

One Voice



The Newsletter of the
International Stuttering Association
(ISA)

Issue No. 12 June 2000

Edited in New Zealand

Incorporating The Voice of ELSA, the Newsletter of the European League of Stuttering Associations

Scatman John: 1942-1999

*Everybody stutters one way or the
other.
So check out my message to you
As a matter of fact don't let nothing
hold you back,
If the Scatman can do it so can you.
Ev'rybody's saying that the Scatman
stutters
But doesn't ever stutter when he
sings.
But what you don't know I'm gonna
tell you right now
That the stutter and the scat is the
same thing
Yo I'm the Scatman.
Where is the Scatman?
I'm the Scatman!*



(From *Scatman*, Iceberg Publishing 1995.
Text and music: T. Catania/John Larkin.)

Inside

Reports from the ISA chair and the ELSA chair	page 2
Obituary: In memory of John Larkin — “Scatman John”	page 3
Obituary: Remembering Canada’s Laurent Bouchard	page 5
Reaching out to the Czech Republic, Brazil and Slovakia	page 6
News from ISA and ELSA member associations	page 9
Reports from the ISA working groups	page 16
The Voice of ELSA: News from Europe	page 17

Report from the ISA chair:

ISA mourns the loss of two great supporters

The stuttering community is sad to hear of the death of John Larkin (Scatman John). I just listen to his songs: *I am a Scatman*, *Scatman's World*, *I wanna be someone* and *Everybody Jam*. John, we can hear you!

We are also sad to learn of the death of Laurent Bouchard, founder of the Canadian association ABC (l'association des bègues du Canada). As Jaan Pill said: "Laurent had many expressions that summed up the work of ABC. One such expression was, in translation, 'I am not proud to stutter, but I am a proud stutterer'."

This is the first joint issue of *One Voice* for ELSA and ISA. Both boards hope readers of *One Voice* and *The Voice of ELSA* will benefit from this decision. It is fitting that ELSA is celebrating its 10th anniversary this year, as is the International Fluency Association (IFA). Congratulations to both.

In August the Third IFA World Congress will be held in Denmark. We wish IFA the best for the congress and appreciate that self-help is again a big theme.

What about attending the next ISA World Congress next year? Best wishes to the Belgium association in their preparations for the sixth ISA World Congress in Belgium.

ISAD 99 was again a great success. In the newsletter of the British Stammering Association, Judith Kuster said: "We want to thank everyone's positive energy in making the second annual International Stuttering Awareness Day (ISAD 99) come alive in our community and around the world. Through ISAD, consumers and professionals can work together to share, give support and educate one another and the general public on the impact that stuttering has on individual lives. We can each do our part to make this world a better place for people living with stuttering."

Hopefully ISAD 2000, dedicated to children who stutter, will again be a day to remember, especially for our kids.

ISA looks forward to future co-operation with ELSA. Greetings to chair Edwin Farr, vice-chair Anita Scharis Blom and Konrad Schafers, co-founder and former co-chair of ELSA, who is now responsible for the ELSA part of *One Voice*.

Should we dance in Belgium next year to the music of Scatman John? I think John would be delighted if we did.

Thomas Krall,
Chair, International Stuttering Association.

Report from the ELSA chair:

ELSA very active at lobbying in Europe

Welcome to this new edition of *One Voice*. For those who do not know about the European League of Stuttering Associations (ELSA), or even for those who have heard about ELSA and wish to know more, let me briefly tell you a few things.

ELSA was formed in 1990 when many of Europe's national stuttering associations formed an umbrella association to exchange information on stuttering and stuttering self-help. In ELSA's 10 years of existence, the association has had many achievements, not least the relations with the European Commission and the Council of Europe. During this period, ELSA has been successful in obtaining funding for over 10 projects, enabling people who stutter (PWS) and Europe's national stuttering associations to come together. These meetings have ranged from exchange of information seminars to youth meetings for young PWS. ELSA is a founding member of the European Disability Forum (EDF) and a voting delegate. EDF is the definitive organisation working at a European level that represents disabled people. EDF has status and direct links with the European Commission.

ELSA sits at times in an environment somewhat removed from the grassroots level of people who stutter. However, that is not true of the board members of ELSA. All are people who stutter, with many years of working at grassroots level.

The board of ELSA feel that it is important to understand, and

if possible participate, at the highest level. EDF and other European non-governmental organisations (NGOs) have been instrumental in ensuring that the rights of individuals and citizens are strengthened. Article 13 of the Amsterdam Treaty provides for the European Union to take appropriate action to combat discrimination based on, among other things, disability. It is too early to say how effective this treaty will be for improving conditions for people with disabilities and indeed for PWS. But it is a massive step forward for everyone connected with all forms of disability.

There are many other issues and developments that are briefly worth mentioning. These include the United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities. The European Parliament has adopted 22 rules that underpin equal opportunities for people with disabilities, including PWS. EDF is currently working on the definition of disability. Words such as social exclusion, social inclusion and mainstreaming will soon be cascading down to grassroots levels.

This editorial is too short to discuss all the above. But it is ELSA's intention in future editions to explore these issues in greater detail.

I hope you all enjoy the new look of this magazine.

Edwin J. Farr,
Chair, European League of Stuttering Associations.

Obituary:

In memory of John Larkin: ‘Scatman John’

By Thomas Krall,
Germany

People who stutter from all over the world will be sad to learn of the death of jazz pianist and songwriter John Larkin (“Scatman John”).

He passed away at his home in Los Angeles, California, USA, on Friday, December 3, last year after a battle with lung cancer. He is survived by his wife, Judy; his mother, Harriet; and a brother, Bill, to whom we send our heartfelt condolences.

It is fitting that the first joint issue of the ISA and ELSA newsletter *One Voice* is dedicated to his memory.

Michael and Ellen Metzger wrote: “John was a man of kindness, tolerance, great warmth and a childlike pureness of heart. He was a man filled with music, fun, talent and a profound love for people.”

I had the privilege of assisting in the memorial gathering in Los Angeles at 1pm on Sunday, December 13, last year, and stayed for two days at the house of Annie Bradberry, executive director of the National Stuttering Association, based in Los Angeles, California. I will never forget these hours of sadness and love and the kindness of Annie, her husband and their parents.

Many people took part in this service at the house of Judy and John Larkin. There were candles, pictures of John, open mike speeches, and a jazz band playing good music. We could watch a video of John’s hits and an interview with him. Near John’s video, three guests danced with reserve to his music. John would have liked the positive atmosphere of this meeting of friends. He was with us.

His brother told the story of how proud John was around 1996 when he won an award for the record sold most all over the world during a certain time.

“I have beaten Michael Jackson,” John had said, radiant with joy.

Here is part of the speech I made to the audience about how John and I met, and the reasons why I attended his memorial — both personal and related to stuttering:

“John, can you hear me? You died too early, but we are not angry. It’s OK. Wonderful that you were on Earth.

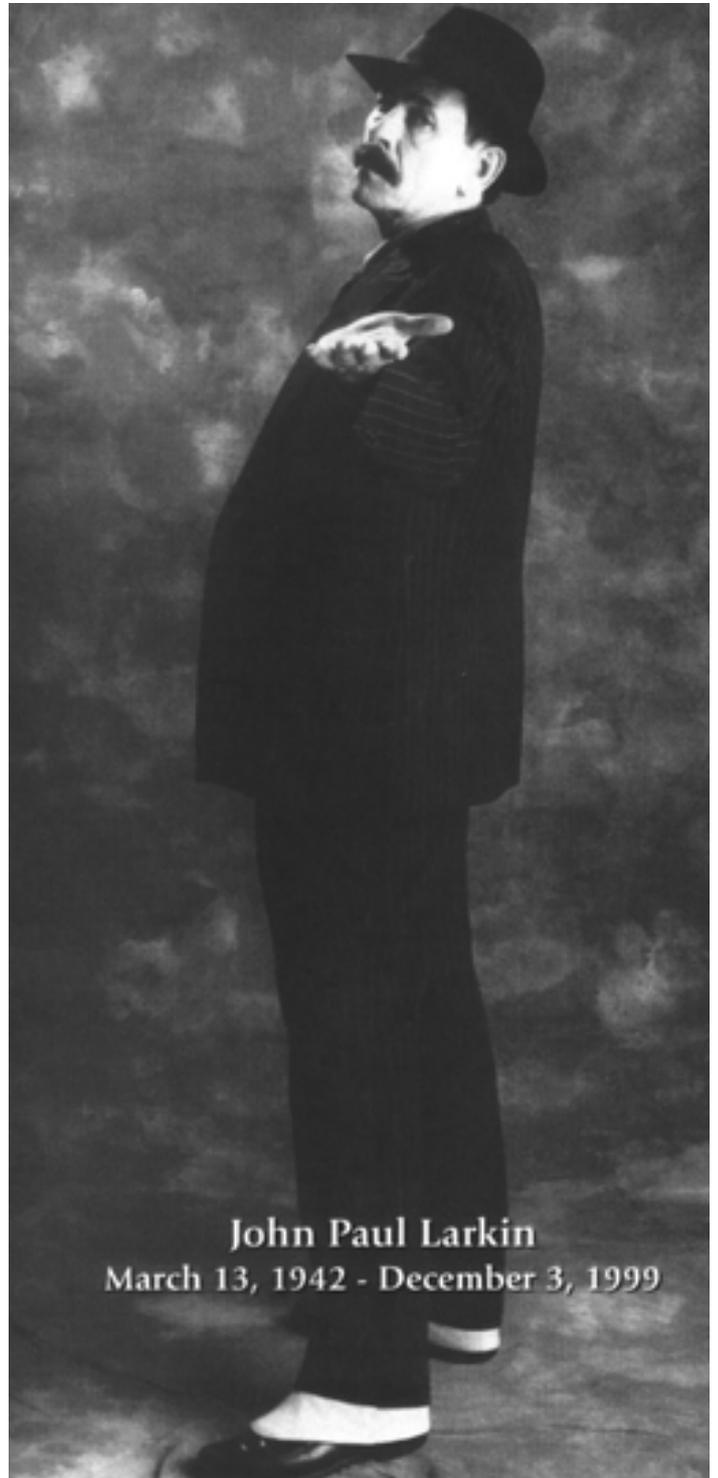
“You made the following steps in our world for the first time:

“1. You are the first known-all-over texter, composer and singer in our world relating to stuttering.

“2. You have founded the Scatland Foundation, an international foundation which serves people who stutter worldwide.

“By these innovations you helped and will help people who stutter around the world, especially the kids.

“This was your life project. This surely gave a big sense to your life. I am sure that people who stutter around the world are very thankful for your worthwhile part of building a world that understands stuttering. You helped in a big way to reach that goal one day.



“You were the ambassador of the International Stuttering Association (ISA) and the European League of Stuttering Associations (ELSA), the ambassador for people who stutter in all countries.

Thank you, from the International Stuttering Association and the European League of Stuttering Associations, for your openness related to stuttering, your courage in writing songs, singing them and doing interviews. Thanks for making stuttering a bit more kind and more understandable. Your ideas, your songs, your texts and your love will help the stuttering community forever.

“John, you gave us hope, and this hope will be forever. Scatman’s World — your Scatland — will grow.

“You are living in our hearts. We will never forget you.

“And if you want you will be our ambassador further. Thank you John.”

Scat singer overcame lifelong stutter

John Larkin, a lifelong stutterer who in middle age turned his speech problem into international fame as “Scatman John”, has died of lung cancer at age 57.

Larkin, a jazz pianist and songwriter before he turned to scat singing, selling some 8 million CDs and earning 14 gold and 18 platinum records, died in his Los Angeles home.

“I’m a star . . . not although I stutter, but because I stutter,” Larkin often told his fans, spread from Japan through the United States to Europe.

That success, and how he used it to inspire other stutterers, earned him the Annie Glenn Award from the National Council of Communicative Disorders in 1996.

In addition to his framed gold and platinum discs, he set world records in 1995 and 1996 as the artist whose recordings were sold in the largest number of countries.

Stellar success came to Larkin only in the past decade. After two top-selling singles, *I’m the Scatman* and *Scatman’s World*, his 1995 debut album, *Scatman’s World*, earned him Japan’s artist of the year award, Europe’s Goldene Europa and Echo awards and the MTV music award for best male artist.

Scatting — adding ad-lib syllables to vocalized lyrics — was his key.

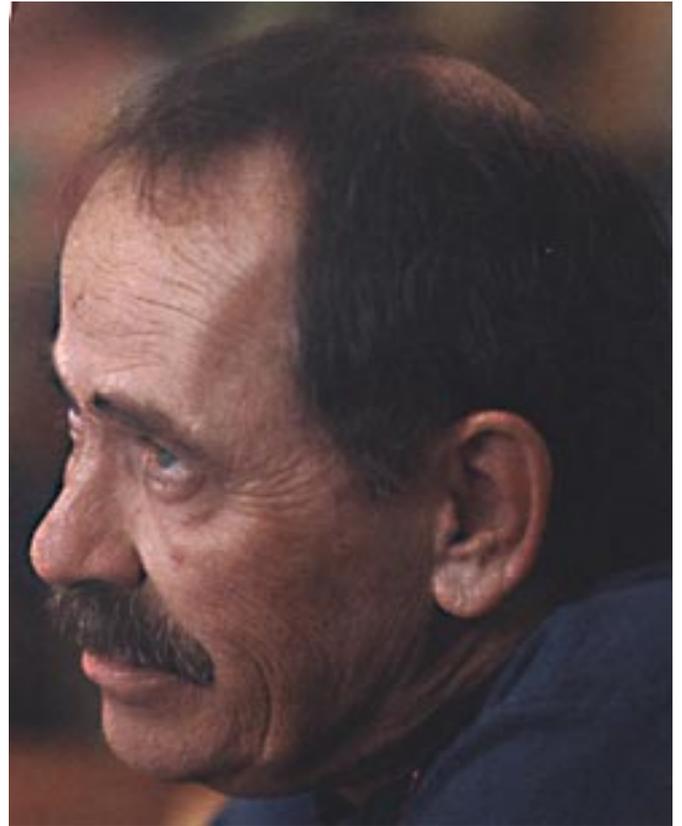
Born in El Monte, a Los Angeles suburb, and raised in nearby El Sereno, Larkin was enamored of jazz since childhood when he heard a recording of Ella Fitzgerald singing scat.

“Scatting gave me a way to stutter freely,” he said later. But he developed his career not by singing, but playing piano in jazz clubs around Southern California. It was 1984 before Larkin added singing to his act, while entertaining on a cruise ship.

Larkin had an unusual ability to sing chords with as many as four notes at a time, a technique he likened to ancient Hindu throat singing. Combining that with scat and a little modern urban rap and dance music, he became “Scatman John, the master of ‘scat-rap’,” in 1994.

“My greatest problem in my childhood is now my greatest asset,” Larkin said in 1996. “I’m trying to tell the kids today that Creation gave us all problems for a purpose, and that your biggest problems contain a source of strength to not only step over those problems, but all our other problems as well.”

Source: Los Angeles Times, December 8, 1999



Scatman John . . . what if the world finds out that I stutter?

Scatman learns to face elephant following him

Scatman John told *One Voice* in 1996 that he used to pretend that he didn’t stutter.

“Rather strange, isn’t it? It was as if I was going through life trying to conceal the fact that an elephant was following me everywhere I went.”

In August 1994, his agent suggested combining scat singing and rap music. He had a hunch that it was perfect timing for something like “scat-rap” to happen. BMG Music in Hamburg loved the idea and gave the go-ahead to record a single.

“Now any normal artist would have been happy about that kind of news, don’t you think? But not me. I’m still trying to conceal this elephant following me and my thinking was: ‘Oh, my God. What if the world finds out that I stutter?’

“Well, panic set in and I had to face the fact that this single I was about to record may have the chance of possibly becoming a hit . . . I had to turn and face the elephant.”

His wife Judy suggested he should start telling the world that he stutters.

“We both decided that the best way for me to start was to talk about my stuttering in the lyrics to the song that I was about to record.

“The name of the song was *Scatman*, and I chose the stage name Scatman John. The rest is history,” he said.

Obituary:

Remembering Canada's Laurent Bouchard

**By Jaan Pill,
Immediate Past Co-ordinator
Canadian Association for People Who Stutter**

Members of ABC and CAPS were saddened to hear of the passing away, on March 3, this year, of Laurent Bouchard.

Laurent, as well as being founder of ABC (l'association des bégues du Canada), was involved from the beginning of CAPS as a CAPS member. He also played a role in the founding of CAPS, and in helping CAPS get off to a good start as a national organization.

I got to know Laurent during the early days of CAPS. Laurent had played a key role in the development of ABC many years ago. The association had already been founded but was not yet active.

The suicide of three people who stutter in the province of Quebec convinced Laurent that it was time to develop as a self-help organization offering support to people who stutter in Quebec's francophone community and across Canada. He really made a difference in the lives of a tremendous number of people. Our lives as people who stutter, whatever language we may speak, have been enriched as a result of Laurent's work and the example that he set.

Laurent Bouchard offered highly valuable advice during the time that CAPS was being created. I recall that one of the things that he really emphasized was that a self-help conference should be, above all, a place where people who stutter can meet each other, talk to each other, and learn from each other. He also emphasized that if

ABC and CAPS were to work together then members of both organizations should have the opportunity to speak at meetings in their first language.

Laurent also attended some of the earliest international events involving people who stutter from different self-help organizations worldwide. He was among the pioneers in establishing contacts among self-help associations and individuals who stutter in countries around the world. Dr Fred Murray, of the United States, was another

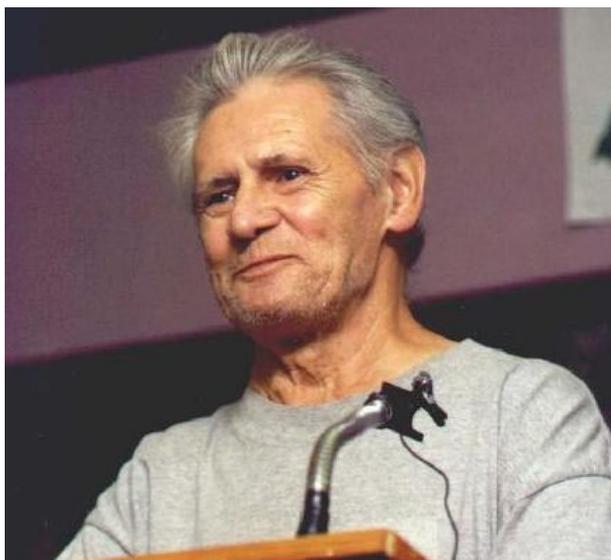
pioneer in developing contacts at the international level that subsequently led to the founding, in 1995 in Sweden, of the International Stuttering Association, among other international bodies.

Laurent had many expressions that summed up the work of ABC. One such expression was: "I am not proud to stutter, but I am a proud stutterer." That's a translation and I may not have the wording right. But I recall that when I heard Laurent Bouchard express this statement in French, it really summed up the message of his life's work so powerfully.

Laurent had a strong impact on CAPS, in helping to ensure that CAPS 93, in Ottawa, and CAPS 95, in Toronto, had translations in French and English. The success of the bilingual

ABC/CAPS 99 conference last August in Montreal owes much to the groundwork done by Laurent, in consultation with other individuals who co-founded CAPS.

I am very pleased indeed that I had the opportunity to meet once again with Laurent at the 1999 ABC/CAPS conference in Montreal. The event was a direct outcome of more than a decade of voluntary work by him on behalf of people who stutter.



Laurent Bouchard . . . I am not proud to stutter, but I am a proud stutterer.

ISAD 2000:

Reaching out to children who stutter

**By Michael Sugarman,
chair of ISAD Working Group**

The Third Annual International Stuttering Awareness Day — ISAD 2000 "Reach Out to Children" — will be celebrated on October 22 this year.

While ISAD is "officially" celebrated once a year, the opportunity to bring together consumers and professionals for the purpose of helping people who stutter is an on-going effort. The integration of self-help and clinical programs is already in place around the

world. ISAD encourages the creation of activities in communities and countries around the world which enable people living with stuttering, their families and the professionals who work with them, to come together in their involvement with the issues surrounding stuttering.

"Reach Out to Children" is this year's theme. To help you observe this year, please read the ISAD 2000 brochure which is inserted in mailed copies of *One Voice*.

If you have any questions, please don't hesitate to write to
ISAD22OCT@aol.com

ISA Outreach Working Group:

Special Friends group extends global links

**By Stefan Hoffmann
Beijing, China**

After an ISA board decision late last year, the Special Friends group was established, providing a forum for stuttering persons or experts from countries without an ISA member association.

They can develop a feeling of belonging to the worldwide stuttering community and can benefit from the network. They will receive *One Voice* regularly and ISA is ready to support them in establishing their own national associations, which can be future ISA members.

I am happy that in this edition of *One Voice* some of our stuttering friends from these countries take the opportunity to explain to us their situation and that of other stutterers in their country. We can learn from them and of course help them to develop their network.

Up to now the ISA Outreach Working Group has had responses from Algeria, Brazil, China, Czech Republic, Slovakia and South Korea.

All of our readers are encouraged to introduce the Special Friends Group to fellow stutterers or experts from countries without ISA membership. They are invited to contact me by e-mail at sthoff160@gmx.net

Czech Republic lacking in therapy for adults

**By Jiri Mazoch,
Czech Republic**

I am a stutterer from the Czech Republic, aged 43. I have been stuttering since the age of seven.

As I got older my speech tended to deteriorate. When I reached the age of 15 my speech problems had developed to such an extent that I could hardly utter a word in particular situations. These problems have persisted over the years. I have undergone many therapies at speech therapy clinics but only with temporary success. It always involved individual treatment — no group therapy.

In my view the speech therapy in the Czech republic focuses solely on curing children. Speech therapy centers exist only in a couple of large cities.

Unfortunately, there is no special therapy for adults. The speech therapists I have seen so far have not been able to provide me with any sort of intensive treatment or to advise me on how to carry out self-therapy.

This unsatisfactory level of speech therapy in my country is due to a lack of awareness about stuttering. Only last year there were no Czech publications about stuttering in adults. Now the situation

has slightly improved, with two books (by R. Parent and M. Fraser) available. The general public has not been informed. There have been no articles on this issue in newspapers until recently.

The only existing self-therapy group for stutterers, named BALBUS, was established at the College of Pedagogy in Olomouc. The members, who are not so numerous for the time being and who come from various parts of the country, get together about once a month over a weekend. At these sessions the members practise various speech skills and they generally support each other.

(Jiri Mazoch can be reached at jmazoch@iol.cz)

Brazilian bid to set up stuttering group

**By Daniela Veronica Zackiewicz,
Brazil**

Here in Brazil I've been working with stuttering since 1994, when I entered the Investigation Laboratory of Fluency and Fluency Disorders, Speech and Language College, at the University of São Paulo.

This lab, under its director Dr Claudia Regina Furquim de Andrade, assists a lot of children, adolescents and adults who stutter. At this place I am gaining great experience as a clinician and hope to study the evaluation of disfluencies to obtain my masters degree. I have had the chance and pleasure to assess more than 70 stutterers and have treated about 40 patients, including children. I intend to continue with my studies on different stuttering assessments and therapy methods. When I finish my masters degree, I hope to gain work as an assistant at the lab.

At present we are working to found an association for people who stutter.

I would like to see more Brazilian stutterers working together. In February we started co-operating with a person who stutters, called Lucas, in preparation for the founding of the first Brazilian stuttering association. We hope that it will become an important organisation for people who stutter here.

But we have encountered a lot of problems. So far accessible help for stutterers is very limited and we have to start from a rather low level. I am not a stutterer but I think that I can help stutterers to organize themselves. Lucas, too, is very interested in founding an association. We hope that we can make a good job of it.

Suggestions, help or comments are very, very welcome.

(Daniela Veronica Zackiewicz can be reached at dvz@bol.com.br)

Steps made towards association in Slovakia

**By Tomas Simko,
Slovakia**

I have been stuttering since I started talking. It bothers me a lot.

In the beginning it was not as severe so I was able to hide it. (I learned a couple of tricks, for instance getting all the air out and then saying a word which was for me hard to say.) That was why I became extremely sensitive about my stutter. Everybody knew me as a perfectly fluent boy so even the thought of me stuttering was completely unacceptable for me.

The older I became the harder it was to hide my stutter and to pretend I was “normal” and totally fluent.

At the age of 13, I grew rapidly taller. During this time my speech grew suddenly worse. I realized I was not able to hide my stutter any longer and it changed me completely. I started creating my own world of silence. When I did not talk I did not stutter.

A couple of my classmates had a negative attitude towards my speech difficulty. Many teachers also did not behave appropriately. I had several therapies, with no success, because I had exactly the same attitude and approach as described below.

After finishing secondary grammar school, I decided to go to England to spend a year as an au-pair. I stuttered in English as well — exactly the same way as in Slovak. I believe that stuttering is for me a psychological problem, not a physical problem.

I contacted the British Stammering Association and for the first time in my life realized that I am not the only person who stutters.

I attended a self-help group there as well. It helped me a lot. It was amazing to share feelings with others, because their feelings were similar to mine. I started thinking positively and I became aware of a very important fact — I do not need to overcome stuttering in order to become happy. I needed to desensitize myself towards it.

SELF-HELP GROUP

When I returned home I decided to establish a self-help group in Slovakia. I knew what the group should look like as I had seen it in England. I found the English group very well organized.

When I started my studies in Bratislava I contacted several competent people from the pedagogical faculty and several teachers from a school for children with speech difficulties. They helped me find about 10 stutterers — potential members of the group — and they even offered me a classroom in the school for children with speech difficulties as a suitable place for our meetings.

In September 1998 we had our first meeting. Almost every stutterer I contacted came. Some of them came out of curiosity. Because no one had any suggestions about what to do during the meeting, I explained to them how self-help meetings worked in

England and suggested them as a good example to follow. They agreed.

From that point our meetings were split into two parts. During the first part everybody tells how his or her speech has changed since the last meeting. This part sometimes lasts very long as some of us stutter severely and have so much to say. In the second part a topic is chosen and we discuss it. Often our attitudes and opinions are similar.

We meet every other week for 1½ hours. Some people did not return after the first meeting. Probably they did not like it. But about five or six of us usually attend each meeting. Others come occasionally.

There is just one woman coming to our meetings. The rest of us are men. All of us are relatively young, from 18 to 25 years old. People in the group have different levels of education and different levels of disfluency.

After a couple of meetings I felt the atmosphere was getting warmer. People were less tense and more open. They started to talk more about their problems, what they had tried, what helped them and what did not.

But no one was talking about the future. It seemed to me as if all of them had put up with their problem and they did not want to work on themselves because, according to them, they had tried everything. I felt we could do more than just talk about our problem.

Of course it is also important to talk about our problem. It makes people happier when they feel they are understood by others. But it does not solve the problem.

Therefore I brought to one meeting a person called Miro, who is a student of speech pathology. I wanted him to make our meetings more lively, to make people more active. He was young. I thought it would be better to have somebody there who is our age so that we did not have to take him as an authority.

And it worked. Since then I have been satisfied, because the group fulfils my expectations. I am sure the same can be said about the others.

Our favorite activities in the group are pretending that we call each other, reading in front of others and discussing various topics.

We have also tried speaking circles, but it was too early. Most of us felt awkward about that.

Two of us in the group are in therapy, so it is a great opportunity to practise what we are working on in therapy in a group setting and a safe place.

During spring and summer we had our meetings outside in a park.

At the moment about six people attend the group regularly. I think it is very important to see people regularly, because it gives us an opportunity to get to know each other deeply and it results in better co-operation between people.

During one meeting Miro spoke about several therapies and explained to us how each of them works. We tried them all in the group. This helped everybody explore which therapy might be most suitable for him or her. Our meetings are a suitable time to practise various therapy ideas.

In my opinion a self-help group is particularly useful for those who work on their speech. They can practice there, gain self-confidence and then go outside and work on maintaining it.

I would be glad if our group carries on. Perhaps we could meet more often, like once a week. Meetings could be longer as well — two hours or even longer. But at this moment that is not possible.

I think that because our group is for us as stutterers, we should also know what we want to do. It is fine that Miro is there and leads us. But we should make our meetings even better because we know what we need.

In my opinion one of the most important things is the transition between the classroom, where we hold our meetings where everyone stutters, and the world outside, where almost no one stutters. This is very difficult. I know it from my own experience.

Therefore I would prefer not being inside the classroom all the time, but going outside in pairs, for instance to the shop and asking for things which are difficult to say or stopping people on the street and asking them where the railway station is. But before doing this we need to get ready.

In the future I will be pleased also if each one of us is capable of standing up in front of others and talking for a couple of minutes with no fear and no shame. I do not say without stuttering, because probably we will never get rid of the disfluency.

STUTTERING IN SLOVAKIA

Outside our self-help group, stutterers have no other activities in Slovakia. We do not even have a stuttering association. This is a little bit unbelievable, because all the other countries around us do.

Slovaks are people who do not talk much about their problems to others. It seems like stuttering does not exist in our country, because no one talks about it. But it is not true. There are stutterers here — like everywhere else. People just do not want to see them.

Stutterers very often feel ashamed because of their unnatural speech and isolate themselves.

Even if they want to get help from speech therapists, they mostly do not get any as our speech therapists are not well educated. They use old, incorrect methods and the whole approach to treatment is wrong.

It works like this: The stutterer goes to a speech therapist expecting a cure. The stutterer does not think he is supposed to do major work and that a speech therapist or pathologist can just show him the right direction. The stutterer thinks the therapist is capable of curing him, because he is educated in this field and even paid to do this. The stutterer puts all responsibility on the therapist.

On the other hand, the therapist uses one of his impractical methods and undertakes the work as a routine. He is not personally involved in it. He does his work and does not care whether therapy will be successful or not.

At the end both of them are satisfied — the therapist because he thinks he has done his best and the stutterer because he is resigned to thinking that he has tried to cure himself but stuttering cannot be cured.

Of course this example is a bit of an exaggeration, but a lot of it is true.

In my opinion Slovak logopedics really should expand their range of methods. There are many resources they can use, especially well written American books published by the Stuttering Foundation of America or the National Stuttering Association.

Because I am a student I do not have much spare time. I think I need to find more people — stutterers — who want to change the current situation in Slovakia. If I manage this, we will set up a Slovak stuttering association which will be independent of the association of logopedics but will co-operate with it.

Then it will be very important to raise money.

After that it would be great to translate some books on stuttering and publish them in Slovak.

Also it would be important to set up new self-help groups in different areas, so the association has members spread all over Slovakia.

I see an advantage in co-operation with the Czech republic. Our languages and cultures are very close, and they already have an national association.

For instance, a book published in the Czech republic could be distributed also in Slovakia and the other way round.

To summarize, I hope the situation in Slovakia will change soon. Perhaps some of the ideas mentioned above will come true and my next report will be much more positive — describing our successes and the progress we have made.

(Tomas Simko can be reached at simkot@decef.elf.stuba.sk)

Little awareness of stuttering in Algeria

By **Martine De Vloed**,
Belgium

Daho Benabdellah, who is the first individual member of the International Stuttering Association and a teacher of adaptive education in Algeria, has focused on children who stutter.

He says:

“Stuttering has many causes but it seems that the cause cannot be proved.

“Circumstances which can result in stuttering developing are: heredity, traumatic experience, fear, grave illness, tremendous demands from parents while children are acquiring language, and an intolerant atmosphere at the school.

“To achieve good results it is important to start the therapy when the disfluency appears.

“There are many therapies and there is no unique one. Usually the speech therapist proposes a treatment which depends on the availability of therapy and the personality of the child.

“Because there is little awareness of stuttering in Algeria, it is necessary to inform people so children can receive preventative treatment.”

News from ISA, ELSA member associations

ARGENTINA

Argentina Stuttering Association (AAT)

Our activities last year were:

- Lecture at Hospital Roca's Speech Disorders Service, attended by speech pathologists, students and doctors.
- Speech Disorders Congress and pediatric ORL in the province of Corrientes. The conference theme was: "Stuttering is not only a personal difficulty." Speech pathologists from Chaco, Corrientes and Formosa attended. Acts of the First National Journeys about disfluencies was presented to the library of Corrientes University.
- Postgrade in disfluencies, child's treatment. Dictated in the AAT. Training for disfluent children, comprising evaluation, modelling and cognitive treatment in the stimulation of fluidity.
- Publication, distribution and sale of acts of the First National Journeys about disfluencies (in May 1998).
- AAT corporal workshop, for speech pathologists interested in personal work and an integrated assessment of patients. This annual workshop was open to disfluent people.
- AAT musical workshop, for speech pathologists and disfluent people, with the object of integrating ourselves across rhythms and music, for singing and playing instruments.
- Open consultations, on the second Tuesday of each month. People who stutter, their parents and teachers gather to seek information and take part in a group workshop. In this open consultation, everybody learns from everybody.
- The printing of a guidebook for organizing support groups, so new groups can be organized as well as those at the Hospital Pirovano, La Plata and Bahia Blanca. Co-ordination can be shared with speech pathologists or co-ordinated by disfluent people only.
- The printing of a pamphlet called *The one who listens to stuttering*, containing basic information about how to listen to a disfluent person with the aim of helping communication.
- A new program on TV, in the charge of Dr Socolinsky, about children who stutter and how to prevent their disorder.
- Open consultation in Rosario city, in the province of Santa Fe. One hundred people who stutter and speech pathologists met at this meeting, supported by the AAT.
- OPECADY Congress: Equality of opportunities for people with different capacities. The AAT gave a presentation, called "stuttering changes in professional, teaching, family, working and social criteria". The presentation took place before that of the National Culture Secretariat, which included the AAT-like topic of "social reason".
- Conference on stuttering, with the theme of "From Discrimination to Integration", at the Institute "Piedra Libre".
- Advice for organizing support groups from the AAT's commission of people who stutter.
- Presentation in "Radio con todos" about stuttering and the activities of the AAT.
- An AAT display stand at Buenos Aires University during deafness awareness week.

- Course of continued training in stuttering at Rosario University, on six levels, including adult stuttering.
- Presentation at the Argentinian Catholic University on "Clinic Psychology: Stuttering at School", on overcoming educational problems and on the need for teachers' formation and psychopedagogical training.
- Postgrade about adults who stutter, at Buenos Aires University. Speech pathologists gain training in treating disfluent speech and also take part in AAT corporal workshops.
- Talk in Monte Grande, including sale of publications.
- The Seventh National Universities Journeys of speech pathologies, entitled "Stuttering towards 2000". AAT presentation on pathological speech, psychological focus and points of view of people who stutter. This information was for speech pathologists and students.
- AAT presentation at Buenos Aires University, aimed at preventing disfluencies.
- A group of specialists in stuttering were awarded a prize for their work on stimulating fluidity at Hospital Ricardo Gutierrez, a children's hospital.
- Taking part in the university youthful project on: "Creation of new support groups for people who stutter."
- Planning for a project this year on "Stuttering at school", which includes training, information and distribution of material at educational centers.
- Planning for a project this year for pre-teenagers.
- An article in a *La Nacion* newspaper health supplement about preventing stuttering.
- On ISAD 99, a seminar and a feast were held, included advice from pediatricians about the problems of stuttering.

(Beatriz Biain de Touzet)

AUSTRALIA

Australian Speak Easy Association

The Australian Speak Easy Association has just celebrated 20 years of operations and held its ninth biennial convention.

Twenty years of survival as a self-help group for people who stutter is an achievement that we are proud of. It has not been easy work and there are no guarantees that we will be around for another 20 years. That is the challenge for us and I guess for other self-help groups.

The convention in Terrigal, just north of Sydney, was a great success. We had a mixture of international speakers and local experts, with the keynote speaker being Deborah Kully, from Canada. The theme of the convention was: "The Challenges of Communication."

It was interesting to see a more holistic approach to stuttering and living as a person who stutters. Traditionally in Australia our therapy for people who stutter has focused mainly on speaking fluently.

This represents only a “tip of the iceberg” model in stuttering. At this convention there was more focus on self-acceptance as a person who stutters, and concepts like disclosure and voluntary stuttering were discussed more freely. Many of us find it hard to talk about our stutter with colleagues and friends.

Motivational speakers spoke about “slaying dragons” and “feel the fear and do it anyway”. This once again tested our barriers and challenged us to try things that we may or would not normally do.

This was truly a wonderful convention and has charged our batteries for the next two years. It may also represent a change or turning point in how people who stutter in Australia perceive themselves.

(Peter Dhu)

AUSTRIA

Österreich-Selbsthilfe-Initiative Stottern (ÖSIS)

Last year was an important year for Österreich-Selbsthilfe-Initiative Stottern (ÖSIS), the Austrian self-help organisation of people who stutter.

First of all, the ELSA meeting took place in Vienna, organised with the help and support of ELSA. It was a great experience to come together with people from many different European countries (and also Judy Kuster from the United States and Benny Ravid from Israel) and discuss common problems of people who stutter.

The other highlight of last year was the first summer camp for children and young people who stutter. Initiated by German speech therapist Frank Herziger, this three week event was organised by ÖSIS chairman Herwig Pöhl. It was a truly international event, as participants came not only from Austria but also from neighbouring countries. Herwig did a great job by raising funds for the project, finding the right place and putting together a motivated team to look after the children. Therapy was led by Frank Herziger, who has great experience in working with adults and children who stutter. Beside the intensive therapy sessions, the children enjoyed their spare time with organised activities like an adventure camp, hiking in the mountains, trips to the city of Innsbruck, karaoke singing on a little stage and much more. There was a lot of work to do for the team from early morning until late into the evening but they were motivated by seeing the progress most of the children made after realising that they could take control over their speech and make it more fluent.

Following the summer camp, weekend meetings were held for the participants to stay in contact and “keep the spirit alive”. The camp was the first project of ÖSIS on such a large scale. It was a tremendous success, with so much positive feedback from the participants and their parents. On top of that, ÖSIS received an award for the project from the Bishop of Innsbruck, Dr Reinhold Stecher-Siftungspreis. This award is given annually to a person or organisation involved in social projects. It is clear that there will be another summer camp this year and hopefully in years to come.

Thanks to ÖSIS member Mario Gusenbauer, we now have an all-new internet homepage at

www.infowerk.co.at/oesis/

The homepage gives an overview of our activities. Soon it will also contain a summary in English. We hope it will also attract the attention of Austrian people who stutter but do not know of ÖSIS yet.

(Markus Preinfalk)

BELGIUM

BEST (BELangengroep STotteraars)

Although the attention of BEST has been focused on planning for next year’s Sixth World Congress, the board organised a self-help weekend on February 25-27. We met old friends and made new ones. We were very pleased to welcome stutterers from The Netherlands. Themes of the workshops were: applying the technique in real-life situations, role playing, public speaking and speeches, Hausdorfer therapy, discussion group, and speaking with the delayed auditory feedback device.

A filmmaker and stutterer presented his film *To Speak* during this weekend. It is about his fears as a stutterer. This film has been shown at 45 international film festivals and has won 11 prizes over nine months. After making a deal with the filmmaker, BEST is selling this film in Belgium for the benefit of the World Congress.

First announcements of the Sixth World Congress for People Who Stutter are available from the contact persons of the International Stuttering Association or from the e-mail address

mart.devloed@belgacom.net

(Martine De Vloed)

CANADA

Canadian Association for People who Stutter (CAPS)

CAPS has a new co-ordinator — David Block, of Montreal. David, a computer systems engineer, was a co-chair of the successful ABC/CAPS 99 conference in Montreal, organized by CAPS in collaboration with l’association des bègues du Canada (ABC). He is a co-chair for CAPS 2001, the next CAPS national conference in Calgary, Alberta, on August 23-26, 2001. He is also editor of the CAPS newsletter and director of the award-winning CAPS website at

<http://www.caps.webcon.net>

The new CAPS board of directors has a mandate to fulfil the association’s strategic plan, which includes a focus on staging national self-help conferences, publishing regular newsletters, serving as an advocacy group and reaching out into the community. We’re also planning a major ISAD event for October 22 this year in Toronto with the California-based National Stuttering Association (NSA).

The Calgary Self-help Group recently sent out a call for proposals for the CAPS 2001 conference, to take place at the exquisite Westin Hotel, in downtown Calgary, on the 10th anniversary of the founding of CAPS. Our national association was founded at a conference of

Canadian self-help groups — the first such national meeting in Canada — in Banff, Alberta, in the Canadian Rocky Mountains in August 1991. As with previous CAPS conferences, which have included delegates from many continents, we are publicizing the conference worldwide. For details, refer to the Calgary 2001 website <http://www.hotyak.com/caps/>

CAPS has also assisted with the launching of *Teasing and Bullying: Unacceptable Behavior*, a classroom program addressing teasing and bullying, developed by the Institute for Stuttering Treatment and Research, in Edmonton, Alberta.

Research indicates that many schoolchildren who stutter are often teased and bullied about their stuttering. Schools provide an ideal setting in which to address this behavior. The Teasing and Bullying program offers a comprehensive, research-based, field-tested classroom program for addressing teasing and bullying in elementary schools. For details, contact Marilyn Langevin of Edmonton at

Marilyn.Langevin@ualberta.ca

CAPS is also involved with an ongoing worldwide research initiative, the International Project on Attitudes Toward Stuttering (IPATS), which seeks to determine how stuttering is viewed in different countries and aims to provide a survey instrument to measure the effects of worldwide public education efforts. For details, contact Kenneth O. St. Louis, of Morgantown, West Virginia, USA, at: atkstlouis@wvu.edu

(Jaan Pill)

CANADA

Speak Easy Inc.

Speak Easy Inc. of Canada has experienced a year of unprecedented growth. Our monthly magazine, *Speaking Out*, received a complete makeover, adding color, 40 per cent more pages, greater depth of articles and more information. The new design should meet our needs for several years.

In addition to these improvements, *Speaking Out* is approaching a marvelous milestone. In September this year, we will celebrate the publication of the 200th consecutive issue of *Speaking Out* — a remarkable accomplishment. Credit goes to our members, supporters, board and staff.

Speak Easy's growth has continued in our electronic services. We added a chat list for the use of our members and an announcement list for everyone else. Currently there are over 1500 subscribers receiving our electronic digests and other information every month. To subscribe to this free service from anywhere in the world, simply send an e-mail to

speakeasycanada-subscribe@listbot.com

Our electronic growth continues, with added focus on our website. We have been adding pages at a furious rate and expect to have at least 200 pages by the end of the year. It is at

speakeasycanada.com

Public service announcements (PSAs) are the foundation of any service organization. Speak Easy has been fortunate enough to earn

the respect of the media across Canada. As a result, monthly magazines and daily newspapers from coast to coast regularly publish our informative Letters to the Editor. AM and FM radio stations frequently broadcast our "Do You Stutter . . . Or Know Someone Who Stutters?" messages. Television stations including local, regional, national and community channels broadcast both our video and printed PSAs. Of course, this media exposure generates a lot of interest and we are continually sending our comprehensive kits to those wishing information.

Over the last few years we have held annual Canadian Stuttering Conferences, which have included guest speakers, workshops, presentations, parties and fun for all.

Speak Easy continues to improve many of our existing services and adds new ones. Our professional approach and dedication to service have earned us the respect and financial support of many corporations, granting foundations and government agencies. We continue to meet the needs of our members and to provide valuable information to the public. Our approaching milestone is solid evidence of Speak Easy's commitment and dedication to helping Canadians who stutter.

(Mike Hughes)

DENMARK

Association for Stutterers in Denmark

Denmark will host the next World Congress on Fluency Disorders. It will take place in Nyborg on August 7-11, this year. The congress is for all interested in stuttering — consumers, clinicians, researchers, etc. The Association for Stutterers in Denmark is involved in planning the congress, and also plans to present a mini-seminar with the title "Is stuttering a handicap?" The association will also have an information table at the congress.

In connection with the holding of the congress, the association, together with the Stuttering Information Center of Denmark, plan to raise awareness of stuttering among Danes, with help from a professional media consultant. We will work out how we can approach the press and get the most publicity for a minimal budget. The awareness work will continue for the next three to five years.

Important among the association's activities are its summer meetings/camps/get-togethers. Last year there were two summer get-togethers for small children who stutter and their parents, one summer get-together for school-age children together with one parent, and one summer get-together for adolescents who stutter (with only a few adults as "practical" helpers). All the meetings/camps/get-togethers were very successful. The plan is that these get-togethers will take place every year.

The association is supporting an ongoing research project. The purpose of the project is to study early childhood stuttering by direct interaction with children who stutter and their close environment. That will involve all children born during a certain period in the county of Bornholm.

(Per F. Knudsen)

FINLAND

Suomen Änkyttäjien Yhdistys (SÄY)

The highlight of activities in the last year was the 30th anniversary of the Association of the Finnish Stutterers (SÄY) on October 24 last year.

The speech for the occasion was given by Pertti Paasio, former leader of the Social Democratic Party and Foreign Minister of Finland. Based on his own experiences, he pointed out that stuttering is a serious handicap for school-age children, in the form of punishments from other pupils, and later hinders many during their studies and in their working lives. Therefore, a therapy starting during childhood is very essential. For this purpose, university-based education of speech therapists should be increased and made more versatile, particularly regarding stuttering therapy.

At the end of his speech, Mr Paasio referred to his own experiences in public life. He had learnt to give shorter speeches and to set aside some minutes of rest before each speech, especially when feeling tired after long meetings. Thus the meaning and subject of speech have gained more importance for him than the form of the speech.

During the 30th anniversary ceremonies, the founder member of the association, Seppo Heikkinen, and the former chairmen were honoured by a standard and flowers, followed by Professor Aatto Sonninen accepting the call for honorary membership of the association. Greetings and congratulations were presented by representatives of the National Life Assurance Association of Finland, the Association of Speech Therapists in Finland and by the stuttering associations of Sweden, Denmark and Norway.

The 30th anniversary festivities were shown that evening in the main news of the Finnish TV-1.

In the editorial of the association's periodical, *Painokas*, it was pointed out that several projects this year and next year will support self-help groups' activities. These are the publication in the Finnish language of the book *Self therapy for the stutterer*, by Malcom Fraser, the printing of a leaflet *Michael stutters* and the production of a video *Stuttering child*.

(Antero Tiilikka)

GERMANY

Bundesvereinigung Stotterer-Selbsthilfe

This year *Stuttering and School* is again a big topic for the Bundesvereinigung. In May we launched our first information tour. In connection with the campaign for the equal treatment of the disabled, as demanded by German Basic Law, a bright red double-decker bus travelled the north of Germany. In five towns, the bus stopped at schools and central locations, where leaflets and balloons were distributed. Members of the bus team talked to numerous teachers, pupils and passers-by about the problems that stuttering children may have at school. The team is supported by members of local self-help groups. Thanks to high-profile press publicity, the tour enjoyed broad media coverage, and a daily progress report

was posted on the Bundesvereinigung's home page. All in all, a highly successful first venture into the field of public relations.

A new book for stuttering children has been published by Demosthenes Verlag, the Bundesvereinigung's publishing house. Called *Sometimes I Just Stutter* (an English translation has recently been issued by the Stuttering Foundation of America), its author Eelco de Geus, a Dutch speech therapist, sensitively explains what stuttering is and what feelings and reactions it can engender — in the child and in those around him or her. Its central message is that stuttering is just one of many traits. The book helps parents and children to talk about stuttering and overcome the taboo still associated with stuttering in many families.

(Konrad Schäfers)

IRELAND

Irish Stammering Association

The Irish Stammering Association has now been running for four years. We are now attempting to expand and make the association more professional by hiring a director to run operations, with the committee.

We have organised a number of self-help groups throughout the country and run a residential intensive course for one week each year with follow-up courses after each course. These courses have been very successful by allowing people to understand stammering and to be able to control their stammer. The course is open to all Irish Stammering Association members and interviews are held to choose eight to ten people for the course. Six speech and language therapists attend the course, two of whom are experienced and the other four learn more about stammering therapy and hopefully organise further courses in their own area of the country. The Irish Stammering Association funds 50 per cent of the costs and the therapists do not profit from running the course. The week is very intensive and allows people to become very close to each other, creating an atmosphere where deep feelings can be discussed in a safe environment.

We hope these courses can be continued on a national basis as up to 50 per cent of adults are not seen for speech therapy if they are over 18 years of age.

(Patrick Kelly)

LITHUANIA

Mikëiojimo Problemø Klubas

Lithuania is a Baltic state situated between Poland and Latvia. Lithuanian history goes back 1000 years. The country is the size of Ireland and twice the size of Belgium. The number of inhabitants is 3.7 million, with 600,000 living in the capital, Vilnius. The Stuttering Problem Club of Lithuania was founded in 1992 and has about 60 members. A quarter of our members are speech therapists, including the heads of Lithuania's two logopedist associations.

We are a social organisation, without government funding and without our own rooms. But we still keep on working.

Our activities are made up of four programs — information, stuttering correction, communication and self-help. These programmes don't always work as we wish they would but we try our best.

Most of our work today is information — enlightening people about stuttering in a society where not much is known about the subject. Strategically we concentrate on help for children.

We also translate pamphlets and brochures from the Stuttering Foundation of America, the British Stammering Association, the German Stuttering Association and the Austrian Self-Help Initiative for Stutterers which are aimed at parents of children who stutter, at youths, at teachers and at pediatricians. We translate free of charge. But translations of these publications are complicated and can take several years.

Funding is our main problem.

Another one is the passivity of people who stutter. We only have one self-help group — in Vilnius. We need to become organised countrywide.

Today in Lithuania it quite often seems to me that we have more logopedists than people who stutter.

I want to thank many associations for their help. We regularly get *Den Kieselstein* from Germany, *Dialog* from Austria, *Speaking Out* from the United Kingdom, the *SFA Newsletter* from the United States and many other good publications.

We are members of ISA and ELSA, even though unfortunately we are still not able to pay for our membership.

(Dr Vidunas Ramsa)

THE NETHERLANDS

Nederlandse Stottervereniging Demosthenes

In the past few months, our main concern was to organise a Stuttering Awareness Day together with our annual general meeting on March 25. Our aim was to give members and non-members an opportunity to share experiences about therapies and stuttering in general. We asked therapists from all over the country to join us and give information. This day proved to be a success.

In conjunction with the Dutch Federation, we are preparing a 100-question booklet about stuttering, which we plan to have published in the first half of this year.

The preparations for this year's stuttering awareness week, planned for October 16-22, have started already. We will integrate ISAD into this week.

Our website, part of the website of the federation, has more and more visitors. About 50 more people joined the mailing list compared with last year. The mailing list proved to be useful for short-term messages and other announcements about stuttering. The website is at

www.stotteren.nl

(Alien Timans)

NEW ZEALAND

New Zealand Speak Easy Association

New Zealand, nearly 2000km from the nearest country, is now less remote for those with internet access. The New Zealand Speak Easy Association now has a website containing back issues of its quarterly magazine, *Air Flow*, going back nearly four years. The website, designed by Ren Rui, a Speak Easy member and computer programmer from Rotorua, contains about 80,000 words. It can be found at

<http://homepages.ihug.co.nz/~rren/AirFlow/Airflow.htm>

The New Zealand Speak Easy meetings manual has been published. This 44-page handbook was compiled after members were surveyed to find out what they wanted at meetings. The manual gives plenty of ideas to keep people talking at fluency maintenance meetings. It should strengthen metropolitan Speak Easy groups and allow the organization to expand into more provincial areas.

Lester Loomes, of Christchurch, was elected national president at the association's annual general meeting in Mosgiel on May 13. He is compiling a set of annual goals for each branch to aim for. This should ensure that every branch reaches or exceeds a certain standard of activity in areas such as booster courses, membership skills development, publicity campaigns and social events.

(Warren Brown)

SOUTH AFRICA

Speakeasy South Africa

Speakeasy South Africa has continued to flourish since holding the Fifth International Stuttering Congress in Johannesburg in 1998. Immediately after the congress we had a big surge in enthusiasm and membership. Obviously we could not continue on this high but we are still going strong.

We have self-help groups meeting monthly in Johannesburg, Durban, Cape Town and Potchefstroom. Although they all fall under the broad umbrella of Speakeasy, these are autonomous groups each following their own programme and agenda.

In the Johannesburg group, which I belong to, we have monthly meetings which are attended by people who stutter, their family and friends, speech therapists and students. Attendance usually ranges between 12 and 18 people a month. Each month a different member volunteers to prepare and run the meeting so a variety of different approaches and issues are offered. Motivational speakers have also addressed the group.

The group was started by and for adult people who stutter (PWS) but lately we have found several school-age PWS and their parents have been attending meetings. This has encouraged the young PWS. Their parents' contact with adults who have survived what their children are experiencing serves to educate and motivate the parents in how best to interact with their children. We have also had parents of young preschoolers attending the group.

Therapists and PWS are equal members of Speakeasy and we find this to be a pleasant and rewarding relationship.

We have published an annual newsletter for our members for several years but in the last year increased this to four issues a year. We try to present a mix of local contributions, overseas news and information from the internet in each newsletter.

Simon Woolf, who has served as chairman of Speakeasy since its inception, has indicated his desire to pass on the reins of the association to somebody else at our next general meeting, although he will remain a member. We know Simon will continue to share his knowledge and experience with the group, and I would like to express our appreciation of all he has done for Speakeasy as one of our founder members.

Since the congress our congress organisers have attended to all our secretarial and administrative matters and this has been a great boon. With their participation we have been able to increase our services in disseminating information on stuttering, bringing stuttering into the public eye and being proactive in supporting our members. Speakeasy Johannesburg intervened on two occasions recently on behalf of PWS who were facing discrimination in their workplaces.

(Joan Girson)

SWEDEN

Swedish Stuttering Association (SSR)

The millennium gave us a great start and a lot of work to do.

Last year we received funding for a two-year information project in which we will produce new information material to spread over Sweden. It also includes surveys, seminars, ISAD and political work. Want to help? Please send your information material to Anita S. Blom, Vättilösa, Källåker, 53391 Götene, Sweden, as we can use new ideas. Thanks in anticipation.

This year the SSR will host the Nordic seminar in Nässjö on September 15-17. We are happy to welcome all members from the Nordic associations as well as others. The theme will be "Hidden Resources" and will include workshops, lectures, a bus trip, outdoor activities and lots of fun. The Scandinavian language will be used. For seminar details, take a look at

<http://www.stamning.se>

We will hold two youth camps in Sweden this year. A European Youth Meeting, arranged by ELSA for July 9-15, will be held in beautiful Mullsjö where young people aged 18 to 26 from all over Europe will meet, work and build new friendships and relationships. The other camp is a Swedish Youth Camp for young people aged 13 to 25. It will be held in Härmösand on August 7-13. Want to take part? Contact us immediately.

As we have had so much success with our children camps, we have been arranging two camps for parents with children who stutter in Nynäshamn. The first one was held on May 19-21 for all those families who have taken part in camps since 1997, to talk about what has happened, play, go on a boat trip and have lots of fun. The second one is for parents and children who have never been to a camp before. It will be held on August 25-27. For more information, please look at our homepage

www.stamning.se

(Anita S. Blom)

UNITED STATES OF AMERICA

FRIENDS: The Association of Young People Who Stutter

We have been concentrating this (northern) spring on exhibiting at conventions sponsored by the state speech, language and hearing associations. We did well, hitting eight of them, which is six more than we were present at last year.

At one convention, the table was staffed totally by parents and young people in our association, rather than by professionals or adults who stutter. Both families involved took the time from work to be there for two days. This is a painting of our future, we hope.

The vision we have for FRIENDS is an organization generated and directed by families; old dogs like me should take a back seat. There is enough concern and empathy in the parents Lee Caggiano and I have come to know to run five organizations like ours; all it needs is to be channeled, and then we can step aside and watch the healing energy flow from family to family. Parents are so eager to reach out and help other families once they have seen the FRIENDS network create such positive changes in their own.

On August 3-5, we will have our Third Annual Convention, outside Washington DC. An author of a series of books featuring a young girl who stutters and a nationally syndicated columnist from the Chicago Tribune who stuttered when young will be our main presenters. We expect close to 300 people. All are welcome. If you would like more information, e-mail me at

JTAHLBACH@aol.com

(John Ahlback)

UNITED STATES OF AMERICA

National Stuttering Association-National Stuttering Project

We are busy preparing for our 17th annual convention, this year being held in Chicago, Illinois, on June 21-24. With over 35 workshops dealing with research, coping, managing and positive attitude, we promise all who attend a fantastic time.

This year's convention Youth Program promises to be exciting and fun as it continues to grow each year. Activities include an annual pool party, workshops for kids, teens and parents, and discussions for siblings too.

For over 10 years the NSA's youth day programs have been providing hope and encouragement to our youth and their families. This and much more makes our convention youth program fun for all.

We are excited that Bob Love, of the Chicago Bulls, will be speaking on Friday, June 23. Bob played for the Bulls from 1969 to 1976 and was leading scorer for seven straight years. In spite of all his success, Bob still dreamed of being able to talk without stuttering. With the help of speech therapy, Bob now speaks without the hard struggle of years ago and is the community relations director for the Chicago Bulls. His message is: "Don't give up."

Working directly with the professional community continues to be a goal for us. At this year's convention we are very honored to have two distinguished speakers presenting two very exciting

programs for our continuing education seminars. These programs specialize in the area of knowledge and practical information for the clinician. Dr Barry Guitar will discuss “Group and Individual Stuttering For Children of All Ages” and Dr E. Charles Healey will present “Treating People Who Stutter: What Decisions Have You Made Today?”

Our Youth Day workshops for children who stutter and their parents continue to educate families, speech clinicians and preschool teachers on early diagnosis and effective intervention strategies for children who stutter.

We also continue to sponsor our regional adult workshops, and our national chapters continue to grow and flourish as more NSA members take on roles as leaders.

This (northern) spring we are going to print the following brochures: *Why Does the NSA Participation Promote Positive Change? Or We Know the NSA is Good For Us — But Why?* by Dr John Wade; *The Impact of Childhood Disability: The Parent's Struggle*, by Dr Ken Moses; *Coping with Anxiety*, by Dr John Wade; *Therapy Programs, Services, Devices and Medications*, by the NSA's Professional Relations Committee; and *Stuttering Therapy Is A Family Affair: Integrating Parents and Teachers In The Process*.

On October 24 a group of dedicated individuals met to discuss how they could help the organization move to the next level. Our board chairman Lee Reeves facilitated the meeting. Other board members in attendance were Randy Hoover and Nina Reardon, as well as executive director Annie Bradberry. The group established a restricted fund — set up with specific restrictions and guidelines — called the Fund for Tomorrow. This fund was created to hire another full-time staff member — director of membership services. NSA member Joel Thinnes was hired and began work on February 1.

Clinicians have reported that *Our Voice* and *Stutter Buddies* continue to help in involving parents and opening up channels of communication.

We are also very excited with our new *Stutter Buddies* poster. This poster highlights each of our *Stutter Buddies* characters, dealing with stuttering and issues surrounding stuttering in their own special way. This full color poster is designed to accompany the *Stutter Buddies* publication for children aged 6 to 12.

Our new *Classroom Poster* is aimed to generate acceptance and tolerance in the classroom. This poster shows the importance of celebrating the uniqueness in all of us and is to be used as a springboard for discussions regarding the acceptance of differences. Speech-language pathologists and educators are finding that this poster is playing an integral part in the expansion of positive self-esteem for all children with communicative disorders.

Finally, after years of development, our *Pediatrician Rolodex Card* is available upon request at no charge. Containing basic facts of childhood stuttering and the importance of early assessment and intervention, we designed the card to be given to parents, who in turn will deliver it to their medical professionals. This card is vital in minimizing the negative consequences of early stuttering on young children and their families.

Our newest book *Our Voices* is filled with inspirational insights from young people who stutter, including special sections for parents, speech-language professionals, reflections from adults who stutter and helpful hints for teachers. This book is being used in many universities across the country as a textbook for fluency courses. Therapists are using the book as part of therapy. Parents are finding new avenues for discussing stuttering with their child by reading stories together.

The NSA continues to grow and change every day. This is only possible with the help and support of our members. Their expertise and passion helps us to make a difference for the next generation of stutters. As an organization we look into this new millennium with hope and courage.

(Annie Bradberry)

UNITED STATES OF AMERICA

Speak Easy International Foundation

Speak Easy Symposium XIX was held on May 5-7 at the Totowa Holiday Inn, New Jersey. Speakers at the symposium included:

- Julia Boberg, administrative assistant at the Institute For Stuttering and Research (ISTAR) in Edmonton, Alberta, Canada, on “Celebrating Change in a New Century: A View From the Other Side of the Block”.
- John Stossel, an award-winning ABC news correspondent, on “My Traumas With Speaking”.
- Alan Davis, psychotherapist and member of Speak of Paramus, New Jersey Chapter, on “Getting the Most out of Self-Help”.

There were 14 workshops, including: Self-Help Formulas For Success, Accentuating the Attitudinal Approach for Stuttering, A Do-It-Yourself Tuneup, How to Feel Certain in an Uncertain World, Steps to Restrain Relapse, Combining Self-Talk With Spontaneity, The Brain at Work During Communication, Theories Behind Various Types of Stuttering Therapies, and The Magic of Movement.

The 2½-day meeting began with a Friday evening reception. The symposium banquet and entertainment on the Saturday evening was another highlight of a rewarding weekend.

Among those who registered for Symposium XIX were people from Canada, Israel and Australia — truly an international meeting.

Symposium XX will be held in April or May next year.

The 11th annual Speak Easy Retreat will take place in September or October this year. This retreat is being planned by the Greater Hartford and New Haven, Connecticut, chapters of Speak Easy International.

It will be held at the Mercy Center in Madison, Connecticut, on the shores of Long Island Sound. About 25 to 30 people who stutter will meet for a weekend of peace, relaxation, re-dedication of speech goals and camaraderie. It will be a refreshing time, inspiring us to face the coming winter months with hope.

(Bob Gathman)

Reports from the ISA working groups

Working Group No. 3

OUTREACH

The Outreach Working Group works with the ISA board of directors to establish contacts in countries where ISA has few contacts.

A recent initiative (which Stefan Hoffmann of Germany highlights on pages 6 to 8 in this issue of *One Voice*) involves the Special Friends category of ISA membership. We also continue to share information on the starting of national associations, as we have recently shared with Daniela Veronica Zackiewicz, of Brazil, who can be reached at

danielaveronica@zipmail.com.br

We also seek to foster contacts among francophone individuals and associations around the world. We would appreciate hearing from any French-speaking individuals (whom we invite to write to us in French) who want to help us in this task.

Another ongoing initiative focuses on outreach to China. Stefan Hoffmann, currently working in China, notes that the first meeting of a Chinese self-help group is planned for the (northern) spring of this year. Work is proceeding on translating Stuttering Foundation of America pamphlets. Planning has also begun for an ISAD-type event in China in October this year.

We encourage member associations of ISA to post electronic versions (e.g. PDF files) of recent issues of *One Voice* on their respective websites, as CAPS has done with issue No. 11, to assist in ISA's worldwide outreach efforts.

For assistance in posting such files to the internet or for assistance in setting up a website, please contact David Block, of CAPS, at

dblock@videotron.ca

The more widely we post ISA-related information on the internet, the more likely it is that new people will discover the ISA. Creating an ever-wider international network of self-help groups and associations involves creativity, serendipity and chance encounters. Each of us can help in this process.

If you wish to help ISA in its ongoing outreach efforts, please contact Stefan Hoffmann at

sthoff160@gmx.net

or Jaan Pill at

jpill@interlog.com

(Jaan Pill)

Working Group No. 5

EMPLOYMENT AND STUTTERING

In my report in the last issue of *One Voice*, I expanded our scope and asked for input regarding:

- (1) Medical insurance for speech therapy.
- (2) Tax benefits.

In that report, I presented some information on both points regarding Canada, thanks to Tony Intas of CAPS (Canada).

Konrad Schäfers (of the German Stuttering Association) reports

the following about health insurance and disability benefits in Germany:

(1) Health Insurance: The cost of speech therapy is covered by health insurance if the therapist is registered with and acknowledged by the insurance companies. If not, a PWS may apply for coverage. Sometimes treatment programs outside Germany are covered if it can be shown that comparable therapy programs in Germany have already been tried. Speech therapy programs must be prescribed by a general practitioner, an otolaryngologist or a pediatrician.

(2) Disability benefits: Legislation in Germany provides a rating system to classify the severity of handicaps. Those classified as disabled qualify for "compensations for disadvantages", including tax reductions, five additional days off work, better protection against dismissal and preferential employment (mainly with public employers) if job qualifications are equal to those of non-disabled applicants. However, most "compensations" require a disability degree of 50 per cent. While stuttering is recognized as a disability, Konrad reports that it is difficult to get the "magic" 50 per cent. Usually the best you can get is 30 per cent. This may entitle you to job-related compensations but not tax reductions and additional holidays.

Litigation in the USA on employment and stuttering

Bill Parry, chair of the Advocacy Committee of the National Stuttering Association (NSA), has been following (and sometimes assisting with) three stuttering discrimination cases in which litigation has been started or contemplated.

Here are the details of one of these: A warehouse worker, who was frequently ridiculed because he stuttered, was fired for allegedly "not getting along with co-workers". Bill and his committee assisted the worker and his attorney in drafting the complaint by providing information about the nature of stuttering and the problems of negative stereotyping and discrimination and suggesting language designed specifically to comply with the definitions of "disability" under the Americans with Disabilities Act. Just before the start of the trial (in the US District Court for the District of Nebraska), the plaintiff obtained a very favorable settlement from the employer. So the plaintiff was successful. But since the case was settled before trial, no legal precedent was established.

Bill is following the other two cases. More next issue (perhaps).

Do you have information to share? My e-mail address is

Melhoffman@aol.com

(Mel Hoffman)

Working Group No. 7

INTERNATIONAL STUTTERING AWARENESS DAY (ISAD)

Information on this year's International Stuttering Awareness Day is on page 5 of this issue of *One Voice*. An ISAD brochure is also enclosed.

The Voice of ELSA now in One Voice

This is the first joint issue of *One Voice* for the European League of Stuttering Associations (ELSA) and the International Stuttering Association (ISA).

The Voice of ELSA will comprise two pages towards the back of *One Voice*. The chair of ELSA will have a column

on page 2 of *One Voice*.

Thomas Krall, ISA chair, writes: "Both boards hope readers of *One Voice* and *The Voice of ELSA* will benefit from this decision."

Edwin J. Farr, ELSA chair, writes: "I hope you all enjoy the new look of this magazine."

ELSA report:

French group tries to prevent stuttering

By Oliver Humez,
APB correspondent for ELSA

The Association Parole Bégaiement (APB) was created in 1992 in Paris, France, by speech-language pathologists, persons who stutter and other persons concerned about stuttering.

They had noticed that very little was being done in France to help people who suffer from stuttering. Some of them had been to the United States of America in the 1980s and were struck by the dynamism of associations and therapy centers there in dealing with stuttering.

Seven years after its founding, APB has 450 members — half of them people who stutter. The mixing of these categories of people, with their different approaches, has proved to be very fertile and profitable for our association during the past few years.

APB has concentrated on the prevention of stuttering. In 1994, a 61-page booklet, written by Henny Bijleveld, Francois Le Hunche and Anne-Marie Simon, was sent to 12,000 speech-language pathologists all over France. The following year, a document on the prevention of stuttering was sent to 10,000 pediatricians, school psychologists and child care center personnel. In 1997, a four-page article on early intervention with children beginning to stutter was mailed to 25,000 kindergarten teachers. All in all, we believe that since 1992 at least 120,000 people have been made aware of the possibilities of preventing stuttering if parents receive appropriate

help early enough.

We organized two national conferences, bringing together 250 people on each occasion for two days. The theme at the 1995 conference was: Speak about stuttering and dare to say. The second conference last year dealt with the stuttering of adults, with papers on stutterers' stories, therapies and social integration.

As a link between our members, we publish three times a year a 10 to 16 page paper, reflecting events in the life of the association and various information on stuttering.

Another important way of spreading information on stuttering is through our website

<http://home.worldnet.fr/humezol/parole-begaiement> which now receives more than 500 connections a month.

Finally our actions are reinforced and relayed all over France by 22 regional branches and associated correspondents.

After seven year's work and action, from volunteers only, we think we can be legitimately proud of the job we have done.

But many other things still need to be done to help people who stutter get over their suffering and isolation. For us, this is a vital challenge for the third millennium. To achieve this goal, we are pursuing European grants and co-operating with other national associations.

ELSA report:

Measuring the effectiveness of therapies

By Konrad Schafers and Ulrich Natke

Bundesvereinigung initiates an evaluation program

The majority of stutterers' associations make it their business to promote stuttering therapy and research. The German association, Bundesvereinigung Stotterer-Selbsthilfe, is also constitutionally committed to such activities and as early as 1984 founded the Demosthenes Institute. This institute plans and initiates, for example, the publication of specialist books under the Demosthenes imprint

and organizes seminars for the further training of experts in the field.

In 1998 the Therapy and Research working group was set up. Its mission is to develop concrete measures for promoting therapy and research. It is made up of researchers and therapists from all the major treatment-providing groups. Its first project is now taking shape: PEVOS — Program for the EVALuation Of Stuttering therapies.

The aim of PEVOS is to use scientific methods to gather data on

the type and effectiveness of stuttering therapies. This means: What type of treatment, what combination of different therapy elements are used, and what effect do they have?

DATA GATHERED BY QUESTIONNAIRES AND “AUDITIONS”

The methods of testing the effectiveness of stuttering therapies are fraught with difficulties, and this is reflected in the extensiveness of the study.

After therapists enrol their stuttering clients in the program, the clients are sent questionnaires to elicit their attitudes and assessment of their stuttering. In addition, telephone conversations are used to determine clients' fluency. This data is collected before treatment, immediately after treatment and two years after therapy, primarily to determine long-term effects. The therapists also supply precise details of the nature of their therapy programs. Evaluation is performed in the Demosthenes Institute. The data is of course protected, being fed anonymously into the evaluation process. Therapists are only given their own clients' data.

MORE EFFECTIVE THERAPIES, BETTER ADVICE

The Bundesvereinigung hopes that the results of the project

will enable stutterers to be given better advice on treatment options. Publication of the overall results should also increase knowledge on the treatment of stuttering. Also, participating therapists will get feedback about the effectiveness of their therapies, further raising the quality of their work.

Another important aspect is that health insurance schemes and other cost centers in health care will require more and more quality control in future. So it will be important for therapists to demonstrate that they are working in accordance with verifiable standards.

Participation in the PEVOS project is very much in the therapists' interest.

As is usual with projects, the funding of PEVOS is a problem. Although the Bundesvereinigung is applying for grants from public bodies, it has decided to use its own resources to fund the trial phase, currently under way with its own therapists. Potential sponsors are more likely to come forward if initial data is already available.

The PEVOS project will be presented at the Third World Congress on Fluency Disorders in Nyborg, Denmark, in August this year. Further information will also appear in One Voice/The Voice of ELSA.

ELSA report:

CPLOL represents therapists, logopedists

We've all heard of the International Fluency Association (IFA). And most stutterers' associations are familiar with the International Association of Logopedics and Phoniatrics (IALP).

It is less well known that there is another international therapists' association at European level known as CPLOL, or Standing Liaison Committee of Speech and Language Therapists and Logopedists.

This association, whose name trips so easily off the tongue, was founded in 1988 and originally represented logopedists and speech therapists in European Community countries. Their number is currently estimated at 50,000 and now includes not only the professional associations in the European Union: CPLOL is now composed of 19 member countries and 21 professional and scientific organizations of speech and language therapists-logopedists.

Aims and objectives

CPLOL was created with the aim of harmonizing the profession at European level by putting in place structures that would enable members of the profession to share the experiences of each European Union country, to compare professional activities, and to set up exchanges and scientific research. The objective is therefore to harmonize all the components of the profession in Europe.

These aims and objectives find expression in concrete projects under the aegis of various committees:

Training and professional profile: After a statement of minimum, necessary and required standards for speech and language therapists' proficiency, the committee started on the difficult task of classifying speech and language disorders which will make it possible to have a European harmonized classification.

Prevention: A study on speech disability prevention in Europe will be published soon. A European poster project has just been finalized, for publicizing and detecting communication disorders among pre-school children.

Scientific exchange: The third scientific CPLOL congress is being held in Paris in June this year.

International relations: CPLOL endeavors to promote contacts with other national therapists' associations in Europe — not only with European Union countries.

ELSA and CPLOL

Like ELSA, CPLOL is represented in the European Disability Forum in Brussels. Unfortunately, direct contacts have until now been somewhat casual. One reason for this may be that CPLOL concentrates very heavily on its role as a professional association. Also, stuttering is only one element in a wide spectrum of speech and language disorders covered by CPLOL.

Nevertheless, the organization is of interest to ELSA and national stuttering associations in such matters as establishing contacts and exchanging information with national therapists' organizations. And topics such as mutual recognition of university degrees and the registration requirements for language therapists in European countries cannot be matters of indifference to stutterers' associations. ELSA must therefore endeavor to establish regular contact and exchange.

Information about CPLOL and links to numerous national therapists' organizations can be found on the CPLOL website cplol@wanadoo.fr

Book review:

Australian research into fluency highlighted

Treating Stuttering in Older Children, Adolescents and Adults

By Dr Ashley Craig

(Feedback Publications, Aust\$55)

Reviewed by Warren Brown

This Australian book might be of interest to those looking for techniques to improve their fluency.

Its subtitle is “A Guide for Clinicians, Parents and Those Who Stutter”. Dr Ashley Craig, an associate professor in the Department of Health Sciences at the University of Technology, Sydney, and a number of his colleagues have compiled a number of manuals over the years for speech therapy courses and boosters. They are printed here.

Chapter 5 is a manual for a one-week smooth speech intensive course. Chapter 6 is a manual for a four-day course, held one day a week over five weeks and containing a large component of “homework”. Chapter 7 is a manual for a one-week intensive electromyography (EMG) course, a ground-breaking technique which uses computer technology to teach people who stutter how to relax facial and throat muscles.

For those who relapse after treatment, Chapter 10 is a manual for a five-day course, spread over three weeks, using both smooth speech and EMG feedback.

Manuals for two booster courses are also included. Chapter 11 is a four-day relaxation course, which teaches relaxation techniques

along with smooth speech and EMG feedback. Chapter 12 is a three-day attitude change course, which imparts psychological techniques for improving the success rate of fluency after a quick refresh of smooth speech.

To complement these manuals, Dr Craig fleshed out his book with information from academic research on stuttering.

Chapters 1 and 2 outline what various researchers on stuttering have found. Chapter 3 shows research into the effectiveness of the speech techniques outlined in the book.

Chapter 4 outlines the five characteristics of smooth speech: Continuous airflow throughout the phrase.

- Gentle onsets.
- Organise speech so that it is composed of a phrase-pause-phrase-pause-phrase structure.
- Reduction and control of muscle tension around the lip, throat and chest areas.
- The use of interesting tones in speech.

This chapter provides important background information for the smooth speech manuals in the following two chapters.

Chapter 8 outlines which form of treatment will work best for which type of stuttering. Chapter 9 looks at relapse — how it is defined, how often it occurs and what factors are likely to bring about relapse. It is placed before the three manuals for speech courses which assist in recovering from a relapse.

The book is available from Feedback Publications, 54 Holden Street, Gosford, NSW 2250, Australia.

International project:

Bid to determine attitudes toward stuttering

By Jaan Pill,
Canada

Our planet is home to about 60 million people who stutter — about 1 percent of the world’s population of six billion people.

Are there differences in how stuttering is perceived in countries around the world? Are listeners more at ease with people who stutter in some countries than others? What are the results of efforts to increase awareness about stuttering, in different countries in the world?

Many self-help groups and related organizations around the world seek to educate the public about stuttering.

The International Project on Attitudes Toward Stuttering (IPATS) seeks to determine how stuttering is viewed in different countries and aims to provide a survey instrument to measure the effects of our public education efforts. The project, which involves a large number of countries, languages and cultures, features close collaboration among people who stutter, researchers and speech professionals.

In April last year, members of an IPATS task force met in Morgantown, West Virginia, USA, to organize development of a

public opinion survey to measure attitudes about stuttering. The team aims to develop a survey that can be translated into different languages and that can be used to assess public attitudes toward those who stutter in selected communities, cultures and countries. In developing this survey, the task force seeks to explore and use research designs that generate reliable and valid data across international and intercultural boundaries.

The IPATS task force has been seeking reports of public education efforts by member associations of ISA, IFA, ELSA and other organizations. These reports might relate to:

- Attitudes toward people who stutter, and people with disabilities in general.
- Projects that seek to reduce teasing directed at schoolchildren who stutter.
- Employment equity issues.
- Provision of treatment services.
- Role of self-help groups.

The task force has also been seeking copies of media interviews and videos which educate about stuttering.

One Voice

One Voice incorporating *The Voice of ELSA* is published twice a year by the International Stuttering Association and the European League of Stuttering Associations.

ISA vision: A world that understands stuttering.

ISA mission: To improve the conditions for children, adolescents and adults who stutter and parents of children who stutter in all countries, especially by sharing concepts and experiences in stuttering self-help and therapies.

International Stuttering Association:

Mohrunger Str. 17
40599 Dusseldorf, Germany.
Phone: +49 211 74 1585
Fax: +49 211 740 4428
E-mail: 100605.2720@compuserve.com

European League of Stuttering Associations:

31 Grosvenor Road
Jesmond, Newcastle-on-Tyne, England E2 2RL.
Phone/fax: +44191 281 8003
E-mail: edwin@ejfarr.demon.co.uk

Editor this issue: Warren Brown.

924A Papamoa Beach Road, Papamoa 3003, New Zealand.
Phone/fax: +64 7 542 2126

Acknowledgements: Thomas Krall, Konrad Schaefers, Stefan Hoffmann, Ulrich Natke (Germany), Edwin J. Farr (United Kingdom), Martine De Vloed (Belgium), Andrew Harding, Peter Dhu, Dr Ashley Craig, (Australia), Jaan Pill, Mike Hughes (Canada), Mel Hoffman, Michael Sugarman, John Ahlbach, Annie Bradberry, Bob Gathman (United States of America), Oliver Humez (France), Jiri Mazoch (Czech Republic), Daniela Veronica Zackiewicz (Brazil), Tomas Simko (Slovakia), Daho Benabdellah (Algeria), Beatriz Biain De Touzet (Argentina), Markus Preinfalk (Austria), Per F. Knudsen (Denmark), Antero Tiilikka (Finland), Patrick Kelly (Ireland), Dr Vidunas Ramsa (Lithuania), Alien Timans (The Netherlands), Joan Girson (South Africa), and Anita S. Blom (Sweden).

Disclaimer

One Voice is a forum for views and information about stuttering. The opinions expressed are those of the individual contributor and are not necessarily the opinion of the International Stuttering Association and the European League of Stuttering Associations. The ISA and ELSA accept no responsibility for the accuracy of any opinion or information provided by a contributor and does not endorse or reject any therapeutic strategies, programs or devices mentioned.

Not copyrighted

The material in *One Voice* is not copyrighted. Articles may be reproduced freely without permission. If desired, the entire newsletter may be reproduced without permission. Wide distribution of the newsletter by stuttering associations is encouraged. When quoting an article or a portion of an article, a reference to *One Voice* as the source would be appropriate.
