

THE ELSA ELECTRONIC NEWSNOTES

November 2005

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FINALLY

WELCOME

A lot has happened since the last Newsnotes, for example, the now official International Stuttering Awareness Day (ISAD) and the outreach of ELSA, but we would also like to share other news from all over the world with you. May this newsletter give you new inspiration for the coming year.

ELSA NEWS AND REPORTS

- **ELSA Website**

Please **check your entries** on the ELSA website “member associations” section and let us know about your **latest updates**. We would also like to create an **agenda** where we would like to list activities in your country. This can be annual meetings, seminars, youth meetings etc, if possible with a link and a contact person. Please let us know if the meetings are open for all or members only. Previous newsnotes are still available on the ELSA website www.elsa.info.

- **EDF and the EDF discuss European Funding**

A meeting organised by the European Disability Forum (EDF) brought together European Non Governmental Organisations (ENGO's) in Brussels to discuss the ENGO's relationship with the EU. This is particularly relevant to ELSA as over the years many of ELSA's projects have been part funded by EU programmes. Edwin J. Farr and Konrad Schaefer of ELSA attended this meeting on 8 April 2005. More about this meeting at http://www.stuttering.ws/news_apr05_brussels_ngos.htm

- **ELSA presents at the EDF Annual General Assembly**



The European Disability Forum, the representative organisation of 50 million disabled people in Europe, held its Annual General Assembly in Barcelona on 28-29 May 2005. More than 150 leaders of the European disability movement from 29 countries (including ELSA) participated in this key meeting. More about this meeting at http://www.stuttering.ws/news_may05_edfaga.htm

Picture shows EDF President Yannis Vardakastanis with Gina Waggott of ELSA.

- **ELSA's 5th Youth Meeting a Success**

July 2005 saw ELSA's 5th Youth Meeting take place in Nijmegen, The Netherlands. The feedback has been overwhelmingly positive, and the theme, "Educating and Empowering Young People to Work with the Media" has already been realised with international press coverage. Young people from 15 countries gathered to learn more about the media and discussed and produced a media campaign. But this week is also about meeting, sharing and letting go. For reports please check http://www.stuttering.ws/news_aug05_ym.htm



- **Anita Blom of ELSA speaks in Croatia**

Outreach and contacts with Speech Therapists are two of ELSA's key objectives, and we are happy that Vice Chair Anita Blom was invited to Dubrovnik to speak and give a workshop at the 3rd Congress Of Croatian Speech And Language Pathologists (28th of September to 1st of October 2005). Around 250 SLPs learned more about the life of a person who stutters, the work of ELSA and the need for cooperation between ELSA as well as National Stuttering Associations with SLPs. More about the congress at <http://www.kongres.hld.hr/>

- **Statement on Stuttering And The International Stuttering Awareness Day (ISAD) signed at European Parliament**

An important step towards greater awareness of stuttering at political level was taken in Strasbourg on 25 October 2005. All Members of European Parliament (MEP) had been invited to a reception on the occasion of the International Stuttering Awareness Day. The event was jointly organised by ELSA and the Spanish Stuttering Association (TTM Espana), and supported by the European Disability Forum. Special emphasis had been given to inviting the members of the Disability Inter-group which is an inter-party working group of Members of the European Parliament (MEPs) engaged in disability politics.



More than 30 MEPs accepted the invitation which – according to insiders at the European Parliament – can be regarded as a success. Also, representatives of several National Stuttering Associations attended the reception. Short speeches were given by Adolfo Garcia, President of TTM Espana, Richard Howitt MEP, Chair of the EP Disability Inter-group, and Edwin J. Farr, Chair of ELSA. In the course of the reception MEPs were asked to sign a “Written Statement” on “Stuttering and the International Stuttering Awareness Day” that states important needs and demands of people who stutter and calls upon European Parliament to officially recognise International Stuttering Awareness Day. (For the full text of the declaration see www.elsa.info)

- **Anita Blom of ELSA speaks in Czech Republic**



Anita has also been invited to the prominent speech clinic LOGO in Brno, Czech Republic, to celebrate the ISAD by giving a workshop about stuttering and by being the keynote speaker at a conference in the City Hall of Brno where the audience, consisting of PWS, SLPs, politicians and other people working with or interested in stuttering, could learn more about ELSA, the ISA and the ISAD as well as stuttering. More about the clinic at <http://www.logoped.cz/>

- **ISAD online conference**

ELSA board members have once again participated with different articles at this year’s ISAD online conference. The conference is still available at <http://www.mnsu.edu/comdis/isad8/isadcon8.html>. Previous conferences are still on-line, linked from www.stutteringhomepage.com

- **ELSA AGM**

The ELSA Annual General Meeting took place in Göttingen during the German BV Congress on Sunday 25 September. These annual events give ELSA the opportunity to let the National Stuttering Associations of Europe know what ELSA has been doing, is currently doing and has plans to do relating to stuttering. The meeting also gives the NSAs an opportunity to discuss future initiatives for raising awareness of stuttering. Representatives from 8 NSAs attended the AGM.

- **ISAD 2006**

The international awareness day, ISAD, is a day for everyone to celebrate. We can either play it big, by organizing events, information campaigns and visits, or why not write a paper for, the ISAD on-line conference. (Previous years’ conferences are still available through the links from www.stutteringhomepage.com.) But also small events are just as important. For example to talk to your child’s class or teachers, to wear a stuttering t-shirt, to talk to someone who doesn’t know you stutter. Any effort to spread the word is a way to increase the butterfly effect.

Every year there is a new theme that has inspired us to focus on the same direction. So far themes have been as follows:

1998: The Power of Your Voice

1999: Many Languages, One Voice

2000: Reach Out to Children Who Stutter

2001: YOU ARE NOT ALONE: Transforming Perceptions

2002: Don't Let Stuttering Stop You...from creating the life you want in relationships, academics, professional development and personal fulfilment

2003: International Stuttering Awareness is really everyday...We just celebrate it on October 22

2004: International Year of the Child Who Stutters

2005: Stuttering Community Vision for Global Action

Now that the ISAD is officially recognized by the European Parliament, we would like the National Stuttering Associations to come up with proposals for next year's theme for the ISAD, with the result to be presented at the IFA world congress in July next year. Please send your suggestions to elsa.europe@telia.com before the **31th of May 2006**, and there will be a vote for the most catchy theme.

NEWS AND REPORTS FROM OUR MEMBERS

• Bulgaria

Irina Papancheva writes: "This year Bulgarian Stuttering Association (SIZ) decided to have fewer activities than the previous year but to focus more on the details. In the beginning of April we had a two day national seminar under the motto "To Understand the Nature of Stuttering and To Help People Who Stutter" in Bankia, a small town near Sofia. We got a small funding for its organisation from the German-Bulgarian Industrial-Trade Chamber. The seminar was very successful for our standards. Some 50 people, among which people who stutter, parents of children who stutter and speech therapists participated in it. All of the participants said they were very satisfied with the seminar and SIZ gained new members. After the seminar SIZ started monthly meetings of people who stutter in a restaurant in Sofia. These meetings are still visited only by people who know us, but we hope that in the future unknown people will join us too."

At the end of April the first coloured book for children about stuttering "I Stutter", written by SIZ' chairperson Irina Papancheva under the initiative of the Bulgarian children's website "Me, the Child", was published with the financial help of ELSA and "Me, the Child". Its presentation took place at a children's event in mid-May.



Other activities:

- SIZ made a number of projections of "To Speak" in schools and at its initiatives.
- leaflets with information
- interactive version of the website created, with forum and a short English version
- leaflets on How to React to People Who Stutter
- stuttering event in Burgas with presentation of "To Speak" and the new book
- lots of appearances in media
 - the trendy female magazines EVA with Irina being the Hero of the Month
 - the publishing of the new children's book "I Stutter" was widely covered
 - article for the ELSA Youth Meeting
 - occasional articles and TV reports
 - Irina is also among the 12-th finalists of the Cosmopolitan competition "Smiling, Successful, Amazing", where she speaks about stuttering

- **France**

France meets Africa. Anne-Marie Simon went on a trip to West Africa to visit Burkina, Benin and Togo with the purpose to meet stuttering people and their families and to train in speech therapy different groups of individuals. Here is her report: “The audience was mainly educators and nurses in ORL and pediatrics departments. They meet stuttering people in their professional environment . In Burkina, where Moussa Dao, who has created an association ACB (Action Contre le Bégaiement) already had done a tremendous job in preparing our work there; we were able to have a seminar every morning at the Ministry of Families and Solidarity and during the afternoon we were able to meet stutters or families with their children for individual sessions (more than 50). With a public conference at the French Cultural Center in Ouagadougou we ended our visit with a 150 people attending. The film “To speak” by Erik Lamens was shown and opened very rich exchanges between the speakers and the public.

Then in Benin, in the North West of Cotonou, a week was devoted to a development project I am participating in for 12 years now. But stuttering was present also we promoted our goals with the local colleges for sensitization, and distributed the pamphlet telling the teachers how they can help their stuttering pupils. This has been partly covered by the local media. Then back to Cotonou for another week of training in stuttering therapy was held. This time mainly directed at psychiatrists, pediatricians and teachers. The audience was quite disparate but the sessions went well. At the end of the week the participants decided to help G Gansou - the APB (Association parole Bégaiement) delegate for Benin - to develop and structure the association and to conduct campaigns in schools and colleges.

Then I went to Togo : this time it was a mission H I (Handicap International) and ODM (Orthophonistes Du Monde) gave me : such mission was to give a week course on stuttering to ten students of the ENAM (National School for Medical Auxilliarities -first one in West Africa, sponsored by HI and ODM) It was a very challenging and enriching experience. The course went smoothly with no time wasted and very motivated students. Fortunately, during the previous days, the meeting of all the people affected by stuttering taught me the true meaning of the cultural place of stuttering has in these societies. Through these meetings but also through letters and E mails received after an RFI program (Radio France International) on stuttering in September 2004 I realized :

- first that the suffering of stuttering people is the same as every where else, even if there are many other crucial health problems and economic distress
- second the reactions of parents towards children who stutter is worse than in Western countries. Children who display a disorder or an handicap are frequently rejected, beaten . Many of the young ones we met had left school unable to bear the laughing and mockeries they were subject to. The traditional methods were difficult to be discussed, such as : “ Yes I drank something but I can’t tell you “ I decided to meet a French video producer whose work compares traditional medicine with Western one , The project could be to study the both approaches, traditional and western one for stuttering treatment. A very difficult and exciting project. A professor of psycholinguistic in Cotonou will also work on the project, sending his students to enquire about these methods in local villages. Next October the Conference in Douala Cameroon will be the next step to sensitization and prevention of stuttering in black Africa.”

- **Israel**

Benny Ravid writes: “After a long and exhausting process that lasted about three years, the Hebrew translation of the SFA publication "Do you stutter - A guide for teens" is ready for distribution! It is a happy event for us here in Israel as this is the first publication initiated by AMBI - Israel Stuttering Association. It is also the first publication for young PWS in Hebrew in the last 35 years (or more).”

- **Italy**

Milena Michele from Italy writes about the March for peace and justice from Perugia to Assisi which was held on September 11, 2005; it has been organized by the Association for Peace of Perugia (Italy). The website to visit is: www.tavoladellapace.it. “200.000 individuals from many different countries have been walking together covering the 24 km which separate Assisi from Perugia. The march – whose first edition took place in 1961- is today a point of reference for a lot of different movements, syndical and political organizations, cultural and religious associations. Also some associations working in the field of disabilities joined the march. Stuttering was absent as usual. I proposed to the other members of the Italian association to share the march acting as a stuttering association. This suggestion was repeated for weeks on our mailing list and some members, besides our president Piero Pierotti, seemed to appreciate the initiative. But nobody took part in the Perugia – Assisi march. I’ve been the only exception, but I’m also the only member living in Perugia!



I’m writing these lines to underline two points, the first having more to do with Italy and the second more with Europe:

- 1) the Italian stutterers use to attend very seldom either events like the march or any other event / meeting, although closely related to the association’s activity. Time, money, family or other engagements and difficulties make it hard doing long journeys and getting to a remote destination to share a meeting.
- 2) I couldn’t say how much a march can be a step towards democracy, but supposing it is, no doubt democracy means attention and respect to everybody, especially to those who have more difficulties to be seen, heard, respected, loved.....like the thousands of individuals who stutter all over the world. I have the impression that other associations, compared to the Italian one, can rely on a more constant and conspicuous participation of their members in the social initiatives. But in spite of any differences among the national associations perhaps the moment is coming for us to “think European” as stutterers when public and symbolic events happen, which could involve our reaction as ELSA I feel that many could agree, but this or similar statements could be still hardly given a “translation” into the everyday life. In 1993 I said from the pages of one of the first issues of the ELSA newsnotes: ”Let’s get together!”. Now I’d like to ask you and myself : are we ready to “get together” as people who stutter to pay attention and care for the world of tomorrow?”

- **Latvia**

Please visit the new website from the Latvian stuttering association, LSA, at www.latvsa.org. You can reach Ilmars Danilevics at Bruninieku iela 50-10, LV-1011 Riga, Latvija, Phone + 371-7271112, Phone (work) + 371-7016153 email ilmars.danilevics@mfa.gov.lv

- **New stuttering association in Serbia and Montenegro!**

I would like to inform you that the statutory meeting of Serbia and Montenegro Self-Help Association for People with Stutter took place on Saturday 15th of October. We hope that we will be able to make a difference by providing information, help and support. We are very interested in making connections with all similar organizations, exchange experiences and organize joint projects. Best regards, Ognjan Maletic, president of the board, ognjan@tesla.rcub.bg.ac.yu

NEWS FROM OUTSIDE EUROPE

Although the following countries are not members of ELSA, we would like to share the experiences of other countries receiving the ELSA Newsnotes to give us new ideas and inspiration.

- **Africa: Creating Stuttering Awareness, Self Help Groups And Treatment For Stutterers In Africa**

Joseph Lukong, Conference Convenor had the following great news: “The International Stuttering Association (ISA) in collaboration with the SPEAK CLEAR ASSOCIATION OF CAMEROON (SCAC), organised in Douala Cameroon, the first ever African Conference on stuttering. This conference that took place from the 6th to the 8th of October 2005, brought together people who stutter (PWS) from some African countries, prominent member of the ISA, speech pathologists, psychologists, researchers and educationalists from Australia, North America Europe and Asia. The conference had as theme « UNDERSTANDING STUTTERING AND ITS TREATMENT »

It should be pointed out here that about 17 million Africans are affected by stuttering. The situation of this people who stutter in Africa is quite difficult due to the absence of adequate information on the causes, prevention and treatment of this disorder. In the absence of modern health care for stutterers in Africa; PWS often go for the available traditional and at times very crude methods of prevention and treatment for stuttering. It was to remedy this situation that some speech pathologists in collaboration with the ISA and SCAC decided to organise this conference as the first step to helping stutterers in Africa. Attendees to this conference came from 15 different African countries and the following non African countries:- Germany, France, India, Australia, England, and the USA.



Before the start of the conference, some speech pathologists attending this conference, organised in collaboration with the SCAC a series of free speech therapy sessions for stutterers, and training sessions for the medical corps, teachers, social workers and parents of children who stutter. These specialists equally used socio cultural, religious and the mass media to pass over useful information on stuttering to the public. During the conference itself key note presentations and workshops were done and valuable information on stuttering treatment, research and self help were passed out. African delegates equally gave testimonies relation to the state of stuttering in their respective countries.

Before the conference rounded up an important project called INTERNATIONAL SPEECH PROJECT – STUTTERING was launched. This project aims at developing the concept of self help groups in many African countries, which groups will raise with specialists to provide adequate information to PWS and the general public. The project also aims at helping to train local speech professionals that could help to fill the existing vacuum. It was also decided that for this project to be successful, some funding bodies and African countries should be lobbied to support it. This conference would not have been organised without the support of the International stuttering Association that obtained private donations from her affiliated member associations and some private donors to help fund part of the travel cost, feeding and lodging of African delegates who accepted our invitation and attended the conference and those who other people who help to support it in one way or the other.

- **Argentina**

Claudia L. Díaz writes: "Following are our Projects and Activities:

- The organization of seminar for speech therapist interested in the specialization in stuttering.
- Monthly meetings about different topics in charge of specialists invited.
- Free consulting room open to the community, talking place every fortnight, coordinated by the president of the A.A.T., Miriam Lobato (stutterer), and speech therapist.
- Meeting of integration for people who stutter, professionals and parents.
- A.A.T's participation in the International Conferences on Language Therapy in Rosario, Santa Fe Province Argentina.
- Informative lectures in different hospitals of Buenos Aires.
- We are organizing the second updating conference on Stuttering and meeting for people who stutter on 27 and 28 October owing to the International Day of the Awareness of Stuttering.
- The capacity area is developing an investigation issue: Bullying at school based on the work developed by language therapists from Canada and Australia.
- The international contact has become very usual since the Congress in Perth in 2004.
- The A.A.T. participates in the media, spreading this difficulty."

- **Brazil**

Daniela Veronica Zackiewicz, Vice-president of ABRA-GAGUEIRA, writes: "Greetings from Brazil. It's wonderful see how the ISAD join people around the world. Here in Brazil we are working a lot to make ISAD a national campaign, involving people who stutter, speech language pathologists and Brazilian people. **Activities:** Online conference, October 16 to 22 and on October 22 - *São Paulo* Stuttering Awareness Meeting. Our complete program can be found at three websites: www.cefac.br, www.abragagueira.org.br, www.iampse.so.gov.br."

- **Canadian Association for People Who Stutter (CAPS)**

Shelli Teshima, Canadian Stuttering Association Coordinator, writes: "CAPS has had a very busy few months that culminated in our biennial conference and had a name change. The 8th National Conference of the Canadian Association for People who Stutter (CAPS 2005) was held in Edmonton, Alberta on August 18 to 21. All conference delegates enjoyed attending the many workshops, the three keynote speakers, and sharing their stories. We are already thinking about where to hold our next national conference in two years time.

At the conference, it was announced CAPS is now the Canadian Stuttering Association (CSA). We are happy with this change as it is much easier to say and easier to remember! There have also been some changes in the CSA board of directors. David Block has resigned as national coordinator after five years of hard work. David's involvement will be missed. Shelli Teshima, from Edmonton, has taken over the position of national coordinator. Shelli brings many years involvement with local and provincial self-help groups. Another new member to the board is Bernie Dobrucki. He will be working on the CSA newsletter."

- **China**

Dr. Huang writes about the First Stuttering Research and Treatment Seminar of China (SRTSC), held in Beijing Normal University from October 15-16, 2005. This seminar was the first meeting about stuttering research and treatment in China. It offered a platform to share experiences with experts and people who are affected by or interested in stuttering. It has the potential to have great impact on the further development of research and treatment about stuttering. The theme of this SRT seminar was "Caring for the stuttering group; and pushing forward the research of stuttering."

- **Nepal**

Indra Shrestha writes: “The Nepal Stutters’ Association conducted a two days workshop for celebrating the “International Stuttering Awareness Day”. The workshop was held with the theme “Planning of NSA activities for 2006 to 2008” on October 19 & 20 at Marshyandi Hotel, Thamel, Kathmandu. The chief Guest of the program was Mr. Hermann Christmann (President of The Association of Stutterers in Denmark) and Mr. Torben Moller Jensen (Manager of DSI Affairs) from Denmark. Other guests were Mrs. Hanne Tranberg and Mr. Jan Jeszke Nielsen (journalist) from Denmark, Speech Pathologist Mr. S.L. Kurn and Mrs. Renu Lohani from DSI-Nepal. NSA President Mr. I. L. Shrestha presented the paper on the Planning of NSA activities for 2006-2008. 49 participants, among which 40 stutterers, were coming from the different parts of the Nepal. They discussed and planned the NSA activities for year 2006-2008. This two days workshop was held with the collaboration of “The Association of Stutterers in Denmark”.

We are going to conduct one day workshop on 4 December, 2005 at Malangwa Municipality, Sarlahi District. We are also going to conduct Second Annual General Meeting of NSA on 24 December, 2005 at Kathmandu.

OTHER NEWS AND REPORTS

- **Lee Reeves receives ASHA award!**

The American Speech-Language-Hearing Association, ASHA, has presented numerous awards over the last 70 years to recognize the contributions of individuals and groups to the professions of speech-language pathology, audiology, and speech and hearing science.

The Honours of the Association and Fellowship in the Association are the highest honours awarded by ASHA. Recipients of these awards are honoured each year at a ceremony at the Annual Convention. This year Lee Reeves has been selected in recognition for long-standing dedication and effort on behalf of those who stutter. Also this year, J. Scott Yaruss and Charlie Diggs were selected to receive the ASHA Fellows Award. This award is one of the highest honors a professional can achieve, and Fellow status is retained for life. Scott and Charlie have joined the "giants" in the field of speech-language pathology.



- **The 2007 World Congress for People Who Stutter**

The next World Congress will be held in **Cavtat-Dubrovnik, Croatia** in May 6-10 2007. Cavtat is located at the very south of the Republic of Croatia (also called the Dubrovnik Riviera!); 18 kilometers from Dubrovnik and only 6 kilometers from Dubrovnik International Airport, which makes it easy to reach. The congress will be held in the magnificent 5 star Hotel Croatia <http://www.hoteli-croatia.hr/> . If you are looking for a budget stay you can either book in Hotel Superstar, a sister hotel to Hotel Croatia, http://www.hoteli-croatia.hr/supetar/hotel_supetar_eng.html, or find your own stay in the cosy village of Cavtat or in Dubrovnik. Beside interesting workshops and speakers from all over the world there will also be different tours, both during and in conjunction to the congress. So put the date in your agenda, as you don't want to miss this! We will keep you updated through the newsnotes and the ELSA website.



Do you have any news, reports or invitations to share? Please contact us.

FINALLY

We would like the electronic newsnotes not to just contain the latest information about ELSA, our website, EU disability policy and other European news, but also news from YOU! Upcoming events and dates, links to interesting websites, address and contact changes, news from your association, requests for help, information and contact, co-operation and projects, sharing information and experiences about the International Stuttering Awareness Day (ISAD) and lots more. So please help us to make the newsnotes a pulsating vein with interesting news for all, that reaches out to everyone who stutters, is working with people who stutter or is interested to learn more about what's happening.

The board of ELSA would like to wish you all a positive and successful 2006!!!

Do not hesitate to add this letter to your own newsletter, website and chatgroups.

Anita Blom (S) Edwin J. Farr MBE (GB) Gina Waggott (GB) Konrad Schaeffers (D)