

The Voice of ELSA

New Series, #3

Summer 1998

Magazine of the European League of Stuttering Associations

From the ELSA officials:

Dear Readers,

Welcome to the Summer 1998 edition of *Voice of ELSA (VoE)*. The main emphasis of this edition is on the topic *Helping Stuttering Pupils* - the theme of our latest ELSA seminar in Dublin/Ireland - and an interesting news from ELSA member associations.

Again, 1998 has provided a number of remarkable events. The ELSA seminar in Dublin turned-out to be one of the most successful meetings in the European stuttering arena. In July, *Speak Easy South Africa* hosted the 5th World Congress of *People who Stutter*, organised in conjunction with the *International Stuttering Association (ISA)*. The annual Nordic Meeting will take place in Denmark in September, featuring pop star Scatman John as a special guest.

So, obviously the idea of international co-operation in stuttering self help is alive and well. If you want to be a part of this exciting network there is always a way to contribute - don't hesitate to contact your national stuttering association or ELSA!

For ELSA, ÖSIS of Austria, SSR of Sweden and BV of Germany, May and June have been very busy with applications for the next round of European Funding for stuttering projects. These applications have been put together by Edwin Farr and Anita Blom with the help of Hans Kröppel and Konrad Schäfers. The applications include, amongst others, a *Stuttering Awareness* seminar in Vienna.

However, don't book your tickets just yet as ELSA and the other national stuttering associations are up against stiff competition in this bid for funding, lots of non-governmental organisations (NGOs) are competing for very little money. We keep our fingers crossed, as they say in the UK.

Sincerely,

Anita S. Blom, Edwin J. Farr, Allen Timans.

Stuttering self help organisations are welcome to publish extracts from VoE, but please inform us and acknowledge the source.

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"The child in me thanks you for coming here"

Konrad Schäfers reports on ELSA's seminar "Helping stuttering pupils" in Dublin/Ireland, 27-28 February/1 March 1998

In his moving final statement at the end of the 11th ELSA seminar Des Cunnane, member of the Irish Stammering Association, summarized why helping stuttering pupils is one of the important topics for virtually all national stuttering associations. 40 participants from 13 European countries attended the conference, a large number of speech therapists among them. The meeting was devoted to the exchange of information. "To ensure that no child who stammers suffers again as much as I has previously been the case in our schools", as one delegate put it. The event was opened by a speech from Proinsias De Rossa, member of the Irish parliament and former Minister for Social Welfare, a person who stutters himself.

Presentations started with Susan Page and Cherry Hughes who introduced the comprehensive work for pupils who stutter carried out by the British Stammering Association/UK. Future work will include initial teacher training and involving parents of children concerned. It was stressed that stuttering associations should strive to co-operate with other statutory and voluntary agencies to improve outcomes for the children.

The Stuttering Information Centre of Denmark was represented by Tine Egebjerg and Per Fabæch Knudsen. The Centre produced an information pack for teachers consisting of various leaflets and brochures which can be distributed complete or in parts. Furthermore, the presentation focused on the help given by Danish speech therapists to stuttering pupils in the clinic, at school and at home.

Anders Lundberg from Sweden presented a Swedish video on a boy who stutters. Detailed information was given as to the planning and production of the film. Margaretha Lundskuy and Annika Willfors introduced a model project executed in the district of Lund/Sweden, whereby people working professionally with children within child care and schools are offered educational and information during half a day.

Thomas Krall, a teacher who stutters from Germany, talked about a school-based working group for stuttering pupils he established at his school in Düsseldorf. Verena Mentzel and Konrad Schäfers explained what the German BV offers to help pupils, parents and teachers and how the topic has been made public in a current anti-discrimination campaign in Germany.

Andrea Grubitsch, Karman Mitterwallner and Hans Köpfl, from ÖSIS/Austria, gave an example of how comparably small associations with limited resources can tackle the problem of stuttering pupils.

In her presentation *What's a teacher to do?*, Lou Heite from Iceland highlighted the problem from the teachers' point of view. One of her main points was that beside further research, there is a need to sensitize educators and those who teach them.

A link to scientific research was provided by Margaret M. Lealey and Laura Loftus from Trinity College, Dublin/Ireland; they presented their study on *Children's attitudes to communication*.

The meeting was funded by the Commission of the European Communities. This successful ELSA seminar once again proved the benefits of European networking.

The full presentations of the seminar have been published in a meeting paper which is available at 5 EURO (yes, ELSA goes EURO!) including postage and handling. Until 2002, we will gladly accept national currencies. Please contact Konrad Schäfers at the ELSA office.

There was a healthy mixture of participants in Dublin - stutterers, teachers, parents of stuttering children, speech therapists etc. - some of whom had attended many ELSA meetings, and some, like speech therapist Claudia Villa Hamann from Berlin/Germany, who were at their first ELSA event. Claudia gives her impressions of the experience for VoE:

Not just nice memories

Since this was my first ELSA meeting, I would like to describe my impressions. As you see, I'm talking about my *first* meeting, which shows I hope there will be a next time.

When I came back to Berlin, a lot of friends asked me: "How did you like Dublin?" ... well, I liked it a lot. I liked the pubs and the seaside I went to after the meeting. But most of all I liked the seminar. I got a lot of new impressions from the presentations of the projects, material and activities that exist in the different European countries. Besides that, I talked to a lot of stutterers about their own experiences in school with their teachers and classmates, which helped me to get a better understanding for the stuttering pupils who come to me for therapy.

Also, it impressed me a lot how much activity and energy comes from the stutterers themselves. So what this seminar did to me was the wish to get active myself, not alone but together with a stutterer. So when I returned, I contacted some stutterers to work in the campaign at the end of April *Helping Stuttering Pupils*. This was my first step of becoming active with stutterers and I'm sure there will be more to come.

So the visit to the ELSA meeting not only gave me more knowledge about stuttering and school, but the feeling that together with active stutterers you can really change something. And that is what I will try to do. ❖

The Dublin meeting marked the official exit from his duties as an ELSA official of ELSA co-founder Konrad Schäfers. Now working at the BV (and ELSA) office in Köln/Germany, Konrad will continue to figure behind the scenes with ELSA, which remains close to his heart. At the Saturday night out in Dublin, the newest ELSA official Anita Blom stepped up to the microphone and delivered a personal tribute to the departing Konrad. Written spontaneously between courses of food and conversation, it was felt too good to be allowed to disappear into the Irish air that night, and so here - with thanks to Anita and apologies to Konrad - it is:

Now all you people from ELSA
You really seem to feel very good
I am also enjoying this great evening
But still I'm in a sad mood:

I'll probably see most of you again
But I'm not quite sure about one
I've only just started to get to know him
But he resigned and I've only just begun

He was my friend from the very start
And has taught me almost all I know
Warm-hearted, experienced and lots of fun
And we all hate to see him go

I hope tonight to get some promises
Because he can't leave just like that:
I want an e-mail once a week, or ...
You'll get the worst virus you've ever had !

You're the guy with the ELSA champagne
You're the guy who has our bucks
And the thought of not dancing with you
We girls think that really sucks !

You're the guy with the positive thoughts
A little shy, but the greatest pal
Playing the guitar, singing Leonard Cohen
Well, that's about you in a nutshell

And we won't accept any excuses
For you not to come back again
We'll see you at the next ELSA meeting
For KONRAD, you're our man ! ♣

During the Dublin weekend seminar, the annual ELSA affairs meeting was held. Konrad Schäfers formally stood down as an ELSA official; there were no new nominations for the board, but Anita Blom, Edwin Farr and Allen Timans confirmed their willingness to stand again and were all unanimously elected for the next period.

YOU'RE READING VoE ... WHY NOT WRITE FOR THE NEXT ISSUE ?!

The Voice of ELSA (VoE) is normally published twice-yearly, and provides an opportunity for stutters across Europe to exchange information. Your articles, views, news, ideas etc. are very welcome for the next issue. Please send articles to VoE editor Tim Powell at: Owl House, 7 The Avenue, Healden, Canterbury, Kent, CT3 4HL, U.K. Or fax anytime on +44 1227 711869.

Thanks very much to everyone who contributed to this issue of VoE.

- Tim Powell, VoE editor.

Though 13 countries were represented at the ELSA meeting in Dublin, sadly we were not able to be joined by any of our friends from Bulgaria; life is difficult for our Bulgarian stuttering colleagues these days, as this very welcome piece from Irina Papancheva confirms:

Bulgarian Stuttering Association - the only thing we have is our enthusiasm

Problems of stutterers aren't much treated in Bulgaria. Perhaps it's because the country has such serious problems to solve; the responsible government institutions are not interested in spending money on such activity. They don't care how big the number of stuttering people is in Bulgaria (about 90,000) and how we might be helped.

Our stuttering association doesn't even have an office, despite the efforts which our Chair Peter Tonev has been making. There isn't a specialised issue either - the only thing we have is our enthusiasm.

In October '97 the National Stuttering Meeting was held in Banka, a small town near to Sofia, which lasted for 2 days.

After that we, the youth who live in Sofia, began to meet once a week in a pub. We used to do it for a month or two but then stopped. Pubs don't provide the atmosphere you really need for meetings of this kind.

Now we're thinking of taking the key of an empty room in the students' town; we hope to have a little more luck this time. Otherwise - there are many parks in Sofia. It's summer now and we'll have a better time. ♦

Some news from Belgium

by Martine De Vloed

In March Vzw BeSt Belangengroep Stotteraars, the Belgian Stuttering association, organised a self help weekend. About 25 stutterers attended this weekend and shared experience with each other. Topics of the workshops were *Stuttering in everyday life, Telephone practices, How can we manage stuttering in a spiritual way, Discussion group* and *Hausdorfer method: sound control*. We met several new members and we had a great time together. ♦

Speaking up for Sofie

Kim Lindbom Carlsson writes of her experience as the mother of a daughter who stutters

Sofie is now 9 years old. She started to stutter when she was 3½. She was an early talker; not at all shy, always singing and dancing, a real show-off. She used a lot of grown-up words, and was always talking.

When Sofie was 3, my husband and I got divorced. And when she started stuttering after about 6 months I, for many years, blamed myself and thought that it was my fault that she had started to stutter. And I think many parents try to find a reason for why their child stutters.

When she started stuttering, I took her to the children's doctor, where they first said that 'all children do that', and 'it will soon stop', 'she maybe gets mixed-up a bit'. But I would not accept that. I demanded to let her go to a speech therapist; to go there, you have to have a doctor's letter to say that you have the right to go to the speech therapist. In the end they said "okay, but it's not really necessary".

Sofie went to the speech therapist, together with me, once every 2 weeks. Mostly we played games, and she enjoyed it. In Sweden you start play school when you're 6, and "real" school when you are 7. The problem is that the community pays for the treatment, until you're 7. But once you reach 7, the school takes over the health care of the children (in most of the towns in Sweden). Before Sofie started school I went down to the school and met her teacher, to tell her about Sofie's stuttering. I asked if she could sit in the front of the classroom, to have eye contact with the teacher. I also asked her to let Sofie be one of the first to read out loud, so that she didn't have to sit and wait a long time until it was her turn to read. I also spoke to the women in the school restaurant: I told them that Sofie speaks in her special way, so that they didn't think she was too shy to speak. I even gave all the school staff information folders about stuttering. Then I had the hardest thing left, the head master.

I booked an appointment with him, told him about Sofie, and that she needed help. "Sorry, sorry, we haven't got any money for that kind of thing" was of course what he said. But what I did was to go home and read the law books, make a lot of telephone calls and make sure that I knew my rights, and what help I was entitled to.

So, a week later, I was back at school again; this time I knew what I wanted. And after a long talk, I at last got help: they pay for a speech therapist to come to school once every 2 weeks. Sofie likes him a lot, and feels really good when he comes to school. I often talk to him on the telephone, so that I know what they are doing, and how he thinks Sofie seems to feel about her stuttering. We have a good contact, and that is really important. Sofie stutters a lot, and she needs help. I have done all I can for her, I try and read everything I can get hold of about stuttering. I have been to stuttering courses with her. We also went to an intensive stuttering course: that was very good, one week in the spring, one week in the autumn, and one week in the winter. There were 9 children of similar age, with one of their parents, together with teachers, speech therapists, and it was really great for the children ... they all were stuttering a lot! Sofie said that it was so great, the kids listened to her, and she felt really good. Those weeks meant a lot for her. A lot of the stuttering children feel that they are the only one that stutters. We have also been to weekend seminars for children with their parents. It's very important that the stuttering children meet others who stutter too. My advice to other parents is not to take "no" for an answer: do what I did, find out your rights, and insist on them; as all children should be treated with respect. ✦

In the Spring '97 (#1) issue of VoE, we heard about the encouraging initiatives for stutterers in France, through the work of the two French associations.

Now comes news of major campaigns by the Association Parole-Bégaiement (APB) from Anne-Marie Simon, General Secretary of the APB. Says Anne-Marie, "Their influence has been very important, and we think that stuttering will never again be seen in France as it has been before."

APB's campaign to prevent stuttering

Stuttering prevention was the first goal chosen by the board of the APB in 1992. It took 2 years to raise adequate funds from the French Health Authority. The first effort was directed towards professional speech pathologists and phoniatrists. 12,000 clinicians received a 61-page booklet, written by Henny Bijleveld, Francois Le Hucque and Anne-Marie Simon. Drawings by children who stutter, illustrating their feelings about speech are included. Clinicians all over France have received this booklet. In addition, a document about prevention was sent to paediatricians, school psychologists, and child care centre personnel. Great appreciation was expressed by these groups.

The second big effort was the mailing of a 4-page article on early intervention with children beginning to stutter to 25,000 kindergarten teachers. Pamphlets for parents were also provided. These pamphlets included facts about stuttering and guidelines for helping children, parents and teachers. An emphasis was placed on the communicative relationship between children and adults. All in all, it is believed that at least 120,000 people have been made aware of the possibilities of preventing stuttering if the parents receive appropriate assistance early enough.

APB would hope, in some way, to assess the impact of these efforts on the incidence and prevalence of stuttering in, say, 10 years time. Such epidemiological studies have not been undertaken in other countries, and it is admitted that such investigations are difficult.

It may, therefore, prove difficult to be objective about the results of this work; but in general, we hope that families will never again hear the advice to "wait and see". Each child and family should receive the guidance they need. So much past counsel to concerned parents has been based on inadequate knowledge. ❖

An Irish teacher casts a cold eye ...

by Des Cunnane

"The Greeks say it was the Turks who burned down
Smyrna. The Turks say it was the Greeks.
Who will discover the truth ?
The wrong has been committed. The important thing
is who will redeem it."

It was the intensity got to me. The day of the parent-teacher meeting Aoife's parents queried why their daughter had lost 10 marks in her essay. She is very bright. They told me how they had withdrawn her from normal class in primary school. For the previous 2 years she had sat in a room on her own, pursuing an alternative programme.

Each day I look at this 12 year old, with her owl-sad face, a stranger and afraid in a world she hasn't made. Aoife's "going to make it big" but my hope would be that someday she will redefine success, for herself, and then she will really have it made.

Simon comes from a large family. His parents were moved, from the inner city, to better housing in the suburbs. He was very young then but narrow, huckster streets left their mark. At 14 his young face is already set in defiance, his back stiff with resistance. Life is a feud. His older brother was caught robbing but Simon tells me "that's because he's stupid". Some day "he's goin' to make it big and he won't get caught". My hope for Simon is that someday he will redefine success and then he will really have it made.

In Media Studies, last year, a boy shouted from the heart of the class: "Sir ! Did you see *A fish called Wanda* on telly last night ?" Before I could answer he struck a pose and did an amusing imitation of the dim-witted tongue-tied character played by Michael Palin. Others tried to outdo him by distorting their faces and acting out a collage of potent and disturbing images of stammering. Order gave way to unruly laughter.

Noticing Aaron I put an end to it. He was grim faced and saucer-eyed. Because he has a stammer this must be close to the bone. How could he escape the message: that stammerers are ridiculed because they are ridiculous; that stammering is linked to some neurosis; that shattered speech equals shattered psyche ? The words of Liverpool poet Roger McGough come to mind:

"from generation to generation
a poisoned apple passed along
domestic, daily cruelty,

no-one thinking it was wrong
and it was ... "

After class I spoke to Aaron and told him that we shared a problem. I told him that many "have made it" despite having a stammer.

But the important thing is that Aoife, Simon, Aaron and I have it in our power to one day make a radical choice, to one day free ourselves from the grip of what others think. Then we will really have it made ... big time. ❖

Some news from Denmark

from Per Fabach Knudsen

FSD Denmark (the Danish association for stutters) arranged 2 weekends for children who stutter and their parents in August '97. The weekends were very successful; FSD also had a week for young people in the summer at the island Bornholm, arranged by local parents.

FSD has an increasing number of members - we are about 460 members out of a population of around 5,000,000 people. Denmark will host the next Nordic meeting, in September '98. The topic will be *Happy talks in Denmark*, but we don't know anything about the content yet.

The Stuttering Information Centre of Denmark has new offices now, much improved on the previous ones; we have a new professional colleague, and Denmark will host the next IFA World Congress in 2000. ❖

Some news from the Netherlands

from Allen Timans

In the second week of November 1997 there was a Stuttering Awareness Week, initiated by the Dutch Stutter Federation. It was a great success, everyone has heard about it in one way or another. The theme of the week was *For a stuttering child every talk is a speaking engagement*. The week was opened by our Vice-Minister of Health, Erica Terpstra, at a school in Rijswijk, near The Hague. She also officially opened the Stuttering Information Centre in Utrecht (see last issue of VoE).

During the week, the media paid lots of attention to stuttering. A short film has been broadcast several times on national TV and many articles were written about the issue.

On Thursday evening, people who were interested could go to playgroups in their neighbourhood to get more information and to talk to people concerned. ❖

"Dancing with words"

In the previous VoE, Nick Conrad wrote about "Speaking Circles", now Jan Logan reviews Be heard now! How to compel rapt attention every time you speak, a book written by Speaking Circles founder Lee Glickstein with Carol Costello

I bought this book having spent a fascinating morning, along with a number of other speech and language therapists (SLTs) and people who stutter, involved in a *Speaking Circle* (SC) run by the author of this book Lee Glickstein. Speaking circles, created and developed in California by Lee Glickstein, are for people (whether they stutter or not) who are uncomfortable speaking in front of groups.

As I too have often found public speaking rather daunting, I was surprised that the experience had been such a positive one. Along with other participants I was also surprised that people had been able to give so much of themselves, and that we had gelled as a group so quickly, without any "gelling" activities. It had also been fun! I was keen to purchase this book so that, perhaps, I would be able to build on what I had learnt.

On the cover it states: "How to compel rapt attention every time you speak - from agony to ecstasy; miracle cure for stage fright ... and beyond." Had I seen the book without having been part of the circle, I feel sure I would have been extremely sceptical. The claims sound the very stuff of "miracle cures" which I tend to take with a "pinch of salt"! However, as it was, I couldn't wait to read on, and eagerly started the initial chapter on the return journey to London.

I have since attended a further SC practice day, and have incorporated SCs into some therapy sessions. In writing about the book now, I find it difficult to separate the book from the experience. Whilst I will endeavour to focus on the book, I will also include some reflections on what I have found both useful and interesting about *Speaking Circles*.

The book is very accessible, written in a personal and informal style. I found it both inspiring and encouraging. Lee Glickstein uses personal experiences as well as those of other SC members to talk about how to develop confidence speaking to a group. He offers ideas on how to make public speaking "work for you" as well as a clear and practical guide on how to set up your own SC.

Lee calls his approach *Transformational Speaking* (TS), and sees it as a "new paradigm" to challenge "old myths" about public speaking. It is not about developing formal styles and techniques, or mastering "performances" which mask our true selves, but more about discovering and expressing our "authentic selves". Glickstein claims that often our ability to be ourselves when speaking to a group has been lost through negative past experiences. He suggests that rather than trying to become someone else - "a good public speaker" - we can learn to communicate creatively and effectively through the process of trusting oneself to be oneself, and allowing oneself to "connect". The focus on connection is important because TS is about connecting with the audience, and is essentially a change in the listener and the speaker.

Whilst TS and SCs have been found to be helpful for people who

stutter, Lee suggests it may be useful for a range of people including business people, teachers, therapists and inexperienced as well as professional speakers. He feels it can be used equally effectively in the boardroom, classroom, community meeting, sales presentation and interview situation as well as in relationships when communicating something difficult.

What interests me is the notion that TS is not a skill or technique which is outside ourselves and needs to be taught by an expert, but something which "we already have within us". Interestingly, the book itself reaffirms the idea that we can help ourselves and each other by offering a format and clear guidelines which enables readers to set up a SC for themselves.

The process of TS is about developing self-acceptance, and allowing our true self to be. What a SC does is create the conditions which allow this to happen. What are these conditions, and how do we achieve them in a SC of relative strangers? Lee states that they are the "unconditional support and positive regard" offered by the group. SCs are conducted in a safe and supportive atmosphere where people are free to take a risk. They offer a place where people are listened to and "fully seen and heard" on the deepest level. The feedback given is positive. This challenges the old myth that "critical feedback spurs improvement". Lee suggests that instead, "positive feedback nurtures growth" and that the opportunity to be fully seen and heard and receive this positive feedback offers people a glimpse of themselves which they may not often acknowledge. In doing so, he believes that people may begin to become more accepting of themselves as people and speakers.

What I find interesting is feeling able to make connections between TS and Carl Rogers' *Person centred approach* where the core conditions of genuineness, unconditional positive regard and empathy create the conditions for growth. In TS the focus is on the environment which creates an atmosphere in which people feel safe to experiment and can develop. Rather than encouraging development of a technique, Lee focuses on working from the inside - "healing the inner speaker", finding your true self, "facing the fear", being real and vulnerable, but most of all being accepting of yourself.

TS also focuses on the quality of the listening; people listen in a "non-judgmental" and accepting way. Feedback is positive and essentially honest, about "looking for the best" in someone. There is an acceptance and valuing of the deeper core of members of the circle. Like Carl Rogers' approach, where people operate in the "here and now" in terms of their feelings, in TS the approach is about a way of "being" rather than "doing" and people are encouraged to stay in the moment.

Lee states that one of the primary functions of a SC is to create a healing climate where members can "heal the inner speaker" by experimenting with being themselves. As one member puts it, "The main thing a TSC gives me is permission to be myself". A central part of TS is the "connection" between the speaker and the audience, it is a shared experience. Rather than public speaking being one way, the connection is reciprocal. Not only do people learn to give but also to receive, and this mutuality is central. A sense of this is conveyed creatively by one TS speaker: "I'm less intimidated by the idea of being the one 'up in front' now that I've changed my approach to speaking. It's not me and them; it's us and 'we're dancing together'".

Finally, there were elements of TS which connect to Buddhist philosophy and practice. Being "in the moment" is central to both, and is something to strive for. In TS people focus on their feelings "in the moment". Lee states: "to be heard now, you have to be here now - TS helps us to be exactly the person we are in that moment". The other aspect I could connect to Buddhist principles is that of looking for the best in someone, searching for something positive. In Buddhism, the Metta Bahavana (which loosely translated means "loving kindness") is about looking for the best. Lee suggests that if we focus on looking for the best, we will usually be able to find something.

What Lee Glickstein offers us in his book is really a fairly simple concept with a clear format. If I criticise anything, it may be that the book is over long and towards the end tends to feel rather repetitive. Nevertheless, it was extremely useful and I felt he was able to get across a real flavour of the approach. From my albeit rather limited experience of SCs it seems to me that what people appear to discover in SCs is really very simple: they don't have to perform; all they have to do is be themselves. By learning to receive support from the audience, they can find their own voice. ♦

As VoE was going to press, we were delighted to receive some news from Association Vaincre Le Bégaiement/France; Hubert Zeiger reports:

These last months, our project was to spread as widely as possible information about our organisation AVB. So far, very positive feedback has been received - the people greatly appreciate having information coming from all over Europe.

To help the people of the different communities living in France, our brochures have been translated into various languages: Turkish, Arabic, Spanish, Portuguese and Vietnamese. So, these people can find some information about stuttering in their native language. A detailed booklet, gathering information and guidance for people who stutter, as well as for parents and teachers is now completed and available. At present, we are looking for grants for publishing and distributing it as widely as possible in schools and youth organisations.

Finally, action on spreading information on stuttering is also made via the media (newspapers, magazines and radio). One of the results was that stuttering was the day's theme on a French radio programme, on which Hubert Zeiger has participated along with other people who stutter and a speech therapist. This experience was very positive and we are willing to initiate and participate again in such an event. ♦

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