

# One Voice



International  
Stuttering  
Association

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Incorporating *The Voice of ELSA*, the newsletter of

**European League of Stuttering Associations**



Mauritius: Friends 4 Fluency announces its winding up. See page 8.

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*A world that understands stuttering*

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# The ISA is short of funds

By Michael Sugarman, USA

Imagine a place where people who stutter are supported and accepted – meet other people who stutter and learn about themselves and about speech therapy – the association in Argentina will be hosting a World Congress for PWS in 2011.

The ISA is a non-profit organization. This means that our very existence depends on financial support from our member associations, from people who stutter, and from other sources.

One of the goals of the ISA is to educate PWS and SLPs regarding what is available in terms of mutual support and speech therapy. Annual dues from member associations provide the ISA only with a very small amount of money. We have both individual PWS and member associations asking for help. Giving help requires that we have money. I am asking those who can to help by donating money for those who are unable to participate because of lack of funds. Any amount will be welcome.

I want to tell you about two specific areas where help is needed:

The first is the *2011 World Congress in Argentina*. As stated above, the ISA needs money to provide scholarships (sponsorships) to help some PWS who apply to go to the Congress, especially from less developed countries.

The second is *ISP-S teams*. The ISA has developed the idea of small teams of qualified people going to countries where help has been requested and is needed to assist in providing ideas and therapies to assist those who stutter. The teams consist of one or two SLPs/SLTs, to talk about diagnosis and therapies, and one or perhaps two ISA Directors or Advisory Board members to talk about self help groups / chapters and to give personal accounts of what can be done. These teams talk to PWS / CWS (Children Who Stutter) / SLTs / STPs / teachers in schools / employers / and the local health service about Early Intervention / local and national media / and Self Help Groups or

Chapters. The main thrust of the talks is to help the educators and CWS improve the communication skills of children (and adults) so that they become potential providers. In the long term, this benefits both the CWS and the country. These teams have worked very well in Africa. They are needed in many places around the world. The ISA needs to pay travel and some accommodation costs of the members of the teams. Sadly, right now the ISA has no teams working in the field because of lack of money. One ISA Director went, with no ISA financial support, to India a few months ago and participated in this kind of a program to great effect. There are details about this trip on the Indians' blog site. This is an outstanding potential kind of aid. It helps the local people to help themselves. This becomes a very great benefit to the country concerned, as it increases the number of net providers.

One ISA Board member has suggested that those who donate 10% of their income to their church or synagogue consider diverting say 2% of their income to the ISA (reducing their church or synagogue donation accordingly). An Advisory Board member has suggested that if instead one has a total donations budget of say 10% of gross income, maybe half of that 10% should go to charities other than the church, including cancer, diabetes, the Red Cross, the university from which they graduated, *and the ISA*.

Donations can be made by direct transfer as follows:

**Nordea Bank DK, 9800 Hjørring - International Stuttering Assn c/o Christmann, Bregnevej 10, 988 Hjørring, Denmark . Reg. # 2620 Acc # 5005 992 674. IBAN DK 60 2000 5005 9926 74 SWIFT/BIC:NDEA DK KK**

Or, payments can be made by mailing a cheque payable **to the International Stuttering Association** (or just **ISA**), addressed to **Hermann Christmann, Bregnevej 10, 9088 Hjørring, Denmark**.

Or, if more convenient, a donation can be made via PayPal to [keithmaxkb@yahoo.com](mailto:keithmaxkb@yahoo.com).

For any donation, please send an email about your donation to me ([msugarman1@sbcglobal.net](mailto:msugarman1@sbcglobal.net)). The

ISA will acknowledge your gift to you if you provide your name and address. Please let me know whether you want public acknowledgement of your gift.

## Message from ELSA

By Edwin J Farr MBE

The **European League of Stuttering Associations (ELSA)** celebrates 20 years this year. It was in Darmstadt in 1990 after 3 years of preparation that ELSA came into being. On 22 September 1990, 12 European Stuttering Associations formed an umbrella association and we named it – well you know! We all signed a set of working principles which later formed the basis of statutes that govern the work of ELSA. We had great ambitions, our preparations had identified funding available from European bodies and we wanted to target these funds to raise awareness of stuttering. The formation of ELSA actually goes back to 1987 when the German Stuttering Association held the very first European Meeting for people who stutter in St Andreasberg. This was a milestone in stuttering self help. Following that meeting three of us Konrad Schaefer (D) Odd Bjorn Ure (N) and myself, Edwin J Farr (GB) were asked by the European National Stuttering Associations to look into the possibility of forming a Europe wide umbrella association. We prepared a report for presentation at the World Congress in Cologne in 1990. This got the thumbs up and the rest is history with ELSA being born later that year in Darmstadt.

20 years later, in brief, let's look at what have has done

I would say a lot given that all the Board and volunteers have carried out their work together with their full time jobs. So many people have worked many hours helping others.

We have held 7 Youth Meetings for young people who stutter part funded from the European Council. Some delegates from the youth meetings have gone on to great things, with many becoming chairs of their own national stuttering associations and many others becoming very successful in their own career. I have lost count of the number of delegates who came to me at the end of the youth meetings and said it was the best week of their life.

We have secured funding from the European Commission for stuttering awareness programmes and held weekend seminars across Europe for National Stuttering Association delegates in locations from Vienna to Strasbourg to Dublin.

ELSA introduced the issue of stuttering as a disability, a very brave concept in the mid 1990s. We had our critics but it was clear to many of us on the Board that stuttering can be disabling and at the time we felt compelled to align ELSA with the disability movement. Indeed ELSA was a co-founder of the European Disability Forum (EDF) and plays a part on their General Council. Recent work has included liaison with, and giving presentations for, an organisation named the European Clinical Specialization Fluency (ECSF) contributing to raising awareness of stuttering self help for young speech and language therapists.

That's the last 20 years.

Back to the recent times. Just recently we held our 7<sup>th</sup> Youth Meeting in Giggleswick, UK and are currently

looking to organise our 8<sup>th</sup> in 2011. Since 2009 we have a new webmaster, Richard Bourgonien, a member of the Dutch Stuttering Association. Richard took over from Gina Waggott in 2009 who managed the website for the previous 5 years. The Board of ELSA would like to take this opportunity to thank Gina for her work and her time as an ELSA Board member.

If you are interested in the history of stuttering self help over the last 20 years then go to the ELSA website, [www.elsa.info](http://www.elsa.info) and read some past editions

of the Voice of ELSA. Also on this website you can read about ELSA's current work.

Best wishes to all this summer.

Edwin J Farr MBE

Chair of ELSA

## Message from ISA Outreach

By Keith Boss, ISA Director

It is a privilege to continue working in ISA Outreach. This task allows me to see many initiatives around the world to help people who stutter. My own personal highlight was a visit to India to meet members of The Indian Stammering Association (TISA). It was a whirlwind two weeks where I made many new Indian friends. Together we had many meetings with people (adults and children) who stammer / Self Help Groups / Speech Language Therapists / all staff at several schools / staff at one teachers training college / employers / employees / hospital staff / media, both TV and newspapers and last but not least, supporters and friends and families of people who stutter. It was a very useful and rewarding visit. I thank everyone in India who helped to organise all the wonderful events.

In May 2010, the ISA circulated an Executive Summary of the work carried out by the 10 Recommendations committee, started in 2007. I am very pleased that this Executive Summary contains some practical tasks, for all National Associations and their Self Help Groups / Chapters, that will enable all of us to reach more people who stutter; make some of their working lives a little easier and to raise the awareness of stuttering around the world. In an article from Denmark in this One Voice you will read about Ambassadors-at-Large. I know that many National Associations carry out this kind of work already, but what caught my attention was the job title -----

### Ambassadors-at-Large

May I make a suggestion or two? Can every ISA Member Association initiate an Ambassador-at-Large program for their own Association? The Ambassadors will be volunteers from the National Association and hopefully at least one from every Self Help Group / Chapter. The Ambassadors can study action ideas (even if it is only ideas from the first three recommendations) suggested in the Executive Summary to link these two initiatives. This will accelerate the mission 'to raise awareness of stuttering around the world' to benefit us all. This is a very practical way for all of us to reach out (Outreach).

Many people who stutter around the world request information / help on the Internet. If the request has gone to say the BSA / NSA they will pass the emails from non-nationals to me. I also receive emails passed on from other sources. This is both troubling --- the number of requests for help, and rewarding --- because there is usually a way to help. It is always very good to link up people in one country, especially if they think they are alone. I have one cause for concern. I have a very big daily email spam box that I need to delete. Although I do scan through the content, there is a chance I may miss the occasional

important email. So please, if you think I may have missed an email from you, do send me another email.

I know that more Outreach is required because of the emails asking for help. There is a need to help small / new National Associations; to help to start more Self Help Groups / Chapters and to begin to work in countries where there is no help. The knowledge about how to help exists within the ISA but the time to help other Countries is limited. We need volunteers who can spend a few hours a month working on the Internet and we need funds to send working teams (ISP-S teams) to countries for face to face meetings with PWS / Health services / Teachers (Early Intervention) / Employers. Can you help the ISA by either donating some time or donating some money? If you are a National Association Chair, can you divert a little money to help the ISA to spread the best practices of Early Intervention around the world, or can you put a message on your website that the ISA needs volunteer's time? If you can help in any way, please contact me.

I would like to reinforce our Chair's request for donations towards helping people, with limited or no funds, to attend the next ISA World Congress in Argentina. A world Congress is an ideal opportunity to

meet other people who stammer/stutter and people who wish to help to deal with our disrupted communication. So much can be learned and so much confidence can be found by those of us who are usually silent and withdrawn. New ISA Directors / ISA special friends are born at an ISA World Congress. Please can you help with a donation of money? Many people donate a percentage of their Salary to a favourite Charity or Church. Will you change what you do by giving say 2% less and donating that 2% to the ISA? This would help us to help others. None of your donation will go in administration costs. All of it will go to helping others.

(If you wish to donate money (or your time), please look at the end of the message from our Chair, or contact [keithmaxkb@yahoo.com](mailto:keithmaxkb@yahoo.com). You will be contacted as soon as possible. The ISA would like to acknowledge donations in our next e-newsletter, but if you ask for no publicity, we will mention the amount, but not disclose your identity.)

I look forward to working with more of you over the next six months.

Keith (UK)

## 2010 is Big at the British Stammering Association!

The British Stammering Association jumped into 2010 with the creation of the BSA Facebook page. The page is forever growing in popularity, with nearly 600 followers! It continues to grow as a worldwide online forum for all those affected by stammering. We also have an ever-growing presence on Twitter, with over 100 followers. You can find out more about our social networking presence here: <http://stammering.org/socnet.html>.

We've also started Non-Avoidance Days, which take place on the last Friday of every month. The aim of NAD is to encourage people who stammer to gain confidence through speaking in challenging situations.

Every month, more and more people are participating, sometimes with fun prizes to be won. Generally, those who do take part are finding the experience of non-avoidance to be a positive one. One participant commented: *"I called a computer company to get my laptop fixed!!!! I just spent about an hour on the phone getting transferred to different departments, but I did it! My mom would usually call them for me."*

On 11<sup>th</sup> July 2010, six participants will be running the ASICS British 10K London Run for the BSA! This group of dedicated individuals will be running around central London to help raise money to support people who

stammer. No matter what the result of the World Cup Final may be, they will all be winners to us!

The next BSA's London Open Day will take place on Saturday, 4<sup>th</sup> September 2010. Although plans are still underway, this year promises another great turn out with informative and interesting sessions planned. The BSA's annual general meeting will also be held on the day, making decisions for the year ahead.

There will also be other events held throughout the country, including a further two open days in Durham and Norwich later in the year. Also, the BSA Scotland "Walk N Talk" Weekend 2010 will be held at Invergarry Lodge from 10th to 12th September. As usual, the weekend promises fun, fresh air and friendship...and of course, lots of talking!

Overall, here at the BSA we are, as ever, working towards a world that understands stammering.

## What's up in Germany?

### *Current Projects of the German Stuttering Association (BVSS)*

**By Ulrike Genglawski**

The German Stuttering Association, based in Cologne, is realizing medium-term and long-term planned projects, relating specific education about stuttering and concrete support for people who stutter and relatives. Here are three examples of our work:

- ✚ Producing a nation-wide register of stuttering therapists. Four of the 16 federal countries are already registered; four further countries will follow this year. So, the register is constantly growing step by step, to support everybody's searching for a qualified stuttering therapy.
- ✚ An investigation relating to the rights of people who stutter in Germany. For example, pupils who stutter in Germany have help for the disadvantage (e.g. being given extra time or allowed to write), to produce their oral achievement by equal opportunities. Unfortunately only very few people know about these options and how to use them. Our investigation, which is already finished, will bring clarity. Initially, it will be published

as a book and we plan a brochure in parts for parents and teachers.

- ✚ An education film about stuttering is under construction. Professional filmmakers are producing a DVD by order of the German Stuttering Association, which will cover the whole spectrum of the stuttering, from personal dealing with stuttering, therapy and self-help approaches up to an excursion about the representation of stuttering in the media.

In addition, we have naturally informed, advised and will inform, advise many parents, young persons, adults and teachers for schools and kindergartens. Leaflets and pamphlets will be updated or published in a new form, e.g. the new leaflet for young persons who stutter, called: "S as stuttering - what you should know and what you can do". We also work at public relations and cooperation with the media. Last, but not least: We celebrated a birthday! In 2009 the German Stuttering Association celebrated its 30<sup>th</sup> anniversary at the congress, which took place in Cologne.

# Ambassadors-at-large

**By Per Fabæch Knudsen (coordinator) and Hermann Christmann, Denmark**

One of the activities of The Association for Stutterers in Denmark (FSD) is offering schools, institutions, teachers' colleges, work sites, associations, and other interested all over the country, is a visit by one of the "Ambassadors-at-large".

The Ambassador-at-large Corps has existed since the 1990'es, and for the time being it consists of about 12 individuals and one coordinator. The ambassadors will tell about their experiences with stuttering and about the FSD and its work. All of them speak from a long personal experience with stuttering, either as a pws or as a parent of a child or adolescent who stutters.

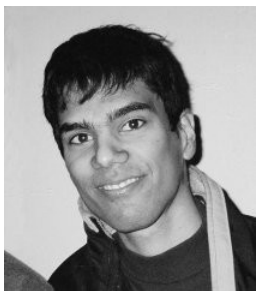
A visit of an ambassador is free of charge, as the ambassadors work voluntarily. If the host is not able to pay travel and entertainment expenses for an ambassador, the FSD will reimburse the costs. To have an ambassador visiting you, you may contact the coordinator or one of the ambassadors directly.

Contact information and other information as well as brief personal introductions of the ambassadors is available in Danish at

<http://www.fsd.dk/ambassador.pdf>

## The year 2010 in Finland

**By Timo-Matti Fahmy, AFS Board Member**



Association of the Finnish Stutterers (AFS) is very active despite its small size. It has got about 500 members all over the country. It is estimated that there are 50,000 stammerers in Finland so a lot of work needs to be done to reach them. In the

autumn 2009 AFS celebrated its 40th anniversary. The association works on a voluntary basis and most of the money comes from Finland's Slot Machine Association which funds about 1000 organizations in Finland. AFS was founded to help stammerers in Finland to keep in contact with each other and increase awareness of this speech disorder. In the year 2010 AFS has organized one meeting for its members and there are two more coming in the autumn. Socialising and sharing experiences are the most important reasons why stammerers gather together three times a year.

In between the meetings, stammerers can attend self-help groups which are located in different parts of the country. Problems and therapy techniques can be discussed there. Sometimes speech therapists or other experts on stammering visit self-help groups. In the autumn 2009 AFS tried to start a peer support group for stammering children's parents. This hasn't succeeded very well so far because very few parents have attended it. There are also several therapy courses available for children and adults. They are completely free for participants and they are led by speech therapists and psychologists.

Two years ago, AFS started a project to spread knowledge about stammering and the association. It is going to end this year but its work will be continued as a normal part of the association's work. Making leaflets and attending fairs and training occasions have been the most important things the project has done. Leaflets have been made for example about peer support groups and stammerers of different

ages. They have been delivered to speech therapists, nurses and remedial teachers. The response to the leaflets from experts has been very positive. During the project, it has become clear that in Finland there is a huge need and demand for up to date information about stammering. This year the project focuses on translating leaflets into different languages to serve immigrants in Finland.

Awareness of stammering has also been increased by articles in newspapers and magazines. Members of AFS have given many interviews this year. Journalists have contacted the association to find information

about stammering which shows that work done by AFS has been fruitful. On October 22 on the International Stammerers' Day, AFS is hoping to get an interview with a famous stammerer published in the biggest newspaper in the country.

Next autumn AFS is planning a training day for students who are specialising in marketing and tourism. It is going to be held in a polytechnic and the idea is to teach students how to deal with a stammering customer. This kind of cooperation is very useful because it spreads knowledge about stammering to people in business life.

## Message from Mexico

By Carlos Montes-Aviles



As stuttering associations continue to evolve and expand worldwide, it is inspiring to know that lives are being changed, and enriched, through stuttering help and awareness. As a person who stutters (PWS), I feel very fortunate to live in a country where a variety of stuttering associations exist, and where stuttering help is available for those who stutter. It is difficult to imagine how my life would have turned out if I had not received speech therapy services.

My name is Carlos Montes-Aviles, and I am a person who stutters and a current graduate student in the

communication sciences and disorders program at Wichita State University in Kansas, USA. I was born in Mexico, but at the age of 9, I was brought to the United States by my parents. Like many people who stutter, I never received services until I reached adulthood. At the age of 21 I was lucky enough to find help for my stuttering at the same school where I am currently enrolled. Although I had to drive 3.5 hours to get to my destination, speech therapy was worth the drive. After experiencing the benefits that I was receiving from speech therapy, I realized that I also wanted to help others.

Being born in Mexico, where stuttering associations are non-existent, and where stuttering services are limited, I began to dream of a better future for those who stutter in my native country. The perfect opportunity came when I had to come up with a non-thesis project for my graduate studies. After brainstorming a variety of ideas with my mentor, Dr. DiLollo, we came to the conclusion that I would create a proposal to create and establish a stuttering association in Mexico. With a Spanish speaking population of approximately 109 million, it desperately needs a stuttering association to expand services and to continue raising awareness.

I realize that I need many helping hands, especially because I do not live in Mexico. Fortunately I have been able to get in touch with other PWS in Mexico thanks to the online stuttering group TTM-L Latin America. I have also received great feedback from a variety of stuttering associations who were kind

enough to share important facts about the development of their associations. If you are interested in helping with this project, or simply have thoughts or ideas, please email me at [camontes@wichita.edu](mailto:camontes@wichita.edu). Thanks to all, and special thanks to Joseph Lukong and the International Stuttering Association.

## New Zealand Speakeasy Conference

**By Marty Van der Kley, New Zealand Speakeasy Association**

On May 14<sup>th</sup> and 15<sup>th</sup> 2010, the New Zealand Speak Easy association held its annual conference in Auckland, NZ. Our conference began on the Friday evening with our oratory competition with the topic being "What winners do to win", which provided participants of the competition the opportunity to each give their different slant on the traits they think people need to be winners, e.g., Attitude, Perseverance, courage and Confidence as well as their own experiences on what they do to be winners. The Friday evening concluded with a light supper which provided members with an opportunity to mix and mingle from other speakeasy members from other speakeasy groups with NZ.

On the Saturday afternoon following our AGM, our keynote speaker was Ian Grant who is the founder of a Parenting organization in NZ – Parents Incorporated, and is also a stutterer himself. The first part of his presentation focused around is we going to let our stutter control our lives, or are we going to choose to live, and be the driver of our own life bus. The second half of Ian's presentation looked at some of the areas that can be important to be an effective communicator, and the importance of communication. Our annual conference concluded on the Saturday evening held at the hotel where our conference was, that was enjoyed by all who attended.

## Mauritius: Friends 4 Fluency announces its winding up

**By Jim Caroopen, Mauritius**

Dear friends,

I am writing to inform you that during a general assembly held on 27th June 2010, the members of Friends 4 Fluency have decided by six votes for and one vote against to put an end to the activities of the self-help group, and to proceed with its winding up.

It is with regret that we announce this decision, but at the same time, it is a well-thought and concerted decision that has been reached after a frank and open

discussion. We have taken into account both the undisputable requirement to maintain on the island an organisation that could provide information and support with regard to stuttering, but also the motivation and availability of each one of us to take responsibility for this work. In very simple terms, we found that we shared a common desire to continue to work for the well-being of persons who stutter in Mauritius, but at an individual level, no one of us was ready to get involved within the organisation in a sustainable manner.

It should be said that the discussions were very animated, but at the end we reached a decision that reflected our situation in a honest manner and with which everyone was happy. In any case, however, we could not escape the fact that in some way we were setting aside the hope that Anne-Marie Simon had to see our group develop into a full-fledged organisation for persons who stutter in Mauritius, i.e. one that is widely recognised and that can bring PWS, parents, SLPs and government authorities to work together. Indeed, one of the underlying objectives of our intensive therapy week of March 2008 was to prepare us to undertake this kind of responsibility in the future – but regretfully it is clear that we have now forfeited our rights to lead this project.

As far as I am concerned, I had both the motivation and the time to continue my involvement within Friends 4 Fluency, but I felt it was important that I leave the lead and the responsibility of new projects to other members of the group. Indeed, I had taken the initiative for a lot of projects of the group since its creation, and I am convinced that no group whatsoever can be sustainable if it is built around one single person. Moreover, it was according to this line of thought that a new organisational structure for was set up in June 2009, and a managing committee of three persons was elected. Their main role was to lead Friends 4 Fluency into the future. But during our general assembly on 27th June 2010, most of the members of the group expressed their lack of motivation to be involved anymore within the group. From that time on, it was clear in our heads that the Fluency Initiative had reached an end, and we rather agreed on how we wanted to proceed with the winding up.

Just to recall, the Fluency Initiative in Mauritius started in September 2005, following my unexpected meeting with Mark Irwin, who was at that time the president of the International Stuttering Association. The unsettling discussions that took place during that meeting ultimately lead to the creation of a self-help group for persons who stutter, the first one in Mauritius, which attracted more and more members, and eventually became a registered association, before reverting back to being a self-help group under the name of Friends 4 Fluency. The Fluency Initiative has contributed to bring about many positive improvements for persons who stutter all over the

island. The self-help groups that were regularly held between 2005 to 2009 have provided PWS with the opportunity to meet other persons sharing the same situation, to discuss freely about stuttering, to learn about stuttering and to benefit from the expertise of Anne-Marie Simon who came twice to Mauritius to participate in a stuttering awareness campaign in 2007, and to deliver an intensive therapy session in 2008. As an attachment to this note, we are sending our souvenir album, which regroups a few photos of some memorable events of the Fluency Initiative.

Before concluding this note, I would like to briefly remind how far this whole adventure has been a defining moment in my life, and has helped me achieve both personal and professional development. The encounter with Mark has been a decisive element, in that it prompted me to adopt a new approach to my stuttering. At the very right time, Mark said the right words that pushed me to do those simple things that lead me to regain self-confidence. These first steps were overwhelming and prompted me to go further ahead, and eventually to make a second important meeting, this time with Anne-Marie Simon. I have learned and received so much from Anne-Marie! But what I keep as being more precious are her friendship, her openness and the comfort of knowing that during harsh times, she has been present to take my defence. Between these two heroes of my life, there are of course a lot and a lot of friends, parents, SLPs and persons from diverse fields that have supported me, guided me, and enriched my life in an incredible manner.

On behalf of all the members of Friends 4 Fluency, I would like to convey a big thank you to all the persons who have participated to our exciting adventure in one way or another; a big thank you to those who were present on the first day, and to those who were present on the last day; a big thank you to all parents, friends, SLPs who have been here to encourage us in our journey, to all the persons who have provided us with a place to meet, to journalists and bloggers who have help us spread our messages; and last but not least, a very big thank you to all our friends abroad for their support and caring attention to us, all through this venture. There are so many of them that I would prefer not to cite any name, by fear of missing out someone. But I would nonetheless like to say a special thank you to Joseph Lukong, who is the one who had

the marvellous idea of putting me in contact with Mark!

Jim Caroopen  
18th July 2010

So, that all folks! Here ends Friends 4 Fluency!

# A Guide for Working with School-age Children Who Stutter

**By Shinji Ito, Executive director, Japan Stuttering Project**

In Japan, speech therapists are employed mostly by hospitals, and school-age children who stutter go to a special class as part of regular school education. In public school, teachers of special classes work with children with various challenges, including speech disorders, learning difficulties, etc. The program focuses on children's total development, not simply focusing on symptoms. This is a unique program in Japanese elementary school education. However, since there is no standard manual or guidelines for these teachers who work with children who stutter, some teachers have difficulty dealing with them.

In Japan, like other countries, effective approaches to working with people who stutter have been explored by researchers and professional organizations, including the International Association of Logopedics and Phoniatics, the Association of Speech-Language-Hearing Therapists, the Association of Special Education, etc. In addition, speech pathologists who have studied in the United States are engaged in the training of speech therapists, and literature on stuttering has been translated into Japanese. Such works include *Treating the School-Age Stutterer: A guide for Clinicians* by Carl Dell, in line with the theory of Dr. Charles Van Riper, and *Stuttering: an Integral Approach to its Nature and Treatment* by Barry Guitar, among others. However, few useful workbook-style guidebooks are available for speech therapists, school teachers and parents to use with children.

Given these circumstances, the Japan Stuttering Project (JSP) and fifteen public school teachers working with children who stutter organized a project

and published a 144-page guidebook focusing on children from school-age to adolescence with work sheets attached.

## ***Basic Concept of the Guidebook***

Japan Stuttering Project has been endeavoring to verify the effectiveness of clinical approaches to stuttering in Japan and around the world. We place importance on facing the fact that we stutter and focus on learning ways to deal with it effectively. We choose not to spend a huge amount of energy to cure, improve and control the symptoms, based on the following three realities:

1. Many people have not recovered from stuttering even after undergoing therapy.
2. There is no effective approach that leads to complete recovery from stuttering anywhere in the world.
3. The severity of the stuttering varies greatly between individuals.

The Japan Stuttering Project, as a certified non-profit organization of adults who stutter, is actively engaged in self-help activities such as holding weekly meetings, publishing books for enlightenment, and offering lectures and workshops for people who stutter. Twenty years ago we began to work with children who stutter. This summer we will have the 21st summer camp for children who stutter and their parents. We are expecting to have about 150

participants from all parts of Japan. This is a collaborative project with speech therapists and school teachers. The new guidebook is based on our hands-on experience and ideas gained from our regular self-help group meetings and summer camps.

### ***Outline of the Guidebook***

We have learned a lot from the approaches proposed by American speech pathologists. These include the language relation figure by Wendell Johnson, the stuttering equation by Charles Van Riper, and the stuttering iceberg theory by Joseph G. Sheehan. These are illustrated in our new guidebook as well.

Dr. Sheehan severely criticized clinical approaches to stuttering which focused only on the symptoms of stuttering. His rationale was that stuttering which is visible above the surface of the water is only a small part of the total picture and that most of the major problems are hidden under the water. In fact, it is difficult to change stuttering behavior above the surface with our will, but it is possible to change behavior under the water, once we are determined to, which has formed in response to stuttering, such as hiding stuttering, avoiding speaking situations, having negative thoughts about stuttering, and having irrational beliefs about stuttering as in rational-emotive therapy. If behavior and thoughts can change, emotions will change.

In our weekly meetings we discuss ways to deal with stuttering effectively, rather than simply spending time talking with each other, and place special emphasis on such learning opportunities as:

1. Learning about issues surrounding stuttering; theories of its cause and effects and the history of related therapy, and approaches to dealing with anxiety and fear.
2. Learning about psychotherapy, focusing on interpersonal relationships in order to understand ourselves and others.
3. Developing communicative skills: speaking, listening, writing and vocal expression.

We invite specialists from various disciplines, including clinical psychology, psychiatry, social psychology, philosophy, education, etc. to our meetings as guest speakers. The main aim of the guidebook is to help children from school-age to adolescence cope with their stuttering. We incorporated the ideas and approaches from the activities of our self-help group meetings into the book.

We also illustrate the "language relation figure" invented by Wendell Johnson, who proposed that stuttering is not just a matter of symptoms, and emphasized how the attitude of the speaker towards stuttering affects the person. We use blocks and paper and clay to make figures so that children can comprehend easily and think about their stuttering. In this way, children can understand what the problems are by externalizing their stuttering. They can eventually take steps to work on their stuttering by themselves.

The most important feature of the book is that it does not focus on stuttering symptoms but emphasizes the importance of working on them from various perspectives. The exercises we presented in this book are all things that we have used in our work with children.

The guidebook also includes messages from Charles Van Riper, Joseph Sheehan, and Scatman John as well as 36 other well respected people from Japan and around the world such as Nobel Prize winners, prime ministers, well-known announcers and movie actors. Thus, the book is designed to draw children's interest.

We've also made *karuta* (Japanese traditional playing cards). There are two sets of cards with pictures and words. Children compete to find a colored picture card that matches the card being read aloud. There are 47 syllables in Japanese. We made 47 short sentences like *haiku* poems (short, traditional Japanese poems), beginning with each syllable. Each card with words gives information about stuttering and conveys our messages. The game is designed for children to enjoy matching the cards, but these are also good teaching materials, full of humor which helps children think about their stuttering. They also learn from these cards how they can assertively handle being teased by other children with humor.

# Increasing awareness for speech-language pathologists

**By Alan Badmington**

To celebrate US National Stuttering Awareness Week, I completed the 11,000 miles transatlantic round trip from Wales (in the UK) to California to undertake the role of guest speaker at the annual luncheon of the Santa Clara County Speech-Language Hearing Association (SCCSHA).

The event was held at the impressive La Rinconada Country Club in Los Gatos, located in the San Francisco Bay area.

This year's SCCSHA President, SLP Mary Ellen Jones (pictured below) enjoys a close association with the San Jose NSA Chapter (support group).

During the talk (entitled 'Lost for Words'), I recounted my lifetime struggles with stuttering. I also shared the many exciting and challenging paths that I have trodden in recent times.

I purposely included several humorous personal anecdotes because I strongly believe that laughter can be an important and powerful tool with which to convey a specific message.

My presentation also touched upon the implications of avoidance; the restrictions imposed by our disempowering beliefs and limited self-image; as well as the importance of expanding our comfort zones in order to achieve personal growth.

I took the opportunity to tell the audience (which comprised principally speech-language pathologists and students) that, in my opinion, addressing the mechanics of our speech (in isolation) has only limited value. I explained how changing my stuttering mindset had allowed me to enjoy permanent gains.

Although our long-established beliefs may be deeply entrenched, it is important to understand that they

are NOT set in stone. The realisation that I could reappraise (and adjust) my beliefs was hugely empowering and a cornerstone of the advances I have made during recent times

Over the years, I have been a regular visitor to the US, facilitating workshops at National Stuttering Association conferences, Chapters and other stuttering-related events. In addition, I have visited several American universities to provide student speech-language therapists with an insight into what it is like to live with stuttering.

I also draw the students' attention to the importance of recognising the uniqueness of their future clients. I emphasise the need to make good use of listening skills; earn the respect of each individual, and appreciate the difficulties associated with transferring speech gains and techniques from a safe therapy environment into the outside world.

I never fail to be impressed by the enthusiasm and interest that the students display. They have an insatiable thirst for knowledge and I am always inundated with questions.

The seeds of this association were initially sown when I was invited to spend four days at Arkansas State University. On that occasion, I gave a series of talks that were video-recorded for future training.

Next, I travelled to Temple University in Philadelphia, where I spoke to a class of graduate clinicians who were reading my life-story as part of their studies. The following year, I returned to Temple University as part of a panel drawn from the Philadelphia NSA Chapter.

I have since widened my US connections by speaking to students at other universities in Pennsylvania, Mississippi, West Virginia and Missouri. On these

occasions, the presentations were given from the comfort of my own home in Wales, via a telephone or Skype online link.

I genuinely believe that such interaction is to our mutual benefit. Most speech-language establishments

now incorporate these exchanges as an integral part of their training programs. I have found it to be a most rewarding activity that has also allowed me to step outside my comfort zone. I encourage other persons who stutter to seek out similar opportunities – perhaps a little nearer to home.



*Photographs from the SCGSHA annual luncheon 1: Alan (left) spends time in the company of Mel Hoffman, a member of the International Stuttering Association Advisory Board and a former member of the NSA Board of Directors from 1983-1994. Mel attends and occasionally facilitates the San Jose chapter. In 1996 he was elected to the NSA's National Stuttering Hall of Fame.*

### **ABOUT THE AUTHOR:**

Alan is a retired police officer (from Wales in the UK) who commenced stuttering at the age of three. Childhood days were troublesome, adolescence problematical, while his police career was blighted by the difficulties that he encountered.

During the past 10 years, Alan has become an extremely active and highly successful public speaker. He has won numerous trophies (in competition with

fluent contestants), as well as appearing as a finalist in the Association of Speakers Clubs UK national public speaking championships on two occasions.

Alan regularly addresses diverse community organisations in the UK in an attempt to increase public awareness about stuttering, while his many BBC radio interviews (and other media involvement) have further brought the subject to the fore.

He has travelled extensively to fulfil speaking engagements on three different continents, including a keynote speech at the 7th World Congress for People Who Stutter, held in Western Australia in 2004, where he also won the Oratory Competition.

He has undertaken a number of trips to Scandinavia as a guest of the Swedish Speech Academy

(Talakademin) and is engaged as a motivational speaker for personal growth programmes.

His papers, articles and poems (about stuttering and related subjects) have been reproduced in numerous publications and on various international websites/forums. Several have been translated into different languages and are used (by persons associated with stuttering) in many parts of the world.



*Photographs from the SCCSHA annual luncheon 2: Alan (centre) with Mel Hoffman and Mary Ellen Jones, MA. CCC-SLP, President of the Santa Clara County Speech-Language Hearing Association.*