

THE VOICE OF ELSA

Newsletter of the European League of Stuttering Associations

Number 6

Winter 1992/1993

Introducing the "Editorial Board"

One of the decisions of the ELSA meeting in Denmark, Autumn '92, was to develop the ELSA magazine. **Voice of ELSA** now has an Editorial Board, all 4 of whom have been involved with ELSA since its conception at Darmstadt in 1990.

Mariette van Eekelen, from Leeuwarden in the Netherlands, started stuttering at age 4, "an event which would mark my further life". She became involved with several self-help groups, working groups, the board of Demosshenes (the Dutch association for stutterers), with ELSA and now its Editorial Board. Mariette hopes this will prove to be not an end but a further extension of her activities in the stuttering arena.



Stefano Tulini, 29, lives in Pisa where he was one of the founders of the first Italian self-help group for stutterers. At present he is National secretary of

Italy's stuttering association "La Lingua Amara". Stefano has a degree in computer science, is experienced in editorial work with the Italian magazine "Res Publica". He will concentrate on design and layout of this European newsletter.



Tim Powell, as the English member of the Board, will act as proof reader for VoE. Tim is 34, lives near Canterbury, and is a member of the U.K. Association for Stammerers (AFS), where he has been a committee member since 1989 and is mainly involved with organising stammering "Open Days" across the country.



Konrad Schäfers, from Bonn, is 39, married with 2 children and works as a library assistant. He has been a member of the German BV Stotterer-Selbsthilfe since the early 1980's and has been an ELSA official from the beginning. Konrad aims to link the Editorial Board to the

work of the officials and the ELSA office in Köln.

We are all looking forward to helping **Voice of ELSA** to progress, and particularly to involve more members from all European stuttering organisations in the content of the magazine. Your thoughts and contributions are welcome, and invited!

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The views expressed in this newsletter are not necessarily those of the Editorial Board.

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SNOWFLAKES, T-SHIRTS, THINKING AND TALKING...

Report of the 5th ELSA meeting in Viborg, Denmark

Welcomed by Per, our host for the weekend, we arrive in Viborg at the conference centre. The world around us is getting whiter and whiter, as we are in a Scandinavian country now... after a good meal, sitting in a luxurious meeting room and having a good look at the snow flakes whirling beyond the windows, the meeting starts:

Viborg, Denmark 30 October - 1 November 1992

About 25 people from all corners of Europe came together to talk and think about European co-operation. From Italy to Iceland and from the United Kingdom to Bulgaria, stutterers were represented.

There have been several meetings already, but this one will be special, because of the presence of several chairs of stuttering associations. All chairs had been specially invited to this meeting to consolidate the relationships between the associations. So: a special welcome to the chairs of Austria, Denmark, Germany, the Netherlands, Sweden, Iceland and Finland.

After a welcome from Edwin, an introduction from each of us follows - usual in this kind of situation and for stutterers a possible source of bad dreams; anyway, we are allowed to keep it short. Now we know who is who, the officials Edwin (UK), Konrad (Germany), and Odd Bjørn (Norway) give us a short summary of their activities since the last meeting.

Very interesting of course; nevertheless we are looking forward to the Danish video-tape about stuttering in children, to be

introduced by Per. As the tape is subtitled, it's not too difficult to understand the contents: a clear and nice tape, interesting to look at.

For most of us, the evening continues in the relaxation-room, while some are looking for their beds after a long days of travelling (the Polish delegates have been travelling for more than 40 hours...)

Saturday: after a goodless good sleep we're all present at 9.00 to continue our meeting. As some people have to leave early Sunday morning, the agenda will be finished this evening, if possible. Discussed subjects, too interesting to omit:

- Sweden have invited (at their expense) the whole of Estonia's self-help group for a meeting in Sweden. An example of international co-operation and mutual involvement between European stutterers!

- A lot of work has been done to prepare an ELSA brochure and it's ready now! From now on we can present ELSA as she deserves.

After lunch we go and talk - in 3 sub-groups - about the ideas and expectations concerning the future of ELSA by "brain-storming", subdividing, discussing and plenary reporting. Some ideas will be too laborious considering the results, or could be worked-out more effectively at national level. Still, there are some subjects we agree to work at during the next 1/2-year.

Odd Bjørn has been canvassing us during the day towards possibly taking over his function of co-official. When the time comes, no-one can be found to do his interesting job, so Odd Bjørn is happy to stay

The Third International Convention of People Who Stutter

San Francisco 13-16 August 1992 hosted the world's largest ever gathering of people who stutter. Every stutterer in the world was invited (via their own National Association) to come to California, as the invitation said: "to celebrate, to communicate and further commit ourselves to the crusade for dignity and support for children and adults who stutter".

"Many Tongues One Voice" was the Convention theme, and well over 500 people of all age groups made the trip, 75 from Europe, 20 from Japan, many others from the rest of the world including Australasia, Africa and of course the USA and Canada who provided nearly 400 delegates. The majority of delegates were stutterers themselves, but many speech clinicians attended, including Vivian Sheehan, wife of the late Joseph Sheehan, Gerald Johnson, David Daly, Mary Cassar, Carl Scott. America is renowned for it's speech therapy profession which contains many stutterers who have come to terms with their stutter and are passing their wisdom on to fellow stutterers. There were simultaneous translations for the Japanese and the Germans, and many linguists helped out with French and Italian.

Most countries had members of their Associations' Committees at San Francisco, and each Association gave a presentation on their work. A presentation of the work of ELSA was also given by Odd Bjørn Ure (N) and Edwin Farr (UK). It was probably the first time that the delegates this side of the world had heard of ELSA, so the presentation included the what, why, who, and

where of ELSA. Emphasis was placed on ELSA's main roles, i.e. the linking together and furthering the cooperation of Europe's National Organisations, providing a forum for exchange of concepts of self-help and stuttering therapy, representing the interests of stutterers to European and international bodies and putting stuttering on the European agenda.

ELSA's successes were detailed such as the funding from the EC for meetings, the setting up of a data base, a survey of the work of the National Associations and the Local Self-Help groups in the form of a questionnaire, the preparation of an information leaflet, ELSA's presence at Therapists conferences in Paris and Athens, as a member of the EC Non-Governmental Dialogue Group, recognition by the UN, WHO and the ILO.

ELSA's future plans were also given, some of these being: to establish links in countries which have no formal organisations, the spreading of information to stutterers and therapists in these countries, help for East European countries and the search for funds to enable these plans to reach fruition.

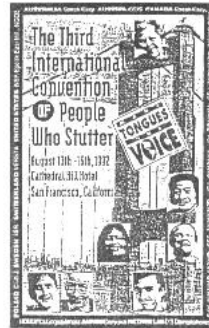
An ad-hoc meeting of each National Association Committee met on the Saturday evening and discussed the linking together of the Worlds' Associations, much debate ensued and the USA, Canada and Japan will be doing some more work to see how this link up can be best effected.

The Convention also had a full programme for the four days in addition to the International Presentations. Guest speakers

included a local San Francisco Humourist, Joel Rutledge, Journalist and Author Kare Anderson and two Speech Pathologists David Day and Carl Scott, all four stutterers and coping very well.

The opening ceremony had a nice touch with slides and videos being shown from the previous World conventions in Kyoto and Cologne in 1986 and 1989. The slides had background music of all the songs with San Francisco in the title. Tony Bennet seemed to be a great favourite.

There were 30 workshops for delegates to attend, with time during the Convention for each delegate to attend four. The workshops consisted of diverse subjects such as: Meeting Strangers and making Conversation, the Joy of Movement and Improvisation, Stammering and Perception, The Mind-Body-Spirit connection, the Hausdorfer Method (a German stuttering therapy from early this century), Transferring Fluency feelings, Demosthenes - what can I learn from him, Say 'Hello' to the opposite sex, Self Acceptance and Rational Thinking, and many more.



There were theatre presentations: the Germans gave a play called the "Wall" about the coming down of the Berlin Wall and likened it to the stutterer finding self-help,

acceptance of the stutter, stopping avoidance, relating it to the freedom this brings; the Speak Easy association from the East coast gave two presentations of their World famous play "Why can't we talk" to rapturous applause on both occasions. There were "Open Mike" presentations where stutters from all over the world were able to practice their speech to large audiences and say what they wanted to say.

The Convention was staged at a large Hotel in Downtown San Francisco, many delegates stayed at the hotel, and during the evenings split into groups to enjoy the delights of the San Franciscan restaurants, all at favourable prices due to the current low value of the dollar. After the trips to the restaurants it was back to the hotel for drinks, multinational games and conversations lasting well into the night.

The Swedish Association confirmed their intention to host the next World Conference and gave a tourist slide show of their country.

The climax of the Convention was a Banquet on the Saturday evening with food, speeches and dancing into early Sunday morning. With hardly any time for sleep, delegates got up on Sunday morning for a boat trip around the San Francisco Bay in sight of the Golden Gate Bridge.

By Sunday afternoon many people were saying goodbye, especially the Americans most of whom had to go to work the next day and were flying off home to all corners of the States. But for the Europeans, nearly all of them came not just for the Convention but as part of their annual holiday, nearly all stayed on to further enjoy the sights of San Francisco and the glorious West Coast.

— Many thanks go to John Ahlback and his team at the National Stuttering Project for organising such a wonderful event.

— Some parts of this article have been also printed in the AFS (UK) magazine "Speaking Out"

EDWIN J. FARR

Can non-Europeans learn anything from ELSA?

ELSA was allowed to deliver a seven minute speech at the Conference. After enumerating the member countries and our results so far, I went on by describing our future plans for creating associations for stutters in more countries.

Besides the substantial assistance that the new German Länder have got from West-Germany, there are more examples of how initiatives from ELSA members facilitate the diffusion of European self-help work:

— Poland holds meetings for stutters from neighbouring Slavic countries;

— the Nordic countries assist Iceland & Estonia;

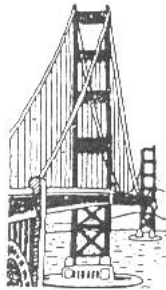
— UK has helped Ireland.

At present, the adjacent countries to Luxembourg, Portugal, Spain and Greece are trying to establish contacts in these four countries with a view to including them in ELSA.

Against this background, my message to the world conference on behalf of ELSA was:

The European umbrella organization is no fortress. The present ELSA-members don't only strengthen each other, but use the network to offer services and ideas to new and weaker associations.

Compared with, let us say, Africa and Latin America: economic and cultural factors make it easier to start a cooperation among European stutters. But it is not straight forward or easy to cooperate, because in many ways Europe is a patchwork quilt, and the (so-called) Old Continent is now undergoing serious divisions and cleavages. ELSA has a formidable task to include stutters in the new states that are mushrooming in Central



and Eastern Europe.

Our way of working can perhaps not be copied by other continents, nor may it serve as a model for a worldwide stuttering association. Europe is a comparatively small geographical unit. In addition, we can make use of existing political structures (like EC, EFTA, European Council).

But the way we encourage contacts with neighbouring countries can be used as a stepping stone for closer relations between associations on the same continent.

International conferences are important; in between them, we must work with our stuttering neighbours: domestically to set up a national network to support stutters to overcome our common problem, bilaterally and internationally to strengthen each other and thus achieve our common goals:

— encouragement to speak when we want;

— therapeutical assistance organized by ourselves or assisted by others;

— greater public understanding of stuttering.

ODD BJØRN ULF

Saying it with a FLOWER

Or: ELSA and how to make the most of it

True, the world would still turn around the sun if ELSA had not been founded two years ago. Apart from that, looking at what we have achieved since then, I feel the European League has been quite a success in many ways. The national stuttering associations are now linked to a European network, which means they have come much closer to each other. Exchanging information and experiences has had an inspiring influence not only on the work of the older groups but also on younger organizations and initiatives who felt encouraged to continue their initial efforts. In terms of representation, stuttering is on the European agenda now: as a member of a working party of European handicapped organizations ELSA has been able to publicize the issue of stuttering and self-help on the EC level.

Does the cooperation pay off?

Yet, despite all these encouraging achievements, there might well be concerns on the part of the national associations and their membership regarding the benefits of international cooperation. "Does it all pay off?" people may ask themselves and their national Boards. After all, the associations are spending part of their low funds for paying the ELSA membership fee, sending their delegates to ELSA meetings and submitting newsletters, books and other material to the common data-base. So what do they get in return?

Like most things in life you can approach this question from different points of view. If you think of the relation between the European League and their member associations in terms of "On the one hand ELSA, on the other the national

groups", concerns like those mentioned above seem quite understandable. This is why I would like to suggest another perspective which I tried to illustrate with the following model:



Even though the sketch looks a bit like the model of an atom I prefer to look at it as a flower. The ellipses (or petals, to stay with the flowers) are to symbolize the national associations, while the centre formed by the overlapping ends of the ellipses is ELSA: a common pool containing information, data, experiences, materials, ideas, activities.

All these resources are at hand – it's up to the national associations and their members to make use of them. Given the lack of personal and financial capacities ELSA cannot work by way of a service organization. ELSA rather is a *self-service* organization – so take a look at what's in the shelves and grab what you need!

ELSA: a self-service organization

How can we put this into practice? Let me give a few examples based on the priorities the European groups have set up for future ELSA

work:

Personal exchange is one of the highest-ranking aims of international cooperation. Unfortunately, it is not likely that ELSA will be able to organize big European meetings in the near future. But what about opening the national meetings to stutterers from abroad? Why not combine a holiday trip with a seminar of one of the ELSA member associations? If you are interested in doing so, take a look at the meeting announcements in this issue!

In order to promote the **exchange of information** ELSA is currently carrying out a survey on methods and concepts of self-help. The findings of this survey will make it easier for the national groups to make use of the experiences other associations have gained. Are you planning to organize Open Days? Are you thinking of producing a video on stutterer's self-help? Maybe some other association have carried out projects like that before and can give you hints and advice.

On the national level ELSA can also be useful when it comes to **PR work and representing the interests** of people who stutter. For instance, you may refer to the fact that your association is a member of a European top organization. But you can also request for more active support if you think that an official ELSA letter might be of help in any concern. NIFS from Norway did so when fighting against the closure of a speech therapy institution.

So far for the examples. There are certainly more ways to benefit from European cooperation, so no matter if we relate to a flower or a supermarket when thinking of the ELSA – let's help ourselves!

KONRAD SCHÄFERS

Self-help in Estonia: "Claudius Club"

The only self-help group for people who stutter in Estonia, Claudius Club (CC) was formed in late Autumn 1990; the name comes from the Roman emperor Claudius, who was around some 2050 years ago and had some problems with his speech.

The extent of the problem of stuttering is not fully appreciated yet in Estonia, and the number of active members in CC, 5, reflects this. So stutters in Estonia can feel quite isolated... as indeed they can in every other country in the world! Estonian speech therapists deal mainly with child stuttering.

CC's activities are generally based on examples of stuttering support groups and national

organizations in other countries. We have received a lot of printed material from our colleagues abroad - this has proved the only way for us to gain information about stuttering problems, self-help, therapy, etc. We are very glad that we have enjoyed close contact with Konrad Schafers, who has been a great help.

In April 1992, CC member Helen was interviewed by Estonian television. During a 30-minute programme on aphasia, 10 minutes featured stuttering. Helen spoke briefly about her experiences as a stutterer.

We hope very much that CC will soon be able to join ELSA as an equal member - unfortunately, at the moment Estonia has too many problems in everyday life and stuttering is unable to gain much attention. But stutters need help now, and of course we try to help as much as we can.

Kind regards to all readers of "Voice of ELSA" from Claudius Club in Tallinn.

ANDRES LOORAND

Claudius Club, c/o Andres Loorand, Aluskivi vald, Tartumaa, EE 2413, Estonia.



International News

• Sweden (Stanningsföreningars Riksförbund) have announced their intention to hold the 1995 World Convention, in Linköping. The date is still to be announced.

• IFA Support Group Committee revived

VoE readers will recall that the International Fluency Association (IFA) is an interdisciplinary organisation open to everybody who is interested in fluency-related issues. As such, the IFA provides a platform for further communication between therapists, researchers, and people who stutter, as well as enabling the mutual representation of interests.

Also, the IFA Support Group/Consumer Affairs Committee can be of help in organizing the exchange of information and experience between stuttering groups across the world, thus forming a kind of pre-stage of a future International Stuttering Association.

Jaana Pili, who founded Canada's Association For People Who Stutter (CAPS), recently took over the position of Chair of the SG/CAC. Jaana is determined to speed-up the work of the Committee. He plans to start with a project on popularization, and is inviting us all to send him samples of recent media efforts in print and electronic media which he can then share with people in future mailings.

Please send submissions and comments to: Jaana Pili, 403-29 McCaul Street, Toronto ON, M5T 1N7, CANADA.

• ELSA's first leaflet (see article by Edwin Farr, page 3)

CALENDAR

Nordic Meeting 1993

Helsingør/Denmark; 24-26 September 1993
Contact: Henrik N. Jensen, Tusborgvej 8
DK-9310 Vodskov, phone - 45 98 29 21 70

The Speak Easy International Foundation: Symposium XII

**Montclair State College, Upper Montclair, NJ;
June 11-13, 1993**
Contact: The Speak Easy Int'l Foundation
233 Concord Drive, Paramus, N.J. 07652

Ottawa Conference '93:
2nd Canadian National Stuttering Conference
Ottawa Ontario, July 29 to August 1, 1993
Presented by Speechmasters of Ottawa in
cooperation with the Canadian Association for
People Who Stutter (CAPS)
Contact: Richard Inomata or Norm McEwan,
National Stuttering Conference, c/o The
Communications Disorders Department, The
Rehabilitation Centre, 505 Smyth Road, Ottawa
ON, CANADA, K1H 8M2, Fax 813/737-7056

Mainz invites Europe!

The stuttering self-help group of Mainz/Germany
invites you to attend the
20th National Convention of People Who Stutter
Friday 3 September - Sunday 5 September 1993

On the programme there will be workshops on
a variety of stuttering-related topics, and the
traditional Saturday night party, including a raffle
(everybody is requested to bring something nice!).
As part of a supporting programme on Thursday, 2
September, a guided tour to the city of Mainz
including a visit to a champagne producer's will be
organised. The conference fee will be ca. DM 200
(probably less, depending on funds); the additional
night on 2 September has to be booked separately.

Contact:
Stephan Imre Michael Schwarzel
Nahestr. 3 Philippbergstr. 17
D-6096 Haunheim D-6200 Wiesbaden
Phone +631-2570 Phone +611-599970

National Stuttering Project: NSP X "Celebrate Freedom of Speech"

Arlington, Virginia: July 8-11, 1993
Contact: Paul Young, 8165 Bayonet Way, #202,
Manassas, VA 22110 (Phone 703-330-2901)

Polish Association for People who Stutter (PAPS)

The Gdansk chapter of PAPS
cordially invites you to the
VI Polish Convention for People Who Stutter
with the participation of guests from abroad
Gdansk, Poland
14-17 October, 1993

The meeting will be held in a holiday home in
Gdansk. There will be speeches, workshops,

exchange of experiences, sight seeing tours and
parties. The conference fee is ca. DM 100. We are
expecting about 200 participants, among them
people from the CIS and other Eastern European
countries.

Please send your registration to Euzbieta
Haponiuk, ul. Gospody 13-B-18, PL-80 344 Gdansk,
Poland, as soon as possible

Registration Form

I will attend the VI Polish Convention for People Who Stutter in Gdansk.

Name: Date of arrival:

Address:

I would like to present a workshop a speech on the following subject:

Date Signature