

One Voice

What can you do during 2012?



Can you Create communities / Chapters / Self help Groups ...where it is safe for people who stutter to discuss stuttering? I want to encourage organizations to organize an event.

Resources can be found by going to:

www.isastutter.org

www.stutteringhomepage.com

www.stammering.org

ISA is an organization that functions because of People who Stutter who volunteer time and energy to assist others who stutter to

pursue personal aspirations and alleviate possible problems during daily life activities. Your time, energy or ideas are always welcome to be discussed by Board of Directors and Advisory Board of Directors to create a positive experience for people who stutter.

We need Board Directors, Advisory Board members and volunteers who have time, energy and ideas.

IS THIS YOU?

*Warmly,
Michael*

MESSAGE FROM OUTREACH...

In recent issues of One Voice I talked about a Danish Ambassador at Large program. A specific example of it is the work done in Nepal. A PowerPoint presentation is available (contact me please if you want a copy). We have translated this to a PDF and you can view this from <http://www.isastutter.org/wp-content/uploads/2012/02/Partnership-NSA-and-FSD-ISA-Congress-May-2011.pdf>

Michael our Chair has raised a wonderful question. What can you do in 2012 to help PWS in your own Country and / or around the world? We are starting a new year with several events already known see <http://www.isastutter.org/>. But what are you doing, or what have you done? If you are on either Board of the ISA, what will you do in 2012 to keep the ISA committees active and progressing for the good of all (<http://www.isastutter.org/initiatives/isa-committee-structure-draft-2?>) If you are part of your National Association, what will you, and your Association, do in 2012? If you are going to volunteer, what will you do to step outside your comfort zones?

For myself, with the support of a local Speech Language Therapist, I have started a new Self Help Group in my own City of Peterborough (UK), which is recognised by the BSA (British Stammering Association). We had some informal get-togethers last year and have had 2 formal meetings this year with 4 more planned meetings. There will be a break of a month and then we will plan 6 more meetings etc. I am also working with the BSA Board of Trustees. Can you do something new during the next 6 months and send me an article for the following issue of One Voice (OV32)?

In 2006, I volunteered to work with the ISA. Mark Irwin and Stefan Hoffmann asked me to raise Stuttering Awareness in India, because many Indians were asking for help outside their India. Local Indians and a few others started a movement which resulted in TISA being accepted as a National Charity in 2009 and holding a National Conference at the end of December 2011. In 6 short years Indian people who stammer transformed their thinking and their ability to help themselves. Details of the National Conference can be found at http://t-tisa.blogspot.com/2011_12_01_archive.html and http://t-tisa.blogspot.com/2012_01_01_archive.html.

Very good pictures can be seen at <https://plus.google.com/photos/117465129517612405511/albums/5693856388158108817?authkey=CKOxLXkgK3kFw&banner=pwa>

Two example pictures can be seen on the following page....

There is an article about this conference later in this issue. I expect there are some thoughts about their next National Conference, and sometime they might even look at an Asian Conference(???). (LoL) The ISA would help them as much as possible.

The ISA has been contacted by Greece and Portugal in recent weeks and contact to many Nations around the world continues.

If you are interested in poetry, look at <http://www.poetpatriot.com/poems-stutter.htm>.

Have you looked at our Facebook site? (<http://www.facebook.com/isastutter>)

Pay us a visit and tell us what you want.

As often, I will close my contribution by reminding all of us that the ISA exists to help People Who Stutter in any Country of the World. For the ISA to succeed, we need

-volunteers with time;

-we need volunteers to help with translation between other languages; and

-we need money.

If you can give the ISA some of your valuable skills / time / money, please do so. However we are also seeking volunteers to help in fund raising to send PWS to the World Congress in 2013. If you can help, or know of someone else who can help please contact either Michael Sugarman <msugarman@sbcglobal.net> or Keith Boss <keithmaxkb@yahoo.com>.

I look forward to working with more of you over the next 18 months until the 10th World Congress for People Who Stutter in Holland in 2013 (<http://www.demosthenes.nl/wc2013>)

Please pass this to all your members.

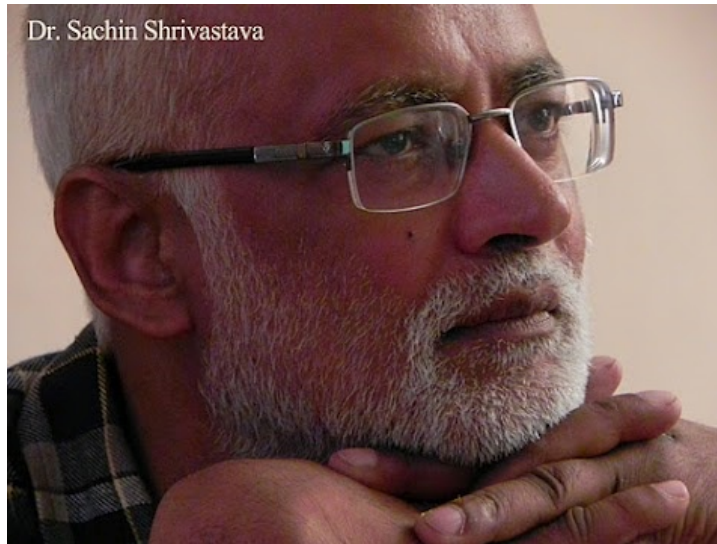
Keith Boss

ISA Chair of Outreach

Vice Chair and Treasurer

keithmaxkb@yahoo.com.

TISA National Conference (complete write-up on Page 9)



MOUSSA- MY REVENGE.....

One of the worse periods of my life as PWS was the defense of my thesis. How can I face to my oral presentation? How can I be proud to become a doctor without been able to read like children in elementary schools? Since the first day of my school year in pharmaceutical department of medicine school of Ouagadougou I have been scared about this final act of my study. I lived this situation during 7 years. Every year when I graduated, of course that made me happy but I become sad when I thought that thesis defense was been approaching.

Thanks to the work of our association ACB in raising the theme of stuttering from the silence, Mr yaya member of ACB decided to work on stuttering as subject of his thesis. The theme was: Stuttering in schools, case of the basic education Ouaga IV. He found that 1,95 % of 5,636 pupils of the last four years of elementary schools stuttered.

Thanks to my commitment in my country for the theme of stuttering and as I learnt so much from meetings and friends, today I am viewed as one of the persons who is specialized in stuttering. I'm regularly asked to deliver speech or do presentation.

The president of board of examiner asked me to join his team. I could not imagine such honor.

The first ever defense of a thesis in Ouagadougou took place on 7/23/2011 at the medicine school of the University of Ouagadougou. The room was full.

The president of board of examiner started his speech by asking the participants to congratulate me. He said that this event is the fruit of my efforts.

I started my speech by telling: « exactly, Twelve years ago, at the same month and day of the week, because of my stuttering I was very afraid by the defense of my thesis, today thanks to my work on behalf of PWS, I am honored to seat among famous professors of our medicine school in order to examine the first thesis on stuttering in our country.” My comments were much appreciated.

The president of jury said: “after the comments of Dr Dao, I think there are nothing more to add, we should recognize that the real specialist of stuttering in our country is Dr Dao”.

Several studies on stuttering have been doing in different fields (Sociology, psychology...)



Board of examiners and the new Doctor
Front, from left to right, Dr Yaya Sourabié, Pr Ouoba and Dr Tarcissus
Back, from left to right, Dr Moussa Dao and other



The Crowded Room



The Board of Examiners

ACCURATE PUBLIC AWARENESS OF STUTTERING REMAINS LIMITED

The award winning film “The King’s Speech” has certainly resulted in the general public taking a greater interest in stuttering. Newspaper, radio and television articles on the topic are now a regular occurrence. For this, the film’s writer David Seidler deserves the sincere thanks of people who stutter everywhere.

However, in spite of this increased discussion, public awareness of what stuttering is remains limited. Most strangers to stuttering say that the film reinforced for them what they already suspected about the cause of the disorder. So, whether they previously thought stuttering resulted from an overbearing parent, childhood punishment, a desire for perfection, general anxiety, or bullying and teasing, the film served to strengthen their previous opinions. Also the issue of covert stuttering (word substitution and circumlocution) was not discussed.

A similar issue exists with therapy. While the film highlights the success of Lionel Logue’s therapy, it is well known that King George VI continued to stutter throughout his life, so he can hardly be said to have provided a cure. In addition, there has been no development in awareness of most effective therapy since those times. In fact, a recent Journal of Fluency Disorders article by International Fluency Association President, Willie Botterill, highlights how a 1902 self-help book by a Mr. Beasley contains advice that is remarkably similar to what might be given today.

Unfortunately, without wanting to be critical of the well intentioned efforts of so many kind, thoughtful and caring individuals who make up the speech pathology profession, it seems that this situation is a result of the professional body failing to develop its understanding of stuttering, and consequently, how it should be managed. Willie Botterill says that, “despite the considerable work that has been undertaken, there is no consensus amongst clinicians and

researchers about what to count or how to count it. This lack of consensus has considerable implications for research, as the findings from research studies cannot be compared, making meta-analysis problematic.” (p166, Journal of Fluency Disorders 2011). Furthermore, in a review of the literature from 1953 to 2008 Bloodstein and Bernstein-Ratner concluded ...”substantial improvements, as defined by these studies typically occurs as a result of almost any kind of therapy in 60 -80% of cases”. (p380. A Handbook of Stuttering 2008). This means there is little evidence that one programme is any better than any other, or what specific ingredients account for success in therapy.

What has been known for some time is that a significant number of adults who stutter seeking therapy have associated Social Anxiety Disorder, the severity of which is unrelated to the extent of their dysfluency. (Stein , Baird, Walker. 1996. Am J Psychiatry.) Since cognitive-behavioural therapy has been shown to be effective for SAD, it should be offered as a therapy for people who stutter for whom SAD is an additional disability. This assumes that stuttering therapists screen their clients for SAD, and where necessary make appropriate referrals.

The ISA, through its Public Awareness Committee, seeks to ensure that accurate public awareness messages are widely and frequently conveyed. It is grateful that “The King’s Speech” has done so much to increase the readiness of the general public to empathise with people who stutter, and hopes to use this as a springboard for greater understanding.

Mark Irwin

(Chairman of ISA Public Awareness Committee)



PRESS RELEASE:

“PREDICTING STUTTERING ATTITUDES: FAMILIARITY WITH STUTTERING, MENTAL ILLNESS, AND OBESITY”

Authors: Ken St. Louis and Amy Rogers

A great deal of research has documented that the general public has negative or biased attitudes and beliefs about people who stutter. For example, they believe that if a person stutters, he or she must be introverted, shy, weak, and psychologically affected. This so-called “stuttering stereotype” and other beliefs (e.g., that people who stutter cannot hold certain jobs) are simply not true.

Current research is still documenting these negative, stigmatizing attitudes toward stuttering in numerous studies worldwide, as well as trying to understand why the nonstuttering majority feels and believes what it does. This study dealt with predictors of such attitudes. In order to understand it, a little background is necessary.

I, Ken St. Louis, am the first author of this study. I’ve been involved for a dozen years on an initiative called the International Project on Attitudes Toward Human Attributes (IPATHA). The main goal of IPATHA so far is to develop a standard measure of public opinion (attitudes) toward stuttering that can be used anywhere in the world. I developed the Public Opinion Survey of Human Attributes-Stuttering

(POSHA-S), a survey instrument that has been tested in nearly 60 different studies. As of February, 2011, 3751 respondents from 12 different countries had filled out POSHA-Ss in eight different languages.

One unique aspect of the POSHA-S is its general section that asks respondents (the persons filling out the POSHA-S) a few questions about four human attributes besides stuttering. Those are mental illness, obesity, left handedness, and intelligence. One of the general items asks respondents to place a check mark for any of the following persons they know who have each of the five attributes: “nobody,” “acquaintance,” “close friend,” “relative,” “me,” and “other.”

This study focused on three related research questions. To what extent does familiarity with (a) people who stutter, (b) people with mental illness, and/or (c) people who are obese affect their public attitudes toward stuttering? We developed a formula to gauge three familiarity indexes. The indexes referred to the strength of familiarity with stuttering, mental illness, and obesity, for example, by giving a 60 out of a possible 0 to 100 weighting for anyone who indicated that he or she stuttered, was mentally ill, or was obese. The additional 40 potential weighting points were assigned according to who else and how many others with each of the three problems were known by the respondents.

Next, we rank-ordered from lowest to highest the 3751 people in the database separately according to

the familiarity indexes for stuttering, for mental illness, and for obesity. We then divided those ranks into four groups or quartiles, the lowest 25th percentile with “None/Few Known,” the 25th to 50th with “Limited Known,” the 50th to 75th with “Some Known,” and the highest 75th to 100th percentile with “Many Known.”

We compared each POSHA-S item and its summary scores between each of the quartiles with each of the other quartiles using statistical tests. Typically the largest differences relative to attitudes toward stuttering were between the “None/Few” group and the “Many” groups, with improved attitudes with greater familiarity, but there were a few exceptions. We used another statistical test to determine the “effect size” or the magnitude of the differences that were significant or those that one could be confident were real differences.

The largest effect sizes occurred for stuttering indicating that familiarity with stuttering strongly predicted positive attitudes toward stuttering. With smaller effect sizes, familiarity with mental illness moderately to substantially predicted positive attitudes toward stuttering. With the lowest effect sizes, familiarity with obesity weakly to moderately predicted positive attitudes toward stuttering.

From this study, we concluded that experience with stuttering and other undesired human attributes fosters more positive, understanding, and empathetic opinions about stuttering and those who stutter than lack of this kind of

“PREDICTING STUTTERING ATTITUDES: FAMILIARITY WITH STUTTERING, MENTAL ILLNESS, AND OBESITY” CONT'D.....

than lack of this kind of experience. Still we must be cautious in generalizing these preliminary results to all groups of people.

A quote from the first author that states what makes the research compelling. If first author is NOT an ASHA member the quote should come from an ASHA member.

Confirmation you and/or your other author(s) are ASHA members.

Ken St. Louis is a life member of ASHA. Amy Rogers is not a member but is a student in the Vanderbilt University AuD program.

“With the only standard measure of public opinion and growing database of research-based samples, we now have the capability to compare attitudes toward stuttering from populations all around the world. This will allow speech-language clinicians and other professionals such as teachers to better understand the role of culture in stuttering attitudes. A standard measure will also be extremely helpful in determining which strategies designed to change or improve attitudes are effective and which ones are not.” (Ken St. Louis, 2011)



TISA

I am an American who currently lives in Shanghai, China. I am also a person who stutters. Interesting? Maybe, but let me share an interesting adventure I went on last month. As I was planning my holiday trip I discovered that TISA (The Indian Stammering Association) was planning their first national conference in Bhubaneswar, India. I was thinking about India and what a great journey to learn about India and spend some time with Indians who Stutter. Little did I know what a powerful journey I was heading towards.

India is a wonderful place full of customs, traditions, faith, vegetarians, and a huge love for family. Oh and many, many wild animals. I showed up at the Institute of Health Sciences in Bhubaneswar with an excitement to learn about stuttering in India. Dr Satya Mahapatra and his wife own the facilities and created a beautiful natural environment for his speech pathology and audiology students. Dr. Satya explains he stuttered as a child and shared many inspirational stories with the participants of TISA. The facilities were remarkable and he provided tea, lunch, and personal experiences that will be remembered for a long time.

I spent 4 days with the most brave, sincere, honest people that anyone could come across. Dr. Sachin Shrivastava and Jai Prakash Sunda (JP to his family and those who stutter) organized the first National Conference for TISA. TISA has local self-help groups in different cities throughout India and this was the first national conference. Kudos to these organizers for pulling off a fantastic event.

I met many men who stutter who had never left their hometown before. These men were brave enough to attend this conference in a place they have never been with people they have never met. I met young men who talked of depression and suicide in the past. They now know there is support and hope for a bright future. I was privileged to observe this conference completely change lives. Wow! These young men saw the ocean for the first time true but I think some saw hope for the first time! Hope: learning that they can be good communicators with a stutter and that there is a bright future for them. Yes this will take work and they all seemed up for the task. They all began by taking the step to attend this conference and face their fear of stuttering.

Our stories are similar; getting teased, feeling alone, and no one understanding our struggles. This seems to be universal. I was once again reminded the power of surrounding oneself with others who stutter. This support is immeasurable and an important tool on the



road to acceptance. My only disappointment was that there were no Indian women who stuttered attending the conference. I was told there are women in the association but they do not attend meetings. They say there is some kind of stigma against women who stutter in India. I truly believe it is okay to stutter. I want to get the word out to other women who stutter that it is okay and there is support. If you stutter please reach out and talk to others who stutter. You are not alone. Let's all work together to get rid of all stigma against stuttering everywhere!!!

For me meeting 25+ people who stutter in India was very meaningful. It gave me a wonderful taste of home and feeling of family and togetherness that I miss living in Shanghai. Thank you to all my Indian friends/family. I love you and thank you for touching my life in a very special way. Keep up the TISA work and your own work. You are all special and remember it is okay to stutter.

Elaine Wigdor Robin

<http://t-tisa.blogspot.com>

PWS IN GREECE NOW HAVE A VOICE

In May 2011 a group of PwS in Greece took the initiative to form an association for Stuttering. This initiative came from the need to support PwS and the need to create awareness to the general public.

The lack of awareness is manifested in the way other people see us. They tend to think that PwS are people of low mental capacity. Unfortunately in Greece there is no institution or legislation to protect and defend PwS. In schools and other educational institutions the awareness and knowledge of the educators is vestigial. Children that stutter should have equal treatment from their teachers as well as from their peers, but this rarely happens. Unequal treatment is found in all aspects of the life of a .

Seeing that, we had the need to give psychological and emotional support to PwS, we felt the need of unity and support between us and the need to gain knowledge on stuttering.

That was how the association “Initiative of PwS” was created. It’s goals are set in the memorandum and they are:

- The support and the defense of PwS rights
- The distribution of information about stuttering for children (and their parents) – teens – adults who stutter.
- Create and increase public awareness about stuttering
- Inform PwS about all the professional institutions and associations that provide specialized help and support
- Communication and co-operation with other associations of PwS world wide

-Collaboration with associations, organizations and institutions for the promotion and support of the rights of PwS

-Increase awareness and distribute information about stuttering to health professionals and educators

There are several ways to communicate with the “Initiative of PwS”:

Email: sillogostravlismou@yahoo.gr



Πρωτοβουλία Προσώπων που Τραυλίζουν



Protouvoulia PpT



Πρωτοβουλία Προσώπων που Τραυλίζουν



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KELLY IRELAND

I qualified as a Speech and language Therapist as a mature student in Manchester in 1986 and have stammered as long as I can remember. I was appointed to the UK National Health Service (N.H.S.) as a generalist therapist and became a specialist in stammering and worked with people of all ages who stammer. I was also actively involved with the B.S.A. until my family and I moved to Ireland where we now live. I recently retired from the Irish Health Service where I worked for 18 years and am now enjoying retirement but still run adult residential intensive courses on a non-profit basis. I decided to continue running these courses due the successful and very rewarding “Patmar” courses which we ran for the Health Service in Ireland.

Because I have worked for many years with people of all ages who stammer I could see clearly how a stammer can develop from the very early stages, through adolescence and into adulthood. To be honest my college training taught me very little on how to treat stammering in early childhood but It soon became apparent that the problem can be resolved if the appropriate therapy was provided as soon as possible after the onset of dysfluency. I have read many of the world’s “experts” in childhood stammering and have presented with some of these people at world conferences but there still appears to be little agreement on how to treat young children who stammer. Do we use direct intervention or try to change the child’s environment

and hope the stammer resolves? Are these children’s brains “different” from other children? It is very difficult to decide on which is the best way forward to help these children and there is still the fear among many people that intervention might even make the stammer worse!

I have always felt that stammering in very early stages can be resolved if treated by a specialist experienced in childhood stammering who believes that the treatment will be successful. Where did I reach this conclusion? When I worked in the U.K. from 1986-1993 it became apparent that practically all of the children under 5 that I treated no longer stammered. A basic questionnaire was sent to ALL the parents of those children who were then either discharged or failed to attend the clinic. The results of this showed that nearly all the children treated no longer stammered. Although this was by no means an accurate measure of therapy outcomes it showed me that I was on the right path to helping these children becoming fluent. Another aim of the questionnaire was to assess the parents’ attitude to my therapy techniques and asked if and how it could be improved. At this stage in my professional career these results gave me the confidence to tell the parents that if we all work together their children can overcome the stammer.

When I moved to Ireland in 1993 my catchment area covered a large but sparsely populated rural area in the west of Ireland with a population of around 19,000 people. I worked in Community

Care which meant I liaised closely with all the other health professionals as well as the schools in that area. Significantly I lived in that same community and would see many clients socially within the area. I also worked very closely with teachers in the schools, many of whom referred pupils for therapy. This was important because I would have been informed if a child was stammering, not only by the teachers but also the school nurse who covered the same catchment area. I worked with stammering people of all age groups and was the sole therapist in the community for 18 years which allowed me to follow up most of my clients.

The Audit-

I decided to send out a questionnaire to the parents of all the children under 5 years old who were referred and treated because they were dysfluent (I use the term “dysfluent” because some young children were “normally non-fluent” which can be a phase of normal speech development). All of these children were seen over an 11 year period from 1993-2003 inclusive and had since been discharged from therapy either because they gained fluency or failed to attend the clinic.

Therapy was based on a client centred eclectic approach which combines elements of direct therapy focused on the child’s speech and a number of indirect approaches to treatment which focus on the child’s environment. Each child was given an individual programme and involved the parents and any other significant adults involved with the child.

KELLY IRELAND CONT'D...

Follow-up of the children in the audit was conducted by means of a short questionnaire to the parents. Non-responders were assessed informally by a school nurse with responsibility for the same catchment area over the 11 year period of the audit. Questionnaires were returned by 46 of the 64 of children in the audit, of whom 43 were reported as not stammering, 2 with persistent stammer and 1 child with missing data on fluency status. No stammering was detected by the school nurse who spoke with all 18 non-respondents. Thus 61 of the 63 children with documented fluency status were reported free of stammer at follow-up. The mean age of onset of dysfluency was 3.2 years and the children received an average of 5.2 sessions. The outcome measures exceeded expected natural recovery rates.

Methods-

The study was carried out in Leitrim where 1,900 of the 19,000 population are under 5 years. The Speech and Language clinic has a high profile and there high rates of referral from school nurses, general practitioners, consultants, teachers and other health professionals. Parents can also refer directly to the clinic. The service is free in Ireland. Children referred as dysfluent were seen within 2 – 4 weeks. The initial assessment was 1 hour and a full history was provided by the parents and both parents were asked to attend the assessment, All aspects of both speech and language were assessed. The type of stammer (normal non-fluency, repetitions, blocking), any associated tension and both the child's and parent's attitude to the stammer were noted. Each

child was given an individual programme involving the parents and each programme involved either indirect or direct therapy or a combination of both. They were seen for 1 hour each week for 6 weeks and a further block of 6 weeks a month later where necessary. Children who were aware of the stammer were given direct therapy and were encouraged to talk openly about the stammer to the therapist and the parents. Others who were unaware of the dysfluency were given a programme to change the child's environment ,especially to reduce any parental anxiety which is common with this client group.

(The full paper can be found in the May 2011 edition of the Irish Medical Journal)

Discussion-

I have always worked as a “hands on” therapist and am not a researcher. As a person who suffered in childhood due to stammering I always wanted to help others from going through life stammering. The aim of the audit initially was to prove to myself that stammering can be significantly reduced if detected and treated early. Treating stammering as we all know can be difficult – regardless of the age of client.

I sincerely believe that practically all stammering can be eliminated if treated in the very early stages by an experienced therapist who specialises in stammering. I also feel that treating young children is a speciality in itself, differing markedly from adolescent and adult stammering. Even with all the advances in our understanding and treatment of stammering the prevalence of the disorder does not appear to reducing. I have been at odds with colleagues over the years by telling parents that

their child can be fluent if the therapist and family work together. I do not believe that there is any difference in general terms between the brains of people who stammer and those who do not. I feel that parents must have complete confidence in the therapist, especially when they ask will their child be fluent. The therapeutic programme can easily fall apart if parents do not have confidence and will quickly revert back to reacting negatively to the child. This anxiety shown by the parents can easily transfer to the child resulting in more stammering behaviour.

I also feel that one reason why the “Lidcombe” programme has been relatively successful treating young children is because the therapist is confident it will work and this helps reduce parental anxiety and thus stick with programme.

In conclusion I again stress that I am a therapist and not a researcher and base my opinions on many years working with people who stammer. I must thank my Professor Ivan Perry from Cork University, himself a person who stammers who published the audit with me. Indeed Ivan has had a number of papers published over the years and I could not have done it without his help.

As mentioned earlier we run a non-profit adult residential course in Ireland and invite people from the U.K. to attend the next course which is in March 2012.

Contact – E mail
info@patrickkellystammering.com

Or -
patrickdrumkelly@eircom.net



One Voice 31- EXTRA

Additional OV₃₁ articles from....

France-

<http://www.isastutter.org/wp-content/uploads/2012/02/AM12France.pdf>

Chile (Spanish)-

<http://www.isastutter.org/wp-content/uploads/2012/02/ARTICULO-PARA-ONE-VOICEChile-1.pdf>

Chile (English)-

<http://www.isastutter.org/wp-content/uploads/2012/02/ARTICULO-PARA-ONE-VOICEChile-2.pdf>

Partnership between the Nepal Stutters Association and the Association for Stutterers in Denmark

<http://www.isastutter.org/wp-content/uploads/2012/02/Partnership-NSA-and-FSD-ISA-Congress-May-2011.pdf>



PHOTO FROM FINLAND...



This picture is from the Nordic Stuttering Meeting in Finland last September. This picture shows the atmosphere and the friendship at this meeting. The people in the crowd all come from different countries; Netherlands, Denmark, Finland, Estonia, Sweden, -and Switzerland. The next Nordic Stuttering Meeting will take place in Hamar, Norway. I'm already looking forward to it..

PHOTO FROM SOUTH AFRICA...



SAZ Mike Mabika (South Africa)



Edited by: Josh Denault U.S.A.
(email: jdenaultoo@yahoo.com)

Liaison: Keith Boss U.K. (email:
keithmaxkb@yahoo.com)