

One Voice

International

Stuttering

Association

Issue 17 - May 2004

Incorporating *The Voice of ELSA*, the newsletter of
the European League of Stuttering Associations



Special edition from the seventh world congress for people who stutter

Perth, Australia, February 15-20, 2004



Reach out and get together

Stefan Hoffmann
ISA Outreach Working Group Chair

The long awaited 7th world congress for people who stutter is now already history. But I believe that for quite a few people, the memory will be meaningful for long time to come. I had the

pleasure to organise the group of overseas attendees who with scholarships from the world congress organisers and ISA were participating at the meeting. For most of them it was their first such event and I believe it strengthened their commitment to work with and for the ISA family. Here above, you can see the photo taken at the congress venue. 15 countries are represented from all continents.

I invite you to read on the next pages about how the meeting was seen by them.

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'A world that understands stuttering'

ISA is making a real difference to people who stutter

Report of board chair to ISA meeting, February 14th 2004

Mark Irwin
Australia

Slowly but surely the word is spreading. I believe the ISA can feel strongly that over the last three years it has taken significant steps towards fulfilling its goal of a world that understands stuttering. We must remember that half the world's population live on less than \$2 per day and even in the developed world access to professional therapy services is often limited. Given these problems with access to affordable treatment, the ISA's work of providing information on stuttering and helping to promote national and local self help groups, is as vital as ever.

Specific steps taken by the ISA over the last three years include:

1. admission of six new member associations
2. continued outreach efforts in China and Africa
3. holding of a world congress for PWS (in Australia for the first time!)
4. completion of a CD ROM containing stuttering information

Some of the new member associations are from Burkina Faso, Cameroon, Nepal and Spain.

In addition we welcome two new international groups: Passing Twice, for gay, lesbian and transgender individuals who stutter, and TTM-L, an internet self help group for Hispanic speaking people throughout the world.

Stefan Hoffman is to be thanked and congratulated for his outstanding commitment to outreach on behalf of the ISA. Stefan developed a plan for his activities and I believe he has worked through it with great success.

The upcoming world congress is sure to be memorable with more people than the Ghent conference three years ago. I am sure this is due to wonderful promotional work by the congress convenor Peter Dhu. I have been delighted to serve as programme committee chair and know how hard Peter has worked in every aspect of the congress arrangements.

A CD ROM with stuttering information suitable for distribution in schools was an initiative developed at the Ghent conference three years ago. I am pleased to say the CD is now complete and is available to member associations for distribution throughout their countries. I would like to acknowledge the following people for their involvement. Judith Eckardt (USA), Claudia Groesman (Spain), Erik Lamens (Belgium), Marilyn Langevin (Canada), Michael Sugarman (USA) and Melissa Urquhart (Australia).

The ISA has continued to produce its newsletter One Voice. I thank Andrew Harding of the British Stammering Association who has edited and produced the last four issues and before him Warren Brown of the New Zealand Speak Easy Association. Both men are journalists and have been extremely diligent and creative in their efforts. We at the ISA owe them a large debt of thanks for their willingness to give so much of their time for this effort. Also I would also like to thank Martine deVloed from Belgium who has served as One Voice coordinator. It is with regret we must accept Martine's resignation from the Board. Her efforts on behalf of the ISA also included serving as vice chair, and convenor of the last ISA conference.

Our efforts at outreach and international communication in general have been helped significantly by the development of the internet. Benny Ravid from Israel has served our association wonderfully well as an extremely competent and committed web master. I thank him for his efforts. Benny has also serves as a board member and deserves our thanks in this regard as well.

On an administrative level there is also concern that many of our member associations have not paid their affiliation fees. Despite of this we have been able to meet all our financial commitments as well as raise money for travel scholarships for people from disadvantaged countries to attend our congress. Again I thank Stefan Hoffman for his fine work in coordinating this activity.

I also thank Stefan for his support as vice chair of the ISA for the last three years. He has always conducted himself professionally and I have very much appreciated his timely replies and reminders. He has been extremely effective in his role and made my job much easier. I am sure the entire ISA is sorry to hear of his decision to resign from the board but we are heartened to hear he will continue to lead our outreach efforts. We understand his retirement from the board is a temporary situation and we look forward to his involvement at board level in the future.

Mary Wood from Canada and Beatriz Touzet from Argentina are also retiring board members. Both have been extremely enthusiastic ISA supporters and their presence will be missed at our congresses where their laughter and energy were infectious. I thank them for their efforts as I do our other board members not already mentioned; namely Annie Bradberry and Judith Eckhart from the USA and Gert Reunes from Belgium. In addition to their general involvement in discussions and decision making, Annie has served as board secretary and with Stefan helped coordinate the new ISA logo while Judith has helped with the CD ROM project. We thank Gert for accepting the

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Delegates from Germany had something big to celebrate (left and below)

continued from front cover

For me personally, I had huge pleasure to experience the multinational atmosphere the world congress for people who stutter generated. Especially, the evening dinners were amazing. To go out with 10 or more people from as many countries can be very funny, as long as you can agree on a type of food that everyone is happy with!! The scholarship included accomodation in a backpackers hostel. Some may think that this is not the most desirable place to go, but actually I heard from many that they so much enjoyed to stay there. They had time to get to know fellow stutterers from different places, take time to discuss their experiences, get new ideas how to enhance awareness about stuttering back home and just have a good time. Of course ISA would have liked to have even more people attending the conference. But we are already very happy that our three member associations from Africa were represented and could make an important contribution to the congress. However, more steps are necessary to help the many stutterers there. In Perth a few ideas were



developed to begin this work. Small steps can already make a difference. A beautiful example on **pages 6-7** is described by Jane from Rwanda and Dan from Canada, who met last autumn in Rwanda. Please read for yourself how this nice example of ISA networking came into place. Again, I want to invite all who read this issue of One Voice to get involved with ISA outreach working group. It is a very rewarding task to bring people together from various parts of the world. The opportunities to actually meet each other face to face are always highlights, and if I had to choose between fluency and attending such international meetings, I would choose the latter!

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difficult position of liaison officer to the World Health Organisation. Unfortunately it seems professional commitments as well as his forthcoming marriage have reduced Gert's ability to accomplish as much as he would have liked. Gert and his new wife Petra were very hospitable to all ISA delegates during our Ghent conference.

I would like to acknowledge the fine work of ISA advisory board member Michael Sugarman who has coordinated the ISA's international year of the child who stutters. This event will gather momentum with the distribution of the ISA's CD ROM and the accent given during the international online conference in October.

Now to the future. I feel extremely optimistic about our future for three reasons. First, with the new technology provided by the internet we have been able to spread information about stuttering throughout the world. Our ability to do this in the future will only be enhanced as internet access spreads globally. Our consumer voice is getting stronger; consistent with a general empowering of consumer groups throughout the world. This will enable both the ISA and our member associations to be more effective in our public education and advocacy work. We are yet to tap the resources of UNICEF, UNESCO, WHO and the World Bank.

Second, our liaison with the speech pathology profession has never been better. The strength of the relationship was amply demonstrated at the recent IFA congress in Montreal where speech pathologists and people who stutter interacted both in professional discussion and social events. Of particular relevance was the fact that the congress welcome as well as three of the four keynote addresses were given by people who stutter.

Third, I am impressed by the competence and experience of the people who have already nominated to serve on our new board. There is no doubt our future is in good hands.

It is obvious to say our situation would be improved if we were able to attract sufficient finances to fund professional staff. At the moment all our work is the result of voluntary labour. This limits our ability to get things done as quickly as we would like as our board must balance their community service with their work, family and social lives. However, while we are not moving at a fast pace, perhaps we are moving at sufficient pace. Steps are being taken and our dream is slowly becoming a reality. And at the same time people who have served the ISA are able to experience the positive benefits that come in so many ways from community service. I know I have. I have drawn energy and inspiration from the successes of the leaders of our member associations. My involvement with the ISA particularly over the last three years has been both an honour and a privilege. Thank you.

My stutter can't

Pablo Ibáñez
Spain

On December 2003 I received an e-mail relating this subject: "Scholarship confirmation Perth 2004". Seeing this e-mail today, in March 2004, I realise I could never give enough thanks to ISA for offering me this great opportunity.

The congress is now over, I am back in Spain. Western Australia is on the opposite side of my world, somewhere down, down under, but I keep a place in my mind (and in my heart) for that wild country, for so many caring friends, for those proud stutterers I met from all over the world. I am back to work, to normal life. Stuttering is still my partner everyday. When I wake up, I know I will have to stutter that day one moment or the other. I know someone will look at me with a strange face, I know maybe someone would laugh. I know I have a stutter. It sometimes pushes me down, I sometimes push it down. It is my whole life battle. But for this battle I now have got new arms, the ones my self help group gave me, and the ones I gained in Australia. Having these new arms, I know my stutter won't knock me down anymore.

How can my stutter knock me down if I have listened Mel and Stefan Hoffman, Thomas Krall and Mark Irwin speak? How can my stutter knock me down if I have listened Alan Badmington, John Harrison, David Shapiro, Peter Dhu, and so many others, speak? How can my stutter knock me down if I have myself spoken in front of an audience and felt so great? How can my stutter knock me down if I have shared a room with nine other people who stutter, all from different parts of the world, and we have laughed at our own stuttering? How can my stutter knock me down if I have attended the congress? It is impossible. My stutter can't knock me down anymore. I hope to meet all these great friends again in Croatia 2007. Meanwhile, I will try to improve my Didgeridoo playing.



knock me down anymore

Right: Speech therapy students with Mathew Martin and Peter Dhu. The students who helped to organise the congress gained valuable experience.



Aboriginal dancers in traditional paint and minimal costume performed at the congress opening ceremony.

Right: Opening night drinks brought together people from around the world.



Feel free to stutter

Albert Zhang
Jianliang



Although over one month has passed since the day I left Perth, Western Australia, the beauties of Fremantle, the kindness of the local people, and all the chattings with other PWS throughout the whole world, are always lingering in my mind. It's because of stuttering that I have the chance to get friends from different areas, speaking different languages.

I saw lots of persons there that although they stutter more severely than me - even in my worst days I did not stutter that much, they don't treat stuttering like a shameful thing, they don't avoid, don't change the difficult words, they manage to continue the flow of speech with the blocks. I wonder what they will act like if they are made fun of, but I figure they'd smile and leave it off. This attitude, I think, is what I lacked when I was young.

As a severe stutterer in my childhood, I feared to be ridiculed when I stuttered, and would be furious if that thing turned up. In most occasions when there was a block awaiting me, I would stop speaking, or even become angry with me. I chose to excel in school, so as to gain respect from classmates and affections from teachers, yet I dared not to expose my stuttering, though it was clear everybody knew I stuttered and most of them kindly told me I would grow out of it. Various methods to treat stuttering were collected and exercised by myself; sometimes I could speak better, and I made the decision to speak all the day, yet sometimes I still stuttered severely.

I did not talk about this problem with anyone else until when I was reaching 30. When looking back at my life, I found the happy times were all when I was alone: reading books alone, enjoying music alone, traveling alone, etc. Usually I was bold and optimistic, but when facing an audience, all my confidence vanished away, and I could only speak in a weird, slow style, with lots of "hesitations". This torment was deemed as a necessary ordeal to be full fledged by myself, and I just kept working hard on it, hoping one day, it would go away and I would own the whole world.

Now that I realize, stuttering might be our life-long company, and I must live in peace with it. I stutter, yes, but what else? With the help of some techniques and an electronic device, I sometime can speak better than many people. Just feel free to stutter, and with this attitude, life is more beautiful. Stuttering has changed my life, and I have to try to improve my own life with stuttering.

It is so good to talk

A chance meeting led to the chance of a lifetime for Jane Ngabirano in Rwanda and Dan Doyle in Canada.

Jane Ngabirano
Rwanda

I am 35 years old and I have battled with stuttering for as long as I can remember. I wrote an article 'The Agony of Stuttering in Africa' for One Voice 15. For those who may care to read it, please refer to that newsletter issue, which is also available on the internet. (www.stutterisa.org/isa006.html#inonevoice)

I am writing this article, mainly to thank the International Stuttering Association (ISA) as an organization in general, and the individual ISA executives and staff (who add a human touch to it all) for the work they are doing in their global outreach efforts. From a position, where many of us feel isolated in our respective corners of the world, ISA and its dedicated staff have managed to draw us out through provision of useful information about the concept of stuttering and contacts to the stuttering world that seemed out of our reach.

Throughout my stuttering life, I had never met and talked to another PWS until recently. For a long time while I was growing up, I even thought I was the only one in the whole world who had such a problem, one can only imagine, how that belief might have impacted my entire perception of life, self esteem, self confidence etc and how these in turn affected my speech problem, back to the central point of stuttering (a vicious circle). I recently met Dan Doyle, another PWS when he visited my country on a work mission. I would like to talk about this experience and to thank the person who made it possible, Stefan Hoffman of ISA. By putting us into contact, Stefan gave me my first ever opportunity to meet another PWS.

This might seem insignificant to some people, but to a person who has lived through the anguish of stuttering alone, meeting another PWS is something special. For the first time, I felt I had the freedom to stutter and I didn't mind whether I stuttered or not because I knew he would understand. I knew he would not think I was weird or nervous or simply not smart (and all those other reactions we fear getting from our fluent/non-stuttering friends), and I liked the feeling.

Perhaps, true to the ISA mission and I quote: ***"We dream ... of a world that understands stuttering, where people who stutter will not feel the need to hide their***

without being afraid of people's reactions

stuttering any longer, will not be misjudged as fools, psychopaths and figures of ridicule, and that stuttering will not affect their lives negatively...”

If the world understood stuttering better, it wouldn't be such a formidable problem to us. In an environment, where we feel understood, the fear of stuttering considerably subsides, and I believe, at least in my case, that fear (fear of stuttering itself, fear of negative reactions from people, fear of repeated speech failures etc) plays a major role in our stuttering.

I can now understand the importance of self-help groups (though we don't have one in my country), the world congress for PWS and other such conferences, and I urge the ISA and other stuttering organisations all over the world to keep up the good work they are doing in educating the world about the complex phenomena of stuttering and facilitating PWS to come to terms with their problem through provision of information and forums to meet and share their experiences.

Dan Doyle
Canada

In June 2003 I met Stefan Hoffman from Germany, at the CAPS (Canadian Association for People who Stutter) Conference, in Toronto. I knew of Stefan and his association with ISA (International Stuttering Association) and asked if there were any ISA members in Rwanda. I was planning to be there in September. As it turned out he knew Jane from past correspondences and was able to contact her for me to see if she was interested in meeting with me. Oh! The wonders of e-mail - he was able to contact her and give me an answer almost within 24 hours. She agreed to meet me and we eventually connected.

It was a pleasure to meet Jane. Like her I have stuttered since I was a child. Even though we were strangers, our stutter gave us lots to talk about. We spoke at length about our experiences. It came as no surprise to me that they were similar. I think all persons who stutter experience more than their share of the fear and frustration that is generated as a result of stuttering. I told her about the various therapy programs available in Canada. She recommended websites that I was unaware of which she

uses to keep her in the loop with the latest developments in stuttering. The main difference between Jane and myself, with regard to stuttering, is that I have been fortunate enough to have had access to both professional help and self-help groups. This professional help and my exposure to others with this disability have helped me immensely to improve my overall fluency skills. To be able to communicate to and listen to others with the same disability cannot be underestimated. To personally know others with this disability helps me feel more normal.

Jane, on the other hand, described to me the isolation she was going through. She is virtually alone to deal with her disability because there is no professional help or other

stutterers she can commiserate with in her country. Obviously I understand to a certain extent what Jane is going through. I think the only thing I've gone through that comes close to her experience is when I was growing up in a small town in Ontario in the 1950's and 60's. Help of any kind was nowhere to be found. It was only after I moved to Toronto as a young adult, that I was able to access the help available.

Jane really wants to take the intensive speech fluency program at the Institute for Stuttering Treatment and Research (ISTAR) in Edmonton Alberta, and since meeting her I have taken this cause on. Through a lot of great organizations like CAPS and private individuals, I've been able to raise money to help her. As well, ISTAR has kindly offered Jane a substantial scholarship and the possibility of subsidized accommodation.

However, a roadblock has been placed in front us, which, through my lack of experience, I was not expecting. Because of Canada's tight immigration policies, Jane may have difficulty obtaining a visa. It is not yet known how serious this is because I've just started to do my research here in Canada and it is too early for Jane to approach Canadian immigration officials. What I have found out so far is that it is not easy for people from certain parts of the world to get a visa, no matter how legitimate the reason. Only time will tell if we succeed.

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I have many friends and experiences to take with me

Indra Lal Shrestha
Nepal

I want to share my experience of the congress. I think that my knowledge will be fruitful and may also be feedback for the planning future programmes.

The Danish Stuttering Association had decided to provide a scholarship for one person to participate in the Seventh Triennial World congress For People Who Stutter. That was a good opportunity for Nepal Stutters' Association. Because after formation of NSA, we were getting chance to participate in international program within few months. We had a chance to introduce our association at an international level.

As the Danish Stuttering Association decided to provide a scholarship for the President of NSA, we found some good news within few weeks as Mr Mark Irwin (Chairman of ISA) informed me that the application of NSA for membership was accepted and NSA became a member association of ISA. It was a good event in the short history of NSA because it increased our relation on a vast area. We got many new friends. One of friend, Mr. Benny Ravid offered to open an NSA website.

I got an invitation letter from the International Stuttering Association and also from the Australian Speak Easy Association mentioning that they would provide free registration and accommodation. The Danish Stuttering Association also sent a letter for bearing travel and other charges. I then applied for a visa. Unfortunately, it was rejected the first time. I informed this event to Mr. Hermann and other friends. I collected some more documents and again requested a visa. The second time my request was accepted.

I had visited India and Bangladesh before my Australia trip. I studied in India. I visited Bangladesh in my official observation tour for 10 days. During my visit to Australia, I had a transit in Bangkok for 22 hours before flying to Perth. I found some Nepalese friends in Bangkok and it made it easy to spend my time. When I went to the waiting place for the Perth flight, I found one stutterer friend talking with another person. I talked with him, found that he was a stutterer and was going to the world congress in Perth. He was Pablo from Spain. He also had accommodation in the Sundancers backpacker resort as me. We felt very easy after meeting each other because Perth was new place for us.

I talked with other friends staying in the same room in the Sundancers. I found that they were also attending the world congress. One of the friends told me that there was also a delegate from Nepal who was staying at the Sundancers. I found that person was Shree. He attended

the World congress from Japan. I met with many new friends as Lasse, Moussa, Josep, Albert, Ricker and many others.

At the congress I met with many new friends among which some friends, I knew through email and website pictures. They were Mark Irwin, Stefan Hoffman, Thomas Krall, Judith Eckhart, Mel Hoffman, Kazue Shinji, Shiji Ito and many other friends. We introduced each other and attended the meeting of the ISA on the 14th and 15th February. In the meeting of ISA, various reports were reviewed and new board members were elected.

On 15th February, there was a welcome party at the Esplanade Hotel. The President of the Australian Speak Easy Association John Steggles gave the welcome speech. The Chairman of the 2004 world congress, Peter Dhu gave the welcome and conference outline speech. In the opening ceremony, David Shapiro and Gerald Maguire also gave a speech.

Various papers were presented by various professors, speech pathologist and therapists and many associations. They expressed many techniques recently used and effective for stuttering. Many association's representatives presented papers about the situation of their association. There was also an oratory competition held among participants.

During the conference time, I made bilateral talk and discussions with many friends for developing close cooperation between associations and sharing experiences and had some memorable discussions.

I returned to Nepal with a large experience of the 7th world congress. While I was returning, I was feeling the world congress was one of the largest meetings of stutterers. I found that there was many stutterers from developed countries who were facing too much difficulty while talking. In Nepal, we think that people have low awareness, poor and no facilities of speech therapy, so stutterers are facing more problems. But there was also stuttering as a great problem in developed countries though there is sufficient people awareness and facilities of speech therapy.

During our conference, many papers, theories and devices were presented. I evaluated that there was not any perfect theory, therapy and devices that can be generally helpful for all stutterers. It was observed that unless the stutterers increase their self confidence, the stuttering can not be properly treated by any therapy or devices. We have to provide appropriate situation for increasing the confidence of stutterers.

I realized that I am important and above all I am not alone

Shree Hari Gautam
Nepal

My life as a student in Japan had not been different from that of other people who stammer in general. I was living with my own tricks. Until about a year ago I was totally unaware of what was going on around the world concerning stuttering. Then I came across the exciting news about an event called the world congress for PWS. I felt like finding the real cure for my stuttering at the moment. I had a dream to attend the congress. With a lot of excitement and hope I started to correspond to ISA, ASEA etc., postponed several of my important day to day duties and ultimately managed to see my dream come true to be there at the congress traveling all the way from Sapporo, Japan. I acknowledge and appreciate ISA for the financial and moral assistance extended to me to make all this happen.

Evaluation and feelings

Having been able to meet, talk, be with and share among hundreds of PWS and professionals from around the world I gained a strong feeling of self-worth and security. I came to realize that I am important and above all I am not alone.

ISA at the world level and several other self-help groups at national or local levels have been bringing PWS close to each other for their own benefits. The cooperation among such self-help groups has been bringing a lot of positive changes in the lives of PWS world wide. This congress has fueled new energy in this endeavor.

While the problem of stuttering speech is still there, several emotional pain and social stigmas in the minds of the participant PWS have been healed by this congress. I take it as a bonus for myself.

The congress has given me a broader vision about stuttering. There can be several approaches to improve our fluency but whether they work for us to improve fluency or not we should live our life fully. In this context it is okay to stutter and we have to learn to detach our limiting beliefs, emotions and shame associated with our stuttering. Rather, we have to create social awareness to clean wrong beliefs about stuttering from society and fight against social discrimination for PWS worldwide. I guess every participant have more or less similar experience. I learnt that several people have been trying to understand the stuttering problem from every possible angle and sooner or later we will have an answer to this problem. The congress has stressed the fact that the mutual cooperation and understanding among PWS, researchers and professionals are crucial in this endeavor.

The management and conduct of the congress was better than I could have expected.

It's unbelievable... there is really a congress that caters to us...

Ben
Singapore

On December 12th 2003 when I was having a group therapy session, my speech therapist introduced us to the 2004 world congress for people who stutter. My mind was saying, "Wow it's unbelievable. There is really a congress that caters to us". I was just feeling euphoric. Desiring not to miss this opportunity, I gave myself a shot at it. Together with my devil partner Wei Cheow and of course our angel speech therapist, Lynnette, we headed to Perth.

In the five hour flight from Singapore to Perth, as the distance drew near, my anxiousness grew but my spirits was at an all time high, just like a child who is going to a playground.

The congress was great and I met a lot of people who stutter from different parts of the world. I really learnt a lot and it was an eye-opener for me. I somehow felt that it was so weird speaking to other stutterers and the best part of it was that majority of the people there were stutterers. It was a kind of feeling that I'll not forget in my entire life. And for those stutterers who proudly said: "I stutter and I'm a stutterer", I simply take my hat off to you as I do not even have the courage to say it. Right here I give you my salute.

During the congress, I heard individual stories and formulae for success which were given out by Peter Dhu, John Harrison, Alan Badmington, Bob Bodenhamer and many more to name. That gave me optimism for my future and my passion is growing. I also learnt a lot of techniques from both the speakers and delegates. It was truly wonderful.

Back home, I'm into normal life again and stuttering is still part and parcel of my life. But this time, I have grown stronger as what I have learnt there gives me courage and hope. I ask myself: "How can I let this stutter control my entire life? "How can I just resign myself to fate without giving a fight"? Nobody can help me if I myself don't give a try.

Besides going for my usual therapy sessions, I try to keep myself happy, cheerful and laugh a lot as I feel that will keep my stutters away. I always believe that nothing is impossible unless you don't try. How time flies, it has been nearly two months now and it seems like just last weekend when I was having joy and laughter with Wei Cheow and Lynnette (oh, and Lynnette's mum too). And I eventually always get "bullied" by the both of you....

I hope to meet all of you people again in Croatia 2007.

Now I see I need more than technique for my stuttering

Ang Wei Cheow
Singapore

It was really an enriching and fruitful experience for me to be able to participate in the 2004 world congress for people who stutter. Before I embarked on the journey to the world congress, deep in my heart, I always hoped that there exists a miracle cure for stuttering that I can discover in the congress. But now, I can firmly state that there is no such thing as a miracle cure for stuttering and the only way for me and for those people who stutter to find comfort and hope in their condition is to try and live their life to the fullest. I strongly believe that those who have made the trip to the world congress will surely share the same sentiments with me that the speakers at the congress are our role models to follow in our route to living life to the fullest, especially so when the speakers have all underwent great difficulties and hardships trying to get out of their comfort zones to achieve stutter-free and fluent speech. I must admit that the experiences that Alan Badmington had shared with us were exceptionally inspiring. He related how he has stepped out of his comfort zone and finds every opportunity to talk – even to the extent that he will make phone calls to strangers everyday to inquire about some services or products. He will try to strike conversations with strangers on the train and also try to participate actively in a public speaking club similar to Toastmasters. The kind of stuff that he actually forced himself to perform are things that I would definitely, before attending the world congress, not even consider doing.

Before the congress, I had the impression that once I mastered the speech techniques taught by my speech therapist, I would surely recover from the much-dreaded stuttering problem. Fortunately, this congress has taught me to look at my stuttering problem from a holistic viewpoint. I am particularly captivated by the stuttering hexagon that John Harrison presented in one of his workshop titled “Understanding the Stuttering Block” and in his later talk on the last day of the congress titled “A New Paradigm For Stuttering”. I have never suspected, before attending the congress, that even perceptions, beliefs and emotions can play such significant roles in upsetting the new balance that is created by the new learned skill (physical behaviors) that we inherited through intensive speech therapy programs.

Cognitive therapy is another new area that I get to further explore whilst at the congress. Especially after attending



Alan Badmington - inspiring us to live beyond our comfort zones

the Neuro Linguistic Programming Workshop conducted by Bob Bodenhamer, I realized that there is a need to constantly bombard our brain with positive thinking so as to overlap or suppress those negative thoughts that we, as people who stutter, have accumulated over the years. This is something that I personally find quite relevant to my stuttering problem. I often stutter in situations where I do not have much confidence in myself and also in speaking situations which I feared most – such as making phone calls or striking a conversation with people of higher authority.

I hope that with all the knowledge and experiences that I have gained out of this congress, I can pass on to my

comrades (a new term by Gerald Maguire which refers to our close companion who share the same stuttering problems as we do) back in Singapore who unfortunately can't make it to the world congress due to work commitments. Hopefully, our aim to set up a stuttering association in Singapore can proceed according to plan. The stuttering association will be a new avenue for me to share my experiences and a chance for me to step out of my comfort zone.

Last but not least, I must make use of this opportunity to thank the International Stuttering Association and the Australian Speak Easy Association for all the kind help given to us – the Singapore delegates.

Oratory win

British Stammering Association member Alan Badmington overcame a strong international challenge to win the oratory competition at this year's world congress. The contest, which attracted entrants from all parts of the globe, was spread over several days, culminating with a final event with nine speakers.

Each contestant was required to give a four minutes speech, selected from six specified subjects. Alan's entry was entitled, “If I could change one thing”.

In addition, Alan was the sole UK keynote speaker at the event, while he also presented a workshop. The theme of both was, ‘STEP OUTSIDE: Why expanding comfort zones can improve our stuttering and lead to more fulfilling lives’.

The valentine's day I'll never forget

Watson Lekalake
South Africa

QUE MARAVILHA! How marvelous ! I would like to thank the International Stuttering Association for making it possible that I was part of the experience of the 7th world congress for people who stutter, in Perth, Australia. It started on Valentine's Day and was the most expansive Valentine I ever celebrated because it lasted for a week, in the exquisite Esplanade Hotel near the coast in Fremantle. It was like something being fulfilled, as a last piece of a puzzle being inserted as I flew all the way from where the Indian Ocean starts, in the east coast of South Africa to where it ends, in Fremantle.

"Hello, I am Mrs Dhu," as Peter Dhu's wife introduced herself. This, to me, was the evidence that a person who stutter can live a normal and successful life, as illustrated by Peter, who had a lead role in organising the congress. Something ISA is taking care of. 'Fluency and Beyond: a Holistic Look at Stuttering...'!

I am a student working towards completing my undergraduate curriculum. I was also representing SpeakEasy South Africa (SESA). Thus, I was like a researcher in the field of stuttering. I was impressed by the organisation of the conference, how things ran, from the first day till the sixth and last day. I learn from Malcolm Fraser's book, Self-help therapy for the Stutterer page 11, that I mustn't dwell longingly on my fluency in the magical belief that some day my speech blocks will disappear. There is no magic potion, no pink pill that will cure stuttering (Self-therapy for the Stutterer, publ. #12, p11). We are in a journey hoping for a destination where we will achieve fluency and we need skills to achieve this

*I am inspired to contribute in
the Africa initiative to reach
out for people who stutter*

(David Shapiro, USA) The competence of the keynote speakers unfolded that destination before my eyes. I realized that I have the relevant curriculum in my university studies as I listened to speakers presenting on scientific research and linguistic research in stuttering, the likes of Mark Onslow (Australia), Bob Bodenhamer (USA), etc.

... so that PWS may lead a normal and balanced life is one of the slogans of the ISA. I found myself a tourist in Australia, of which most of my fluent-friends are still finding it difficult to achieve. It was time to review my life from all aspects. We are part of the same family said David Shapiro. I met and interacted with interesting people from all the continents of the world map. Some were old friends

from the previous ISA conferences and some were the youngsters - the future of ISA. We exchanged contacts, thus looking forward into the future. It came to a point where I witnessed that life can be fun and easy-going when I dined in MacDonalds where I found prices very cheap as compared to McDonalds South Africa.

I tried to maximize on the workshops offered at the conference, most of which were for communication and employment. This amplified my need for therapy.

I realized my significance for the community of PWS, after attending a welfare evaluation and a disaster management course, both of which occurred in South Africa. The world conference was thus a seal of my membership confirmation to ISA. As most of the delegates in that congress, I suppose, I am inspired to contribute in the Africa initiative to reach out for people who stutter in the southern Africa, as we will be preparing for Croatia, 2007.

Revisiting the problem of choice, it is very difficult these days, with numberless treatment methods and models available. The major challenges will be finances to carry out most of our operations here in southern Africa.

The conference was a success. I felt successful and am still anticipating for more success in my overall life. My fellow South Africans never stop congratulating me as they amazingly enquire more from me about what my trip to Perth was all about. My family feels blessed to have me as part of them. My friends found me unique, but not weird. I learnt more about love as the preacher would elaborate more on the chapter from the bible, 1 Corinthians 13. Learn, live, laugh and love (David Shapiro). May the spirit of ISA live long. Congratulations to all those who made it to the board for the period 2004 to 2007.

"Fear is the gatekeeper to our comfort zone," says Alan. "People experience nervousness and apprehension if they don't wish to step outside their comfort zone. But failures are learning experiences — stepping stones to success. 'Being comfortable' often means 'being in a rut'.

Three years ago, Alan learnt new speech tools through the McGuire Programme. But he had to dismantle the fears that he felt before he could be confident using the speech tools. He decided he wouldn't substitute words. He decided he would accept every speaking situation offered to him, rather than shirk the opportunity. He said he has never avoided speaking situations since that day. People who stutter need the courage to take risks, to transform their attitudes and self-image.

Shanghai Stuttering Association is formed

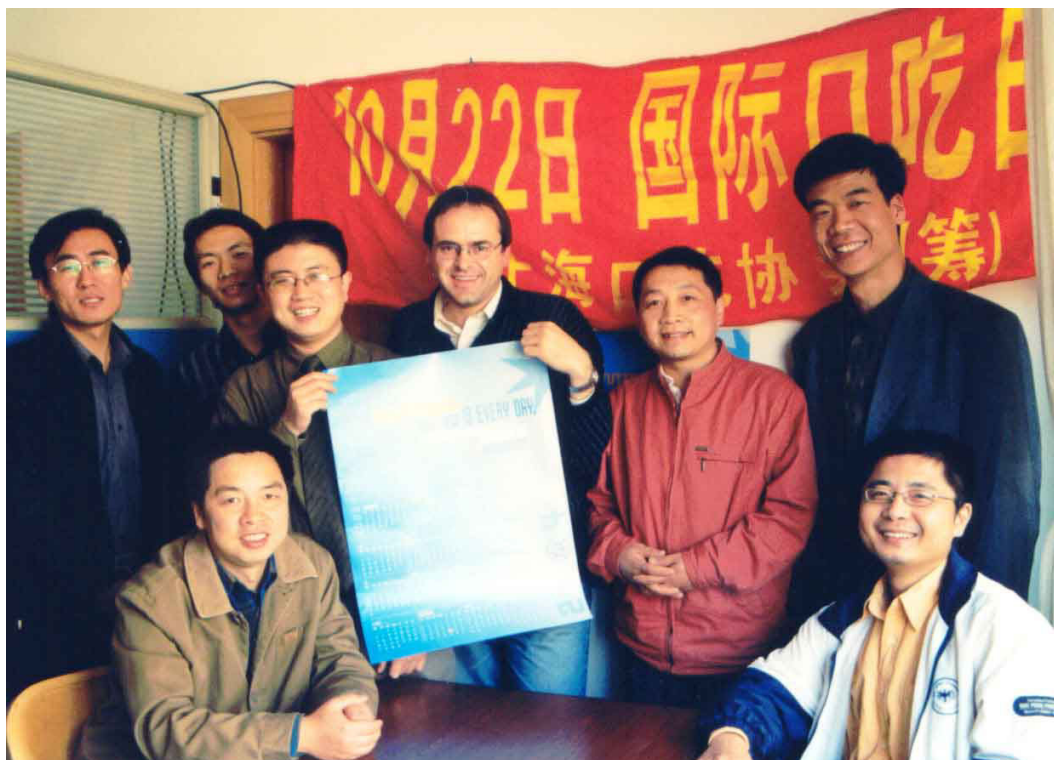
In July 2003, at Ju Xian Mansion, West Yan'an Road, Shanghai, Shanghai Stuttering Association (SHSA) was founded.

SHSA is a self-supporting group organized by stutterers in Shanghai. Its fundamental goal is to help members to improve the fluency of their speaking demanded by jobs and daily life, at the same time, changing their attitude toward life to be more positive, more confident, increasing the ability of social contact and cooperation. Besides, SHSA aims to inform to the whole society what stuttering is, how to treat stutterers, how to treat children's stuttering, etc, so as to bring benefit to thousands of stutterers in Shanghai and many more in China.

The research of stuttering has long been neglected in China. Compared to western countries, China lacks speech and language therapists and academic papers on the treatment and research of stuttering. There has been no department of speech pathology in any university in China until now. Stutterers are generally treated by a small number of practitioners who recovered (or improved) from their own disorder of stuttering. The whole situation can never meet with the demands of millions of stutterers for treatment. However, though the research of stuttering in China lags behind western countries in many aspects, there have been some insightful views and effective therapies for stuttering in China. We believe that Chinese stuttering therapies can give an important contribution to the global progress in the treatment of stuttering, based on the introduction of scientific research methods and advanced theories of western countries.

The role of SHSA

SHSA will provide stutterers in Shanghai and China with new information on the treatment of stuttering, create more opportunities of speaking for members of the association, by varied means and activities such as: inviting successful PWS to introduce their successful experiences, making connections with other stuttering associations, introducing effective domestic or foreign therapies and devices, consulting to speech-language therapists, etc, to



Stefan Hoffman (centre) with the members who are starting to provide help to the more than 150 000 people who stutter in Shanghai

guide our members to choose effective programs or devices, to avoid those ones which have been proved ineffective or of little value.

SHSA is a non-profit organization and its working staff is voluntary. It is to be a big family of stutterers in Shanghai, and every stutterer, every non-stutterer who cares for the well being of stutterers is warmly welcomed. SHSA has contact with International Stuttering Association (ISA), and has communication with some famous speech and language therapists, who will kindly offer their suggestions to SHSA members.

Our friends! SHSA lacks experience in its infancy. We are willing to set up friendly relationship with other brotherly associations in the country, to learn from them with an open mind, to exchange information and positive results, to join hands and advance together. We shall take the advantages of Shanghai as an international metropolis, such as large numbers of talented people, quick access to information and other favorable conditions, to make SHSA one of the first-class stuttering associations in China and among the top self-supporting groups in the world. May SHSA bring forth light and heat for the treatment of stuttering in China! May China make an important contribution for the cause of stuttering research in the world!

International Stuttering Awareness Day:

Michael Sugarman
San Francisco

The purpose of ISAD is: *to change public attitudes and eliminate societal discrimination toward people who stutter; to promote the self-esteem and opportunities of people who stutter to reach goals and aspirations; and to build a community and provide opportunity to exchange ideas and strengthen the relationship among researchers, people who stutter, clinicians and parents of children who stutter.* ISAD continues to grow with more people joining in to spread its message. Some of the wonderful events that have occurred over the years include:

World congress overcame my expectations

Vilma Makauskienė
Lithuania
Speech therapist and psychologist
PhD student, Siauliai University

These two weeks in Australia look like a nice dream. It was wonderful to change cold winter into summer and meet many new friends from around the world. There are a lot of differences between Lithuania and Australia: differs seasons, day and night time, traffic in the street, nature, even the color of the sea. Despite these many differences, people feel the same feelings and have the same delights and difficulties in both countries. All of them have purpose, appreciation, cooperation and value in their community. All people want to have friends, seek success in their job and family life. All of them want say their names without shame and fear.

I am very thankful for the Australian Speak Easy Association, ISA, Mr Cizeika (the president of Lithuanian Community in Perth) and Director in Kaunas Child Clinic Mr. G. Aukstakalnis for help and support.

Organisators and assistants must be proud of their big work in what they did during the preparation and congress time. I am surprised very much, that Mr Peter Dhu found some time to pick up me from the airport. This was big event for me to participate in workshops and presentations of such experienced specialists as D. Breintfeldt, J. Eckardt, J. Harrison, D. Shapiro, M. Onslow, M. Langevin and many others. I feel responsibility to share my experience and knowledge with other specialists in Lithuania. A lot of experience as person and as specialists I got from my friends K. Abercrombie, C. Diaz, G. Smith, V. Mentzel, R. Hayes and R. Butnoris. I appreciate warm and open conversations with many participants of this congress and I will never forget it.

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ISAD from conception to present day



- The ISAD online conference coordinated by Judy Kuster for professionals, parents and people who stutter to discuss issues and research papers on stuttering, via the internet.
- The Argentina Stuttering Association made and distributed ISAD posters for children and adults and hosting a convention on October 22.
- The Israeli stuttering association (AMBI) held its first conference in Tel Aviv on October 22. AMBI is now six years old.
- In Brazil, the Communication and Disorders Department of Sao Paulo University organized a seminar for students in speech pathology and professionals.
- In Korea, Moonja Shin's speech clinic hosted a meeting of people who stutter and professionals.
- In the United States, Friends sponsored a workshop "Working together: Families, Professionals and Friends for children, adults, families and clinicians."
- ISAD posters designs coordinated by Gregg Benedict have been distributed by Amy Johnson to the stuttering community energizing ISAD around the world.
- In Canada, CAPS and NSA co-hosted a one day symposium on stuttering for ISAD.
- In India, the Swar Sudhar Society initiated an ISAD celebration that saw parents and children sharing their views and experience.
- Proclamations declaring October 22nd as International Stuttering Awareness Day in communities such as Pittsburg, PA. and Buenos Aires, Argentina.
- Around the world, children have presented on ISAD and stuttering to their classes.

Those are some of the amazing events which communicated our stories about stuttering to others and invited dialogue, participation and change. For a list of events from 1998 to present go to www.stutteringhome.com and click ISAD online conference. Then search for ISAD events and click on it.

International Year 2004 Children who Stutter

Now I am going to turn to the future. This year has been designated by the IFA, ISA and ELSA as the International Year 2004 Children who Stutters.

As a child who stuttered, I did not know anyone else, peer or adult, who stuttered. I felt alone, embarrassed. There was no one I could relate to. However I was not

alone in this regard. Most people living with stuttering that I talked to felt the same way. As adults who stutter, there are many of us who want to end the isolation associated with stuttering and give back to the community. To reach out to help a child who stutters.

In 1996 the National Stuttering Association in the US held 10 workshops that brought together over 600 parents, children and teens who stutter and leading speech language pathologists. The NSA produced a book 'Organizing a Workshop' The handbook can be found on the internet www.mankato.msus.edu/dept/comdis/kuster/workshop/intro.html

The *International Year 2004 Children who Stutter* initiative seeks to inform parents, teachers and other professionals about the need for early intervention and effective treatment of childhood stuttering and to change how children who stutter are viewed by themselves and others.

- The British Stammering Association on October 22nd, 2003 launched a CD ROM on stuttering to be sent to every government school in England. Also, BSA launched a unique collection of poems, stories and drawings about how it feels to stammer: *When the words won't come*
- Korea celebrated its sixth annual ISAD on November 8, 2003 at Ewha Women's University. One hundred and sixty clinicians, students, and parents attended a Stuttering Children's Therapy Workshop.
- The ISA released a CD ROM at the ISA conference in Perth, Australia, on teasing and bullying to national stuttering associations to distribute to teachers around the world.
- 2,000 IYCWS buttons were distributed to national associations around the world.
- 500 IYCWS posters were distributed to national associations around the world.
- An international group for parents of children and young adults who stutter was formed.
- The IFA, ISA, and ELSA with the support of the national stuttering associations around the world and the professional community will sponsor community wide workshops for parents and children who stutter or summer camps for children.
- This year's campaign is to help speech language pathologist to have a child to speak to his or her class on ISAD, IYCWS and stuttering.
- The 2004 online conference will be dedicated to IYCWS with possible panels by parents and children.
- In sponsoring your events, feel free to use the IYCWS logo for brochure and website
- Follow the IYCWS 2004 on the International Stuttering Association website. Updates on events around the world will be listed there. Find out what is happening or what will happen, at www.isastutter.org

- To celebrate IYCWS we would like to invite all children who stutter to help create a mosaic of images and metaphors they use to describe stuttering, which will help adults and other children understand what it is like to stutter. This mosaic was inspired by "Stutter House" created by Sander, a 10 year old from Belgium to symbolize his stuttering. Sander used Lego blocks. All children are invited to send their ideas and images, either digitally to (Judith.kuster@mnsu.edu) or mail to J. Kuster, Communication Disorders, 103 Armstrong, MSU, Mankato, MN 56001, USA. Their work will be displayed as an online exhibition on next year's 2004 ISAD/IYCWS online conference.

- A first grader completed his class presentation on stuttering. His parents were able to go as well. It was a great success. He demonstrated smooth speech, bumpy speech and stretchy speech. The class asked questions about stuttering and he talked about famous people who stuttered. His parents were amazed at how calm he was speaking in front of an audience. He distributed 20 IYCWS and ISAD buttons to his classmates (Nov. 2003).

- Bulgarian Stuttering Association started a contest for paintings, poems, short stories, essays focused on stuttering. Presented the movie To Speak in a School, inviting the media. SIZ plans to organize and camp for stuttering children as well as to create leaflets and posters for IYCWS. SIZ plans to publish a book at the end of the year.

- On the occasion of its tenth anniversary, the Foundation for Stutterers in Budapest, Hungary asked for stone donations by its supporters and well-wishers. Stones can be adorned by any technique, paint, crayons etc. The stones will be put on display in September 2004. The senders of the finest pieces will get a prize on ISAD. There will be auction a fair and gala program when prizes are handed over on 16 October 2004.

The purpose of IYCWS is to carry out our mission—to connect with others who stutter around the world. I would urge you to join with other members of your community to get involved. Sponsor a workshop, talk at your local school, or post the Bill of Rights and Responsibility of People who Stutter poster up at your speech therapist office or room.

All of us, from different countries and cultures use different words to describe stuttering; *stammering* as the British call it, *begaiment* as the French call it, *amalimi* as the Zulu call it, *uu uus* as the Hawaiians call it or *yutamten* as the Arabs call it or *tid ang* as the Thai call it. But whatever word we use, stuttering is a unifying experience that brings us together from all parts of the world. It is that common bond that we can use to fight ignorance and discrimination and replace it with acceptance, civil rights and self determination.

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Keep on pushing, once at the congress, you will know it was worth the trouble!



Dr Moussa DAO
Bukina Faso

Will it be possible or not possible? Is it worth keeping on pushing?
These questions tormented me before my departure to Perth.

In fact, it was really troublesome to get my visa. It began in November 2003, when I sent my documents to our embassy in Nigeria for an Australian visa application. Despite my insistence, our ambassador used to say: “don’t worry you will get your visa in time”. Unfortunately, when he finally got in touch with the Australian embassy in January 2004, they said that visas were no longer delivered in Nigeria but in South Africa. I had only four weeks left before my probable departure. Yet visa approval should take several weeks. So the count-down started.

Stefan and the conference chair, Peter Dhu, encouraged me to try if there was any chance at all. After insistence, I finally got my documents from Nigeria on Wednesday 21st January (about 2 weeks left now). Peter sent me a email: “Be careful, for Burkina Faso, South Africa is wrong”. I then looked at the Australian website. After that, faced with confusion, I sent messages both to Australian embassy in Kenya and South Africa. There was a lot of confusion about where to send my visa application – to Kenya or South Africa. Finally I found out that it was to Kenya.

Kenya got my documents but sent me a message by telling that my application form was bad. So I had to print the good form and fax it as soon as possible. I did it on January 31 and on the Monday 2nd February, my visa was approved. Unfortunately Monday was holiday, so the day after, I informed DHL to ask their counterpart in Kenya to collect my passport. Besides Australian visa, I had to apply for Algerian transit visa. And the deadline for that was on Friday 6th.

By Wednesday afternoon, Kenya DHL had not replied. I embarrassed our DHL staff and sent a message to the Australian embassy and all agencies of Kenya DHL. By Thursday, still no reply from Kenya, so I called their boss and for about 20 minutes and explained the urgency of my situation. DHL Kenya collected my passport but promised that it will arrive around the 9th. So I contacted one member of our foreign ministry who asked the Algerian embassy to postpone my deadline to Tuesday February 10 at 4pm. On Monday, no plane because of the fog! Why fog at this moment? I felt very bad and was almost sick. DHL staff said: “the plane will arrive on the 10th at 10.30 am”. At this time they said: “come back at 3pm. The plane has a delay”.

At 3pm, they said that the plane has arrived but that I should wait a moment because there was much luggage at the airport. I got angry and threatened to go by myself at the airport and pick up my passport. Their boss personally went and looked for my passport for me.

I arrived in the Algerian embassy at about 4pm and their person in charge of visas said “I thought it was a diplomatic passport, you are really lucky, if you had met our boss be sure he would refuse to deliver the visa”. I got the visa at 6pm, and bought my tickets, went to my office until 8.30pm and went home for bath and then to the airport at 9pm.

By keeping on pushing, my participation at the congress became a reality.

Once again I overcome one challenge “In the field of stuttering nothing will stop me!”

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At Perth, I really enjoyed my room. Even though it was on the second floor, I would never have changed it for anything else. In fact it was like a little village made up of the world.

Far away from bad news in the world, we discussed, laughed and learned from each other.

Trips are a good school. They form people.

As promised by Stefan, once at the congress, I realised that it was worth all the trouble!

During congress, I noticed that stuttering is a reality every part in the world.

I was fascinated by people who stutter severely but have the courage to talk, discuss and participate at any debate.

*This conference
reinforced my
determination to keep
on fighting in the
field of stuttering*

I also enjoyed seeing that with courage and determination many people managed their stuttering.

My deepest finding is the fact that many aged people stutter too.

This conference gave me the occasion to do my first presentation in English, improve my English, and increase the number of friends around the world.

Stuttering is really a gift, thanks to him I had the chance to visit Australia.

That is really amazing.

I would not finish without thanking all generous donors who supported ISA to get funds for a scholarship

ANITCHE, ANITCHE , ANITCHE

(Thanks in Mandingo or Jula, one of the mostly spoken languages in West Africa)

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Stages of growth in

By Jaan Pill
Toronto, Canada

As a volunteer, I have been involved in the founding of the Stuttering Association of Toronto (1988), the Canadian Association for People Who Stutter (1991), the Estonian Association for People Who Stutter (1993), and the International Stuttering Association (1995). In this article, based on a keynote presentation at the IFA Fourth World Congress on Fluency Disorders in Montreal in August 2003, I will discuss what sociologists have learned about the stages of growth in self-help groups for people who stutter.

Volunteer work

I became involved with volunteer work a year after attending a three-week stuttering treatment program developed by Einer Boberg and Deborah Kully at the Institute for Stuttering Treatment and Research in Edmonton, Canada. At the Edmonton clinic, which I attended in July 1987, I learned to speak in a new way after many decades (starting at age 6) of moderate to severe stuttering. During severe stuttering, I at times could not make any sounds out at all. I like to say I learned fluency skills as a second language.

After I had learned those skills (and had learned how to maintain them), I began to make fluent presentations to large audiences. But I found it hard to adjust, psychologically, to the fact I could now readily engage in public speaking. I decided that, to help myself in adjusting to this new level of fluency, I needed to compare notes with others who stutter.

For that reason I formed a self-help group, the Stuttering Association of Toronto, in 1988. That marked the first step in my involvement with the self-help movement. Two years later, in 1990, I delivered a series of lectures in Estonia – in Estonian, my native language – discussing the self-help concept, and describing Western approaches to stuttering treatment. That led to the founding of the Estonian Association for People Who Stutter in 1993.

In 1991, I assisted in the founding of the Canadian Association for People Who Stutter. Around that time, I also served as chair of the support groups and consumer affairs committee of the International Fluency Association. This enabled me to establish contacts with leaders of national self-help associations around the world. In 1995, acting on my belief that people who stutter need to speak on their own behalf at the international level, I assisted in founding of the International Stuttering Association.

self-help groups for people who stutter

Research about self-help

In discussing self-help, I will begin by defining several key terms. Two major resources with regard to definitions and research about self-help are Tomofumi Oka at Sophia University in Tokyo and Thomasina at George Mason University in Fairfax, Virginia, USA. As Thomasina Borkman has noted, a widely known definition of self-help groups emerged from a national workshop on self-help and public health that the United States Surgeon General set up in 1987. At that workshop delegates arrived at a consensus regarding a definition of self-help groups. Starting with that consensus, and with minor changes in wording, here is a definition I like to use:

- Self-help groups are self-governing groups whose members share a common specific concern or situation and give each other emotional support and material aid, charge either no fee or only a small fee for membership, and place high value on experiential knowledge in the belief that it provides a special understanding of a situation.
- In addition to providing mutual support for their members, such groups may also be involved in information exchange, public education, material aid, and advocacy.

It may be noted that sometimes self-help group is used as a synonym for support group. Within the wider self-help movement, however, of which self-help groups for stuttering are an integral part, a consensus has emerged that a self-help group is a group controlled by its members, whereas a support group means a group where the ultimate responsibility for group management lies not with group members but with supporting professionals.

Extensive research has been conducted about self-help groups of all kinds, including for people who stutter. Thomasina Borkman has studied self-help groups for people who stutter for over 30 years. She has studied stages of growth experienced by individuals in self-help groups, and stages experienced by self-help groups themselves. For heuristic purposes, she has proposed a three-stage process to describe these stages.

For individuals, in Borkman's model we can think of a person progressing through one or more stages. The first is the Victim stage, where people feel shattered, vulnerable, and alone. The second is the Survivor stage, where members have moved to a stronger place where they feel confident of their experiential knowledge and recognize how their experience is helpful to others. A third, Mature, stage occurs for some people. They become certain of their experiential understanding over time and develop

experiential authority, which can evolve in two ways. Some people (the Thrivors) grow and thrive, continuing to learn and change while remaining flexible in their thinking. For others (the Dogmatics), the certainty of what they know from personal experience leads them to become dogmatic. Borkman also speaks of three stages of growth for self-help groups. First is the Fledgling stage, in which the group has no clear meaning perspective or frame of reference. Second is the Developed stage, in which the group has created a workable meaning perspective or way of looking at the world, and has developed an organized structure. The third, Mature, stage can take at least two forms: an Open Learning group, which remains flexible and open to new learning, and a Closed Dogmatic group where the meaning perspective is largely fixed and the group believes it has the ultimate "truth" about solving its problem.

Borkman has studied several American stuttering self-help groups that developed a meaning perspective focusing on avoidance-reduction and self-acceptance. More recently, the sociologists Michael Petrunik and Thomas Klassen have studied Canadian groups whose leaders are often graduates of fluency-shaping programs, and whose meaning perspective includes an emphasis on learning and maintenance of fluency skills, within a framework that also includes self-acceptance and avoidance-reduction.

Application of Borkman's model

Borkman's model suggests a framework that can assist us in reflecting upon the stages of growth in varied self-help associations. For example, I was impressed by remarks by Mark Irwin of Australia, chair of the ISA board of directors, at a panel discussion on self-help at the 1997 IFA Second World Congress in San Francisco. Many years ago, graduates of the Smooth Speech program in Australia formed a national self-help association, the Australian Speak Easy Association (ASEA). In its early years, ASEA was dominated by the philosophy of Smooth Speech and the speech professionals who taught this program. In recent years, however, ASEA has promoted a more expansive self-help focus, as a way to supplement the Smooth Speech pattern of speaking.

I would add that, in many cases, a self-help group that focuses on a particular treatment approach eventually begins to explore other approaches. This broadening of outlook is perhaps inevitable when people meet regularly, and compare notes about different ways of dealing with stuttering. Sometimes, as in the case of the Canadian Association for People Who Stutter, and the International Stuttering Association, a self-help association or network

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Stammering and school

‘Stammering and School’ project at the Bardoschule (secondary school) in Fulda, November 2003)

Volkmar Seibert

Bad Hersfeld/Fulda/Vogelberg self-help group

This project was held in cooperation with senior school staff and the regional stammerers’ self-help group in November 2003.

Initial contacts were made back in April 2002 in the run-up to the visit of the *Stammering and School* bus tour in May 2002. A discussion forum was set up, bringing together pupils, teachers and parents. The forum focuses on the exchange of information and experiences and on joint strategies for dealing with stammering in the everyday school situation.

In May 2003, senior school staff and the regional stammerers’ self-help group convened a working party to

lend further support to the discussion forum and publicize the subject of *Stammering and School* throughout the school. They jointly decided to hold the *Stammering and School* project in November in two modules.

Module 1: Lessons for 11- to 14-year-olds on 13th and 14th November 2003

The lessons started with a presentation of the stammerers’ self-help group and its tasks and an explanation of the structure of the national association. After this, we encouraged pupil participation by asking questions:

What actually happens when we speak? How does stammering arise?

What are the causes of stammering?

Some of the 11- to 14-year-olds were close to the mark with their answers:

Stammering is hereditary or results from a traumatic event.

During stammering, the stammerer runs out of breath or tenses up while speaking.

The less encouraging replies included:

Stammerers cannot speak fluently because of a brain malfunction.

The speech organs are damaged.

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determines at the outset that it seeks to offer an impartial forum for sharing of information, rather than being aligned with a particular approach to dealing with stuttering.

Bryan Hunt, active in the early years of the Association for Stammerers (AFS) which later became the British Stammering Association (BSA), has shared reflections concerning early years of the stuttering self-help movement in Great Britain (Edwin Farr, personal communication, Oct. 17, 1995). Hunt has noted that when it began in 1968, AFS focused on exploration of varied group therapies without professional input. The association took a more defined shape as a nationally organized self-help group in 1978, when self-help enthusiasts and a handful of interested speech therapists set up a formal constitution. This led to charity status for the association, the hiring of paid staff, and a substantial expansion of activities.

A particular area that warrants sociological analysis is the transition that occurs when a self-help association ceases to be an all-volunteer association and begins to hire paid staff. Paid staff can get more work done than volunteers, but their presence also changes the structure of an organization. As Michael Sugarman of the USA has remarked, “Once you have to pay people you change the whole framework” (Sugarman, personal communication, Aug. 10, 2003).

I have met several key people, including Laurent Bouchard of Canada and Frederick Murray of the USA, involved with some of the earliest international contacts among

people who stutter. Their insights are of much value to sociologists – as are archives from varied self-help associations. If you know of a person or group wishing to make their archives available for sociological research, please get in touch with me.

The Bill of Rights and Responsibilities of people who stutter

This is a strong statement regarding the human rights of the millions of people who stutter worldwide. It also sets out responsibilities of people who stutter to be resolute in increasing understanding about stuttering, in the creation of a just and compassionate world.

The Bill is the result of collaboration between two world-wide international organisations, the IFA and the ISA. Luc de Nil and Michael Sugarman spearheaded the work on the Bill; Ava Barbour of Barbour Design New York, provided the superb art work; and the IFA and ISA supported the efforts both spiritually and financially.

The Bill has direct relevance for ALL people who work with stuttering. Its sentiments stretch beyond stuttering to provide a basis for improving understanding of all people with communication disabilities. If YOU are concerned about improving the quality of life of people who stutter, and of people with communication disabilities, the Bill of Rights and Responsibilities will serve you well.

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By intervening appropriately it was possible to quickly dispel these assertions, and the following questions from pupils were answered with a clear "No":

Do stammerers stammer when thinking?

Do stammerers write the way they speak?

It was astonishing to see how quickly pupils lost their shyness about the subject in this didactic setting and showed a high level of interest. Some pupils talked about their stammering friends and that, after overcoming their initial uncertainty, they no longer find stammering a problem. And they also said that they help their stammering friends when nasty kids make fun of them. In this discussion block, it soon became obvious that children are far more relaxed about handicaps than adults.

Constitution Campaign

In another teaching session, we presented the *Constitution Campaign*, highlighting the *Stammering and School* project and statutory measures to offset disadvantages with reference to case studies.

We also presented different treatment forms, e.g. how symptom-free speech is possible by consistently applying a speech technique. Towards the end of the lesson, each pupil was given the opportunity in a one-to-one situation to discuss personal concerns and obtain information material.

With reference to the discussion forum and encouraging words for the frank treatment of stammering as a handicap at this school, the lesson was brought to an end with the following final sentence:

Let's talk together

and not about each other.

Let's laugh together

and not about each other.

Module 2: Parents' evening on 24th November 2003

In a letter, we briefed the parents of the 11- to 14-year-olds on the subject in advance and invited them to this parents' evening. Astonishingly, not only the parents of stammering children came along, but also parents with a general interest in the subject.

After a round of introductions, we first explained the tasks of the stammerers' self-help group and the structure of the national association.

As an introduction, we gave a talk on the speech process and on speech development in small children and made a clear distinction between speech dysfluencies and possible symptoms of stammering. It is very important that parents are able to counteract possible symptoms of stammering by taking appropriate remedial action. Unfortunately, many parents are given false advice by medical specialists at this stage of speech development, a fact confirmed by the parents of stammering children. It is important at this point to relieve parents of feelings of guilt and co-responsibility. To precisely define stammering, the primary and secondary symptoms were differentiated and explained in greater detail.

After this, parents reported on their own and their children's experience of stammering, with special emphasis on therapy experience.

How stammering is dealt with in the family and how people react to it was another important discussion point.

Make yourself a specialist

This was followed by the *Constitution Campaign* and the main theme, that of *Stammering and School* and the statutory measures to offset disadvantages. At this point, parents were encouraged to play an active part in dealing with the problem of stammering, i.e. become specialists themselves, seek contacts with headmasters and teachers, and if necessary claim their statutory right to measures to offset disadvantages.

Parents were also encouraged to make the future choice of job dependent on the child's actual abilities and not on stammering.

Towards the end, the current range of treatments was presented.

The evening was rounded off with a few one-to-one conversations on matters of personal concern. Information material was also made available.

The parents' evening was brought to a close with reference to the discussion forum and the following encouraging final sentence.

*Let's learn to understand stammering
and learn to understand the child.*

It is worth mentioning that the project was announced on a regularly updated notice board near the school offices. This made sure that all pupils and teachers were aware of the project.

Special thanks go to the Bardoschule's senior school staff for making the project possible.

After a thoroughly positive evaluation of the 2003 project, the school's senior staff and the regional self-help group have agreed to hold another project in 2004.

An invaluable source of ideas for South Africa

**Dina Lillian
South Africa**

The world congress was an experience that I will never forget, both as a speech pathologist and a person who stutters. The four day congress was filled with diverse, enlightening and entertaining speakers ranging from research presentations to belly dancing. The days were filled with interesting, charismatic and sometimes controversial speakers while the evenings provided opportunities to mingle with other delegates at some of the exotic restaurants in Fremantle. The atmosphere of the congress was at all times friendly and the organizers – Peter Dhu, Pippa and the team – ensured that every last detail was taken care of.

From a professional viewpoint, the congress provided me with an opportunity to learn about different programmes

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Fremantle is one of the sunniest places in Australia. Watching the sun go down over Fishing Boat Harbour, you could look forward to sunrise the next morning, even if the 37 degree temperatures drove delegates into the air conditioning of the congress venue.



Vacancy: Editor of One Voice

Andrew Harding of the Australian Speak Easy Association, now working with the British Stammering Association, who has edited the past five editions of One Voice, has decided this will be his last issue.

Andrew has always carried out his work in an extremely professional manner as befits his training as a journalist. Andrew ensured One Voice remained a comprehensive, accurate and interesting newsletter while adding some new concepts in layout. His work is very much appreciated by the ISA Board and I am sure by the stuttering community in general.

Mark Irwin (ISA Board Chair)

Anyone interested in helping the ISA by taking on this role should contact the ISA via Board Chair Mark Irwin mirwin@cobweb.com.au. Information about the position is below.

The purpose of One Voice is to provide news and ideas that can be shared between all member associations to improve the effectiveness of their work.

The editor should have the following skills and abilities:

1. Experience in editing a newsletter or magazine, or the ability to create a publication for a specialist readership.
2. Experience in desktop publication and good access to email and desktop publication software.
3. High level of editing and proof-reading ability to ensure that articles are well-written in standard English with a high level of accuracy.
4. Good organisational skills to plan a production schedule for each issue.
5. Good access to the email and internet to co-ordinate the editorial process as almost all articles are received by email.
6. Experience in photo sourcing to ensure images of high quality are received from contributors.

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and methods of stuttering therapy used overseas. It introduced me to different perspectives and outlooks of the etiology and management of stuttering. As the co-chairperson of Speakeasy South Africa and a presenter of the research conducted by Nola Watt and myself entitled 'the perception of people who stutter towards self help groups', I feel that it was very important and beneficial to compare the structure and state of self help groups globally to South Africa and to exchange and share ideas of how to enhance and maintain these groups.

As a person who stutters, I feel that I gained personally from conversing with others and sharing experiences, trials, tribulations, successes and failures. Hence, I have made wonderful new contacts and friends with whom I shall hopefully remain in contact. As a bonus, I was also able to visit the beautiful city of Perth and explore the historical town of Fremantle.

I thoroughly enjoyed the congress and will relay some of the invaluable experiences and information about stuttering to the self help group in South Africa. At times Speakeasy South Africa feels isolated from the rest of the world and therefore contact with similar groups internationally is most welcome. I hope that with the support and advice of other countries and the ISA, the availability of speech therapy for people who stutter, basic education about stuttering and maintenance of self-help groups will improve in the years to come. On behalf of Speakeasy South Africa, I would like to thank the organizers of the congress for a job well done!