

One Voice



International
Stuttering
Association

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

European League of Stuttering Associations



Edited by Jianliang Zhang, jz1208@ecu.edu

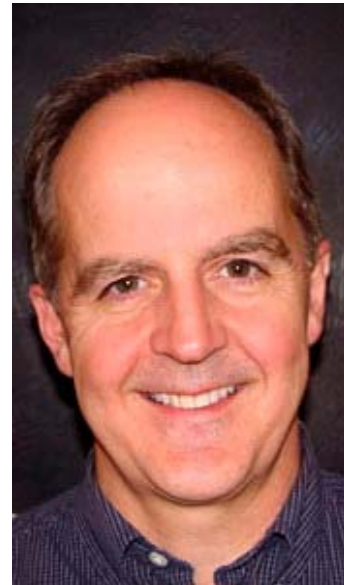
A world that understands Stuttering

Message from the Board Chair

What would you say if a television crew came to you and said “What do you want the general public to know about stuttering?” The ISA is the umbrella organization for other international and national stuttering associations throughout the world. It does not seek to form consensus views rather to leave it to national associations to present their own perspective. However in the interests of stimulating discussion in these groups I would like to present how I responded to this question when it was asked of me during television interviews in Cameroon and Kenya last year.

I gave the following information:

- ◆ Stuttering otherwise known as stammering is more than just dysfluent speech. The hesitant speech or overt stuttering the listener hears is just the tip of the iceberg. Below the surface often lie feelings of shame and embarrassment which are accompanied by fear of social encounters. In addition there may be varying degrees of covert stuttering, that are word avoidance, substitution, and circumlocution, which are used to hide the overt stuttering behaviour. A shy, quite child may be hiding a stutter and it is important for teachers to recognise this.
- ◆ The cause of stuttering is unknown although it appears to have a multifactorial origin with current research suggesting 70% environmental and 30% genetic aetiology.
- ◆ Treatment for the very young (before age 6) appears to be reasonably successful although thereafter, with increasing age, it seems recovery is far more difficult.
- ◆ Amongst other things it seems recovery from stuttering requires personality restructuring and a support network. Some people do not or cannot make the required changes and, rather than follow a recovery path, choose to move to a path of self-acceptance as a person who stutters. The



Dr. M. F. Irwin, ISA Board Chair
217-9 Payneham Rd. St. Peters, SA 5069, Australia

International Stuttering Association regards either path as valid.

- ◆ The general public can support people who stutter by being a partner in the communication process rather than a judge. It helps if people listen well, smile, and make eye contact.

I hope this message will help with awareness raising by national associations

Looking forward to seeing as many of you as possible at the ISA World Congress in Dubrovnik in May next year, where awareness issues can be discussed further.

Best wishes

Mark

PS. On the subject of awareness raising ISA's special thanks are due to Masuhiko Kawasaki (Japan) for the Stuttering Essay Contest initiative, to Moussa Dao (Burkina Faso) and Anne-Marie Simon (France) for their recent work in Togo, and to Keith Boss (UK) for his work to develop an Indian Stuttering website.

Editorial - European League of Stuttering Associations (ELSA)

The last 6 months have been quiet for the European League of Stuttering Associations (ELSA) regarding our liaison with the National Stuttering Associations. However, there has been the following background work carried out by the Board of ELSA and volunteers.

In October 2005, ELSA's joint initiative with TTM Espana (where we successfully held a reception at the European Parliament, and the Members of the European Parliament endorsed a statement on Stuttering and the International Stuttering Awareness Day) has led to an increase in ELSA's work with TTM Espana.

Together with TTM Espana and eight other organisations, we made a funding application to the EU under the 5th Framework (Research & Development). The application was to research and develop the use of mechanical aids to help people who stutter. We felt that this was a huge opportunity for raising awareness of stuttering and for the research into the benefits, if any, of the various mechanical aids available. There was much debate within the Board of ELSA as to whether this type of activity was right for us, and because of this we consulted worldwide as to whether our organisation should be part of the consortium bidding. We eventually decided that we should, however, the consortium of ten organisations were narrowly unsuccessful. The European Commission praised the good aspects of the application but sadly there was not enough money to go round. We now await the call for proposals from the 6th Framework funding.

The month of May saw ELSA represented at the European Disability Forum Annual General Assembly, held in Rome. Two delegates attended - Irina Papancheva from Bulgaria and Milena Michele from Italy. Early reports from both of them indicated that there is still a lot of work to be done within the disability field to

raise awareness of stuttering and the impact that stuttering has on peoples' lives.

Going back to ELSA's work with TTM Espana, ELSA and TTM recently agreed an initiative to look deeper into stuttering self help in Portugal. Currently ELSA does not have any representative association from Portugal. Accordingly, TTM nominated Rafael del Castillo Gomariz from Seville. Rafael has done good work in identifying some small self help groups in the region of Coimbra, additionally a speech and language therapist interested in stuttering has been located in Lisbon. ELSA and TTM Espana are currently looking at ways to make further contact with these groups.

Currently work in hand as of June 2006 is the ELSA Annual General Meeting, and possibilities for an ELSA 6th Youth Meeting to take place in conjunction with the World Congress on Croatia May 2007.

In all my previous editorials I mention the work done by volunteers across Europe (and indeed the world) to help improve the conditions for people who stutter. I repeat again how this is so important to raising awareness of stuttering. To all of you who are volunteering your time, please continue, and to anyone else interested - please contact your national stuttering association or ELSA, all offers of help are gratefully received.

When you read this the European summer will be nearly over, I hope you all had a good summer and a break from your work and routine to refresh you for the coming autumn and the end of the year.

I look forward to meeting many of you in Croatia in 2007

Best wishes
Edwin J Farr MBE, Chair of ELSA

Message from ISA Outreach Working Group *India Initiative*

By Stefan Hoffmann

As usual, a few words from me about the Outreach activities of the ISA. Since the last report, the main news is the increased activities in South Asia. Working Group member Keith Boss from Great Britain has taken over the task of co-ordinating efforts in India and Pakistan and if coming up, Afghanistan and Bangladesh. This part of the world is most densely populated, and people who stutter should be quite frequent. Due to the economic situation professional help is likely to be often unaffordable, if available at all. The goal of the initiative is to use the web to make contact to stutterers, therapists, and other persons interested in the field, and introduce to them the self help concept. Mid term goal is to have people organise themselves in their state, and as a long term goal the establishment of The Indian Stuttering Association (TISA). The approach ISA took in China in the 90's was similar and it is hoped that the result can be also called a success in a few years. Please check the Indian Website at www.indiastammering.com. ISA is grateful to Keith for his dedication and attitude.

From China we can report an event that happened in May. ISA Honorary Member Prof Judy Kuster was on a private trip to China. In some spare time during the stay she met with people from Beijing and Shanghai Stuttering Associations for exchange of ideas. Judy Kuster is also well known among Chinese Stutterers for the online conferences for ISAD, where Chinese people have published articles in the past. It is good that a personal contact has been made.

How personal contacts bear fruit in the future also shows another example. Barry Ma who is now studying in US took part in the Ghent Congress in 2001. As did Carlos Pimentel Ferrari from Peru. Barry informed me in March

that he is going to visit South America for a field study about fluency disorders in June 06. It may well be that both will meet in Lima and renew their contact. It shows how beneficial personal meetings can be when a common issue like stuttering passes cultural and language barriers. So everyone is invited to the next World Congress in Croatia in early May 2007.

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



Prof. Judy Kuster (left) was giving a presentation to Shanghai Stuttering Association. Albert Zhang (right), editor of One Voice, acted as the translator.

Thanks to Stuttering Foundation of China (www.okoci.org) for the photo.

ISA Stuttering Essay Contest

By Masuhiko Kawasaki

I believe that one of the most important roles of stuttering self-help groups is to provide opportunities for their members to share their ideas, feelings and experiences with each other.

If a person who stutters is always disturbed by stuttering and feels isolated, the person will find it difficult to find a breakthrough. If the person reads essays written by other people who have similar experiences, the person may feel that he or she is not alone.

We all have some painful experiences in life. Through writing about our experiences, we are able to organize our thinking and broaden our perspectives. More importantly, by sharing experiences with each other we can have a more objective view of our stuttering.

At the time of publication of this edition of One Voice, the International Stuttering Association board was considering a proposal to hold an international stuttering essay contest every three years.

According to the proposal, the contest would be held in the year before an ISA World Congress.

The ISA would recommend the stuttering essay contest to all member associations, supply the judging panel, and publish the finalist essays in One Voice and on the ISA website.

The member associations would conduct their own contests, promoting it to schools and speech-language therapists as they wish. Judging would be based on the clarity with which an individual's experiences, feelings, and ideas were expressed.

While therapists and therapies might be mentioned, the essays were not to serve as recommendations or testimonials for particular therapeutic techniques.



Masuhiko Kawasaki
ISA Board member

No prize money would be offered. However, the winner might be granted free registration to the forthcoming ISA World Congress.

If the proposal was accepted, the contest would be open not only to those who stutter but also to parents and siblings of children who stutter, and to spouses of people who stutter.

The program of recent world conferences on stuttering certainly gave us many opportunities to hear lectures by researchers and clinicians as well as reports by self-help groups worldwide. But I have a feeling that many of those who stutter felt that they did not have much time to share their personal experiences with each other.

I believe that one of the important goals of self-help groups should be to explore ways to live fully and to grow as people who stutter, rather than seeking "Cure" in vain.

If the proposal is passed, the contest guidelines might include:

- ◆ Language: English (Translation by computers is not acceptable.)
- ◆ Length: No more than 1000 words.
- ◆ Each self-help group selects two essays in the group and emails them to ISA.
- ◆ The author's name, self-group's name, and country name should appear on the cover of the entry.
- ◆ Submission due date: February 28, 2007.
- ◆ Screening method: ISA board and advisory board members would read all the essays by March 31, 2007. Each member would select three essays in early April, then the three top essays would be selected. First, second, and third prizes would be determined through voting.
- ◆ All the essays submitted to ISA would be printed and displayed at the world conference in Croatia (except for the ones obviously meant for advertisement of



Picture is from Stuttering Homepage.
<http://www.mnsu.edu/comdis/kuster/Creativeexpression/heite.html>

therapy) for conference participants to read freely.

- ◆ The ISA chair would announce three winners at the world conference.
- ◆ Winning essays would be printed in One Voice and publicized on the ISA website
- ◆ This contest would be held during the world conference every three years.

Shinji Ito, a former board member of the ISA, commented: "I'm sure everybody will agree that sharing is one of the main objectives of self-help groups – sharing of experience, feelings, and ideas.

"We proposed this stuttering essay contest from our own experiences in our group (the Japan Stuttering Project), as we aim to share individuals' experiences, feelings, and ideas as persons who stutter, based on the attitude that we should accept ourselves as who we are and live fully with stuttering.

"In our group, those who have read these essays were deeply touched, felt empathy, and were inspired to live their lives to the fullest with stuttering.

"Our group aims to make this essay writing mutually beneficial, without confining it to individual members' personal experiences, so that members may learn from each other's experiences, have opportunities to reflect on themselves, and share wisdom with each other.

"I believe that self-help groups should operate their own initiatives, free from the influence of clinicians and researchers on stuttering.

"In this regard, this stuttering essay contest should only serve for the benefit of people who stutter to help them achieve their personal growth," Shinji Ito said.

Message from Croatia

This is a very exciting time for our Association - we are busy planning the 8th World Congress for People Who Stutter. This will be held from the 6th to the 10th of May, 2007, in Cavtat – Dubrovnik, Croatia. We were delighted to be awarded the Congress at the last meeting in Australia and we have been working hard to make it a success. The President of Croatia, Stjepan Mesic, has agreed to support the Congress - a great honor. The venue for the Congress, Hotel Croatia in lovely small town of Cavtat, only 19 km from Dubrovnik, is most attractive – we are sure all the delegates will love it! You can see some details about the hotel here:

<http://www.hoteli-croatia.hr/html/location.html>

Before the Congress there will be several workshops by Dr. Trudy Stewart (St. James University Hospital, Leeds), Frances Cook and Willie Botterill (Michael Palin Centre for Stammering Children, London), and others. During the Congress we will have a very full schedule, but also plenty of time for delegates to meet and talk with each other. Speakers will include Mark Irwin, Rachel Everard, Mark Onslow, and many other experienced people who stutter and speech therapists. We are also delighted that the Croatian singer Zlatan Stipisic, better known as Gibonni, will attend the Congress. He is a person who stutters and a UNICEF Goodwill Ambassador. We also have several trips arranged so everyone can see more of our and neighboring beautiful countries. These include trips to the old city of Dubrovnik, Mostar and Neretva river delta, Konavle and Monte Negro.

There will also be a gala dinner at the Revelin Fortress in the old town of Dubrovnik. The musicians will play Renaissance music on original period instruments, the dancers – all dressed in beautiful Renaissance costumes – will perform a number of Renaissance dances.

After dinner, a dancing band will entertain us till late hours. If the weather permits, the whole event will be on the magnificent terrace of the Fortress, illuminated by torches.

Registration for the Congress will be handled by ATLAS, a well-known travel company. To be put on the mailing list to receive further information please email hinko.freund@kdb.hr

We look forward to hearing from you and seeing you in Croatia in 2007.

By Suzanne Jelcic-Jaksic (Convenor)
The Croatian Association for People Who Stutter "Hinko Freund"



[Hotel Croatia, from www.hoteli-croatia.hr](http://www.hoteli-croatia.hr)

Report from National Stuttering Association

Since our last report to you in the Volume 20 issue of *ONE VOICE* in December, 2005, America's National Stuttering Association (NSA) continues to change, and refocus its coordination and delivery of services to emphasize key consumer groups where the greatest need, benefit, and potential for growth is perceived.

Our Director of Operations and Membership, Tammy Flores, has indicated that she will be resigning from this position in October in order to pursue other personal goals. We thank Tammy for 12 years of dedicated service to NSA. The Board of Directors is currently seeking qualified candidates from which to select a new person to perform this function, at a time when our national office is receiving more telephone calls and delivering more support to families than ever before. The headquarters of the organization will remain at its current location in New York City.

At its winter meeting in February in Long Beach, California, the Board of Directors approved a plan to focus NSA's outreach efforts toward two significant service consumer groups: family programs and speech language pathologists. The Board voted to approve two new part-time positions to strengthen our relations and interactions with these two groups. Increasing our emphasis on activity in these two growth areas will further enhance our ability to help more and more people who stutter—especially children and their families.

Nina-Reardon Reeves, an SLP from Frisco, Texas, will be the National Family Programs Administrator on an interim basis. She is the wife of Lee Reeves, who was a former Co-Chair of the NSA. Nina serves several school districts in the Dallas area and treats children and adolescents in her private practice. She presents continuing education training workshops in stuttering for SLPs around the United States,

and has authored and co-written various materials for NSA and other publishers, including NSA's very useful book, "Bullying and Teasing: Helping Children Who Stutter." Nina was a member of NSA Board of Directors and currently serves on the Family Programs Committee.

Kristin Pelczarski, M.A., CCC-SLP, will be the National Professional Relations Administrator. She works with pre-school and school-age children and adolescents who stutter at the Children's Hospital of Pittsburgh, and is a candidate for doctoral degree in the Communication Science and Disorders Department at the University of Pittsburgh. Her research interests include phonological encoding and other linguistic and motor factors involved in stuttering. Kristin is a member of NSA, the International Fluency Association, and the American Speech-Language Hearing Association's Special Interest Division 4 (Fluency Disorders), and has recently submitted her application to become a board recognized specialist in fluency disorders.



We are on track with all planning and scheduling for our upcoming 23rd Annual Conference in Long Beach, California, from June 28th to July 2nd. We will have many great workshops, seminars, tours, and other events.

This year our keynote speakers will be Dr. Gerald A. Maguire and, possibly, Bruce Jenner. Dr. Maguire is an Associate Professor in the Department of Psychiatry at the University of California at Irvine, and he [will discuss with his fellow NSA members not only the latest in research investigating pharmacological treatments for stuttering--including recently announced preliminary promising trials indicating reduction of severity of stuttering with the medication Pagoclone--but also his own personal journey as a person who stutters.](#)

We look forward to continued growth, outreach, and service to people who stutter in America in the year ahead, with a new Director of Operations and Membership in place this fall, and planning underway for our 24th Annual Conference in the summer (June/July) of 2007 in Atlanta, Georgia.

--Lou Madonna

*Philadelphia NSA Chapter, USA
NSA News Online Team*

Self Help in the Netherlands

The secretary of the Dutch "Demosthenes", the association which represents people who stutter, asked me to write something about self help in The Netherlands.

As I have been involved in self help groups for quite a number of years I can relay some of my experience with these groups.

I think that the first self help groups started in the 1970's together with a new form of therapy, which involved residential periods of therapy, and included learning to deal with negative emotions, relaxation, and speech training on social skills, which was quite new at the time. I became involved in 1993. There were two self help groups in Rotterdam at that time; one of them concentrated mainly on the social and emotional aspects of stuttering, the other put the emphasis on the acquiring of speech techniques. Some of us frequented both groups; some of us frequented the group which was most appropriate for us at the time. I was always in the "speech technique group". Following a more or less fixed routine we practiced speech techniques we had learned in therapy. We used to start with relaxation exercises, and then we would discuss our individual goals and how we had fared during the previous weeks. During the break we had time to socialize. After the break we would practice group discussion.

The objectives of self help groups were: emotional support from fellow sufferers, acquiring better speech techniques and gaining more confidence in one's social and private life. For me being involved in self help groups helped me because it gave me emotional support and it helped me acquiring a better speech technique which enabled me to do the work that I have always wanted to do, which is social work.

There have been quite a number of self help groups throughout the country functioning more or less along similar lines, over the past three decades. "Demosthenes" would also organize a self help weekend once a year.

However, over the last few years the concept does not seem to be working as well as it used to. In our search for a new way to involve people who stutter in self help, several initiatives have developed; for example the "speaking circle groups" and the StotterCafe, an informal meeting place for people who stutter (The Cafe for People who Stutter).

I hope that together we will find new ways of involving people who stutter because of the benefits and the support it can bring and to help us in our aim to get maximum fulfillment in our professional and private lives.

Sjanie van Gelder
Rotterdam.

Message from Germany

The BV will definitively buy an office in Cologne in June or July 2006 as investment for the future and the children of our children. There is no problem any longer in the finance plan. Most important part of the finance plan is the fact that 50% of the costs are specially supported by a special handicap umbrella organization. They are able to support the BV in this way, because the BV office is the only stuttering information centre in Germany. Future costs every month are the same as the BV had to pay for renting their old office during the last 12 years.

On ISAD October 22, 2005, there were many interesting projects in Germany. We want to share with you the following new one: a classic orchestra charity concert in Altenkirchen to help stuttering children. It was organized by a self-help group of this region especially by the stuttering husband of a violinist and his family. The chair of the German association took part as well as some politicians from this area. A wonderful concert, a wonderful event, and a wonderful idea. A concert to remember.

The very new Board of the German association is:
Chair: Christoph Lotz, lawyer.
Vice chair: Matthias Losert, law student.
Finance chair as years before: Dr. Reiner Nonnenberg, tax advisor.

An expanded working group, "stuttering and school", was founded in April at the 2006 Future Workshop of the BV. One main goal of the working group is for the very near future: there should be at least one teacher at every school who takes intensively care at the stuttering pupils. Another goal is that kindergarten should be developed better concepts relating to stuttering, especially relating to Early Intervention. The campaign should be started by sending letters to all leading politicians in our country in autumn or winter.

Greetings from Germany

Thomas Krall

Message from France

Association Parole Begaïement has been able to complete 2 major projects during the past 12 months.

The first one was initiated in Mid 2005, where the French Ministry of Health granted €10,000 for the publication of the new edition of the 40-pages booklet "Prevention of stuttering for the child". This made possible to print 10,000 copies and make them available during the meetings organized all over the country on October 22nd for the International Stuttering Awareness Day. A second grant of €10,000 has been allocated in April of this year to pursue the project, and will be used to distribute 10,000 additional prints to Speech Pathologists and Paediatricians.

The second outstanding event took place on 17th and 18th of March in Toulouse, where 350 persons attended our 4th International Congress, under the theme "Stuttering and Art". As you probably know Association Parole Begaïement has the particular nature to bring together Speech Pathologists and Person Who Stutter with exactly the same status. This was fully reflected in the programme where lectures and workshops were given alternatively by persons from both groups.

During 2 full days, more than 20 sessions and 10 workshops were offered to participants. Furthermore, we were very proud to have with us a large delegation from Africa, among them Joseph Lukong and Moussa Dao. Those 2 days were really memorable in all aspects: presentation of therapies, discussions on research, stuttering awareness, and socializing events.

By Olivier Humez
www.begaïement.org

How do the stutterers in Lithuania live now?

There are two books in one edition translated and published in Lithuanian. These are: "Stuttering: an integration of contemporary therapies" by Stuttering Foundation of America (SFA), published on No. 16, 1999 and "Counseling those who stutter" by SFA, published on Nr.18, 2000.

Lithuanian stutters already have 12 SFA books - seven of them are already published and five already translated into Lithuanian, and I am waiting to be financed.

Lately two self help groups have got interested in oratory art. Sandra, a young teacher of scenic language who works in Lithuanian music and theater academy, is giving lectures and practical assignments for young stuttering people in Vilnius and Kaunas for they can easily speak on the stage. The idea itself is not new, but young people know almost nothing about it and not everyone would dare even think about standing on the stage and speaking fluent.

There are a few computer programs for stuttering correction. It is almost a year since **BreathMaker** appeared in Lithuania and rouse aggitage. According to the internet information (<http://www.dictor.ru>) this program is designed to teach the broadcasters first of all. Its effect on stuttering people was noticed by accident. I have seen the demonstration of this program; I have spoken into the microphone and have listened to young people who have followed this program for a few months. The effect is impressive.

The methods and programs are interesting and are based on blocking the Broca's centre in the brain (in the brain of stuttering people this center is too much stimulated). I believe in qualification and good intentions of specialists from Moscow as well as the effectiveness of the program. The only thing that makes me doubt is its very intensive marketing actions. Neither me nor Lithuanian speech therapists can not believe in advertised "effect of the program - 95-96%" (indeed, later it is clarified that stuttering people should work with qualified speech therapist to reach the result). We all know very well how hard

stuttering is to remove and we worry that in the case of failure a lot of stuttering people might get disappointed again. And we still want to believe...

There is a big interest in this program. Almost everybody has a computer, especially young people. Unfortunately only few can allow buying this program and trying it out. The costs of a program are equal to average monthly salary.

But market is market. There are speech therapists in Lithuania who have been taught to work with another Russian program - **Demosthenes 03** (<http://www.zaikanie.ru>). This program is analogical to British program **Speech Helper** (<http://www.speechhelper.com>) and it is twice as cheap.

One of the authors of BreathMaker wrote to me that the English website is almost done. Maybe it is already working?

I wish success to everyone who is going to try this new method!

Vidunas RAMSA, Ph.D.

President of Lithuanian Stuttering Problem Club



Message from Sweden

After a long and cold winter, spring has finally reached Sweden. The SSR has had its annual year congress with a new board, new ideas and new challenges. On the second day of the congress, we learned more about the UN standard rules for people with disabilities, a very important document we need to forge, as it has been ratified by many countries all over the world and as such it is a working tool for all of us. Our new chairman of the board is Anita S Blom. You can reach her at anitablom@telia.com, address: Vattlosa, Kallaker, S-533 91 Gotene, Sweden, ph. +46-511-51504 fax +46-511-50535

Our first board meeting was held in Stockholm May 4-6, and as there are both new and young (!) board members, we chose to have a Sunday course about the do's and don'ts for board members, which made the board innovative, involved and interested in each other personally, and gave us a great start. An important start, as 2006 will be a busy year for us here in Sweden, as we have elections this year. We need to get the political attention and plan to reach out to all decision makers, locally as well as nationally. For example, write interpellations and declarations, visit our new school minister after the elections, and to inspire

the local self help groups to become engaged in local (disability) politics. And the rules for national support and funding are getting tougher every year, so we need to focus on fund raising from other sources.

We also want to put focus on children and young people with focus on the children's situation in school. A place was our children spend many hours a day. A place where everyone should feel safe. We are planning new brochures for school teachers, and parents as well as other new brochures and a survey to learn more about how parents experience the situation of children in school. This year we shall have two family camps. One is for new families, with stuttering children 7-12 years old. And later on, in the autumn a reunion camp for families that have attended our camps under the years 2000-2005, as it is important to meet again, and follow up the stuttering problems. For our young members we will have our yearly camp as well as a youth congress, called Stand Up! A special congress to build up your self confidence and to become active to change your situation by speaking up and become active within the self help groups. A member congress will take place in the autumn, where we hope to meet the chairmen from all our 16 local chapters as well as others, including members from our brand new chapters. In October the SSR will attend a two days' congress for speech therapists. This year's theme is speech problems children 0-8 years old. We also try to get more interest from the local and national media.

In the next issue of One Voice we will tell you more about our progress. Please don't hesitate to contact us.

Kind regards,

Kim Lindbom-Carlsson
Parents and children issues
SSR



Stuttering Can Be a Friend or a Foe
Submitted by Kristin Chmela
Taken from Stuttering Homepage

Message from New Zealand *Academic links anxiety with stuttering*

Members of the New Zealand Speak Easy Association met in Dunedin on April 28-29 for their national conference.

The main speaker was Associate Professor Ross Menzies, head of the Anxiety and Stress Research Team in the School of Behavioral and Community Health Sciences at the University of Sydney, Australia.

Prof. Menzies said the link between anxiety and stuttering was controversial. Research had shown that anxiety was clearly involved for 97 per cent of those who stutter. But it was hard to measure that anxiety in the laboratory.

He noted that when people who stutter talk to their pets they never report any stuttering. He said that behavior requires an explanation, as those people are not having a speech motor problem. He suggested that small doses of anxiety could trip the stuttering mechanism.

The other speaker at the conference was J. B. Munro, a former Labor member of Parliament and a long-time worker for the IHC which helps those with intellectual disabilities.

He spoke about his work with Inclusion International, for which he is the Asia-Pacific regional coordinator, and about the leadership New Zealand is showing in the United Nations in the writing of "the convention on the rights of people with disability".

At the conference, Ian Taylor was elected president of the New Zealand Speak Easy Association. He is a retired medical pathologist. Those who were in Perth in 2004 for the World Congress for People Who Stutter might have heard him speak about his life.

Dave McGuire, head of the McGuire Programme, was in New Zealand on May 17-21 to evaluate four instructors at latest course, in Palmerston North. The course attracted 12 new students and 32 returning graduates.

Chris Bland, Peter Kidd, Dan Tuohy, and Bruce Whitfield have become the first New Zealanders to be certified course instructors for the McGuire Programme.



Attending the four-day McGuire course in Palmerston North in May were (from left): Bruce Whitfield, winner of this year's New Zealand Speak Easy oratory competition; Ian Taylor, president of the New Zealand Speak Easy Association; Dave McGuire, head of the McGuire Programme; and Chris Bland, regional director of the McGuire Programme (New Zealand).

Three Major Accomplishments

The Japan Stuttering Project has been collaborating with researchers and clinicians who specialize in stuttering, while working on its own self-help activities. Three of the following projects, which we completed recently, demonstrate such collaboration:

1. Shinji Ito published a handbook, "FAQ on Stuttering", for parents of children who stutter. He also coauthored a textbook with a Japanese speech pathologist "To Live With Stuttering, Freedom From Therapy", targeting speech therapists in training.
2. A major TV broadcasting corporation in Japan televised the JSP's 16th summer camp in which 140 children who stutter, their parents and siblings participated. Some children were shown in the documentary declaring with a big smile "Now I feel it is all right to stutter." The JSP made a DVD and a video tape documentary under the title "Learning about Stuttering" covering the camp and our self-help group meetings, which were also televised by the national broadcasting corporation several years ago. Now 500

copies are on sale.

3. Last spring a new handbook "Support for Children Who Stutter: Practice by Special Speech Class Teachers" was published by 14 school teachers working with children who stutter in the public school system. This handbook is an exercise book for both teachers and children, designed to help children face their stuttering and accept who they are and to live with their stuttering. For example, a question "What kind of jobs do you think people who stutter have?" is posed to the children in the book as well as other exercises to help them develop their communicative skills, self-esteem, and the ability to express themselves.

These three projects advocate the JSP's philosophy that stuttering is not a matter of cure but a matter of how to live fully with the condition.

By Shinji Ito
Executive Director
Japan Stuttering Project



Message from Ireland

The Irish Stammering Association is currently putting forward a proposal to the National Health Service for a national "Centre of Excellence" for people in the whole of Ireland (North and South) to assess and treat people of all ages who stammer. The Centre will be run by Specialist Speech Therapists who will provide individual and group work, intensive courses, parents groups and advice for Therapists in all parts of the country. The need for such a Centre is vital to treat the disorder in the very early stages as research has proven that stammering can be greatly reduced if treated under 5 years. Maria McDonnell and myself already run intensive group courses for parents, teenagers and adults (the "Patmar Programme") twice yearly with very successful results and these courses should be provided on a national

basis. Research currently being carried out by myself which will show that children can be successfully treated under 5 years and not only frees children from the possibility of a lifetime of stammering but is extremely cost- effective to health service providers. We currently have no "Specialist" posts in the Irish Republic and this needs to be addressed but the Centre can offer training for both therapists and students as well as carry out further research into the disorder. We hope our proposal will be successful and I will keep the I.S.A. updated on future developments.

Patrick Kelly,
Senior Speech and Language Therapist,
Chairperson, Irish Stammering Association.



From left to right:
Willie Botteril(Michael Palin Centre, London);
Prof. Ivan Perry(University of Cork and ISA member);
Norbert Lieckfeldt(British Stammering Association);
Mary Harney(Deputy Prime Minister of Ireland);
John Sutton(ISA Committee);
and Patrick Kelly(Chair ISA).

Message from Argentina



Work Group A.A.T

The Argentinean Stuttering Association keeps working on raising the stuttering awareness, and on participating in our association of the people who stutter as well. We have a lot of projects this year. A.A.T. organized a meeting on May 13th, which was the therapist of speech's day.

This meeting has meant a very important exchange between people who stutter, therapists of language, and special education teachers and students. It was a very interesting moment of integration.

We are working on a newspaper. It's a new project that will enlarge the participation and spread the awareness of stuttering.

A.A.T. is planning for the October 22th - the International Stuttering Awareness Day. At present we are assisting therapists of speech who want to devote themselves to working on stuttering. They are preparing themselves in practical and theoretical knowledge.

We need a lot of money to carry on with our work.

We are trying to find a place to be our headquarter. It's a very big necessity at the

moment because we are developing a lot of activities, such as meeting of self help groups, courses for psychologists, therapists of language, parents, teachers, free consultants, workshops, etc.

It's very important to us to share aims with ISA. The people who stutter here in Argentina need this contact.

We know that the massive participation in our country has not taken place so far but the Argentinean Stuttering Association works everyday to make it happen.

Claudia L. Díaz
Vice-Chair
A.A.T.



Miriam Lobato (president A.A.T. PWS and Marcelo Arce PWS

African delegates participated in Stuttering colloquium in Toulouse (France)

From March 17th to 18th, some persons who stutter (PWS) from Africa participated the 4th stuttering colloquium organised by APB (French stuttering association).

After my participation in 2003, 6 other African joined me this year. That reveals the fact that PWS in Africa are rising from the silence. They are doing their best to attend meetings to exchange and increase their knowledge in order to help their countrymen. There were Joseph from Cameroon, 3 delegates from Mali, 1 from Benin, and 1 from Chad.

There were about 350 participants. The theme of this colloquium was stuttering and arts or the art to stutter. Many presentations were on this theme.

Joseph and I did presentations.

Joseph did a presentation on last African first conference on stuttering in Douala and the launching of International Speech Project.

I did a presentation on Communication and stuttering in African arts.

I presented the different modes of communication in Africa, the place of PWS in these modes of communication and the result of a study.

The aim of my study was to collect the point of view of population on the representation of stuttering in African cinemas and theatres.

I interviewed 100 persons composed by PWS and people who don't stutter. The participants were recruited randomly. Only 7% of participants said that they never viewed films or theatres where actors play the role of PWS. That

shows that the representation of stuttering is important in such arts in Africa.

This study revealed that for population the representation of stuttering in African cinemas and theatres has an impact on the image of PWS in societies, and they think it's important to sensitise the theatre and film makers.

An analyse of the results show that participants who stutter and those who don't stutter but have a link with a PWS estimated that this representation is degrading for the image of PWS while participants who don't stutter and have no link estimated that this representation is without any impact.

By Moussa Dao
ISA Board Member



"A Stuttering Philosopher", by Stanislaw Szukalski, 1915.
Taken from Stuttering Homepage

Message from India

Group therapy helps stammerers faster



The Fluency Club holds group activities in a public park

It has been our experience with adult stammerers when attending group meetings – I will not call it group therapy – that better results were seen in the change of attitude towards communication through speech. Total behavior changed in a very short time.

A study was carried out to see whether individual or group therapy is more effective to achieve better results in a short time. A group of 15 adults were registered for this experiment. The age range was 14 years to 20 years. All stammerers were schoolboys. Before the experiment started, they were told about the programme and prepared to join the meeting twice a week for three hours. A space was selected in an open public park with lots of people. No formal therapy procedures were used. Rather the boys were free to interact in their own fashion. Introducing each other and speaking about themselves were encouraged. Those who were introverted and shy in their behavior were prompted to take part.

To change their mental attitude, they were not forced to reduce their rate of speech. Rather they were encouraged to talk a little slower in a normal way. They were also encouraged to mix with other people in the park, talk to them about the Fluency Club and explain about the problem of stammering – either briefly or in detail. Meeting with strangers was a big success in the group. One would say something and the other would complete the answer if the partner failed to do so. Everyday activities were designed, like chatting or discussing personal problems in the family and outside the family. Discussions took

place on topics like movies, sports, politics, social problems, and other things of their interest. They could give public lectures on any social issues or tell the news or stories from the news channels. Theatre activities, dance, music, mimes, and anything funny were encouraged. Going to a coffee shop, malls, and places of historical importance were also included. The whole idea was to make the group more social and active in situations where communication is required.

The result was wonderful. The group improved day by day. Their total speech profile was changed.

During the session, all the stammerers were told to think over the following points:

1. Accept that you stammer, as you have accepted your name and religion.
2. Don't avoid meeting people.
3. Initiate your conversation easily, taking your own time.
4. Don't be in haste or panicky.
5. Learn to relax and learn deep breathing – not to reduce your stammering but to improve your health.
6. Take part in all social activities.
7. Learn time management for daily activities to achieve success and confidence.
8. Tell people about yourself and about stammering.
9. Consult your speech pathologist when there is a need.
10. Take care of your general health.

By J. C. Nigam

Speech and language pathologist



The most successful speaker is rewarded.



Message from Cameroon
Witnesses A Remarkable Growth In Its Activities After Hosting The African Stuttering Conference

Since last October when we were honored by the International Stuttering Association (ISA) to organize and host the ever first African conference on stuttering, our activities have witnessed a remarkable progress. Inside Cameroon, more Chapters of our Association have been created in some new localities by some delegates who attended the conference. Delegates who attended the Conference from out of Cameroon have been in regular touch with us and we are sharing with them some practical ideas on how to set up and run a support groups for people who shutter in their countries.

During the first quarter of this year we were able to sample some 100 people who shutter in three different localities of Cameroon as part of the genetic research project on stuttering that is being carried out here in Cameroon in collaboration with the researchers of the National Institutes of Health (NIH) of the U.S.A. Equally we have discovered two large families here with several individuals who stutter and we are planning to sample them by the end of the year in Collaboration with the NIH.

We were able to conduct interviews with several traditional healers who treat stuttering here in Cameroon as part of an International Research Project conducted by Dr. David Shapiro of the Western Carolina University in the U.S.A. aimed at

finding out the role traditional healers play in treating stuttering. Also, data we collected from Cameroon as part of a Global project to measure Public attitudes about stuttering (IPATS) in Collaboration with Dr Kenneth ST. Louis of the University of West Virginia has been completely analyzed. The results of this study will be presented in July 2006 during the World Congress on Fluency Disorders to take place in Dublin Ireland.

We have been able to influence policy makers in certain Universities in Cameroon to consider instituting the teaching of speech Pathology in their Universities with the help of Dr Shapiro of the Western Carolina University. Contacts have been made at the University of Buea Cameroon and discussions have already been opened by these two institutions on how they can collaborate in the training of specialists to help treat stuttering in Cameroon.

We were also contacted by the American Speech-Language-Hearing Association. (ASHA) to contribute an article in its Magazine – the ASHA leader and the said article was published on its edition devoted to International Focus on stuttering.

Last March we were invited by the Association Parole Bégaiement (APB) (French Stuttering Association) to take part at an International Colloquium on Stuttering that took

Place in Toulouse France. At the colloquium we made a presentation on the African stuttering Conference and the launch of the International speech Project –Stuttering (ISP-S). Many French speech pathologists indicated their willingness to be part of this project. We wish to thank Anne Marie Simon and the organizers of this colloquium who invited us for the event.

By Joseph Lukong
P.O. Box 9598 Douala
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19, One Voice 21, June 24, 2006

Message from Burkina Faso

On December 17th, 2005, we organized our Stuttering awareness Day (ISAD). It was the most successful ISAD. Despite the numerous difficulties and the lack of means, for the fourth times, we decided to make this event a permanent reality in our country.

Yet we didn't respect the real date (October 22). The essential for us was to find a day in the 4th semester of every year to celebrate a stuttering awareness day. It was an opportunity to attract government and media attention in order to stop taboo and talk about stuttering and sensitize population.

This ISAD was so particular. His excellence, the ambassador of France in Burkina Faso accepted to be our godfather. He honored our opening ceremony by his presence. It was our first

The organization of this ISAD was particularly exhausting for me.

The participation of the ambassador gave me fears. I was afraid by the great protocol that such arrival would require. I had also fears about the effective participation of the representative of our education Minister who was absent.

The weeks before our ISAD, my schedule was very busy.

- I was doing workshops with teachers in schools
- I was leading a student who was doing a study on stuttering in elementary schools.
- I was also very busy in my job

Obviously we had a team to organize this ISAD; but as the chief of this team and one of the persons who imagined and developed the activities, I had a great



From left to Right: Moussa Dao, the Ministry representative and the Ambassador

time to welcome this kind of VIP.

This ISAD was marked by the launching of our sensitising project of teachers of several schools of Ouagadougou. This project was funded by France embassy. The general idea of our project was:

School is one of the places which could influence the evolution of the stuttering of children (it was also my personal case). We think that by teaching teachers how to handle with CWS in their classrooms, they will improve their school year and also contribute to prevent the worsening of their stuttering.

responsibility as far as the achievements of activities are concerned.

I was so tired and had so many worries. Sometimes, when I worked until too late (2 a.m.) and was thinking that everybody was sleeping peacefully, I had those thoughts: "why do I involve myself into this adventure? If I didn't create this association surely I would be sleeping peacefully as others".

But, when I receive encouragements from my wife and family, from an important personality as the ambassador, from our national authorities...

When I hear moving testimonies from persons who estimated that thanks to our association their lives have been positively changing

When I hear words like: "thanks a lot Doctor, for your initiative to create this association, if it was not existed it must absolutely be created"

When...

That encourages me to keep on going this difficult but noble and saving task.

The day of our ISAD (December 17th), my fears due to the wait of participants rapidly decreased when I noticed the arrival of numerous persons (there was a social strike in our country).

My happiness was so great when I noticed that the ambassador came without any body guards. The opening ceremony started by my speech, then a theatre. This theatre showed the difficult situation for a stutterer during his childhood at home and school and then when he was looking for a job. After that the representative of our education minister who was absent gave his speech.

After opening ceremony we started our conference. A student presented the result of her study. Then a SLP from France who live in Burkina Faso did a presentation on different speech pathology. Then I did my presentation on what is stuttering and what a teacher could do in classroom to help children (special thanks to ISA CD rom project and the book of Marilyn Langevin from Canada titled Teasing and Bullying unacceptable behavior).

After that many persons gave their testimonies. I was so touched when my boss who was 80 years old gave his testimony. Many members of our association were so happy to be able to talk without fears before so many persons.

The conference finished by questions and an interesting exchange between teachers, stutterers, and parents of children who stutter

After this exhausting event, I will face to the biggest challenge that I ever face.

Since last year, our national TV has had a live broadcast on health problem called SANTE MAG.

It's one of the broadcasts most watched by people. The guests talk about a health problem and respond to the questions of viewer who are from Burkina and many other countries.

When preparing our ISAD I met the director of our national TV, and he told me that he wanted to do a live broadcast on stuttering and he wanted me to be the guest.

I was so afraid by such proposition and tried to convince him to give up this idea. I told him: "it would be particular difficult for me to ask other stutterer or university professors to join me. I am not a specialist of stuttering. It would be good to wait when Susan Felsenfeld (Pittsburg, USA) will come on, we may find a translator, or when Sylvie (France) will come on October 2006 or when Anne Marie Simon (France) will come on January 2007".

The director replied: "things change quickly here, I'm not sure to be here when they come, it would be better to do quickly and take the opportunity of your ISAD. I think we have not necessarily need a specialist. Your personal story and what you told me could allow us to do a good live broadcast.

Accept, I am sure that you will touch and help many people".

Facing such words, I could not be indifferent. After thinking I decided to accept this challenge. As our National TV is on internet, I will inform you in time.

By Moussa Dao



Front left to right Oumou Diallo (Mali), Moussa Dao (Burkina Faso), Sangare (Mali), back left to right a lady from (Mali), Joseph Lukong (Cameroon), and Grégoire Gansou (Bénin)

21, One Voice 21, June 24, 2006

Message from Passing Twice

By Nora A. O'Connor

For the past eight years I have grown to understand the importance of talking with graduate students (who are obtaining their degree in communicative disorders) about stuttering.

Each school year I arrange with the local university's Communicative Disorder Graduate Program to speak with students in the fluency class. As a lesbian who stutters, misconceptions are often associated with both identities.

I talk with graduate students about my life as a stutterer and the importance of self-help groups, including the organization Passing Twice.

Often, students are quick to understand the similarities between "coming out" or "passing" as a person who stutters and being a sexual minority. It means either coming out of the closet and being open as a person who stutters and a lesbian or it means hiding in the closet and not coming out. It means either passing as a fluent person (i.e. hiding stuttering or a covert stutterer) or it means pretending to be heterosexual.

The gay community has shown to the world how important it is to come out of the closet and not hide. As a person who stutters, the same process often applies when a stutterer realizes the relief and liberation of emerging in the world as an open person who stutters.

I provide graduate students with a Passing Twice sample newsletter. Frequently, conversations with students continue beyond my presentation about being a lesbian who stutters.

A number of years ago, a student chose to write a paper on gay people who stutter. She used me as a resource to assist with her research.

As a person who stutters (and a lesbian), it is vital that I make myself available to speak with the future speech-language pathologists of today.

ISAD celebrates 9th year

By Michael Sugarman

International Stuttering Awareness Day (ISAD) was conceived by a joint effort of people living with stuttering and professionals specializing in stuttering.

In 1998 October 22nd was designated as ISAD. ISAD provides an opportunity for building a world community that is more humane and compassionate for millions of people living with stuttering. For many people who stutter daily verbal communications are constant struggles. Despite advances by clinicians and researchers many people around the world who stutter and parents of children who stutter do not have access to the services and support they desire.

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.

October 1st -22nd the ISAD online conference everyone can participate by going to www.stutteringhomepage.com

