December 2009 e-newsflash

To: ISA member organizations, Board members and Advisory Board Members

I want to extend wishes to everyone for a healthy, peaceful and hopeful holiday season.

World Congress dates:

The Ninth World Congress for People who Stutter will be held in May, 2011 in Buenos Aires, Argentina. The ISA Board of Directors voted to hold the Tenth World Congress in 2013. The attached letter is requesting submissions by member organizations to host the 2013 World Congress. We are also asking for approval, by our member associations, of the selection of these dates, which are inconsistent with our Constitution but which we believe represent appropriate decisions by the ISA Board of Directors under the circumstances.

Update on Voices Across Borders:

I want to update you on some information on the Voices Across Borders project. Please take a look:

http://bayareansa.com/Site/VAB.html

Below are two sites that offer information on "Organizing a Workshop" & "Peer Counseling"

http://www.mnsu.edu/comdis/kuster/workshop/intro.html

http://www.mnsu.edu/comdis/kuster/SupportOrganizations/peercounseling.html

Research Project:

Below you will find a research project that has been approved by the NSA research committee. Mr. Forst is looking for participants (see below). It is widely believed that stuttering is the result of a myriad of influences: neuro-psychological, psychological, social, and linguistic (Peters & Guitar, 1991). Due to the strong behavioral-neurological component in stuttering etiologies, pharmacological intervention may play a role as a potential treatment strategy (Stager et al., 1995). The objective of this study was to obtain responses from a population of adult persons who stutter (PWS) who received pharmacological treatment for stuttering/fluency disorders. A 12-question survey was distributed; questions regarding type of drug, dosage, effectiveness, side effects, and participant perceptions on this method of intervention were included. The researcher sought to compare and contrast experiences derived directly from PWS themselves and discuss the positive and negative aspects of this method of treatment. Results will answer the research question, "What are the effects of the various pharmacological interventions on fluency, as reported by persons who stutter?" Please take a moment to fill out this

A perspective on stuttering:

Each month the ISA will try to present a 'different perspective on stuttering' to provide a discussion on a topic. This month we're looking at 'transfluency'. This is not an endorsement of a particular therapy or definition. However, it is a chance to examine and explore different perspectives. It was written by Cristobel Loriente. Please contact her at cristoloriente@yahoo.com.

Here are my conclusions and thoughts:

- 1. Stuttering is very resistant to clinical modification.
- 2. Stuttering in adults seems to be an irremediable attribute of humankind, as are other attributes which have been demedicalized: the need for freedom (drapetomania) or hemispheric dominance (left-handedness). Stuttering belongs to human nature and thus, is not a pathological symptom.
- 3. I propose demedicalizing stuttering and the construction of the term <u>Transfluency</u> to designate stuttering. Demedicalizing means conceiving a phenomenon as a distinctive feature or a manifestation of human diversity. Transfluency is a natural speech pattern or in other words, Transfluency is a speech pattern as human as fluency.
- 4. Demedicalizing and dignifying stuttering requires us to carry out the process of "Coming out." Coming out dignifies stutterers because it transforms their way of life into an authentic and transparent one, which allows him to participate in communication and human contact.
- 5. Self-help groups are becoming the most adequate social spaces to start the process of "Coming out."

Final thoughts

- 1. And if turns out in the future that biomedicine discovers the cause of stuttering and if it turns out to be irremediable what would have been the good of medicalization? And what about the harm that has been caused and the hopes that have been dashed?
- 2. Let's consider the reverse situation: can a fluent speaker become a stuttering speaker? I don't think it's possible. In the same way, I believe most adults who stutter can never become a truly fluent speaker.

After 77 years of stuttering – thoughts from Advisory Board member Mel Hoffman:

I asked Advisory Board member Mel Hoffman to write something for this edition of the enewsflash. Here's what Mel wrote:

I'm 80 – so after 77 years of stuttering, what do I have to say about it?

Well, more than I can write in a couple of paragraphs. Here's #1 on my list.

In 1957 I took a leave of absence from my job and went to Dr. Charles Van Riper in Kalamazoo, Michigan, and learned about preparatory sets, pullouts, cancellations, and desensitization (among other things). All this is important. However, as I think back about it, the words of John Ahlbach (former Executive Director of the National Stuttering Project, and a co-founder of the ISA along with Thomas Krall and Shinji Ito), come to mind:

"...I am going to publish my compete theory of how to overcome stuttering.... I am going to sum up all of my experience in one lucid, compact, profound prescription for conquering the problem we all share. Ready? I've been saving it. Here it comes. In order to conquer stuttering, just live with it as best you can and you're there, my friend."

Sure, it's important to reduce your fears. Sure, you need to find a way to control your really bad blocks. Sure, you need to find the best way for you to communicate effectively, even though you stutter. But, most important – you've got to LIVE your life, and realize that (just maybe) you are putting too much emphasis on trying to cure your stuttering and not enough emphasis on just handling your stuttering the best way that you can and *comfortably living with it*.

Once again, best wishes for the Holidays from me and all of us at the ISA.

Michael Sugarman, Chair