

One Voice



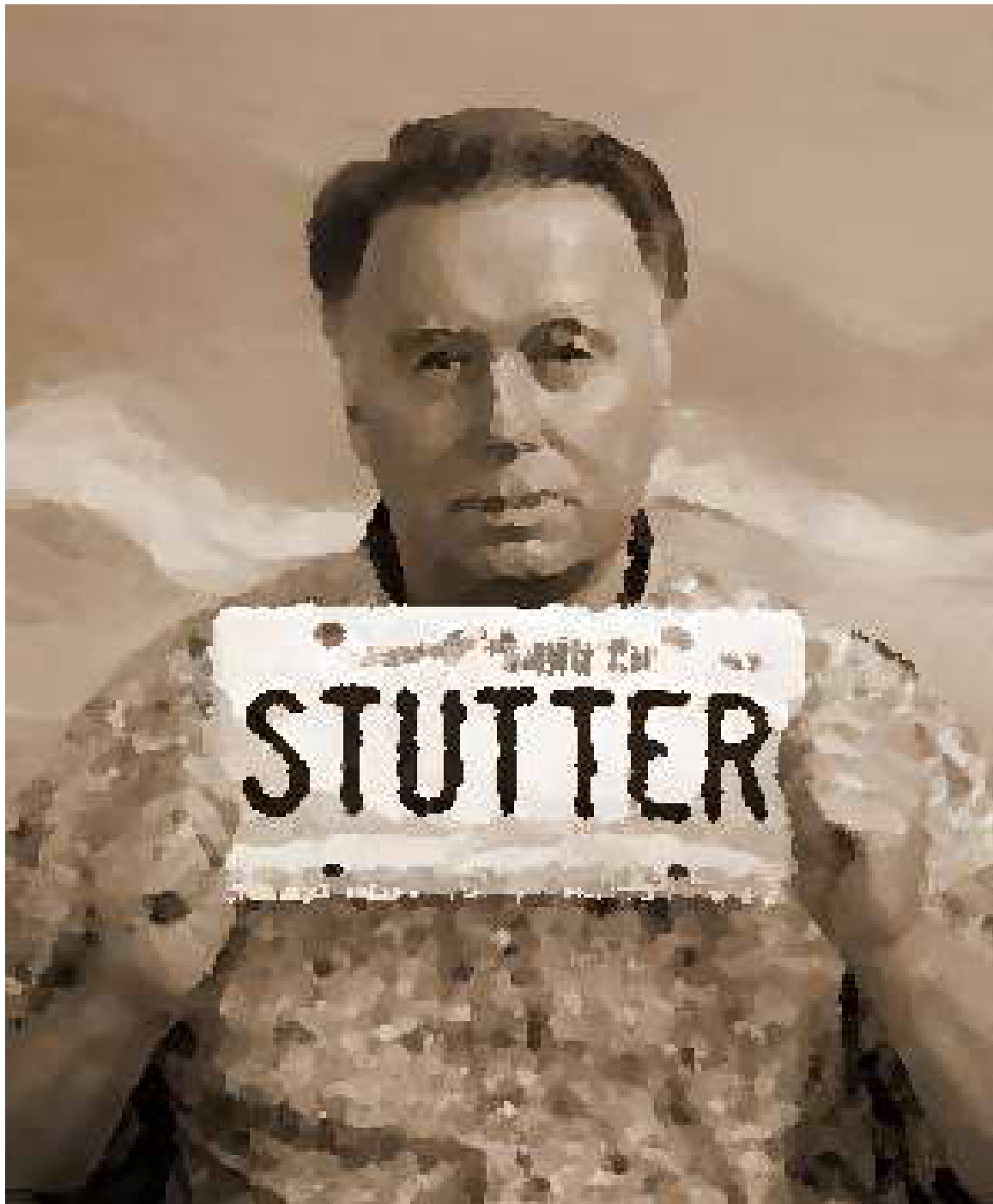
International
Stuttering
Association

Issue 22 – Dec 2006

Downloadable at www.stutterisa.org

Incorporating *The Voice of ELSA*, the newsletter of the

European League of Stuttering Associations



John Paskievich, Director of the documentary *Unspeakable*. See page 10

Edited by Jianliang Zhang, jz1208@ecu.edu

A world that understands Stuttering

FROM THE BOARD CHAIR

By Mark Irwin, ISA Board Chair

This will be my last article as Board Chair of the ISA, a position I have thoroughly enjoyed. I will use this as an opportunity to provide a summary of the ISA activities and my personal perspective gained after 9 years of ISA Board service.

The vision of the ISA is a world that understands stuttering and its mission is to work towards that vision. In its work the ISA has involved itself in various activities aimed at collecting information on stuttering, and relaying that information to the rest of the world. In particular I speak of its efforts with Outreach and Self Help group development, International Speech Project-Stuttering, Essay Contest, CD Rom project, holding of a triennial World Congress, participating in the IFA Congress, reassessing Stuttering Definitions and Terminology, Website maintenance, and of course circulation of this One Voice newsletter. In this way PWS (People Who stutter), many of whom are not able to access speech pathology services, are best able to empower themselves in their social and therapeutic endeavors.

Our progress in all these activities would not be possible without the continued good work of many people. I would like to acknowledge the efforts of Board members Warren Brown, Judith Eckardt, Joseph Lukong, Masuhiko Kawasaki, Benny Ravid, John Steggles and Michael Sugarman who together with various members of the Advisory Board and the ISP Committee, have assisted me in the management of these activities.

Again I thank Albert Zhang and Warren Brown for their fine work on this newsletter, Hermann Christmann as treasurer, Stefan Hoffmann as Outreach group Chair, and Suzana Jelcic Jaksic as convener of the forthcoming World Congress (everyone welcome!).

Of particular interest to me lately has been the work of the discussion group on stuttering definitions and terminology. I see this work as fundamentally important to our efforts in public awareness. We cannot expect to give the general public accurate messages about stuttering if we do not have enough words to describe it or if there is confusion over the use of current words. My thoughts on this topic together with the role of speech language pathologists' and self-help groups are included in a separate article later in this newsletter.

It was with extreme sadness and shock I received the news of the death of advisory board member Konrad Schaeffers. Konrad worked tirelessly on behalf of PWS and he will be greatly missed. His death is a reminder to us all that life is short. Hence I urge you all to make the most of your opportunities, contribute where you can, and enjoy it all: we never know when it will end.

Best wishes for a happy and healthy New Year

Keep smiling and keep speaking

Mark

From European League of Stuttering Associations

*By Edwin J Farr MBE
Chair of ELSA*

This last 6 months has seen the following activity from the European League of Stuttering Associations.

The International Fluency Associations meeting in Dublin was a popular event for speech and language therapists, researchers, clinicians and personnel from the national and international stuttering associations. Contacts were renewed face to face and new contacts were made. Anita Blom, Vice Chair of ELSA attended for the full week and Edwin J Farr, Chair, and Gina Waggott, Board Member attended for the last 2 days.

September saw ELSA's annual general meeting held in Münster, Germany. It was good to see delegates from ELSA's member associations come to our annual meeting to hear and discuss about the last years work and future work.

September also saw the submission of ELSA's application for our 6th Youth Meeting and I am pleased to write that we have just had the good news that we were successful with our funding application. The next Youth Meeting will take place at our familiar venue in Nijmegen, Netherlands, in July 2007 and the theme on this occasion is "Human Rights".

ELSA's aspirations for this meeting are to educate young people who stutter to make a positive change by 'Standing Up' and 'Speaking Up' for their human rights in society. It is intended that this youth meeting will educate and inform delegates of the various rights and the disability policies available. ELSA's existing publication "***International and European Disability Policy - What you need to know and why***" will be used (see www.elsa.info for this document).

In October Gina Waggott attend the European Disability Forum's Youth Committee for people with disabilities. Gina has been an active member of the committee for the last two years. The focus of this meeting was to prepare for the European Day of People with Disabilities 2006, a conference sponsored by the European Commission on the 4th and 5th December and held in Brussels. The conference theme was: "*Youth = future: let's make an equal future for all*" At this conference Gina was a keynote speaker and the issue of stuttering was brought up at the highest European level.

I have to end this editorial on a very sad note.

On 13 November Konrad Schäfers co- founder, former chair and board member of the European League of Stuttering Associations died.

Konrad was taken ill earlier this year with cancer of the bladder. All those who knew of his operation had hoped that the cancer had gone. Sadly the cancer returned to his lower body in September. He went into hospital in early November and was operated on again on Friday 10 November but the cancer had spread so quickly there was nothing the surgeons or doctors could do.

He will be remembered by all as a dedicated worker for the Bundesvereinigung Stotterer-Selbsthilfe and the European League of Stuttering Associations and to many of us as a very good friend.

Konrad's aim was always to raise awareness of stuttering and give help and support to people who stutter, parents of children who stutter, and speech professionals.

3, One Voice 22, Dec 24, 2006

Through his work with the Bundesvereinigung Stotterer-Selbsthilfe and the European League of Stuttering Associations Konrad touched

thousands of people's lives and he will be sadly missed by everyone who knew him.

To all readers I send my best wishes for 2007.

Sad News

By Anita S. Blom

It is with great sadness that ELSA and the BV announce that board member Konrad Schäfers died on 13 November 2006.

Konrad was taken ill early in the year with cancer of the bladder. All those who knew of his operation had hoped that the cancer had gone. Sadly, the cancer returned to his lower body in September. He went into hospital in early November and was operated on again, but the cancer had spread so quickly there was nothing the surgeons or doctors could do.

He will be remembered by all as a dedicated worker for the Bundesvereinigung Stotterer-Selbsthilfe and the European League of

Stuttering Associations. To many of us, he was a very good friend.

Konrad's aim was always to raise awareness of stuttering and give help and support to people who stutter, parents of children who stutter, and speech professionals.

Through his work with the Bundesvereinigung Stotterer-Selbsthilfe and the European League of Stuttering Associations, Konrad touched thousands of people's lives and he will be sadly missed by everyone who knew him.

Our thoughts are with Beate, Till and Anna Lena Schäfers.



*Konrad Schäfers
1953 – 2006*

International Stuttering Awareness Day '06

By Michael Sugarman

Every ISAD for the past nine years has been the catalyst for many exciting personal and community stories. In '05 children who stutter gave presentations in their classes about stuttering. This year a parent Cheryl Starr requested an ISAD poster for her son's birthday. He was five years old on October 22nd. ISAD committee mailed him a poster. Also, Cheryl shared, "my son is getting better at his speech every day with the help of a great speech pathologist! Thank you very much."

This year's online conference featured 89 individuals representing 22 countries. Also, 20 professionals served as experts for the "Professor is In." Statistics for the month of October during the online conference 723,276 requested information.

Events on stuttering took place from Israel, Peru, Brazil, Spain, Argentina, India, Croatia and Cameroon to name a few. Thank you for what you do for and behalf people who stutter in your country and world wide in changing how the general public view stuttering and how people who stutter analysis their own stuttering. Truly this is a group of people who stutter families who have a child that stutters and professional community to change the perception of stuttering.

For further information go to www.stutteringhomepage.com and click '06 ISAD online conference analysis articles or short films on stuttering and view announcements by organizations.



The Road to Dubrovnik

*By Stefan Hoffmann
ISA Outreach Working Group*

Again, from me some information about the Outreach activities of the ISA. Those of course are now more and more focused on the upcoming World Congress in Dubrovnik, Croatia. A scholarship fund has been set up again, in order to allow as many people as possible from all continents to participate. It is usual that especially those contacts that haven't been made since the previous congress are encouraged to do all efforts to come to the Congress. Where some economic difficulties threaten the success of those efforts, ISA tries to support to some extent. Unfortunately there is never enough funding to give all applicants what they have inquired for. So the outreach group together with the ISA Board and the Congress Organisers has the difficult task to judge where the limited funds are best allocated to. Wherever among the people reading this some coin is left over for the purpose, please get in touch with your association. All help is appreciated.

Working Group member Keith Boss from Great Britain is still continuing with his efforts in India and Pakistan. He is showing much dedication and positive spirit in this difficult task working from outside the target countries. Please check the Indian Website at www.indiastammering.com.

There has been a new example on how the international cooperation builds bridges across

oceans and cultures. Former ISA Board Member Beatriz Touzet from Argentina was on a trip to China in October 06 accompanying her husband who went to a medical conference. Prof. Touzet took the opportunity to visit Dr Li Shengli at Beijing Rehabilitation Research Centre. They had met first on the World Congress in Ghent 2001. They exchanged views about how stuttering treatment is done in both countries that geographically and culturally lie as far apart from each other as they possibly can.

The IFA Congress in Dublin in July 2006 was a good opportunity for some Outreach Group contacts to meet face to face for the first time. It was a pleasure for me to meet Joseph Nsubuga from Uganda and Yemi Akitundenj from Nigeria personally and build some bond that should last.

As usual, I want to invite the readers to consider joining the ISA Outreach Working Group. By doing so, you help directly with spreading news and information about stuttering to places still far away from ISA. Apart from helping ISA, you also have a chance to grow personally in the process. Welcome!!

Finally, at this point a very cordial call for everyone to consider attending the 2007 World Congress and witness for yourself how is a "World that Understands Stuttering"!

National Stuttering Association Update

*By Lou Madonna
Philadelphia NSA Chapter, USA
NSA News Online Team*

In the New Year of 2007, America's National Stuttering Association (NSA) celebrates 30 years of service in promoting and improving understanding about stuttering in the United States. We remember our humble beginnings in a bar in San Francisco, where a handful of people who stuttered formed the National Stuttering Project in 1977, with the bold and visionary idea that no one understood stuttering better than people who stutter, and that by networking with and reaching out to others who stutter with self-help support and peer counseling, we could most effectively disseminate that understanding to those who needed it and inspire improvement in their individual worlds. We've come a long way since then, with extensive national growth, including outreach to and integration of significant sectors of the SLP community within our ranks.

At this time of our 30th Anniversary, we have a new Executive Director, Elaine Saitta. Elaine was installed in this position in September, when our then National Director of Operations, Tammy Flores, concluded 12 years of dedicated service to the NSA. Elaine is currently based in Seattle, but will be transitioning to the national office in New York City during the next year. (Part-time staffers currently operate the office in Manhattan.) Elaine is a person who stutters; a speech-language pathologist and member of the American Speech-Language and Hearing Association; has been a member of the NSA for ten years; led the Seattle NSA adult chapter; and has served on the Board of Directors, as the Chairperson of the Website/Internet Committee. She earned her Bachelor of Science and Master of Science degrees from the University of Washington. In both her private practice, and

practice that is school district-based, she has worked with, reached out to, and supported people who stutter of all ages. She has extensive experience treating children who stutter and their families, and interacting with the professional SLP community. As a person who stutters, she remembers what it's like to stutter and feel alone and ashamed. So, in her new capacity, she is more determined than ever to do all she can to prevent others from feeling that way, to offer support, and to promote understanding of and education about stuttering.

Therefore, we have full confidence that all we do to enhance the understanding of stuttering in the U.S.--including the continuity and growth of: our family programs for kids and teens, our continuing education programs for SLP's, our adult support chapters, our Internet resources, newsletters, literature and conferences—will be in good hands.

In 2007, our 24th Annual Conference will be held in Atlanta, Georgia, from June 28th to July 1st at the Sheraton Atlanta Hotel, located in the heart of Atlanta's convention, sports, business and entertainment district. This conference promises to have more interactive workshops, inspiring motivational speakers, and family and kids activities. For up-to-date information about this upcoming conference, and everything else that's going on in the NSA, be sure to visit our website often at: www.WeStutter.org.

As we embark on our 30th year, our new service mark tagline is: "Changing the Lives of People Who Stutter." In order to effectively accomplish this, our mission continues, with Elaine Saitta's coordination and guidance, to bring hope, dignity, support, education and empowerment to people who stutter, and to

7, One Voice 22, Dec 24, 2006

foster better understanding of stuttering to the population-at-large in the United States.

Best wishes to all for peace and prosperity in 2007.



Elaine Saitta



Atlanta, Georgia

8th World Congress for People Who Stutter

*Suzana Jelcic Jaksic,
The Congress Convener*

Dear Colleague,

We are delighted to send you an email telling you about the 8th World Congress for People Who Stutter. You may already have heard about this Congress, which will be held next year in Cavtat/Dubrovnik in Croatia, 6th to 11th May, 2007. If so, please take a look at our updated web site: <http://www.udrugahinkofreund.hr/congress/>. If you are unfamiliar with it, please read this email to get a brief overview of the Congress, and then visit the web site.

The theme of the Congress is Creating Our Place in Society

We want this to reflect our view that People Who Stutter can create their own place in society and not just be given the place that society thinks is theirs. Individuals who stutter, self-help groups and national associations can give voice to their aspirations and make sure that PWS are able to achieve these ambitions. Creating a place in society means children making a place for themselves in their family and in their school, adults making themselves a place in work as well as in the complex web of inter-relationships that makes up society.

Programme

We have arranged some workshops before the Congress:

Frances Cook and Willie Botterill from The Michael Palin Centre for Stammering Children in London will be giving a workshop for starting on Friday the 4th of May and ending at lunchtime on Sunday 6th of May. This workshop is entitled "The MPC Approach: Under 7s Who Stutter".

Trudy Stewart from St. James University Hospital, Leeds, UK, will be giving a workshop for two days, 4th and 5th May on Personal Construct Therapy entitled "Psychological Approaches to Help Us Understand Stammering".

Patrick Kelly and John Sutton from Ireland will be giving a workshop on the 5th of May entitled The Patmar Programme for Adults Who Stammer.

The Congress proper will start with registration on Sunday afternoon, followed by a Welcome Party at the Hotel Croatia.

On Monday we will have a full working day followed by dining with specialists.

On Tuesday we will be working in the morning and in the afternoon we will have a half-day excursion to Dubrovnik on old-timer sailboats.

On Wednesday we have another full working day followed by the Gala Dinner with renaissance music and dancing.

Thursday is a full working day and the evening is free for delegates to enjoy themselves.

On Friday there are several trips arranged too. You can choose between a trip to Mostar taking in the Neretva River Delta en route and a trip to Montenegro. (Please remember your passports)!

We are very excited about our keynote speakers - we have keynote speakers from each continent to reflect the truly international nature of the Congress.

Many thanks for taking the time to read this.

We look forward to seeing you in Croatia!

Canadian Stuttering Association

*By Jaan Pill
Member, CSA board of directors*

The new name for our national self-help association – we're now known as the Canadian Stuttering Association – was officially announced at our most recent national conference, in Edmonton in August 2005.

We found that our previous name, the Canadian Association for People Who Stutter (CAPS), was too long when talking with reporters, school and government officials, and the like. The old name had six words, with 15 syllables. The new name has three words, with 12 syllables.

We've found this name change has made a noticeable difference when talking with the media. As well, if a CSA spokesperson is identified in a caption on the screen in a TV interview, Canadian Stuttering Association easily fits across the bottom of the screen. The older title did not fit.

In other news from Canada, planning is well under way for our next national conference. CSA has staged eight national conferences since 1991, bringing together people who stutter, clinicians and researchers, and anyone else keen to learn about stuttering. We've held such conferences every two years since 1991, in cities across Canada.

Our next conference, the 9th Canadian Stuttering Association Conference 2007, or CSA 07 for short – with the theme of Voices Taking Flight – will be staged on Aug. 16-19, 2007, in Toronto. This conference is a biennial national event for Canadians who stutter. Visitors from outside Canada are also most

welcome. The conference website is at www.stutter.ca/csa2007. If you have questions about the event, please email us at csa2007@stutter.ca.

Keynote speakers for CSA 07 include Marilyn Langevin of Edmonton, John Paskievich of Winnipeg, and Shelli Teshima of Edmonton.

Marilyn Langevin, clinical director at the Institute for Stuttering Treatment and Research (ISTAR), in Edmonton, is now completing her PhD at the University of Sydney, Australia. As clinical coordinator and then clinical director of the program at ISTAR, she has made major contributions to the form and structure of the therapy programs, developed a clinician training program, conducted research and published papers on fluency, and given presentations around the world.

Her research interests include Evidence-Based Practice (EBP) in stuttering treatment, and the social impact of stuttering on children. She has developed Teasing and Bullying:

Unacceptable Behaviour (TAB), a school program designed to educate students about stuttering and change attitudes towards teasing and bullying. You can find web resources related to this anti-bullying program by doing a Google search for Langevin bullying.

The professional literature on fluency disorders has explored the concept of evidence-based practice (EBP) extensively in recent years. Some of the literature is not available on the Internet unless a person has access to online academic journals.



However, the American Speech-Language-Hearing Association (ASHA) has posted a readily available online article, Evidence-based practice in fluency disorders, The ASHA Leader, 23, pp. 10-11, by Deborah Kully and Marilyn Langevin of ISTAR in Edmonton, which offers an overview of this topic. You can find the article by doing a Google search for Langevin evidence-based research.

John Paskievich is an award-winning Canadian documentary filmmaker and still photographer whose documentary about stuttering, entitled Unspeakable, had its world premiere at Montreal's World Film Festival in August 2006. John Paskievich, a person who stutters, narrates and is an active participant in the film. The film was three years in the making with a budget of \$350,000 (Canadian dollars).

Born in Linz, Austria, John Paskievich immigrated to Montreal in 1953. In 1959 his family relocated to Winnipeg. He studied sociology and anthropology at the University of Winnipeg. He had thought of going on to graduate school but because of his stutter, and self-consciousness about it, did not pursue that path. After a trip to Europe following his graduation, where he discovered he might prefer photography, he studied photography at Ryerson University in Toronto in the early 1970s.

As a photography student, he was relieved to be in a situation where people weren't reacting to how he spoke. "They were reacting to what was on the printed page, on the pictures, on the work," says John. "When the focus became more on the product, than on me, I just found that a really remarkable experience, a remarkable feeling. I remember this weight being lifted."

In 1978 he received nationwide attention in Canada for his first solo show, A Place Not Our Own. In 1980, he traveled to Europe to amass a collection of images of the people of the Eastern Bloc, a pilgrimage that resulted in a 1988 show,

A Voiceless Song: Photographs of the Slavic Lands.

In his films Paskievich has explored similar themes, beginning with Ted Baryluk's Grocery (1982), in which a Ukrainian-Canadian store owner talks about his store in the north end of Winnipeg, the customers who've come and gone, and the changes his neighborhood has seen.

The film, based on an experiment by Paskievich and a soundman, in which natural sounds were matched with still pictures, won a Genie Award, and was chosen to represent Canada at the 1982 Cannes Film Festival. You can find more information about Unspeakable, and other films by John Paskievich, by doing a Google search for John Paskievich.

Shelli Teshima, the third keynote speaker at CSA 07 in Toronto in August 2007, is the national coordinator for the Canadian Stuttering Association, taking over from the previous national coordinator, David Block of Vancouver.

Shelli lives in Edmonton and works as a speech-language pathologist. She became involved with CSA in January 2004 when she was asked to chair the 8th national conference of the Canadian Association for People Who Stutter (now CSA). She has been the coordinator since August 2005.

She was also co-founder of a self-help group for people who stutter in Kamloops, BC, was involved in the Alberta Stutterers Association in a variety of director positions for eight years, and is currently involved in a self-help group for people who stutter in Edmonton. Shelli became involved in the CSA to support other people who stutter by sharing her personal experiences, and to be a strong voice for people who stutter in Canada.

ABRA GAGUEIRA - Brazilian Stuttering Association's Self-help groups

*By Daniela Verônica Zackiewicz
President of Abra Gagueira
daniela.veronica@itelefonica.com.br
www.abragagueira.org.br*

The Brazilian Stuttering Association was founded in 2000 and since then, it has supported and promoted stuttering groups in Brazil.

Group organization has been modified. Firstly, there were no pre-established activities and the participants could lead the activities according to their own requirements. Since then, all the groups have pointed out the necessity to change some of the principles, including how to lead the organization, in order to aggregate more participants.

Nowadays the group meeting comprises the following structure:

- ABRA GAGUEIRA's introduction for new members;
- ABRA GAGUEIRA's plan of action;
- Introduction of new members and presentation of their expectations;
- Scientific session – books chapter or papers about stuttering discussion;
- Free time activities when each member has 5 to 15 minutes to talk about a non-specific subject, to read, to perform an activity or testimonial – the focus is free talk independent of stuttering;
- Final comments about the meeting and planning the next scientific session.

The group meeting is three-hour long and is held once in a month. The number of participants varies between four to ten stuttering people.

In the beginning, group meetings were located just in São Paulo city. Today three more cities have welcomed stuttering group meetings.

Since the beginning the very important rule has been that only people who stutter could participate the meeting. Nevertheless, a speech language therapist specialized in stuttering, who is also a person who stutter, participated on the group meetings in São Paulo. When she quit, group members demonstrated to prefer the presence of a therapist (speech language pathologist) to conduct the group.

In addition, the association is having a huge challenge now - the creation of more groups. However, it has been noted that a good strategy is having the speech language pathologist creates a new group in the city, since she or he knows more people who stutter than a PWS by him/herself.

Now members and associates are having an important argument about this topic. What is the impact of the participation of a therapist in the group? In which conditions it will be positive? What the rules to direct such participation?

We would like to share this discussion with others associations. Please, send your message to abragagueira@abragagueira.org.br

Thank you!



Brazillan abra gagueira

UPDATES FROM CAMEROON

*By Joseph Lukong
P.O. Box 9598 Douala, Cameroon
lujotar@yahoo.com*

Since the past six months, our association, the SPEAK CLEAR ASSOCIATION OF CAMEROON (SCAC), recorded a good number of successes. First, the genetic research project on stuttering that we have been carrying out since 2002 with the National Institutes of Health (NIH) of the USA continued as we collected speech and blood samples from 100 members of our association. This research project has just undergone the annual review by the local Institutional Review Board (IRB) for the protection of human subjects. The board is attached to the Institute of Tropical medical research station Kumba care of the University of Buea Cameroon. This IRB after examination of the protocol submitted was satisfied with the work done and gave the ethical clearance for the project to continue next year. We have identified 2 new large families having several individuals who stutter and we are planning to study these families in 2007. So far the preliminary results from this study recorded some significant progress as a gene has been discovered in chromosome 1 of the Cameroon population that may be responsible for stuttering in this population.

Also, a representative of our association was invited to take part at the 5th world conference on Fluency Disorders that took place last July at Trinity College, Dublin, Ireland, organized by the International Fluency Association, the IFA. During the congress, our representative co-presented two papers – one was captioned as ‘linguistic, cultural and geographical influences on public attitudes towards stuttering’. The data for this research project was collected from Douala Cameroon, Ottawa Canada and from Morgan town West Virginia in the USA. The other presentation was on the International speech project and outreach effort in Africa and China. Our representative also met with leading researchers, speech pathologists and leading members of the International self help for people who stutter and had fruitful exchanges with them for our association.

Last October 22nd, the international stuttering awareness day, was celebrated in several localities of Cameroon.

ISP Mission In Togo (West Africa)

By Moussa Dao

In October 2004 in Douala, Cameroon, during the first African conference on stuttering, one of the important projects of ISA was launched.

It is called International Speech Project. It is aimed to launch the concept of self-help group in developing countries and to contribute to set up speech services in these countries.

From May 25th to June 1st 2006, Anne Marie SIMON, a Speech language pathologist (France), and Dr Moussa DAO (Burkina Faso), an advisory board member of ISA, conducted the first mission of ISP in Lomé. It was the pilot mission of ISP.



Anne Marie and Moussa during meeting with PWS on self help concept

15, One Voice 22, Dec 24, 2006

Lomé is the capital of a west African country called TOGO. Togo is a French speaking country. It is bordered in west by Ghana, North by Burkina Faso and East by Benin.

The population is about 4 million.

The objective of this mission was to sensitize population, to launch concept of self-help group and to help people who stutter in Togo to set up their association. This mission involved the collaboration with Handicap International.

The main activities did during the mission were:

- ◆ We had two training sessions. The participants were composed of 20 RBC agents, 2 members of Handicap international and 1 representative of Togo social affair Minister.

RBC agents are from village communities. They were trained in identifying persons with disabilities in their communities. They got knowledge to give first care or to address the patient to relevant structures.

- ◆ Anne Marie was invited to the night TV news.

TV2 is the second national TV of Togo. It's watched from all the country. Inside the TV news, she responded to the question of the journalist. The questions were on what is stuttering, the purpose of our mission and the different activities that we will do during our stay particularly the conference.

- ◆ We animated a conference in the conference room of French cultural centre of Lomé.

The room with capacity of 100 persons was so crowded that numerous persons were obliged to stay outside to follow the conference. There were about 150 participants.

- ◆ For one hour, Anne Marie, Agnes Gascoin and Moussa Dao were the guests of a Togo national radio broadcast called "Carte sur Table".

During this broadcasting Anne Marie responded to the questions related to stuttering and her treatment, Moussa responded to the question related to his own experience as PWS, and Agnes responded to the question about Handicap International.

- ◆ We had a meeting with 42 PWS in order to discuss about the concept of Self Help Group.

We had a meeting with 45 PWS on how to create a stuttering association in Togo. There was a small group of PWS who was working on the project of setting up an association.

The mission was successful.

It has revealed the benefit for such mission to have a Speech Language Pathologist and a Person who stutter work together. It's important to give information on stuttering and to have also a person to give his personal experience and how in their country they face to stuttering.

The British Stammering Association

By Norbert Lieckfeldt

2006 has been a successful year for the Association.

It started in 2006 with the launch of our training CDs for Scottish schools in Edinburgh. The CDs give ideas for best practice on how to support a child who stammers in a whole-school context. After the launch, all primary and secondary schools in Scotland and all speech and language therapy departments received free copies.

Another important development has been the establishment of a parliamentary group of three Members of Parliament (one each from the three major parties), thanks to BSA patron Jon Smith and BSA trustee Leys Geddes. This group will be invaluable when we raise the issue of stammering in the context of the government's legislative programme to ensure the needs of people who stammer aren't overlooked.

Our Pre-School Dysfluency Campaign has produced a report on the quality of speech and language therapy provision in England and Wales for pre-school children according to 13 criteria developed during the campaign. Services can be very variable across the two

countries. We are currently working with six NHS trusts to implement the recommendations and see what it would take to improve their outcomes. We hope to have firm results in 2008 which will form the basis of a political campaign to ensure that the current 'postcode lottery' where your location determines the quality for the service you receive will be replaced by equitable services for all.

2006 saw out 11th National Conference at Telford – it was so good that we have decided to return to Telford in 2008. For international visitors, Telford is only 30mins away by train from Birmingham International Airport.

Our Scottish branch, BSA Scotland has also been active and successful, with much political lobbying, a weekend away in the Scottish Highlands and an Open Day especially for children in Dundee. For more information, please see www.stammering.org/scotland

Further details on the Association's activities can be found on our website at www.stammering.org

Passing Twice Workshop Arrives in the UK

By Nora O'Connor and Andrew Janes

Passing Twice was founded at the 1993 National Stuttering Association convention in Washington D.C. Passing Twice is an informal network of gay, lesbian, bisexual, and transgender stutterers and their friends. At the heart of Passing Twice's movement is facilitating workshops at stuttering conferences around the world. A Passing Twice workshop creates a safe place for LGBT stutterers to meet

and talk about life experiences, as well as addressing the similarities between "coming out" as a person who is gay and as a person who stutters. Gay people who stutter recognize that they are not alone, and find much needed support and friendship. As men and women who have been through struggles twice, we have much to offer, both to people who stutter and to the LGBT community. Workshops draw in

17, One Voice 22, Dec 24, 2006

people who do not identify as LGBT, but want to learn from LGBT stutterers who have “come out of the closet” not once but twice.

Passing Twice has consistently held a presence in the stuttering self help movement at many conferences around the world: World Congress of People Who Stutter (1992, 1995 and 2001), International Fluency Association (1997), ASHA (1997 and 2000), Queer Disability Conference (2002) and numerous workshops at conferences hosted by the Canadian Stuttering Association and the National Stuttering Association.

This year we are proud to add the British Stammering Association conference to our list of locations that we have held workshops. Andrew Janes, a gay man who stutters from London, facilitated the first Passing Twice workshop held at a BSA conference, September 2006. Andrew says, “We were very encouraged by the positive response from conference delegates, both those who did and those who did not attend the workshop.” Andrew also found the facilitator experience fulfilling as a personal challenge. There were more “straight” stutterers at the workshop than LGBT stutterers. Passing Twice is delighted and reassured to see so much support and interest in the stuttering community for LGBT stutterers. Even after the workshop,

Andrew was approached by a half dozen people asking how the workshop had passed off.

In addition, Passing Twice held our 14th workshop at the National Stuttering Association conference, June 2006. The workshop was a great success with over 20 people in attendance. Nora O'Connor, a lesbian who stutters from California, facilitated the workshop. Nora states, “I attended my first Passing Twice workshop in 1995. I met some of the closest friends I have today at that convening. I always thought I was the only lesbian who stuttered. I was wrong. I have since had the honor of facilitating many Passing Twice workshops and have provided hope and strength to hundreds of people. The new person is not always gay, lesbian, bisexual or transgender. Often speech language pathologists are interested in learning how to work with LGBT persons who stutter or a father who stutters looks for people to talk with about his gay son or straight stutterers attend a PT workshop to find authentic and powerful dialogue.”

Passing Twice can be reached at www.passingtwice.com or passing_twice@hotmail.com



Passing Twice members enjoy food and conversation at the NSA convention

The Support Groups For Pre-School And Primary School Children And Their Parents

*Vanja Brdar Mustapić
Zagreb, Croatia*

The Croatian Association for People Who Stutter, "Hinko Freund", was founded in 2000. Part of the Association's activities consist of self-help groups, among which the most regular and most efficacious is the one meant for pre-school children with its leader Doctor Senka Sardelić, senior lecturer, who leads this group with great knowledge, experience and unselfish commitment.

The group is organized in two separate groups: parents and children. The session includes discussion with the group leader and with other parents about current situations and problems which are displayed and analyzed so parents gain knowledge of stuttering, its symptoms and characteristics with children. They also learn how to communicate with their children at better and more appropriate ways. Moreover, these meetings are helpful for parents in solving some uncertainties and overcoming emotional problems.

Other speech therapists work with children in a group. This includes not only the therapeutic work, but also the development of a culture of communication, and, above all, the self-

confidence which helps in everyday life and situations.

I am writing this article as the mother of a child who stutters and therefore I have four-year's experience of attending group sessions. The success of this group is shown by the fact that the members of the group for pre-school children (parents and children who are now seven and eight years old) go on to work in the group for primary school children. We have sessions once per week and we are organized in the same way as we were in the pre-school group, except for the fact that the parents lead the group rather than a speech therapist and are discussing and talking mainly about the problems and situations the children face in the new school environment.

Finally, after these few general facts I want to stress how helpful support groups are as much for children, who have become real buddies, as for us parents in gaining the capability to live and cope with our child who stutters.

Early stuttering research

By Patrick Kelly

Chairperson of the Irish Stammering Association

Senior Speech and Language Therapist, HSE, Western Health Board, Ireland

Phone - 087 950 2991(m), 00353 7196 50311(w)

Having worked for over 20 years with children who stutter I firmly believe that given the appropriate specialist treatment in the early stages the disorder can be resolved in nearly all cases. Controversy still remains regarding treatment of very young children who show stuttering behaviors and well-documented discussions between Yairi and Onslow highlight this important issue. After working in the U.K. as Specialist Speech and Language Therapist for seven years I sent out a questionnaire to all the parents of children I had seen who stutter and found that practically all showed no signs of stuttering. Following a move to Ireland I decided to carry out a similar survey to follow up all children who had been assessed as either stuttering or normally non-fluent over a 10 year period from 1993 to 2003. The aim was not specifically meant to be a research paper but more as a guide to assess how these children had progressed following therapy.

A total of 64 people were questioned and 46 replied. Of those who replied, 30 were males and 16 were females and the average number of sessions each of these children was seen was 5.2 and the average age was 3.2 years. Three of those who replied were reported as still "stuttering", two of whom were given further therapy and now do not stutter. One child still has a mild stutter which it is hoped will resolve

and the other child who was reported as stuttering failed to turn up for therapy. The 18 who failed to respond to the questionnaire have also been followed up by a school Nurse who covers the same catchment area as mine, and initial feedback indicates that none of these children still show any signs of stuttering. The population of the catchment area is around 19000 of which approximately 1800 are children under 5 years old. These children would now be up to 17 years of age and it is doubtful that they will ever stutter again. Perhaps one reason why this research is unique is that I am the sole therapist in this part of rural Ireland and have been for the past 13 years and would be aware of any child under 17 who shows signs of stuttering as the referral rate by doctors, community nurses and teachers is extremely high.

As previously mentioned this survey was not intended as a research paper but will hopefully add to the discussion on how to treat stuttering in the very early stages. I do believe that the disorder can be resolved under 5-years IF the appropriate specialist therapy is provided and probably more importantly if the therapist BELIEVES therapy will work. I intend to continue to follow up all of these children and provide any therapy if and when required.

For One Voice 22

By Shinji Ito
Executive Director, Japan Stuttering Project

The Japan Stuttering Project focuses on three major activities besides weekly regular meetings. One of them is a summer camp for elementary school children to high school students and their families. The program consists of (1) discussion by children and their parents to understand stuttering and themselves as persons who stutter; (2) performance of play as a form of self-expression; and (3) study meetings for parents to learn ways to support their children who stutter. We have organized 17 camps so far, and this year about 150 people participated from all over Japan. This year's camp was special because on the staff there were five college students, for whom the 2005 camp was the last one before they graduated from high school. These young people took very good care of the children. They were actively engaged in the discussion both with children and parents as facilitators, and they provided valuable insights for them. The well-balanced mixture of membership including new staff, experienced staff, adults who stutter and clinicians worked very effectively for the camp.

Another important aspect of JSP's activities is the program designed for the personal development of the members. At the annual fall workshop on stuttering we focus on various approaches to learn ways to live with stuttering. Dr. Joseph Sheehan is well known for his iceberg theory: most of the problems of stuttering are hidden under the water. These are the emotions of fear, shame, and anxiety about stuttering; the behavior of hiding stuttering and

avoiding speaking situations; and preconceptions that stuttering is bad and inferior. This year we studied cognitive therapy in relation to stuttering, which was considered as effective in dealing with the hidden part of iceberg - in other words, emotions, behavior and thought. It was a two-day workshop, facilitated by a psychiatrist, specialized on cognitive therapy in Japan. Shinji Ito and this psychiatrist had a public discussion for three hours on the last day of the workshop and discussed how cognitive therapy could be effective in dealing with stuttering. The psychiatrist demonstrated the approach of cognitive therapy using an interview with a person who stuttered from our group. The live interview helped participants to understand cognitive therapy better.

Another important activity is to disseminate information on stuttering in society. Last year JSP's activities were broadcast by one of the major TV broadcasting corporations, and this year we published 1,000 copies of a booklet "Life with Stuttering: Stories of Persons Who Stutter." We regard writing as an important activity for us to see ourselves and our stuttering objectively. We also find it important to publicize our stuttering experiences to increase awareness of stuttering among parents of children who stutter and the general public. We selected 26 essays out of more than 100 that JSP members wrote over many years. The publication of the booklet represented significant progress for us.



JSP's recent Summer Camp

The Value of Self-help Groups - People who Stutter helping People who Stutter

*By Geoff Johnston
Regional Director, The McGuire Programme, Australia*



Geoff Johnston

For many people who stutter, the years and years of treatment without success have resulted in them having a “victim” mentality. They may feel they don’t have any ownership of their blocking behavior and that improving their speaking is beyond their control. They believe the solution will come from someone else, perhaps the speech pathology profession will “cure” them or that drugs or fluency devices provide the answer.

The key to moving forward with long-term recovery from stuttering is to be truly empowered which requires being fully responsible and accountable for our own recovery. Also involved is the ability to give ourselves the authority and permission to do what’s required to move forward. Certainly we can use the resources available to us such as speech pathology services and other treatment programmes, but in the end, “If It’s To Be, It’s Up To Me!”

The first step is to take ownership of our stuttering behaviour and embrace the commitment required to work hard and persistently to challenge feared speaking situations by expanding comfort zones. Self-help groups are a necessary part of long-term recovery from stuttering. There is evidence, at least in the McGuire Programme here in Australia and world-wide, that recovery from a life-time of stuttering is achievable.

For recovery to be possible we must take a systemic approach to treatment with focus not only on speech but also more importantly on the whole person and the framework of perceptions and beliefs that support the behavior. To quote John Harrison, “stuttering is not so much a problem with speaking but rather it’s more a

problem with the experience of communicating with others and how we see ourselves in relationship to the world around us and the people with whom we interact”.

A strong speaking technique, as taught on the McGuire Programme, provides the tool to go out into the real world and START the recovery process! 99% of our students are completely fluent by the end of a 4-day intensive course and have experienced the freedom of speaking to 100 strangers in the street and making a public speech in a significant place (eg Darling Harbour in Sydney). The end of the course is just the start of their recovery process.

The strength of the McGuire Programme is that everyone involved is a recovering/recovered stutterer with a passion to help other people who stutter to gain freedom from this debilitating behaviour. Graduates of the programme form a world-wide extended family providing coaching, support and encouragement via support groups, telephone, refresher courses, email chat, internet Skype discussion groups, public speaking clubs, theatrical productions and employment networks.

No matter where a McGuire graduate is located from the Outback of Australia to Iceland, if they have a phone or internet connection, help is just a call away. Membership of the programme includes life-time support for as long as the person requires help.

The following are examples of self-help for people who stutter in action:

Graduates of the programme are able to access support groups in all capital cities in Australia (three in Melbourne) and some regional centers. Similar support groups operate in the more than dozen countries conducting McGuire courses. Leadership of support groups usually rotate with an emphasis on participation. "Back to basics" is a normal part of a meeting with practice time for the McGuire speaking technique. Feedback is given on the "commend, recommend, commend" basis with most groups containing a trained instructor or certified primary coach.

Refresher weekends or 4-day intensive courses are available as part of a graduate's membership of the programme. These activities are organized and conducted by recovering/recovered stutterers to help themselves and other graduates of the programme. Street contacts and public speaking is a necessary part of refresher activities.

Telephone support is available from coaches throughout the world via the international phone list consisting of people who have been trained and are being successful in their own recovery. Many graduates access internet telephone services and Skype to keep the costs down. A common use of the telephone network is to practise warm-up drills before a job interview or an important speech or presentation. Via internet Skype and video cams support groups world-wide are able to share meetings or receive coaching and instruction from a person in another country again as part of their membership of the programme.

The email group "Freedoms Road" is available to graduates to ask for advice, share experiences including problems and success stories. Inspirational stories provide encouragement to graduates world-wide. Graduates are able to share personal stories and strategies, for example how to approach a new job in tele-marketing or attending that critical job interview.

Public speaking is an important part of challenging feared situations and changing perceptions and beliefs around speaking. Involvement in Toastmasters, Rostrum and other public speaking clubs is encouraged. In Adelaide, South Australia graduates of the McGuire Programme started a new Toastmasters' club called "More Than Words" to facilitate the transfer of technique and speaking skills to the real world. The club has attracted many "fluent" speakers with nearly a 50-50 ratio at present. Graduates of the McGuire Programme, recovering stutterers, in this club and other clubs throughout the world are regularly winning club, area and divisional public speaking competitions against non-stutterers.

Many people who stutter have learnt and drilled a speaking technique whether smooth speech, McGuire or another fluency shaping method. This enables them to speak without stuttering in a very short time. However, for many people they have been unable to transfer that skill into real life with its often perceived pressures, judgments and fearful situations. It follows then that to recover from stuttering long-term we have to change the system which is supporting the stuttering behavior. We have to change ourselves, our perceptions, our beliefs and the way we look at the world around our speaking.

Without support and help from like-minded people, this task is exceedingly difficult if not impossible for most people. Technology has made self-help groups throughout the world more accessible with many "stuttering" forums available via the internet (eg neurosemantics of stuttering, just to name one). By talking to other people in self-help groups and possibly seeing their pre-treatment videos, people who stutter realize that permanent speech improvement is indeed possible. Owning the process required for that improvement brings about real empowerment to move forward with the belief "Yes, this will work for ME!"

Personal stories from Mauritius

Parole d'Espoir – from stuttering to freedom

Hi! My name is Jim Caropen, I am an accountant and I live in Mauritius. I am now a recovering stutterer, but before that I met Mark Irwin and embarked myself on the Parole d'Espoir adventure, speaking had always been a very problematic activity for me. I had always endeavored to overcome my stuttering by all means. However, with time I had appreciated that I would never overcome it but with the help of other people around me. Then in September 2005, I received a letter from Mr. Joseph Lukong of Cameroon that set me into contact with lots of people all around the world and helped me achieve tremendous breakthroughs in all areas of my life. Here is the story of how it all started...



From a trip in Seychelles in 2002, I had brought a WorldSpace satellite radio and since then I regularly listen to the programmes of Radio France International (RFI). I had become aware of the existence of self-help groups for persons who stutter abroad and gradually began to cherish the secret wish of launching such a group locally. In a first instance I contacted RFI and they transmitted to my address to Joseph who at that time was organizing the first conference on stuttering in Africa. I received the conference brochure from Joseph and of course applied to attend the conference. Unfortunately, I later realized that I would not be able to attend, but by mere chance Mr. Mark Irwin, the president of the ISA, was transiting through Mauritius from Australia on his way to Cameroon and Joseph put us both into contact.

On a sweet Sunday morning, Mark phoned me and we agreed to meet near the Pizza Hut in Caudan. Mark was accompanied by his wife Isobel and all three we had a superb lunch at Le Capitaine restaurant after which we made a quick tour of Port Louis. During the lunch, Mark explained to me the functioning and objectives of self-help groups and all of a sudden suggested that I could launch one of these locally. Absolutely NO did I answer immediately! I could not imagine myself acknowledging that I encounter stuttering difficulties in my speech. Indeed, I had always strived to hide this fragility of mine.

Finally, to cut short of all my protests, Mark left it all to me and went straight to Cameroon. He only told me that he would be back after the conference and would like to proceed with the launching of the group! After much reflection and hesitation, I finally decided to go forward, and I picked up my phone and called La Vie Catholique – the only newspaper I knew would publish our advert for free. I fell on Sandra Potié – who has now become a good friend of mine – and contrarily to what I had feared she showed great interest in our project. On the 1st of October 2005 an attractive advert was published in the weekly newspaper conveying persons who stutter – including their friends and families – to an information meeting to be held at the Centre Sociale Marie Reine de la Paix on October 13th.

On the eve of this fatidic day, Mark and Isobel came back to Mauritius and we met for lunch at the Pizza Hut, a convenient place to prepare the forthcoming meeting. We were expecting 4-5 persons to attend but were surprised by an attendance of over 15. I introduced myself, and mentioned that I am a person who stutters. I also introduced Mark. Then he explained to us all what is a self-help group and how it would be beneficial to stutterers in Mauritius. He spoke in English and I translated everything in Creole. All those present were very attentive but also participative when came the time to ask questions and make comments. Before leaving we all agreed to hold our first meeting on the 22nd of October – the international stuttering awareness day. After the meeting, Mark persuaded me to record a small talk about my experience on his camera. I had always been avoiding the camera as my fiercest enemy, but we finally agreed that I would face it! The recording took the form of an interview conducted by Isobel, and everything went brilliantly well. This 13th of October was a very memorable day. On the spot I thought of it as being an absolute breakthrough in my life; but it turned out to be only the first one in a whole series of breath taking breakthroughs I had never dreamt I would ever attain!

With time, efforts and energy we have developed our very own self-help group concept. Our self-help group is not a permanent one, but has a limited number of meetings – usually 16. We have divided the program into three phases: 1 – acquire 2 – transfer and 3 – maintain. In the first phase, the longest one – around 10 meetings – we get to know each other and we work on acquiring techniques to regain control over our breath and speech. We practice breathing and relaxation exercises, slow flow reading, picture reading and group discussions. Members are also invited to practice the exercises at home and to note the details of these on a follow-up sheet.

At the end of this phase, we will make an evaluation – both in group and individually – of the achievement of

each member and the progress that remains to be done. The means to attain these are also identified and highlighted. By that time the group has become a homogeneous one and members readily help each other – most of the time without being aware of doing so. By that time also, all members have acquired basic knowledge about stuttering and they also know what means are available to them in order to attain a more fluent speech. They then make a personal affair of it and take their speech fluency in their own... hands.

During the remaining meetings, we would perform the same exercises as before but into more depth, while paying attention to the ways to transfer this confident way of speaking into our day-to-day life. And during the last phase, we think about how we will maintain our achievements in the long run even without the help of a self-help group. Our self-help group also has a library facility and this helps our members to do further reading to empower themselves with regard to their speech. We are very thankful to the Stuttering Foundation of America for their highly appreciated contribution in terms of books and DVDs to our library.

The objective behind this batch style of our group is to give members the opportunity to interact with fluent persons outside the group, once they have acquired sufficient confidence in their speech. Also, due to the fact that we have no permanent structures – in terms of meeting place etc. – this way of functioning is very convenient to us. To date, we have run 2 batches: the first one from 22.10.2005 to 17.12.2005 and the second one from 28.01.2006 to 03.06.2006. We are planning to launch a third batch early in 2007. On December 17th 2005, our group decided to take the name of Parole d'Espoir – literally "Hope for our Speech".

I am very happy to have embarked on this wonderful adventure. I have met a lot of new friends – both stuttering and fluent. I have gained much control over my speech. Still now, when I tend to speak quickly, I also tend to stutter. But deep inside me, I know that if I am attentive to my speech, I will not stutter. This confidence in my speech has encouraged me to be more active in life. I make friends more easily, I participate more willingly in group discussions and I occasionally dare to talk in public.

I am thankful to all the members of Parole d'Espoir: Angèle, Alain, Steffy, Yonell, Mathieu and Yasvin. They have been the most caring friends I ever had. I am thankful to their parents, friends and relatives who have encouraged us all through our venture and have happily participated to our meetings and outdoor activities. I am thankful to ALL those who have helped us in one way or another to transform ourselves into persons who are happy to talk!

E-mail: jimcarroopen@yahoo.com

How far would you go?



Hi! I am Angèle, I am 22 years old and I live in Mauritius. 18 years of my life have been based on fears, uncomfortable situations and silence. As from the age of 4, I was different from others. I was afraid to open my mouth and speak because of others' reactions.

Today, most of these fears have melted away; I'm not saying all because the feeling of being a person who stutters remains. However I'm doing my best to say I've been a stutterer.

I had followed several speech therapies with speech and language therapists, but had decided to abandon as I found no improvement at all. The best course of action I could envisage at that time was to stay silent or to say little words. Avoiding situations where I would be brought to speak was the only way for me not to feel inferior from others. My mum who was however not discouraged by my decision came across an advert about the launching of a self help group in Mauritius in "La Vie Catholique", a weekly newspaper, and asked me if I would be interested to eventually seize this opportunity. With little conviction I told her to phone the contact person.

From this phone call, my life started to change but as usual I did not realize. The day I saw other people like me, having the same problem, I understood that it was time for me to make something about my stuttering. The self-help group "Parole d'Espoir" was the only thing I really needed to overcome all the uncomfortable feelings I had met during my past 18 years.

I've learned how to breathe and how to control my breathing. Saying vowels loudly and slowly also help to regain the control of my speech. Most people usually speak quickly and for a person who stutters this is surely his greatest enemy. I've learned to slow down and to breathe deeply before each sentence. This group was not only a place to learn about oneself but it was also a place to relax and regain trust in ourselves.

However it was not always easy to speak fluently. It was like a dance step; one step forward, two steps backward, two in front and one back. But I was never discouraged for long. My objectives were to be as a normal person, to speak clearly so that I make myself understood by others. My desire to pursue university education and to be a professional woman was increasing greatly.

And today I am proud of myself. Although the journey is a difficult one and not yet completed, I have

27, One Voice 22, Dec 24, 2006

acquired a better speech. But more importantly, I regained trust in all my actions, in all my words and particularly in myself. I remain convinced of my ability to overcome my stuttering and I am sure that I will soon say, "I've been a stutterer ago".

Whoever you are, stutterer or not, I just would like that you believe in yourself and in your abilities to overcome your fears and all your problems. Being a person who stutters does not mean that you are inferior from others or abnormal; you are a human being equal to your neighbour, just like any person. Just search and you'll find how great you are and how far you can reach.

Email: ngel_mel@yahoo.com

My Transformational Story

Hi, my name is Alain Kwan. I am 45 years old, and I am married with two children: one boy of 20 years and a girl of 16 years. I am a Sales Supervisor in a private sector company and I believe in God.



Alain (centre) and his friends

I came to know about Parole d'Espoir through a friend who gave me the phone number of Jim Caroopen and I decided to contact him. Unfortunately, he was not available because he was on holidays. I kept on trying and after one week we finally met.

What motivated me to join the group was that I had enough of not being able to express myself and to effectively communicate my views to others. Very often, due to my stuttering problem, I avoided arguing with my subordinates and preferred to remain silent during management meetings. I suffered a lot from this situation and also all my prospects of professional advancement were hindered.

Today, I am very happy to have joined Parole d'Espoir. It was not easy for me to attend the weekly meetings because I work until noon on Saturdays, but

I was motivated to recover from my inability and did my level best to attend all meetings.

At first it was not easy for me to admit that I stutter but as the weeks passed I was literally transformed. During a reconciliation exercise linking my present situation to my past, I became conscious of the behaviors and circumstances that had lead me to stutter. Little by little I gained confidence in myself and most importantly I learnt how to control my feelings and emotions because I am a very emotive person.

During the meetings, I was had the occasion to practice breathing exercises, reduced flow reading exercises, and relaxation exercises. All these helped me to progressively obtain confidence in me and I looked forward to overcome my stuttering totally.

It was beneficial for me to meet and interact with other persons in the same situation and strong solidarity links were created between us. During the meetings we encouraged each other to fight on and persevere and paid special attention to those who had difficulties in practicing the prescribed exercises. We were like a family and Jim Caroopen was our father.

It was not so demanding for me to make the efforts because I wanted to overcome this fear of stuttering. Through the books I read, I learnt that fear was a normal feeling but it could be controlled and overcome.

Today, I have achieved a lot thanks to Parole d'Espoir. I am a confident, enthusiastic and optimistic person and this has extended to my family and colleagues. I feel a well being person but I am also conscious that practising exercises regularly is important. I know that there will be some situations where I might stutter (for example, in case of conflict with fellow colleagues) but I will dramatise such situations. I am prepared to face the truth.

To all those who suffer from stuttering, the message I want to convey to you is that we are not alone and sometime somewhere we shall meet someone to help us overcome this handicap.

In my case my wife has always been by my side and God also.

I am now cleared out of this feeling of guilt and shame that had accompanied me all these past years and I now assume myself fully.

Email: alainkwan@intnet.mu

My transformational story

Hi, I am Yasvin, 19 years old and I live in Phoenix, Mauritius. I have been stuttering since my childhood – frankly speaking can't remember since when. I am a shy person and also a person who stutters. As such, I usually avoid talking to strangers or to those not close to me. However I live like a normal person within my family and friends, smiling, joking and of course stuttering without caring. Till now I had shared my problem with only two of my close friends: Shameer and Ahvee. Nobody else is aware that I am sharing it to you through this article except my friend Shameer. I believe the reason for which I don't confide is the fear of pity; I can't stand people feeling sorry for me. And also, even talking about my stutter is painful for me and makes me feel inadequate. I use my own techniques to communicate, by using my hands when explaining, for instance or starting my sentences with "huemmm". It seems stupid at times to use these flop methods of mine but I have no other means.

When I do my prayers, I always ask for a cure to this inability but until now nothing has really happened. As I avoid going out to meet people, I spend a lot of time surfing on the internet. I have made some research on stuttering and I have come to know Keith Boss through a Yahoo support group (<http://health.groups.yahoo.com/group/stutteringchat>). He is a recovering stutterer who lives in the UK and he works part-time in a primary school, as he has retired. Keith helped me a lot in regaining confidence I myself, especially at a time where I was asking for help in the forum.

Through e-mails we became close friends and shared our life experience. I told him that there was no self-help group in Mauritius that could help me. Within five days he surprised me by tracing out a support group here in my island! Keith contacted the chairman of International Stammering Association and from there he got in touch with Jim Caroopen, the local contact of "Parole d'Espoir", a self-help group in the capital of Mauritius, Port Louis.

I was very happy on hearing that and immediately contacted Jim for an appointment. He proposed me to join the group on Saturdays. I revealed my nervousness and shyness to be among strangers, but he reassured me and encouraged me to continue with them. On the day of the first meeting, I realized that I would have to go alone there – something to which I was not used to. But with the support of my parents I finally joined the group and found that I was not alone with my problem. There I met other people having the same problems as me and thus felt more confident in life.



I have attended meetings regularly for three months. I have been learning techniques about how to acquire control over my speech. We made relaxation sessions and learn how to breathe when talking. Jim showed us how to talk slowly and smoothly without any rush and what to do when we have blocks in our speech. Every week we learn one or two new exercises. I am very grateful to "Parole d'Espoir" thanks to which I have learned many things that will help me in my daily life.

I am very much interested in the IT sector and wish to continue my studies in this field; I have already created my own website and wish to interact with people all around the world. There are no magic pills for stuttering, the only treatment is speech therapy. Those of you who feel concerned and who are interested to joining me and my friends can contact me on somootee@yahoo.com or you can visit my webpage on <http://stammer.atspace.com>.

My message to persons who stutter is: Don't think that you alone in the world if you have a stuttering problem (like I used to think before). There are many famous persons like Prince Albert of Monaco, Rowan Atkinson – British actor who plays Mr. Bean, Bo Jackson – football and baseball star, Yasvin (just joking) etc. I believe that every person wherever he is has his abilities and importance in this world and whatever happens, life continues, so live the way you wish without fear.

29, One Voice 22, Dec 24, 2006

News from New Zealand

*By Warren Brown
Vice president, New Zealand Speak Easy Association*

The 2007 New Zealand Speak Easy Conference will be held on May 18-19 in Christchurch, hosted by the Canterbury Speak Easy branch.

The venue will be the Coppertop conference room in the commerce building of the University of Canterbury. Accommodation is arranged through the Academy Motor Lodge in Clyde Road, near the venue and opposite the Communication Disorders Department. Costs are expected to be about \$NZ80 a person.

Patron of New Zealand Speak Easy, Judge Andrew Becroft, has agreed to be a speaker.

The conference theme is "New Directions". The conference dinner will be held at the Thai Orchard restaurant in Riccarton Road, a short drive away.

For registration or other queries, contact Stephen Hoare-Vance at shore_vance@hotmail.com or phone 0064 3 332 6707 before March 1.



Parole d'Espoir Group Photo (Mauritius)

STUTTERING TERMINOLOGY

– Using labels and definitions to reflect our current understanding.

By Mark Irwin, Chair of ISA Board

The fact that stuttering can be more than just dysfluent speech is surely well recognized by most PWS and speech-language pathologists (SLPs). They would also appreciate that an understanding of what that “more” is, is crucial to providing effective therapy.

For me, one of the most interesting comments on this year’s International Stuttering Awareness Day (ISAD) 2006 online conference was the report of a Russian study on the association of social phobia with stuttering (See Greg Snyder’s article via ISAD 2006 online conference at www.stutteringhomepage.com). Dr Ilia Rasskazov, a psychiatrist and Director of the Scientific Research Centre, Moscow, quoted a 2005 study of 157 people who stutter (PWS). Using the Lebovich Test, which according to Dr Rasskazov is the measure used by the World Psychiatric Association for determining severity of social phobia, he reported that 91% of the PWS had some degree of social phobia with 43% having severe social phobia.

Assuming this study contains results applicable to all PWS, clearly those SLP seeking to help would benefit from awareness of treatment modalities appropriate for social phobia. This statement applies as much to leaders of self-help groups (SHGs) as it does to SLPs.

INTERNATIONAL PERSPECTIVE

The International Stuttering Association (ISA), the umbrella organization for national self-help associations throughout the world, takes the view that in therapy “different strokes suit different folks.” The ISA is very grateful to SLPs for their involvement in assistance for PWS. Many SLPs have freely donated their time to provide information and support to members

of SHGs. A particular example is found in the ISA’s International Speech Project –Stuttering which co-ordinates philanthropic visits of SLPs specializing in fluency to countries of the developing world. Recent visits of David Shapiro (USA) and Anne-Marie Simon (France) to Africa have proved extremely helpful. Another example Judith Kuster’s (Minnesota State University) work on the annual stuttering online conference and the collation of wonderful resource information on her website (www.stutteringhomepage.com).

In addition the Stuttering Foundation of America (SFA) continues to support PWS in developing countries by forwarding pamphlets and books. The ISA very much appreciates the work of Foundation director Jane Fraser in this regard.

The support provided by SLPs, the SFA and the support PWS are able to give each other, has been significantly enhanced through the arrival of the Internet. There is no doubt it has been a real boon to the lives of PWS. From my position as Chair of the International Stuttering Association since 2001, I have been able to witness the dramatic growth in empowerment for PWS through the development of self-help groups that has mirrored the increasing availability of Internet use. Discussions now occur freely within groups and between groups, all of which have led to an increased understanding of stuttering, and what can be done about it. But while our understanding has developed it could be argued that terminology remains limited and confused.

WHAT IS STUTTERING? TERMINOLOGY CLARIFICATION

The word stuttering is variously used to describe dysfluent speech, a speech syndrome and the symptoms of a speech disorder. Little has happened since Culatta and Goldberg (1995) concluded that if 10 speech language pathologists were put in a room, 11 different definitions of stuttering would emerge. This is largely because there is confusion over the term covert when applied to stuttering. Shapiro (1999) refers to covert as internalized thoughts and feelings. Gregory (1986) refers to covert features of stuttering as the expectation of difficulty and frustration, which lead to avoidance and inhibitory behaviors. Moore and Rigo (1983) refer to covert symptoms of stuttering and Guntupalli et al (2006) refer to covert forms of stuttering. In addition following the work of Douglas and Quarrington (1952) British commonwealth countries use the label "interiorized" to signify masked stutterers who are currently also referred to as covert or closet stutterers. However it is clear the covert features of expectation of difficulty and frustration mentioned by Shapiro and Gregory also may apply to both interiorized and exteriorized stammerers, and as such a clear distinction between covert features and covert behaviors needs to be drawn. That is covert behavior is a speech event. The speaker avoids, substitutes or circumlocutes as away to hide an overt stutter. On the other hand frustration and anticipation of difficulty are emotional reactions to speech events. It is not necessary to label these as covert features since we would expect emotions to be hidden from view. In any case the word covert is usually applied to give the meaning of secretive or deliberately hidden as opposed to the simple meaning of hidden. Describing emotional responses as covert introduces inaccuracy. Emotional responses may be covert if they are secretive or deliberately hidden, but they cannot be regarded as covert simply because they are not on view.

Also not all people who demonstrate covert stuttering behavior will have negative emotional reactions consistent with diagnosis of social

phobia, so a separation of these terms allows greater accuracy with diagnosis.

It seems academic definitions while showing an understanding of stuttering are often either vague or cumbersome. They do not specifically mention covert stuttering and use very general terms when describing the attitudinal and emotional components. Examples with comments follow:

1. "Stuttering is a diagnostic label referring to a clinical syndrome characterized most frequently by abnormal and persistent dysfluencies in speech accompanied by characteristic affective, behavioral and cognitive patterns. Cooper (1993)". Comments: the characteristic affective, behavioral and cognitive patterns are not described. This is important because without it the statement is too vague as all human conscious behavior has characteristic affective, behavioral and cognitive patterns.
2. "Stuttering is the involuntary disruption of a continuing attempt to produce a spoken utterance. Perkins (1990)". Comments: There is no reference to covert behavior (word avoidance substitution and circumlocution) which if used by the speaker results in no such disruption in a spoken utterance.
3. "Stuttering is a disorder which affects the fluency of speech production. This may also affect the individuals' attitude to communication and to themselves. Disorders of fluency are usually characterized by both overt features e.g. blocking, and covert features e.g. avoidance behaviors and feelings such as anxiety. RCSLT (1996)". Comments: A distinction between the covert form of stuttering (word avoidance, substitution and circumlocution) and the covert features of avoidance and anxiety is not made. This is important since overt stuttering and covert stuttering may

both be associated with avoidance behaviours and feelings such as anxiety.

4. “Stuttering refers to individualized and involuntary interruptions in the forward flow of speech and learned reactions thereto interacting with and generating associated thoughts and feelings about one’s speech, oneself as a communicator, and the communicative world in which we live. Shapiro (1999)”. Comments: As with the previous definition there is no clear distinction between overt and covert stuttering. In addition there is no clear reference to the negative psychosocial impact of involuntary disruptions and the possibility that this negative psychosocial impact may not necessarily be present in all people who stutter.

. In summary it seems

- ◆ Many definitions describe stuttering from the listeners’ perspective only.
- ◆ Most definitions do not cross reference stuttering and stammering.
- ◆ Many academic definitions do not directly mention covert behavior.
- ◆ There is confusion between covert features of stuttering and covert stuttering behavior.
- ◆ Covert stuttering is a term not universally applied within the speech pathology profession.

To my mind stuttering cannot be discussed without mention of covert behavior and social phobia. Since not everyone who stutters uses covert behavior or suffers social phobia, distinctions are needed in stuttering terminology. Leaving aside questions of cause, and neurological, genetic and biochemical events, the definition that makes most sense to me is: **Stuttering** (*synonymous with stammer*) – *to produce dysfluent speech characterized in overt form by repetitions, prolongations and blocks, or in covert form by avoidance,*

substitution and circumlocution. With regard to the link to social phobia, it is my opinion this is best made by creating a new term: **Stuttered Speech Syndrome** which is defined *as various behavioral, attitudinal, and emotional responses resulting from the complex interplay between stuttering and social anxiety disorder (social phobia).*

These definitions have value as they allow easy separation in the labeling of the 9% of PWS of the Rasskazov study who did not have social phobia, from the 91% who did. The former group does *not* have Stuttered Speech Syndrome while the latter group does. This has implications for treatment and prognosis. Specific examples of this can be found in reading Alan Badmington’s paper in the ISAD 2006 online conference. Alan’s personal experience mirrors my own and that of Marty Jezer’s to whom Alan refers in his article. That is, success came from dealing with social anxiety as much as from attempts to deal directly with stuttering behavior. It seems Marty felt relieved of the burden of stuttering even though his speech was still relatively dysfluent, because he had clearly been able to overcome negative perceptions of himself as a person who stutters. In other words, Marty may have still stuttered but he did not suffer what I have suggested be called Stuttered Speech Syndrome. This would also be true of other people who have dealt effectively with their lives in spite of stuttering. They come to see it much like a limp and manage their lives accordingly.

Let me highlight this with another point. I remember reading a personal description of stuttering some years ago. Unfortunately I have forgotten the author and the exact wording, but it went something like: “Stuttering is more than just dysfluent speech. For me it is the fear, low self-esteem, shame and embarrassment I feel when I have to speak. When I am cured of this I will be cured of the pain of stuttering”.

The value of this statement is that it separates stuttering behavior and pain, which to me calls into question what should be treated first. As a dentist, I know relief of pain is the first priority in treatment. I would suggest to those SLPs interested in consumer feedback that relief from the pain of stuttering should be the first priority in their therapy too. There may not be a cure for stuttering but there is certainly a cure for Stuttered Speech Syndrome. That is, it is possible to eliminate the negative behavior, attitudes and emotions associated with stuttering.

WHAT CAN BE DONE

How can SLP's best help with the therapeutic process? The answer to this question links to the answer of another. If there was a practicing SLP on every street corner in every country of the world offering free therapy, is that all that PWS need? The answer for me is NO.

Other obvious needs for PWS are:

- ◆ Access to SLP's *experienced* in stuttering therapy and counseling
- ◆ Access to assistive technology (Masking devices, DAF, FAF)
- ◆ Opportunities to practice and experiment with new speech techniques in a safe environment
- ◆ Opportunities to create successful experiences and feelings
- ◆ Opportunities to deal with social anxiety, shame and embarrassment.

It is clear to me that self-help groups are the best forums for dealing with the latter three of these needs. It is, therefore, fundamental that SLP's interested in stuttering therapy be aware of the nature and types of self-help and support groups suitable for their clients. SLPs are then in a position to make appropriate referrals or even to mentor their clients after visits to the chosen SHG. Accompanying clients on visits to the

self-help group for direct observation and feedback is also helpful.

TYPES OF GROUPS, STRENGTHS AND WEAKNESSES

In sociology a distinction has been made between self-help and support groups. Self-help groups discuss experiential knowledge, are non judgmental, and encourage role play. Support groups are distinguished by being defined as those controlled by a professional. With stuttering support groups there is a general agreement that members support each other in following a particular speech or breathing technique. However as there is frequently overlap between the activities of self-help and support groups the terms are often used synonymously. These groups have strengths (members learn from others, practice and develop skills, discuss their feelings, gain encouragement and gain validation), but they also have weaknesses. They are dependent on leadership skills and are subject to personality clashes and negative group dynamics.

Another problem is that no matter how well led and cohesive the group, it may not have a philosophical perspective consistent with helping the client meet their objectives. For example some PWS lead quite lonely lives as a result of their communication difficulty and are content to belong to a social group rather than one that encourages personal development.

No matter what the group or its philosophical perspective, it is my experience as a result of participation in Australian SHGs, my observation of other international groups, and my experience as a husband, father and managing partner of a 30 employee dental practice, that empowerment is the key to the door of long-term behavioral change. By this I mean that unless an individual owns the problem and is free to decide on the appropriate course of action, then long-term change is unlikely no matter what the situation. Where

self-help groups act to empower their members then improvement in attitudes, feelings and behavior usually follow.

CONCLUSION

In summary, it is my contention that small steps are needed in overcoming stuttering and associated negative behaviors, attitudes and emotions (Stuttered Speech Syndrome). These small steps are most effectively taken when the PWS takes ownership of the therapeutic journey. The role then of the SLP is to act as a guide/coach/mentor in providing direct therapy as well as referrals to appropriate SHGs. SHGs are necessary, as they provide healing and development opportunities that cannot be managed otherwise, opportunities that are vital in overcoming the pain of stuttering.

It is my experience that the SHG's work best in a therapeutic sense when members move beyond victim to survivor. And the survivor group works best when it moves from "dogmatist" to "thrivor". The latter group

encourages and *empowers* its members to embrace new knowledge and grow. However all groups are dramatically affected by their members' abilities and philosophies. So SLPs may encourage their clients to visit several groups before deciding on the one that best meets their needs. Examples of groups in America appropriate for PWS are the National Stuttering Association, Friends, McGuire Program, and Toastmasters International.

In developing expertise in most human activities, people need both coaching to learn the skill and a forum or club for practicing it. With regards to development of the therapeutic, social and political aspirations of PWS, professional bodies like ASHA Division 4 and IFA and philanthropic organizations like SFA represent the coaches while the self-help groups especially those affiliated to ISA are the clubs. The relationship is synergistic. The needs of PWS cannot be met without both the professional bodies and the self-help groups functioning well and functioning together.

References

- Cooper, E.B. (1993) Red herrings, dead horses, straw men, and blind alleys: Escaping the stuttering conundrum. *Journal of Fluency Disorders*, 18, 375 –387.
- Culatta, R., & Goldberg, S.A. (1995) *Stuttering therapy :An integrated approach to theory and practice*. Needham Heights, MA: Allyn & Bacon
- Douglass, E., & Quarrington, B. (1952) The differentiation of interiorized and exteriorized secondary stuttering. *Journal of Speech and Hearing Disorders*, 17, 377-385.
- Gregory, H.H. (1986) *Stuttering: Differential evaluation and therapy*. Austin TX: Pro-Ed Inc.
- Guntupalli, V. K., Kalinowski, J. & Saltuklaroglu T. (2006). The need for self-report data in the assessment of stuttering Therapy efficacy: repetitions and prolongations. The stuttering syndrome. *Journal of Language and Communication Disorders* 41, No1 1-18
- Moore J. A. & Rigo T. G.(1983) An Awareness of the Covert Symptoms of Stuttering. *Journal of Fluency Disorders*, 8, 133-145
- Perkins, W. H. (1990) What is stuttering? *Journal of Speech and Hearing Disorders*, 55, 370-382.
- Royal College of Speech and Language Therapists (1996): *Communicating Quality 2*. Professional standards for speech and language therapists. 2nd Ed. RCSLT
- Shapiro, D.A. (1999) *Stuttering Intervention: a collaborative journey to fluency freedom*. Austin TX: Pro-Ed Inc

ISA is Now Inviting Member Associations to Enter Submissions to the Stuttering Essay Contest!

By Masuhiko Kawasaki

Have you already written an essay for the ISA Stuttering Essay Contest? ISA is now inviting member associations to enter submissions to the Stuttering Essay Contest (SEC). The winners will be honored in a commendation ceremony at the upcoming Croatia Congress, by the ISA Chair.

One of the most important roles of stuttering self-help groups is to provide opportunities for their members to share ideas, feelings and experiences with each other. The SEC enables self-help groups to achieve this goal, in addition to promote intercultural exchange. Through formally writing about our experiences, we are able to organize our ways of thinking about painful experiences and so broaden our perspectives. Furthermore, through the ISA network of self-help groups all over the world in combination with the miracle of the internet, we can easily share our experiences with people living in other countries.

Here are the SEC Submission Guidelines.

Language: English (translation by computers is not acceptable)

Length: No more than 1000 words

Submission due date: February 28, 2007

Each self-help group will select two essays from within their group and email them to ISA. The

author's name, the self-help group's name, and country name should appear on the cover of the entry.

The ISA board and advisory board members will read all the submissions by March 31, 2007. Each member then selects three essays in early April, and then the three top essays would be selected. First, Second, and Third place prizes will be determined through voting.

The ISA chair will announce the three winners at the world conference in Croatia. The winning Essays will also be printed in One Voice and publicized on the ISA website. In addition, all the essays submitted to ISA will be printed and displayed at the world conference for conference participants to read freely. However, please note that submissions obviously intended as advertisements for therapy will not be displayed.

This contest will be held during the world conference every three years.

Here at the Japan Stuttering Project (JSP), we have held a JSP Stuttering Essay Contest for 9 years running. In the near future, it is a goal of the JSP that the SEC be held not only in English, but in many other languages as well. This way, even more people can have the opportunity to share their experiences through the Stuttering Essay Contest.