‘The fifth International Stuttering Awareness Day Online Conference will be starting on October 1, 2002’

‘There are three weeks in October to read, ask questions and make new discoveries about stammering’

From a person who stutters: “Special thanks. As a PWS, I should thank all people involved in making ISAD Conference happen. Many respected professors/slps give their valuable time in replying to questions posted by PWS like me.” (India)

From a presenter: “Thank you so much for the wonderful work you achieved. I can hardly believe that there were so many people to join the conference and ask questions and give comments. This is the most democratic conference I ever attended!” (Belgium)

Judith Kuster, Minnesota State University, USA
Conference organiser
Welcome to the latest edition of the joint ISA/ELSA newsletter. In the last edition I mentioned that ELSA was preparing for two events in 2003. A youth meeting in Poland and possibly an ELSA seminar in France.

In July this year a funding application was made to the European Commission for an ELSA seminar in Strasbourg, France, together with the Association Vaincre le Bégaiement (AVB). The title of the proposed seminar will be “Stuttering Awareness”. ELSA's application is within the framework of the European Year of People with Disabilities – 2003. In December 2001 the European Commission agreed to provide funding across Europe for initiatives to raise awareness of all disabilities. In fact the funding does not just extend to European Associations like ELSA but to all national and local associations. On ELSA's website full details of all the national contacts for funding information is given. So whether you are a national or local group you should take advantage of this lump of money that is available. If your association or group is looking for a European partner then contact ELSA at  

elsa.europe@totalise.co.uk

ELSA is known for its successful youth meetings for people who stutter. These go back to 1995 and many young people aged under 25 have attended. The meetings last a week and they give the delegates an opportunity to make friends, learn about their national and local association and generally network. Many graduates of the youth meetings have gone on to become board members of their national association and one day I am sure a graduate will become chair of their organisation. We are planning to organise the next meeting in Nijmegen, the Netherlands. It was originally planned for Poland but due to organisational reasons the Poles were unable to confirm they could host the meeting. These meetings are usually funded by the European Youth Foundation of the Council of Europe and if ELSA is successful with the application it will be held in July 2003. Please regularly check ELSA's website www.elsa.info for further details.

During 2002 ELSA has been working with the European Disability Forum (EDF) on an important initiative. This is a proposal for a new European Union Directive to combat discrimination on the grounds of disability. There is an existing Employment Directive (called the Framework Employment Directive) which addresses employment discrimination on the grounds of disability but as yet there is no all encompassing disability Directive. The first draft of the Directive did not include speech or communication. Through lobbying by ELSA the draft Directive now includes discrimination based on a communication. I believe if this is included in the final draft then it will have huge favourable implications for people who stutter.

I attended a very interesting convention in Anaheim, USA in June 2002. It was the annual National Stuttering Association convention. It was special because for the first time, in a two day seminar prior to the main congress, researchers, speech and language pathologists, other clinicians and consumers (i.e. people who stutter) came together to exchange ideas, listen to each other, network and reduce the polarisation of the disciplines. The event even provided accreditation and continuous development for professionals in training. I believe this was the first event of its kind and was a great success. Well done to NSA Chair, Lee Reeves, his board and NSA staff for facilitating such a meeting. I believe all stuttering associations across the globe can learn from this initiative.

Finally, on a personal note. I am proud to write that in June 2002 I received an award, Member of the British Empire (MBE), from HRH Queen Elizabeth II for services to the British Stammering Association and the European League of Stuttering Associations. When I heard this I was delighted, proud and humbled. I believe the award recognises not just my efforts over the past 18 years, but those of a great number of others who work tremendously hard to improve the conditions for people who stutter. I know of and I have worked with many people who give their time freely, at seminars, working late at night on funding applications, giving presentations on stuttering at various local, national and international events, writing articles on stuttering and generally increasing the awareness of stuttering through their tireless and unselfish work. These people from all over Europe have inspired, motivated and sustained me; many have become good friends. I thank them all and I sincerely hope that everyone connected with stuttering self-help will share this award with me.

Edwin J. Farr  
Chair of ELSA
Greetings from Canada! The focus for Canadian Association for People who Stutter (CAPS) at this time is the ISAD workshop on October 19 and our biennial conference in August 2003.

The ISAD workshop will be focused on the theme for this year ‘Don’t Let Stuttering Stop You’ - a wonderful, inspiring thought! Our speakers for this day are Gary Rentschler, the director of Speech-Language-Hearing Clinic at Duquesne University in Pittsburgh, Pennsylvania, and Tony Churchill, a speech language pathologist from the Dufferin-Peel Catholic District School Board in Mississauga, Ontario. Both of these speech language pathologists are wonderful examples of the theme - people who stutter and have not let stuttering stop them. Adults and children who stutter, families and speech language pathologists will spend the day together in Toronto. This is a wonderful opportunity for all people to share their experiences, and learn from one another.

Plans for the CAPS conference in August 2003 are progressing well. It will be held from August 6-10, in conjunction with the International Fluency Association conference in Montreal that runs from August 11-14. A four-star hotel in central Toronto has been chosen as the site, close to fine restaurants, good entertainment, and wonderful sites to see. As our plans progress, they will posted on the CAPS website: www.caps.webcon.ca. We invite all of you to attend the conference, to experience Canadian hospitality, and to know that you are part of a world-wide family that supports people who stutter and their families.

One last important announcement. David Block, our esteemed chair, and Kim Hall were married in Montreal on August 24. Their day was filled with love and laughter. They are honeymooning in Cuba, and then will return to Montreal to move into a new house. Lots of changes in their lives! We offer them our congratulations and wish them many years of happiness!
This is how to grow

Reports from conferences

I consider myself very fortunate to have attended the meetings of the National Stuttering Association in California and the British Stammering Association in London. Annie Bradberry (NSA Executive Director) and Rachel Everard (BSA Chair) ran well conducted and highly successful meetings. Both meetings allowed the sharing of much worthwhile information and had a strong social emphasis which made them even more enjoyable.

John Harrison from the NSA ran workshops at both meetings as well as being a keynote speaker in London. Based on his personal experience of overcoming his own stuttering behaviour as well as his involvement in the Californian self-development movement, he said that in order to change speech behaviour it is necessary to change the whole person. In other words, changing speech in isolation will not produce long-term results.

Assuming this to be true, I think the conferences provide a wonderful environment in which to express yourself differently and to experiment with the ‘new you’. There is no doubt too that attendees are able to draw ideas and inspiration from discussions with others. I encourage all associations to continue to provide these opportunities for their members.

ISA Conference February 2004

Information about the next world congress of people who stutter, to be held in Perth in February 2004 is available at www.speakeasy.org.au

New Member

The Burkina Faso stuttering self help organization, ACB, has recently joined the ISA family. They are a very welcome member.

This new membership again highlights the value of the internet in enabling links to be made with people from all over the world. ISA outreach chair Stefan Hoffman is to be congratulated for his work in this area.

Thanks

Thanks are due to at least four hard working individuals. Judy Kuster who maintains www.stutteringhomepage.org, Benny Ravid who maintains www.stutteringISA.org and Alan Tyrer who maintains www.stammering.org do an enormous amount in ensuring that appropriate information on stuttering is circulated to those in need. I would also like to acknowledge the ISA editor Andrew Harding for his work on One Voice.

Mark Irwin,
ISA President

Australian Speak Easy gets a national director

By Richard Harding

In October 2001, the Australian Speak Easy Association (ASEA) opened an office in Sydney for its first paid employee, the national director Jennifer Alderton. The position is part time, due to Speak Easy being not able to afford a full time position. However, the plan is to eventually make it full time.

A lot of fundraising work is being done to ensure Speak Easy continues to employ a national director. We have several fund-raising plans, one of which was a national raffle held in June 2002.

Our state branches also help with fundraising. For example, the Western Australian branch received $5,000 from the Lotteries Commission to develop a Policies and Procedures Manual for Speak Easy group leaders in Western Australia. (This will bring together all the policies and bits of information that are scattered around into an easy to read document.) The national director has been given the task to develop this manual, thus receiving funds to keep working. The manual will be relevant to Speak Easy nationally, so all states will benefit.

Despite the difficulty in making the position long term, the benefits of having a national director are already apparent. Through Jennifer Alderton, Speak Easy has vastly increased the amount of applications it makes for grants and sponsorship. She makes applications directly and she assists the state branches in making applications for grants and sponsorship.

Retaining the national director position was not the only issue that Speak Easy was involved with this year. In March we held our bi-annual convention in the state of Victoria. Barry Guitar from the United States was the keynote speaker. Peter Dhu decided to not continue as national president and will focus on the 2004 World Congress for People Who Stutter in Perth.

There were also changes to the ASEA constitution which has enabled Speak Easy to formally have a group of speech pathology advisors rather than relying on advice from a single speech pathologist. This involved amending the reference from ‘Speech Pathology Advisor’ to ‘Speech Pathology Advisory Board’ in the constitution.
Österrreichische Selbsthilfe - Initiative für Stottern

By Markus Preinfalk

Every year ÖSIS organised a summer camp for children who stutter in the mountains of Tyrol. The camp lasts for three weeks and aims to show children and teenagers who stutter how to get control over their stuttering, in a place where they can socialise with others who have the same problem. Besides the therapy itself there are many different holiday activities such as a weekend in the wilderness or a course in the use of African drums. Another traditional event is the weekend meeting Austria-Bavaria for people who stutter. It provides an opportunity to spend a weekend with common holiday activities and discussions. This year the meeting took place at the shore of the picturesque lake Attersee.

Since the last election of our board we have to deal with the situation that our new board members live far away from each other, so can’t come together for the monthly board meetings. For this reason we organised regular internet chats on a chatroom. After a few initial problems we now use the AOL Instant Messenger, which works fairly well. With this means we are able to communicate and make our board decisions. However, it is a different kind of communication than talking face-to-face and we have to be aware of its disadvantages.

A few years ago the German Roland Pauli developed a method (which he named the Ropana-method) that enabled him to overcome his stuttering. Now he gives seminars to introduce other people who stutter to his method. Since last year he has held, in cooperation with ÖSIS, three seminars in Austria, attended by people who stammer from both Austria and Germany. Starting last autumn, the speech therapist Andreas Starke from Hamburg offers his therapy, following the VanRiper method, also in Austria. Here he is supported by the highly motivated Austrian therapist Gabriela Fuchs. Until now, 24 people who stutter have finished the therapy with great success.

National Association for Self-help and Initiatives on Stuttering, Bulgária

By Peter Tonev, Chairman

In spite of very difficult times of transition to be a more normal society according West European standards, we endeavour to do our best to supply people who stutter and especially of parents of children who stutter with more updated information about nature of stuttering and the variety of attitudes to that multidimensional speech problem.

National Association for Self-help and Initiatives on Stuttering (NASIS) uses basic forms to do that, by open telephone line, using every case for participation in TV and radio presentation, publication in newspapers, personal answers of every question by post and email, distributing of brochures and handmade materials.

We rely on enthusiasm of some stutterers and speech therapists in many towns. In fact we work on goodwill only.

We also try to give appropriate information to members of family, friends, teachers of people who stutter. The goal is to change their attitude in understanding the complex problems of persons who stutter. Close people to stimulate his/her communication skills in different situation and participating in meeting of self help groups.

Summer camp had hypnotic effect

By Hermann Christmann/Per F. Knudsen

This year too, The Association for Stutterers in Denmark (FSD) has arranged various summer camps. A one-week summer camp for stutterers of all ages was arranged in rented school premises in the countryside. All in all some 30 participants were present, some for a shorter stay, many for the whole week.

The four summer camps for children, adolescents, and young people were a great success according to the participants, the younger age groups being accompanied by one or two parents each. We very much hope to be able to get funding for these summer camps in the future, as they are a necessary tool for children who stutter and their parents to get in touch with other people addressing the same problem. Many of the children (and their parents) are recommended by their speech therapist to participate.

The adult group of the FSD held a Saturday afternoon session with a hypnotherapist who presented a basic understanding of hypnotherapy and discussed the possible use of hypnotherapy as therapy for stuttering. At the end of the session he hypnotized those who wanted to try to be hypnotized. The idea of hypnotherapy was also presented and discussed in the magazine of the Association for Stutterers in Denmark, named “Udtryk”.

The project on facilitating treatment of stuttering in children and adolescents, mentioned earlier in One Voice, is proceeding according to schedule. Seven treatment sites are participating, and all are very eager to try and develop models for establishing the frames for rendering a more consistent service, than is presently the case in a great number of treatment sites, toward stuttering in children and adolescents. Especially regarding school age children there seems to be a lot of work to do.

FSD is a member of a group of handicap organisations trying to establish a job agency. We feel, with our first-hand knowledge on various handicaps and their ramifications that we are able to offer a contribution to the efforts of securing a road for those who want to get into the labour market. We are applying for the job agency to be government authorised, which would secure the necessary funding for the future work.
Gareth opens the floodgate to stammering awareness in Britain

By Andrew Harding

A large part of BSA’s work is providing information to people who contact us by email or on our telephone helpline. Our website: www.stammering.org has become a major source of information on stammering in Britain, and is updated each week by a dedicated volunteer, Allan Tyrer. We respond to more than 3000 enquiries for information each year from the UK and around the world.

This year we have had people from Cameroon, Hungary, and Turkey visit to see how we operate, and in September, Annie Bradberry and John Harrison from the USA’s National Stuttering Association were here for our annual conference.

Stammering has had a record amount of publicity this year. Week after week, millions of people saw a 17 year old who stammers called Gareth Gates sing his heart out to the whole country on a talent quest called Pop Idol. Through Gareth, stammering was on the front page of the newspapers and on prime time radio and television. This generated a huge amount of publicity for stammering in the UK. The British Stammering Association has had its busiest year ever, and ISAD hasn’t even happened yet. Thousands of young people have been inspired by Gareth, and thousands more have seen that stammering does not have to hold you back in life.

The extra work and publicity has been in addition to the British Stammering Association’s regular work. A campaign that has sent out tens of thousands of leaflets to parents and people who work with young children is nearly finished. In its place is a project to provide extra training for speech therapists who need to work with people who stammer.

The BSA Speaking and Listening Project aims to produce three informative CD-ROMS on supporting children and young people who stammer. Two for staff in primary and secondary schools respectively, and one for students preparing for the oral component of the GCSE in English. All include authentic film of pupils in classrooms with parents and therapists also providing their views. The three CDs will be launched at the House of Lords on International Stuttering Awareness Day, 22nd October 2003, prior to distribution to schools for staff and to Health Trusts to be used with GCSE students.

The employment booklets have been sent to professional employment organisations, careers advisers and the government’s agency for people who are unemployed. The booklets are now being sent to companies as part of this year’s ‘bring a pound to work and school’ campaign. BSA members and professional contacts are being asked to collect one pound (about US$1.40) from colleagues, which will then be given to BSA. This is the first year the campaign has run, which will be expanded for our 25th anniversary year in 2003.

President’s Invitation

On behalf of the International Fluency Association it is my pleasure to invite you to the Fourth World Congress on Fluency Disorders in Montreal, Canada.

The congress will provide an outstanding opportunity to share information on research developments, advances in treatment and self-help initiatives.

Not only will it be a memorable international event and stimulating and exciting learning experience, but it will also enable you to savor the charm of Montreal’s unique culture and hospitality.

Plan to attend the IFA’s Fourth World Congress! You will have an opportunity to engage with colleagues, and develop new links and friendships. Enjoy one of Canada’s most interesting cities and take advantage of spectacular vacation opportunities.

We look forward to your participation.

Margaret Leahy, President IFA

4TH WORLD CONGRESS ON FLUENCY DISORDERS

August 11 - 15, 2003
Montreal, Quebec, Canada

www.ifacongress2003.com
Stuttering and school roadshow for Germany

By Konrad Schäfers

In May the Bundesvereinigung Stotterer-Selbsthilfe e.V. (German Stuttering Association) held its third Info Bus Tour on the subject of Stuttering and School. This time the week-long trip went from Cologne via Bochum, Kassel and Fulda to Marburg. Again the team gave lessons at numerous schools on the subject of being different, taking stuttering as the example. And again the tour was a big success. The campaign has so far been awarded three prizes. Targeted at people who stutter, parents and speech therapists specialising in stuttering, an appeal for donations to finance the campaign yielded over 1,000 euros. The next Info Bus Tour is already being planned. Pictures and reports on the tour can be found on the Internet at: www.stottern-und-schule.de.

Another video film in the series Methods for Treating Stuttering is on the verge of completion. This new film focuses on stuttering in childhood and will be a valuable addition to the programme of the Demosthenes Verlag, the Bundesvereinigung's publishing house, for training, teaching and treatment specialists.

The 29th Federal Stutterer Self-Help Congress is taking place in Cologne at the beginning of October. In addition to the usual workshops and information events, there will be an Open Day at which the members of the Bundesvereinigung are invited to its offices. A highlight of the congress will be a public campaign in the centre of Cologne, for which the London bus from the Stuttering and School tour will be back on the road.

With its new programme of seminars, the Bundesvereinigung wishes to improve its contacts with local self-help groups. There are at present about 70 stotterer self-help groups in Germany. Under the motto “Let’s get to know each other better”, representatives of the groups will be invited to regional conferences. Talks will be held, outlining the work and goals of the Bundesvereinigung. The first regional conference for the Land of North-Rhine-Westphalia will be taking place in Cologne in November.
Pictures from a VERSTA camp in Switzerland

By Beat Meichtry

New Zealand members to get out and talk about stuttering

By Warren Brown in New Zealand

Speak Easy is launching its community speaker programme. Members will go out to community groups, such as service clubs, and give speeches on stuttering and Speak Easy. The idea is to raise public awareness for stuttering, and also maybe elicit funding for Speak Easy’s work.

Changes have been made to Speak Easy’s national oratory competition, to allow more people to take part. Planning is well advanced for a new pamphlet for Speak Easy. All that is required now is the funding to pay for the printing.

The New Zealand Speak Easy Association has decided not to change its name. Members had raised the issue at last year’s annual meeting, believing that the name should include the name “stuttering” to reflect the association’s work. But after much discussion at this year’s annual meeting, members decided to continue with the present name as it had a positive connotation. However, the words “a support group for people who stutter” have been added to the organisation’s letterhead.

The New Zealand Speak Easy website has gained plenty of attention, with 18,500 hits in its first 11 months. The website is at www.shopzone.co.nz/speakeasy

Rising awareness in Sweden

By Anita Blom

Once again the Swedish Stuttering Association, SSR, organised a youth camp for young people who stutter. 47 youngsters under the age of 30 attended the camp, which is a record! The camp starts with activities for the leaders only, to get to know each other better and get prepared for the different activities. There were workshops (for ex musical exercises, speaking in front of the group, theatre and other workshops on how to deal with stuttering), sports (rounders, boxing, dancing…), games (charades, play tag and other funny games) and time to relax. And as Sweden has had the warmest summer in 150 years, the water was always tempting. New for this year was a “godmother/father” for all new participants, which means someone who has been to the camp before, to guide, talk to and help the new ones. Benny Prézent and Peter

continued on page 9
Stuttering disappeared in therapy camp

By Andres Loorand

Estonian Association for People Who Stutter (EAPS) held traditional summer-camp in the beginning of July in little village Pala near Peipus Lake. Every summer EAPS organise a camp for members of the association and other stutterers, where participants can get a short intensive speech therapy and also relax, go in for sport and to communicate with each other. In Estonia there are today no intensive courses, so EAPS try to offer for young and adult stutterers some intensive therapy courses.

During four long days, 15 stutterers trained in a slow and fluent speech under the guidance of speech therapist Pille Ilves. She has put together materials for intensive therapy in Estonian.

In the evenings the director of culture-house of Pala and stage manager Tiina Eres led people, who quite often avoid speaking situations, to the world of public performance. In spite of stuttering, everybody gave a speech in which him/her played a role fluently and expressively.

During the camp there was time also to play basketball and petanque, to socialise and to make excursion to local sightseeings.

At the end of speech therapy all participants could speak absolutely fluently without any kind of stuttering. Most of campers were much impressed by the extremely warm atmosphere between people.

The Stutterers’ camp was financed by The Estonian Chamber of Disabled People.

Engström, you did it again!

In some regions in Sweden people still have to go to the doctor to get an admission note for a speech therapist, while other regions don’t. Not all doctors have a sufficient amount of knowledge about stuttering and won’t refer to a speech therapist, while even today child health care personnel still tell the parents to wait and see. And with this year’s election the SSR has used this issue to call on decision makers on the highest political level.

On October 18-19 the SSR will be present at the speech therapists convention. Because of our engagement there last year, they have decided to have children who stutter as this year’s theme! The SSR will be represented by an adult who stutters, and a teenage stutterer and her mother who will give information about stuttering and the work of the SSR.

On the same weekend the SSR will organise an education weekend for all local chairs, secretaries and treasurers, to help them learn more about their rights and obligations. The weekend is co-organized with ABF, an educational association, who will provide instructors.

Last but not least, the new chairman of the board is Ove Stadig. You can reach him at ove.stadig@swipnet.se

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Passing twice – a network linking the resources of the gay community to the stuttering community

By Warren Brown

The term “stuttering closet” has been heard increasingly over the last few years. It refers to the behaviour of people who try to hide their stuttering.

The term is similar to the idea of the “gay closet” – the kind of behaviour that some gay men, lesbians and bisexuals indulge in to hide their homosexual activities from society.

Indeed, the idea of a stuttering closet resulted from a gay workshop at the Third International Convention for People Who Stutter in San Francisco, on August 15, 1992. Ten people were present. Seven were gay. The person who ran the workshop had no structure or preconceived notions of where things would end up. Each person was given time to introduce themselves. What followed was a discussion on the similarities between being gay and being a person who stutters.

As the workshop participants talked about coming out of the gay closet, the realisation grew that people who stutter need to come out of the stuttering closet. We need to be open with people about our stuttering. We have to face the fact that we do stutter in some situations. We need to accept that stuttering is part of us. We need to stop hiding our true personalities.

From this workshop, a movement has grown. It looks to the gay community to find strategies to overcome problems faced in the stuttering community. It calls itself Passing Twice. The name refers to the way gay, lesbian and bisexual people who stutter have tried to “pass” in society.

The gay community has much to teach the stuttering community. Gays, lesbians, bisexuals and transgendered people have struggled over the last 40 years to gain visibility and acceptance. During that time, many Western countries have repealed laws that banned homosexual love and have sought to outlaw discrimination against those in the gay community.

Only a few decades ago, most people believed that homosexuality was a psychological condition that needed curing. The strategy that gays and lesbians took to overcome this impediment was to come out of the gay closet.

Yet some people still believe that stuttering is a psychological condition that needs curing. The strategy that gay and lesbian people who stutter have come up with to overcome this impediment is to come out a second time – as people who stutter.

It is true that the stuttering community hasn’t collectively had to face its equivalents of the Stonewall Riots, unprovoked bashings or an HIV-AIDS crisis. The gay community has had to become more politically aware to survive such hostility.

But people who stutter do face issues that can only be resolved politically – the lack of resources for treating stuttering, the ridicule that some of us face when we speak and the discrimination that some of us face as we try to achieve our dreams at school and in the workplace. The gay community can provide skills, strategies and inspiration for people who stutter.

That is why it was so important that Passing Twice was recently accepted as a member of the International Stuttering Association. Passing Twice can bring a new perspective to issues involving stuttering. It can bring a more political way of doing things. It can energise people to reach their full potential by leaving the stuttering closet.

Passing Twice has nearly 200 members, mainly in North America, Europe and Australasia. Only about half belong to their national association for people who stutter. Members are linked through a quarterly magazine and many are also linked through e-mail. Recruitment has mainly been through workshops held at conferences on stuttering and through the Passing Twice website on the internet, at http://www.geocities.com/passing-twice

A stuttering event that just has to be experienced

By Benny Ravid, chair of AMBI, Israel Stuttering Association

AMBI - Israeli Stuttering Association is organising self help events held every two months for about a year.

Called ‘Experiential events’, the preparations usually start several weeks ahead by a special team. Each such event is devoted to a specific subject and is held in a self help fashion. This means that all the participants are taking active part in all that happens. There is also a group leader whose purpose is to instruct the participants about how to perform the prepared processes.

To visualize an experiential event I’ll tell about one event whose subject was: ‘Do I respect myself enough’.

At the beginning the participants were seated in one big circle. Each participant introduced himself, by telling something about his life and his stuttering. Then the first experiential process started. Participants were asked to give compliments to the group leader. Here the people got an opportunity to experience the feeling of giving a compliment to other person (sometimes that is not easy at all).

Then all the participants were asked to walk around the room and to meet each other. On each meeting (or an encounter) people were asked to exchange compliments. That was funny and also embarrassing to some of the participants, as when getting or giving a complement, something happens to the respect we are giving to ourselves and to others.

People were the asked to split into groups of five to continued on page 11
Outreach Towards 2004

By Stefan Hoffmann
Vice Chair of the ISA Board of Directors
Chair of the ISA Outreach Working Group

After the eventful year 2001 with the World Congress in Ghent, the year 2002 is the time of consolidating the achievements and maintaining the contacts made in previous years. However, outreach is an ever-continuing process, and ISA should do it with future projects and challenges in mind.

As could already be seen in the last year, especially the contacts in Latin America and Africa have been promising. This trend was continued in the first half of this year, and it is with pleasure to report that by the time you read this, there will be a new member association in Africa: the Stuttering Association in Burkina Faso. This brings the numbers of participating countries from Africa to three. ISA hopes that the evenly split geographical position of those three member and the ‘special friends’ contacts (South Africa in the South, Cameroon in the Center, Burkina Faso in the West, Algeria in the North and Uganda in the East of the continent) will have a favorable influence on the further spreading of contacts there. It is encouraging to know about the increasing connections between Africa and the rest of the world concerning stuttering, with visits by researchers from the US to Cameroon, sending of ISAD material to and planning of a conference with guest speakers from abroad in Burkina Faso.

In Latin America a milestone was reached with the “1st Latin American Congress on Stuttering and Convention of People Who Stutter” in Buenos Aires, Argentina in May 2002. This meeting was a huge pleasure to take part in, and proved to be rich source of new contacts in places like Uruguay, Paraguay, Chile, Brazil and Venezuela. ISA hopes a good start has been made for cooperation in South America.

Since joining the ISA Outreach Group in early 1998, it was a dream for me to see one day a World Congress of People who Stutter with all member and contact countries represented. For Ghent we did a step on the road to fulfill that dream, when a scholarship fund was set up to support 12 persons from countries who reported difficulties in making it to Ghent. I have recently been in contact with Peter Dhu from the organising committee for Perth 2004, trying to define a strategy for finding enough sponsors who assist people to attend the next World Congress.

For a lot of us, the trip to Australia will be a financial challenge anyway, and one solution is an early planning to have the money in place when it is needed. I want to encourage all ISA member groups to spread the news about the World Congress actively and early enough, so that the individuals can make proper arrangements for February 2004.

For better planning, I propose that around one year before the Congress (early 2003), the ISA secretary Martine de Vloed martdevloed@hotmail.com and Peter Dhu peterdhu@bigpond.com should be informed by the ISA contact persons of each association about an approximate number of people who plan to go to Perth. It must be feared that some associations will not be able to send anyone there due to the cost involved. If ISA knows early enough how many associations have such a problem, we will be in a better position to try to arrange a support, in cooperation with the organizers.

I want to appeal to the member associations with a traditionally stronger financial background for considering being a sponsor themselves for one or two not so well off fellow associations. Please discuss inside your organisation to do an extra fundraising activity in 2003 with the goal of raising the equivalent of $US 1000, which would be enough to support one person from places like Latin America, Africa or Eastern Europe on their trip to Perth.

If you want to know more about the various sponsorship incentive programs set up for the congress, please visit the congress webpage: www.2004worldcongress.speakeasy.org.au.

With so much experience in self help, it is hoped that most people who want to go to Perth 2004 find ways themselves to get to their dream place. But when necessary ISA, the member associations and the congress organisers will work closely together in their efforts to enable as many representatives from associations as possible to go to the next World Congress. This is outreach at its best.

 Discuss topics like: ‘What makes me respect myself more’ and ‘What makes me respect myself less’.

Later the participants left the groups and came back to sit in one big circle. While seated in the big circle they were talking and sharing whatever comes up.

Then the evening came to its end and the group leader declared that the event finished. But most of the participants didn’t left the room… They went on and on talking and sharing....

Until now we had experiential events about subjects like: ‘Do I say what I want to’, ‘Stuttering on the first date’, ‘Stuttering and my family’ and more.

One such event was given as a workshop at the last National Stuttering Association conference in California.

One may ask what the difference is between an experiential event and a self help meeting. The difference is in the organisation. An experiential meeting is preplanned and the instructors instruct the people at each stage about what to do. Self help meetings usually do not require such preparations or instructions.
En el mes de noviembre de 2001, nuestro Grupo “TTM-L” fue reconocido por ISA como el primer Grupo de Autoayuda Internacional que trabaja a través de Internet y que está dirigido a todos los tartamudos de habla hispana. Actualmente somos más de 200 personas, en su mayoría tartamudos, que nos comunicamos a través de internet e intercambiamos experiencias y opiniones acerca de qué es la tartamudez y cómo manejarla.

A través de esta sección “TTM-L Informa”, la cual aspiramos sea permanente en ONE VOICE, queremos llegar a la comunidad de tartamudos hispano parlantes e informarles acerca de las actividades que, como grupo comprometido con la atención a los tartamudos y la difusión del conocimiento de la tartamudez, desarrollamos.

Varias han sido las actividades que hemos realizado en estos meses, la primera de ellas fue el seminario “Hablemos de Tartamudez” dictado por Pedro R. Rodríguez C. el pasado mes de septiembre de 2001 en la ciudad de Rosario (Argentina), a esta actividad, auspiciada por el Colegio de Fonoaudiólogos de Rosario y la Facultad de Medicina de la Universidad Nacional de Rosario, asistieron cerca de 100 personas y durante dos días estuvimos conversando sobre lo que es la tartamudez, la significación que ésta tiene para el tartamudo y el rol que debe cumplir el fonoaudiólogo en la atención del tartamudo.

Posteriormente, el 22 de octubre, celebramos el día Internacional del Conocimiento de la Tartamudez. Desde países como España, Chile, Perú y Venezuela nuestros asociados informaron acerca de la realización de diferentes actividades: charlas, cursos, entrevistas por la radio, carteleras en hospitales y escuelas, reparto de material informativo y reportajes en revistas y periódicos.

En mayo del 2002, algunos de nuestros miembros asistieron al Primer Congreso Latinoamericano de Tartamudez y personas que tartamudean que auspició la Asociación Argentina de Tartamudez. La organización de este evento estuvo a cargo de Beatriz Touzet, miembro de TTM-L y presidenta de la Asociación Argentina de Tartamudez; Beatriz también es miembro de la Junta Directiva de ISA

El 26 de junio de 2002 se constituyó legalmente en España la Fundación Asociación Española de la Tartamudez (TTM-España), esta iniciativa nace de la idea de un grupo de hombres y mujeres tartamudos/as y padres de niños tartamudos miembros de TTM-L, que deciden crear en su país (España), una Asociación sin fines de lucro con personalidad jurídica propia y al amparo de la legislación española, que tiene por finalidad atender las necesidades de los tartamudos y difundir el conocimiento de la tartamudez.

Quienes deseen mayor información sobre TTM-España, pueden comunicarse directamente a: Fundación Asociación Española de Tartamudez Montserrat 24, 1º08190 Sant Cugat del Valles - Barcelona Tel: 650 810 347 E-mail: ttm_es@yahoo.es

Entre el 26 y el 29 de junio se realizó en Salamanca (España) el “Congreso Internacional de Foniatria, Audiología, Logopedia y Psicología del Lenguaje” en Homenaje al Dr. Jorge Perelló Gilberga, a este evento asistieron varios de nuestros miembros. El Dr. Fernando Cuesta expuso el trabajo: “TTM-IB: Una experiencia virtual de atención y difusión del conocimiento de la tartamudez” donde tuvo la oportunidad de conocer qué es nuestro Grupo, las actividades que realiza y los logros alcanzados hasta el momento. Otro de nuestros miembros, Pablo Ibáñez Grana, intervino para exponer su experiencia como tartamudo. Ambas intervenciones fueron muy aplaudidas y despertaron el interés de los profesionales asistentes al evento. Es de hacer notar que Fernando y Pablo fueron los dos únicos tartamudos participantes. En este evento, la Junta Directiva de TTM-España, colocó un stand donde suministraba información acerca de la recién creada Asociación.

A continuación presentamos algunas gráficas de este evento. Para finalizar, queremos invitarlos a visitar nuestra Página Web “Nosotros los Tartamudos” (www.ucv.ve/tartamudez.htm) donde encontrarán información actualizada en español sobre la tartamudez. En esta Página hemos creado una Sección denominada: ISA en Iberoamérica, donde informamos a la comunidad hispano parlante qué es ISA, sus actividades y tenemos un enlace a su website.
New Spanish Stuttering Association has very successful start

By Adolfo Sanchez Garcia, President

The Foundation: Spanish Stuttering Association “TTM-España” was born of the idea of men and women who stutter, parents of children who stutter, members of TTM-L (internet group of Hispanic speakers), that decided to create in Spain a national non-profit foundation to help stutterers and persons interested in stuttering, to improve their life quality.

Things moved fast. On June 26 we were legally recognised as TTM-España and on June 28 we attended for first time the International Congress of Foniatrés, Audiology, Speech Therapy and Psychology in Salamanca, Spain, with a massive welcome of the Speech therapists and Professionals that attended the congress.

At present we have numerous groups as members – both adults who stutter and non-stutterers in the majority, speech therapists, parents and family of children who stutter. The Patronage of the Foundation of TTM-España is composed in the following way:

Honorary President: Sr. Pedro Rodríguez
President: Sr. Adolfo Sánchez García
Vicepresident: Sr. Álvaro Garaizabal Elizalde
General Secretary: Claudia Groesman

We count on the support of members of TTM-España, of an incalculable professional and human value, among who are:

Ing. Álvaro, Garaizabal Elizalde (Telecommunications Upper Engineer), Dr. Pedro Rodríguez (Psychologist of the University of Venezuela and moderator of TTM-L), Dr. Fernando Cuesta (Medical of family), Dr. Eduardo Gallego (psychoanalyst), Lic. Amador Blas Round (Psychologist and investigator), Ing. Pablo Ibáñez (Engineer in data processing), Lic. Anna Bagó (language therapist) and Lic. Claudia Groesman (Social Psychologist).

It is important to emphasize the strong loop that joins the patronage and the professional associates that cooperate in the daily job: the love of the objectives, and values such as: integrity, uprightness, seriousness, ethics, respect, quality and professionalism.

We believe firmly that by informing parents, teachers, pediatrics, medical of family, associations, Government institutions and the public in general, we will be improving communication among persons who stutter and the wider society, to reduce the injustice that exists with a person perceived as ‘different’. We know that the mokeries and laughers borne by children who stutter are the product more of ignorance that of wickedness.

It is because of this that we begin our activity in TTM-España, working for the ISAD 2002, elaborating and designing brochures, flyers and posters, explaining “What is Stuttering” and “How to react to a person who stutters” which we will try to distribute in person so we can explain its content. We count on representatives in distinct provinces of Spain, and members of our Foundation, to help our objective.

We are working with the parliamentary groups of the Congress of the Representatives, to request a change in the law to allow the person who stutters to choose to have oral or written assessments in their final university exams. In September we should concur personally to the Congress of the Representatives to such end. This would be our first great achievement in the field of the stuttering, helping many youths have not yet graduated, who have to pass two exams together, with the emotional stress that is involved.

Likewise, we are advancing in the project to carry out chats and courses specialised for speech therapists and professional interested in the stuttering for the next year. We have begun an international search to find better interdisciplinary therapies in the stuttering field.

Finally, we are in contact with one of the Spanish telephone companies to obtain a free telephone line to offer a 24-hour service for people who need to communicate with TTM-España in a moment of anguish, solitude, or depression.

We thank the very warm reception that we have had from ELSA and ISA, the priceless help of the Stuttering Foundation of America (SFA) and the National Stuttering Association (NSA) from whom we have received the invitation to be member associates, which will be able to be carried out as soon as the legal aspects of our constitution are finished. We are sure that in the smallest possible space of time we will be intensifying the aid to that our dear country so that ‘Spain understands stuttering’.
In November 2001, our group TTM-L was recognized by ISA as the first international self-help group that works through internet and that is directed to all Speech Hispanic stutterers. We have more than 200 memebrs, in its majority stutterers, that we communicate through the internet and exchange experiences and opinions about what is stuttering and how we handle it.

Through this section “TTM-L Informs”, which we aspire be permanent in One Voice, we want to meet the Hispanic stutters community and to inform them about the activities of the group.

The first of several recent activities was the two-day seminar ‘Speaking about Stuttering’ by Pedro R. Rodríguez C. in September of 2001 in the city of Rosario, Argentina. It was hosted by the Speech Therapists School of Rosario and the Medicine Faculty of the National University of Rosario, attended by nearly 100 people. We were talking about the nature of stuttering, the meaning that this has for the stutterer and the role that speech therapists should have in the stuttering therapy.

Subsequently, on October 22, we celebrate International Stuttering Awareness Day. From countries as Spain, Chile, Peru and Venezuela our associates were informed about the different activities: chats, courses, radio interviews, posters in hospitals and schools, distribution of informative material and reports in magazines and newspapers.

In May 2002 some of ours members attended the First Stuttering Latin-American Congress by the Argentine Stuttering Association; Beatrix is member of the Board of directors of ISA.

On June 26, 2002 the Spanish Stuttering Foundation (TTM-ESPAÑA) was legally constituted in Spain. The Foundation was born of the idea of a group of men and women who stutter and parents of children who stutter, and members of TTM-L. The Foundation is a legal entity and covered by Spanish legislation, and its purpose is to meet stutterers needs and to spread the knowledge of stuttering.

For more information on TTM-España, contact:
Montserrat 24,
1º - 08190 Sant Cugat del Valles
Barcelona, Spain
E-mail: ttm_es@yahoo.es

Among the 26 and June 29 was carried out in Salamanca (Spain) the “International Congress of Foniatría, Audiología, Logopedia and Psicología del lenguaje” in Homage to the Dr. Jorge Perelló Gilberga, to this event they attended various of our members. Dr. Fernando Cuesta exposed the job: “TTM-IB: A virtual experience of attention and diffusion of the stuttering knowledge” he brought to light what our Group is, the activities that carries out and the achievements reached at the moment.

Another of ours member, Pablo Ibáñez Grana, intervened to expose its experience as stutter. Both interventions very were applauded and they awoke the interest of the Dr. Jorge Perelló Gilberga, to this event they attended various of ours members. Dr. Fernando Cuesta exposed the job: “TTM-IB: A virtual experience of attention and diffusion of the stuttering knowledge” he brought to light what our Group is, the activities that carries out and the achievements reached at the moment.

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The Speak Clear Association of Cameroon (SCAC) is recognised by the Cameroon Government as a non-profit organisation to fight to better the situation of stutterers in Cameroon. SCAC is a full member of the ISA and the second association from the African continent to be admitted since October 2001. Our membership is currently 376.

Several persons within and out of Cameroon have shown a lot of interest in SCACs activities and have been very supportive of our work.

The situation of stuttering persons here is very difficult due to the absence of modern speech and language therapists to work with stutterers To fill this vacuum, stutterers often resort to traditional, and at times very crude methods of treating stuttering, and the superstitious beliefs often associated to stuttering here.

Our struggle consists of educating stutterers and the general public to abandon those beliefs and practices that cannot help them. We help them to understand that by inflicting cuts on a stutterer’s mouth with a razor blade and applying elephant dug to it cannot help, not can offering sacrifices involving costly items to the gods.

We encourage our members to read and spread to those who cannot read and write the valuable and useful information contained in books and video tapes on stuttering that we have in our library that have been generously donated by people in Canada, the US, Britain, the Netherlands, France, and Denmark.

Since April this year, SCAC has a website: www.stutterisa.org/cameroon, thanks to the ISA webmaster, represented by Benny Ravid, from the Israeli Stuttering Association, who freely designed our website. It is linked to the stuttering homepage and the website of the British Stammering Association.

Letters and articles from our association or about us have been published in six newspapers here in Cameroon, and in magazines of the Danish Stuttering Association, Speakeasy of New Zealand, Der Kieseltein of the BVSS of Germany and seven newspapers in the United Kingdom.
In March 2002, two coaches from the McGuire Institute paid a visit to SCAC and did a four day seminar for 11 members of SCAC on how to control their stuttering. In April 2002, SCAC invited Dr. Denis Drayna, a human geneticist, who undertook a genetic study of some 60 members of SCAC. It our hope that his study will throw some light on the hereditary nature of stuttering. One member of the Italian stuttering association also paid us a two-day visit to see how SCAC functions.

In July 2002, I visited the UK at the invitation of the Starfish Project and went through their three-day course. The knowledge acquired will be transmitted to other stutterers here in some localities of Cameroon. During the UK trip, I visited the British Stammering Association. We have to express our thanks to the Starfish Project who sponsored our trip to the UK. In the months to come, a specialist speech therapist from the West Swindon Health Centre in the UK who works with stuttering children and teens will pay a research visit to us to see how she can later apply her speech therapy knowledge here in Cameroon.

We are talking with administrative, political and religious leaders here on how to prepare and celebrate in a big way this year’s International Stuttering Awareness Day in some of the major localities of Cameroon. Prior to this event we expect a lot of our members to participate in the online conference on stuttering, to which we have already sent in two papers from Cameroon.

Our vision is a Cameroon that understands stuttering and to that effect, we have plans to soon create an SCAC Stuttering Information and Counselling Centre in Douala, the economic capital of Cameroon, with liaison offices in the major towns of Cameroon. Such a centre will have printed materials and video tapes on stuttering for our members and the general public. It will also have stuttering counsellors who will act as our own specialists on stuttering, and who will work with stutterers.

We intend to have a computer linked to the internet for our members to have access to valuable information that is available on the internet.
The agony of stuttering in Africa

By Jane Ngabirano, Rwanda

The aim of writing this article is to give some insight to fellow stutterers out there about the life of a person who stutters in Africa. It is also a way of breaking the silence about the matter reminiscent of Africa. I will start by giving a brief account of my life growing up as a person who stutters and then I will give a general description of problems faced by PWS in Africa.

Being a person who stutters is a challenge anywhere in the world but having the problem and living in Africa is agony itself.

I am 34 years and I have stuttered for as long as I can remember, but my most vivid memory of failing to speak in a ‘normal’ way was when I was about 6 years old. I remember the teacher calling me to recite a rhyming poem and I stuttering hopelessly. From then on I became aware of my speech problem and started to develop the negative feelings associated with stuttering: shame, failure, frustration, anger, fear and so on. I was lucky that from earlier on, I was a bright pupil in school and also very good at sports. I guess I had to compensate for my lack of proper speech. It also helped that my mother was a teacher in the same school and so I was really never teased or discriminated against by my peers or teachers.

Real problems started when I went on to secondary school. Most secondary schools in Uganda where I grew up and was educated were boarding schools. And so I found myself in a boarding school with total strangers. It is the first time you are leaving home and the comfort of your own people (a challenging experience for both stutterers and non-stutterers). I was in the company of new people – fellow students who sometimes teased you about the way you talk and certain teachers who didn’t understand your problem and mistook it for poor English language skills, English being my second language. My stutter deteriorated at around this time. I learnt to talk less and kind of withdrew. I only talked when I had to or in the company of a few friends I managed to make. Teachers often didn’t understand because my grades were very good at the end of the term or year. While in school, I lived in constant fear that the teacher might pick me to answer a question orally or read a passage in front of the class. I sometimes wonder how I managed to concentrate on studies with a constant imposing fear of speaking at the back of my mind.

Going through all this would have been easier, if my teachers had been more understanding and my parents had been more open about my problem. In a way I felt my speech problem was entirely mine to handle – nobody else understood what I was going through, nobody cared (or so it seemed) and there was nothing that could be done. If I got malaria fever or developed a cough, they rushed me to hospital, where as my ‘chronic’ speech problem that was even more devastating (at least emotionally) was completely ignored.

I have continued to witness this conspiracy of silence against stuttering up to today. I can no longer talk in terms of parents and teachers. The circle of silence against stuttering has grown to include entire societies; national, regional and the entire continent of Africa.

Thanks to the internet, I at least now have a source of information on the ‘taboo’ topic of stuttering and it has helped a lot. It helps to know that you are not the only one who faces the problem and sometimes you draw strength and consolation from reading other people’s experience with stuttering.

What worsens the problem in Africa is that even the medical scientists, and the media have continued to ignore the problem of stuttering up today. Apart from, maybe, the Republic of South Africa, there are no speech therapy centres and/or pathologists. So for the majority of us, speech therapy is not an option. A big percentage of the population in Africa, especially Sub-Saharan Africa, lives in the rural areas and in most cases these rural areas have no access to electricity, let alone internet facilities, and so they have no access to information that can only be found on the internet, including information on stuttering.

One can only imagine the confusion, fear, anger, frustration, hopelessness, helplessness – agony itself experienced by a majority of people who stutter – especially young children and those who live in the rural areas or even town dwellers who have no access to the internet or who have not used it to research stuttering. I would say they are in a total ‘black-out’ as far the problem is concerned and it’s not a great way to live one’s life.

A future hope

“I hope that one day I will also be able to initiate an association for people who stutter in my country and eventually to be a member of ISA. My heart especially goes out to the young children in our society/in schools who might be stuck with stuttering they don’t even understand and they have no one to ask. I hope to help young people (especially) this by sensitising school/government officials as well as parents. My deal with God is that I am saying; if he can help me to attain enough fluency and confidence(either through therapy or otherwise) to address groups or carry out public speaking fairly well, I will go out and rally support for people who stutter in my country.”
Risen from the silence

Since my childhood, stuttering was a worry for me. Coming from a stuttering family and conscious of the suffering caused by stuttering, I always asked myself these questions:

How can I find a solution for this trouble?
How can I help my brothers who stutter in Africa?

Unfortunately, I'm born in an environment where people know nothing about stuttering. Stuttering is a fatality for them. There is no specialist in the field of stuttering. Stuttering is shamefully and hidden by people. In poor countries like African countries, it is very difficult for people who stutter to access a computer and the internet. So we must have an active method.

When I was able to use a computer at university in 1999, one of my first wishes was to learn to use the internet. This is a wonderful means of communication, which brings the world to a small village. I exchanged correspondences with some French stuttering associations, and in 2001 I was able to get a videotape and primer for stuttering therapy written by Howard Schwartz.

Through the Canadian Association of People Who Stutter (CAPS) I heard of the ISA. It was a wonderful revelation. CAPS put me on the orbit of stuttering. Once again I thank them. Stefan Hofmann encouraged me to set up an association, Jaan Pill from CAPS and Joseph Lukong from Cameroon helped and encouraged me. In February, we created our association. Thanks to the action of CAPS, people who stutter in Burkina Faso are raised from the silence.

In August 2002, our association became an ISA member. Paraphrasing Neil Armstrong, I will say that it's a little step for ACB but a giant step for people who stutter in Burkina Faso and in Africa.

We must go to get in touch with people who stutter and encourage them to set up their own associations. We are developing an active method in order to get in touch with people who stutter in West Africa. Associations who are ISA members must be alert, and refer all people who contact them, to the ISA.

Moussa DAO is a young pharmacist. Since his childhood he has stuttered. He is chairman of ACB (Burkina Faso stuttering association), and the ISA contact person in Burkina Faso. He is physically disabled.

African traditional healers: what they know about stammering and its treatment

From March 28th to April 6th, the international African traditional healers was held in Ouagadougou, the capital of Burkina Faso.

This meeting gathered more than one hundred of African traditional healers coming from several African countries. Conscious of the contribution of African traditional medicine in developing of drugs in modern medicine, while evaluating knowledge general of the stuttering by African traditional healers, we wanted to explore this medicine to see whether it could also contribute in the field of the treatment of stuttering. Benefiting from this meeting which is a unique opportunity to gather these traditional healers, we conducted a pilot study by addressing open questionnaires to some African traditional healers.

This study related to 10 African traditional healers, in which six were originating from the Burkina Faso and four abroad. On the level of the causes of stuttering,

Two said that stuttering is caused by not cutting of the membrane which joins the base of the tongue to the mouth during the childhood;
Two said that imitation of adult’s stuttering by children;
Four said that stuttering is heredity;
One said that disease (mainly meningitis) is the cause;
One said that stuttering was the result of a curse.

On the treatment of the stuttering,

Eight affirmed that the stuttering can be cured
Four affirmed to know old stutterers who were cured

On the possession of remedy for stammering,

Two affirmed to have a remedy for stuttering: the root of one specific plant that must be used in a drink; the mixture of juice from the leaf of specific plant and honey, to use like a drink. Three said they did not have a remedy, but said they knew traditional healers alive in their area who had a remedy.

Our sample being very weak it appears difficult to us to draw great conclusions. Nevertheless, this study has the merit to show some ideas of African traditional healers on the stuttering and opens the way with a more thorough investigation. It would be interesting to make a second study in 2004. The contact with African traditional healers is also a means of raising awareness for a good treatment of people who stutter in the most undeveloped places of Africa.

Reports by Moussa Dao, right, of the Burkina Faso Stuttering Association, ACB, the newest ISA member.
By Cheng Ma (Barry)

Through the Internet, I got to know Stefan Hofmann, vice chairman of the International Stuttering Association (ISA), who is dedicated to outreach efforts in China. At our initial meeting in Beijing, I learned about self-support activities and the stuttering awareness movement in Western countries. These were all new concepts to most of the Chinese stuttering community. In May 2001, Mr. Hoffmann and I witnessed the first official self-support group meeting in a Stuttering Treatment Center in Shenyang, Liaoning province. With the help of other Chinese stutterers, we set up the ISA’s official Chinese website.

In July 2001, I was sponsored by the ISA to attend the Sixth World Congress in Ghent, Belgium, as the only Chinese stutterer representative. At the conference, I got the chance to meet with stutterers from all over the world and exchange ideas on how to cope with stuttering. I also gained an extraordinary amount of knowledge on the latest developments in stuttering therapy and considered myself to be extremely fortunate to have this rare opportunity to speak with distinguished professionals in this area. My participation in the conference had become a permanent enrichment in my life and was instrumental in encouraging me to pursue a career in speech pathology. This is the story of my journey.

I stuttered as early as I can remember, though my mom said that I used to be very fluent and articulate at the beginning. I was born in the countryside in Hebei province at the end of China’s Cultural Revolution. At that time, in answer to Chairman Mao’s call, young people from the cities were sent to the countryside to learn from the peasants. As natives of Tianjin, a metropolis in the North near Beijing, my parents were no exception. Since life was a lot better in the cities, when I was still a kid, my parents decided to send me back to Tianjin to stay with my grandparents, a “mistake” for which my mom will never forgive herself. According to my mom, she began to notice my problem when she visited me one day and I remained that way ever since.

Soon I found that whenever I did it, little girls would laugh — a talent that I considered extraordinary at the time. Thus my new discovery encouraged me to stutter more and earned me more attention, until I realized it was too late.

True or not, I became a stutterer during childhood. Other kids in school gave me names and laughed at me when I spoke — this time I knew it was mocking. The teachers seemed to be at a loss for what to do and simply never called on me in class. At the end of the semester, my school report card always remarked, “Not good at expressing himself.”

As to my problem, my parents thought I wasn’t paying attention when I spoke and always asked me to slow down. My new strategy made me a perfectionist. I would repeat my hard work seemed to pay off. Now I had this consolation: From then on I decided to give up Chinese and started to speak English. I had this underlying rationale: I was conditioned to stutter because those Chinese words were all linked to my past embarrassment and humiliation. Thus the easiest way to cut off those links was to set up a whole new system with an English sound hundreds of times until my tongue and throat hurt to make sure all the muscles of my speech organs got in the right position. I never let a stuttered English sentence pass and practiced it again and again until it came out smoothly.

After a few attempts to shape up failed, I soon became defiant of their wrongful accusations and cut off all conversations with them, thinking they would not catch me again. Though my parents did not know how to make me talk, they didn’t seem too worried, hoping I would outgrow stuttering one day. As my dad always said, he used to be a severe stutterer when he was young and he became “normal” in his early twenties.

Although I took my dad’s story with a grain of salt, I sort of managed my speech, as by and by I learned to avoid a block by changing to an “easy” word along the way. I was also “blessed” that there always were some “bigger” stutterers in class who could not even say a complete sentence. Thus I could avoid being labeled as a stutterer.

As I grew older, I became more and more self-conscious of my problem. As a result, I began to have a strong urge to get rid of my stuttering. In China, though a lot of people are ignorant of stuttering, people in general believe that stuttering is not hereditary and that stutterers are physically and intellectually healthy, as can be seen by the fact that a lot of famous Chinese people are stutterers. The traditional perspective on stuttering is that it is an acquired incorrect speaking habit formed over time and can only be cured by replacing it with a normal speech habit, which involves a lot of hard work and perseverance.

With this in mind, I started my long journey of treatment. At first, I tried reading out loud, hoping that by tedious and time-consuming practice, I could establish a new speaking habit to inhibit the old one. While my reading skills improved by leaps and bounds, my daily speech was still somewhat shaky.

Ruthless reality kept goading me to think hard about the acquisition of my speech ability. I really wished I could go back in time to become a baby fresh from my mom’s womb and start this process all over again. One day, while I was in college, I thought to myself: I’ve been stuttering for almost 20 years and it’ll be awfully hard to change such a longstanding habit. But if I pick up a new language, maybe I can develop a correct way of speaking from scratch and this time I won’t screw up.

From then on I decided to give up Chinese and started to speak English. I had this underlying rationale: I was conditioned to stutter because those Chinese words were all linked to my past embarrassment and humiliation. Thus the easiest way to cut off those links was to set up a whole new system with positive feedback.

My new strategy made me a perfectionist. I would repeat an English sound hundreds of times until my tongue and throat hurt to make sure all the muscles of my speech organs got in the right position. I never let a stuttered English sentence pass and practiced it again and again until it came out smoothly. My hard work seemed to pay off. Now I had this consolation:
for so many years. Despite the chastening, I've learned patience, sympathy, and humility

although I stuttered in Chinese, when it came to speaking English, it was other people's turn to “stutter.”

After graduation, I was assigned to work in a court in Guangzhou, Guangdong province, but my fluency disorder persisted. The flame of my hope for a cure was rekindled one day when I found an ad in the newspaper about a Stuttering Correction School in Chengdu, Sichuan province, run by Mr. Wei Wang. My trip there turned out to be one of the memorable adventures of my life.

Like other Chinese stuttering specialists, Mr. Wang was a homemade stutterer-turned-therapist. Without higher education, let alone any medical background, he claimed to have cured his stutter through intensive research and arduous effort. His techniques mainly consisted of deep breathing and slowing down the rate of speech by beating time and drawing to inhibit the stuttering compulsion, we were required to speak each syllable while patting on our thigh once. In this way, Mr. Wang suggested, it was impossible to stutter.

Mr. Wang also thought psychology played a role in stuttering. To set our minds free, every day we had a “speak bitterness” session, when every stutterer would go in front of the class to describe one of his dreadful stuttering experiences. Mr. Wang contended that stutterers always get nervous when they speak because they don’t want other people to find out their speech problem. To deal with this abnormal mentality, we were asked to go to public places wearing a board that stated, in conspicuously large characters, “I am a big stutterer.” To become more brazen, we went to the marketplace and begged for small things from the hawkers. Several times, we were asked to go to public places wearing a board that stated, in conspicuously large characters, “I am a big stutterer.”

As it is common superstition in China that stuttering is contagious, stutterers don’t tend to talk amongst themselves for fear of further deterioration under each other’s influence. Thus, when I first arrived at the school, I felt a little ill at ease to meet so many stutterers for the first time. But since we could talk freely about our stuttering, which seemed to be the perpetual topic of our lives, I found out we really had a lot in common and soon we began to encourage each other in our war against stuttering.

While we appeared shy and nerdy in front of other people, together every one of us seemed talkative and humorous and had so many stories to tell. There was a guy from Hunan province who stuttered all his life. As he’d already married and was running a small business, he didn’t bother to do anything about it. But he had a three-year-old daughter who was very cute and adored by all his neighbors. He said his heart really ached when he could not talk with his daughter as other fathers did and feared that his daughter might be “infected” by him one day and she would suffer as he did. So for the sake of his daughter, he came all the way from his hometown for the treatment.

There was another guy from Jiangxi province whose job was to drive trucks smuggling cigarettes from the southern border to his hometown. He said his stuttering became very bad whenever he saw cops or was stopped at checkpoints on the highway. We advised him that the first step to cure his stuttering was to quit his job and find something legitimate to do for a living.

There was also a guy from Xinjiang province who claimed to have found a way to control his condition. He discovered that after drinking some beer he would become more fluent. We were all jealous that he had found a solution for his problem. But then we asked him why he came for therapy if he already had a way out. He said he just couldn’t stand the life of being drunk all the time.

By the time I left Chengdu, I thought I had also left my problem there for good. But I just could not speak with my colleagues in court while patting on my thigh, and before long a relapse set in. As a Chinese proverb goes: the more hope you place in something, the more disappointed you will be. And I was a couple of times more disappointed one day when I received an e-mail from an English stuttering Web site that said the latest scientific study showed that stuttering was impossible to cure, but could only be controlled to a certain extent.

I felt so helpless in my struggle against stuttering that I experienced several breakdowns afterwards. Once my speech was so out of control that, after I started speaking and had a block, my brain suddenly went totally blank and I stood there not knowing what to say. Feeling like an outcast, I developed autism. I shied away from any speaking situations if possible. I ached to be with people, yet I hated to be misunderstood. Every day I was counting the hours to be off work, so I could be alone and drown my sorrows in books and websites about stuttering. Not being the type of person who took things lying down, I set my mind to try every affordable therapy, because I just bank on the fact that the more informed I became about stuttering, the better off I would be.

Sometimes when I look back on my life, I feel that stuttering was always playing a joke on me. Although I did not have as much of a good time as other people and gave up a lot of opportunities, I don’t regret being afflicted with stuttering for so many years. Despite the chastening, I’ve learned patience, sympathy, and humility. My ambition is to get a graduate degree in speech language pathology in the near future so I may one day solve my own problem and help other people to fulfill the dream that was once thought impossible. So wish me luck and may God bless us all.
Proposition for a renewed approach to phonoaudiologic science: application in stammering

By Adolfo A Barrales

I am pleased to have been invited to show my work on stammering in One Voice, especially to Stefan Hofmann, who I met in Buenos Aires in May 2002 during the First Latin American Congress on Stammering, for his kindness and interest in the ideas I will express. Thanks also to Martine de Vloed for her attention and support.

Introduction

In my constant exploration of advances for phono-audiology nothing has impressed me more than studying and applying a new perspective which has side-stepped the empirico-rational approach which was the basis of all western scientific work on the human being, within which phono-audiology was developed. This new perspective, post-rational, revolutionary in its application, is changing both theory and practice in several human fields – medicine, education, sociology, psychology, and more. Taking account of this, I think that phono-audiology, taking part in interchanges with other sciences, should take its place and, in its own field, accompany and apply the step which is being developed from a universal, descriptive vision to a manifold, explanatory vision of human experience, where language is relevant not as an instrument but to understand the totality of the human being.

Thus I have rethought the traditional approach, proposing a “Epistemological, phono-audiological, renewed, constructivist approach”, neither expansive nor complementary to existing approaches. A step to one side in understanding the organisation of phono-audiological pathologies and thence how to apply therapy, based on the contributions of disciplines which gave birth to the post-rational perspective (the sciences of complexity, biology of knowledge, systematic, strategic, solution-oriented models, ontology of language), about what human experience and language is, and how it functions.

Development

Looking again at phono-audiological problems, taking off our descriptives glasses in the third person, we can see the reality in the first person that the patient himself experiences “living in the language”. This changes both the conceptual and therapeutic phono-audiological activity for each pathology. How does this epistemological phono-audiological proposition work for stammering? Taking off our descriptives glasses to observe the regularities which allow us to group patients into the same “ontological being” (diagnosis), we realise that that stammering is more than biological facts, than a phono-articulating apparatus which is out of control. To go to the “Totality” we realise that the “Epistemological being” which every patient is, as a closed system and in its relationship to the outside environment in which language operates, each one builds its pathology in a unique way, differentially and manifoldly. This allows us to see the ‘whys’ and ‘hows’ of the great symptomatic variability, courses of evolution and the different grades of planes affected in the communicative experience (emotional, behavioural, cognitive, social and of identity) between patients and from situation to situation. Thus we understand why stammering takes as many forms as there are ways of experiencing reality. It becomes clear in clinical work why there are no standard therapies for stammering.

With these ideas clinical practice takes a turn from a therapeutic path centred on limitation to one centred completely on a lens on the fluency portion of complete speech. This allows us to take the patient from his stability, liberating him “to fight” with the stammering, as has been traditional. The therapy is transformed into a “process” of co-creation between the therapist and the patient, not hoping for a particular technique or conception for the whole range of patients but rather “reading” each patient as his own theory and thus “building custom-made therapies” for each one. The therapist becomes a facilitator and disturber, providing resources for expression and communication, capturing things specific to each patient and expanding the fluency portion. With the principle of “utilisation” of the “style of being a patient” even of “resistances”, understanding them and managing them to advantage.

Creating physical and emotionally contextual for slowly experiencing “emotional satisfaction” of the use of expressive resources in different planes of communicational experience (social, emotional, behavioural, cognitive). Considering the systematic network with “Group link” and “inter-subjective and self-referential” sessions. Achieving a “Semantic and Syntactic” change, which allows each patient to become the “owner” of his experience and confront, by means of a tertiary change, new communicative situations.

To finalise

In my work, using this proposition: It is working in stammering and other phono-audiological pathologies, allowing work at the varioDus levels affected with a renewed way of evaluating, diagnosing, treating, investigating and preventing: it is incorporated as a pilot plan in the Raihuen Language School for pre-school children (Borough of La Florida, Santiago de Chile); broadening phono-audiological work in different tasks where communication is involved; I am publicising it in several seminars.

It is very pleasant for me to share with the international community of stammerers, friends and associates of ISA these advances which I have been developing for an evolution in phono-audiology, with the direct object of benefiting those
NSA gives wider access for more people

By Annie Bradberry, executive director

The National Stuttering Association just completed its 19th conference, celebrating hope, empowerment and support. These conferences provide attendees with a full range of workshops to choose from, exciting keynote as well as a family program for the young and their parents and siblings. This year was extra special for the organisation as we celebrated our 25th anniversary!

We were particularly grateful this year for a special general session coordinated by Judy Kuster, ‘Voices Across The Sea’, This session featured short reports from seven guests from around the world as well as the US screening debut of To Speak, a 15 minute, autobiographical documentary from the award-winning Belgian producer, Eric Lamens. Speakers included: Anita Scharis Blom, Sweden, Martine De Vloed, Belgium, Edwin J. Farr, England, Dr. Lieven Grommen, Belgium, Dr. Mark Irwin, Australia, Konrad Schaefer, Germany and Gina Wagott, England.

I am very excited to report that this year we have become an American Speech-Language and Hearing approved Continuing Education provider. This program is our commitment to providing those in private practice, school based clinicians and educators with opportunities to learn together about stuttering. We continue to fulfill our obligation to help the school based clinician to become more effective with the constraints of their employment settings through this new Continuing Education Program. Our goal is to bring quality programs to clinicians throughout the United States on an ongoing basis.

The NSA has published several books on stuttering. In fact, more and more universities are using many of our books as texts today. Our newest book, Preschool Children Who Stutters: Information and Support for Parents — 5 Steps to Help Your Child, written by Nina Reardon and Scott Yaruss, launched in November 2001 and is already being stocked in many university libraries. This June brought two new booklets written by Bill Parry and Rachael Resk, dealing with the employment setting. Mastering the Job Interview for People Who Stutter, offers practical advice to help make the best impression and Stuttering: What Employees Should Know, is intended to provide information about stuttering for business owners, managers, human resource professionals, supervisors, recruiters and interviewers.

In June of this year we hosted our first research symposium, Pioneering Stuttering Research in the 21st Century: The First Joint Symposium for Scientists and Consumers This conference is unique because it was the first time consumers – people who stutter – and researchers meet in a formal manner to discuss the current status and future of stuttering research. This exceptional event was June 25 –27, 2002 preceding the annual NSA conference, which began on June 27th. ‘Pioneering Stuttering Research in the 21st Century’ was designed to provide participants with an opportunity to influence the direction of research in the coming years. There were no formal research presentations at this conference. Rather, participants were divided into small working groups depending on their interest (for example language and motor interactions in stuttering, genetic aspects of stuttering, outcomes of stuttering treatment, etc.) A noted researcher facilitated each small group discussion. Current status of research, future needs, and methods of implementation, among other issues, were discussed. At the conclusion of the small groups sessions, participants convened to a general session in which group discussions were summarised. And a publication is currently being prepared that will contain the results from this historic meeting.

All of the above came to life with the help, dedication and countless hours of many volunteers including parents, speech pathologists, adults and educators. These are just a few of our accomplishments, which, without the support of our members, would never have come to life.

The possibilities for the stuttering community and what we can accomplish together continue to grow and amaze me. Last year I had the honor of attending the International Stuttering Association World congress in Belgium where I met many of you and where I personally expanded my stuttering journey. This experience confirmed that together we are making a difference and it is an honor to be working with all of you.

who need our help. Especially for the stammers who suffer not only because it is difficult to speak but because in this highly competitive society it would seem that personal abilities were the only parameters by which to measure people. Thank you.

Adolfo A Barrales is a Phon-audiologist of the University of Chile. He is trained in psychotherapy and Ericksonian Hypnotherapy, and is the Director of the Centre for Phon-audiological Development in Santiago, Chile
Making a mark with Red Cross

By Othieno Daniel Kiracho, Uganda

Public speaking is not a joke! I guess you will certainly agree with me if your stutter is beyond mild like mine. The daily frustrations and embarrassments we face while speaking to large audiences, make the adoption of the avoidance method, a largely preferred weapon. Unfortunately, this methodology seems not to be the solution to this dehumanising handicap.

My personal experience with public speaking has been both challenging and rewarding. I remember, not long ago, anything to do with it making public addresses was unwelcome. In fact any attempt to do so was like inviting my self-embarrassments. However, when I got my present job, there was some kind of a renaissance. I mean a complete shift in my way of life. The job was so demanding in terms of talking to the public. It involved going out to meet students and disseminating the Red Cross messages. In fact at first it looked like I would not be able to measure up to the requirements of the job due to my stammer.

It was a tough experience, though in the end, it modelled me to what I am today. The first major challenging task was when I was invited as the Red Cross district officer, Tororo, to launch a Red Cross link in a secondary school of over 2000 students. There were also some other invited guests for the occasion. It was my first time to encounter such a large and difficult audience to handle.

It was close to a disaster! By the time I stood up my heartbeat had already doubled and I was about to start sweating. The hell of uneasiness and fear were so great that I realised I was heading for the worst since under tension or fear my stammer is so cruel. As I delivered the speech the nightmare of bad stammer also set in and so were the laughter by some students. It was a very distressing moment. But all the same I struggled to the very end, until I said all that I wanted to say.

While back at home, the sad memory was still haunting me. I decided to read some stuttering materials, I have so far received from our dear friends of CAPS, BSA, ISA, Stuttering Homepage and Institute for Stuttering Treatment and Research in Canada. It was a wise idea! All I could get from the materials were immense courage and determination. So, I went on full gear to organise several Red Cross dissemination trips in schools across the district.

In the end what was exciting was the kind of stamina and confidence I developed over time. Talking to large audiences became no problem to me. The confidence building went hand in hand with improvements in my fluency. I realised I could no longer stammer too much in front of the students. In fact, very few would even laugh at me. Instead I was nicknamed Henry Dunant, the Swiss founder of the Red Cross Movement, by some students.

I now feel much more comfortable to address large audiences regardless of their size or composition, than ever before. My last word to you and others, please, regardless of how severe your stammer might be, never fear public speaking. Just give it a trial, your fluency will improve with time.

Much has been accomplished – more remains to be done

By Mike Hughes, executive director

It has been an extremely busy time for Speak Easy. As Canada's national organisation for people who stutter, our public information campaigns continue to reach thousands of families across Canada and we see solid evidence that our activities are helping to change attitudes towards stuttering. With the financial support of the Federal Government and several granting foundations, our informative pamphlet series has been revised and enlarged to include the titles:

- Introduction to Speak Easy Inc.,
- Suggestions for Parents of Stuttering Children
- ‘Relative’ Support for Stutterers
- How the Teacher Can Help the Stuttering Child
- Start a Speak Easy Chapter
- Guidelines for Greater Fluency
- Advice for Partners/Spouses
- Notes to Listeners
- Using the Telephone
- Potential Stuttering Solutions

These pamphlets are included in our free information kits, which available by request anywhere in Canada. More than 10,000 of these kits have been distributed. Speak Easy's Internet services continue to be widely accessed around the world. Our website has been simplified for ease of use. Electronic digests of our monthly magazine, Speaking Out, in addition to our monthly electronic articles on a variety of topics go to hundreds of subscribers around the world. To subscribe, simply send a blank e-mail message to speakeasycanada-subscribe@yahoogroups.com

We are now developing plans for future projects to have continued national impact. Speak Easy has earned the respect of the media – newspapers, magazines, radio, and television continue to support our information and outreach public service announcements, which sustain a widespread demand for our services. Membership continues to grow with a great deal of interest being shown by families and friends of people who stutter. Much has been accomplished – more remains to be done!

website: www.speakeasycanada.com
Good media interest in Croatia

By Suzana Jelicic

In October 2001 in Zagreb, the Croatian Association for People Who Stutter, Hinko Freund, for the second time has commemorated ISAD. A press conference was held by our association together with our general sponsor Croatian Telecom. During this event, the famous Croatian pop singer Gibonni, who also stutters, was virtually contacted from Split.

Also in October, a member of our association, Mario Gotovac, created and set up the web site of the Association. Soon after, a discussion forum was opened on request of one of the web site users, and it is useful for all who are interested in stuttering, especially for people who stutter, parents of the children who stutter and speech therapists. During May of this year chat line has also been set up and it is well accepted.

In November 2001 we organised the first International self help workshop for adults who stutter, in cooperation with Netherlands Association for People Who Stutter, Demosthenes, with whom we initially contacted at the world congress in Ghent. During this workshop in Zagreb, we signed a memorandum of understanding. This event was also well presented in media.

In March 2002 in the Netherlands, two international workshops were organised. These were very useful because members who attended the workshops became much closer, more self confident, independent, and they made progress in confronting and overcoming the fears of communication which can be recognised and proved by their own attendance in radio and TV interviews. Because the Croatian Association for People Who Stutter has less than 100 members, we are satisfied with all recent successes, but also aware that this is the beginning of seeing our future plans of publishing, increasing our library, that the Association aims in our future plans and programs.

Ten ways to meet other people – and reduce stammering

By Maria (Croatia)

The first meeting of this kind between Dutch and Croatian stuttering associations was held the Croatian capital, Zagreb, in November 2001. It consisted of workshops and getting to know each other, plus some tourist activities.

The second meeting took place in Wernhout, Holland, from 23rd to 31st March 2002. The task of the associations was to collect finances from many sponsors, which included lots of media work, printing flyers, books and going on TV and radio as much as possible. In this way stuttering is being promoted.

Seven stutterers (four boys and three girls) flew from Croatia to Amsterdam on March 23rd, with a speech therapist. Their Dutch colleagues organised transportation to Parc Patersven, a peaceful village of bungalows near the Belgian border. The hosts had organised a very fulfilling week, with days for workshops and days for sightseeing. Every morning one group was joining the other for breakfast, then workshops were conducted from 10 or 11am until 5pm when it was time for grocery shopping. The dinner was cooked for all – mostly from many sponsors, which included

Workshops

On Monday everybody introduced him or herself to the group sitting in a circle, and told something about the therapies they had undergone. It was obvious that there was a range of speech difficulties: from stammering and talking too fast to high-voltage blocks, ticks and body-battles.

In the next days we underwent many exercises, such as:

1. Choral reading - everyone reading together
2. Counting - there is no anxiety when saying numbers
3. Acting - playing the role of someone else
4. Overacting - emphasising pleasure at seeing someone
5. Talking about a subject within a given time
6. Imitating another stutterer's stuttering - helps a person get a better view of where to try to change the speech
7. Babbling all together - proof that all stutterers CAN speak fluently
8. Forcing into a conversation - to practice persistence and confidence
9. Ask the president - to practice assertiveness
10. One side against another - to practice debating

Exchange of thoughts and feelings

Most of us agreed that stuttering is something we need to accept to be able to fight against. It is a part of us but there is so much more to who we are.

Being a part of a group has helped some to feel like they belong, that they're not alone with this problem, that there are people who have been through the same or even worse, and are still there and smiling.

We agreed that stuttering was or is a problem, especially while growing up, but most have this positive thinking that a lot good came out of it: we are more sensitive to other people's states and feelings, we can connect to people with difficulties, we are more gentle and polite because we are aware of how much these qualities can make a difference for us.

Like on the ISA poll, we disagreed about helping a stutterer finish his/her sentence. Some like it, some do not, and the majority would like to be asked first.

The next meeting is vaguely being set around October 2002, in Croatia again, this time on the Adriatic coast. Care to join?
Disclaimer: One Voice is a forum for views and information about stuttering. The opinions expressed are those of the individual contributor and not necessarily those of the ISA or ELSA, who do not accept responsibility for the accuracy of opinions or information provided by contributors. Neither ISA or ELSA endorse or reject any therapies, programs or devices mentioned.

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ISA Mission: To improve the conditions for children, adolescents and adults who stutter and parents of children who stutter in all countries, especially by sharing concepts and experiences in stuttering self-help and therapies.

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