Message From the Chair:

10th World Congress for People Who Stutter

ISA Membership Meeting Sunday 9 June 2013
One of the very important tasks is to elect a new ISA Board of Directors. Currently we estimate there will be 7 vacancies to fill.

Please will you advertise these vacancies via all your normal means of communicating with your members.

I look forward to meeting as many of you as possible in June,
Have a very good 2013.
Warmly,
Michael
2013 is an important year for people who stutter in Europe, with the “World Congress for People Who Stutter” being held in the Netherlands. ELSA has been involved on different levels and is hoping to meet up with member associations, other national stuttering associations as well as speech and language therapists.

ELSA invites all its member associations to a General Meeting, to be held during the world congress, the time and place will be announced as soon as the program is finalised.

Directly after the General Meeting there will be a 90 min session, hosted by ELSA, and open to all stuttering organisations, where three different national organisations will present the different status of the work of a national stuttering association: how to start, how to maintain, how to reach out, followed by a Q&A session.

For young people who stutter from all over the world ELSA will host a workshop during the WC. The aim is to bring the young together, empowering them globally to use their voice to make a difference.

During the WC a Declaration on choosing therapy will be launched. This declaration is the work of the German, Dutch, and British stuttering associations, together with the European League of Stuttering Associations.

Because of all these activities ELSA won’t be able to host a European Youth Meeting this year, but is hoping to be able to greet young people who stutter to yet another youth meeting soon.

We are proud to have ELSAs vice chair Anita S. Blom as one of the keynote speakers and even more proud to see so many of the former ELSA Youth Meeting delegates being on the different organising committees, which will give the congress a modern youthful touch and will hopefully attract more young people.

There is a group booking arrangement for different apartments during the world congress offering young people who stutter from all over the world to share, for cheaper accommodation. Please contact youth@stuttering2013.com for more information.

ELSA board member and co-organiser of the World Congress Richard Bourgondiën and Maartje Borghuis, congress chair and former Youth Meeting delegate warmly welcome you all to an amazing world congress that could be a life changing experience!

Looking forward to see you soon!

Anita S. Blom (vice chair) Richard Bourgondiën (board member) Edwin J Farr MBE (Chair)

www.elsa.info
www.stuttering.ws
MESSAGE FROM ISA
OUTREACH...

Many of our readers work hard in national associations to help people who stutter (PWS) in their own Countries. This help can take many forms and can take many hours of thought and work. Whether you are a member of an association, or on the Board of the association your work locally is very valuable to PWS in your Country. Some associations have close links with newly formed associations in other Countries. You will work in a variety of ways to assist in the development of the new association in the other Country. This is a very good start to International work. If you are doing this, would you like to extend your International expertise by joining the ISA Board and helping in more countries? If yes, Please contact either our Chair or myself.

Michael Sugarman
<msugarman1@sbcglobal.net>
Keith Boss
<keithmaxkb@yahoo.com>

When the new Board is elected at the membership meeting on the 9th June 2013 we will need to fill Officer positions and are looking for a new Chair, Vice Chair, Treasurer, Secretary, someone to lead Outreach from 2014 onwards and someone to learn enough to be Chair of the ISA in 2016. Officer positions and committee chair positions can be found on our website. www.isastutter.org.

Currently, we are looking at requests for financial help to attend the WC2013. The combined requests exceed 20,000 euros. Our only income is our membership fees, so our 'scholarship' fund is only 7000 euros. This means many hard decisions by the committee.

Please can you check that your association is correctly represented in the members area of our website. http://www.isastutter.org/who-we-are/member-associations.

As always, I will close my contribution by reminding all of us that the ISA exists to help People Who Stutter in any Country of the World. For the ISA to succeed, we need
-Board Directors and volunteers with time;
-volunteers to help with translation between other languages;
-money;
-volunteers to stand for election on to the next Board of Directors on 9th June 2013.
(Do you need information about what is expected?)

If you can give the ISA some of your valuable skills / time / money, please do so. If you can help, or know of someone else who can help please contact either our Chair or myself.

Michael Sugarman
<msugarman1@sbcglobal.net>
Keith Boss
<keithmaxkb@yahoo.com>

I look forward to meeting many of you at the 10th World Congress for People Who Stutter in Lunteren in June 2013 (http://www.demosthenes.nl/wc2013)

Please pass this to all your members.

Keith Boss
ISA Chair of Outreach
Vice Chair and Treasurer
keithmaxkb@yahoo.com
In my Lifetime….thus far 😊 and what the future may hold for Peer Support

Protests:
As I near 60 years old there have been a variety of events which have shaped my perspective:
* Participated in protests to end USA involvement in Vietnam
* Participated in occupying Department of Rehabilitation in San Francisco 1977 with Disabled people…This led to the American Disabilities Act
* Participated with Act up Protest at the International AIDS Conference in San Francisco…This led to the development of ‘cocktails’ for people living with AIDS to survive
* Participated in events to demonstrate on behalf of People who Stutter
* Seen the election of USA first African American President, and, by the way, hope to live to see the first woman President of USA.

Studies document favorable results from inclusion of peer supporters on treatment teams (Mead & MacNeil 2006). In the Creation of the Pillars of Peer Support Services Transforming Mental Health Systems of Care by Emily Grant, PH.D.; Allen Daniels, Ed.D.; Ike Powell, CPRP; Larry Fricks; Lisa Goodale, MA; and Sue Bergeson, the MBA article from www.psychosocial.com/JPR_16 reveals that information provided by peers who have lived the experience often appears more credible than that provided by mental health professionals who do not have firsthand experience (Woodhouse & Vincent 2006). There appears to be a call for USA states to shape recovery programs with Certified Peer Specialists integrating into Behavioral Health treatment.

Peer Support in stuttering may change and may be integrated in treatment with SLP’s for the recovery of Adults who stutter. What we in the stuttering peer support movement can learn from the mental health community is long term viability and common principles for strategic development, implementation, promotion and maintenance of peer support services. Maybe it is time for us to do training for peers? 😊

Peer Support
In general, peer support occurs when people share common concerns or problems and provides emotional support and coping strategies to manage problems and promote personal growth. Peer support has demonstrated productive outcomes in areas of substance abuse, parenting, loss and bereavement, cancer, and chronic illnesses (Kyrouz, Humpherys & Loomis, 2002; White 2000) and has now being implemented in mental health systems of care.

Peer Support for People who Stutter (PWS)
Peer Support refers to PWS helping each other by listening, sharing common experiences, exploring options and giving support. Peer Support is based on communication, empathy and understanding. PWS can provide support in a variety of settings including one to one, support group and possible future integration of peers with speech therapy services.

Support Group
When PWS meet together in a support group, it creates a safe and comfortable environment, giving all members an opportunity to share and help to better communicate with and listen to each other. A peer facilitator assists in setting individual life and support group goals.
You can check out ‘Peer Counseling for Self Help Groups Facilitation for People who Stutter’ by going to www.mnsu.edu/comdis/kuster/supportorganization/peercounseling.html

Promising Discussion

In the future, success and barriers to implementation of Peer Support in the treatment of stuttering may have us PWS create a set of standards for program implementation. Peers can play an active role in the recovery process for People who stutter.

See you at World Congress 2013 and can talk more...

Michael (ISA Chair)
Bert Bast, also on behalf of Martin Sommer (Chair BVSS), Norbert Lieckfeldt (CEO BSA), Edwin Farr (Chair ELSA)
Netherlands Federation on Stuttering (NFS) Utrecht, the Netherlands
voorzitter@stotteren.nl

Purpose
To improve the understanding as to what to expect from therapy. This approach may reduce the danger of believing misleading claims. The target audience consists of people who stutter themselves, their relatives in the broadest sense, parents of children who stutter, and the society at large.

Materials and Methods
We started from the German declaration on this subject. We then discussed and agreed this (after some adaptations and a linguistic brush-up) with the German Bundesvereinigung Stottern und Selbsthilfe (BVSS, the Dutch Association of People who Stutter (Demosthenes), the European League of Stuttering Associations (ELSA) and the British Stammering Association (BSA). Now we have discussed it within the International Stuttering Association (ISA), and we present it here. We wished to combine a clear as well as modest wording in this declaration.

Results
A Declaration by the Bundesvereinigung Stottern und Selbsthilfe (BVSS, Germany), Demosthenes (the Netherlands) and the European League of Stuttering Associations (ELSA).

1. Although research in recent years has demonstrated a neurological root cause of stuttering (which may relieve possible feelings of guilt), there is no treatment that is guaranteed to be effective in terms of recovering normally fluent speech.

2. Despite an improvement in understanding, many people who stutter, and many parents of children who stutter, still only know a little about the causes and treatment of stuttering. When they seek help, they are often faced with a wide and potentially confusing range of interventions which can increase uncertainty.

3. To further confuse matters, many treatment providers advertise aggressively, often promising a fast and complete 'cure' giving false hope to those who stutter and fuel misconceptions amongst the general society at large. But there is no easy 'cure' for stuttering, in the medical sense of the word.

4. Although there is still little evidence to support the total effectiveness of any one therapy, it can reasonably be claimed that some therapies will usually help people who stutter to improve their fluency, as well as their life skills and resilience.

5. However, it is widely accepted that the chances of full recovery are very much more likely if treatment is sought at an early age, ideally within 15 months of onset. Postponing treatment for too long after onset reduces the likelihood of a recovery.

6. In order to help people who stutter and parents of children who stutter, the national stuttering associations of Germany and the Netherlands have, with the support of the European League of Stuttering Associations, drawn up this declaration, in order to help identify the hallmarks of good therapy.

(i) Not all suppliers of stuttering treatments are qualified speech and language therapists; in some cases, the therapy offered is based mainly on personal experience – which, because of the very personal and individual nature of stuttering, will only suit a small percentage of people who stutter. Our advice: ask critical questions about the therapist’s academic and vocational training and also if possible seek feedback from their current and past clients.
(ii) Professional therapists are bound by a code of ethics, which ensure the therapists abide by the code, continue their education throughout their working life and allow a client to seek redress if they are unhappy with the service they received. **Our advice:** ask about membership of relevant professional bodies.

(iii) The frequency and severity of stuttering can sometimes be reduced very quickly by making simple changes in the manner of speaking, sometimes with the help of fluency devices. This may give the impression of a short term ‘cure’. However, for most people who stutter, these simple changes do not continue to work in the long term, when they return to their normal daily lives. **Our advice:** be skeptical of therapies which concentrate on learning methods designed to improve speech fluency quickly with no or little practice in the real world.

(iv) It is generally accepted that a successful stuttering therapy requires a good deal of personal input, over a period of many weeks or months and often years. **Our advice:** be very careful about ‘miracle’ treatments, promising success within a short time and provide no follow up free access.

(v) A major aspect of many stuttering therapies is that they require the long term implementation of techniques learned in daily practice. Relapses into old patterns of speech and behavior are common. The quality and the duration of aftercare, following a therapy course, is therefore crucial. **Our advice:** ask critical questions about whether and how the aftercare is provided and which kind of self-help is available.

(vi) Even ‘good therapies’ as described above, don’t do the work for you. The only way people who stutter will progress is to take personal responsibility for their stutter, get out and lead a full life. **Our advice:** resolve to do that.
JMB 2012 IN MALI

With the support and guidance of the National Directorate of Social Development, the Malian Federation of Persons with Disabilities (FEMAPH) and the Centre Aoua Keita, Overcoming Stuttering Association in Mali (Mali- AVB) celebrated the 15th World Day of stuttering Center October 20 Aoua Keita by a lecture by two speakers and co-chaired by the National Director of Social Development and the representative of the Malian Federation of Persons with Disabilities (FEMAPH).

This year, the World Day of Stuttering was celebrated at a time when Mali is going through a difficult situation in its history by the occupation of two thirds of its territory by terrorists. The objective of this conference was to inform and educate the public and the authorities on the disability of stuttering.

During the conference, speakers widely spoken of stuttering causes of stuttering types of stuttering, support early childhood and the various methods of treatment of stuttering. After their brilliant presentations, they responded to various questions that have been asked by their people who stutter, parents and the public came stuttering massively participate the conference.

Despite the lack of therapist specializing in the treatment of stuttering, the AVB-Mali becomes more organized and always seeks to bring together people who stutter to fight against the disability of stuttering is a reality among adolescents in Mali.

Finally, we thank all our partners who have supported us in organizing this conference.

Long live the next day Stuttering
Dear friends of our International Stuttering Family, again for me is a great pleasure to Share with each of you two realizations, within many others, which I’m doing in Chile. Realizations that are contributions for speech and language therapists and especially for the community of Friends Who Stuttering in my country. Certainly, for me it is a great honor realize these activities as special friend of ISA.

First, the Great honor to continue my work at San Sebastian University, Santiago, as part of teacher’s team to the “Diploma in Phonoaudiologic Intervention for People who Stutter”. Diploma for Speech-Language Pathologists. Teaching them my Neofonoadiologic Approach. Approach that applies advances in neurosciences, especially, born it of listen carefully in first person our Friends Who Stuttering, in my conviction that “you are the book to read”.

Second, I am very happy to be ending a study of research and therapy. Important contribution for children who Stutter and Chilean Society. Especially, to incorporate the Chilean Education System the Universal Design Concept: “Systematization Neofonoadiología as an approach innovative, applied to people with stuttering” at University of Christian Humanism. Research with students who are opting for the title of Education in Special Education of that University.

Objectives:
- Describe and apply the process Neofonoadiologico therapeutic approach in cases of young Who Stuttering.
- Neofonoadiologico Approach, an innovative experience, to maximize speech fluency, providing contributions therapeutic, intra and interpersonal transformations to PWS.
- Contribute incorporate into the Chilean Educational System the Universal Design Concept to children who stuttering.

Contribute a transformation in the consciousness and a change of attitude of the Chilean Educational System, at the time to educate, to contribute eliminating: exclusion, discrimination, pathologize and tagging to children who stutter.

This contribution keeps me be really happy and motivated. It is the first time in Chile that makes a contribution of this type. Soon, I will share with each of you in more detail about it.

This year is full of fascinating contributions, activities. I'll share with each of you.

With humility, always proud and honored to present and share with each of you my contributions, as a special friend of the ISA.

“The true victory means Victory over yourself, with courage”

"Victory over yourself symbolizes efforts without hesitation"

Have a very good 2013, If you want to know more about the above, get in touch with me. I will be pleased to share with you.

Warmly,

Adolfo Barrales.

Speech Language Pathologist and Psychotherapist.
President of Chilean Stuttering Association: Grupo de Amigos de Personas con Tartamudez Chile.
External Professor and Relator for the Faculty of Sciences, Universidad de Chile.
Special Friend of ISA. Member Representative of Chile to the International Cluttering Association..

http://gaptartamudez.com/ (website is on renovation process).

gaptartamudezchile@gmail.com
contacto@gaptartamudez.com
I would like to outline the ISA International Speech Project-Stuttering (ISP-S). It began in 2004 when David Shapiro (IFA Chair) and Peggy Wahlhas talked over the concept of “Medicines Sans Frontieres” with Mark Irwin (past ISA Chair) and Stefan Hoffman (Past ISA Outreach Chair). It has developed into a range of valuable activities.

Keith Boss (ISA Vice Chair)

**International Speech Project-Stuttering. (ISP-S)**

**The general mission.**

**Objectives.**

Sensitise the general public;
Explain about stuttering to a range of Government ministers, civil servants, health professionals, large employers, police, Universities and schools;
Talk with parents of children who stutter;
Talk to as many school teachers at as many schools as possible;
Explain the self help concept in use around the world;
Help People who Stutter (PWS) to set up, or set up more, Self Help Groups (SHG);
Once at least one SHG is set up, provide ideas for some members to go outside the SHG and help other PWS in a nearby villages / towns or cities to start more SHGs;
If not in place, discuss setting up a national stuttering association with a website or web area on the ISA website;
Provide local speech therapists with current methodology for the full range of general speech therapy services in use elsewhere in the world;
Request that this training is passed onto other speech therapists in the country;
Request they encourage clients to form new SHGs
Hold many meetings / then area conferences / then a national conference / then International conferences.
An SHG is the same concept as a Chapter (used in America)

**How to meet the Objectives.**

*Most of the organising should be done by local PWS with guidance if required from local speech professionals. Each destination city doing its own thing, but coordinated to give a comprehensive coverage.*

As many interviews as possible with all different forms of local media;
As many meetings, conferences as possible with Government ministers, civil servants, health professionals, large employers, police, Universities and schools, talking about

- stuttering
- giving help to PWS to change them from being a drain on the economy to an asset
- dealing with how to help PWS in public places where they have to talk
- helping PWS and all employees to help themselves to benefit employers
- explaining to police that typical behaviour of PWS could be similar to guilty criminals
- help in Universities
- help in classrooms and playgrounds in schools

Talk to parents about their role in helping their children;
Talk to teachers as above;
Talk about self help groups, and spreading self help groups to nearby towns / cities and Toastmasters International;
Give guidance, if needed on National Associations / websites or web areas in the ISA website;
Professional members of the ISA ISP-S team can give education, if useful, to local speech professionals and discuss the latest effective ideas on the full range of speech therapy in use around the world;
Local newly trained speech professionals should pass the new knowledge around the Country;
Generally have many meetings / conferences where local PWS meet other PWS as well as speech professionals and talk. This would start at area level, then state level, then national level etc.
Format of events to meet the objectives

Meeting places in Universities / Government buildings / Health Buildings and large employers;
Larger state / International conferences could be 3 days in each of up to 3 cities (? travel costs);
Some meetings may be audience specific e.g. a Human resources team of a large employer;
Where possible both PWS and professional therapists are involved in all meetings, however one exclusion of this could be professionals talking to professionals in a very scientific way;
Weather permitting, some meetings might take place in interesting open spaces;
Always allow time for questions and answers.

Adjusting the composition of the team

The composition of the team from 2 ISA SLPs and 1 or 2 ISA Directors can be adjusted. If funding is a serious concern then you may rely more on local nationals who have much experience which is worth spreading around the country. They must be comfortable talking to large groups of people.
But take care, bringing in ISA International experience with a full range of speech and language therapy at least once, is very valuable, even if it means using an interpreter. Internationally experienced SLPs and PWS can give many different perspectives which will bring greater benefits than only home acquired experience.

Funding

This is always a difficult issue. Compromises on costs should always be sought.
Travel and sleeping costs should be provided for the travelling team. However, it they could pay for food. If any members of the team can fund themselves, they may do so, but not everyone would be in this position.
News from Latin America

International Stuttering Awareness Day:

As in others years, in a joint effort of the Graduate Audiology at the Catholic University of Sao Paulo, the Stuttering Foundation of Rosario (Argentina), CHPR Phonoaudiology Service UDELAR Phonoaudiology and Bachelor of Uruguay, the Venezuelan Association of Stuttering and the Iberoamerican Association of Stuttering, was prepared and distributed a brochure alluding to the subject. Equally, the Perú Group of Stuttering, prepared a material related to October 22th. These materials can be viewed at http://ttmib.org/docu4.html

On October 16th, the Radio Program "Quiero Vale 4" that transmits the 90.1 FM La Boca Argentina was devoted to addressing the issue of Stuttering inviting to Ms. Claudia Diaz.

In Venezuela, on October 24, the radio program "Superando Barreras", was treated of the stuttering topic. Were as in-studio guests, Dr. Pedro R. Rodríguez C. President of the Iberoamerican Association of Stuttering and his wife PhD. Ruth Diaz Bello and were interviewed by telephone Mrs. Margarita Serizier, Consultation Coordinator Specialized Speech Therapy (Cetel) Children's Hospital of Caracas and Melani Echeverría, stammering and student Pure Mathematics and Economics. The program was conducted by Mr. José Ramón Fernández, General Producer of the same.

Aloud, solicit the word the puppets:

On 23 January, in the Specialist Language Therapy (Cetel) Children's Hospital of Caracas, began a Puppet Workshop involving children and adolescents Fluency Group of the Centre. Objectives of this workshop is that, through the use of puppets, participants can freely express their emotions to work cognitive and behavioral aspects and thus strengthen their language pragmatic skills in different contexts and social situations. The workshop is directed by Lic. José Ramón Fernández, Manager of Cantalicio Puppet Theatre at the Central University of Venezuela and supervised by Lic. Margarita Serizier, Manager of Cetel. In addition to children and adolescents who attend Fluency Group, in a first step, involved their mothers, who help in making the dolls then used in theatrical performances.

Photo1: Participation in Radio Programme Overcoming Barriers
Photo 2 to Photo4: Puppet workshop activities
Versión en Español

Noticias de Latinoamerica

CELEBRACIÓN DEL DÍA INTERNACIONAL DE CONOCIMIENTO DE LA TARTAMUDEZ:

Como en años anteriores, en un esfuerzo conjunto de el Postgrado de Fonoaudiología de la Universidad Católica de Sao Paulo, la Fundación para la Tartamudez de Rosario (Argentina), el Servicio de Fonoaudiología C.H.P.R. y Licenciatura en Fonoaudiología UDELAR de Uruguay, la Asociación Venezolana de la Tartamudez y la , la Asociación Iberoamericana Iberoamericana de la Tartamudez, fue preparado y difundido un brochure alusivo al tema. Igualmente, la Agrupación Peruana de la Tartamudez, preparó un material alusivo al 22 de octubre. Estos materiales pueden verse en: http://ttmib.org/docu4.html

El 16 de octubre, el Programa de Radio “Quiero Vale 4” que transmite la Emisora La Boca FM 90.1 de Argentina estuvo dedicado a tratar el tema de la Tartamudez teniendo como invitada a la Lic. Claudia Díaz.


EN VOZ ALTA, PIDEN LA PALABRA LOS TÍTERES:

El pasado 23 de enero, en la Consulta Especializada de Terapia del Lenguaje (CETEL) del Hospital de Niños de Caracas, se dió inicio a un Taller de Títeres en el que participan niños y adolescente del Grupo de Fluidez de ese Centro. Este Taller tiene por objetivos que, a través del uso de los títeres, los participantes puedan expresar libremente sus emociones para trabajar aspectos cognitivos y conductuales y así, fortalecer las habilidades pragmáticas de su lenguaje en diferentes contextos y situaciones sociales. El Taller está dirigido por
el Lic. José Ramón Fernández, Director del Teatro de Títeres Cantalicio de la Universidad Central de Venezuela y supervisado por la Lic. Margarita Serizier, Directora de CETEL. Además de los niños y adolescentes que asisten al Grupo de Fluidez, en una primera fase, asisten las madres de éstos, quienes ayudan en la confección de los muñecos que luego serán utilizados en las representaciones teatrales.

Fotos:

Photo1: Participación en el Programa de Radio Superando Barreras

Photo 2 to Photo4: Actividades del Taller de Títeres.
Light from Many Sources
Frederick P. Murray, Ph.D.
Keynote address, ISA Conference, Argentina - 20-05-2011

Stuttering remains an enigma. These days, however, we seem to understand it better. Today I will attempt to enhance an effective management of stuttering. I'd like to share with you factors gained from many of the leaders in the field. Many are now deceased. These contacts, most of which began in the decade following WWII, afforded me a glimpse into their thoughts about stuttering that might be expanded in the ensuing years. I kept in touch with these friends. Some of what I absorbed from them greatly increased self-understanding allowing me to propel forward toward the goal of recovery from stuttering.

My focus today, is on fully-developed adult stuttering. Information I have acquired from these different individuals might be listed under the heading of "theories of alleged causes of the disorder". However, theory has its place. It seems to account for why therapy for adults may fall short of a complete elimination of stuttering behaviour. Before I go any further, I’d like to share with you my own experience with stuttering. It occurred suddenly at the age of thirty-two months, after significant blood-loss from a nasal haemorrhage in the mountains. This was followed by a 300 kilometre car trip home over the roads typical of the year 1928. On awakening the next day, my family was horrified to hear me emitting jargon, despite my apparent good speaking a day or two before. It had the symptoms of a stroke. The physician ordered bed rest for several days. Eventually, meaningful words appeared, interspersed with frequent spasmodic interruptions. I have always supported an organic neurological view of what underlies the anomaly.

While on this point, I'd like to cite my friend, the late Renato Segre. He was born in Italy but lived the majority of his life here in Buenos Ares. He was a neurosurgeon and served as president of the then - World Association, dealing in Speech with some parts concerning Speech Pathology. Our first encounter was in France after a conference in Alicante Spain. We met on Mallorca Island and shared an excursion in my rented car. He told me that stuttering was a neurological abnormality.

Dr. Segre was a largely recovered stutterer as well as a top neurosurgeon. He spoke four or five languages. Unfortunately, in my late 1970's visit to this city, he had suffered a severe stroke that left only the Spanish language functioning. I will always recall my last visit with him. It was at his apartment that had a bird-cage-type elevator. As I peered upward from the descending elevator, I could see him in a great struggle attempting to say "adios" to me. I doubt this was due to stuttering. I am sure it was a result of the stroke. That was the last time I saw my friend, Dr. Segre.

I would like to share a little bit about my early life concerning stuttering. My first recollections of it began around age four. An important point is that my family observed me through the windows playing with cats or dogs. I was fluent when talking to the animals but the minute a human arrived I would begin to stutter. A silent movie film from 1931 shows me blocking, with forced facial movements, when attempting to describe a squirrel climbing up a tree.
About that same time, I was taken to see Mrs. Mabel Farrington Gifford, who was Chief of Speech Correction for the state of California. I remember seeing her in her studio and having to repeat a story that she had recited to me. I received the Gifford method of therapy, applied by various clinicians, through my elementary school years. We were taken out of class and assembled with others in our own speech room and were put through relaxation exercises. We spoke well in that controlled environment but when one of us would begin to stutter, he or she was told to focus on becoming calm. It was implied therefore, that it was wrong to stutter and should be prevented. I spoke rather well in most of those sessions but I would collapse outside, especially when having to recite in class or being under any communicative pressure. The telephone had been an obsessively feared situation. This may be true for most stutterers.

My stuttering frequently bothered me and at age eighteen I began attending private therapy with Mrs. Gifford. She said she had developed an inner calmness, from what she had learned from European authorities, in particular Emil Coue of France and his associates at his school of auto-suggestion. She recovered from stuttering at age twenty-seven. She believed that with positive suggestion applied in the correct way, we could overcome whatever had made us stutter, due to her theory of the subconscious mind. I remember practicing often and I enjoyed being with her. She had the power to make the devil himself feel good.

I participated in that therapy for a year or so before hearing of Mr. Waldo Coleman, who was in his sixties. He had improved a great deal under Mrs. Gifford's therapy. I understood that Coleman had meetings for adult stutterers in his office most Monday nights and I began attending them. I stuttered violently in those particular situations because I was by far the youngest, the most naive, and I felt very insecure. I produced only two or three words a minute with constant bodily struggles. Some people suggested that Mr. Coleman exclude me from the group but he kept me in the group and I will always be grateful. Somehow I gained control of myself after a year or so and I achieved an improvement in speech in that overwhelming situation.

I then began to learn new concepts from reading the works of Dr. Charles Van Riper who played an important part in my life. I never had direct therapy from him nor was I signed up in his clinic at Western Michigan University; however I was around him a lot, often visited, and heard him when he would lecture at national and state conferences. In reading his books, I learned that one didn't have to keep trying to prevent stuttering. That was something I had done often, only to stutter more. I had tried to hide it by using substitution and avoidance. This eventually backfired. It was like putting a lid on Mt. Vesuvius. The steam constantly emitting from its crater must not be suppressed. If it is, lava will build up inside and hasten an eruption. Van Riper recommended that a person confront situations when they stuttered badly. One example was being forced to say my name. It often took almost a minute of contorted spasmodic blockages to pronounce it.

Around that time, I had attended a meeting where we were asked to introduce ourselves. This threw me into absolute fits and I stood there helpless, struggling, with everyone looking at me. Afterwards, I went home, read Van Riper's book again and realized what I should do. I should try to look at myself in the mirror and attempt to
duplicate the way I stuttered at that meeting and try to vary that, by seeing if I could stutter in a more streamlined way. I experimented with this for a couple of weeks, knowing that the same meeting would again occur. Sure enough, this happened. However, this time I had worked at it and had found that I could change the form of my stuttering. I had gained control of it. This, looking back was a critical point in the beginning of my "recovery". I found that it was possible to stutter straightforwardly which lessened the penalties and looks from the people who had heard it.

At this time I would like to cite Dr. Wendell Johnson. I met him when I was in Iowa in the summer of 1947 for speech therapy. I was in the clinic that was also supervised by Dr. Joseph Sheehan, about whom I will speak later. Dr. Johnson had improved his speech a great deal by then but he was still stuttering a fair amount using what we call the "Bounce" pattern. This pattern is a voluntary repetition of initial syllables of words. If I’m speaking now and I want to say "It is a fine day today," I might say "It is a f-f-f-f-f-fine day to-to-to-day." Dr. Johnson taught the course Speech Pathology with about 75 students in the class. He was a good lecturer despite his frequent interruptions in speech and always appeared quite relaxed. Wendell possessed good writing skills. His first book entitled Because I Stutter, which appeared in 1930, is a fine example of describing what a severe stutterer undergoes.

In writing the book, he believed that if he could establish unitary dominance in one hemisphere of his brain, he would cease to stutter. He found out later, that this was not true and spent many years trying different things to improve his speech. It was mainly his having met a man named Alfred Korzybski that influenced his thinking along the lines of using appropriate words to describe his speech behavior. This meant that the self language he had used to portray his behavior to himself had a great influence on what that behavior would manifest. In other words, rather than merely using the word "stutter," use the word to describe what you are doing to interfere with your speech. For example: A person might say, "I press my lips shut." Then, use a problem-solving type of language such as "I focus on relaxing my lips when I talk."

Dr. Johnson established a way of thinking among the speech pathology field that essentially said that stuttering was the result of mislabeling the normal deficiencies that occurred in childhood. His theory has largely been put aside in recent times but it had a tremendous influence on the field of stuttering. I have found it useful to employ a type of language describing what I’m doing in speech. I think it has been a good supplement that paves the way for further improvement. Wendell Johnson became very fluent in later years; he spoke essentially normally with occasional repetition.

Being in Iowa set up many future situations where I met, came to study with, and read the writings of various authorities in the field of stuttering. One of them was Dr. Lee Edward Travis, considered the "Father of Speech Pathology," having been initiated in mid-1920. He was the founder of the department at Iowa. It was to him that Wendell Johnson and Charles Van Riper had come for study and therapy and the non-stutterer Bryng Bryngelson came to take his Ph.D. The well-known theory of stuttering called Cerebral Dominance was formulated at Iowa by Dr. Travis and Dr. Orton. From being in Iowa, I had developed many contacts in the field and from them I learned things that later proved useful in finding new pieces to expand the clarity of the puzzle of stuttering.
Lee Travis had left the University of Iowa in 1938 and had gone to U.S.C in Southern California, where I undertook graduate studies a decade later. He had previously made a complete shift in his thinking about therapy and stuttering. While not totally divorcing himself from the Cerebral Dominance theory, he decided to focus on exploring repressed emotional conflicts as the possible chief culprit in throwing off a safer balance of dominance in one's brain. This called for deep psychotherapy as the manner of uncovering these conflicts. Dozens of stutterers underwent these procedures with many persons spending up to 300 hour-long sessions on a couch verbally pouring out whatever they were thinking and feeling.

I was one of the subjects in this huge undertaking, starting at age twenty-four and finishing almost three years later, after more than 250 sessions with Dr. Travis himself. This procedure was fascinating but after completing the session I stuttered almost as much as when I started. However, it was beneficial in many aspects of my life and I coped better with challenge and stress. On my last session with him, I expressed support for his writings in his 1931 book entitled Speech Pathology that cited neurologic anomalies as causal factors. I did not endorse his psychoanalytic concepts as the basic factor in stuttering.

These concepts appeared in books of the 1950's and 1960's, written in part by Travis. However, I noticed that beginning in the 1970's he went back strongly to his original thinking. This had been clearly exemplified by the first sentence of the chapter on stuttering in his 1931 book, which read: "In general, stuttering is a deep-seated neurophysiological disturbance." In his last writing, done in the mid-1980's, he indicated that the reactions and feelings of a stutterer are resulting consequences of a fundamental root cause of the disorder and that currently there is no elimination of the real possible cause. Drugs being prescribed for stutterers are giving indicative leads that may some day achieve our hoped-for goal. Brain surgery, one potential solution, is too risky to undertake.

However, at this point, I feel obligated to share something of importance: I had read a handwritten letter, by the widow of a then recently-deceased man in his sixties, who had been a severe stutterer for most of his life. I witnessed his obvious speech problem on the only occasion that we had met. The letter indicated that following brain surgery to remove a tumor from his brain, he stopped stuttering and spoke fluently for his final nine months of life. My efforts to obtain more information on this matter have failed. I had hoped to reach family members or co-workers who might have been around at that time.

By mentioning Dr. Charles Van Riper and Dr. Lee Edward Travis, I've referred to the two men that had the most influence on me as far as my degree of recovery from stuttering has been. I think I owe Dr. Van Riper explicit gratitude because he allowed me to see what to do about the actual overt symptom itself and to understand that I could modify it. I do believe that my Freudian free-association-type of psychotherapy from Travis was beneficial but by itself it would not have reduced the severity of my over-all disorder.

The previously-mentioned Dr. Bryng Bryngelson served as a therapist for Van Riper when he went to Iowa around the year 1930 and was practically speechless.
Bryng initiated voluntary stuttering, which loosened his speech and lessoned the severity of his blocks. This laid the foundation for him to become a "fluent stutterer." Dr. Bryngelson helped to wash the windows of my mind. He had confronted me after I had completed a catastrophic speech at the American Speech and Hearing National Meeting in 1956. I displayed symptoms as severe as they had been much earlier in my life. As I was leaving the hall he said, "Young man, you exhibited everything I have said about this. You cannot convince me that this is not neurological disintegration." His well-known statement that the "Stutterer is performing according to the dictates of his organism" certainly held true for me on that occasion.

The public sometimes asks, "why does a stutterer sing without difficulty?" Personally, I have a hunch that it has to do with the communicative pressure involved when a person talks. The moment a stutterer begins to speak he is committed to transmit a message to the listener. Once begun, he or she must continue to talk for the message to be understood; there is no turning back.

A person in the field who became famous was Dr. Joseph Sheehan, who had stuttered severely. I first met him at the University of Iowa for the Summer Session Speech Clinic in 1947. His speech was good then, with only slight remnants of behavior that had been so severe. His major emphasis was on reducing avoidance. . . especially of speech situations and of words. He felt that most adult stuttering therapy was focused on suppressing and trying to prevent moments of blockage. He favored working to modify the behavior by developing smoother ways to stutter. He compared stuttering to an iceberg, saying that the overt symptom formed the smaller part of speech at the top of the iceberg but the larger more destructive part was submerged. Therefore work had to be done on how one felt while speaking. These factors included self image, attitude, fears, guilt, shame, etc., which form the submerged part of the iceberg.

I used to think the solution to stuttering would be similar to finding the right combination to open a lock. Once it was opened, the person would not stutter anymore. This has been proven to be completely false. Normal speaking has a lot of bobbles in it. I find it interesting that some people dislike talking on the telephone and that public speaking is said to be the most dreaded fear of all. Such situations are harder for many who stutter. Perceived stress in a speaking situation is of prime importance.

Another person whom I came to know at the end of his life was Dr. Charles Sidney Bluemel. He was a Denver Psychiatrist, who originally lived in England, came to the U.S. and attended some charlatan schools back around 1906. Bluemel became disgusted with the con artists and initiated a campaign against them. He began to study speech disorders and read everything he could find in French, English and German about stuttering. One lesson I learned from Dr. Bluemel was that in order to speak well you have to think clearly. He put emphasis on the fact that we don't breathe our way to good speech, we think our way to good speech and that the mind broadcasts to the mouth. When I was reducing the severity of my overt blockages, mainly by the system advocated by Dr. Van Riper, I was left with a lot of non-rhythmic, sloppy speech, going from one pot hole to the next, while talking.
I was stuttering far less than I had but I was left with a poor example of speech. I began learning to speak in whole phrases, sentences and thoughts. This had been taught chiefly through Dr. Bluemel. Another thing he said was that it would take several lives to learn how to live. I think this is true in dealing with stuttering. We have to execute a certain amount of trial and error within ourselves in order to gain knowledge of what seems to apply to us regarding the procedures we need to follow.

Robert West was a well known specialist in the field of stuttering. He was originally a faculty member of the University of Wisconsin and I met him in the early 1950's. He was a fascinating man who spoke slowly in a deep voice. I asked Dr. West, "What do you really think about stuttering?" He had a very rich deliberate laugh, and he said "HUH, HUH, HUH, HUH, second cousin to petit mal epileptic fits, huh, huh, huh!" I have never been able to disassociate myself from that explanation. He further elucidated by declaring the likely cause of stuttering as being a weakness in the nervous system and that it is perpetrated by a continuation of that cause, a morbid awareness of stuttering or most probably a continuation of both of these factors.

One day Dr. West shared a concept that rang a bell with me and there is a lot of truth in it. He explained instinctive speech vs. acquired speech. By that he meant that instinctive speech was the basic rhythm pattern underneath all utterances with the acquired part being the specific languages, which are the words and the sounds. A good example of this would be to use a comparison of the sea. When a person looks at the sea from a mountain top there are swells in the water. They might be a kilometer apart, or they might be a hundred meters apart but within each swell there are countless waves. I believe we can make an analogy about the basic underlying pattern of speech by saying it's like a swell in the sea, and the articulation part, the words and sounds, would be like the waves within the swell.

A victim of a severe stroke may be left with only a grunting sound without any sense to it. That would be an example of the instinctive level of speech. The core of the break that manifests itself in a stutterer occurs in that deep underlying and basic level of oral communication, the instinctive part of speech. A stutterer may be stuck on a "d" sound but the required assemblage toward production is impaired due to a mal-function at a deeper level.

I had heard of a girl who stuttered severely until she was around age nine and spoke normally for some decades after that. A traumatic event occurred that caused her to go back to the same pattern and severity of stuttering that she had displayed years earlier. An example of the return of behavior thought to be eliminated would be the case of a Frenchman of sixty, speaking English without an accent. Originally, up to age seven, he spoke only French and claimed that he had totally forgotten all French, unable to speak in that language any longer. Under a deep hypnosis, correctly spoken fluent French flowed from his mouth.

I compare this to a cement sidewalk that is being laid down. A child comes along and lays his hand on the fresh cement and the hand print becomes solid. How is that solved? A person has to pour new cement on top of the old cement. The handprint could be dug out but we can't remove those parts of the brain that might have stuttering recorded in them. We would have to apply a new coat of cement and
everything would look normal until a sand storm arrives. If it is a moderate storm, it might wear down the cement sufficiently to reveal a finger of the hand. But if it were a violent storm, it might wear the cement down and the imprint of the hand would again be revealed. I think this is very similar to what we encounter with stuttering. My past experience has been that in certain speaking situations there is accumulating anxiety or sudden stress occurring. Likely-stored, old stuttering imprint patterns can erupt as fast as a Chinese firecracker. The sequential explosions that follow can be thought of as representing the suppressed stuttering motor patterns exploding in a flash. Dr. George Kopp, one of the early scientists exploring stuttering, would no doubt call this a re-appearance of "psychomotor speech patterns."

Conrad Wedberg, author of the 1937 book, The Stutterer Speaks, wrote that while the cause and cure are unknown, the road toward recovery for an adult stutterer is made accessible only after a person started to explore a personal quest for self-knowledge. He ended it by saying that he stuttered because of the way he felt at any given time. He also stated that cures are never 100% but could be as high as 99%. It is still a mystery. During one's life, a person needs change as circumstances change. These would dictate the best approach to stuttering at that moment, in someone's life. A person should always keep in mind the Credo from Science: "Structure precedes function in the development of a human", therefore any fault in the structure will affect the function emitting from it.

It was the writings that I had read, and then later personally having known Lee Edward Travis, that had given me a meaningful understanding of the physiological aspects involved in this condition. As I originally said, it was Charles Van Riper, a student of Travis, at Iowa, who initiated my first valid options in order to alter my overt stuttering behavior. This resulted in what I prefer to call "wiggle room". I was allowed to stutter and became less "shut in by walls." Until that time, all of the therapy I had received involved preventing stuttering from occurring, so the implication was that it was wrong and something to be avoided and hidden. Dr. Van Riper had mentioned to me years ago that he felt self-help groups would serve a stutterer well. He was not completely satisfied with certain therapies, including his own. If people, who had largely recovered, were able to serve as models for those who felt helpless, much benefit would be gained. He had intended to find means to increase the amount of recovery possible in confirmed adult stutterers. Self-help groups had provided mirrors for me to see myself better and to gain from others experiences in coping with this baffling disorder.

Barry Guitar of the University of Vermont has formulated three helpful goals of therapy for the advanced stutterer. Number one: Talk naturally in your usual way, without using voluntary control. Most stuttering is intermittent and does not comprise the majority of one's speaking. Number two: When necessary, learn to introduce better responses to stuttering and learn how to apply voluntary direction for such moments to your speech mechanism. Try to keep the speech-flow moving forward. Number three: If you feel that you will stutter anyway, learn to do it as gracefully as possible.

Something that had proven helpful to me in the past was written by Harry Heltman, a professor at Syracuse. He felt the four most important things for creating a better chance for an adult stutterer to recover would be the following:
Number one: Having a successful speaking experience. Regardless of how this happens, as long as it is a successful speaking experience it will tend to create a base toward further progress. Number two: Diminish expectancy of stuttering. Number three: Improve social ability to interact with other people. And number four: Increase confidence. These four things to professor Heltman seemed to be the necessary ingredients for improvement in speech, and a successful march toward the path to recovery.

Dr. Bluemel had said he did not make major improvement in his speech until he was in his sixties. He had learned to be kinder to himself keeping his inner-self language and thoughts on the positive side as often as possible.

Bryng Bryngelson, whom I've already spoken about, said something very meaningful. He proposed that truth is a direction and we keep working toward the destination. Think about that for a moment.

I'd like to conclude this speech by summarizing in a loose sense, my credo with regard to stuttering. It recapitulates what I've learned in regard to theory and therapy that I felt might be applicable to my individual situation. This applies to different times in my life when I had different needs. First of all, it is safe to say that no one knows the cause of stuttering and no one knows the cure. However, Professor Vivian Siskin, of the University of Maryland, has cited the important points comprising a good recovery from stuttering: Being able to say what you want, when you want, comfortably and spontaneously without the mental baggage of worry about listener reaction, fear of stuttering and dread.

Finally, we may never reach the wall representing truth completely, but we can move our hand half way to the wall without being able to grasp it fully. But the joy of living and substance behind a durable recovery, involves the spirit of moving forward, toward what ever may be defined as the truth.

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