



# EUROPEAN NEWSLETTER of Stuttering Self-Help Groups

Number 2

April 1990

## *Editorial*

*Welcome to our second newsletter! This issue is completely devoted to the subject of European cooperation. The story so far: At the workshop 'Europe' during the International Conference in Cologne in August 1989 a general agreement was reached to continue and enhance the cooperation. One practical result of this agreement was the setting up of a preliminary working group consisting of one representative of each national association. A first meeting of the working group will be held in September 1990 to discuss further steps on European affairs.*

*In order to provide a common basis for this discussion we asked the national groups to state their points of view on the founding of a European top organization, and to express ideas, suggestions and expectations regarding future Europe-level work. In addition you will find articles on initial contacts with the UN in Vienna and the Commission of the EC in Brussels, and a more general statement on both the importance of European cooperation and the active role umbrellas seem to play in European politics...*

*If there is anybody complaining about 'boring organisational stuff' please consider that we first have to dig the earth and plant a tree before we can reap the benefits of our cooperation. All this organisation today will hopefully enable us to turn to more satisfying activities tomorrow. And if you take a close look at the following pages, you will find exciting traces of the overall changes taking place in Europe these days - see the article by Christian Gerlach from Leipzig/GDR where a young plant of self help is finally being able to sprout (to stay with botanical images).*

*We hope this newsletter will reach many European stutters or people connected with stuttering via your own association's publication. Should anybody have any comments, suggestions, ideas, etc. on European cooperation, please do not hesitate to write to the editors.*

*Furthermore we hope to produce another number of the newsletter in late 1990 to review the outcome of the September meeting of the working group in Darmstadt/West Germany. Thanks to everybody who contributed to this issue!*

*Edwin J. Fair      Sonrad Schäfers*

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**NORWAY**

The Norwegian Association for Stutterers welcome the idea of a working party of European stutterers. We really appreciate the work already done in Germany and England to make this idea possible.

In Norway we have discussed how to contribute and what to expect from a European cooperation.

First of all, as part of the national association of disabled (FFO), NIFS also look at the European FFO as a natural partner of cooperation for a European working party.

**Ideas and suggestions**

Coordinating contacts with funding, nonprofessional and professional associations can also give research on stuttering a more broader perspective. This is especially important from the observation that only one or a few types of treatment is offered in many countries. A differentiated knowledge of treatment methods is also necessary outside the professional community.

Information to the public also involves knowledge of stuttering research and literature on stuttering in different countries. A central data registration of research and literature in the association would then be an advantage.

For the purpose of making the stuttering problem more known to the public we also see the development of a more regular and comprehensive newsletter as very important. A consequence of this would be even more coverage for the national papers as well.

An important aspect of the work done in the Norwegian organisation, as in other European countries we believe, is based on an interest in social and human affairs and responsibility. We believe that the European cooperation will contribute to an even more extended consciousness about the importance of work like this nationally, hopefully with the consequence of more active participants.

**European summer camps?**

We think that the annually arrangements of summer stam-camps and Nordic Seminars (every fourth year) have

given us many ideas about how to run social arrangements combined with discussion on stuttering with and without professionals. In this regard we feel that we have something to offer when it comes to arrangements for seminars and conferences.

Regarding the possible relation between a working party like this and professionals working in the field of stuttering we have recently made some advances in Norway. Nevertheless we are still in need for more powerful strategies in this type of work. Cooperation with professionals in speech therapy can bring us further in a new situation when it comes to making explicit what needs we have as users. The reference to a European working party and top organisation would certainly be one advantage.

(Tom Green)

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The board of the Dutch Association of Stutterers 'Demosthenes' is very much in favour of European cooperation for the interests of stutterers, as well as a foundation of an official umbrella organisation. We are prepared to do everything within our power in order to start up and efficiently run such an organisation.

## THE NETHERLANDS

The association endorses the ideas and conditions as mentioned in the statement of May 1, 1989. However, we are in the process of comparing them with our own statement of principles. We hope the results will contribute in order to complete the foundation of the European top organisation. I am convinced the Darmstadt meeting will be successful.

By the way, a suggestion for a new name of the 'European Newsletter' can be "TALK-ABOUTS. Newsletter of Stuttering Self-Help Groups".

Looking forward to see the other members of the Working Group in September. Kind regards!

(Clemens Nietsch)

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## ITALY

Unfortunately, we received the request for an article in late January while we were busy doing the move of our national seat, so there was no time to convene the board and discuss the matters you report. Nevertheless, we totally agree with you about the foundation of a European Organisational Council.

We would like to inform you of the initiatives our association has carried out over the last two years:

- two national congresses organized to enable stutterers get to know each other and to generally discuss stuttering;
- several broadcasts and telecasts;
- two summer camps;
- the start of a training programme for the coordinators of the district divisions of our association. The first programme took place at the Centre of the Italian National Olympic Committee in Tirrenia (Pisa); the presence of 86 of us at the Second World Conference in West Germany;
- the first 'Meeting Week', open for members and non-members of our association, offering a series of optional activities and experiences for individuals and groups.

### Membership up to 620

Until now, the strong engagement of some willing people has made our association able to carry out a work of information reaching nearly everywhere. This has made the number of our members rise from 160 in 1987 up to 620 in 1989.

For the near future we are planning the following programme:

- a meeting camp at the end of the school year for our youngest members;
- the third summer camp;
- the organisation of further 'Meeting Weeks';
- a trip to Brazil in 1991;
- strong attendance at the Third World Conference in California in 1992;
- last but not least we will continue publishing our newsletter 'Res Publica' and intensely engaging in public relations work. This will include contacts with mass-media and various ministries (Education, Health, Employment, Interior, Defence etc.).

Of course we would be pleased to see members of foreign associations taking part in our activities, for instance in summer camps. As for other events, we know that the different languages we speak form an almost insuperable obstacle, but we hope this will not prevent us from continuing on our way to cooperation and friendship.

Best wishes from Italy!

(Piero Pierotti)



Our association is determined to join a European top organisation, yet we would like to see all European countries doing so.

## FRANCE

Please find the following suggestions for the work of a European organisation:

- Research should be done to
  - + find out why extreme tensions of certain muscles affect the fluency of speech;
  - + analyze which part of the nervous system causes these contractions;
  - + develop a therapy (e.g. a drug or something else) to calm the speech system.

It is obvious that all therapies and techniques can fortunately provide a certain degree of fluency. In our opinion it is important to learn more about these possibilities, so maybe one day it will be possible to find a way to influence the affected point in the larynx at a very early age and thus avoid a lot of harm.

**Keep in touch with those who suffer from their stammering**

- We must keep in close touch with those who suffer from their stammering, but we also have to reach the European and the international bodies to become better known.

Public awareness of the problem of stammering should be increased by an information campaign through the media. This could also help stammerers from being automatically laughed at.

- A European organisation should set up a data bank with information about all the literature existing on stammering.

- Both international and national research groups should be established or suggested. Currently, virtually all over the world research on stammering is being done. All of the researchers should be in contact with one another to make sure that their works complement one another and do not overlap.

No doubt, projects like this would take much more money than the national organisations will ever be able to raise by themselves. Yet, all together we can give a certain impetus in this direction.

With regard to the European newsletter, it should be continued. For this purpose and for the setting up of a European top organisation we would like to make a donation of 100 DM.

Best wishes to all of you!

(Georges Marquet)



## SWEDEN

It was very nice to meet so many other stutterers in Cologne but now is life back to normal again. We have discussed a lot about the European Working Party in our association (SSW) during the last months and selected a delegate for the meeting in Germany. His name is Christer Åström, and he lives in Stockholm. Some of you perhaps remember him from Cologne.

#### Informal cooperation preferred

The Swedish Association for Stutterers (SSR) has a very positive attitude towards some kind of collaboration between the stuttering associations in Europe. It is our opinion that the work should be aimed towards information of how work is carried out in other countries. It should include therapeutic methods and other miscellaneous items. SSR is however not interested in forming some kind of 'top organisation', particularly if this organisation is to have its own staff and economy. Our opinion is that the collaboration should be run in a loosely put together working group, where the representatives (1-2) come from as many countries as possible. In principle, each country should finance their own representatives.

The collaboration should be open to informal contacts between stuttering associations in various countries. Meetings should be held in the participating countries in such a way that different countries host the meeting each time.

(Thomas Pettersson)



We are interested in a European organisation to enhance the exchange of experiences and to be able to represent our interests to official authorities more effectually.

BELGIUM

#### Need for statistical data

Above all, however, we would like this European association to provide the European Communities with the actual number of people who stutter in Europe, the number being derived from reliable sources. All countries should find out their respective percentages.

As far as we are concerned, we have made several enquiries at the Ministry of Defence and the Ministry for Health and Social Affairs to get the statistical data. The extent of the population concerned will mirror the importance of the new organisation.

We are also interested in the different self-help models of the other associations and how they engage in public relations work.

#### Comparison of therapy approaches

In addition, we are open to all therapy approaches which have proved successful in terms of eliminating our common problem. This will enable us to compare the different techniques and aids being used.

As French speaking people we would of course appreciate receiving all the information in French. We would be very grateful to you for that.

Jacques Hellemans  
President of the AB.BEB

Francine Leeuwerck  
Vice-President



## FEDERAL REPUBLIC OF GERMANY

At the 1989 membership meeting of the BV Stotterer-Selbsthilfe a motion was proposed and carried to support and contribute to the cooperation of European stuttering self-help groups.

If it comes to founding a European top organisation the BV will become a member. Yet the assignment of financial and/or personnel means for purposes of the top organisation will be subject to further Committee decisions.

**A top organisation at any price?**

As already previously stated, we are well aware of the disadvantages and dangers of over-organisation, and we do not advocate an official unification at any price. We feel, however, there is evidence of possibilities with potential we could take advantage of as a European organisation, e.g. making use of the EC structures and funding possibilities, applying for grants from other bodies like the UN, and (definitely) engaging in public relations work.

During the past two years the Bundesvereinigung has made considerable efforts to promote the idea of European cooperation. In a sense we felt obliged to do so considering the fact that in comparison to most of the European groups in Germany we work under reasonably favourable conditions. We are prepared to continue our efforts, but we believe that a European organisation should be carried by more than two or three national groups. This is why we will only advocate the founding of a top organisation if a majority of the European associations are willing to participate. Otherwise we should give preference to some kind of loose cooperation.

**What do we expect from the work of a top organisation?**

- Seminars and meetings to provide an exchange of information on concepts and models of stuttering self-help, maybe on general issues regarding stuttering and therapy as well.

According to the EC funding guidelines it should be possible to set up a seminar programme with for instance 3 to 5 seminars or meetings per year. Actually this is what other European "NGO's" (Non-Governmental Organisations) do!

- Public relations work in the widest sense of the term. This can include different kinds of activities like contact with the media, acting as an 'information network' to collect and disseminate information on a European level; participation in fairs and exhibitions; rendering assistance to people in countries still without self-help groups.

To show that the idea of engaging in PR work is more than mere theory: We received an invitation to a European Fair of Handicapped People to be held in

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Avignon late this year, and we have been in touch with people in Spain, the Soviet Union and the GDR.

- Representation of interests. This aim has also been derived from activities which already have taken place - see the articles on initial contacts to UN and EC. This point also pertains to the social dimension of the changes within the EC as of 1992 - an important topic which should be discussed in more detail on another occasion.

We are looking forward to the meeting of the working group in Darmstadt in September 1990 to see if we can take another step towards a common answer to a common problem!

(Konrad Schäfers)



## AUSTRIA

After discussing the European matter with our members we would like to make the following statement:

- I) We advocate and support the idea of European-level cooperation in principle.
- II) With regard to a European top organisation, we first have to establish a national organisation in Austria before being able to join a European union. The setting up of the Austrian group is being planned for May 1990.
- III) As for ideas and expectations regarding the work of a European organisation we cannot make any concrete statements before May 1990. We will do this later on, perhaps at the Autumn meeting in Darmstadt.

**Are we "stutterers"?**

We would like to close with a suggestion which is meant as a thought-provoking impulse: Among our members we realize an increasing antipathy against the term "stutterer". We feel this word tends to be discriminating by reducing the personality of a person who stutters to just his speech problem. Considering this it is strange to see that for instance the West German group (which is a shining example in many respects) bears the word "stutterer" in its name. We, the people concerned, should take the first step and eliminate this degrading expression from our vocabulary. After that we could ask so-called 'normal' speakers to do the same! In Austria we want to give an example; this is why we chose the name "Austrian Self-Help for Stuttering".

We are keen to hear your opinion on this matter.

(Georg Goller)



We, people who stutter in Poland are the members of the Polish Association of People who Stutter, a non-governmental organisation, seeking to improve the conditions for stutterers, to improve and promote self-help and to encourage researchers and speech pathologists to undertake the difficult problems of stuttering.

**POLAND**

We welcome the suggestion to set up a European top organisation warmly, seeing in it an opportunity for further cooperation among the national organisations.

**European seminars**

What we consider to be most important for the Working Party is to organize and support European seminars, workshops and meetings, devoted to the exchange of information and experiences as well as personal contacts among European organisations. That will help keeping the groups alive and growing.

Furthermore it is important to continue to publish the European Newsletter. We badly need to have our own, international journal that will be a mirror of our self-help idea.

Finally, we should shape an image of people who stutter and explain stuttering problems to the public, using TV, radio and press.

#### **Improved education for therapists**

With reference to therapy we should advocate improved and continuing education for therapists in the area of stuttering. In particular we should cooperate with those therapists who are interested in self-help in stuttering. The self-help idea needs support and encouragement, for it links lots of people: patients suffering from different illness, researchers and therapists all over the world effectively. A world congress on self-help in therapies would be very welcome and could be supported or even organized by the European Working Party in the future.

A lot of love from Poland to all of you!

**Bogusław Pietrus**  
President of PAPS

**Aldona Grzybowska, Ph.D.**  
Consultant of PAPS



## **DENMARK**

The Committee of the Association for Stutterers in Denmark have discussed the association's attitude to the European cooperation. The Committee find the idea about cooperation very good, of course depending on what is put into the cooperation.

We think the associations of the different countries must be independent associations. It means that each association has its own way of doing things dependent on the tradition and the possibilities in that particular country.

These individual, independent associations can work together in a cooperation with other associations in Europe. One way to do this is to found a top organisation like the working group which was established in Cologne. This top organisation will be a kind of an 'umbrella organisation'.

The top organisation will have several purposes like those listed in the statement by Konrad and Edwin. So the Association of Stutterers in Denmark can join the statement presented at the conference in Cologne.

#### Realistic goals and expectations

But what is possible for the moment? We can have great ideas and high expectations, but the circumstances tell us that we have to be realistic in our goals and expectations. Our association is not very strong; we guess it's the same in other countries. We have a lack of members and we have a lack of money, even if the latter is getting better. So, if we (the Association of Stutterers in Denmark) "shoot too high" we are afraid we will fall down. Therefore we do prefer to work slowly in the beginning and see what will happen. This is something very important which should be discussed in the working group in September.

(Per F. Knudsen)



At its meeting on 9th December 1989 the General Committee of the Association for Stammerers (AFS) approved Edwin Farr to continue playing an active role together with other members of the European Working Party (E.W.P.) to seek to obtain the best conditions for stammerers in every country. The AFS Committee also confirmed their agreement to the setting up of a European Top Organisation together with the four steps suggested in the Part IV of the Workshop Europe Statement.

UNITED  
KINGDOM

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The AFS Committee have said that very limited funding can be made available at this moment in time, but can be reviewed once the outcome of the AFS's government grant application to cover years 1990-93. However a donation of DM 30-50 can be made as suggested in the E.W.P. letter of January 1990. *(Refers to a suggestion to set up a small preliminary budget to cover secretariate expenses)*

A European Top Organisation based on the current European Working Party is an essential prerequisite for contact with all international organisations and funding bodies.

#### Activities suggested

We look forward to the next meeting of the delegates of the E.W.P. to enable us to plan the work and organisation for the next 2-5 years. Suggested activities are:

- A schedule of contact organisations to be drawn up
- Agreed method of contact
- Aims of this contact
- Who makes the contact, individuals or group
- Determining the hierarchy of the Top Organisation
- Projects
- Funding

We look forward to reading other countries' suggestions.

(Edwin J. Farr)

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## Project Funding Possibilities

### A meeting with the United Nations in Vienna

by Edwin Farr

From recent research I have located two possible funding organisations, this is how it happened.....

Following the 1987 1st European Stuttering Self-Help Conference in St. Andreasberg I was so impressed with the commitment of various people representing their respective countries' self-help organisations. Here was a group of people dedicated to self-help. I realised through discussions that paramount to the success of our organisations was funding. Following the conference I decided to carry out some research into funding both for the AFS and for future European cooperation. I started with a letter to my local Member of the European Parliament who put me in touch with contacts in Brussels, London, and Strasbourg. The most encouraging replies I got from these organisations was from the Commission of the European Communities. The Commission confirmed that funding was available for projects involving at least three member countries. This has been confirmed by West Germany's successful application for funds to stage the 2nd World Conference. Konrad Schäfers can provide further information on this type of application at the next meeting of the European Working Party (EWP).

### 'World Programme' for disabled people

Another encouraging response I received was from the United Nations in Vienna. The office in Vienna is a centre that provides advisory services on request for non-governmental organisations, i.e. organisations such as our self-help groups. The centre has been administering a 'World Programme of Action' concerning disabled persons in the 'United Nations Decade of Disabled Persons' during which time finance and technical support are available.

I recently visited Vienna on a short vacation, prior to my visit I wrote to the UN centre and asked for a meeting to enable me to obtain a clearer picture of what was available for our organisations and for the EWP. The UN wrote back just before my departure from GB with an appointment, this lasted 3hrs at the main office in the Vienna International Centre.

I described the work of the Stuttering Self-Help Organisations, the past conferences and their successes, the Workshop Europe in Cologne at the 2nd World Conference, problems of our organisations such as finance, and

the setting up of the EWP. I asked what help is available for people disabled by stammering.

We were congratulated on the work carried out so far, especially the setting up of the EWP; I was told the way forward was with such an organisation as the EWP. It was explained to me that the UN had developed a World Programme of Action to be carried out during the decade 1983-1992. This programme had approved projects of all kinds to varying disability organisations. No help has been given to stuttering organisations yet, and I was told that the EWP would have a good chance of having a project approved if it was suitable.

Based on my knowledge of stammering and self-help I described the types of therapy and help available in Gt. Britain and to some extent the rest of the world. This description helped to put into context the setting up of self-help groups all over the world.

#### Funding details

I was given booklets and application forms and it was suggested that any application for project aid should refer to the booklet 'World Programme' in as many ways as possible. This booklet was based on resolutions formed at the UN 1987 Stockholm conference. In addition, I was told that any application should refer if possible to:

1. Benefits that could accrue for use in developing countries.
2. The making of an international application if possible to include the Japanese, who are currently a substantial world monetary force; the UN value the use of their Yen in subsidising projects.



3. Try to link with Universities who could perhaps help with the provision of support staff.

It was suggested that contact with other similar disability bodies who had made successful applications to the UN would be beneficial.

I was advised that if a project was put together it should report before 1992 as this would coincide with the end of the UN Decade of Disabled Persons, and the results of the projects could be referred to at the UN's closing conference. The UN even recommended that the 3rd Stuttering World Conference in the USA currently programmed for late 1992 could be brought forward so the UN conference could make reference to it.

When making an application it was suggested that a draft be submitted initially, discussed and fine tuned before a final one is presented. Costs incurred in the preparation of the application would be refunded if the application was successful. The UN will not fund all the project but once a project is accepted they will search for sponsors to make up the shortfall. The application initially goes to the officers of the UN who are the people I spoke to. When they are satisfied and the application is correct and complete they will take it through the various committees for approval.

**Other funding bodies**

During the latter part of my discussion I was introduced to Hans Hoegn, the head of the department for information on the UN Decade of Disabled Persons. I outlined the work of our various organisations and discussed our needs for funding for various activities. Hans Hoegn also suggested contact with The International Labour Organisation, UNESCO, and WHO (World Health Organisation).

applications for projects will only come after there is a clear mandate to continue with the EWP or a future European Top Organisation. It will be wrong for any of us to assume anything as grand as this can happen straight away when there is so much to do initially in sorting out our constitution and hierarchy. I feel all this initial research will at least help us plan a little easier.

**Conclusion**

Delegates of the EWP have a lot to discuss at the next meeting. Any

## An Exciting Encounter of the European Kind

### Report on the 8th meeting of the EC Dialogue Group

by Konrad Schäfers

Before even a European organisation of stuttering self-help groups has been founded we had the opportunity to take some first steps on the stage of European politics. By way of a previously made promise representatives of the Working Group had been invited to take part in this year's meeting of the EC Dialogue Group of Non-Governmental Organizations (NGO) in the field of handicapped people. Ari Köpf of the German BV office and I attended; Edwin Farr unfortunately was not able to come.

The amount of information and printed paper we received in Brussels was overwhelming. I will try to give a brief and basic summary of what we heard; more detailed information will be available at the working meeting in September 1990.

#### The HELIOS Programme

The main topic of the meeting was the implementation of the HELIOS programme (HELIOS: Handicapped People in

the European Community Living Independently in an Open Society') established in 1988 by the EC Division 'Actions in favour of disabled people'. "The absolute policy of the Commission was, and still is, the economic, social and cultural integration of disabled people in the European Community... An important aspect of the HELIOS programme is to provide a platform from which the Commission can encourage and initiate policy developments." At a general political level, the Commission for instance collects and processes statistical data which result in recommendations aimed at the governments of the member states. A Social Charter has recently been adopted. The national governments are encouraged to coordinate their measures in social policy, the overall aim being not only to improve but also to adjust the conditions of disabled people within the Community.

At a more practical level projects are developed and funded. An outstanding part of HELIOS is the funding of LMA's (Local Model Activities), model projects like for instance rehabilitation centres which are to promote innovative ways of rehabilitation and integration of disabled people. Other projects are a data bank providing information on products and services in the field of disability, and a documentation system referring to literature on related subjects.

#### **Non-Governmental Organisations and the Dialogue Group**

Commendably, the EC Commission does not try to solve the problems of handicapped people by isolated decision-making or by contacting the

governments of the member states only: "An important level of exchange is taking place between non-governmental disability organisations and the Commission of the EC... By bringing them together for dialogue and discussions, the Commission helps to ensure that they are all moving in similar directions, exchanging up-to-date information concerning developments in their fields, and sharing technical expertise and experience." The forum where this dialogue takes place is the Dialogue Group which is formed of representatives of the EC Commission and currently 39 European NGO's such as the European Blind Union, the Association Internationale Autisme Europe and - as one of two new groups - a 'European Stuttering Self-Help Organisation'. (This is what they called us; we always referred to ourselves as 'Working Party'.)

The terms 'exchange' and 'sharing' imply that the members of the Dialogue Group do not only have certain rights, for instance to take part in the annual meetings, obtain information and submit suggestions. There are responsibilities as well: The Commission expects us to participate in projects like the above mentioned documentation system, make statements and deliver reports on request, and to serve as a source of information the Commission can refer to if necessary.

#### **The cup floweth over...**

This model worked fairly well until recently when the number of NGO's applying for membership in the Dialogue Group began to swell dramatically. The Commission feels compelled to seek a way to handle this problem as soon as possible because

the work of a group of 100 or more organisations would become ineffective. A couple of suggestions were made, and the Commission will take a final decision before the next meeting in early 1991. This will probably amount to a model of associated members and full members, the latter being elected by the former. The full members then would be obliged to disseminate news and information to all the other groups.

#### What is in it for us?

Three qualifying remarks first:

- It should be stated clearly that belonging to the Dialogue Group or not is no matter of living or dying in terms of funding. Every NGO can apply for grants provided that some preconditions are fulfilled.

- Only groups with the status of European organisations can participate in the Dialogue Group.

- Due to the many different types of disabilities the Commission has to deal with, measures and actions are necessarily wide-spread, and to me it seems that priority is given to actions in favour of physically handicapped people - maybe simply because the number of people concerned is that high, and the organisations representing them form a strong lobby. This is why the smaller organisations might find it difficult to promote special measures related to their handicaps.

On the other hand it is not without good reason so many organisations try to become members of the Dialogue Group. Being a 'chosen one' brings

with it some invaluable possibilities:

- first-hand information on all aspects of social policies;
- direct personal contact not only with EC officials but also with representatives of all kinds of European NGO's;
- excellent possibilities regarding public relations work (for instance, all members of the group are invited to contribute a profile of their own organisations to a booklet published by the Commission);
- and, last not least, it is not unlikely there will be some feedback from the Commission to the national governments which could result in an increasing awareness of the national groups.

From informal talks with EC officials we had the strong impression that the Commission is very interested in the participation of self-help groups - or 'consumer groups', as they called it - run for and by people directly concerned in a handicap.

Like any involvement at a political level, the work in the Dialogue group does not promise any spectacular short-term results. However, an opportunity is provided to make a modest contribution to both the advancement of our own concerns and the social life in a future Europe. It will be our decision to take it or leave it.

*[direct quotes taken from "HELIOS Magazine" no.1 (1989)]*



## Our European Umbrella Organisation

by Odd Bjorn Ure

A European umbrella is blue, contains one yellow star representing each member of the European Communities and can often be seen in rainy Bruxelles.

A European organisation which coordinates some of the work normally done by each national association of stammerers, must keep an eye on how the Europe of the twelve is developing and expanding. However, it is not sufficient to queue up among all other umbrellas in front of the EC buildings in Bruxelles...

### A pan-European perspective

The pan-European perspective is for stammerers i.a. attached to "the social dimension" of EC 1992. The social systems vary substantially within "the Europe of 12", and the rights stammerers have to get support from public sources are equally different. Countries outside the EC are affected by this dimension for a united Europe (cf. how EFTA countries are "adapting" to the EC). And my guess is that East Europe will be offered West European investments with a "social dimension" so that the side-effects will become less painful.

A united Europe is conceivable. Stammerers must somehow take part in this unification, we cannot remain divided, but must do something more in our national bodies than sending delegates to European meetings. The first step to enlarge our activities could be to ask ourselves: - Do any of the goals in my national association demand a European answer? Then we could try to be more specific: - Which tasks until now mainly carried out by the national associations could be solved on a European level? Could the work be better and more efficient done there?

Some other questions could be: - What does my national association expect to learn from other associations (e.g. how to overcome obstacles, improve weaknesses)? What can our contributions be; in which areas have we been successful?

### Joy must be channelled to activities

I have attended two European meetings where all speakers - myself included - expressed joy of being there. Joy is important and should be maintained. But it is time to go on discussing how this joy can be channelled to activities that can even better underpin our European meetings. One aim of this issue of the Newsletter is to spark off an exercise. The introduction was done in a discussion paper put forward to the workshop 'Europe' on 14th of August last year in Cologne. The workshop took place during the Second International Conference on Self-Help in Stuttering; it was open to all participants. This indicates that our European efforts have nothing to do with creating a "fortress Europe", but enable us to deal better with what is outside "the old continent".

## There's Even 'Hereos' Who Stutter . . .

News from the German Democratic Republic

by Christian Gerlach

My name is Christian; I am a 27 year-old stutterer from Leipzig. It is one year ago I first heard about the existence of stuttering self-help groups, and since that time I am lost in this idea. I intended to take part in the 2nd World Meeting 1989, but unfortunately the restrictive authorities of my home country refused me to go to Cologne. Obviously the mere term 'self-help' evoked the suspicion of subversive activities...

Actually there were no special restrictions within the "really existing socialism" for people who stutter and other handicapped persons - except for the prohibition of organising themselves alternatively to have the chance to take part actively in a social life.

### Conditions changed

The changes of the political system of the GDR (which started at Leipzig, having earned the town the surname 'City of Heroes') also changed the conditions for stutterers. It is now possible for them to establish an organisation to represent their interests, and this is why I made up my mind to set up a self-help group.

Some details on the current therapy situation: In the Leipzig area (5000 sqkm) there is one special school providing therapy for children with speech disorders. Therapy programmes for adults are available on a very small scale only and mainly apply to people with voice disorders. Programmes considering several aspects of stuttering therapy and special approaches like for instance the non-

avoidance theory, speech exercises done in groups or the sounding method have not been offered so far. This is due to a chronic lack of therapists, but also to an almost complete ignorance on the part of public authorities when dealing with people suffering from speech disorders. As there was no therapy in private practice and the possibility of joining a group for self-help and mutual aid did not exist, people concerned were left to themselves. Isolation and resignation often was the effect.

### A group at Leipzig started

The group at Leipzig wants to bridge this gap, and if our model works we will strive to set up a national organisation. As yet, however, we are lacking almost all the prerequisites. Great help was rendered to us by Konrad from the West German BV Stotterer-Selbathilfe e.V. After all, without any experiences it is not that easy to go to the public and find fellow stutterers. We will be grateful for any further ideas and donations to promote our matter, and even though you cannot expect the small group of ours to organize any seminars and meetings or to publish a newsletter in the near future, we would like to cordially invite all those who are interested to get in touch with us on a visit to Leipzig!

(dedicated to Konrad Schäfers)

Contact: Christian Gerlach  
Schkeuditzerstr. 6  
Leipzig  
DDR - 7022

#### THE LATIN CONNECTION

One country absent from all the stuttering self-help conferences over recent years has been Spain. One might be forgiven for thinking this Latin speaking country does not contain people who stammer.

Unfortunately this is not the case; the Spanish people are not as organised as 'us' Europeans when it comes to the setting up of self-help organisations. Perhaps it is just a case of *mañana!*

Recent correspondence with the Division of Health Promotion of the City of Barcelona which is a refe-

rence point for self-help groups in the country confirmed that self-help activities for stutters do not exist in Spain, but **stammering therapy** is alive as witnessed by an International Symposium on Stuttering held in Salamanca three years ago.

Professor Miguel Serra, a Spanish expert on stuttering, has expressed interest in the self-help philosophy, especially what is being done in other countries around the world. - We look forward to welcoming the Spanish people in the near future.

(EJF)

#### A FIRST LOOK AT THE BALTIC SCENE

Just take the chance and see what happens - This is what I said to myself when a colleague of mine who is Latvian-born offered me the use of a personal contact with a friend who works at a newspaper at Riga, the capital of the Soviet Republic of Latvia in the Soviet Union (so far). In late December 1989, a small advert appeared (free of charge, by the way) in 'Riga Balsa' ('The Voice of Riga') reading: "A European self-help association for people who stammer collects information about the situation of stammerers in European countries. Information on the social situation, forms and accessibility to therapy, and any other information in requested in English or German to ..."

**RIGAS REKLAM.**  
4. DECEMBRĪ, 31. DEKLAŠĒR 1989. G. O. D. A.

Gimene piedāvā nemt mūža apgādību vecāku cilvēku, kam ir personiskā cilvējamā plātība. Garantē laimīgu vecumdienas.

Rakstīt: 220200, Rīga, pasta Nr. Dievprātuma, 2. Sērtiāls.

Eiropas pašpalīdzības asociācija, kas veido, vāc informāciju par stamstāru situāciju Eiropas valstīs, par viņu sociālo stāvokli, iespējām, terāpijas formām un informāciju konkrēti angļu vai vācu valodā.

Adrese: Konrāds Spārgers, Langsberģer Str. 69, D. 10000 Bism. l. Bism.

Latviešu ģimenei vajadzīgs kredīts 10 000 l. uz noteiktam pāc vienošanās.

Rakstīt: 220200, Jēkātēdīl. pasta Nr. Dievprātuma, 2. Sērtiāls.

In all, I received four replies, the first of which was a bit surprising but nevertheless sounded very interesting: A person of Riga asserted that there was a recipe for a liqueur based on certain Latvian herbs, which - so he said - proved helpful in cases of stammering. He offered some kind of 'joint venture', stating that the only things he needed to produce the liqueur were a Landrover, alcohol, sugar, and a distilling apparatus. (Unfortunately, the European Working Party currently is out of Landrovers...)

To get back on the three replies left, those were quite serious ones from people of different ages who stammer. Although the advert was formulated in a rather general way,

so as not to wake any false hope, the letters were very personal, reflecting an immense need for information. In my replies I tried to explain in broad outlines the idea of stammering self-help, stressing that we are seekers ourselves and that in most cases there is no fast and simple cure for stammering. In addition I encouraged the three of them to contact one another, and to keep in touch with the Working Party.

What I started was an attempt, although I am not even sure if this is an adequate way to promote our ideas. What do you think? I would appreciate your opinions on that.

(Konrad Schäfers)

## Directory of European Stuttering Self-Help Organisations

Including contact persons of the European Working Party  
Address correction requested

### AUSTRIA

Österreichische Selbsthilfe für Stottern  
Georg Seiler  
Ing.-Friedl-Str. 69  
A - 5020 Innsbruck  
Phone 0512-739582

### BELGIUM

Association Belge des Dégués et Exdégués  
Jacques Hellemons  
Rue du 1101 100  
B - 7700 Nouvion  
Phone 055-36667

new address

### DENMARK

Foreningen for Stammers i Danmark (FSD)  
Taleinstituttet  
Tjørnevej 5  
DK - 8240 Skovov

### GERMANY

Ernst Kruden  
Bachringstraße 5  
DK - 1055 Kopenhavn K  
Phone 33 91 15 35

### FEDERAL REPUBLIC OF GERMANY

Bundesvereinigung  
Stotterer-Selbsthilfe e.V.  
Ueyerstr. 245  
D - 5650 Solingen 12

Günrad Schäfers  
Landsberger Str. 45  
D - 5300 Bonn 1  
Phone 0228-553885

### FINLAND

Finska Stammers Förening rf  
Box 50  
SF - 00131 Helsinki

### FRANCE

Lasse Rann  
Savogatan 18C 44  
SF - 03150 Helsinki

### FRANCE

Association des Sôgues de France  
Georges Jacquinet  
7, rue de la Villette  
F - 75019 Paris

### ITALY

Associazione Nazionale "La Circo Anara"  
Piero Bianchi  
Via di Tratalia 100/2  
I - 50127 Pisa  
Phone 050/544742

new address

### THE NETHERLANDS

Nederlandse Stottervereniging 'Denoethens'  
Postbox 118  
NL - 3500 AC Utrecht

Claens Nietsch  
Industrielaan 37  
NL - 5342 EV Oss  
Phone 04120-22442

### NORWAY

Norsk Inneassosiasjon for Stamme (AIFS)  
Postboks 5826  
Hegdehaugen  
N - 0308 Oslo 3

### IRELAND

Tom Green  
Tronpergt. 5  
N - 04777 Oslo 4

### POLAND

Policki Związek Jawnajacych się  
Stowarzyszenie Zarejestrowane  
Dr. Aldona Grzybowska  
ul. Maja 6/21  
PL - 31-113 Kraków  
Phone 22-10-59

new address

### SWEDEN

Svenske Stammersföreningar  
Riksförbund (SSR)  
Box 9514  
S - 10274 Stockholm

new address

Thomas Pettersson  
Kungätern 54 F  
S - 73500 Kungälv  
Phone 0227-13257

### SWITZERLAND

VERSTA  
Postfach 8118  
CH - 8023 Zollikon

### UNITED KINGDOM

The Association for Stammers (AFS)  
Unit 509, 188 Blackfriars Road  
GB - London SE1 8EY

new address

Edwin J. Farr  
13 Lahn Drive  
GB - Droitwich Spa  
Worcestershire  
WR8 4TQ  
Phone 0905-770355

new address