

November 6, 2009

To: ISA board and advisory board members and to ISA member organizations

Re: **E-newsflash from ISA November '09**

Some thank-you's:

First and foremost I want to thank people who coordinated activities from Sweden to China to Greece to Uruguay to West Africa to name a few participating in International Stuttering Awareness Day (ISAD) activities culminating on October 22nd. In the forthcoming One Voice you'll read ISAD events and individuals who used the media for outreach to their community.

A huge thank you to Judy Kuster in coordinating ISAD online conference from October 1 -22nd. The online conference has been the anchor to International Stuttering Awareness Day.

I want to thank the ISAD committee: Anita, Suzana, Judy, Amy and Anne-Marie for their dedication every year to ISAD. A special thank you to Danko for his inspiring ISAD '09 poster and to Jaime, Nina, Josh and Mike in discussing and establishing 'sea green' color to symbolize stuttering awareness.

ISAD – Use of media:

One person who used the media during ISAD was Tom Weidig

<http://thestutteringbrain.blogspot.com/2009/10/press-release.html>

Facebook:

Another exciting activity was creating a Facebook for ISAD

<http://apps.facebook.com/causes/267261?m=3f1cca43>

The International Stuttering Association and the National Stuttering Association East Bay chapter have launched a Facebook site to connect people who stutter with each other and discuss current concerns. Topics include education, employment, relationships, stigma, speech therapy, community organizing, resources, life goals and anything else of interest. I am inviting all stuttering organizations worldwide to link to this site and encourage members who stutter to join!

<http://www.facebook.com/topic.php?topic=10897&uid=159581778043#/pages/Voices-Across-Borders/159581778043?ref=mf>

Covert 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 'covert stuttering'. 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 Mark Irwin, former ISA board chair.

Did you know.....

1) Research shows that 50 -75% of people who stutter (pws) suffer symptoms of the disability of Social Anxiety Disorder (a state of psychiatric ill-health involving clinically significant anxiety and embarrassment related to social experiences, and frequent social avoidance.)?

2) only SOME pws use the escape behaviour of word substitution and circumlocution to avoid saying words on which they expect to stutter?

THE KEY POINT: These facts indicate there are various subgroups of pws including

1. those that stutter with no symptoms of Social Anxiety Disorder (no significant anxiety, embarrassment or avoidance behaviour)

2. those that stutter WITH symptoms of Social Anxiety Disorder

3. those who use the escape behaviour of word substitution and circumlocution

What does this mean?

Words/ labels/ definitions are needed to differentiate these groups so that we might give more accurate public awareness messages about stuttering, conduct more specific research and apply more appropriate therapy modalities. (There is a difference between treating dysfluent speech and treating the fear of dysfluent speech.)

[A Proposal for New Stuttering Terminology.](#)

1. People with stuttering plus Social Anxiety Disorder to be labelled as having [Stuttered Speech Syndrome](#).

2. Word substitution and circumlocution to be labelled as covert stuttering (this label would not then be confused with avoidance behaviour and extreme embarrassment related to stuttering) to contrast with overt (audible) stuttering

READ MORE

Definitions <http://stutteredspeechsyndrome.com/definitions/>

Covert Stuttering <http://stutteredspeechsyndrome.com/definitions/covert-stuttering/>

Frequently Asked Questions <http://stutteredspeechsyndrome.com/for-academics-clinicians/frequently-asked-questions/>

New Advisory Board member from India:

Each month I plan to ask an advisory board member or a board member for a short bio on his or her stuttering and the member association that he or she represents and include this in the E-newsflash that I send out on behalf of the ISA. Here is some information on Akash Acharya of India, who recently has been invited to join the ISA Advisory Board:

Akash writes: I have been stuttering since childhood and I remember my difficulties in school while answering roll call and being unable to say 'yes sir' or 'yes madam'. Even in college I used to write notes for all lecturers about my 'presence problem' and despite that used to get marked absent as sometimes they forget to look at my face...Today in my professional capacity I am required to make presentations and I clarify the speech issue beforehand. In interview committees also I inform in advance and it is there on my CV as well (copy attached)

TISA has developed mainly due to Sachin's efforts and the history is at <http://t-tisa.blogspot.com/2008/05/tisa-history.html>. We do have contacts with SLPs but as a matter of policy TISA doesn't recommend (we do give contact information though) SLPs especially the cure claiming ones and there are many such!

Akash

10th World Congress:

Next month the ISA board will be discussing and reviewing the 10th World Congress for PWS and whether it should occur in 2013 or 2014, plus location, committee formation, and other matters, in consultation with the advisory board.

Warmly,

Michael Sugarman, ISA chair

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