

To: ISA Board of Directors; ISA Advisory Board Members; and ISA Member Organizations

Date: January 11, 2010

From: Michael Sugarman, Chair, ISA

I sincerely hope that 2010 can bring us all peace, hope, health and spiritual attainment--- an organization such as ISA will benefit many people who stutter and their loved ones if and only if we as members of this community can strive for coordination and a shared belief that we/people who stutter are not alone.

End of 2009 the ISA Board of Directors created working committees and chairs to help facilitate change not only for people who stutter around the world but as well, general public toward stuttering.

To Advisory Board Members please pick one committee and e-mail the chair to serve. June 2010 ISA Board of Directors will re-assess committees: Please understand that some of the committees are closed due to desire to keep the committee manageable. The closed committees are open to feedback by Advisory Board Members. Please be respectful in your words—thank you. You can email me directly about your concerns or joy ☺

Keith will Chair, Outreach, One Voice and ISA internal Face-book.

Suzana will Chair, ISA World Congress.

Thomas will Chair, Ten Recommendations

Masuhiko will Chair, Constitution (Committee is closed)

Michael and Mel will Co-Chair, Finance (Committee is closed)

Benny will Chair, Website---Judy Kuster will serve as an consultant (Committee is closed)

Many of you know that the end of 2009 was a transition time for ISA. Please let me know how I can improve my communication. Please send me feedback on my position as Chair. For example, Areas in which I can improve----thank you

Each month ISA tries to present a different perspective on stuttering to provide discussion. This is not an endorsement of a particular therapy or definition: Eugene Cooper's take on Stuttering:

After 53 years of professional involvement in research and treatment in the area of stuttering, Cooper concludes the following.

The term "stuttering" is most productively viewed as a diagnostic label referring to a clinical syndrome characterized most frequently by abnormal and persistent dysfluencies in speech accompanied by characteristic affective, behavioral, and cognitive patterns.

Stuttering results from the interactions of multiple coexisting neurological, psychological and environmental factors.

As many as 5 children out of every 100 children between the ages of 2 and 5 experience stuttering:

1. Two of those five children experience what Cooper has labeled the "*Developmental Stuttering Syndrome*." These children will attain normally fluent speech by the age of six.
2. Two of the five children experience what Cooper has labeled the "*Remediable Stuttering Syndrome*." With professional help and knowledgeable support from parents and caregivers, these children will overcome stuttering by the end of their school years or in early adulthood.
3. One of the five children experiences what Cooper labeled the "*Chronic Perseverative Stuttering Syndrome*." For these individuals, maintaining an acceptable level of fluency (for the individual) may require a lifetime of coping. Because the Chronic Perseverative Stuttering Syndrome consists of multiple coexisting and interacting affective, behavioral, and cognitive components coalescing over a period of years, the hope for a complete cure or a total remission of symptoms appears remote. However, the outlook for these individuals is not bleak. With assistance, these individuals typically are able to develop and maintain a "**feeling**" of fluency control - not necessarily "**fluency**" control. With that **feeling** of fluency control, many, if not most, individuals with the CPS syndrome are enabled to communicate successfully and effectively in even the most challenging speech situations. The abundant number of professionally and personally successful individuals having coped with the CPS Syndrome testifies most tellingly to an optimistic outlook for those experiencing the CPS Syndrome.

The end goal of the Cooper's "*Personalized Fluency Control Therapy (PFCT)*" treatment strategies for the affective, behavioral, and cognitive components (the ABCs of stuttering) of the three stuttering syndromes are designed to assist clients in obtaining the **feeling of fluency control**.

Cooper concludes that stuttering syndromes, even that of a chronic nature, can be controlled, if not conquered. Finally, for most individuals experiencing a stuttering syndrome, the long-term prospects for successful remediation and control are excellent.

Eugene B. Cooper
January, 2010

Professor and Chair Emeritus, Department of Communicative Disorders, The University of Alabama, Tuscaloosa, AL

Distinguished Professor (Retired), Programs in Speech, Language and Communication Disorders, Nova Southeastern University, Ft. Lauderdale, FL

Each month I try to solicit a board or advisory board member to share their experiences and thoughts on stuttering. This month Anita Blom shared:

My life with stuttering has been a long and winding road. I've stuttered since I was 9 and the people around me never understood, acknowledged or accepted it. I didn't understand what I was doing and why it was so wrong. I just knew I did something very wrong and that I should stop doing it. Well, I couldn't. I'm still doing this weird thing people know so little about. And not until I was 27 I found out that what I did was called 'stuttering', that there was nothing wrong with me other than a different way of speaking, that millions of people do the same thing and that my life could be pretty satisfying anyway. I have a family, a job and a life that's fun and fulfilling. And yes, I still stutter.

After learning all these things I decided to not leave any stones unturned to give stuttering a voice, a face and a reputation that anything goes. I became active locally, nationally, on European level and on International level and feel I can really make a change. Very slowly, but still, leaving traces. It can be anything from getting an EU politician to officially support the International Stuttering Awareness day (ISAD), to simply speaking to people on the bus that I'm going to a stuttering meeting, or wearing a button. From ordering dinner with lots of other people who stutter at a world congress and watch people's faces, to letting pre-school kids try a DAF device, laugh together and tell them about the children camps and other trips and fun activities they are missing out on because they don't stutter. From having a role on the board on a large, international scale, to simply join my stuttering friends from the local chapter.

No matter what you do, YOU can make a difference. Nobody can do it all, but if we all do something, what a wonderful world this would be! ?
Join us!

S-s-sure I s-s-stutter. What are you good at?

Anita Blom

Chair local support group, SSF

Chair Swedish Stuttering Association, Stamningsförbundet

Vice Chair European League of Stuttering Associations, ELSA

Advisory Board Member International Stuttering Association, ISA

warmly,

Michael