than in any previous year – and more than 300 people attending their first conference. The surge in conference attendance may have been partly a result of the popularity of "The King's Speech" and the keynote speech of David Seidler, the film's award-winning screenwriter.

Because a stuttering conference is an unfamiliar experience for first-time attendees, a welcoming committee of NSA volunteers greeted new arrivals at the hotel entrance. Those attending for the first time also attended a special orientation session and lunch.

52 adult workshops included sessions on stuttering treatment and support. A special workshop series for young adults focused on that age group's unique challenges. Career workshops offered tips for job interviews and coping with stuttering in the workplace. The NSA distributed a new booklet at the conference to help people who stutter address workplace issues.

The family program attracted 115 children and teens who stutter, along with their parents and family members. Separate workshops were conducted for school-age children, teens, parents and siblings. A teen advisory council helped organize the conference.

Speech-language pathologists attending the conference participated in a half-day continuing education session and also received continuing education credit for other workshops at the conference. A two-day applied research symposium for speech-language pathologists preceded the conference.

The NSA also announced that it will award annual "seed money" grants for new research on stuttering.

The organization's 100 local support groups helped build momentum for the conference by using the popularity of "The King's Speech" to generate local newspaper and television stories on stuttering. The Nashville, Tennessee, chapter worked with a local theater to present information on stuttering and the NSA at the movie's screening.

The NSA receives no government support and is funded primarily by its members. With a full-time executive director and three part-time employees, much of the organization's work is done by volunteer directors, program coordinators and chapter leaders.

Jim McClure

National Stuttering Association

NATIONAL STUTTERING ASSOCIATION CONT'D...

PASSING TWICE IN BUENOS AIRES

About 25 people attended the "Passing Twice: LBGT People Who Stutter and their Allies" workshop at the 9th World Congress of People who

Stutter. It was a facilitated conversation about the links between "coming out" as a stutterer and "coming out" as a lesbian, gay, bisexual or transgendered person. It was open to all participants regardless of sexual orientation.

During the workshop, we talked about how, for LGBT people who stutter, there are striking parallels between sexuality/gender identification and stuttering. Both involve coming out of the closet; choosing between community and isolation; contending with well-meaning professionals who want to make us "normal"; dealing with families who don't fully accept us; and creating circles of understanding friends.

People talked about their various reasons for attending the workshop. Some were gay or bisexual. Some had LGBT loved ones. One was a father seeking advice on how to help his son come out. One had recently watched a coworker transition from male to female. Many had come to hear what LGBT people could teach them about coming out as stutterers.

People shared their coming-out stories—mostly stuttering stories—in a safe, intimate environment.

Afterward, several people remarked about how powerful the conversation was. One woman, for example, told me that she had never discussed her own stutter with anyone except her parents, even though all her friends have heard her speak dysfluently. (A mild stutterer, she can often "pass," but that doesn't lower her anxiety.) At the end of this conversation, I gave her an assignment: Make a list of 12 loved ones who have heard you stutter, and mention your stutter to a new one each month for a year.

It is my hope that participants came away with support and concrete strategies for "coming out" as stutterers (or as LGBT) to their friends, relatives, and acquaintances.

-Barry D. Yeoman

BUENOS AIRES, ARGENTINA

I would like to thank every single person who participated in the 9th World Congress for people who stutter that took place in May in Buenos Aires, and especially to the Argentina stuttering association that gave us so much time, effort and love, as well as each of the professionals who attended.

I am a person who is disfluent at times but more fluent at other times and I would like to emphasize that this meeting gave me so much and helped to heal some wounds which sometimes cause this problem. I found a space of warmth, acceptance, understanding and integration that I have never experienced before . I only wish that this warm feeling could be spread around the world and that society could be part of this feeling, and become more informed about stuttering and gain an understanding and know that we have much to say. It is not how or the way we use words, but the content. We just need more time to speak.

To everyone who lives with this difficulty, you have to know that we are not alone. There are many people who feel like us and many professionals willing to help us and give all their love. To them, thanks for sharing knowledge and life experiences. I keep in my heart your very helpful advice. I miss this warm feeling, but I do not feel so alone. Now, I know that in every block, many people feel for me and accompany me. Show how much we can communicate, sometimes without a fluent speech, but with the body, eyes and heart. thanks to all!

-Clara Maria Sotelo Vionnet

9TH CONGRESS FOR PEOPLE WHO STUTTER OR STAMMER

My name is Mike Mabika and I stutter. I am also the founder member of the Stuttering Association of Zambia. I was fortunate to attend this very important conference for people who stutter last month in Buenos Aires, Argentina. A lot of people who stutter from so many different parts of the World attended the congress. Also present were speech therapists, parents of children who stutter, members of the public, researchers with the view of sharing ideas and learning more about stammering. It was a fantastic experience.

The theme or the objective of the congress was to give more awareness to the public regarding stuttering as the Americans call it or stammering as the Brits call it. In Nyanja stammering is known as Chibwibwi. Stammering or Stuttering is a speech disorder or speech disability if you like.

While the spoken language is taken for granted by most, the use of spoken language is a big challenge for the millions of people who stutter around the world. It is estimated that 1% or 70 million of 7 billion people with whom we share this world stutter. That implies that about 130,000 Zambians from the current population of 13 million stutter.

From time immemorial people who stutter have often been misjudged as fools and figures of ridicule in our society. Literature, film and television have repeatedly intensified these wrong, one sided and distorted views. Some of our very own Zambian musicians have sung songs that make fun of people who stammer.

In 2000 the International Stuttering Association (ISA) published The Bill of Rights and Responsibilities for people who stutter which provides a framework for building a humane, just and compassionate world for the millions of people who stutter.

I am particularly saddened that most people in Zambia are totally ignorant about stuttering. They assume that stuttering is caused by nervousness, lack of confidence, fear, demons etc. Stuttering is caused by so many factors and some of these are very complex and each individual case is different from the other. Some of these causes are actually genetically related.

Anyway the GOOD news to all my fellow stutterers is that an Association called the Stuttering Association of Zambia (SAZ) has now finally been formed. The objective of SAZ is to promote and educate the masses of our people on stuttering issues. Many thanks to the Zambia Agency for Persons with Disabilities (ZAPD) for acknowledging that stuttering is also a disability in accordance with the Persons with Disabilities Act No.33 section(b) of 1996 and also for acknowledging the importance of forming the Stuttering Association of Zambia under the umbrella of ZAPD.

Persons who stutter in this country are stigmatised and

marginalised and usually lead isolated lives because of such speech impediments.

My main concern is mostly with children who stutter who are teased and in some cases even bullied by their friends because of their stuttering and unfortunately school for these Children is nothing but a nightmare. A child may soon become withdrawn and will not play an active role in discussion matters in class for fear of being laughed at when he or she stutters in an attempt to say something. In some extreme cases, some children who severely stammer have committed suicide because of harsh treatment from society.

I would like to appeal to persons who stutter especially children and adults not to feel depressed or isolated but to think positively and not to let stuttering deter or hinder them from achieving their dreams. The first lesson to learn when you stutter is to accept that you stutter. That way you won't feel so terrible when you stutter because you have come to understand and accept who you are. Some stutterers have actually received treatment from speech therapists especially at a tender age and have actually achieved more fluency. However most adults who stutter do not completely stop stuttering even after seeing a speech therapist but in some cases the stuttering may reduce to some extent.

9TH CONGRESS FOR PEOPLE WHO STUTTER OR STAMMER CONT'D

SAZ would like to see children who stutter to start enjoying and having a wonderful time at school in an environment where their classmates and teachers understand that they stutter and do not make them feel like they are second class citizens.

Most countries especially in the developed world have the services of a speech therapist at each and every School to help children with such speech disorders. SAZ would like to see more training of speech therapists in our country. SAZ feels this move will help children who stutter and others with speech disabilities to receive appropriate treatment from properly trained and informed therapists.

The school-age years represents a time during which children are the most vulnerable and therefore the influence and support of school personnel is key. Schools should respond in positive ways so that each child who stutters will realise his full potential within a safe and joyful environment.

October 22 is designated as the Annual International Stuttering Awareness Day by the International Stuttering Association, so this year SAZ would like to see this event fully recognised in our country where people who stutter can come together and celebrate this auspicious occasion.

Most stutterers at the conference agreed that self help groups are an effective avenue for people who stutter to meet and share ideas and see how best they can help one another.

If you are a person who stutters and would like to be part of the self-help group, please send me an email.

Remember you have a Voice and you have a right to be heard.

Mike Mabika

Write to: stutteringz@gmail.com

STAMMERING CAUSED BY STRESSFUL WAR SITUATIONS. HOW MUCH STRESS CAUSES STAMMERING IN CHILDREN?

This is an abstract by Ljiljana Špidla. It is hoped the complete work will be available in One Voice 31.

ABSTRACT

The research has been conducted on small randomly selected sample consisting of 11 children – five boys and six girls. All participants reported stammering that had occurred during the war. The stammering was influenced by both parents' informing on the problem and their level of education. Cause of the disorder in speech fluency, heredity and phonological speech development in compliance with chronological age at participants was conducted by instrument measuring intensity of stammering (G.D. Riley). Some of the variables relating to stress non-adaptive situation were included. Statistical data show that that the percentage is big. Post operative condition and hereditary factors influence stammering in children. Parents' education as a variable was considered because of motivation and rehabilitation outcome.

Aim of the paper is to determine stammering intensity that occurred during the war in children affected by given situation; to encourage the need for help and support that will motivate the child for rehabilitation and that will help him / her to overcome their difficulties in communication with others, in school, in a shop, with his peers, in public place etc.

Key words: stammering caused by non-adaptive situation, child in war situations, stammering intensity.

MESSAGE TO MEMBERS OF THE INTERNATIONAL STUTTERING ASSOCIATION

I am writing this message to the members of the ISA who are gathering in Buenos Aires, and Michael Sugarman kindly agreed to take a moment and read it for me. In 1965 I organized a Japanese self help group of people who stutter and in 1986 my group and I held the first international congress of people who stutter in Japan. Since then I have been involved with ISA activities, but this time, to my great regret, I was not able to make it to Argentina.

More than two months have passed since the huge earthquake and tsunami hit the north eastern part of Japan. We received many emails from the members of ISA to ask about our safety, which warmed our hearts. Relief goods and manpower arrived right away from all over the world. Rescue troops, medical staff, nuclear power specialists, scientists, etc came to help us. We felt we were not isolated but connected to the rest of the world. This meant a lot to us and will help us to regain our strength.

About 15,000 people have been confirmed dead and about 10,000 are still missing. As you may have seen on TV many times, some villages were completely swept away. People lost their houses, jobs, everything. There are still more than 120,000 people who live in shelters. Many of them are elderly and frail. It is too difficult for them to reconstruct their houses and pull their life together. However, we are learning a lot from the devastation. The children in the affected area are now learning about the safety issues surrounding nuclear power and are exploring ways to make contributions as survivors.

Now I must give you very sad news. Our group has been holding summer camps for children who stutter and their parents for 21 years, and a junior high school girl and her mother were washed away by the tsunami and died. The girl had attended the summer camp for three years. She had been affected by her stuttering so badly that she had to miss school a lot. However, she regained her strength and learned to deal with her stuttering at the camp and was ready to start going to high school in April. This was too difficult to take. I felt as if the girl and her mother had been encouraging us saying "Please give strength to children who stutter as you did to me." We are trying to overcome the sadness and carry on.

Furthermore, the devastating nuclear reactor accidents are affecting our lives in various ways. This is a man-made disaster. Many of us are now aware that we had been brainwashed by the government's and the electric power company's campaign that nuclear energy is safe, clean and less expensive, but unfortunately, this was proven to be wrong. It's as if we had been dealing with something that human beings were not supposed to handle, as nuclear power is beyond our control. We should look for alternative energy. I hope this can be shared with the rest of the world as there is nothing which we can say is definitely safe.

Many Japanese people, who took material affluence and creature comfort for granted, are beginning to reconsider their life style. They think that the age of placing economic growth above everything else should be over; we should be more frugal, tolerate inconveniences, and explore ways to seek a spiritually fulfilled life; and that we should think more of contributing to society and other people. These thoughts are beginning to disseminate among many Japanese people, including children.

Now let me touch upon a film in the news, "The King's Speech." Thanks to this film, awareness of stuttering seems to be growing more than ever throughout the world, and in Japan as well, it has been given a lot of coverage by the media. I am glad that there is finally a movie that depicts the truth about stuttering. When we look back at the time when George VI was struggling with his stuttering we realize that we are still struggling with stuttering. In this situation the social role and significance of self help groups becomes very important. Researchers and clinicians are expected to keep working on their research, but people who stutter must be responsible for finding ways to "live with stuttering." I hope at the meeting you will have opportunities to discuss how self help groups can help people who stutter in dealing with their stuttering and help them to increase their confidence, and thus realize the importance of self help groups.

Lastly, as stated in the declaration made at the first world congress of people who stutter in Kyoto, taking this opportunity in which people stutter, researchers and clinicians get together from different countries, I hope you will respect each other's viewpoint, share stuttering experience with each other, listen to what people who stutter, researchers and clinicians have to say, and work together in discovering solutions for the problems we have.

The members of the Japan Stuttering Project and I wish you success.

Thank you,

Shinji Ito

Executive Director

Japan Stuttering Project

STUTTERING COMMUNITY IN BOSNIA AND HERZEGOVINA- ARGENTINE AFTERTHOUGHTS

As a stutterer. I am not like other people. I must think differently, act differently, live differently. Like other stutterers, like other exiles, I have known all my life a great sorrow and a great hope together, and they have made of me the kind of person that I am. An awkward tongue has molded my life - and I have only one life to live. (W. Johnson)

Bosnia and Herzegovina (country in South-Eastern Europe) with population of 4.5 million people have, by conservative estimates, at least 40 000 persons who stutter. However, in the past very little attention has been given to our stuttering problem. There are but few speech therapists, their voice cannot be heard, and there is no association or community for people who stutter. Our media rarely mentions this problem, and people who stutter are frequently exposed to all kinds of discrimination. In Sarajevo, capital of Bosnia and Herzegovina with population of around 400,000 people, there are no more than a few speech therapists!!! It is far better to admit ignorance where ignorance exists than to insist on knowledge where there is no knowledge. A special problem are charlatans, claiming to cure stuttering in a few hours.

I am not a Speech Therapist, rather I work as a senior assistant in University of Sarajevo (Engineering Department). For a long time I had this idea to develop a web portal for people who stutter in my country. For several years I was buying and collecting books, papers, brochures. Everything I could find on stuttering. So began my adventure in research of stuttering: reading, writing, accumulating knowledge and literature. After the initial investments and efforts which took around two years, I published the first edition of a web portal in November 2009. Since then, stuttering portal www.mucanje.info (mucanje means stuttering in Bosnian) has been visited by approximately 118,000 visitors, all around the world.

Suzana Jelčić-Jakšić, M.S. CCC-SLP at Children's Hospital Zagreb from Croatia, told me about the opportunity to go to Argentina - 9th Congress for People who Stutter ISA, May 2011 in Buenos Aires. So I applied for a scholarship, hoping for a chance. People from ISA, especially Mr Keith Boss and Mr Michael Sugarman were very kind to me, so I got an opportunity to visit and to be a part of a Congress for People who Stutter.

I was excited and surely the experience in Argentina was indescribable. For the first time I was among my own, my real brothers and sisters, who can understand me perhaps better than my own family.

I met a lot of good people, nice friends who will be in my heart for the rest of my life: Michael, Keith, Gudda, Marko, Mike, Mark, Barry, Matias, Obam, Anita, Thomas, Ed, Elaine, Julieta, Leandro, Richard, Sanjay... They all gave me hope – we have a voice! Also there were speech therapists, parents, members of the public, researchers with different views about stammering. The theme of the congress was to raise public awareness for stuttering.

After I came back to Bosnia and Herzegovina, I met with a few young people who I met via my web portal and we agreed we should form an Association for people who stutter. Several SLP are also supporting this and one of them agreed we can use her office as an initial meeting place. At the moment we are finishing some legal issues regarding forming an Association, so hopefully soon we will have the first Association for people who stutter in Bosnia and Herzegovina.

That will be a huge step forward, because there are a lot of opportunities to change public opinion on stuttering in my country, to raise awareness, help the others, and share ideas with people around the world. Stereotypes must be broken.

Some may disagree, but my personal opinion is that one man can make a difference. There is a saying: "A lion leading an army of donkeys is better than a donkey leading an army of lions", a phrase popularly used to describe the British infantry of the First World War and to condemn the generals who commanded them. The contention is that the brave soldiers (lions) were sent to their deaths by incompetent and indifferent leaders.

I couldn't wait for someone else to solve my problem, but I started this project, hoping that it will do for others as much as it did for me. I have stripped from my speech defect its ominous mystery. Mystery is always a breeder of fright and terror and despair; it is the worst tyrant of the unenlightened stutterer. The terror of stuttering and the least unpleasantness of it lie not in a stumbling tongue, but rather in the stutterers inability to understand himself and his situation with a speech defect.

STUTTERING COMMUNITY CONT'D...

My future goals are oriented toward establishing Stuttering Self-Help Groups. This task should not be difficult, considering the benefits of it. In addition to treatment provided by SLPs, some people who stutter have found help dealing with their stuttering through stuttering self-help and support groups. In general, stuttering support groups are not therapy groups. Instead, they are groups of individuals who are facing similar problems. These individuals work together to help themselves cope with the everyday difficulties of stuttering. Many support group members report that their experiences in the support group improve their ability to use techniques learned in therapy.

Perhaps it may be surmised that stuttering in life's labyrinthine journey can sometimes prove a blessing in disguise.

mr. sci. Alan Ćatović, Sarajevo, Bosnia and Herzegovina, acatovic@gmail.com

Matias, Suzana and me in Buenos Aires

Michael and the others dancing the Tango

BETTER ATTITUDES THROUGH KNOWLEDGE

As an association dedicated to the people who stammer in India, The Indian Stammering Association (TISA) has come a long way since it's inception in April 2008 into forming a formidable representation. Encouraging the self-help approach to stammering through SHGs, conducting communication workshops, keeping an eye on discrimination and lure of cure and above all – spreading the message of acceptance has been the key areas TISA has been religiously working on for the last three years.

TISA has helped initiate 19 self help groups (SHG) across the country. The latest additions in the list were self help groups in Kerala, Ahmedabad (Gujrat) and Bhiwani (Haryana). These SHGs are at different stages of evolution, and keep sharing and learning from each other, which has been a significant contribution to the self help movement.

Conducting communication workshops in various states of the country is another area TISA has been enthusiastically working, with the help of the local SHGs. Since January 2011, TISA has conducted as many as four communication workshops in Chennai (24-25 January), Goa (22-24 April), Herbertpur (2-4 May) and the recently concluded workshop at Chandigarh (24-26 June). TISA is working on devising a framework for it's workshop, which is based on interactive activities accompanied with fun which aim at desensitisation, awareness and exploring beyond the comfort zones. In an attempt to raise the quality, TISA is also planning to nurture and create more facilitators who can mentor PWS into their recovery processes. A positive side-effect of such communication workshops has been the interaction with media and raising awareness about stuttering to the general public.

TISA has also filed a petition against a Hindi movie 'Golmaal 3' for portraying stammer as a constant source of teasing, cheap laughter and stereotyping of people who stammer as socially and intellectually deficient people. A lot of members came forward to help the association for the fund-raising. The proceedings, legalities in the court regarding the same are presently in progress.

In an attempt to put a check on the selling and packaging of 'cure' and in the process dupe PWS of their money, TISA has also initiated a protest against Partha Bagchi's Stammering Cure Center in Bangalore, who has been offering fairly high priced crash-courses that promise cure.

Taking the help from technology, in order to help members to keep in touch and maintain a bond within, TISA has also initiated an SMS service. With this

service, the subscribed members will be able to get updates of various events, news and motivation quotes too as short text messages. A 30-minuite documentary has also been shot by Mrs. & MR. Raja Bhattacharjee, which feature participants of Communication Workshop held at Chennai, discussing about their experiences, feelings, perceptions and myths about stuttering.

With a vision of strengthening it's reach by spreading the message, talking to media, conducting workshops, TISA is aiming at educating society about stammering and changing the attitudes of the PWS. It has not been easy and has been a rough ride for the association. But with our persistent efforts towards our goals and purposes, we are certainly getting there.

TISA on Web-

http://en.wikipedia.org/wiki/The_Indian_Stammering_Association

http://stammer.in/

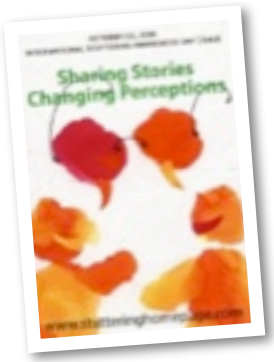
http://t-tisa.blogspot.com/

THE INDIAN STAMMERING ASSOCIATION (TISA)
WELCOMES YOU
FOR THE THREE DAY COMMUNICATION WORKSHOP,
AT GOA YMCA, PANJIM

INTERNATIONAL STUTTERING AWARENESS DAY ANNOUNCEMENT:

The Fourteenth International Stuttering Awareness Day Online Conference - SHARING STORIES - CHANGING PERCEPTIONS opens October 1, 2011.

International Stuttering Awareness Day (ISAD), which began in 1998, occurs on October 22 and is designed to raise awareness about the challenges experienced by people who stutter. ISAD is a joint, world-wide endeavor by persons who stutter and their families, students, and professionals (educators, researchers, and clinicians) interested in stuttering. ISAD is recognized by major international stuttering organizations, including the International Stuttering Association, the International Fluency Association, the European League of Stuttering Associations, the American Speech-Hearing Association and The Stuttering Foundation.



In conjunction with ISAD, an online conference is hosted by Judith Kuster, emeritus professor, Minnesota State University, Mankato. The conference is FREELY AVAILABLE and linked to the Stuttering Home Page website (http://www.stutteringhomepage.com) starting October 1. Papers remain available online after the conference after the conference concludes on October 22. All past online conferences are freely available on the Conference Archives (http://www.mnsu.edu/comdis/kuster/isadarchive/onlineconference.html).

The upcoming and five most recent conferences are also available for Continuing Education CEUs (1.5/15 hours) or credit (either graduate or undergraduate) through Minnesota State State University, Mankato.

Instructions on how to register and requirements for CEU or credit are online:

http://www.mnsu.edu/comdis/kuster/isadarchive/requirements.html

Judy Kuster

LETTER FROM MOUSSA...

From May 13th to 17th I was in Argentina where I attended the 9th world congress for people who stutter. It was my first time to visit the American continent. Once again thanks to my stuttering and the financial support of ISA and friends I got the opportunity to meet friends and experiment other cultures.

The ISA meeting was really difficult. I was elected in the new board member for the following two years. For the purpose of PWS, I will do my best to contribute to make ISA a great and strong association.

I was very happy to meet the writer of the famous book: " the story of a stutterer", Fred Murray.

I did a presentation on the second African congress. It was a report on why, how the congress was managed and what were the impacts. My presentation was positively appreciated and ISA and several participants expressed their willing to support and attend at the next African congress.

I also did a short slide presentation during the closing ceremony in order to thank the organizer the different languages of the participants.

A new big challenge:

Just back home, I was solicited to be member of a jury that will examine in july the first thesis on stuttering by a student in our medical school. It's an honor and a big challenge for me. About ten years ago due to my stuttering I was particularly scared by my public presentation of my thesis and now thanks to my stuttering I'm honored to sit among famous professors of our university and judge a thesis. I am really thankful for my involvement in volunteer work on behalf of people who stutter. I am proud that the works (stuttering awareness) I have started with some persons have given its fruits.

MOUSSA CONT'D

ASSOCIATION PAROLE-BEGAIEMENT (A.P.B.)

Our Association (850 members half people who stutter and half clinicians - 55 delegates) has been very busy with two actions:

-To promote the King's Speech and to run debates after the film shows (42 occurances)

-To obtain permission, from the distributors, to allow an extra video about our Association and stuttering. We were allowed to include, in the French version, a 16 minutes video in which we were able to give information on stuttering and on our Association. (they asked us 2000 euros for that, it is a shame, as they pressed 250 000 dvd of the film!)

Now we want to show the film and the extra video in high schools everywhere in France and Switzerland, and to organize discussions with students.

We will take these meetings as an opportunity to promote the book of testimonials by people who stutter that we published by ourselves and which is a very good book!. Its title is : "To stutter: a question of speech, a question of life."

We will ask all the librarians to purchase the book and organized discussions about it.

We have edited two more flyers of information: one dealing with the stuttering of children aged 6 to 12, and one which catalogues the different therapies available in France.

We had already published flyers for early intervention, for adolescents, for people having an exam to pass, and one for recruiters.

The Publication on early prevention (70 pages) has been re-edited for the third time.

I went to Quebec recently and I gave all these materials to the Association of young stutterers in Canada and they will use them after adapting them.

Now we are looking forward to run a campaign in 2011/13 in primary schools with the new flyer.

The IFA Congress will be held as you know in Tours, along the Loire , a very beautiful spot where I hope to see you all again.

My best thoughts to you,

Anne-Marie Simon

COUNTERING MISCONCEPTIONS

The message on the screen read "THE STUTTERING ECONOMY" for a good 20 minutes on Candy Crowley's State of the Union program on CNN on Sunday. This, I thought, cannot be good for the stuttering brand, as the marketers would call it. Another example of the noxious conversational usages of stuttering and stammering to connote lower intelligence, shame, failure or incompetence. And the problem remains that when members of the public meet someone who really does stutter, those noxious conversational usages are their only frame of reference.

My modest proposal in this regard is that we should "own" the words stuttering and stammering. I was talking about this with Barry Yeoman of the Passing Twice group at the ISA Congress in Buenos Aires and he agreed. Language usage does in fact change. I noted that this is exactly what has happened with "gay". Gay people now "own" the world gay. In the Christmas carol, the line "don we now our gay apparel" means something it does not mean now. When I was a kid, I used to watch The Flintstones cartoon show whose theme song had the line, "when you're with The Flintstones, you'll have a gay old time." These days, when cartoon shows use the world "gay," they are talking about gays.

English is a very, very rich language. There is no shortage of other terms the people at CNN could have used, including the faltering economy, the floundering economy, the stumbling economy, the wavering economy, the doddering economy, the staggering economy, the teetering economy, the wobbling economy, the unsteady economy, the fumbling economy, the vacillating economy, the weak economy, etc.

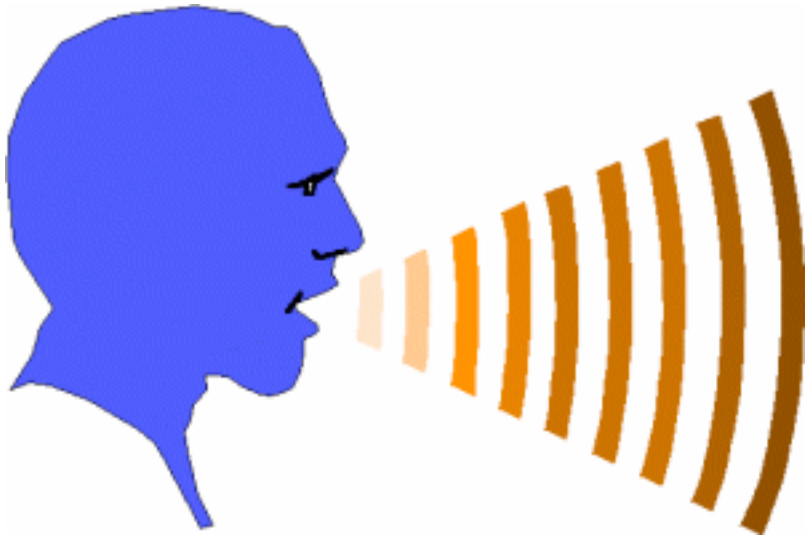
If the U.S. economy were doing well, CNN would not put a message on the screen reading, "THE GAY ECONOMY" expressing the former usage, "happy".

Now obviously CNN and other media are not sensitive to what should be our concern because they doesn't know about the above and have not considered it.

I think there is general agreement here that the public ignorance regarding our problem abounds, the image is terrible and much work has to be done in that area. A company or a politician or an organization, even countries, with an image problem hire marketing firms. The marketing firm determines what the existing image or "brand" is and works with the client to decide what the brand should be and the strategies of how to get there.

Can't see that happening except in the unlikely event we can get a big marketing firm to do a pro bono campaign for us or Warren Buffett or the Google guys pay for it.

Ed Feuer



AUSTRALIAN SPEAK EASY ASSOCIATION

Speak Easy currently has five active states, with about fifteen local groups running throughout the country.

The national association is an umbrella group providing public liability insurance, resources (such as library and internet site), national magazine, national conferences and driving national initiatives.

One of the latest initiatives was a submission for a national review of disability insurance. The association put together a response, which was a collaboration between Speak Easy and speech pathologists. Documentation about the review can be found at http://www.pc.gov.au/projects/inquiry/disability-support, with the Speak Easy submission at http://www.pc.gov.au/__data/assets/pdf_file/0009/108585/subdr701.pdf.

Speak Easy runs a biennial national convention. The next national convention will be held in Melbourne CBD from 17 to 19 February 2012, themed 'Stuttering 2012 – What's new and what's true'. Come along, we would love you to join us!

We were also very proud to welcome ISA Chair Michael Sugarman to our last convention in the Sydney CDB in 2010, together with renowned speakers including Professor Mark Onslow, Dr Ashley Craig, Professor Ross Menzies, Dr Susan Block and Associate Professor Ann Packman.

Congratulations to our ISA representative, Peter Dhu, being elected to the ISA Board at the 2011 World Congress, we know he will represent stuttering issues well, not just for Australia but also at an international level. Peter is a highly motivated and driven individual and has a long history with Speak Easy.

All states try to actively participate in ISAD each year to attract media attention to stuttering. In recent years most groups have had success with radio and newspaper interviews.

The NSW/ACT Branch of Speak Easy celebrated International Stuttering Awareness Day in 2010 with a Forum titled: Stuttering: Bullying and teasing at school. The forum, held at Sydney University, was a joint venture of The Australian Stuttering Research Centre (ASRC), the Sydney University Faculty of Education and Social Work, and Speak Easy. The media also covered the event with interviews that went to air that afternoon.

AUSTRALIAN SPEAK EASY ASSOCIATION CONT'D

The audience of about 200 was made up of speech pathologists, Speak Easy members and teaching students, a great opportunity to reach the teachers of tomorrow! The short version of the film produced by the Michael Palin Institute, 'Wait, wait, I'm not finished yet', gave students an insight into life as a stuttering student. Then Speak Easy members spoke to the students about their experiences in the classroom, including being told to 'sit at the back and be quiet' (because the stuttering was disruptive), feeling extremely anxious about having to speak in class, and being approached by well-meaning teachers who didn't quite know how to help.

Stutterers were very glad to have the chance to tell these teaching students what school was like for them, and to be part of a project aimed at giving the students very useful and practical information about stuttering and how to respond helpfully to the stuttering child in class.

Associate Professor Ann Packman of the ASRC worked hard to coordinate the event with the head of the Faculty of Education and Social Work, Professor David Evans and Professor Mark Onslow did a great job of facilitating the Forum, asking questions to lead each speaker into the Forum.

A similar event is planned for ISAD 2011.

The Speak Easy group is made up of all different types of people, from those who have learnt smooth speech/prolonged speech technique, the McGuire Programme and other programs, as well as people who have not yet sought or been able to access treatment.

Speak Easy always tries to make the best of the hand it's dealt – we don't always have the luxury of great resources or great funding opportunities, but we do have a great group of people who are dedicated to working with and helping other stutterers and working to improve access to treatment and support throughout Australia.

THE IBEROAMERICAN ASSOCIATION OF STUTTERING

The Iberoamerican Association of stuttering has its origins in 1998 when the first virtual discussion group on stuttering in Spanish gets created, which was called "TTM-L".

End of 1999 at the request of many of the people that conformed TTM-L, the website "We the stutterers" (www.ttmib.org) is created, which was initially intended to answer two questions that repeatedly appeared in Group Discussion: What is stuttering? And how I can cure it?

As the Discussion Group was consolidated and its members were involved more enthusiastically in the discussions, the group started to share experiences and life experiences. The stutter participants, with high levels of emotional involvement started talking about their frustrations, desires, aspirations, fears, discomfort and other feelings that accompany stuttering. In turn, non-stutterers offered their views about the disorder, which led to interesting discussions. People involved in this dynamic manifested feeling much better, they were understood and their problem "was not so heavy." This is how TTM-L becomes the First Virtual Support Group for Spanish-speaking stutterer.

Younger people, just like mothers active in TTM-L, as in the case of Ms. Claudia Groesman, current secretary of the Spanish Foundation of Stuttering, seeking to create their own space where they can communicate, exchange experiences and clear their doubtsabout stuttering, this is how emerges "I communicate," virtual space where teens communicate, share their experiences and clarify their doubts regarding stuttering.

Then, create TTM-Family gets created, which is a virtual space for parents, relatives and other close people who stutter, where they exchange information and find answers to their questions.

Of those who interacted virtually anonymous TTM-L arises the concern of those living in the same city, that want to meet personally and Dr. Fernando Cuesta, stutter and physician in Asturias, form a group of participants of the town that get together time on time, with this initial group in December 2001 the GATA gets created (Self-Help Group Stutterers Asturian), this being the first self-help group created in Spain.

In 2001, Dr. Pedro R. C. Rodriguez fromVenezuela and Dr. Fernando Cuesta M. from Spain, with their wives Dr. Ruth Bello and Dr. Marta Díaz García Eguren and Carlos Augusto Pimentel of Peru, all members of TTM-L, attend to the 6th. World Congress for People Who Stutter, held in Ghent (Belgium) and there decided the formal creation of the Iberoamerican Association of Stuttering (TTM-IB). In this event TTM-L is formally admitted as a special member of the International Stuttering Association (ISA).

The following year (2002) Mr. Adolfo Sanchez, originally a member of TTM-L, create in the city of Barcelona (Spain) Spanish Foundation of Stuttering (TTM-Spain).

With the advent of blogs as a tool for disseminating information and opinion, some of the TTM-IB members create their blogs and develop specific themes. Examples of these spaces are "Stuttering and medicine," where Dr. Fernando Cuesta M. comments on the medical advances in the understanding of stuttering, "The hobby of stuttering," where Felix Romo tells what makes every day to improve his stuttering or "Indelible Mark" where Nigita Ruben says his experiences as a stutterer . In the blog "Stutterers saying," presents some of the interventions of the participants in the discussions TTM-L and "Coping with stuttering" describes how experiences of everyday Association members face the disorder.

Through courses, conferences and workshops TTM-IB is involved in training programs for professionals who wish to specialize in the care of people who stutter and guides parents and teachers in the management strategies for the attention of the stutterer.

With the passage of time, in different cities and countries in Latin America, have set up associations, foundations and self-help groups that have as main objective the attention of the stutterer and dissemination of knowledge of stuttering and this disorder begins be known and adequately addressed in many Spanish speaking countries.

Currently, the Virtual Support Group TTM-L has 442 members and the first steps to create support groups and national associations face in countries like Ecuador, Mexico, Peru and Venezuela.

Dr. Pedro R. Rodriguez C.

LA ASOCIACIÓN IBEROAMERICANA DE LA TARTAMUDEZ

La Asociación Iberoamericana de la Tartamudez tienes sus orígenes en el año de 1998 cuando se crea el primer grupo de discusión virtual sobre tartamudez en español, al cual se llamó "TTM-L".

Para finales de 1999 y a solicitud de muchas de las personas que conformaban TTM-L, se crea la Página Web "Nosotros los Tartamudos" (www.ttmib.org), cuya finalidad inicial era dar respuesta a dos interrogantes que recurrentemente aparecían en el Grupo de Discusión,: ¿Qué es la tartamudez? y ¿Cómo puedo curarla?

A medida que el Grupo de Discusión se consolidaba y sus miembros se involucraban con mayor entusiasmo en las discusiones, se pasaba a relatar experiencias y vivencias. Los participantes tartamudos, con unos altos niveles de involucramiento emocional, empezaron a hablar sobre sus frustraciones, deseos, aspiraciones, miedos, malestares y demás sentimientos que acompañaban su tartamudez. A su vez, los no tartamudos ofrecían sus visiones acerca del trastorno, lo que conducían a interesantes discusiones. Las personas que participaban en esta dinámica manifestaban sentirse mucho mejor, que eran comprendidos y que su problema "ya no les pesaba tanto". Es así como TTM-L se convierte en el Primer Grupo de Apoyo Virtual para Tartamudos de habla hispana.

Los más jóvenes, al igual que madres muy activas en TTM-L, como es el caso de la Lic. Claudia Groesman, actual secretaria de la Fundación Española de la Tartamudez, solicitan la creación de un espacio propio donde poder comunicarse, intercambiar vivencias y despejar dudas acerca de la tartamudez; surge así "Me comunico", espacio virtual donde los adolescentes se comunican, comparten sus vivencias y aclaran sus dudas en relación a la tartamudez.

Posteriormente, se crea TTM-Familia, espacio virtual destinado a padres, familiares y demás allegados a personas que tartamudean, donde intercambian información y encuentran respuestas a sus interrogantes.

De las personas anónimas que interactuaban virtualmente en TTM-L surge la inquietud de aquellos que, viviendo en una misma ciudad, quieren conocerse personalmente y el Dr. Fernando Cuesta, tartamudo y médico residente en Asturias, consigue reunir a un grupo de participantes de esa localidad, con los que en diciembre de 2001 crea el GATA (Grupo de Autoayuda de Tartamudos Asturianos), siendo éste el primer Grupo de Autoayuda creado en España.

En el año 2001, los Doctores Pedro R. Rodríguez C. de Venezuela y Fernando Cuesta M. de España, sus esposas las Doctoras Ruth Díaz Bello y Marta García Eguren y el Lic. Carlos Augusto Pimentel del Perú, miembros todos de TTM-L, asisten al 6th. World Congress for People who Stutter, celebrado en la ciudad de Gante (Bélgica) y allí se decide la creación formal de la Asociación Iberoamericana de la Tartamudez (TTM-IB). En este evento TTM-L es admitido formalmente como miembro especial de la International Stuttering Association (ISA).

Al año siguiente (2002) el Sr. Adolfo Sánchez, inicialmente miembro de TTM-L, crea en la ciudad de Barcelona (España) la Fundación Española de la Tartamudez (TTM-España).

Con el advenimiento de los Blogs, como herramienta de difusión de información y opinión, algunos de los miembros de TTM-IB crean sus blogs y desarrollan temáticas específicas. Ejemplo de estos espacios son "La tartamudez y la medicina", donde el Dr. Fernando Cuesta M. comenta sobre los avances de la medicina en el conocimiento de la tartamudez; "El hobby de la tartamudez", donde Félix Romo relata lo que hace día a día para mejorar su tartamudez o "La marca indeleble" donde Rubén Nigita comenta sus vivencias como tartamudo. En el blog "Los tartamudos opinan", se recogen algunas de las intervenciones de los participantes en las discusiones de TTM-L y en "Cómo enfrento la tartamudez" se describen experiencias de cómo día a día los miembros de la Asociación enfrentan el trastorno.

A través de cursos, conferencias y talleres TTM-IB participa en programas de formación dirigidos a profesionales que desean especializarse en la atención de personas tartamudas y orienta a padres y maestros en el manejo de estrategias para la atención del tartamudo.

Con el correr del tiempo, en diferentes países y ciudades de Iberoamérica, se han creado Asociaciones, Fundaciones y Grupos de Autoayuda que tienen como objetivo fundamental la atención de la persona tartamuda y la difusión del conocimiento de la tartamudez y este trastorno comienza a ser conocido y atendido adecuadamente en muchos de los países de habla hispana.

Actualmente, el Grupo de Apoyo Virtual TTM-L tiene 442 miembros y se dan los primeros pasos para crear Grupos de Apoyo presenciales y Asociaciones Nacionales en países como Ecuador, México, Perú y Venezuela.

Dr. Pedro R. Rodriguez C.

Photo 1: Dr. Pedro R. C. Rodriguez, creator of the Virtual Group TTM-L

Photo 2: From left to right, Ruth Diaz Bello, Pedro R. C. Rodriguez, Carlos Augusto Pimentel, Marta GarcíaEguren and Fernando Cuesta M. in the 6th. World Congress for People Who Stutter.

Photo 3: Meeting of GATA occasion of the visit of Dr. Rodriguez and his wife in July 2007

Photo 4: Involvement of Dr. Rodriguez at the Second Conference Rosarina Stuttering (Rosario, Argentina, October 2007)

Entendiendo no a la Tartamudez

sino a Quienes Tartamudean

Adolfo A. Barrales Díaz

Fonoaudiólogo. Universidad de Chile. Psicoterapeuta e Hipnoterapeuta Ericksoniano. Relator para Facultad de Ciencias Universidad de Chile. 2011

Extracto

La tartamudez no ha sido ni es un problema menor. Actualmente, se estima que en el mundo aproximadamente 60 millones de personas la sufren. Cifra que se elevaría si incluyéramos a aquellos casos no estadísticos y aumenta nuestra preocupación si consideráramos su carácter cualitativo. Esto último, debido a que la tartamudez trasunta para quienes la sufren más allá de los bloqueos involuntarios del habla hacia una peculiar repercusión para el normal desenvolvimiento en sus vidas de relación, emocional, social, conductual, laboral y de identidad. La preocupación del hombre por esta patología no es reciente, lleva más de 2000 años. Aristóteles ya se refería a ella 300 años antes de Cristo. En todo este tiempo ha sido una patología de la comunicación que sigue desconcertando y confundiendo tanto a quienes la sufren, sus interlocutores como a las ciencias que han tratado de esclarecerla en su etiología y terapia. En pacientes "heroicos": Llevan años buscando solución. Actualmente, a la luz de todo un nuevo cambio de paradigma posracional del cual estamos siendo partícipes, en el entendimiento de la complejidad humana, es posible dar un paso al lado. Un paso al lado que, sin negar la contribución de los modelos descriptivos en tercera persona en los cuales se ha basado la praxis fonoaudiológica, nos permite ahora ir a la **"experiencia"** misma. Esto es, con un lente en **"primera"** persona, haciendo lectura más bien de quienes la sufren, tanto para su entendimiento conceptual como terapéutico. Entendiendo así, no a la tartamudez sino a cómo se organiza en las **personas** que la sufren y de allí hacer terapia. Esta es parte de la aplicación en tartamudez de una **Proposición Epistemológica Renovada para la Fonoaudiología**. Surgida de las ideas del autor que se han beneficiado con el estudio y aplicación de los diferentes actuales cambios en torno a cómo es y funciona la experiencia humana, avances en neurociencias, modelos estratégicos orientados a la solución, ontología del lenguaje . Una exposición, si bien con contenidos técnicos, con un lenguaje dialógico en la comprensión empática de la experienciación de quienes sufren de esta patología.

Característicamente, la tartamudez ha desconcertado y confundido por varias razones. Por un lado, la variada gama en la expresión de la sintomatología, su frecuencia y magnitud, los diferentes planos afectados de un caso a otro como así también en cada caso y de situación en situación. Por otro lado, las expresiones sintomáticas pueden suceder sin que medie una justificación contextual, tanto externa como interna (situación comunicativa estresante, "nerviosismo"). Confunde el hecho de que esos mismos síntomas en momentos se expresen bajo determinadas situaciones y en otros momentos no sucedan aun cuando tales situaciones sean las mismas. Tanto o más paradojal cuando los bloqueos y/o interrupciones del habla en ocasiones aparecen o no independiente del estado anímico o "tensión" mental o física. Paradójico cuando para

algunos tartamudos con poca frecuencia y magnitud de espasmos en el habla la repercusión en sus vidas emocional, social, de identidad, conductual sea grande mientras que para otros aun teniendo mayor dificultad expresiva el compromiso en tales áreas sea menor, viviendo una vida relacional más satisfactoria. Confundente, cuando vemos que es una patología altamente democrática que se da en toda raza, condición social y económica, sexo (con una mayor tendencia en varones), en todo tipo de personalidades e independiente de la competencia intelectual.

En este contexto, no es infrecuente que cada PCT suela o pueda sentir que la "lectura" que se hace sobre el trastorno en la fluidez que sufre se refiera a lo que está "afuera" y no a "él", en su forma de vivenciarla. Esto es, en tercera persona. Así, en sus experiencias durante el tiempo que recorren en búsqueda de ayuda habrán encontrado tantas y diferentes respuestas a sus inquietudes de explicación y terapia como posturas que "leen" la descripción de las regularidades externas del trastorno existen. Esto puede ser difícil de entender para quienes no son tartamudos ya que implica una experienciación cualitativa del tartamudeo.

UN PASO AL LADO

Los cambios trascendentales posracionales en el entendimiento de cómo funciona la experiencia humana, qué entendemos por lenguaje humano, el avance de las neurociencias, biología del conocimiento, modelos estratégicos y orientados a la solución permite movernos en una dirección nueva, dar un paso al lado. Un paso al lado, que ha permitido una **Proposición Epistemológica Renovada para la Fonoaudiología** y su aplicación en tartamudez. Un paso al lado que significa, reconociendo las contribuciones de las nociones que han sido el fundamento para todo el quehacer fonoaudiológico tanto teórico como práctico en tartamudez y en tercera persona, movernos ahora hacia la **experiencia** misma de quienes tartamudean. Proceso de **"escuchar"** a cada persona con tartamudez que nos permite damos cuenta que cada uno de ellos desea y espera más que nada que la "lectura" que se haga de la tartamudez sea hacia su "propia experiencia". Hacia su "yo" como persona que vivencia esta dificultad expresiva de la misma forma como cada uno de nosotros nos explicamos y ordenamos nuestra vida en relación con el mundo. W. James (1890), al referirse a la organización ontológica narrativa de la experiencia humana, decía: *"...ir a los yo y tú concretos y particulares..."*.

Hacia un entendimiento explicativo de cómo se organiza la tartamudez en primera persona.

Yendo a observar el fenómeno de la tartamudez en la experiencia misma de quien(es) la sufre(n), en la expresión sintomática operarían básicamente un juego dialéctico entre la "Esfera Biológica" y la "Esfera de las Interrelaciones". Un juego de influencia mutua no

subordinados. Entendamos estas nociones. En relación a la "Esfera Biológica", a este tiempo, muchas investigaciones concuerdan cada vez más que en tartamudez lo central sería un trastorno del Habla que obedecería, en su naturaleza causal, a disfunciones en sistemas neurofisiológicos encargados del control senso-motor de la fluidez expresiva , a factores genéticos, neurotransmisores (Ingham, 1996; Braun, 1977; Kalinowski, 1996; Brady, 1991; Fox e Ingham,1995; Dietrich, et als , 1995; Pool, et als, 1991; Postma y Kolk, 1992; Fox , 1996; Rastatter y Kalinowski, 1998; Wu, 1995, Drayna D., 2010; Maguire G., 2007., entre otros). Principalmente disfunciones en los canales de retroalimentación óseo y aéreo. Esto resulta muy coherente cuando al "escuchar" al fenómeno en primera persona, tanto en la experienciación de cada persona que tartamudea y la del clínico, se observa que la tartamudez: Decrece con habla susurreada; se reduce con el uso de dispositivos como el DAF (Delayed Auditory Feedback), FAF (Frecuency-Shifted Auditory Feedback), MAF (Masking Auditory Feedback); y es eliminada casi por completo por la sordera.

Lo anterior concuerda cuando al **escuchar** a cada tartamudo en relación a su experienciación, tanto en su preocupación sintomática como para explicarse los diferentes planos afectados en sus vidas comunicativas (emocional, social, conductual, relacional, de identidad), el foco de cada uno de ellos está centrado en los fallos de la fluidez misma. Este es un punto importante para el quehacer conceptual y clínico fonoaudiológico. Una pregunta estratégica orientada a la solución apunta a este mirar en primera persona .Al respecto, a la pregunta ¿ Qué te encontrarías haciendo mañana si ocurriese un milagro esta noche y despertaras hablando fluidamente?, la respuesta probable es que se encontraría haciendo casi todo aquello que la tartamudez le ha privado o limitado en los diferentes planos de su vida comunicativa, relacional, de identidad e incluso laboralmente (muchos tartamudos escogen, con justa razón, trabajos en donde el habla no sea una herramienta imprescindible). Que la evidencia esté indicando que lo central en la causa y sintomatología esté en el habla no es una posición absolutista ya que aún siendo en la base un problema de tipo estructural, biológico, las reacciones y expresión final de los diferentes planos exhibidos en la sintomatología , pudiendo como grupo compartir ciertos patrones ontogénicos, en cada tartamudo surgen de una **experienciación** epistémica particular y en frente de su interacción con su medio ambiente.

Aquí entra a jugar el rol de la "Esfera de las Interrelaciones". Al respecto, la expresión final de los diferentes planos y síntomas se ven influenciados pero no están determinados totalmente por la "Esfera Biológica" ya que funcionaría como un sistema abierto a la "Esfera de las Interrelaciones". Así, la expresión final dependería más de la operación de esta última esfera en una patología que siempre es **autorreferente**. De este modo, al remirar la tartamudez experiencialmente, en primera persona y en un proceso de respondernos explicativamente, nos damos cuenta que ciertamente encontramos

regularidades ontogénicas que permiten agrupar a las personas con tartamudez dentro del mismo diagnóstico pero la expresión final que hace que la vivencia sea diferente entre uno y otro se constituye como una **construcción personal.** Así, la diversidad de mundos experienciales de la tartamudez en las personas que la sufren (variabilidad entre ellos en: la frecuencia y magnitud de espasmos en el habla y de tartamudeo de situación en situación entre ellos; la expresión de diversos cursos evolutivos y consecuencias en el desenvolvimiento social, emocional, conductual, identidad) estarían reflejando el **cómo** cada persona que tartamudea **construye** su propia historia como tartamudo, según su forma epistémica de ser persona y las tonalidades emocionales que van modelando las relaciones vinculares en el curso del desarrollo de la identidad.

"¿Haz de conocer la voz?.
Haz de conocer al que habla"

Es ir a

TÚ EXPERIENCIA, TÚ ERES EL LIBRO A LEER

Así, al dar un paso al lado, de la descripción en tercera persona de las diferentes observaciones externas (como tipo, frecuencia y magnitud de tartamudeo, diferentes reacciones conductuales, etc) en respuesta a un **Saber Por Qué** de ellas, yendo a la experiencia misma nos damos cuenta de la **persona** que tartamudea. Permitiéndose un proceso explicativo de su propia historia como tartamudo que va actualizando y/o expresando los diferentes síntomas y planos afectados en forma diferencial de la historia de otro tartamudo, desde los primeros estadios de aparición- frecuentemente en la infancia- hasta la edad adulta.

Reflexionando en primera persona en la "Esfera de las Interrelaciones", observamos que cada tartamudo no está ajeno al proceso que va moldeando la historicidad de todo ser humano. Cada tartamudo es un ser humano más que, habitando en el lenguaje, nace y vive en la convivencia con otros. Se desarrolla, crece y va expresando sus diferentes competencias (emocionales, conductuales, sociales, de identidad) por la influencia de juego mutuo entre su ser persona y los agentes que va aceptando de sus interrelaciones comunicativas con su medio ambiente. Dándole a su organización personal una homeostasis, expresada en patrones, particular que se distingue de la de otro con la cual ordena, explica y resuelve su experienciación de la realidad.

En esta Proposición Epistemológica de ir a la experiencia misma, podemos contribuir a entender, más que a la tartamudez, al ser humano que va construyendo su trastorno de forma epistémica, en respuesta ahora a un **Saber Cómo** se organiza la tartamudez en primera persona. En la danza que significa la relación terapeuta – paciente de este

remirar podemos contribuir a encontrar respuestas explicativas a los por qué y cómo de muchas inquietudes, como las mencionadas más arriba. Por ejemplo, un tartamudo puede compartir con otro la misma ontogenia que los delimita en el mismo diagnóstico como tartamudos. Ahora, si consideramos nociones posracionales de que la experienciación de la realidad es una "construcción", "autorreferente", "afectiva" e "intersubjetiva", podemos entrar a "leer" el mundo de cada uno y ayudar a entender por qué la vivencia y los diferentes planos afectados entre uno y otro es diferente. Didácticamente, en forma analógica, la experiencia de viajar en avión puede ser una gran aventura para una persona desafiante y exploradora pero es toda una amenaza para alguien temeroso a las experiencias nuevas. Incluso las resistencias y recidivas aparecen más comprensibles. En un lenguaje estratégico y con el entendimiento sobre qué es comunicación, es algo que tiene que ver con el terapeuta, la PCT y la interacción entre ambos. Ejemplos: El gastar mucho tiempo en la primera entrevista terapéutica a un largo proceso sobre la historia pasada puede contribuir a entrar en el mismo proceso del cual la PCT quiere escapar, corriéndose el riesgo de abandono de la terapia en forma temprana; otorgar recursos que sobrepasan en el tiempo las capacidades actuales; ¿confrontar el escepticismo de muchas PCTs frente a nuevas terapias? que realmente surge como consecuencia lógica y muy razonable de experiencias en su historia previa de soluciones intentadas fallidas; etc.

Hacia un entendimiento explicativo del proceso terapéutico en primera persona.

El ir a esa parte del fenómeno de quien experiencia la tartamudez en un proceso de construcción epistémica guía a un quehacer terapéutico también en primera persona. Al "leer" a cada PCT que busca ayuda "leemos" que desea dirección y habilidades que le permitan un mejor desempeño comunicativo. En un mirar orientado a la solución, esto resulta en centrar ahora el foco de atención hacia aquella porción del habla donde se es fluente. Expandiéndola. Esto es, por un lado, otorgando recursos expresivos. Por otro lado, creando las condiciones contextuales para que evoque y recoja sus propias soluciones o excepciones a la regla del tartamudeo.
Otorgandorecursos "Comunicativos" en dimensiones de la dinámica emocional. Frente a las cuales en parte, aún estando presentes, no ha sabido cómo capturarlas como así también le ha prestado poca atención por haber estado centrado en las limitaciones. La terapia se torna en un proceso de co-creación, donde tanto terapeuta como PCT son activos gestores del cambio. Por ejemplo, al entender la "resistencias" ahora como reacciones epistémicas y que operan también en la dinámica terapeuta-tartamudo. El estilo comunicativo terapéutico es considerarlas como legítimas y resolverlas estratégica y constructivistamente, también en forma co-participativa. Involucrando de la misma forma a la red sistémica. Ubicando el problema "fuera". En esto último, la disociación entra a jugar un rol relevante. Creando desde el inicio un campo emocional adecuado para que los recursos expresivos vayan sucediendo y experienciándose en un proceso paulatino y con mayores

satisfacciones en los diferentes planos de su vida comunicativa (emocional, social, conductual, de identidad). Sin aspirar a que sea una máquina infalible del habla. Así, los límites de los objetivos terapéuticos los da la misma PCT. Como el proceso terapéutico también es una construcción epistémica cabe hacer una pregunta funcional en relación ¿para qué? de ella según **quién** es la persona que recurre a buscar ayuda.

BREVE RECORRIDO NEUROCIENCIA-NEUROBIOLOGÍA DEL CONOCIMIENTO, APLICÁNDOLA EN FONOAUDIOLOGÍA.

Las Neurociencias han sido el campo más explosivo en los últimos años. En los últimos 6 años el conocimiento científico se ha multiplicado 8 veces y se duplica cada 2 años.

.

Al hablar de Neurociencia y Neurobiología del Conocimiento me estoy refiriendo a la estrecha relación que existe entre Sujeto-Mundo y Mente-Cuerpo, que en su aplicación es un mirar que aporta al entendimiento y respuestas explicativas a las preguntas: cómo se "construye" y "organiza" la Tartamudez en "Las Personas que Tartamudean" y desde allí cómo "construir" el proceso de terapia en primera persona hacia el cambio deseado. Sin actitud dogmática ni autoinmune.

Cada vez más hay creciente evidencia de una dimensión biológica en la base de la tartamudez. Ahora, si nos preguntamos ¿por qué fluyes mejor, casi o claramente bien cuando te comunicas con mascotas, al estar a solas, con bebés?. Algo sucede más allá de la dimensión biológica o fuera de ella que incide en tu fluidez. El lenguaje no se actualiza sin que existan otros, muchos niños adoptados comienzan con el tiempo a parecerse físicamente a sus padres adoptivos. ¿Qué está sucediendo entonces, en este mirar?. Al parecer, no somos esclavos de una neurofisiología o genética defectuosa. Esto, en términos muy sencillos, es la Dimensión explicativa de la relación Sujeto-Mundo que operaría en la organización de la naturaleza y las peculiaridades que notas en diferentes contextos y situaciones comunicativas. El fenotipo, al parecer, no es la expresión fiel del genotipo, hay genes que por la interacción Sujeto-Mundo, se abren y cierran. Así también, el cerebro no es fijo, está en constante cambio, moldeado por la experiencia. Estudios de seguimiento del desarrollo desde niñez hasta adolescencia, denotan que la actividad cerebral prefrontal cambia según sea la susceptibilidad de cada persona a aceptar un tono emocional. Como el enrejado sináptico construido de las emociones es más estable, moldea la tendencia a cómo cada uno de nosotros reaccionará frente a la experiencia. Ello, es parte importante que nos estaría ayudando a entender el mosaico de reacciones, frente a situaciones comunicativas, emocionales, conductuales, sociales entre cada persona que tartamudea. Creándose con el tiempo una memoria de reacción emocional asociativa personal a determinados contextos comunicativos. Situaciones comunicativas mantienen al circuito tálamo-córtico temporal-amigdalino hipotetizando y corroborando la inhibición o desinhibición de gatilladores de una pauta de reacción

MACDE (Mecanismo de Aprendizaje y Conducta Dependiente del Estado). Si el circuito evalúa que la situación no constituye amenaza emocional, hay paz. Frente a lo contrario se disparan los procesos de memoria implícita y explícita: Procesos ancestrales de reacción frente al temor como palpitaciones, aumento frecuencia respiratoria, dilatación pupilar y retorno al presente de pensamientos de las experiencias de vivencias similares almacenadas. Como juicios de temor al rechazo, descalificación, anticipación expectante, entre otros juicios. Podríamos según la tendencia emocional aceptada en el desarrollo es diferente de persona en persona. Analógicamente, con los mismos síntomas de una fuerte gripe, frente a ella Pedro reacciona más calmo que Juan. Los resultados de fármacos en estudio ¿correrán por estos mismos caminos explicativos?.

Estudios iniciales que estoy realizando (en la Facultad de Medicina de la Universidad de Chile) han arrojado cierta importante información sobre la relación Mente-Cuerpo y Sujeto-Mundo. Midiendo actividad EEG y Mapeo Funcional Cerebral, aplicando estrategias de memoria asociativa-disociativa emocional (MADE), en paralelo con recursos cenestésicos de fluidez. ¿Qué se ha encontrado?: En estado de habla espontánea con tartamudeo sin MADE, ondas de bajo voltaje y alta frecuencia en zonas prefrontales y temporales del hemisferio izquierdo, área Motora Suplementaria. Situación que cambia a ondas de alto voltaje y disminución de frecuencia en las mismas zonas bajo aplicación de MADE inductora de aumento de fluidez.

EN TÚ NECESIDAD

Este mirar en primera persona está siendo operativo en su aplicación. Siempre expuesto a los principios del falsacionismo de Popper que toda proposición debe tener.

"El terapeuta frente a su paciente no es el único experto ni poseedor de toda la verdad , ambos van siendo constructores de aprendizajes significativos para un objetivo común , en la base del intercambio de la acumulación de experiencias y saberes, de lo que somos capaces de aprender según nuestros propios recursos y de los que somos capaces de aprehender de otros; con una mirada centrada en el presente y orientada a futuro".
(Adolfo Barrales D. 2011)

UN MUNDO DE DANZA RECÍPROCA DE ESFUERZOS PARA BENEFICIAR A QUIENES HAN VENIDO SIENDO HEROICOS: PARA CADA PERSONA QUE TARTAMUDEA

Estas temáticas estarán presentes en el PRIMER SIMPOSIO NACIONAL DE NEUROBIOLOGÍA DE LA TARTAMUDEZ. Simposio a realizarse el 24 de Agosto del presente año en la Facultad de Ciencias de la Universidad de Chile. No es tarea fácil

estar en la Coordinación del Simposio. En Chile, las personas con tartamudez están en una situación muy desventajada. Constituye todo el inicio de esfuerzo por sensibilizar a la ciudadanía de los sufrimientos de quienes tartamudean, por la aceptación de sus diferencias, por su integración a la sociedad, por proporcionarles la ayuda que requieren, entre tantas otras tareas. Con todo ello, concretar este Simposio es todo un desafío. Tomando con *¡¡energía!!* la filosofía del 22 de octubre de 1998 que permitió designar el **Día Internacional de Toma de Conciencia de la Tartamudez**:

"ISAD proporciona una oportunidad para construir una comunidad mundial que sea más humana y compasiva con los millones de personas que viven con tartamudez".
(European League of Stuttering Associations, International Fluency Association and International Stuttering Association, 1998)

Mis amigos, la motivación por la realización de este Simposio se ha basado de un proceso previo: el amor. De un profundo sentimiento de escuchar con comprensión empática a las personas que tartamudean, quienes, más porque el hablar les es dificultoso, sufren por la peculiar repercusión que les frena, limita, el deseable desenvolvimiento en sus vidas de relación, emocional, social, conductual, laboral y de identidad. La cara humana del mundo global y los actuales avances de las neurociencias van de la mano. El pensar y actuar con estas nuevas concepciones está en nuestras manos, contamos con la experiencia suficiente de más de 2.000 años. No debemos desechar la oportunidad que se nos está brindando para que en todos nuestros esfuerzos sembremos y cosechemos para aportar a la construcción de un mundo mejor para quienes tartamudean.

SALUDOS DESDE CHILE ,

Adolfo Barrales D. Fonoaudiólogo de la Universidad de Chile. Formado como Psicoterapeuta e Hipnoterapeuta Ericksoniano. Coordinador Simposio)

Dirección de Extensión
Unidad de Desarrollo Empresarial (I+D) y Capacitación.

Estimados (as):

Junto con saludarlos cordialmente, la **Dirección de Extensión, de la Facultad de Ciencias de la Universidad de Chile,** realizará el Primer Simposium Nacional de **"NEUROBIOLOGÍA DE LA TARTAMUDEZ"**, el día miércoles 24 de agosto de 2011, de 09:00 a 19:30 hrs. en el Auditórium Hermann Niemeyer F., Edificio Milenio, Avda. Las Palmeras #3425 (**Macul con Grecia**), se otorgarán becas especiales para estudiantes y personas con tartamudez, los valores son los siguientes:

Aranceles

Profesionales: De la salud, educación, y otros afines, **$70.000.-**

Estudiantes: Acreditar su status de estudiante universitario o de nivel técnico con algún documento válido (matrícula, certificado de alumno regular, u otro). **$40.000.-**

Personas con tartamudez: Acreditar sus status de tartamudos con Certificado de fonoaudiólogo, médicos (otorrino, neurólogo, psiquiatra) o de psicólogo. **$20.000.-**

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PRIMER SIMPOSIO NACIONAL DE NEUROBIOLOGÍA DE LA TARTAMUDEZ

Miércoles 24 de Agosto de 2011, horario de 09:00 a 19:30 hrs.

Dirigido a:

Personas con Tartamudez, Fonoaudiólogos, Estudiantes de Fonoaudiología, Docentes de Universidades, Psicopedagogos, Educadores Diferenciales, Profesores de Educación Especial, Médicos de Organizaciones de Salud Pública y Privada, otros Profesionales de Carreras Afines.

TEMARIO PRELIMINAR. SUJETO A CAMBIOS

Relatores:
Dr. Juan Carlos Letelier
Dr. Jorge Mpodoziz
Laboratorio de Ciencias
Facultad de Ciencias Universidad de de Chile:
Neurobiología de los Trastornos del Habla.
Sr. Adolfo Barrales D. Fonoaudiólogo, Psicoterapeuta Ericksoniano
Introducción a la Aplicación de Neurobiología del Conocimiento en Tartamudez; Taller para Personas con Tartamudez.

INVITADAS ESPECIALES
Fonoaudiólogas María Hargrove y Vivian Topp (Argentina) de Ambilingual Latin America, Inc. Dispensoras Certificadas de SpeechEasy para Latinoamérica:
Neuroanatomía de la Tartamudez y Efectos de la Retroalimentación Auditiva Alterada.

COORDINADORES:
Dr. Patricio Rivera L.
Unidad de Desarrollo Empresarial
(I+D) y Capacitación.
Facultad de Ciencias Universidad de Chile
Adolfo Barrales D. Fonoaudiólogo
Psicoterapeuta

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ENTREGA DE CERTIFICACIÓN. Inscripciones con anticipación. Becas Especiales de descuento para Personas con Tartamudez.

UNIVERSIDAD DE CHILE
FACULTAD DE CIENCIAS

PRIMER SIMPOSIO NACIONAL DE NEUROBIOLOGÍA DE LA TARTAMUDEZ

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Temario:

- Neurobiología de los Trastornos del Habla

  Dr. Juan Carlos Letelier (Chile)
  Laboratorio de Ciencias, Facultad de Ciencias Universidad de de Chile.

  Dr. Jorge Mpodozis (Chile)
  Laboratorio de Ciencias, Facultad de Ciencias Universidad de de Chile.

- Introducción de la Neurobiología del Conocimiento en Tartamudez.

  Sr. Adolfo Barrales (Chile)
  Fonoaudiólogo Universidad de Chile. Psicoterapeuta Ericksoniano.

- Neuroanatomía de la Tartamudez / Efectos de la Retroalimentación Auditiva Alterada.

  Invitada Especial Srta. María Hargrove (Argentina)
  Fonoaudióloga, Ambilingual Latin America, Inc., Dispensora Certificada de SpeechEasy para Latinoamérica.

  Invitada Especial Srta.Vivian Topp (Argentina)
  Fonoaudióloga, Ambilingual Latin America, Inc., Dispensora Certificada de SpeechEasy para Latinoamérica.

Coordinadores:

Doctor Patricio Rivera Latorre
Unidad de Desarrollo Empresarial (I+D) y Capacitación

Sr. Adolfo Barrales Díaz
Fonoaudiólogo U. de Chile
Psicoterapeuta Ericksoniano

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Personas con Tartamudez: $20.000 (Dispone de Beca arancelaria) Acreditar sus status con Certificado Fonoaudiológico, Médico (Otorrino, Neurólogo, Psiquiatra) o Psicológico.

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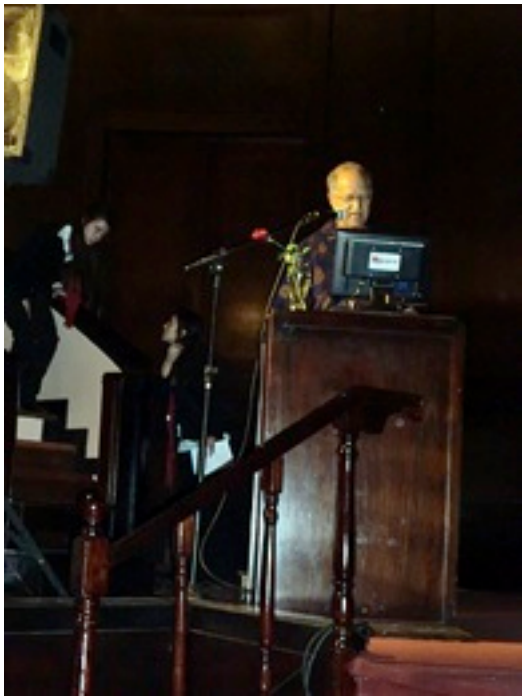

Edited by: Josh Denault U.S.A.
(email: jdenaultoo@yahoo.com)

Liaison: Keith Boss U.K. (email:
keithmaxkb@yahoo.com)