

# One Voice

**International  
Stuttering  
Association**

Issue 18 – December 2004

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



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## Board Chair Report

**By Mark Irwin (ISA Board Chair)**

*"The future is purchased by the present"*  
- Samuel Johnson

The future of the ISA looks extremely positive if we consider 5 activities/ initiatives being undertaken at the moment.

### 1. 2007 World Congress in Croatia

Plans are already underway for the organization of the ISA sponsored 8<sup>th</sup> World Congress of People Who Stutter. Suzana Jelcic-Jaksic of the Croatian Association "Hinko Freund" will be the Congress convener. The ISA is grateful to Suzana for taking on this role and we wish her well. The ISA also appreciates the fine work of Board member John Steggles of Australia who prepared a Congress manual, based on the experience of previous Congresses, which will serve as a framework for the organizing committee.

### 2. 2005 African Conference and International Speech Project -Stuttering

Joseph Lukong of the Speak Clear Association of Cameroon and ISA Board member will be the convener of the inaugural African Stuttering Conference to be held in Cameroon from 6<sup>th</sup>-8<sup>th</sup> October 2005. This conference will also see the launch of International Speech Project -Stuttering. The aim of this initiative is to attract funds from international aid organizations so that stuttering awareness and public education campaigns as well as therapy programmes can be undertaken in developing countries. Moussa Dao from Burkina Faso will be assisting the organizational efforts of both these initiatives.

### 3. New Editor for One Voice

Albert Zhang from China has been appointed by the ISA as the new One Voice editor.

Albert will be assisted in his efforts by ISA Board member and journalist Warren Brown of New Zealand. China has only recently been associated with the ISA following the outstanding contribution of ISA Outreach chair Stefan Hoffman of Germany. The One Voice cooperation is a fine example of international collaboration at its best. We wish Albert well and thank again Warren and Stefan for their support.

### 4. CD Rom Project

I am pleased to announce that the first version of the CD Rom entitled "Stuttering - A Resource for Children, Parents and Teachers", has been completed. I very much enjoyed managing this project and have included more details in another article (See page?). In addition an online version is available via the ISA website [www.stutterISA.org](http://www.stutterISA.org). Thanks to webmaster and ISA Board member Benny Ravid for arranging this.

### 5. Online Conference, International Stuttering Awareness Day and International Year of the Child who Stutters.

The online conference seems to be more popular each

year stimulating an ever more successful stuttering awareness day. Unlike the activities mentioned above the ISA is not directly linked to these events but we acknowledge them as being powerful contributors to further distribution of the ISA vision: "a world that understands stuttering". The continued inspiring efforts of Judith Kuster (for the online conference) and ISA Vice Chair Michael Sugarman (for international stuttering awareness day ISAD), deserve our sincere appreciation. Michael is also chair of the ISA initiated International Year of the Child who Stutters (IYCWS). His report is included in this newsletter and further highlights the progress that is being made.

## Outreach between Perth and Cameroon

**By Stefan Hoffmann, ISA Outreach Working Group Chair**

It is with joy that I read the many reports by participants of the 7th World Congress for People Who Stutter in the last issue of One Voice. The fact that some many countries were represented in far away Australia made the trip "Down under" even more worth the while. I had fantastic 12 days there and made many new friends.

Also good to see that the ISA Board of Directors has now people from new countries among it's members, e.g. Joseph from Cameroon and Masuhiko from Japan. They will bring new ideas and initiatives into the group. The same applies to the whole of ISA when contacts are made in new countries.

ISA Outreach group made some follow up meetings with people and groups from China and Singapore in June 04. And as we read in this issue, ISA Special Friend Yoza Azda from Indonesia is still aiming at getting a group running in his place.

In the time since Perth, ISA had a new contact in Jordan. This is very welcome, as up to now the Arabian speaking area is the most difficult to access for the Outreach activities of ISA.

The next important international event on the ISA agenda is the African Stuttering Conference in Douala, Cameroon in October 2005. The goal is to get stutterers, parents, teachers and clinicians from African countries assembled in Cameroon to discuss how to improve life for PWS in this continent. Joseph Lukong shared with me the list of contacts he already made in African states. I tell you, these are quite a few! ISA more and more becomes a little UN! A great hope of ISA is that from this meeting there will be emerging many ideas and initiatives for the future work of ISA, and not only in developing countries.

The next World Congress will be held in Croatia. This meeting, however still far ahead, should open up East Europe for ISA like the Perth meeting did with South East Asia. I look forward to many more fascinating meetings in the future!

## News from the European League of Stuttering Associations

**By Edwin J Farr MBE (ELSA Board Chair)**

Welcome to the latest edition of this newsletter. Over the last 1-2 years it has been really pleasing to see the progress the national stuttering associations are making in raising awareness of stuttering. As the world is becoming ever closer with faster internet connections it is also good to see international organisations such as the International Stuttering Association, the International Fluency Association and our own association the European League of Stuttering Associations cementing the work of the national associations by international liaison and contact. Some of our readers may be new to *One Voice* and for them I would like to firstly introduce you to ELSA and then tell you what we have been doing over the last couple of years.

ELSA was founded in 1990 by twelve countries as a European umbrella stuttering association, its aims, objectives and main roles are:

- *To co-ordinate, link together and further the co-operation of Europe's national stuttering associations*
- *The dissemination of stuttering information*
- *To provide a forum for exchange of concepts and experiences in stuttering therapy and self help*
- *To represent the interests of people who stutter to European and international bodies*
- *To put stuttering on the European agenda to ensure the needs and challenges faced by people who stutter are considered in a European context*

During the last 1-2 years the focus of ELSA's work has been on the two successful funding projects secured in 2002.

The first project was within the framework of The European Year of People with Disabilities 2003 (EYPD). The project commenced 2002 and ended 2004. It included dissemination of information on stuttering and the EYPD, a stuttering and disability information brochure, improvements to the ELSA website and a Stuttering and Disability Awareness Conference. Funding for this project was all the more pleasing as ELSA was one of only 5 European disability organizations chosen for the EYPD European NGO funding - representing the deaf, blind, autism, stuttering and intellectual disability.

A summary of ELSA's work during this project is presented in the attached extract from the European Disability Forum's "BULLETIN" and reprinted in *One Voice* 18 on last page.

The second project was ELSA's 4<sup>th</sup> Youth Meeting, the part funding was provided by the European Youth Foundation of the Council of Europe. The Youth Meeting was held in Nijmegen, the Netherlands, in July 2003. The title was Extending Communication –

Extending Borders. The aim of the meeting was:

- *To provide information on the workings of a national stuttering association, its structures, management committee and staffing*
- *To introduce young pws to the new information media and its use as a tool for networking, making new contacts and breaking down borders*
- *To encourage young people who stutter to play active roles in the work of their stuttering associations*

The meeting lasted 6 days and consisted of workshops and presentations. The delegates were asked to work on a project to design a website for an imaginary stuttering association. The workshops also included "Body and mind, bringing the body and soul into balance" and "non-verbal communication and theatre" presented by two Dutch professionals. A total of 35 delegates from all over Europe attended the Youth Meeting, it was a great success.

ELSA produced a brochure entitled "*International and European Disability Policy Relating to Stuttering: What you need to know and why*". The brochure provided an overview of European disability policy, an area which through ELSA's research not many people associated with the national stuttering associations knows a lot about. As a gesture of solidarity the brochure was designed not just for PWS but for the disability sector as a whole. This brochure can be found on [www.elsa.info](http://www.elsa.info)

ELSA continued to contribute, together with many European non-governmental organizations, to the work of the European Disability Forum (EDF). Networking with other disability organizations at the EDF's Annual General Meeting and General Council Meeting and by email ensured that stuttering was on the agenda at a European level.

In addition to the above the following ongoing work was carried out:

Liaison with Comité Permanent de Liaison des Orthophonistes. CPLOL is an organization of Speech and Language Therapists / Logopedists in the European Union. Firm contacts were made with CPLOL during the EYPD and after Edwin Farr gave a presentation at their Edinburgh conference on the subject of ELSA, the EDF and the EYPD.

Two invitations from the European Commission to present stuttering at conferences were accepted. 1. Edwin Farr was invited to speak at a European Disability and the Media conference in Athens and 2. Anita Blom was invited to speak at the European Parliament of Disabled People in Brussels.

Gina Waggott is currently on the European Disability Forum Youth Committee where she will be able raise awareness of stuttering as a disability.

Regular liaison with the International Stuttering Association (ISA).

Outreach has continued by making contacts with people and organizations working in the field of stuttering in eastern European countries and some of the western countries that do not have such sophisticated national organizations. For many of these organizations or groups much of what they need is written information in many languages and ELSA has been able to facilitate the provision of material.

The Executive Committee & Projects Committee of ELSA is truly European consisting of myself from the UK as Chair, Anita Blom *Dutch and from Sweden*, Konrad Schaefers *German*, Benedikt Benediktsson *Icelandic*, Gina Waggott from the UK. I would like to thank them and all the people associated with ELSA who have worked on various projects both large and small, they are people who stutter themselves, many have full time jobs, and they give their time and energy to

Hugo H. Gregory, Ph.D.

#### By Mel Hoffman, ISA Advisory Board

Hugo H. Gregory, Ph.D., a leader in the stuttering therapy and research field, died on October 11, 2004, due to complications after what was thought to be successful surgery. He was about 76 years old.



Dr. Gregory participated in the 2<sup>nd</sup> World Congress for People Who Stutter in Köln (Cologne), Germany, in 1989. He and his wife Carolyn facilitated a discussion on how to cope with relapse. He also has spoken at other major conferences, including the 1997 International Fluency Association (IFA) meeting in San Francisco.

For many years prior to his retirement, Dr. Gregory was at Northwestern University in Evanston, Illinois (near Chicago), where he taught and also directed a therapy workshop from 1985 until 2001. One of his publications is "Stuttering Therapy: Rationale and Procedures", which he wrote with his wife, Carolyn, and June H. Campbell and Diane G. Hill.

#### Note:

Thanks for Benny Ravid and Judy Kuster to locate Hugo's picture.

The International Stuttering Association would like to express their condolences to the family of Hugo H. Gregory.

improving the conditions for people of all ages who are disabled by the speech impairment of stuttering. Thanks also go to the National Stuttering Associations of Europe who have supported ELSA and assisted in the co-operation between each other again to improve the conditions of people who stutter.

Additionally, on behalf of ELSA we are grateful for the funding received from the European Commission and the Council of Europe.

By continued networking with international and European organizations and institutions I believe that all the parties involved are making a contribution to raising the awareness of stuttering amongst decision makers which will benefit the national stuttering association's work and ultimately improve conditions for all people affected by the speech impairment of stuttering.

Passing Twice Holds First  
Conference in San Francisco

#### By Larry Lindstrom, USA

On July 25, 2004 about 20 Passing Twice members met at the Ramada Plaza Hotel in San Francisco. For many, being gay stutterers presents us with dual identities that can be purposely hidden, or just not noticed by others. Passing Twice also attracts stutterers who are not gay but who can identify with emotional issues paralleling the coming out process.

A workshop, held by co-founder Barry Yeoman, had us pair up with others. People moved freely. Partners talked privately. Feelings were expressed through motion and emotion such as crying. The environment was non-threatening so a lot came out.

Later members participated in a workshop led by co-founder Elizabeth Kapstein. Members role-played situations where often in the past we would remain quiet. We got the chance to feel our voice was important, to ourselves as well as to others.

The conference concluded with an open forum wrap-up. The day united and cleansed us. We were free to expose ourselves to a loving community. The conference was a success. Passing Twice had us speaking, and feeling, a lot more free and loved.

#### Note:

Passing Twice is an international organization with probably well over 100 worldwide. Founded at the 1993 National Stuttering Association (NSA) convention in Washington D.C., Passing Twice is an informal network of gay, lesbian, bisexual, and transgender stutterers and their friends. Passing Twice meets every year at the NSA convention, and also holds workshops at other stuttering conferences around the world. In between, they keep in touch through a quarterly newsletter, an e-mail list, and an annual mailing list.

# International Year 2004 Children who Stutter

By Michael Sugarman (ISA Board Vice Chair)

2004 was designated by the IFA, ISA and ELSA as the International Year 2004 Children who Stutter.

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. 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 Project now known as NSA renewed the spirit of the stuttering community by initiating a “Year of the Child who Stutters 1996.” Ten workshops throughout the United States 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](http://www.mankato.msus.edu/dept/comdis/kuster/workshop/intro.html)

**The Challenge:** More than a third of children who stutter do not outgrow it. Today, speech pathologists can identify which children are at risk for chronic stuttering and help most of them—if therapy begins at an early age. Yet many teachers, counselors and pediatricians may advise parents to defer speech therapy until it's too late to prevent chronic life long stuttering.

**What causes Stuttering:** There's no single cause. Stuttering is influenced by psychological factors but is not an emotional problem or nervous disorder. It's not the fault of parents or child. Current research suggests a connection between stuttering and neurological coordination of the speech mechanism.

**What is Stuttering:** It's a complex set of behaviors that interfere with normal fluent speech. People who stutter may repeat syllables or “block” when they're trying to get a word out. Interrupted speech may be accompanied by eye rolling, blinking, head jerks or other associated behaviors. There are as many different patterns of behavior as there are people who stutter.

**The campaign:** the IFA, ISA, and ELSA's International Year 2004 Children who Stutters 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.

- Launched International Year 2004 Children who Stutters at ELSA conference in Strasbourg, France, Summer '03 organized by ELSA and the AVB where raising awareness of stuttering within the framework of the European Year of People with Disabilities 2003 was discussed. Distributed IYCWS and ISAD posters and buttons to participants from 22 countries representing stuttering associations.

- The British Stammering Association on October 22nd, 2003 launched a CD Rom on stuttering to be sent to every school in Britain. Also, BSA launched a “When the words won't come” – a unique collection of poems, stories and drawings about how it feels to stammer.
- Korea celebrated its sixth annual ISAD on November 8, 2003 at Ewha Women's University. One hundred and sixty clinicians, students, and parents attended “Stuttering Children's Therapy Workshop.” The program was as follows: Ms. EJ Lee presented characteristics and evaluation of stuttering children. Dr. MJ Shin presented on parent education program. JW Shin and JH Park talked about parent-child interactions. A panel discussion followed by KA Park, KJ Lee, JH Park, HJ Cheon and JW Byan on two clinical studies and research findings on children's stuttering. This was followed by Professor HS Shim from Ewha Woman's University commentary. The third part “Walking Together” all participants had the opportunity to converse with one another and share their experiences in a relaxed atmosphere on (Love, Love interview). The day's activities concluded with a recital by all present of ten statements on stuttering and the Bill of Rights and Responsibilities for those who stutter.

Mein Stottern ist wie ein <sup>3.3.04</sup>  
Korken, mal ist es auf,  
mal zu.



"My stutter is like a cork on a bottle"  
Fabian (8 years, Germany)

- *The ISA released a CD ROM at the 2004 World Congress for People who Stutter in Perth, Australia Feb. '04 on teasing and bullying to national stuttering associations to distribute to teachers around the world. Around 350 delegates participated from all around the world. The Bill of Rights and Responsibilities for People who Stutter poster and brochure and IYCWS poster was available to participants.*
- *The Aussies were able to distribute the ISA/CD ROM for teachers to schools in Australia. Read Mark Irwin's paper on the ISA/CD Rom distribution to national stuttering associations on this online conference.*
- *4,000 IYCWS and ISAD buttons were distributed to national stuttering associations around the world.*
- *2,500 IYCWS posters were distributed to national stuttering associations around the world.*
- *Initiated discussion of an international group for parents of children and young adults living with stuttering.*
- *AMBI convention in Jerusalem, Israel was held March, '04. Dr. Sara Melechson, head of Communication Dept. of Hadassah Academic Institute presented the Bill of Rights and Responsibilities for People who Stutter to 60 participants.*
- *April '04 IYCWS Workshop in Nepal: Nepal Stutters' Association conducted a one day people awareness workshop in occasion of IYCWS '04 on the theme "IYCWS Year 2004" on 1st April '04 at Western Regional Hospital, Pokhara. The program was held with an important Chief guest Mrs. Hanne Tranberg, representative of DSI – Denmark. Other guests were Mr. Bent Lassen (rep. of DSI-Denmark and Mrs. Renu Lohani (Coordinator of DSI-Nepal). 75 people participated in the program. The program was held on chair of President Mr. Indra Lal Shrestha. Two papers were presented. One paper was presented by Mr. Kabiraj Khanal (Speech Pathologist & Audiologist) about speech therapy for stutterers of different ages and the second paper was presented by Mrs. Amala Amatya member of NSA about the introduction of Nepal Stutters' Association. Nepal Stuttering Association coordinated efforts with District Education Office to mail a pamphlet on the workshop to every school in the district for children/youths who stutter to attend.*
- *Upland, California held a workshop for Youths who Stutter and their Families April, '04. Sponsored by California Association of Speech and Language Association, District 10. The Bill of Rights and Responsibilities for People who Stutter poster and brochure and IYCWS poster was available to participants.*
- *Pasadena, California held a workshop for Children who Stutter and their Families May, '04. Gail Wilson-Lew coordinated the activities. The Bill of Rights and Responsibilities for People who Stutter poster and brochure and IYCWS poster was available to participants.*
- *Plans are underway for the First African Stuttering Conference to hold in Cameroon October '05. The Bill of Rights and Responsibilities for People who Stutter poster and brochure was mailed to Cameroon to distribute to conference participants.*
- *Discussion of a project initiated by International Stuttering Association to help support developing countries with speech therapy specializing in stuttering called "International Speech Project-Stuttering". Professionals who specialize in stuttering and people living with stuttering with experience in self help groups will travel to developing countries to provide valuable information on treatment and self help models.*
- *The National Stuttering Association in Baltimore, Maryland, USA June '04, Bill of Rights and Responsibilities for People who Stutter poster and brochure and IYCWS materials were made available to 500 conference participants.*
- *Italy: An excursion to Modena was planned by the Italian National Association "Libera la parola" July, '04. The program was to see the sights of the city and provide a pleasant opportunity to exchange experiences having to do with stuttering- 1) being together; 2) playing games concerning stuttering or not and 3) having fun.*
- *Hungary: On its 10th birthday the Foundation for Stutterers (Budapest) had requested "stone donations" of its supporters and well – wishers. The stones submitted by July 31st will be put on display in September '04. The senders of the finest pieces will get a prize on ISAD. There will be an auction, a fair and a gala programme when prizes are awarded. The venue will be at the International Business School 16th of October '04.*
- *This year's campaign is to help speech language pathologists to have a child to speak to his or her class on ISAD, IYCWS and stuttering.*
- *Friends Conference was held July '04. The city of San Mateo declared Friends Stuttering Awareness Day, July 23rd, '04. The Bill of Rights and Responsibilities for People who Stutter poster and brochure and IYCWS poster and buttons were made available to 250 + participants.*
- *On Saturday, April 17th, '04 ACB in Burkina Faso (West Africa) organized a workshop with teachers. The workshop was the first one of a series of workshops within both IYCWS and a project: children with speech disorder support project. 56 teachers attended from elementary and kindergarten schools. The workshop aim was to explain what stuttering is, what to do with a child who stutters in the classroom. The program consisted of two presentations: Roseline GIndre /Zongo a French slp and Dr. Moussa spoke about what teachers can do to help children who stutter in the classroom. Also, a parent of a child who stutters presented his testimony.*



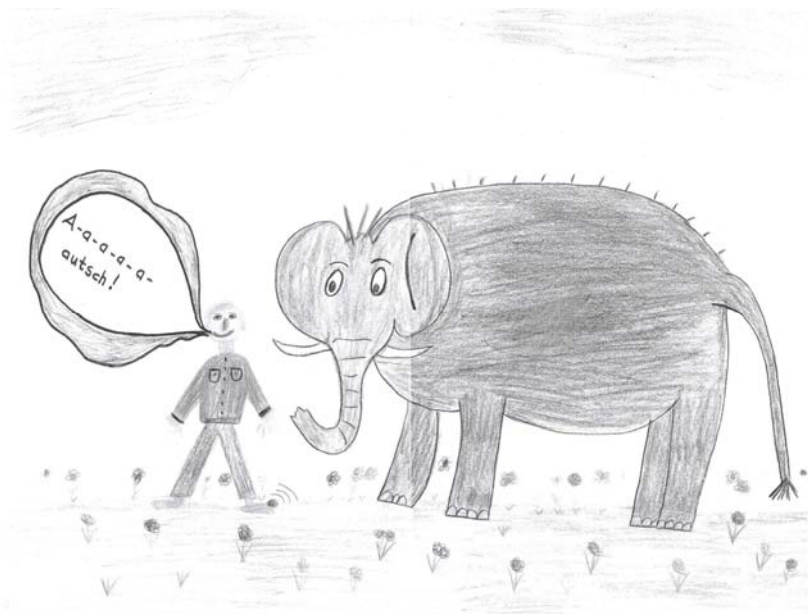
- The 10th British Stammering Association conference was held in Stirling, Scotland, 3rd – 5th September '04. Lee Reeves from NSA will be a keynote speaker. IYCWS and ISAD materials were made available to anticipated 180 conference participants.
- Nordic seminar which consists of participants from Iceland, Norway, Denmark, Sweden, Finland and Faso was held in Iceland 10th through to 14th September '04. IYCWS and ISAD were discussed.
- Bundesvereinigung Stotterer Selbsthilfe (German Stuttering Association) will be celebrating its 25th anniversary (BVSS) Oct. 7 -10th, '04. 220 conference participants are anticipated to attend.
- ISAD in Czech Republic will be on 22nd October 2004 in the boardroom of Regional board of South Moravia district. Invites will be mailed to all people who stutter who were in treatment with OS Logo. The Bill of Rights and Responsibilities for People who Stutter brochure and poster and IYCWS poster and buttons were mailed to Czech Republic.
- Mailed IYCWS poster and button and Bill of Rights and Responsibilities for People who Stutter poster and brochure to twenty five slp's in the United States.
- Will advertise the online conference via internet.
- New Jersey, USA Dept. of Education asked if they can refer to Bill of Rights and Responsibilities for People who Stutter as a technical assistance document for school speech language specialists.
- 1,200 Bill of Rights and Responsibilities for People who Stutter brochures disseminated to Canadians.
- This online conference is dedicated to IYCWS 2004.
- List your IYCWS on the online conference event page.
- 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, and Mankato, MN 56001, USA. Their work will be displayed as an online exhibition on this 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. '03).
- Bulgarian Stuttering Association (SIZ) initiated different activities during the first two months of 2004 in relation to IYCWS. SIZ 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.

The purpose of IYCWS is to carry out our mission—to connect with others who stutter around the world. I would urge you to keep flapping your butterfly wings—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.

In closing, 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 aug” 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 a storm of acceptance, civil rights and self determination.

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Philipp (8 years, Germany). No comment

## The Speak Clear Association of Cameroon Gains International Recognition

**By Joseph Lukong, Cameroon**

The SPEAK CLEAR ASSOCIATION OF CAMEROON, SCAC was honored this year with an invitation to attend and represent Cameroon and Africa at the world congress for people who stutter that took place in Perth, Western Australia from the 14th to the 20th of February 2004. The SCAC was represented at this congress by its Coordinator General, Joseph Lukong who took part at the General Assembly of the International stuttering Association, ISA and also facilitated one of the workshops of the congress dealing with stuttering in Cameroon and the work the SCAC has been doing for people who stutter in and out of Cameroon.

As a sign of recognition for the work our association has been doing, Joseph Lukong was elected into the Board of Directors of the ISA for a mandate of three years.

During the said congress the SCAC was honored further to organizing in collaboration with the ISA, the first ever African stuttering Conference scheduled to take place in the coastal town of Douala Cameroon from the 6th to the 10th of October 2005. The aim of this conference is to bring together people who stutter and speech professionals from all countries of Africa so as to encourage them to set up self help movements for people who stutter in their respective countries.



A very important project for the developing world called INTERNATIONAL SPEECH PROJECT-STUTTERING IPS-S aimed at making stuttering speech pathology services available to many countries of the developing world where some of these services are not yet in existence or well developed will be launched during the conference. Many speech professionals and researchers from many countries of the western world have accepted to be part of this conference and are very supportive of this project. Any person who is interested in attending this conference or supporting this project in any way what so ever should not hesitate to contact.

The SCAC is very grateful to the International Stuttering Association ISA, the Australian Speak Easy association for the support they gave its delegate which support made it possible for the SCAC to be represented at the last world congress.



## A Wonderful Congress

**By Yoza Azda, Indonesia**



My whole stuttering life, 25 years, I was searching what is the matter with stuttering; now I am 32 years. When I was a child I couldn't speak like normal people and some people laughed at me when I spoke. No one could help me, no one could explain what stutter is and how to treat it. Not one Speech

Language Pathologist I found in my country. I thought no one could change my speech, only my self. At young age I promised to myself, that I will speak fluent like other people. By raising my self-confidence 3 times a week, I tried to treat myself with speaking in front of my classmates. Before that I have tried various self-therapies; all that I did by trial and error. At 16, my dream came true, I thought my prayers were answered, I did not stutter any more. But I don't know how to help other people who stutter, I have just told my story to them.

In 2000 I knew about the Internet so I looked for "stuttering". I have found many websites about stuttering, my favorite website is the "stuttering homepage". There I can download many articles, thank you Mrs. Judy Kuster for being webmaster of the "stuttering homepage". In January 2003 I found the ISA website. I learned about the 7th World Congress in Perth, but thought it is impossible

for me to attend, because I never went abroad before and did not have so much money. Peter Dhu and Stefan Hoffmann helped me very much to get me to the World Congress; I will never forget your kindness.

I went to Bali from Bandung first, because from there I could get a promotion ticket which was cheaper. By Air Paradise I flew from Bali to Perth, only 3 hours, such a short distance, and I found not much a different atmosphere from my country. At the airport a nice guy greeted me, thank you Bruce, for picking me up from the airport, I'll never forget you.

Wonderful Perth and the Congress gave me a good inspiration to establish "The Indonesian Stuttering Association" (INSA). I found much information about stuttering and treatment from many people from different countries and from different cultures, but I think we are not so different about our stuttering. But we use different methods to free ourselves from stuttering and we never "give up" chasing fluency. Now I have established the "Indonesian Stuttering Association" for helping and supporting the stutterers, but not many members yet. I work at a hospital as a psychologist, to give advice to people who stutter and on how to treat the stuttering.

In Croatia we will talk more about stuttering and treatment and will get many new friends from the whole world. From the country that never sent anyone to a World Congress before, I hope I will be representing Indonesia in Croatia 2007!

## Fluency Club India

**By J.C.Nigam, India**  
speech\_care@yahoo.com

Fluency Club India would complete 11 years in November 2004. The recent trend in handling the adult stammers has been successfully experimented through intensive counseling to the adult stammerers. During all these sessions we do not ask the stammerer to use any specific method to control the rate of speech. Our experience shows that using prolongation method or using voluntary stammering does not suit the person and they do not like to use it outside situations, rather they loose the faith in doing the most artificial way of speech. We rather convince the client to use the most normal way of speech, provided it should not be out of control. The use of passive air flow method in this technique is encouraged to follow and use vigorously after practical demonstration by the therapist without reducing the rate of speech to the extent of very slow in nature. Many stammerers liked this kind of normal rate of speech using passive air flow method and adopted it seriously to achieve the goal.

## From the editor

Dear All,

Welcome to OV 18, the first edition of me and a collaborative work of all ISA members. I am greatly honored to work for ISA as editor of OV, thanks Mark and Stefan, and all friends around the globe.

2004 is the international year for Children Who Stutter. To change the future of them, is where the meaning of our work lies in, and you can see ISA and ELSA has done a lot to this end, by reading Mark Irwin and Edwin J Farr MBE's reports. As a good example, the paper from Masaki Nagao, a recovering young person from Japan, shows the self-help groups really have changed future of some stuttering children. Yet there are still millions of PWS unable to get help, in Africa, in China, in Arab world, etc.

I hope you can like the look of this issue, and please tell me what you think of OV and what you want from it. Thank you everyone who contributed time and energy to this issue of OV.

Albert Zhang Jianliang  
zhangjianliang@xinhuanet.com

## My Personal Transformation

**By Masaki Nagao, Japan**  
**University student (18 years old)**  
**Osaka Stuttering Project**

I do not remember exactly when I began to stutter, but I was already stuttering at preschool age. After I entered primary school some of the other children started to tease or make fun of me when I stuttered. This made me feel sad and it was really hard to deal with.

During the summer when I was ten years old I had a chance to participate in the Summer Camp for Children Who Stutter, and their Parents, organized by the Japan Stuttering Project. Through my experience in this camp I learned that I was not alone, and I was encouraged by the fact that there were many other children, who stuttered and suffered from stuttering like myself. The experience during the three-day camp, in which the other children and I shared with each other our experience and talked about our problems and feelings, has changed my outlook on stuttering dramatically. I was able to gain a positive attitude about myself and a different approach to stuttering to such a degree that I was able to even think “I am lucky to stutter”.

Since this wonderful experience at the camp I found myself less troubled by my stuttering and thinking “it is all right to stutter.” I also found my school life more enjoyable. I was determined to live positively and happily whatever hardships I might face because of my stuttering. I also thought I would be able to have a happy life as long as I remained positive, without being overwhelmed by my speech disfluency.

However, when I entered junior high school I began to resist stuttering openly in public. One day when I was in the second year of junior high school I stuttered severely while reading a text in a Japanese class. I felt ashamed, frustrated and depressed, blaming myself for not being able to read the simple text normally like the other children. This experience made it difficult for me to remain positive and cheerful. Then I realized that I had forced myself to become positive and happy and disguised my real feelings. I just pretended to be positive and internalized my true feelings deep inside simply because I did not want to admit that I had been ashamed of my stuttering and envied other children who spoke fluently.

When I realized this I said to myself that I should be open and honest about my feelings and face my fears. I realized that it is hard to keep “holding in” what is really on my mind, so I decided to accept and live with stuttering. Since then even though my stuttering got in my way many times, I did not avoid those situations and found solutions on my own. I was thus able to finish junior high school without letting stuttering control my life.

During the last term of junior high school, I had to decide which high school to go to. It was the first time for me

to make an important decision. I chose a school and passed the entrance examination. The fact that I had paved my own way to success increased my self-esteem. I actively participated in club activities and school events and enjoyed my high school life fully. I felt I was capable of doing anything I wanted to do. I also thought that I was no different from other people except that I had trouble speaking. I was then less preoccupied by my stuttering. I was not embarrassed, even if I stuttered badly in public. This made me believe that I had achieved personal growth and gained emotional strength because I accepted and faced my stuttering without avoiding it.

However, one day my music teacher made me realize that this was not true. She said, “You are setting up an invisible barrier of self-containment. You never speak your mind. Are you going to avoid facing yourself all your life?” I did not really understand what the teacher meant. I never imagined that I had closed myself because I faced my stuttering, and believed in my strength. However, while listening to my teacher, I felt penetrating pain and I was crying. I realized for the first time that I had a strong inferiority complex because of my stuttering. Since early childhood I never liked being a loser, and particularly hated being looked down upon by other people. Therefore, I acted as a respectable person and pushed my inferiority complex deep inside by gaining the recognition of other people as a fine character. This is not true strength. I was only acting as a strong person. I used to believe that I had been open to myself and been able to accept and live with stuttering, but I was dishonest to myself, thus avoiding facing myself and my stuttering. When I realized this, I was completely lost, not knowing how to deal with my stuttering. I became apathetic for some time, but at the same time I noticed how peaceful I felt in my heart, even though I was still confused. I understood that this was because the barrier behind which I had pushed my feelings had been removed, which gave me freedom. I said to myself, I should take it easy and take time to think about my stuttering. I was happy to learn that opening oneself gives us a lot of freedom.

In the third year of high school I began to think about my future. Upon listening to my inner voice, it occurred to me that I have wanted to become a dubbing artist since a young age. However, when I thought about this occupation seriously I had a dilemma about my dream because I was concerned that my stuttering would not allow me to become a dubbing artist, because the job requires fluency, but I did not want to give up my dream. Until a little before I entered university I was preoccupied with an idea that I should be able to control my speech 100%. However, the result was that the more I used the control technique the more severely I stuttered. My frustration increased and I could not stop myself from hating my stuttering which, I thought, would discourage my dream.

However, even if I hated my stuttering, nothing changed except that I only suffered more. This made me realize that hating my stuttering is equal to hating myself. I also realized that denial of myself restricts my potential, and I did not want to become a dubbing artist using a controlled voice, which is not my voice. I no longer hate my

stuttering.

Now I am free from controlled speech, but I must admit that I am still tempted to use it because I still think it might be difficult to realize my dream, if I cannot manage my speech. However, I do not want to force myself to control my speech, I want to learn to control it naturally by opening myself to many experiences and things that I hear and feel. By accepting my stuttering, without avoidance, I believe that I will be able to grow and live with stuttering.

I believe that my thoughts and attitude toward stuttering have changed through my contact with the members of the Japan Stuttering Project and my friends whom I met during the summer camps. These people gave me a lot of courage to face both my stuttering and myself. Whenever I was troubled by my speech and feeling down, they were with me and listened to me attentively. They also helped me to listen to my inner voice and organize my thinking. Without their support my personal growth would not have been possible.

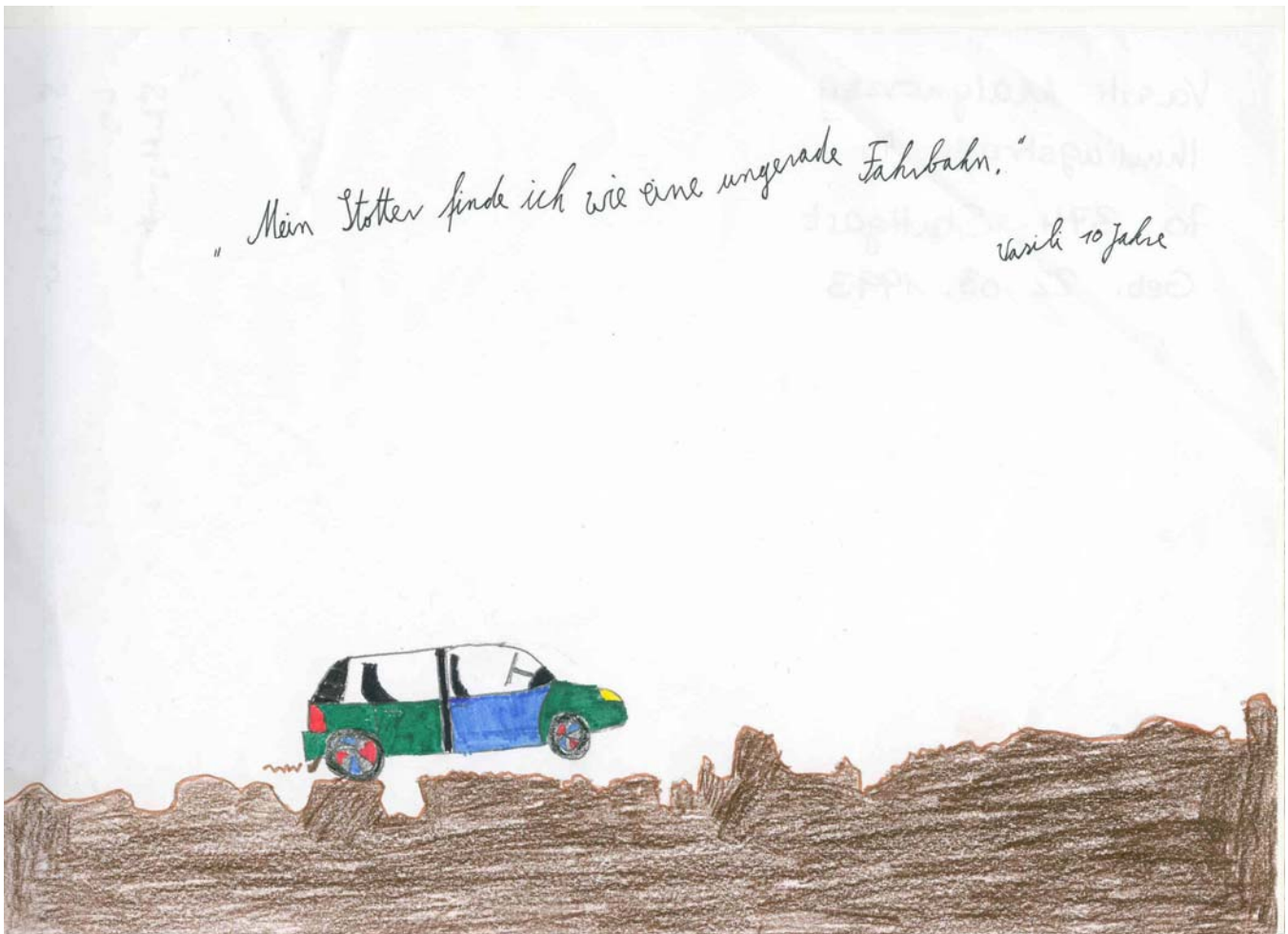
My thoughts about stuttering will keep changing because to live means to change. I want to be in terms with my stuttering whatever changes I experience in the future.

## 2004 Summer Activities of the Japan Stuttering Project

### By Shinji Ito, Executive Director Japan Stuttering Project (JSP)

During the last summer, the Japan Stuttering Project developed its activities not only within the group but also reached out to society. The 15<sup>th</sup> summer camp for children who stutter, and their families was again a great success. More than 100 people participated, including elementary school children, and teenagers. We also organized the Fourth Training Program on Stuttering for the speech language professionals. At the national convention of public school teachers, who work with children who stutter, a famous comic storyteller, who is a member of JSP, was invited as a guest speaker to speak about his life as a person who stutters in front of a large group of 500 people.

A new handbook on stuttering by Shinji Ito was published recently by a major Japanese publisher, and 4,000 copies have already been sold in three months. This book reaches out to adults and children who stutter, their families, and clinicians, emphasizing the importance of accepting themselves as persons who stutter, and raises public awareness of stuttering. We are hoping that this book will also be published in English.



Vasili (10 years Germany) "My stutter is like a bumpy road"



## Thanks to ACB, Olivier managed his oral reports successfully

**By Moussa Dao, Burkina Faso**

The 21st June, 2004 was a great day for ACB.

One of our new members (Olivier) got his diploma after a brilliant oral report.

Olivier was a student in the field of breeding and animal health science.

Some months ago, just being returned from World Congress in Perth, I received this call: "I'm calling from Fada, I heard about your association through newspapers. I have a great problem. I'm a stutterer. I should do an oral report before getting my diploma. I'm very afraid by this exam. Could your association help me?"

The person who was calling is named Olivier. He was doing his research session in Fada, for the last year of his studies. Fada is a town located in the East part of Burkina Faso.

After this calling, monthly, despite the travel cost and the long distance between Fada and Ouagadougou (250 Km), Olivier did his best to participate at our self help meeting. His presence allows him to benefit from the experience of our members.

He got advice and more important he had the opportunities to do training in a safety place.

The day of his oral report, some members of ACB was present in the room in order to support. His report was fine.

Nowadays, although he overcomes his challenge, Olivier continues to participate at our meeting. He is one of the dynamic members of ACB. He released that he had to join us to raise people who stutter from the silence and make stuttering awareness a reality in Burkina Faso.

This year, Olivier was the second member who benefited from our support for oral report. In fact, in the activities of our association, one of the important tasks is to support student and pupils for their oral reports.

Some years ago when I had to do an oral report of my thesis to get my doctorate, I faced to the same problem like Olivier. Unfortunately I struggled alone and developed my own strategies.

Now, thanks to our self help group, people who stutter will find a place where they will learn how to do their oral report.

It's interesting to be helpful for others.



From right to left, Moussa, Olivier and Daouda



The left three drawings are submissions to a drawing contest the German Stuttering Associations organized on the occasion of the IYCWS.

## Letter from Arab World

Dear Sir,

What a pleasure to hear from you again! I am so happy about your interest in the state of stuttering in the Arab world. As I may have mentioned in an earlier correspondence, I am working now on my PhD in stuttering and expect to finish sometime towards the end of next year (2005) or early the following year. I am so looking forward to going back home and using all the information and clinic experience I learned about stuttering in helping and educating people back home about the nature and treatment of this speech difficulty.

As you mentioned in your message, there is very little work, if any, done back home to understand and describe stuttering in relation to Arabic language. If the available prevalence data can be used to predict the number of persons in, for example, Jordan who stutters at present, the estimate would be 50,000 persons. Imagine that there is no available information to confirm or correct this number, and that if it is correct, most of these persons are dealing with this difficulty on their own, because of the simple reason that there are few (less than 10 qualified clinicians) for the whole population to work with these persons. Now, you can imagine how thrilled and excited I am for the great opportunity I have to go back home and do my best to make some change. What adds to my excitement is hearing that there is an international interest in this matter, and that wonderful persons like you want to learn more about the state of things in my part of the world. I will definitely do my best to investigate and provide a clear picture about the situation there, and would appreciate any opportunity I get to make that picture known to others. This in my opinion will increase awareness of persons in my own country and the regions surrounding it, in addition to the international community to better understand the needs of persons who stutter back home. For this reason, I want to say that I will be honored to present, during the next IFA, information about the nature of stuttering and how people deal with it back home. I sincerely want to thank you for this opportunity. I also want to apologize for the lengthy message, but you can imagine how grateful and privileged I feel for your interest. I would love to keep contact with you, and will always be looking forward to our future correspondence. By the way, I don't think I mentioned this to you before, but I am working under the supervision of Dr. Kenneth Logan. He was very happy to hear about our correspondence and about your interest. Thank you again for this opportunity and for your time. You'd mentioned in your message that you'll let me know when the next issue of ISA Newsletter "One Voice" is out, so I'll be looking forward to hearing from you again.

Have a wonderful week.

Sincerely,

Maisa Haj-Tas

from Jordan, currently living in USA

## News from Iceland

**By Benedikt Benediktsson**

The annual Nordic stuttering conference was hosted by Malbjorg in Iceland this year. More than 60 people from all the Nordic countries and a few from the rest of the world attended.

The conference started on Friday, September 10th with a reception by the mayor of Reykjavik. Saturday and Sunday were spent in the small town of Stykkisholmur in western Iceland with a combination of lectures/workshops on stuttering related issues and social activities where sightseeing in the special landscape of the area played a large role. ELSA had its AGM and the chairs of the Nordic stuttering associations also had their meeting. On Monday there was a boat trip on Breidafjörður, watching eagles and eating seafood fresh from the ocean. Tuesday was spent traveling back to Reykjavik through a landscape of deserts, glaciers, visiting places from the Viking age and geothermal power stations. The conference was a great success and everyone left for home with happy memories.

Next year the Nordic stuttering seminar will be held in Sweden.

In connection with ISAD Arni Thor Birgisson Malbjorg's cashier and Johanna Einarsdottir, speech pathologist appeared in a prime time talk show on national TV on October 19th. 2004.

## News from Paris, France

**Anne Marie, Association Parole Bégaïement**

Our association has the desirable feature that half of its members are either stutterers or their families, and the other half are clinicians (750 members). Since its beginning, the aims of our association have been prevention and sensitization.

This year, we have taken three main actions:

- *Information and sensitization of teachers in high schools. We have printed 10 000 pamphlets that are being distributed to the schools, while at the same time conferences and meetings are being held on this topic: how to help your stuttering pupils?*
- *Using the Erik Lamens film "To speak", another campaign towards teachers will be undertaken at the IUFM which are the institutions where teachers are trained in their first program and then during continuing education. Discussions are run by APB members at each showing of the film.*
- *APB has supported the publication of a small book on stuttering for the large public. A total of 12 000 books have been printed, with APB being involved in carrying this book to the medias.*

October 22nd will be an important opportunity to send the message all around the country informing the public about these three important actions. A special telephone number will be set and many meetings will be held on this special date.

## THE YEAR 2004 IN FINLAND

The current year has been time of growing younger in Finland. I mean that our quite small association has got new young members.

We have had three meetings in this year. Christmas party was celebrated at the legendary stammer course place. In spring we met at a water park. There we had creative activity and above all great company. Traditionally summer meeting was more casual than other meetings. We were in the middle of the beautiful Finnish nature having fun.

The vital part of our association is magazine. In this year we bring out four magazines, sometimes less, sometimes more. Some articles have excited the feelings and bring forth conversation. Which I think is good. We also have distributed stammerer's self-therapy books and sold postcards.

The Finnish stutter association have organised and offered courses for stammerers. Participants have got help and friends from courses.

We have local subdivisions all around the country. There is possibility to meet other stammerers, practise, have a cup of tea and stutter freely.

In Finland is also an association for children who stutter. We have been negotiating with them about merger. Unfortunately it is not going to happen in the near future but we are cooperating with each other.

The Finns took part of Australia's world conference and Scandinavian conference in Iceland. We would like to thank both of the host countries.

On behalf of me and my association I wish you all the best.

Regards Ella Valve

Association of the Finnish Stutterers  
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13 October 2004

## Foundation for Stutters in Hungary

### By Eszter Balas Schmidt

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The Foundation for Stutterers was formed in 1994.

Our aims:

- To help stutterers with advice, to give orientation on where they can find a therapist, occasionally to grant financial assistance for therapy,

- Advocacy of the cause of stutterers with various cultural events to which we invite stutterers and non-stutterers alike,

- To promote speech therapy by organizing training programmes and workshops.

Our board of trustees consists of **Adrienne Csengery (chair), Judit Fridli (secretary), Vera Mérei, Zsuzsanna Kovács Fehér** and **József Schmidt**.

The foundation has no paid employee, and it only relies on the work of volunteers.

Fund-raising for the cause of stutterers is difficult because only 1% of the population is affected. As affluent companies are reluctant to act as sponsors for a cause with ostensibly such a "minor" public importance, recently we have fewer funds at our disposal. As the shortage of funds has recently endangered the very operation of the foundation, we have decided to launch programmes of our own to raise money.

Legend has it that Demosthenes, put a pebble under his tongue in his bid to overcome his speech defect. Our foundation bore his example in mind when it chose as its logo the *Pebble with A Smile*, a work of art and generous donation by Hungarian applied artist Gyula Molnár. The logo implies the following message: "If you work really hard, you can do even what seems to be impossible."

Stuttering can be treated in several ways, and "complex arts therapy" is one of them. A stuttering boy who attended a complex arts therapy lesson once drew a pebble that had an angry face and showed its teeth. When asked why he did so, he said his drawing showed his suffering from his stuttering. His words prompted us to embark on a series of art contests whereby participants are asked to decorate a stone (or pebble) and send it to us for assessment. Year by year we invite decorated stone donations and make an auction and sale to raise some money. Not all stones are up for sale though: we have a collection of nearly 1000 pebbles!

This year stone donations have come from Iceland, Japan, New Zealand and Slovakia. Hungarian Olympic champion épée fencer Tímea Nagy has contributed a stone that she picked up in Greece. Among the guests attending this year's gala on 16 October will be Konrad Schaefer (Cologne), who will represent ELSA (European League of Stuttering Associations).



## New Zealand Speak Easy Association

**By Warren Brown**

The New Zealand Speak Easy Association is going through a good patch at the moment with a lot of positive momentum.

Recent applications for funds have been rather more successful than the generosity of the last few years.

The association launched its new, full-color brochure earlier this year and this seems to be generating more interest in the community than past public relations efforts.

Speak Easy's two websites at [www.speakeasynz.org.nz](http://www.speakeasynz.org.nz) and [www.geocities.com/speak\\_easy\\_nz](http://www.geocities.com/speak_easy_nz) continue to generate interest among those seeking help with stuttering - either for themselves or their children.

As well, most of the branches and groups around the country seem to be in good heart. That usually indicates that those who are attending are gaining much from belonging to the organization.



Aurelia Margot (left), a Tauranga speech-language therapist, and Dr Ian Taylor, vice president of the New Zealand Speak Easy Association, who held a poster opening at Tauranga Hospital, Tauranga, to mark the New Zealand Speech Therapists' Association's national awareness day for stuttering on August 19.



New Zealand Speak Easy members at the annual conference in Christchurch on May 15

## National television network made a program on stuttering

By satoru hanazono

All Japan GeNyukai Association (AJGA)

NHK Fukuoka, a local station of national television network, broadcasted a 25-minute program on stuttering, featuring one of our members Yoshikazu Kikuchi, a 25-year-old medical student. This documentary caught his appearance in our convention "Reading Boxing", medical practice in hospital, small talks with people in shops and restaurants he dropped by, regular meetings in his local chapter and so forth.

The audience saw his change from his early days of hiding stuttering, to coming out and acceptance of himself. Kikuchi said "It isn't good just to like myself when I'm speaking fluently. Denying myself when I stutter means denying my friends in stuttering community."

Television staff not only spent two months preparing this program but also joining our annual convention. "It was a wonderful program." said Kikuchi, "when I first saw it, I felt they made a pretty good job because it expresses all my feelings. Many people, including friends in my part

time job, former teachers in schools and even people who I didn't know, gave emails and letters after the program. I want people to know more about stuttering and mass media is a powerful way to promote stuttering. It is just the beginning." (Takahiro Kato, translated by Satoru Hanazono with a help of Charlie Wang)

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### ISA mission

## A world that understands stuttering

### Objectives of the ISA \*

Our main objective is: To improve the conditions for children, adolescents and adults who stutter and parents of children who stutter in all countries, by:

1. Sharing concepts and information about self-help and therapy methods.
2. Outreach to make the movement bigger.
3. Facilitating communication and cooperation.
4. Educating the general public.
5. Stimulating research.
6. Being an advocate.
7. Assisting in founding of international working groups.
8. Initiating public relations projects.

\* From Thomas Krall Keynote speech given in the 3rd IFA congress in Nighborg, Denmark, August 2000

## National Her Child Stutters and she became a pyromaniac

**By Albert Zhang Jianliang, from Shanghai, China**

### *The sad story of a stuttering child's mother*

On Nov. 5, 2003, Xinhua Online (sponsored by Xinhua news agency, China's largest news agency) reported that a mother wanted to set 100 fires to help cure her child from stuttering, and finally was sentenced to 3 years of imprisonment.

Mrs. Zhao, whose child stutters, lives in Tongxu County, Henan province, mid-land China. As she could not find help from hospitals for her stuttering child, she went to a fortuneteller, and was told as soon as she finished setting 100 fires, her child would become fluent. Hence, starting in October of 2002, she began to set fire to her neighbors' straw in the open fields. More than 20 fires were set before she was caught by the scared and angry villagers. In court, she showed great repentance and regret.

The news did not say anything about Mrs. Zhao's child's stuttering:: is it a boy or a girl, how old is him/her, how severe is his/her stuttering, etc. This story demonstrates how much children's stuttering is neglected in China.

When I was a young boy stuttering severely, my mother did not treat it seriously. She thought that this disorder would disappear when I matured, just like another boy in my neighborhood. On rainy days when I stuttered she would slap my face really hard, which is a belief and practice of many, many Chinese. Being a proud and sensitive boy, this action only added to my feelings of humiliation. I became silent, unwilling to talk to her. It took me about 20 years to learn to communicate with her in an appropriate style.

Now, looking back, I feel fortunate that my mother did not choose to set fires to treat my fluency disorder. I could not imagine what would happen to a stuttering child when his/her mother was put into prison just because his/her stuttering. That would be a heavy burden even to a normal child, much less than when the child had great difficulty in communication.

### *The fact: stuttering in children is neglected!*

In recent years the business of stuttering treatment flourishes. Now there are over 40 programmes throughout China, nearly half of them developed since the year 2000. Within 3 hours travel inside and outside of Shanghai city, there are 13 people who treat stuttering. One has been in this area over 40 years (almost retired now), the others, vary from 9 years to several months. Nearly every one of them is self-educated, which is to be expected since stuttering disorders have never been studied in any scientific research in China. From 1988 until the present, 9 devices have been patented to inhibit stuttering, including the "ancient" pace-maker (whose manufacturer has been

advocating it as the magic cure), and the SpeechEasy, the newly-invented DAF/FAF device. Approximately 5 medical treatments, primarily Chinese herbs, are said to be effective to treat stuttering. Since we believe that there are over 10 million people stutter in China, and the developing economy requires of everybody more complicated and efficient communication skills, it is no wonder that there are great demands for fluency disorders treatments.

However, almost none of the programmes, devices or medicines are specially designed for the child who stutters. Some therapists might hold courses for children during their vacations in winter and summer, but usually they will mix the children with adults, and the treatment is the same, that is, most likely smooth speech, or prolonged speech. This summer, Mrs. Lin Lan (a retired assistant professor) started courses for stuttering children and teenagers in Beijing, together with the brain-cognition team from the psychology department, Beijing Normal University. One team member, doctoral student Liu Xugang, had previously been a mild stutterer. Usually they were 5 to 7 days of training, altogether 20 to 30 hours, and parents were required to accompany their children. Since I have not read any published papers about their therapy, and have no direct communication with Mrs. Lin Lan, except their advertisements and the feedback of some of her adult clients, I can say no more.

No investigation has been launched about children's stuttering, at least in mainland China. There may be some investigation about children with hearing loss, mental retardation, etc, but not about stuttering. Most therapists and researchers claim the percentage is 3-5 percent, similar to that in western countries, but some say it is closer to 8-15%. That is obviously astonishing. However I cannot determine where this data is from. According to Dr. Yang Shulan, there were only 116 preschool children who have speech/language disorders throughout Taiwan (from the Taiwan education department's statistics, in 1999) and only 7 in Taipei city in the year 2000. The number was greatly underestimated, as every stutterer knows with instinct. Normal people tend to ignore stuttering, while the stuttering therapists tend to exaggerate its numbers.

No researchers are specialized in area of stuttering. Only in 2004 did the major of speech language pathology appear in universities in mainland China (in East China Normal University located in Shanghai), and to date there still are no professional researchers on stuttering. Dr. Song Luping, a neurologist and psychologist, who received her Ph.D. degree in Beijing Normal University, wrote some papers on stuttering; Dr. Li shengli in Beijing and Dr. Jin Xinming in Shanghai, attended the 6th World Conference For People Who Stutter in Ghent, however they are specialists in rehabilitation medicine. In Taiwan,



there are Dr. Yang Shulang, Prof. Yairi's Ph.D. student, and Dr. Jennifer Zeng, also a speech-language pathologist, but, due to the complicated relationship between mainland China and Taiwan, they cannot help stutterers across the narrow strait.

There are few materials for stuttering in children. In year 1999 or so, Mr. Stefan Hoffman, Vice chairman of the International Stuttering Association (ISA), developed the Chinese website of ISA and translated some papers into Chinese. One that is very valuable is, Sometimes I just stutter, a small book by Eelco de Geus. In addition, I discovered some valuable instructions in Hong Kong and Taiwan. I searched the database of 4 of the most important newspapers in Shanghai and found that in the last 2 years, there were 13 articles with the keyword stuttering -- 12 of them were basically advertisements, the other was a very short article consisting of only about 100 Chinese characters, and was news translated from Western papers.

In the large rural areas where about 70% of the Chinese people live (approximately 0.8 trillion), mothers like Mrs. Zhao cannot get help from any professional therapist, or they cannot pay for therapy. One 5-10 day course for stuttering usually will charge from RMB 500 to 3,000 (about \$60 to \$400), plus traveling and accommodation fees. For a financially poor family, it would be ridiculous to even think of spending half or their year's income to treat their child's stuttering, especially when most rural people regard this disorder either as a inherited disease that cannot be treated, or believe it will be out-grown. The social welfare system has not, and will not in the near future, cover therapy for stuttering.

School teachers have little knowledge about speech/language problems, and are not trained to help pupils with speech disorders. I have contacts with some special education teachers, and to the maximum of their scope of knowledge, they know nothing more about stuttering than a lay person. On International Stuttering Awareness Day, year 2003, our Shanghai Stuttering Association members got together on the lawn of the East China Normal University, with a banner indicating ISAD. The future teachers came and went, and chuckled when they saw our banner. "What is stuttering?" I heard one girl asked the other girls, and the reply was "K...K...Kouchi!" (the Chinese word for stuttering) with contempt.

Social awareness has little to do with stuttering problems. I have only read two articles about International Stuttering Awareness Day, one of them reproduced on several websites. For the 2004 International Year of the Child Who Stutters, not only have people who don't stutter neglected it, but the stutterers active in most

stuttering self-help group and websites do not consider it as a serious topic. I would like to suggest that this problem must be resolved with an increase in awareness of stuttering and other disorders, and raising the responsibility of stutterers themselves.

***The future -- It's meaningful to change the world of even one child who stutters***

In the search engine Google, typing in "kouchi" (stuttering) in Chinese character, there will be approximately 63,100 results, half of them worried young mothers eagerly searching for help about children who stutter. This is a good sign to predict that children's speech development has been taken into serious consideration of parents, and I believe their recognition will lead society to regard stuttering as serious a disorder as hearing loss. When this happens children who stutter can live in a more friendly situation. The problem remains, however that there is still no real stuttering specialist in China, and the so called "specialist" that give advice on the internet, although they can sometimes provide useful ideas, do not have any interest in raising social awareness of stuttering. There is still a long path ahead.

The development of stuttering self-help group has burgeoned since the year 2002. Primarily they are started by ardent young stutterers typically in their 20s, and at present they only focus on improving their own fluency. However, their activities have been reported by some newspapers, radio channels, in some large cities. Stuttering is beginning to catch the eyes of society, and I believe, in time, the self-help groups will advertise to help the stuttering children. There are always people willing to carry these responsibilities.

The professional study about the disorder of stuttering will be carried on in the near future. As far as I know, several Chinese, including myself, have applied for the research program about stuttering in USA, and in other countries. Also several postgraduate students in psychology have shown great interest in stuttering. Now that there is a post-graduate program for hearing loss, and an undergraduate course for speech and hearing science, soon the dysfluency disorder will be included in these programs, as stuttering is really a communication problem that cannot be neglected.

Finally, I would like to thank Mr. Stefan Hoffman and the ISA. Mr. Hoffman's great job in China effectively propelled the development of Chinese people's awareness of stuttering. The ISA, and other national or international groups, have set a model for the Chinese stuttering self-help groups. Following their path, I have full confidence that our effort can help Chinese children who stutter to have a brighter future.

# A Resource for Children, Teachers and Parents

## -The ISA's CD Rom Project

### By Mark Irwin, ISA Chair Board

In our quest to relieve the distress and misfortune of stuttering the ISA has paid particular attention to children in 2004 designating it - the International Year of the Child who Stutters. A CD Rom has been developed which is aimed at educating teachers so they may be more able to recognize stuttering (overt and covert) and support the efforts of Speech Pathologists in their treatment of children who stutter. The text below was included in the recent 2004 Online Conference.

#### The Problems

1. Stuttering is still misunderstood. It is defined from the perspective of the listener who associates it with uncertainty, anxiety and lack of confidence in the speaker. It is not understood that the physical and emotional struggle to speak well takes a heavy toll on the speaker who often resorts to avoidance, substitution or circumlocution to avoid openly (overtly) stuttering. These facts mean the extent of the stuttering is often missed by teachers and parents. They either assume fluent speech will result when the child matures and confidence develops, OR they do not detect situation avoidance (e.g. requests to a person in authority) and word substitution. It was felt the avoidance and substitution behavior, which has been now defined as covert stuttering, needed to be highlighted to teachers and parents.
2. Many children who achieved fluency in their one to one meetings with their speech language pathologist continue to struggle in a class room setting. It was felt a broader understanding of stuttering by teachers would enable them to manage stuttering recovery in their students and also enable them to collaborate more easily with speech pathologists.
3. Only relatively few schools in the world have an appointed speech pathologist. In addition private speech pathology services are only available in relatively few countries. So for most children who stutter, teachers and parents are the only source of guidance and support. Therefore providing teachers and parents with current information and advice on stuttering management is a vital endeavor for the International Stuttering Association.
4. Written information on stuttering is available but it is often poorly packaged. It can be either too scientific, or too general, or too cumbersome for the reader to find the specific information required. Furthermore it is often only appropriate to the region/state in which it was produced. Electronic information (the internet), while providing a slightly easier means to access specific details, is still not available to most children in the world.

#### The Project

At the World Congress in Ghent 2001 a meeting of

interested individuals resolved to have the ISA work with member associations to produce and distribute through education systems world wide in 2004 a CD Rom containing information on stuttering of particular relevance to teachers.

#### Why a CD Rom?

A CD Rom was chosen rather than website development, because internet access was assumed to be available to relatively few schools throughout the world, whereas computer use was far more wide spread. A CD Rom meant information could be distributed more cheaply (saving printing and transport costs) and accessed in a more user-friendly way (saving time for time-poor teachers).

#### Why Focus on Teachers and Parents?

Professional speech therapy administered by specialists in their field is a service that, in world wide terms, relatively few can access or afford. Teachers in most countries are the only source of support outside the family and their ability to sensitively deal with the stuttering child in a group setting is fundamental to long term recovery. In those countries where speech therapists are available, teachers are often the referral source and must work with the speech therapist if the most effective treatment is to be provided. Parents need the same information as well.

#### Why 2004?

A time line was necessary and 2004 had previously been designated by the ISA the International Year of the Child Who Stutters (IYCWS). It was felt that cross fertilization between the CD Rom project and the activities of the IYCWS, would be of mutual benefit.

#### Strategies

- *Gather information in easy to read format*
- *Add film/ pictures/stories- to heighten insights through emotional appeal*
- *Link to popular concerns about Teasing and Bullying*
- *Employ a graphic designer/CD Rom producer*
- *Seek feedback and involvement from ISA member associations*
- *Seek endorsement from the World Health Organization and UNESCO*
- *Liaise with Education Departments regionally and nationally.*

#### Outcomes

The first version of the CD Rom has been produced. It was developed by designers employed at Smart Media of Modbury, South Australia. It was presented and given to

interested delegates of the 2004 World Congress of People Who Stutter which was held in Perth Australia. People from 26 nations attended this Congress. In America it is to be shown and distributed at the ASHA (America Speech and Hearing Association) Conference in November 2004. In Australia discussions have taken place with the Federal Minister of Disability Services with the view to national distribution through schools. (no resolution as of August 04.) In Spain it is being translated with the intention of distributing it to the Hispanic speaking countries of Central and South America. Unfortunately in Africa in 2004 computer use is still not available to school children. (If a school does possess a computer it is used for administrative purposes only.) However Joseph Lukong from Cameroon and Moussa Dao from Burkina Faso have both, on behalf of their associations, been able to print and distribute to schools hard copies of some of the information contained on the CD.

### Content

A huge boost to the project was achieved by adding some of the free access information previously collated by Judy Kuster for the 2003 online conference. Other boosts were the kind donation by Erik Lamens of his film "To Speak", the offering of the "Cracked Jar" story from Claudia Groesman, and the detailed information on Teasing and Bullying provided by Marilyn Langevin.

Content in the current version includes

- *Definition of covert stuttering.*
- *Frequently asked questions.*
- *Identification and management strategies for teachers.*
- *Information for parents.*
- *Specific information on Teasing and Bullying.*
- *Erik Lamens film "To Speak."*
- *"The Cracked Jar", a positive story on stuttering with accompanying pictures.*
- *Links to other sites.*

An online version of the CD on the ISA web site [www.stutterISA.org](http://www.stutterISA.org)

### Availability

The CD will be available at the ASHA Conference in November. It is also available by donation to the ISA from Dr. Mark Irwin c/- ISA, 217-219 Payneham Rd. St Peters. SA 5069 AUSTRALIA. PH. +618 83620387 or FAX +618 83626020

### Acknowledgements

Those present at the first meeting in Ghent Belgium included Manfred Fitzner and Petra Schmiedecke from BSSV, Cherry Hughes and Rachel Everard from the BSA, Jaan Pill and Marlene Green from CAPS, Michael Sugarman from Friends, and Annie Bradberry and Judith Eckardt from NSA.

At that stage the German association, Bundesvereinigung

Stotterer-Selbsthilfe e.V., had already produced a CD of their own, while the British Stammering Association were a few months from releasing their CD specific for use in the education system in Britain. The meeting was able to learn from their experience.

The ISA is also grateful to Claudia Groesman, Judith Kuster, Eric Lamens and Marilyn Langevin for their subsequent contributions.

I appreciated chairing the first meeting (many stimulating ideas were generated) and have enjoyed developing this project since. I trust ISA member associations will be able to encourage and support each other to ensure the CD is distributed as widely as we had initially intended. There is still a lot to be done for children to relieve distress of stuttering. Please contact me for a copy of the CD if you think you or your association would like to arrange its distribution in schools in your area.



Note: Children within this photo, which also appears in ISA's CD Rom, are models that might not stutter.

Please visit ISA at [www.stutterISA.org](http://www.stutterISA.org)

**ISA - International Stuttering Association** is a worldwide network of people who stutter, a non-profit umbrella association dedicated to close cooperation among independent national and international self-help organizations of people who stutter. ISA was founded in 1995.

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## 2003 for the European League of Stuttering Associations

By Edwin Farr

Not all people who stutter regard themselves as disabled. However, they are often treated as such by society, facing discrimination in many areas of life. ELSA, the European League of Stuttering Associations has worked very hard in 2003 to make the Year a success. With the support of the European Union, they have developed several projects to change perceptions and contribute to a political change towards a barrier-free society.

### ELSA's main projects during 2003

- **Further development and maintenance of the ELSA Web-Site**

The ELSA web site ([www.elsa.info](http://www.elsa.info)) has enabled wide dissemination of information on stuttering and disability. ELSA was able to provide the National Stuttering Associations with the opportunity to post their activities and have a link to their own sites from ELSA's. Hits to the ELSA web-site increased by 88% and the content in terms of megabytes doubled over the duration of the information campaign.

- **Production of electronic newsnotes sent out by email.**

The link between ELSA's activities and EYPD activities was highlighted in every news notes email. Distributing information via email allowed for the greatest audience to be reached. The news notes were available to all interested parties linked with stuttering as well as other European NGO's.

- **Production of an information brochure on "European and International Disability**

### Policy and how it relates to people who stutter".

This was ELSA's flagship publication for the EYPD, and the EYPD was deemed the ideal vehicle for the release of such a brochure. The brochure was not just written to relate to the disability of stuttering but, as a gesture of solidarity, for the disability sector in general. The publication was launched at ELSA's Stuttering and Disability Awareness Conference in Strasbourg. It also featured on the online conference for the International Stuttering Awareness Day (22nd October 2003).

- **Organisation of a Stuttering and Disability Awareness Conference, held in Strasbourg 17-19 October 2003.**

This conference brought together key players from the field of stuttering and over 20 countries were represented. It was scheduled to coincide with the International Stuttering Awareness Day. The conference was opened by Bruno Gaurier of the French National Disability Council. The local organisation was carried out by members of the Association Vaincre Le Bégaiement (AVB). Keynote

speakers at the conference presented on a wide variety of topics related to stuttering and disability awareness. Additionally, Bruno Gaurier and Edwin J. Farr presented on the EYPD and the EDF. There were also four workshops held during the conference.

### Challenges ahead

ELSA's challenges that lie ahead include:

- To build upon and maximise the achievements of ELSA's activities throughout the EYPD;
- To continue raising awareness of stuttering, which is an often hidden disorder not widely acknowledged as a disability;
- To ensure individuals who stutter are not discriminated against, prejudiced against or held back in any social capacity;
- To assist in strengthening the capacity of fledgling Stuttering Associations within the accession countries;
- To further develop the exchange of experience and good practise;
- To promote work focussing on children and young people who stutter;
- To seek resources for the challenges above.