

THE VOICE OF ELSA

Newsletter of the European League of Stuttering Associations

Number 8

Spring 1995

Welcome again to the Voice of ELSA. This issue again reflects some of ELSA's objects by focusing on (i) past and future meetings and (ii) extending our contacts and knowledge to further European countries: Czech Republic, Spain, Estonia, Lithuania. We also feature some contributions which we hope will help to make VoE a more personal magazine: an article from Austria's Dialog, Pen-Pal exchange, and our newest and intriguing inclusion, the "Stuttering Recipe Story". So now we can try to nourish your stomach as well as your intellect!

ELSA has moved – please note our address: **ELSA**
Gereonswall 112, D-50670 Köln, Germany
Tel.: +49 221 139 1106, Fax: +49 221 139 1370

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MY STUTTER – A PART OF ME

In my childhood stuttering was not a serious problem for me as I was not, consciously, aware of it. I can only remember that my parents (especially my mother) asked me every now and then to speak more slowly. With hindsight, this certainly was one of the reasons why I kept stuttering beyond my developing years.

I am definitely not angry with my mother for that – she always did everything for my own good. It was only her lack of knowledge which caused her to react in the wrong way. It was not until puberty that I felt something was wrong. I retreated more and more and the strain imposed by suffering began. I was 20 years old when for the first time I wanted to put an end to my life.

In the years that followed, I had many speech therapies which treated the symptoms. I was able to benefit from each of these treatments in the short term, but success did not last because – as I found out only later – such therapies were only cosmetic with regard to my stuttering.

Little more than two years ago I was potentially suicidal for the last time

because again my fears of speaking almost exploded due to my passivity. Things were so bad that even my will to live was gone. Quite frankly, at that point I fought for my very survival for many months. It was not until I was deep in trouble that I said to myself that my period of rest was over.

From that moment I was really prepared to tackle the root causes, for I knew there was no alternative. So in those past two years I was invited to schools several times and I also organized two 'Open Evenings' at home. The main topics on these occasions were: how to deal with people who stutter; stuttering in childhood; and overcoming taboos. Further open days are planned.

Initially, it was back-breaking work like jumping into ice-cold water for me. Now I really enjoy it, mainly due to the feelings of achievement. Gradually I have become absorbed in these appearances.

I also modified my attitudes towards stuttering in a positive way. I acknowledge my stutter by often wearing the

sticker 'I stutter – so what?', a message I can now readily identify with.

Today I consider stuttering to be a part of my personality. It is precisely in this important area that Georg (Georg Goller, Editors) was an example to me. Also, I strengthened my much weakened self-esteem by adopting the attitude 'fighting brings honour'.

For fifteen years stuttering was my worst enemy because I had a totally disturbed relationship with it, and tried everything to shake off my arch-enemy; logically, this approach was doomed. Now I accept it and thus can live with my stutter quite well.

Formerly I often stayed silent because of my stuttering. Today I frequently make my own contribution even though I stutter. I realize that I am freeing myself from the chains of my fears of speaking more and more and that is simply marvelous!

Life for me has become worth living again, above all through the help of God. I live much more intensively now for, in a way, each day is a gift of the creator.

Georg Grimm (from 'Der Dialog Austria')
Schnitzersasse 1
A-9509 Lienz

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Editorial Board:
Maritte van Eerden (NL)
Stefano Tadini (IT)
Tim Arnold (UK)
Konrad Schäfers (D)

Contributions in this issue from 'Der Dialog' (Austria)

Layout:
Rainard M. Risse, Köln (D)

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STUTTERING TREATMENT IN THE CZECH REPUBLIC

In the Czech Republic, the parents of a child who stutters have three options: hospital, a special school or private practice. The latter is a recent development in our society following the collapse of communism.

Therapy at hospitals

At the hospital there are speech therapists who will treat child stutterers. The child, accompanied by his/her mother, comes to the clinic every weekday for six weeks to learn a new speech technique. The co-therapist prescribes medicines to relax and calm the stutterer, who is not allowed to communicate with anyone other

than the mother, the doctor and the speech therapist because of the need to eliminate incorrect speech habits. The child learns how to use common words, etc. fluently. This is just the bare outline of how stuttering is treated at the hospital. In my opinion, this process merely reinforces the child's abnormality.

No suitable treatment at special schools

As for myself, I taught for over 20 years at a special school for children with speech problems, mainly stuttering. Not even these schools provide suitable treatment in my view. Attempts are now being made to integrate

handicapped children with normal children. But it's all a question of money for us in the Czech Republic. For example, in order to integrate handicapped children we will have to reduce the number of pupils in a class.

At the present time we also have many special classes in infants' schools. As regards the special primary schools, the pupils only attend these schools for one or two school years. The special class comprises up to 12 pupils. The teaching methodology employed is modified to offer stutterers maximum opportunity to express themselves verbally. Using the slow speech technique - smooth and prolonged - the stutterers benefit above all from psychological support and psychotherapy. The time at the special school also includes medical treatment: the chief speech therapist works as a team with the organizer and the doctor/therapist. Treatment is based on Gutzmann's physiological method, modified by Seeman, his disciple and the founder of speech therapy in our country.

Current therapy suppresses the symptoms

To put it simply, stuttering therapy that treats the underlying cause does not exist because the cause of stuttering is still unknown. Current therapy merely suppresses the symptoms. The nature of these problems and their seriousness are mainly explained in the Czech Republic in terms of neurosis; consideration is given to lateral dominance and left-handedness as well as hereditary factors and educational deficiencies. In our country, one definition of stuttering has become prevalent: stuttering is a disposition and an accident, a trauma. This characterization, even when expressed as a mathematical equation, is no help to stutterers and doesn't offer any solution.

Need for exchange

Our criticism of the situation regarding stuttering care in the Czech Republic is based on several realities:

- as to the cause of stuttering, people only ever talk in terms of neurosis

- only child stutterers are taken into consideration, we ignore adult stutterers as if they didn't exist

- according to public opinion, every stutterer must be mentally defective; we have to keep repeating that it is not a question of intelligence

- we keep on blaming the parents, telling them that they are the cause of their child's stutter and at the same time we recommend a secure environment for the sake of that child's development.

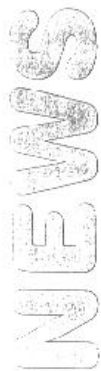
In future we would like to develop an exchange of experience in the field of research into the causes of stuttering in order to help people obliged to live difficult lives with their stutter.

Elisabeth Pavlišková
Zlata 10, 77209 Olomouc
CZECH REPUBLIC



INTERNATIONAL NEWS

A round-up of what's happening within ELSA's member associations



In **GERMANY**, the BV found a bigger office (which meant a move for ELSA, too). The '94 AGM was held for the first time in one of the new Bundesländer, the old GDR. This took place in Cottbus on the Polish border. Within the context of a reform of the German health care system, health insurance institutions and companies are now required to support self-help organiza-

tions. This historic inclusion of self-help in disabilities within the law is a big step forward.

Maastricht (**NETHERLANDS**) hosted the Nordic Meeting in August on the theme of "Self-Image". A bus trip through some of Iceland's finest scenery was part of the schedule.

The FSD in **DENMARK** has increased its membership recently. Many parents of young stutterers have joined the FSD; a summer camp for children/parents and information meetings for parents have been funded through the Ministry of Social Affairs. FSD is on the board of the Stuttering Information Centre of Denmark (see separate article).

Sam-camp "Stuttering camp" is an annual event in **NORWAY** where NIFS offered social training to around 30 members, including someone from the U.K. A social weekend is planned

for autumn '94, on the theme of stuttering and employment, near Lillehammer, Severa. NIFS members attended the Nordic Conference.

NIFS have initiated contacts with stutterers in **LATVIA**. Three members visited Iecava, a village 30 km south of the Latvian capital, Riga. There they met with stutterers and health service and social services officials. Stuttering treatment is rated a low priority in Latvia, with medical treatments applied in the main. NIFS aims to help Latvian stutterers create a stutterers' association.

The **FINNISH SÄY** is 25 years old - SÄY's president, Helmer Tillbacka, was interviewed on television.

In the **NETHERLANDS**, Demosthenes has now become "Nederlandse Stottervereniging Demosthenes" on account of public relations considerations. A new logo for the magazine and stationery has also been chosen. Much effort has gone into the Stuttering Awareness Week, a national event planned for the autumn.

INTERNATIONAL NEWS

in POLAND, PAPS is now more visible within the world of Polish speech pathology. Representatives were able to speak at a Stuttering Conference organised by the University of Warszawa. PAPS hopes this will prove the first step in creating a partnership between professionals and stutters in the process of therapy in Poland. Efforts are in hand to gain recognition as a "handicapped people's organization", which would enable financial support to be sought from the government. PAPS hopes that "the authority of ELSA" will be helpful in this direction.

The SSR in SWEDEN is refining plans for the World Convention next summer. Plenty of work goes on raising awareness of politicians, journalists and logopedes. A weekend meeting for stuttering children and their parents is planned for early 1995. Following on last year's successful visit from Estonian stutters, this spring saw an Estonian logoped - Pille Ives - come to Sweden. During her week, she visited a Swedish logoped who is working with children at a hospital in Falun, Lennart Larsson. In Stockholm, SSR arranged two visits of hospitals and also to the University speech department. In both Stockholm and Falun

there were several activities with self-help groups. There was much interest in meeting a foreign logoped and to learn about how fellow stutters are treated on the other side of the Baltic sea.

In the UNITED KINGDOM, AFS continues to canvass members' views on changes to the Constitution. The idea of accepting (fluent) parents into full membership of AFS is provoking much discussion.



INTERNATIONAL NEWS EXTRA

At the ELSA seminar in Amersham, U.K., in May 1994 there was great pleasure at welcoming representatives from Estonia and Lithuania for the first time, and in formally expanding ELSA to accommodate both the Estonian Association for People With Stutter (formerly "Caudius Club") and the Lithuanian Stuttering Problem Club. The delegates, Andres Loorand and Oleg Lazin, update us on the situation in their countries.

ESTONIA

At present there is actually no stuttering therapy for adults. Therefore the board of EAPS is working on a concrete project to establish the Stuttering Treatment and Information Centre (STIC) in Estonia. The idea is to provide a psychologist, four speech therapists, and one person to be manager/director. The STIC would share information on stuttering in different ways. Unfortunately, at the moment there is no financial support from the Estonian government because of economic difficulty in the country: of course, stutters need help today.

Address: CAPS, c/o Andres Loorand, Tartumaa, Alatskivi vald, EE 2415, ESTONIA

LITHUANIA

The LSPC was formed in 1992, on the initiative of clinical psychologists: Kris-

tina Polukorpiene who had been involved with stutters for more than 12 years. ELSA delegate Oleg Lazin has worked with Kristina as co-therapist since 1984. The stuttering members of a psychotherapeutic group (ages 16-24) formed the Youth Psychological Aid Club in 1989 and LSPC became part of it. LSPC was aimed though at stutters of any age and is progressing towards independence.

There are over 50 members, about 50% coming from the capital, Vilnius. The LSPC is a public organization with its own seal and regulation. Professionals work free of charge, there is no state funding, nor yet any sponsors. LSPC activity springs from the enthusiasm of members - any stuttering person can join.

Meetings and intensive sessions for groups of 20 stutters have been held. Self-help groups have been started, the U.K. "Speaking Out" translated (thanks ELSA!), and lectures arranged. Members exchange experiences of working with their problems.

LSPC aims to continue all activities, and hopes to stimulate all Lithuanian stutters (2-4% of the population). Their principle is "Do those things which work!"

Address: Lithuanian Stuttering Problem Club, Malonija 3, 2064 Vilnius, Lithuania



THE VOICE OF ELSA

INTERNATIONAL FOCUS ON FLUENCY DISORDERS

Report from the 1st Congress of the International Fluency Association

Formed in 1990, the International Fluency Association was a world premiere: unlike other organizations in the field of speech & language pathology, the IFA is entirely devoted to fluency disorders. In addition, it is based on an interdisciplinary and an integrative concept; meaning the association gathers experts from every field contrib-

uting to research and treatment of stuttering, and is open to everyone concerned. The latter is expressed by the fact that one of the IFA standing committees is the Support Group Committee.

The first important project of the IFA was the 1st World Congress on Fluency Disorders held in Mönchengladbach/Germany in August 1994 which gathered more than 300 participants from all continents. Truly an international event, well organized by the German organizing committee. The marathon programme comprised not less than 166 presentations, 34 posters and 5 video presentations covering all kind of aspects of research, treatment and self-help; from highly scientific research reports to the hows of daily therapy practice and self-help related work.

Self-Help Contributions

A number of contributions were made by people associated in one or another way(s) to stuttering self-help. Peter Cartwright and Chris Lewis spoke about the AF3[®] Helping Stammering Pupils project, while Cranja Christmann from Germany introduced the SV's work for parents of children who stutter. Per Fabæsch Knudsen spoke about the Danish Information Centre for Stuttering, Harman Christmann (DK) introduced the Danish Stammering Prevention Programme, and Lurdes Aguirre Bengoa explained the work of a Danish self-help group for parents. Posters were presented by Per Alm from Sweden on studying therapy for stutterers as a part of stuttering therapy, Mary Wainhouse from a South African stuttering association, and Woody Starkweather (USA) on computer networking and establishing electronic self-help groups. North America was further represented by Bob Gathman from Speak Easy International (New Jersey) ('The Self-Help Mirror'), and Mary Wood from Canada whose workshop 'I love me - especially when I stutter' included a crash course in hugging. Jaan P., Chairman of the IFA Support

Group Committee, reviewed the recent work of the committee.

Panel Discussion on 'Self-Help and Professionals'

A panel discussion on the relationship between professionals and self-help, jointly organized by the IFA Support Group Committee and ELSA, took place one complete morning - the longest single session of the congress. The panel featured Pille Ives (Estonia), Einar Boberg (CAN), Fred Murray (USA), Per Fabæsch Knudsen (DK) and Konrad Schäfers (D) and was chaired by Ken St. Louis (USA) and Jaan Hill (CAN). Though the event was more a collection of short presentations and statements than a real discussion, and not all panellists stuck closely to the subject, the audience had the opportunity to gain an insight into the problems professionals and self-help groups have with each other, and how the relationship might be enhanced. A series of prepared questions put by the co-Chairs and a general discussion amongst the plenum completed the event.

Making contacts for ELSA and ISA

As usual, the informal parts of the congress were at least as important as the official programme. Thomas Krall (representing the founding committee of the International Stuttering Association) and Konrad Schäfers used the opportunity to get in touch with therapists from countries still not present in the international self-help scene, eg. the Flemish part of Belgium, Hungary, Spain and Russia. Again the ELSA leaflet proved a valuable tool for helping to convey ELSA's aims and objects. Great interest was expressed in learning about self-help, and even though there is a long way from being interested to actively promoting self-help activities, it's the first step that counts. All therapists will be provided with further information.

No hugs for Mary?

It was Mary Wood, a person who stutters from Canada, who at one working session remarked that - compared to self-help meetings - she was missing the hugging! No question that she re-

THE STUTTERING INFORMATION CENTRE OF DENMARK

January 1, 1994 saw the founding of the Stuttering Information Centre of Denmark. Funded by the Ministry of Social Affairs for an initial 2 years, the staff of 3 hope to be able to prove in that time that the centre should become permanent.

ELSA founding member Per Knudsen, psychologist, is Centre Director and works with a secretary and speech pathologist.

The Centre aims to improve knowledge of stuttering amongst stutterers, parents and professionals; treatment of stuttering in Denmark has been decentralized to therapists in local areas. But the therapists have to treat all sorts of speech & language problems, some only seeing a very few stutterers if any.

The Centre hopes to harness information from journals, conferences and personal contacts with therapists and stutterers internationally. All information will be added to their databases, and newsletters will be published as well as holding workshops and writing articles.

Dansk Videnscenter for Stammeren
Lindøvej 161,
DK-2405 Copenhagen NV
Tel: +45 39695633, ext. 2531
Fax: +45 39692462
e-mail: per_kn@vri.dk



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INTERNATIONAL FOCUS

ceived a couple of hugs after that; this nice story demonstrates that stuttering people have something to share with professionals which is beyond the rational level of exchanging information.

The congress fees of many Eastern European participants had been funded by donors (among them ELSA). Unfortunately, one group of people concerned with stuttering was almost entirely missing: students of speech pathology; they were obviously kept away by the high fee. At future congresses allowances should

be made for students to encourage their participation.

Personal Conclusions

No doubt the congress was dominated by professionals, and no doubt much more interest in self-help topics would have been welcome. But who is to blame for this? It's our job to alter that situation by bringing more self-help people to congresses like this one and by making self-help an even more interesting subject than it has been. All in all, the integrative concept of the FA has passed its crucial test; people who stutter can have a say in

this organization. What is needed now is to fill the magic word 'co-operation' with practical meanings to ensure it does not become an empty phrase. This, again, is something we should not hesitate to tackle ourselves ...

[The congress proceedings will be published in book form. Order forms can be obtained from Dr. Herman Peters, Dept. of Voice and Speech Disorders, University Hospital Nijmegen, P.O. Box, NL-6500 HB Nijmegen. One copy of the book will be held in the ELSA office and can be borrowed from there.]

Konrad Schölers



A LETTER FROM SPAIN

To our great and pleasant surprise the ELSA office in Köln has received a letter from José Necoates Sánchez in Málaga, Spain. He chairs the 'National Association for Stutterers' which was set up in 1991. José enclosed some letters from 91 showing a positive re-

sponse to news of the Spanish Association's foundation being published in a Málaga newspaper.

The Málaga group practises these methods: a rhythmic sensor with variable frequency, a metronome, and

exercises of articulation and relaxation. They have issued information to people visiting the Málaga area. We will follow up this encouraging letter and report in future issues of VoE.



THE ELSA STUTTERING-STORY-RECIPE

After an inspiring ELSA weekend in Amersham/U.K., dozing in the coach going home Anita and I (sometimes known by good friends as the "Double Dutch") were discussing our experiences concerning a Chinese meal, specially cooked for us by an English stutterer before we left the U.K. We concluded: why not share our traditional national recipes ... in the VoE ... together with a stuttering story. To shorten a long story, here are the first recipes!

In the Netherlands in winter, pea soup with pancakes are often eaten, after time on the ice or a walk in the snow ... Let this final balloon be the start of an exchange of stuttering recipes, alongside all our other exchanges. We ask you then to send us your favourite

national recipe, together with some stuttering notes or story!

Thanks, and Bon Appetit!

Manilla van Erksen

Pea Soup (serves 4-5):

500 g green peas or split peas, 2 1/2 ltr water, salt, pepper, 1 knuckle of pork**, smoked sausage**, 100 g bacon**, 2 potatoes, 250 g leek, 1/4 celery-tuber, 1 bunch of celery, 100 g (thick winter) carrot, parsley

** for vegetarians, leave out the meat and add some soya paste.



► ...STORY-RECIPE

be kept for 1-2 days; they say it is even more tasty after 2 day ...

Pancakes (8-10 pieces)

250 g self-raising flour or 250 g flour + 7 g baking powder, 3 g salt, 1 egg, 40 g butter/margarine/oil, 4 1/2 dl milk (0,45 l)

Mix the salt with the self-raising flour (or the flour & baking powder), make a hole in it. Break an egg in the hole and pour in 2 dl milk. Stir from the middle until a smooth batter is obtained, and dilute, while stirring well, with the rest of the milk.

For each pancake, heat some butter/oil in a frying pan. With a deep spoon, pour out just enough batter to cover the pan.

If desired, put some washed dried currants/raspberries/apple pieces on it. Cook the pancake till done and golden-brown on both sides (don't turn until upper side is dried up). When using bacon, first bake the bacon before adding the batter to the pan. Serve warm with sugar, cane syrup, molasses, jam.



MAKING FRIENDS – THE ELSA PEN FRIENDS EXCHANGE

I am a member of AFS in the U.S. The winter issue was the first time I've seen VoE and I was very impressed by it.

I would love to get in touch with stutterers across the world! I am 22 years old and a Medical Student at King's College, London.

I have been on a very interesting course at the VoGure Institute in the Netherlands. There is an article by me in the Summer '94 issue of 'Speaking

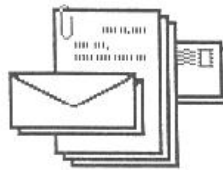
Out' titled 'Re-born in the Netherlands'.

Please do print my name & address details for pen friend exchange.

Thank you again for a very encouraging issue of VoE.

With best wishes,

Nesta Drogi
Flat 4, 100 Lancaster Gate,
London W2 3NY, U.K.



STUTTERING – A LAUGHING MATTER?

Long-awaited quality videotape of "Why Can't We Talk?" released

How many shelves can one fill with literature and information material on stuttering? For sure, there is no lack of source material, which approaches stuttering from a scientific or rational angle. Rare, however, are works which look at the topic by means of the fine arts, such as novels, poems, or plays.

An outstanding example of this rare species is the play "Why Can't We Talk?" written and directed by Irving Burton, a stuttering actor, and brought to the stage by a theatre group of Speak Easy International members of New Jersey, USA. A breath-taking exposition of witty, comical, and subtle

scenes from the everyday life of Mr./Mrs. Stutterer, the play was definitely one of the highlights of the International Conventions at Köln and San Francisco.

In 1992, Speak Easy launched a fund-raising campaign in order to raise the money needed to produce a high-quality videotape of the play. ELSA and many others supported the ambitious project. By June 1994 the required amount had still to be reached, but the tape was produced anyway! It had its first public showing at the FA Congress in München – to a great reception. There is only one thing cap-

able of surpassing the video: seeing the play live on stage.

Conveying its message through humour, satiric and satire "Why Can't We Talk?" is not only a thought-provoking stimulus for every person who stutters, but also a perfect tool with which to help educate speech professionals and the general public. Stuttering is no laughing matter, but laughing at stuttering and ourselves can definitely be helpful on our way to successfully coping.

The videotape (running time: 57 minutes) is available in the European VHS system for US\$ 39. To order please write: The Speak Easy International Foundation, Bob Gatzman, 233 Concord Drive, Paramus, NJ 07652, USA or contact the ELSA office.

Karol Schöfers



INTERNATIONAL FLUENCY ASSOCIATION

Report on IFA Support Groups and Consumer Affairs Committee

Public education about the nature and management of stuttering has been a leading priority of the Support Groups and Consumer Affairs Committee of the International Fluency Association. In 1994, the committee has also focused on the role of self-help groups worldwide as advocates on behalf of people who stutter.

Popularization: Our first priority has been promotion of public education campaigns to popularize stuttering. The committee has widely shared information with support groups and speech professionals worldwide on recent media efforts related to public education about stuttering.

Advocacy: The committee's second priority has involved advocacy on behalf of people who stutter. Popularization of stuttering is one aspect of

advocacy. Another aspect involves lobbying concerning legislation – such as health services legislation and employment-equity legislation – that has an impact on people who stutter.

A recent advocacy that has also met with strong interest has been the Helping Stammering Pupils Project by the Association for Stammerers. As well, the committee has shared information on ELSA's well-designed survey on stuttering and employment.

Advocacy can also mean speaking up for people who lack access to effective treatment. For example, adult stuttering treatment programs currently do not exist in Estonia. However, through the Support Groups Committee an Estonian self-help group has established contact with speech professionals and groups around the world, as a first

step towards setting up an Estonian treatment program for adults.

The committee has also devoted energy to planning for the self-help component of the recent First World Congress on Fluency Disorders in Munich. During the planning process, the Committee has especially benefited from the input of ELSA co-chair Konrad Schöfers.

International cooperation: Self-help at the international level involves the IFA, ELSA and ISA (International Stuttering Association). The next international self-help conference in Linköping, Sweden, offers an opportunity for national self-help organizations to further clarify relationships among IFA, ISA and ELSA.

Jaani Pill, Toronto/Caracas



ARE YOU COMING TO THE WORLD CONGRESS '95 IN LINKÖPING, SWEDEN?

It's getting closer now, the World Congress '95. Phones, faxes and computers are red-hot. All the stutter-clubs in Sweden are engaged with this big happening. Already people from 22 countries have registered, and more are to come. How about meeting people who stutter from Europe, America, New Zealand, and Asia?

And how can we make YOU come? Well, we have a full-time programme for everyone. On Wednesday we have a big opening with many activities and a choir for and by stutters. Her Majesty Queen Sylvia can't be with us that day, but the congress has her protection. What better compliment can we get? On Thursday we start with com-

munication, on Friday the subject is research and child stuttering, and on Saturday you can learn all about self-help.

We also have exhibitions and there are possibilities to make trips through Sweden, some organized, some not. On the evenings, we have disco, Big Band music and open mike sessions.

If you are still not sure whether or not you want to come it maybe helps you that the price for four days is now lowered from 1100 to 900 crowns because of the big support for this congress. But don't wait too long - there might be too many who want to come



Did you lose your registration form? Do you have any suggestions, questions or other needs? Do you want to have your own workshop? Please contact the congress committee at: +46/13-127126 (phone and fax).

Let Sweden be an unforgettable memory. Come to Linköping on July 25-29 '95. Be there when it happens!



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