



# THE VOICE OF **ELSA**

*Newsletter of the European League of Stuttering Associations*

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## *Editorial*

*Dear Readers,*

*one and a half years has passed since we last provided an overview of current developments within the national associations; time to devote this issue of the newsletter to what happened in the European groups during 1990.*

*If you want to know why the German Bundesvereinigung is facing great challenges, what plans Poland has for June 1991, and why both the Austrians and the Dutch 'Demosthenes' have every reason to celebrate - all this and much more you can find on the following pages.*

*Due to limited space the articles are necessarily kept brief. However, we are planning to deal with a special topic in more detail in the Autumn edition.*

*As announced in the last newsletter ELSA is planning to cooperate with the recently founded International Fluency Association (IFA). Some more background information - particularly concerning the Consumer Affairs Committee - are included in this issue.*

*Last but not least, news from a remote Northern country: A letter from a stutterer living in Iceland. The white spots on the map of European stuttering self-help may start to slowly melt away...*

THE EDITORS

### **In this issue:**

2.....News from National Organisations

12.....Special Topics

Re: International Fluency Association

14.....Letters

## GREAT BRITAIN

1990 was yet another year when finance played a part in AFS activities. The AFS Director has a continual balancing act between survival and providing an acceptably high service representing and helping people who stammer in GB.

Despite financial problems, which to some extent were alleviated by early 1991 the underlying position of the AFS is much stronger. AFS has received a small government grant for a period of 3 years and donations from charitable trusts have increased for specific projects.

AFS moved offices in the Autumn of 1990 and now operate from the East end of London, office accommodation being much cheaper in this part of London. The office is now manned by Peter Cartright the AFS Director working full time, his assistant and a Government Employment Trainee who both work part time.

### Membership increased

Public enquiries have increased, membership has increased by almost 50% and the AFS mail order service has proved very popular bringing in revenue which is steadily expanding. The postal library of books and videos is very much in demand.

Closer links are being made with various health professionals and Speech Clinicians, and AFS, via the Director and Committee members are able to comment on relevant topical issues for the benefit of people who stammer. A working party has been set up consisting of Speech Therapists, AFS Committee members and AFS members to comment on the proposed National

Health Service reorganisations as AFS feels the proposals may have a dramatic effect on the provision of speech therapy for people who stammer.

### Weekend event and Open Days

AFS has continued to organise Open Days, these prove very popular, usually held at different locations around the country on a Saturday. The next one is planned for Edinburgh in June 1991. A weekend event is planned for April 1991 at Northampton entitled 'Alternative and Complimentary Therapy'.

Three new leaflets are currently being prepared funded by a charitable trust linked to the BBC. The new leaflets will be aimed at parents, teachers, and teenagers. Another trust has provided a grant to enable the AFS to update a very good book on stammering which is currently out of print. AFS has liaised with the original author, improved the text and layout, and will be organising the reprinting and launch. The new leaflets and book should be available by the Summer 1991.

### Support for ELSA

AFS members are now more aware of the work and strength of many self-help organisations throughout the world and the AFS Committee have approved and supported the work of ELSA in its effort to represent, on the international scene, the interests of people who stammer.

*(Edwin Farr; compiled with the help of Peter Cartright, AFS Director)*

## AUSTRIA

Following five years of preparation, the 'Austria Self-Help Initiative for Stuttering' (ÖSIS) was founded in Innsbruck/Tirol on 10th November 1990 as a non-profit organisation.

Now as before the heart of the association is formed by the self-help meetings in Innsbruck, Wörgl/Tirol and, for some months, in the Federal capital Wien as well!!

### Cooperation with therapists

We closely cooperate with the professional association of Austrian logopedists, the Department for Communicative Disorders of the University of Innsbruck and the Austrian Society for Speech Pathology.

Since January 1990 we publish our bimonthly newsletter 'Dialog'. Beside our self-help meetings we were eagerly engaged in public relations work during 1989/90 by organising information stands, meetings, seminars ('Van Riper' and 'Neurofunctional Reorganisation'), and appearances on radio and TV. In February 1991, we sent 5.000 leaflets to general physicians, psychologists, neurologists, clergy and social service departments in the provency Tirol alone.

### Need for pr work

According to our estimation more than 99% out of all the people who stutter in Austria still have to live in the 'underground'; they avoid to go public because stuttering has an extremely negative image. We want to change this step by step by continual

pr work. It will be up to us to arouse an increased interest with political representatives at national, regional and local levels.

dialog  
Informationszeitschrift der Selbsthilfegruppen

ÖSIS' organisational structure is still in its infancy. During the next few months we would like to recruit more active members nation-wide to enable us to offer 'help to help oneself' to interested people who stutter in the remaining seven provencies in order to help them with coping with the ailment of stuttering.

### Medium-term aims

Medium-term aims are publishing another edition of the information leaflet, setting up an office and recruiting stuttering and non-stuttering members.

Of course we are striving for continuing the building up of the ÖSIS and finding our own identity within the concert of self-help associations for people who stutter - after all it is difficult or even impossible to copy an organisational structure. We are pleased to see our work being appreciated and acknowledged by therapists. This certainly is an additional stimulus for us.

(Georg Goller)

## NORWAY

At the beginning of 1991, NIFS (The Norwegian Association for Stammerers) had 280 members. But our population is 4,5 million and 1% should, in theory, be stammerers. Apart from activities in a local group in Oslo, local work is carried out in Bergen and Trondheim.

In addition to our annual meeting in the frosty capital during mid-February, NIFS gathered members from our long-stretched country to a summer weekend. Last year our Board had chosen the small town of Risør which later was awarded a European prize for the best well-kept town. The members of NIFS kept to the agenda and discussed how to disseminate information about ourselves, and what we can offer as support/therapeutical assistance in cooperation with the national health service. In fact, we experience time after time that after an article referring to NIFS has been published by a newspaper or a magazine, we get quite a few letters and telephone calls, and we succeeded in activating some of the respondents in our organization.

### Successful ELSA press release

On the information side, Liv Sundheim who is well-known among the rank and file stammerers on the European scene has developed our national magazine to a quality one crammed with thorough articles. Also, in January this year NIFS got publicity in our second largest newspaper that found the press release of ELSA interesting. Half a page was devoted to us.

One of the therapeutical activities that NIFS supported last year was a so-called Intensive Course comprising nine participants that were offered a psychological approach to stammering. It was based on Van Riper's method but was no orthodox exercise. Since then, more psychological theory has been put into the course based on the experience that stammering is very strongly integrated in our consciousness and behaviour.

### Professional Board

To ensure that our ideals are embedded in the therapy the national health service and the educational system offers stammerers, NIFS last year set up a professional board which consists of two speech therapists and two psychologists one of whom has a stammering problem. The professionals form an advisory body giving input to our National Board, i.e. when it comes to the treatment stammerers have access to. At present, a burning issue is the threat to close down a multi-disciplinary school offering 6 months courses to stammering pupils.

NIFS is member of an umbrella organization for different associations organizing handicapped people. We consider stammering as a social handicap, but it should be admitted that there has been some discussion among our members on this issue. One member of NIFS' National Board has a seat in the council of this umbrella organization. Last year a government proposal for a combined treatment for different groups of handicapped people was on the agenda. Due to the specificity of stammering, NIFS turned the proposal down.

### Service or interest organization?

In future, NIFS will probably be confronted with different proposals for "user influence on the national health service". At the same time an austerity policy could prevail in our health and social system. Against this background, the chairman of NIFS, Kjell S. Jensen, formulated a pertinent question in the last

annual report: Shall we develop a self-help and service organization for stammerers or a more 'agressive' interest organization? NIFS will try to fulfill both roles, but will perhaps give more priority to the representation of our interests towards government agencies.

*(Odd Bjørn Ure)*

## DENMARK

The situation for the Danish Stuttering Association (FSD) has changed a lot over the last one and a half years because of the sum of money we get from the national lotto-game. It means we are able to pay more for certain arrangements like the Annual Nordic Meeting than we could before. It also means we are able to make it more comfortable to be a member of the Committee of FSD because we can afford to have a parttime secretary who can do a lot of the daily work for the Committee.

### More pr work

FSD have planned to get in touch with more stutterers to tell them about what FSD is and what FSD can do to better the situation for stutterers - and because to get more members of FSD. This will be done by contacting the local institutions for stuttering treatment and together with them arrange meetings for stutterers. The Committee has also contacted other European associa-

tions to hear about their experiences about how to get more members.

### Report on stuttering

FSD are working on revising the report about stuttering treatment in Denmark. This time the report will be made in cooperation with the local institutions for stuttering treatment. This is a way too to get in touch with more stutterers.

Furthermore FSD is planning weekend arrangements and the annual summercamp. This year the summercamp will take place at Langeland, a very beautiful island between Fyn and Sjælland. This is the sixth time the camp will take place.

Last, but not least, Denmark will very much like to host the next ELSA meeting, so if we decide this at our meeting in Strasbourg, FSD bid you welcome in Denmark next time.

*(Per Fabaech Knudsen)*

## SWEDEN

As one of the members of the ELSA the SSR (Sveriges Stämningssför-eningars Riksförbund) would like to wish all of us good luck in the work to improve the exchange between the stuttering self-help groups of Europe. For us in Sweden - far up in the North - it is very important to keep in touch with our fellow stutterers in Europe.

First of all we would like to inform you a little about our work. During this last year the SSR has been working very hard on several questions. The most important ones are:

- Information: The SSR distributes several papers about stuttering to the public and to therapists, schools etc. The SSR has also attended some exhibitions where it presented itself and the problem of stuttering.

- International questions: Through the founding of ELSA the SSR has tried to intensify its international contacts. Sweden will probably apply for membership in the Common Market this spring, and this will put the SSR and other Swedish organisations for disabled persons into new tasks.

### Annual Nordic Meeting 1990

In this last year the SSR arranged the Annual Nordic Meeting for stutterers. The meeting was attended by many stutterers and several therapists, e.g. Prof. Edward Conture and Dr. Carlena Seymour from the USA.

### Campaign for more therapists

- Therapists: The SSR is trying to get more money from the state and local governments for logopedists, especially for children. This work is being done through letters to the ministry of social affairs and through the work in the organisation for disabled persons. Nowadays it is getting more difficult for stuttering pupils to get help from therapists within the schools because of financial cutbacks. For the SSR it is very important that the children and young people get the help they need from well educated logopedists.

### Support of local groups

Of course, the SSR also works with its 'normal' tasks: To support and help the 14 local groups which together form the SSR. Some of the groups need support to survive. The SSR has been arranging some courses for its members, e.g. in how to run a self-help group.

Other self-help groups in Sweden are very active and have many activities. Very popular are for example the courses in 'stutter-free speech' and weekend seminars.

From the Swedish self-help groups and from the SSR we send the best wishes to the stutterers of Europe!

(Christer Åström)

## THE NETHERLANDS

Last year was a busy one for DEMOSTHENES, the Dutch stutter association. June was proclaimed the 'month for the stuturer' and many activities were organised. DEMOSTHENES launched for this special occasion a brochure to call attention to stuttering. A few thousand brochures were distributed with the help of all Dutch libraries.

The founding of a national stutter fund ('Nationaal Fonds Stotteren') and an international scientific congress organised by Dr. H.F.M. Peters of the (Radboud Hospital) University of Nijmegen lead to the idea to proclaim June as stutter-month.

### June Stutter Month

'June Stutter Month' luckily and happily started with a telecast of one of our own video productions 'Ik stotter gewoon...' (I'm just a stuturer...) about the problems of stuttering in young children, the anxiety of their parents and their request for help. The independent Dutch Stutter Information Service, S.V.S., founded by stuturers, received many reactions by telephone.

The foundation 'National Fund Stuttering' (N.F.S.) want to finance activities and projects which improve the position of stuturers; both social and therapeutic. N.F.S. will stimulate:

- scientific research on the causes of stuttering;
- more and better teaching and refresher courses for assistants (therapists, speech therapists, psychologists and medical staff) so that they can better help or refer stuturers;

- to supply information about stuttering because of the notion of stuttering is, in first instance, very important for a good understanding and a better communication;
- patient care by improving the possibilities for stuturers to get help and treatment. N.F.S. will achieve this by setting up specialized regional stutter-centres.

### Activities

A few of the June activities:

- in some cities stuturers and relatives organised information stalls at crowded Saturdays' market places;
- many members of self-help groups successfully asked rural and regional newspapers for interviews to give publicity to stuttering;
- S.V.S. published especially for the stutter month some brochures and during the year a few books;
- with financial help from the government S.V.S. distributed educational materials for pupils of the senior forms of primary schools and the junior forms of secondary schools;
- S.V.S. organised meetings for i.a. teachers as well as student teachers. For the first time S.V.S. gave informative lectures at universities for prospective family doctors.

### Speech-technical weekend

In 1990 DEMOSTHENES organised a so-called speech-technical weekend in which people came together to practise their speech techniques by speaking in a comfortable feeling manner and trying to do this the whole weekend long.

For the first time, in cooperation

with a specialized training institute, DEMOSTHENES successfully set up a training course for information officers of self-help groups.

Last year just like former years, a German-Dutch meeting took place during a weekend. The weekend included excursions, festivities and of course the famous international football match Germany against The Netherlands.

Another important event in 1990 took place in September. It was the start of the first special academy for stutter therapists. Actually it is a secondary training for speech therapists. After a preliminary year it is also accessible for people who studied psychology and similar disciplines.

### 25th anniversary

This year, 1991, will be important for us, because our association DEMOSTHENES will be twenty-five years old. To celebrate this lustrum we are planning to hold a big conference and a sparkling party for young and old, members and everyone who had or has a relationship with DEMOSTHENES. It will take place during the last weekend of September at a location close to the beach.

Hopefully we will meet each other next year in San Francisco, California.

*(Marietta van Eekelen, André Beks and  
Clemens Nietsch)*



## GERMANY

The outstanding event in Germany during 1990 was the unification of the two German states. This historical change had - and it still has - major impacts on almost all sectors of public life, including the work of voluntary organisations of the handicapped. German population rose by 16 million; starting from the well-known 1%-theory there should be some 160.000 persons affected by stuttering in the area of the former GDR. After the opening of the border in November 1989 the Bundesvereinigung faced a dramatic increase of requests for information and help. Initially this increase had not been accompanied by a significant rise of membership; this led to some financial strain which luckily was compensated by public funds available for information work of West German organisations.

### East meets West...

In November 1990, the first seminar took place gathering 36 participants from Eastern Germany, most of whom were therapists. This meeting stood out for an overwhelming interest on the part of the guests and a remarkable frankness on both sides. Another eight seminars will be organised in the new provinces in 1991 covering topics such as "How to set up a self-help group", "Rhetoric and communication", "The Hausdörfer Method". Meanwhile the first groups have started to work, and we all hope to have a 'Bundestreffen' (Annual General Meeting) at Leipzig, Dresden, Rostock or some other place between rivers Elbe and Oder in a not too distant future...

### Basic programme

Following two years of intensive discussion, seven meetings of a special working group and preparation of several versions, a basic programme was passed at the AGM 1990 at Darmstadt. This paper not only defines stuttering self-help and its self-understanding in terms of the position within the social framework, but also formulates a number of demands regarding developments and requirements in a general social context, such as:

- Handicapped people must not be socially desintegrated;
- Self-help must not be abused and used as a substitute for public health care;
- Self-help must not be used by politicians and public administration for their own purposes.

The BV Committee is aware that the self-understanding of a heterogeneous organisation is a dynamic process which likely is to be subject to changes in the course of time. Nevertheless a basic programme is believed to be helpful for internal discussion and simply necessary when it comes to representing the interests of people who stutter to public, governmental and therapeutic bodies and institutions.

### 30 seminars

Seminars continued to be the backbone of BV activities in 1990. In all, 30 seminars on a wide variety of subjects have been organised, including a holiday camp for stutterers and their families.

A new book published by the Bundesvereinigung appeared in 1990 carrying the title "Depriving

Stuttering of Its Power". 23 stutterers wrote about their personal experiences when dealing with their stuttering. The book emphasizes that the most important thing a person who stutters has to learn is not to let stuttering rule her or his life.

In addition, a new series of information leaflets aimed at people who stutter and the public has been produced.


Currently there are four full-time workers at the Cologne office which is being shared by the Bundesvereinigung and the Cologne self-help group. All these positions are limited to [REDACTED]

#### ELSA

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Last but not least, ELSA has become part of BV life. An outward sign for that is a plate at the office door in Cologne, but more essential things are going on inside. The Cologne employment office has approved our application for funding a position devoted to European work, and we are now hoping to find somebody to fill the post soon.

*(Konrad Schäfers/Ari Köpf)*



## POLAND

The first stuttering self-help groups were created in Poland five years ago. Moreover, before March 1989 there were only unofficial groups, called Club 'J'. Then, after long preparations, the Polish Association of People who Stutter became a formal organisation.

PAPS consist of stutterers mostly, but therapists and our friends play an important role as well. Everyone of us has a problem connected with stuttering. It doesn't mean that we all stutter. Some of us want to improve their abilities as therapists, others just enjoy being with us. The first group was founded by Aldona Grzybowska, Ph.D. in Kraków, the next one in Gdansk and then in Pila. The fourth group came into being in Radom a couple of months ago. All of those communities were founded by speech therapists who still are helpful to us. The self-help idea has not been well-known in Polish society so far. People got used to traditional, individual therapy. The idea of getting help through giving help to others is strange for many of them. It takes time to introduce the mutual help which is quite new for us.

PAPS consist of 100 members now. It is enough to organize seminars and congresses and carry on the everyday work activities in particular groups.

### Activities during 1989/90

Now I shall describe our activities during 1989/90. Two years ago John Ahlback from the USA visited Kraków. 30 PAPS members participated in the World Conference in Cologne. In June 1990, Andreas Starke from Germany was invited by PAPS to lead a workshop about Van Riper's therapy. All these contacts abroad were helpful to get more experiences.

### First Slavic Congress

Every year PAPS organizes a congress which is especially important for those members who don't participate in meetings of self-help groups. The congress usually lasts for four days. It is a good opportunity to exchange experiences, to support one another. It is time for parties, games and... Last year a lot of people from Germany, England and Denmark were our guests. Now we are preparing the First Slavic Congress of People Who Stutter. It is, as usual, a courageous idea of PAPS' consultant Aldona Grzybowska. I shall say, our aim is modest. If we manage to gain some people to the idea of self-help, we will consider it a great success.

(Lucyna Jankowska)

**Re: International  
Fluency  
Association**

NEWS ITEM

**International Fluency Association**

Over 60 people from Europe, Asia and North America met in November at the annual conference of the American Speech and Hearing Association to establish the International Fluency Association (IFA). Two previous organizational meetings in the Netherlands and Texas had laid the groundwork for the IFA so it was possible for the group, gathered in Seattle, to adopt the Founding articles and elect an Executive Committee.

The IFA will be a non-profit, "international, interdisciplinary organization devoted to the understanding and management of fluency disorders and improving the quality of life for persons with fluency disorders" (Founding Articles). This goal will be achieved by stimulating research, facilitating communication among researchers and clinicians, helping support groups, serving as an advocate for those with fluency disorders and the professionals who serve them and by educating the public about fluency disorders.

The Board of Directors will consist of the seven person Executive Committee plus the Chairs of 10 standing Committees. Each committee will have representation from at least three countries. The IFA will welcome as members speech-language pathologists, logopedists, psychologists, physicians, basic scientists, laymen and anyone else from any country who is interested in fluency disorders. Information and application forms can be obtained from:

Membership Committee  
International Fluency Association  
Box 870242  
Tuscaloosa, Alabama  
USA 35487-0242

The Journal of Fluency Disorders will be the official journal of the IFA and members of the Association will be entitled to subscribe at a reduced price.

Submitted by: Einer Boberg, President,  
Edmonton, Alberta, Canada

and C. Woodruff Starkweather, Secretary  
Wyncote, Pennsylvania, USA

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## Re: International Fluency Association

### Support Group/Consumer Affairs Committee

[verbatim from the committee's report to the Third Organizational Meeting]

#### Purpose:

To advocate the needs and civil rights of people who stutter, publicize stuttering in various media, develop mutually beneficial interactions between professionals and people who stutter, and interactively coordinate its responsibilities on a world-wide basis with the International Fluency Association.

#### Specific responsibilities:

1. Promote liaison between this committee, the IFA, international organizations, the American Speech-Language-Hearing Association, and other professional associations.
2. Promote the exchange of information on self-help/mutual aid in stuttering.
3. Promote research on stuttering self-help and the role of self-help in the treatment of stuttering.
4. Promote participation in the activities of support and consumer groups.
5. Promote the identity and integrity of support and consumer groups.
6. Assist organizations in their fund-raising efforts.
7. Promote the planning, organization, and participation in national and international meetings.
8. Serve as advocates for people who stutter through public education and interactions with professional organizations and support and consumer groups.
9. Promote cooperation of researchers, therapy practitioners, universities, and support and consumer groups.
10. Develop a policy statement on the rights of persons who stutter on insurance, employment, treatment, and other civil rights.
11. Promote public information campaigns through the various media to "popularize" stuttering, to inform the public about the various treatments for stuttering, and to encourage more people to seek treatment for stuttering.
12. Obtain input from people who stutter about their treatment for stuttering and to promote improvement of the treatment for stuttering.
13. Promote informed participation in research.
14. Develop an informational clearing house.
15. Develop and publicize a speakers' bureau.
16. Publicize names of treatment specialists, researchers, and support and consumer groups.
17. With prior approval of support and consumer group members, contribute membership information.
18. Emphasize the prevention of stuttering and develop programs for caregivers.

Reykjavik 1. april 1991

ELSA  
c/o 29 Stutterer Selbathilfe  
Kasparstr. 4  
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My name is Benedikt Benediktsson, I am a stutlerer and I live in Iceland. Together with two colleagues I am trying to build some kind of an organisation for us stutlerers in Iceland. Until now there has been no form of organisation for stutlerers in Iceland, but we are hoping we can do something about it. We are getting good support from the Institute for hearing and speech, and the organisation for speech therapists. One of the problems we are facing is how few we are (only 250.000 people live in the country).

I have been in contact with the organisations for stutlerers in Norway, Sweden, Denmark and Britain. In the Swedish newsletter last december, they mentioned that one of the things ELSA would do was getting in contact with stutlerers in other European countries, such as Ireland and Iceland. The main purpose of this letter is merely letting you know that we exist and what we are doing.

I think ELSA could become a good tool for us stutlerers in Europe, where we can bring together our experiences and ideas.

I hope that maybe in the next year or two, we will have come so far that we can become a member of ELSA. Until then we will let you know how we are doing, and we would also like to hear how things are working out for you.

I think one of our main problems regarding ELSA is our distance from the rest of Europe. Travelling from Iceland is expensive, and that will make a direct participation quite hard for us. However we are interested in doing what we can do in this aspect.

I would very much like to hear from you about ELSA, how things are progressing and what the next steps are.

With my best regards



Benedikt Benediktsson  
Hraunbae 76  
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Iceland

## A FEW WORDS ABOUT STUTTERING...

My name is Daniel Orla, I'm Italian, 32, an employed translator. My experience with stuttering is not that different from what happens to others like us: one starts as a child, and then goes on. But there's a moment in life when some of us discover that which really helps them. I also experienced the 'magic moment' when I found the method which meant for me beginning a new life with less and less stuttering.

This is how we would like to contribute, as the Italian Stutterer's Association: SPEAKING with foreign 'colleagues', listening to their experiences and suggestions, and telling them ours. This is all we need and must do: SPEAK (is there a better way to solve our problem?...). We can create all kinds of official national/European/ international associations, we can think of the most wonderful organizations ever to be conceived; but if after all this we still continue stuttering, then all we have created is USELESS, because the main and only problem has not been solved...

And so here is our message: you, friends who stutter, get in touch with us: we will SPEAK about our situation, we will compare our various methods, we will all find a solution. In my capacity as a member of LA LINGUA AMARA (the Italian Stutterers' Association) I invite interventions from people who stammer in other languages than Italian.

Now let us stop writing, hoping that very soon we will start SPEAKING:  
DANIEL ORLA, CORSO TOSCANA 192, I-10151 TORINO, ITALY -  
PHONE: +39117394526 is waiting for you!

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