

# One Voice



**International  
Stuttering  
Association**

**Issue 25 - July 2008**

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Incorporating *The Voice of ELSA*, the newsletter of

**European League of Stuttering Associations**



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

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***A world that understands stuttering***

## FROM THE CHAIR

### *From the ISA Chair*

*By: Benny Ravid*

**A**t this time I wish to share with you the idea of an International Parliament of People Who Stutter. I'll also tell you about our efforts preparing a successful African Conference in Burkina Faso (in western Africa) and more...



But first of all:

#### **The deadly disaster in China**

We all have heard the very sad news that is still coming to us from China about the awful earthquake that occurred in the Sichuan district and its deadly consequences.

I would like to take the opportunity to express from the ISA and the rest of the stuttering community the very deep sorrow we feel, and we send our condolences to the people of China.

We have been doing our best to support our Chinese friends in their efforts to promote preparations for the 9<sup>th</sup> World Congress in Beijing in spite of the terrible disaster, and we will continue to do so.

#### **International Parliament of People Who Stutter**

We need a system through which member associations will be able to speak, to share their ideas and problems, to ask for help, to support and/or be supported by other associations, and very much more.

Let us create an International Parliament for People Who Stutter!

Each member association will nominate delegates who will participate in the Parliament discussions and bring their messages to the world.

Such a parliament will be able to function by means available on the Internet. The options we have are:

- Operation by means of a "discussion forum"
- Use of the "good old email" system

- Any other ideas that you may have (please let us know)

There are many other unclear issues relative to the International Parliament for People Who Stutter. For example:

- How and by whom will this Parliament be coordinated?
- Who will provide the agenda?
- How will the agenda be created so it will be acceptable to all?
- How will the delegates be nominated?
- How many delegates from each country will we allow?

We welcome any suggestions/ideas about the International Parliament for People Who Stutter from the OV readers.

At a moment we've lunched a test version of the International Parliament. You may see it on <http://www.stutterisa.org/cgi-bin/yabb2/YaBB.pl>

Please take a look.

Please email your comments and ideas to [admin@stutterisa.org](mailto:admin@stutterisa.org)

#### **Raising funds for the 2nd African Conference in Burkina Faso**

The 2nd African Conference will take place in the city of Ouagadougou in Burkina Faso (western Africa) from October 27 until October 30.

The conference is being organized by the local stuttering association, Association Action Contre le Bégaiement [ACB] (<http://ouaga2008.iffance.com/>), with the support of the International Stuttering Association [ISA] ([www.stutterisa.org](http://www.stutterisa.org)).

Heading the conference organization is the ACB chair Dr Moussa Dao, who is also a member of the ISA Board of Directors.

To be successful funding is essential, because in Africa most people who stutter simply cannot afford the transportation costs to Ouagadougou or the expenses of housing, etc., while at the conference.

Besides helping to provide fellowships for delegates from African nations, there are several other potential events for which we will need to raise funds, including a welcome reception, dinner and/or speaker costs.

These days the ISA is making efforts to obtain donations for the 2<sup>nd</sup> African Conference.

So far we have received donations from Norsk Interesseforening for Stamme (NIFS, the Norwegian Stuttering Association), the French Stuttering Association and a few individuals.

We are asking ISA associations worldwide to donate as much as they are able, in order to ensure a success of the 2<sup>nd</sup> African Conference.

Of course donations from individuals (no matter how small) are also much welcomed.

Donations may be given by means of PayPal, credit cards, electronic checks and bank transfers through a special Donation Website,  
<http://www.stutterisa.org/donation.htm>

**We will be very much grateful for any donation.**

#### **New ISA Webmaster Group and a new ISA Treasurer**

There is a new Webmaster Group whose members are:

1. Bruce Imhoff from Australia
2. Michael Sugarman from USA (who is also a member of the ISA Board of Directors)
3. Liv Goldstein from Norway
4. Zvika Hernik from Israel

The person who leads the new Webmaster Group is Bruce Imhoff. Take a look at the ISA website [www.stutterisa.org](http://www.stutterisa.org), and you will immediately notice the changes at the site.

We also have a new ISA Treasurer, Mr. Yan Hanukiev from Israel. The Treasurer is the "bad guy" who asks

the associations to pay the ISA annual fees and their outstanding dues from former years.

I'm sure you understand that Yan is in fact a "good guy" who wants the ISA to prosper for the benefit of people who stutter worldwide... So please don't ignore Yan's requests and please ask your association to pay its annual fees for the ISA.

#### **New faces on the ISA Advisory Board**

Maybe not all of you are aware that we have an ISA Advisory Board. Its members are experts who are advising ISA Directors.

The main purpose of the Advisory Board is to help ISA Directors lead the stuttering community in such a way that each person who stutters on this planet will be able to receive support as needed.

That is, of course, not an easy task.

Recently we welcomed to the Advisory Board the following new members:

1. Kenneth O. St. Louis
2. Peter Howell
3. Ann Marie Simon
4. David A. Shapiro

I'm sure many of you know these wonderful people who are among the "top of the cream" of the stuttering community.

You may see the full list of ISA Advisory Board members at:

<http://www.stutterisa.org/Board.html#boardmembers>

Regards,

Benny Ravid, ISA Chair



## ELSA EDITORIAL FOR ONE VOICE

*By Edwin J Farr MBE, Gina Waggott, Anita Blom*

*Board Member, European League of Stuttering Associations*

2008 continues to be an active year for The European League of Stuttering Associations. This April, vice-chair Anita Blom was invited to give a lecture at the European Symposium of Fluency Disorders in Antwerp, Belgium. Anita's speech was well-received and stood out as an example of the positive outcomes created when people who stutter educate and share knowledge with professionals in the field on how it \*really\* feels to be a person who stutters.

ELSA's lobbying in the field of Disability was furthered in May when board member Gina Waggott attended the Annual General Assembly of the European disability Forum in Ljubljana, Slovenia. Gina was once again successfully elected to the EDF's Youth Committee for the second time running, and will continue to represent young people who stutter at this international level of disability awareness.

The summer will bring us more exciting projects: Anita Blom will be the keynote speaker at the National Stuttering Association in New Jersey, USA, and upon her return, the board will be busy planning our next Youth Meeting, scheduled for the summer of 2009. Our Annual General Meeting is due to be held at the next Nordic Seminar in Gothenburg, Sweden on 23rd August

2008. Invites have been sent to all member associations, and we hope to see you there.

Irina Papancheva, an ELSA volunteer and former Chair of the Bulgarian Stuttering Association, has been offered a position of Communication Officer at the European Disability Forum (EDF) an umbrella organisation for Europe's disability associations in Brussels. ELSA is a founding member of the EDF and has connections with the EDF for around 10 years. This is great news for Irina, she has an excellent CV and will be well suited to this post, it is also very good that Irina, who is a person who stutters, will be working for the EDF. She will be working to raise awareness of all disabilities and I am sure she will have the well being of people who stutter close to her heart. Irina, has worked with ELSA for 10 years, she was recently a main speaker at the 2007 ELSA Youth Meeting in Nijmegen.

As always, we thank those who voluntarily dedicate their time and efforts to improve the lives of people who stutter in Europe and beyond. Without such people, we couldn't realise our goals and achieve our objectives, and we hope such collaborations will continue into the future.

## WORK IN OUTREACH

*By Keith Boss  
Outreach Chair*

In the last six months, my ISA correspondence has grown to average 73.4 emails every week. Approximately 50 in my inbox and 23.4 sent out by me. (My work for the British Stammering Association (BSA) and my private emails increase this number significantly). Some of the 73 emails required only a few seconds, others a few minutes, others a few hours. However I remember Mark Irwin our previous Chair of the ISA once told me that a lot of activity did not always equate to useful productive work. In the future others can decide if the amount of my activity was useful.

Of the 1908 emails (this includes messages to groups), 959 emails were on ISA business with other members of our two ISA Boards. Because of my work for the ISA with new and existing friends, there were 543 to and

from India; 180 to and from Pakistan and 43 to and from South Africa. The remaining 183 emails were to and from NSA (National Stuttering Association of America) and 23 countries around the world (Argentina, Bahrain, Chile, China, Congo, Ghana, India, Iran (Tehran), Kazakhstan, Mali, Mauritius, Nepal, Nigeria, Pakistan, Portugal, Rwanda, South Africa, Saudi Arabia, Singapore, Slovenia, Somalia, Taiwan and Uganda). This is a considerable amount of work at a computer and I need to get out and talk more.

In One Voice 21, Stefan Hoffmann first mentioned the new Indian website [www.indiastammering.com](http://www.indiastammering.com) and TISA (The Indian Stammering Association). Since those early days the initial ideas have spread to other Indians and begun to grow in strength. One local Indian Dr S K

Srivastava has accepted the challenge and is co-ordinating the increasing tempo of the work in India. Sachin (Dr S K Srivastava) has organised the first meeting of Indian people who stammer to talk and discuss TISA. The meeting was in Mumbai. Sachin with the help of his team has started

<http://t-tisa.blogspot.com/> and is encouraging active use of <http://health.groups.yahoo.com/group/IndianPWS/> to exchange information, especially about new self help groups starting in India. There is a new group in Chennai.

<http://uk.groups.yahoo.com/group/stutteringselfhelp/> was set up for the ISA to offer information to the world about self-help groups and is still used from time to time by our Indian friends. I am discussing with Sachin the idea of an Indian conference with ISA participation in the near future.

A good friend, Alan Badmington very kindly put Julia Irani from Pakistan in touch with me in August 2007. The ISA has had links to Pakistan from people asking for help for some considerable time. After exchanging thoughts and ideas, Julia stepped up to the challenge of co-ordinating the work in Pakistan. In nine months Julia has worked wonders. She has built up a small hard working team. Pakistan stammerers owe her and her team a very big debt. There is a Pakistan website at <http://pakistanstammering.org/>. This is a fledgling website, but its forum is fantastic. It is a popular site, and gives information about two main self-help groups in Karachi and Islamabad. The team also runs <http://health.groups.yahoo.com/group/pakistanstammering/> which has 57 members.

Julia, her team and the two self help groups want to set up a Pakistan Conference in November, maybe in two cities on adjacent days, and want the ISA (an ISP-S team (International Speech Project – Stuttering)) to participate.

I have been in contact with various people in South Africa. South Africa has a 'stammering infrastructure' already in place. The problem put to me, as ISA Outreach Chair, was that activity of much of the infrastructure, with people who stammer, had slowed to a stop over a period of time. Something was needed to reawaken local activity. There are many people who

have helped in this task and there are good signs that South Africa will have a South African conference towards the end of 2008, or early 2009. Again, this may be in two cities on adjacent days, with ISA (an ISP-S team) involvement.

I would like to be part of the ISP-S team, for the above three projects, if time and finances permit. Also I will ask Sachin, Julia and the South Africans to provide an article for every One Voice beginning with One Voice 26 (December 2008).

Dr Moussa Dao (ISA Board Director and PWS), and Anne Marie Simon (General Secretary of the Association Parole Bégaïement; SLP and ISA Advisory Board) and Joseph Lukong (ISA Board Secretary; ISA Board Director and PWS) have written about their Second African Conference at **Ouagadougou on October 27<sup>th</sup> to 30<sup>th</sup> 2008** in a separate article. Please contact the ISA if you are interested in attending. ISA Chair, Benny Ravid, and some other ISA Directors will be attending. Everyone will be made very welcome.

Yasvin from Mauritius (see One Voice 22 page 29) has been in contact with me since 2006. At the beginning of June 2008 he asked if I could go to Mauritius in February 2009. I will investigate and find out if we can send an ISP-S team to help in Mauritius, but before I can make a decision, I need to find out more about local requirements.

The ISA Board has a lot of work it wants to do over the next 2 years. I want the ISA to keep in regular contact with all of our Special Friends around the world, because our Special Friends are part of the lifeblood of the ISA. You the readers can do some of this work. Are you ready for the challenge of giving support to the ISA to help stutterers in other countries who are desperately seeking help from various National Associations and the ISA? If you have a little free time and want to join me in Outreach work, or join in any of the other aspects of ISA work, please contact the ISA. We want to hear from you. The more volunteers we have helping, the more we can do to prepare for a visit by the ISP-S team. The ISA will thrive with additional volunteers with a little free time. You will be made welcome and will grow in stature with the work available.

## IN MEMORY OF VIVIAN SHEEHAN

*From NSA Letting Go April 08 issue  
My “Defining Moments” by Annie Bradberry*

Vivian had a profound impact on my life and the woman I have become. I first met Vivian in her home in 1977 – I was 19 years old. It was this same year that I began to change the way I thought about myself and my stutter. I was attending a local Junior College and for the first time stuttering therapy began to have an impact. I found Glen Smith, a wonderful speech therapist at school and I began to attend group therapy meetings. Glen’s close friends were Dr. Joseph Sheehan and his wife Vivian. My group was invited to visit UCLA where Dr. Sheehan was doing great work in speech therapy and had a group of his own. I remember this night like it was yesterday. There were so many of us and it was then that I saw the benefits of socializing, sharing and being with other people like myself! It was the first step in my NSA (then NSP) journey and for years after that night Vivian would cross paths with me and my journey. I call these my “defining moments”.

I got very active with the local chapter of the NSA, became chapter leader and would see Vivian at local meetings and State ASHA conventions where I would volunteer to run the NSA booth. Many years later I was at turning point regarding my career. Since I was a young girl I had wanted to be a speech-language pathologist but I never thought I could handle the schooling. You see, I allowed my speech to hold me back and I truly didn’t believe I was smart enough. Now it was years later and the thought of going back to school and all the time it would take, seemed out of reach. You see...if I did this, I wanted to go all the way.

In order to accomplish my dream I would need to get a Ph.D. and, well....I’ve never been patient and I truly didn’t know what to do. I just knew I needed to do something! I was at one of those State ASHA conferences and I was riding the elevator to my hotel room. In walks Vivian. This began a repeat exchange that lasted for years. I shared my desire and myself knowledge about how much school I needed and the time it would take to be able to work in the stuttering field. She said to me word for word that day in the elevator, “Annie, there has to be something that will allow you to work and help people who stutter now. This is what you were meant to do. I believe it. You need to believe this and something will come your way very soon”. Six months later I was hired to be a director of the then NSP. I had no previous experience working in the non-profit world and doubted I could do this...would they hire me? Vivian’s words pushed me to go for it and my life changed.

Throughout the years, I would step into the elevator and there would be Vivian. In these short rides she would give me advice, a word of encouragement and even helpful critiques of her observations of me. I always cherished these times and throughout my time as Executive Director, I valued her support and guidance. Later in years the elevator visits turned into saving a chair for her at our booth at national conventions where she would rest her feet. Vivian had a profound impact on my life and though I had not seen her in sometime, 30 years later her influence continues to have a great significance in the work I do and the woman I have become.

## HOW I FOUND THE NSA

*By Joe Mirly  
United States*

I’ve told this story before – but want to tell it again. I’ve been a stutterer most of my life, and have spent much of that time avoiding it. Not that I could avoid stuttering – no way could I ever do that. I had a brief stint of speech therapy in elementary school, but that ended when the SLP either retired or moved out of the area. Incidentally that was a very happy moment in my life! From what I can remember of it the therapy approach was less than helpful, and provided much

frustration and humiliation, and it elated me that this was coming to an end – but that is a story for another day. Anyway, from this point on I avoided anything having to do with stuttering. As I grew up I learned to deal with stuttering in my own way. Or not deal with it; however you want to look at it. I was dealing with it by not dealing with it – that could have been my motto.

Over the years there were certain milestone events that I experienced that surreptitiously added to my own

understanding of my stuttering and how it was affecting my life. These led to mini-epiphanies that on hindsight put me squarely on the road to acceptance. I still stuttered, and still do, but I was giving stuttering less power and effect on my life.

My son started stuttering when he was probably around 3. I can't remember exactly when anymore – but I easily recognized the patterns of stuttering in his speech. I didn't know what to do. Sure, I was a stutterer – but as a parent it was different. I had the responsibility to do whatever I could to help him but I knew hardly anything about it. I started researching on the Internet, and found out about the National Stuttering Association. They had a local chapter in Seattle so I gave them a call and found out they had a meeting the following day. I went to the meeting with the intent of asking questions and finding resources to help my son. I didn't even think that I might get something out of it.

I was almost immediately floored when I attended the meeting. There were 15 or so people – all stuttering – and all talking about stuttering. What what what?? This was the first time I had ever heard a woman stutter, and for some reason that really struck me. It felt weird to talk about stuttering, something that I'd been avoiding for most of my life. It was uncomfortable and liberating all at the same time. The most striking thing was that people were interested in hearing about me and my stuttering, and how I was dealing with it. I didn't talk much at that first meeting – rather I focused on my original purpose for being there. I got some contact info for a local SLP at the University who I could talk to about stuttering and how I could help my son, and came away with that. I didn't know what to think about the "rest of it".

Anyway I decided to attend a couple more meetings as my curiosity was piqued. My wife didn't know why I was bothering to go – as I didn't outwardly seem to have many hang-ups about my speech. I went to a few meetings and started to get to know a few of the attendees. I still kept a lot to myself though, as I didn't know what to say. I'd not talked about stuttering before – especially not MY stuttering, so I didn't know where to

begin. Shortly thereafter the call went out for volunteers to help at the regional workshop/family day in Tacoma. People were needed to help set up tables and chairs, and do whatever else that needed to be done. There was also an adult workshop that was happening, so I decided to check it out. Annie Bradberry was there, and the adult workshop was led by a man named Bob Quesal.

I listened to what Annie said during the opening remarks, and found that I actually learned something and had fun at the adult workshop. I think I was starting to understand what the NSA was about. At the closing ceremony I watched as the kids lined up to talk at the open mic. That is when it struck me – as I looked out over the room of around 100 people and listened to kids eager to talk (and stutter) ON A MICROPHONE, ON A STAGE! I thought back to when I was their age – I wouldn't dream of EVER doing this. I would have run screaming the other way, not lined up eager to talk. It struck me that this organization was doing remarkable things with kids, families, and adults – and needed to continue. And I wanted to be a part of it. After the event ended I made a bee-line to Annie (then the ED for the NSA) and wrote her a check for my membership right there on the spot. My thoughts were not about what I was going to get out of it but rather what I could do help others.

Fast forward to now, I can say that I cannot put a value on what I've got back from my involvement in this organization. I've made life-long friends, learned so much about myself and stuttering, and hopefully helped other people in the process. That's how I found the NSA.

*Joe Mirly lives in Marysville WA with wife Theresa and kids Spencer & Emma.*

*Works at Microsoft as a software engineer, currently in one of the Office product groups.*

*Involved in the NSA for ~7 years, Leader of Seattle chapter for ~5 years, Regional Coordinator for Northwest – 4 years, past director of adult programs for NSA. Enjoys home improvement projects, spending time with family, & golf.*



## SECOND AFRICAN CONGRESS ON STUTTERING

*By Dr Moussa DAO  
President of ACB  
Phone: (226) 70 26 35 29*

**A**t least 1% of people from any population are affected by stuttering. So, 60 millions in the world, in whom

**At least 8 millions are from Africa**

**Because of stuttering,**

Many children will not go to school

Many children will abandon school

Many children will be teased or bullied in classroom

Many children are mistreated in families

Many adults will be stigmatised and discriminated in their life

**Yet, In Africa;**

Stuttering is forgotten and forsaken  
All information on it is related to folk ideas

No speech therapy service is available

Many persons use dangerous folk ideas methods for the treatment of their stuttering

**It's time to make a change**

For that,

the **International Stuttering Association (ISA)** and the **Action Contre le bégaiement (ACB)** is organizing the second African stuttering congress in Ouagadougou Burkina Faso from October 27th to 30th , 2008.

I encourage you to attend.

Once in Ouagadougou you will know the trip was worth your efforts.

Some French travellers agencies used to write on their books: "If you want to visit wild life, go to Easter and southern Africa, but if you want to meet people and know about cultures, go in Burkina Faso"



## NEWS FROM SWEDEN

*By Jens Lundström  
Board Member – Youth Issues  
Swedish Stuttering Association*

**W**hen analyzing the number of members in the Swedish stuttering association from a historical perspective one can easily find no cause to the low number right now. However, the decreasing growth of the number of members can be seen also when looking at other related organizations. Perhaps, these days persons who seek information about stuttering or something else are using Internet to find answers and fellowship. Still we have managed to increase our membership since last year.

Whatever the cause to join a stuttering organization, the information about stuttering should be available in any form. The Swedish Stuttering Association is now in the

process of making information available in form of: folders, WWW-pages and attending conferences. As a step to modernize, the name of the organization changed from SSR (Sveriges Stamningsföreningars Riksförbund) to Stamningsförbundet.

The main event this year is to arrange the Nordic Stuttering Seminar (Gothenburg 22-24 august). Main focus at the seminar will be to "see and be". This term relates to spreading information about stuttering and thereby reducing myths and the lack of understanding about stuttering. Apart from lectures and workshops the participants are offered to visit Swedish historical sites and are invited to a Swedish smörgåsbord. Read more



about the event at: [nordiska08.blogspot.com](http://nordiska08.blogspot.com) (English version: [nordiska08-en.blogspot.com](http://nordiska08-en.blogspot.com))

A recent project within the organization is to develop folders about stuttering divided into several categories: Adults who stutter Children who stutter and Young People who stutter. The latter category "Young People who stutter" is a complement to a new website for the Swedish stuttering youth. Also a handbook on giving

information about stuttering in schools is in progress and more updated information will follow. To Stanningsförbundet it is important to recruit and maintain new young members, especially in these times when associations in general find it hard to keep members. And we are proud to have young people on the board and deputy board!

Hope to see you in Gothenburg for the Nordic seminar!

## BRAZILIAN STUTTERING ASSOCIATION (ABRA GAGUEIRA): NEWS 2007-2008

*By Daniela Veronica Zackiewicz  
Presidente da ABRA GAGUEIRA*

On the last International Stuttering Awareness Day in 2007, we established 3 more ABRA GAGUEIRA branches in 3 different states in Brazil: Pará (represented by Rafaela Silva), Rio Grande do Norte (represented by Wladimir Damasceno) and Rio de Janeiro (represented by Cristine Pombo). It was an important step in the progress of our association. It will give us the opportunity to improve our knowledge of the particular regional characteristics of each group. We believe that such a kind of decentralization will contribute to our Association's expansion and means we can reach a large number of PWS in Brazil. The main goal for this year is the organization of the First Brazilian Meeting of People Who Stutter. It will take place at Rio de Janeiro, on October 18th and we are working together with SLP PhD Monica Britto Pereira (from the University Veiga of Almeida) who is helping us a lot.

For the 2008 ISAD we are planning some activities in São Paulo in a partnership with SLP PhD Claudia

Regina Furquim de Andrade and her team (from the University of São Paulo).

Here is some news of two great events.

We have finished the translation of Self-Therapy for the Stutterer, by Malcolm Fraser (Stuttering Foundation of America) into Portuguese, in partnership with the University de São Paulo. Five SLPs and I carried out the translation. It was a labour of love by Eliane Regina Carrasco Fernanda Sassi, Fabíola Juste, Caroline Galvão e Vanessa Martins and myself. Editora Manole will publish the book with an initial issue of 1500 copies. We've just finished the translation of **ISA intro** into Portuguese, with the collaboration of Márcio Pombo and we are going to put this link page in our own home page.

If some want more information about our activities, contact us at [abragagueira@abragagueira.org.br](mailto:abragagueira@abragagueira.org.br)

*From Rio de Janeiro Support Group  
By Cristine Pombo  
[abragagueira@abragagueira.org.br](mailto:abragagueira@abragagueira.org.br)*

This support group was created in 2005, when I, Cristine, was looking for people who stuttered. I had hoped to find an existing group, but only found groups in São Paulo, a state adjacent to Rio. I talked to the support groups coordinator from ABRA GAGUEIRA\*, Daniela Veronica Zackiewicz.

From that contact, I had access to a number of people that were already participating in such groups, but it was all online. I found many people in Yahoo Groups and even more in a very popular social website, Orkut, which is very similar to "Myspace". I attracted the interest of

12 people in particular, but only 6 showed up to the actual meeting in September 2005.

The first meeting was something very new to me, since I had very little experience talking to others stutterers, and no experience talking to other women who stuttered. Unfortunately, this first time, there were no stuttering women. Only in 2007 did we have other women in the group.

The meetings have been going steadily for more than two years, once a month, lasting about 3 to 4 hours each

time. The Group has a membership of at least twenty people, but we never had the opportunity of having a meeting with all of the members present. We usually have around 6 to 8 people. We try to keep it a very open discussion, always related to our speech, our challenges and experiences as stutterers. It is about how each and every one of us deals with our speech impediment and the way it effects our lives.

I always take something to read at the end of every meeting. An article, a few paragraphs from a book, a study, anything interesting that is related to stuttering. We pass it around so everyone can participate by reading out loud a paragraph or two. There are always one or two that talk less than the others, so we as a group, always

try to encourage everyone to speak and verbally express their opinions and thoughts.

After these few years, this group has been very helpful to me and to all the others who participate. Although it is all about stuttering, it serves as a way of not focusing so much on it as a disability. It is a place where we feel equal to one another, since everyone stutters and shares similar experiences with their speech. There is absolutely no pressure to speak, and therefore we all feel very accepted and it is comfortable to express ourselves.

For me, being the coordinator for this group has been an amazing way of expanding my views and thoughts on the subject, making me feel like I am not the only stutterer in the world.

## NEWS FROM CANADA

The Canadian Stuttering Association (CSA) continues to work to promote stuttering awareness across Canada through awareness days and conferences. The CSA held a successful 9<sup>th</sup> National Conference in Toronto, ON in August 2007. Over one hundred people who stutter, speech-language pathologists, and friends/family of people who stutter attended this memorable three day event. Highlights were the keynote presentations by: CSA Coordinator, Shelli Teshima; speech-language pathologist and researcher, Dr. Marilyn Langevin; and Filmmaker, John Paskievich, as well as the exceptional workshops on topics from personal experiences to genetic research.



Conference Delegates at banquet

The 10<sup>th</sup> National Conference of the CSA will be held in



Vancouver, BC in August 2009. We hope that many international delegates will be able to attend and encourage those that are interested to investigate the process to acquire a visitor visa to Canada at least a year before the conference. The CSA and many international delegates were disappointed when they were denied visitor visas to attend the 2007 conference. The 2009 conference will be a jam-packed three days of presentations, discussions, and time with new friends. We hope to see you in Vancouver in August 2009!



Workshop – “Your Relationship: What’s Stuttering Got to Do With It?”

CSA members in Toronto, ON hosted an International Stuttering Awareness Day in October 2007. This event brought together people who stutter and speech-language

pathologists from the greater Toronto area. They had the opportunity to attend workshops and to also network with each other. Another ISA Day is already being planned for October 2008. A stuttering awareness day, *Words Unbound*, is being jointly planned by the CSA and the Institute for Stuttering Treatment and Research (ISTAR) in Edmonton, AB for May 2008. There are plans for this to become an annual event as well.

The CSA has printed a new information brochure on the organization and a brochure titled "Notes to Listeners." Copies of these can be printed off the CSA website [www.stutter.ca](http://www.stutter.ca). The CSA has been distributing these brochures to speech-language pathologists, health agencies and people who stutter across Canada.

## NEWS FROM CROATIA

*By Suzanne Jelcic-Jaksic*

I thought I should share with you this wonderful news:

*The Croatian Public Relations Association pronounced Dr. Zeljko Rohatinski, a governor of the Croatian National Bank, the best communicator amongst people in Croatian public life.*

*By the way he communicates, Dr. Rohatinski has raised the level of public communication in Croatia. His clear, precise and uncompromising way of communicating proves that complex and important information can be simply said. By his attitude, arguments and style he gains everyone's respect even if they disagree with him.*

*He is skilled with the media, available and relaxed in communicating with journalists, serious and persistent in his advocacy, sharp and concrete at attacking. Moreover, he is always ready for different reactions. In banking, which relies on concrete numbers and results, he has received many professional acknowledgments and plaudits. But besides his results, he has got a unique charisma that attracts attention.*

*And because of that he deserves the respect of communication professionals and this prestigious award given for the first time in Croatia, explained the jury, which consisted of 12 high level professionals in Public Relations from PR agencies, corporations, non-governmental sectors, governmental and local authorities and scientific institutions which study public relations.*

This was announced on Wednesday, June 11th and the Croatian Association "Hinko Freund" had already congratulated Dr. Rohatinski and the Croatian Public Relations Association on this award and the specific choice. The CPR Association put our letter to their web site home page.

<http://www.huoj.hr/Default.aspx>

Some of you might remember that Dr. Zeljko Rohatinski was a member of the Honorary Committee of the last ISA WC in Cavtat. Unfortunately, he could not come to the Congress personally because he had to participate the very important World Bank meeting in Switzerland at the same time. His stutter is severe.

Another interesting thing about it was that yet another PWS (and another member of the same Congress Committee who was there and spent all Monday with children and parents), our national football team coach Slaven Bilic, was also in contention for the communicator of the year award.

The very next day, our Association sent our reaction to this news to the media and it was very well received and published in all major daily newspapers and announced on radio stations. There are a few links (unfortunately, in Croatian only) to those media sites at:

[www.udruga-hinkofreund.hr](http://www.udruga-hinkofreund.hr)

In short, we said how important and encouraging it was for all PWS in Croatia, that it was the proof of the maturity of Croatian society, of tolerance and acknowledgment of PWS as persons and professionals of excellence and that we hoped this would be spread across Croatia. "At times when spin has become the key of public communications, when the form has exceeded and almost excluded the content of communication, this choice shows that public communication needs people who have something genuine to say and the way they say it is not important."

We somehow think that our last year's media campaign before and during the ISA WC in Croatia had helped in making this possible in Croatia.

With best regards,



## NZ SPEAKEASY – HAPPENINGS

*By MARTY Van der Kley*  
*Canterbury SpeakEasy – Secretary*  
**CHRISTCHURCH (NEW ZEALAND)**

New Zealand SpeakEasy currently has four active support groups – throughout New Zealand, which hold support group meetings regularly- Auckland & Tauranga groups in the North and Christchurch & Dunedin in the South with each having varying numbers attending, and structuring their meetings differently. Even though some of our support groups may at times lack numbers – having SpeakEasy support groups in NZ is still seen as very much a valuable resource for people who stutter. In May 2007 the Canterbury SpeakEasy branch which I am part of, hosted the New Zealand SpeakEasy conference here in Christchurch – which included an oratory competition and speakers from the Anxiety & Speech and Language field. The conference attracted SpeakEasy members from our other NZ SpeakEasy groups.

Our 2008 National SpeakEasy Conference has just been held up in Tauranga – NZ, comprising a three-day event with the highlight being a two day Effective Communication workshop – for people who stutter covering issues like

- The change process from a person who stutters, to a person who is recovering from stuttering
- Common elements of various techniques that help
- Handling fear and anxiety around speaking
- Expanding your comfort zone
- Self-Image & Self Talk. How to become more positive and assertive

## NEWS FROM NEPAL STUTTERERS' ASSOCIATION

*By Sanjay K. Jha*  
*(President)*  
*(ask\_matsari@yahoo.com)*

Nepal Stutterers' Association (NSA) is a non-profit-making, non-governmental organization (NGO), which was established and registered on 11 June 2003 by a group of Stutter with the District Administration Office, Kathmandu and affiliated to the Social Welfare Council (SWC). NSA aims at improving lives of Stutterers through organizational strengthening, awareness raising and capacity building of the Stutterers so that they can communicate in a better way.

The Executive Committee of the NSA consists of a group of stutterers who come from different sectors and are highly motivated to improve the situation of stutterers. The NSA Executive Committee was established with an attempt to ensure the participation of the parents whose children stutter, without any gender bias, and active members.

Now NSA has 14 District committees throughout the nation, each of which is called a Self-help group (SHG) in the different districts of Nepal.

Recently in 2007 stuttering has been recognized by the government of Nepal and it has been kept in the disability category. Also the government has planned to provide the disability identity card (I.D.) for the stutterers. The government has assured the reservation and subsidies for the stutterers according to disability act.



It is estimated that one percent of the world's population are stutterers. There are 25 million peoples are living in Nepal. if we will calculate number of stutterers in Nepal (1% as per the estimates) it are 250 thousand stutterers. However 300 stutterers have been recorded by NSA. A large number of stutterers are staying **in the rural areas and they do not know** about stuttering and NSA. They have lot a traditional belief which considers this problem as curse. Unfortunately there are not sufficient speech therapists in Nepal. According to TU (Tribhuvan University), Teaching hospital, Maharajung, Kathmandu, there are 12 speech pathologists in Nepal



and all are staying in urban area only, mostly in capital (Kathmandu). If we look at the ratio of Speech pathologist to Stutterers it will be 1:20834. These days, NSA is working for **Lobby, advocacy, strengthening the organization and many more awareness program**. The entire program of NSA is supported by **Stuttering Association of Denmark (FSD)**.

#### The Activities carried out in 2007- 08 by NSA (Six months)

1. One day awareness workshop was held on 3<sup>rd</sup> November 2007 at Damauli Municipality of Tanahu District.
2. One day Advocacy Workshop was held on 8<sup>th</sup> December, 2007.
3. 4<sup>th</sup> Annual General Meeting (AGM) of Nepal Stutterers' Association was held on 29<sup>th</sup>

December, 2007. At this AGM NSA formed a new Executive Committee.

At this Executive Committee, different people from different District hold different position

4. One day awareness workshop was held on 8<sup>th</sup> March, 2008 at Pokhara.
5. One day Advocacy Workshop was held on 31<sup>st</sup> May, 2008 at Kathmandu.

#### Some NSA problems

- Unable to provide the speech therapy itself
- Unable to provide services (JOB)
- Unable to provide an income generating program.

However we have been trying our best to get donors for above problems.

## **FRIENDS 4 FLUENCY – STUTTERING SELF-HELP TAKES A FRESH START IN MAURITIUS**

*By Jim Caroopen*

*15th July 2008*

*Email: jimcaroopen@yahoo.com*

In March 2008, a big event for the stuttering community took place in Mauritius. For the very first time, a full week Intensive Therapy Workshop was held in our small island. The therapy was run jointly by Anne-Marie Simon and Aude Fresnay, two experienced speech and language practitioners from France and Reunion Island respectively.

During that same period a major change has taken place in the self-help environment in Mauritius: there has been a scission within the first self-help group in Mauritius and the creation of new self-help group – Friends 4 Fluency.

The stuttering self-help initiative in Mauritius had started in September 2005, when I met with Mark Irwin and on his advice decided to launch the first ever self-help group – with the help of some friends. It is true that we all met through a press advert – but on the very first day we met a strong friendship bond developed between us, under the auspices of Mark.

The self-help group was a breath of fresh air to us all – who for most of us had never had the chance to attend therapy before. We all experienced improved self-confidence and this made a big difference in the way we communicate. For some of us there was noticeable

improvement in fluency – but for all of us there was certainly an improved overall communication: less fear, more interaction with others, acceptance of our stutter (or at least a start) and a general feeling of well-being.

Our self-help group took the name of Parole d'Espoir and by word of mouth the number of members increased. A self-help program that was suitable for the Mauritian context was developed by the members – with the kind advice of Mark Irwin. Parole d'Espoir also established fruitful partnerships with friends worldwide; we received, namely from the Stuttering Foundation of America, a whole collection of books and DVDs and started a library facility for members. Everything worked well – until January 2007 when we met with a group of parents in Rose Hill who wanted to launch a national stuttering association in Mauritius.

We held a meeting to decide whether we would join our forces with the parents – and the answer was yes. We wanted to share our experience with even more people in Mauritius. However, no one of us realized that our self-help group, in its original spirit and way of functioning – informal and based on friendship and mutual trust – was nearing its end...

At the beginning, things worked pretty well with the parents of Rose Hill. But as time went by, we started to realise that we had no control over the running of the newly created association. Rapidly, things went very bad and I had no choice but to resign as it became obvious that if I did not I would be summarily expelled from the association. In any case, it was almost impossible to help others in such deplorable conditions. It was indeed very difficult and painful for me and my friends to quit Parole d'Espoir in such a brutal and shocking manner. We also realised that we had lost everything – the name Parole d'Espoir (which had great emotional value to us all), our books and DVDs and even some money that I had lent in good faith to the group of parents for paying the transport fees for an outdoor activity. It was agreed with them that the money would be refunded back as soon as the bank account of the association would be opened – as indeed a sponsorship cheque for that activity had been obtained from a local authority. However, following our divergences they changed their mind and never returned the money.

I will not go in further depth with this absurd and unnecessary conflict – which in my opinion could have been avoided with a minimum of common sense and consideration for persons who stutters in Mauritius. Unfortunately, ego considerations prevailed and we found ourselves on the streets. We had two choices: either we stopped there or we persevered – even if it implied starting from scratch. The decision was unanimous that we had to go forward, and we continued to meet informally on Sunday mornings in a school in Curepipe.

During her visit in June 2007, Anne-Marie Simon had offered to run a residential therapy workshop in

Mauritius. However, following the conflict, she was quite discouraged but was soon convinced by our dedication and good faith and confirmed that the workshop would be held! We were very excited and started the preparation at once.

The therapy week and the quality of care that we received from our two SLPs exceeded by far our expectations. Many activities were carried in group – and at the same time there was a personalised follow-up and feedback for each one of us. At the end of the workshop we had acquired an in depth understanding of our type of stuttering, clues as to the possible causes, and lots of activities and exercises to practice individually and in group.

After the workshop we took some time to come back to earth – but we had to. Our SLPs had given us as assignment to continue our self-help with the new techniques on a regular basis and at the same time to start thinking about activities that we could undertake to reach the local community. This is well under way – and we are presently planning the International Stuttering Awareness Day.

It is true that we had been quite isolated from the stuttering community in Mauritius since we quit the association. Our aim however is to progressively open our self-help group to others who would like to join us. However, we have decided to go step by step as we want to preserve the cordiality and togetherness that prevail during our meetings and in our relationships. We want to remain what we are, in essence, a group of friends making together a journey towards fluency.





From left to right: Balram, Jim, Aude, Briguel, Anne-Marie, Faz, Christophe, Dev and Yasvin.

## A FOCUS ON STUTTERING AND STUTTERERS

**H**ave you ever encountered someone trying to express themselves after asking a question as simple as ‘what is your name? In attempting to tell you their name all you hear is a prolongation repetition or a long pause before telling you m-m-y naaaame is J-J-J-J-J- Ohn. When you did have such encounter, what was your immediate response? If you were like me before I had a better understanding of such situation you would probably burst into laughter or shake your head pitifully at them.

As you are reading this article you may be wondering what all this is about. It is about a condition in which some people have difficulty in speech language as they try to communicate their ideas and opinions. The Americans call this condition Stuttering while the British

call it Stammering. Both terms will be used interchangeably in this article.

In the world it is estimated that 1% of adults stutter though in Nigeria, for now, I am not sure we have any statistics of the population of stutterers or stammerers but the fact is they are there all around us –in homes, schools, workplaces and the society at large. But the question is how much attention do we pay to this category of God’s image? Often, the response to their speech difficulty is ridicule, discrimination and even rejection. Such attitudes do nothing but accentuate the stammerer’s feeling of failure, frustration and hopelessness. The focus of this article is to draw attention to stuttering and the need to see it as a situation that requires the support of all so that stutterers can have

a sense of belonging and can feel as wanted as any other child in the family, school and society. Hence the article will examine the definitions of stuttering, causes and general attitudes of people towards them.

What is stuttering / stammering?

Stuttering can be defined medically, as well as psychosocially. Medically, stuttering is a speech dysfluency characterized by repetitions, elongation and blocks. As described in One Voice Magazine Volume 23.2007, it could also be defined as a disturbance of normal fluency and time patterning of speech characterized by one or more of the following

- (a). Sound and syllable repetition
- (b). Sound prolongations
- (c). Interjections
- (d). Broken words e.g pauses within a word
- (e). Audible or silent blocking
- (f). Circumlocutions (word substitution to avoid problematic words)
- (g). Words produced with an excess of physical tension
- (h). Monosyllabic whole- word repetitions e.g 1-1- see him.

The psychosocial definition of stuttering describes more profound effects on the stammerer than its medical definition. Some of the psychosocial definitions include:

Speech dysfluency characterized by overt behaviours of repetitions and blocks and the covert behaviour of avoidance, substitution and circumlocution.

Here is another definition; shame, fear, frustration, anxiety, embarrassment, low self-confidence and self-esteem which is associated with overt and covert chronic speech dysfluency. This later definition clearly reveals that stuttering is not only a medical issue but also involves social, emotional, attitudinal and behavioural responses. The psychosocial definition not only recognizes the existence of stuttering as a speech difficulty but also the reactions that accompany the stutterer's responses to people's reaction to them as they attempt to express themselves. The feelings of anxiety, frustrations and low self- esteem are emotional responses to people's attitude rather than the stuttering condition. These rather than the stuttering are what creates problems for the stutterer and those around them.

Having defined stuttering, it is pertinent to turn the search light on its causes. Answering this question is a hard task because there are yet inconclusive debates, research and findings on the causes of stuttering. While some believe that it has some organic basis others relate it to environmental and/or emotional stress. There is

some strong evidence now relating stuttering to heredity. Fredrick Murray in his book 'A Stutterers Story' opined that almost half of children who stutter have a family history of someone who stutters. He further explained that it is as a result of a weakness in the nervous system which begins to manifest itself at about the time a child begins to speak in complete sentences at age three or four. In most cases the disorder begins gradually with short occasional repetition or prolongations of words or syllables.

Another school of thought believes stuttering could be caused by 'certain kinds of emotional stress – either a single very upsetting event or a continuous pattern of stress.' However, this seems not to last long enough to make a person stutter permanently. It's note worthy however, that stuttering cannot be caught by imitation neither is it infectious. Evidently, there is some disagreement on what causes stuttering, however the cause to me seems not as important as those things that accentuate it. While we may not be able to do much about the causes (there is no agreed upon known causes anyway), we can change those things that keep it going. Our focus therefore should be on working on attitudinal and behavioural responses that trigger negative emotional responses in people who stutter and those who hear them.

## GENERAL ATTITUDES OF PEOPLE TO STUTTERING & STUTTERERS

As stated above, there are varied accounts of what causes stuttering but the fact is that stuttering is real. We should therefore be more concerned on how best to help people who stutter to cope with or reduce their stuttering by creating an enabling a psychosocial environment for them.

Across cultures in different parts of the world, people's attitude towards stuttering and stutterers seem not to be significantly different. For instance it was reported that to be a stutterer in Japan was a disgrace but it seem people's attitude to stutterers in the developing nations is more disheartening. Research work on stuttering and speech therapy has started in a place like the U.S.A as far back as the 1940s. This I believe has helped to bring about some changes in attitude towards people who stutter in the developed nations. Nigeria is far behind in this regard and so people, even family members, hold various assumptions about stuttering and stutterers. Some of these assumptions paint the person who stutters in bad image such as 'people who stutter are given to explosive anger/ wraths' 'they are short tempered.' 'They can destroy things easily in their anger'

All these assumptions form the basis of people's attitude



which manifest in various forms such as

1. Impatience and attempting to help the stutterer complete what they have to say.
2. Ridiculing the stutterer by laughing at or imitating them.
3. Simply ignoring the person and seeing them as a problem.

Now realistically try to put yourself in the shoes of a stammerer. You are discussing a serious issue of concern with a friend and he bursts into laughter. How would you feel? I'm sure you will not find it funny. Looking at it from that perspective, we should realize that when a stutterer is trying to express an idea or opinion, what they are trying to say is very important to them. Just as it would be out of place to laugh when a friend is discussing a serious issue with you, so it is when a stutterer is speaking. It's important to note that stuttering is not a voluntary action that the stutterer deliberately does. Therefore, when a stutterer is speaking he is speaking; he is speaking as well as he can at that moment.

The effect of people's discriminatory attitude towards a stutterer is what actually fuels the frustration, fear, anger, anxiety, embarrassment low self-esteem and other behaviours that manifest in many stutterers. Like anyone else, they desire to be heard, listened to and understood but since these expectations are not usually met they resort to various defence mechanisms to protect themselves from frustration and embarrassment. Such behaviour includes:

1. Avoidance – the stutterer tries to avoid situations where he would have to talk in class, at home and other places. They tend to avoid any situation where they would be verbally engaged. One avoidance mechanism manifests itself in such forms as laughing instead of speaking.
2. Withdrawal – they also have the tendency to withdraw

from people and keep to themselves. A stutterer shared his experience with this writer that at home he keeps to himself because it seems no one understands him.

**Struggle** – this is another defence behaviour that stutterers exhibit. Struggle involves making an effort to speak which tends to make them become tensed up. They eventually end up stuttering more.

**Conclusion** Speech communication is an important aspect of interpersonal communication which reveals not just the content of the communication but also the intent, emotions and perception of the speaker. It also reveals the acceptance or otherwise the respondent gives the speaker.

The common saying that action speaks louder than the voice is very pertinent in our interaction with people who stutter. The non-verbal cues that accompany our communication with others speak volumes more than we express verbally. Stereotypical perceptions about stuttering and stutterers definitely tend to aggravate the situation. For Stutterers speech language is a big challenge and for them daily communication is a struggle.

In Nigeria, though there are no statistics about the population of stutterers. We cannot on account for their large or small population or ignore their needs and right to speak, be heard and listened to. They are a part of our society and make a meaningful contribution to the economy. Stutterers are valuable because like you and I, they are created in God's image

They deserve love and acceptance not ridicule and pity. Like every other member of the society they are entitled to freedom of expression, their stuttering notwithstanding. Let's be sensitive to their needs. Smile, keep eye contact and give them the time they need. The change in attitude must start in schools and grow with the new generation. The time to act is now!

### Cover Photos

The 2008 National Stuttering Association Annual Conference was held June 25th - June 29th in Parsippany, New Jersey, USA. About 615 people who stutter, their families, clinicians, and researchers attended. Among them were Anita Blom (ISA Advisory Board), Keith Boss (ISA Director) and Albert Zhang (One Voice Editor).

Top left: Keith Boss and his friend

Top right: Anita Blom and Albert Zhang

Middle: Anita Blom and Keith Boss singing an Abba song on stage

Bottom left: Tammy Flores (NSA executive director) and her friends

Bottom right: Singing and Dancing

For more pictures, please visit <http://www.nsastutter.org/material/index.php?matid=552>