



ONE Voice

INTERNATIONAL STUTTERING ASSOCIATION | ONE VOICE EDITION 39 | JUNE 2017

what's inside

- 2 *A World That Understands Stuttering*
- 3 *Introducing the new editor*
- 4 *Message from the Chair*
- 6 *Covert Stuttering*
- 8 *In preparation for Japan 2018*
- 10 *ISA board member honored*
- 11 *Stuttering self-help and business partnerships*
- 12 *News from The Indian Stuttering Association*
- 16 *Remembering Dr. Akash Acharya*



'I WANT TO BECOME A POLICEMAN'

The purpose of this article is to give insight into the work we are doing to create positive change in our community, through education material on stuttering, which we have been translating into the local language, printed and freely distributed, to light up the rural communities. Read Bruce's experience here:

Eleven-year-old Bruce is a kid who stutters who lives in a rural area of northern Rwanda, where stuttering is defined by folklore myths.

Bruce dropped out of elementary school because of the myths about stuttering. When he heard we came

to his school, he put aside the fear that stigma caused him and came to meet us. Bruce told us "My teacher teases me a lot in class every time when I cannot answer oral questions and I feel embarrassed and ashamed to come to school". Really, it's so sad to hear this and it's such a shame.

I gave Bruce a wonderful children's book on stuttering called "Sometimes I Just Stutter" [translated into the local language] and I asked him, "What do you want to be when you grow up?" Bruce replied, "I want to become a policeman." "Ohoooo!! It's good to have a dream. But dreaming alone isn't enough. I had to

'THE KIDS WHO STUTTER AND THEIR CLASSMATES LIVE IN HARMONY AND HELP EACH OTHER' from page 1

explain gently that education is very important in life and attending school is very necessary for him to make his dreams come true. Then Bruce understood the importance of education and expressed his desire to continue his studies.

Meanwhile, all Bruce's school teachers received the 8 Tips for Teachers brochure, thus helping them to develop their knowledge about stuttering so that they can support students who stutter in the class-

room. I also included the brochures on all the teachers' desks. We then equipped Bruce's school library with 60 booklets on stuttering for the teachers, the kids who stutter and their classmates.

Currently, at Bruce's school, the teachers, the kids who stutter and their classmates live in harmony and help each other.

At the present time, Bruce is in the fifth year of primary school and he is succeeding well in class. He will build

the confidence he needs to follow his dreams, through these translations of the educational material on stuttering.

We believe that through education, Bruce can become an important figure in his community, and he will never forget the role we have had in his life.

Please feel free to contact us at: africanstutteringcentre@gmail.com

Dieudonne Nsabimana is the Coordinator of the African Stuttering Center

a world that understands stuttering

This year the International Stuttering Awareness Day celebrates a significant milestone, its 20th anniversary!

The awareness day and related online conference has been celebrated on October 22 since 1998. The online conference was initially set up by Michael Sugarman and run by Judy Kuster up to 2012, then taken over by a small team of people including Anita Blom, Dan Hudock, Bruce Imhoff, Hanan Hurwitz, Keith Boss and others, with the support of the International Stuttering Association. Many countries participate in the International Stuttering Awareness Day event in some way, either by directly promoting the theme and message developed for the online conference, or developing their own theme and message for the event.

Groups often engage in media coverage including interviews on TV, newspapers and holding events with stuttering as the focus.

The Stuttering Homepage was the home on the online conference from 1998 to 2012 and archives of those online conferences can still be found there. Archives of the online conference from 2013 onwards can be found at isad.isastutter.org.

The theme for this year is "A World That Understands Stuttering", which the online conference team thought was fitting for the 20th anniversary of this important event.

HOW CAN YOU PARTICIPATE?

Keep an eye on the ISA Facebook page for news about the online conference and how you can make a submission! Content can be in the form of a formal or informal paper, poetry, images, audio or other creative mediums. Watch the Facebook page for details. Submissions close by Aug. 31. You can also participate by promoting awareness of stuttering in your community, either within your own self-help groups or on your own. If you're the adventurous type you might even be involved in radio or television interviews to raise awareness!



We always love to hear what you're doing for the International Stuttering Awareness Day in your country or community, so if you have ideas or if you just want to let us know what you're planning, get in touch, we can share the information on the online conference pages!

Hope to see you at the International Stuttering Awareness Day online conference!

Bruce Imhoff is the Vice Chair of the International Stuttering Association

introducing the editor

I couldn't sleep. I was physically exhausted from upsetting one of the top players in the state in a three-set marathon singles tennis match and I had to drag myself back to court for doubles.

There was Advanced Placement Chemistry homework that had to get pounded out, and parts of Shakespeare's *Twelfth Night* that needed reading and questions answered before Ms. Lunsford's first-period English class.

I should have still been on that high from winning my match, but just couldn't get the brief conversation I had with my AP History teacher out of my head.

You see, I had never been the shrinking violet. My speech therapist in high school, Mrs. Brooks, described me in such a way that I embraced — almost to a fault.

In her words, I was "fearlessly arrogant". I stuttered my way through a summer play in the biggest auditorium in my small town — and even ad-libbed when one of the characters called me by the wrong name on stage.

During high school, I asked questions in the middle of class when I needed answers regardless of what escaped my contorting face, and I didn't give a tinker's dam how long it took for the words to come out.

But that wall, that dam, was always a little fragile, no matter how hard I fought to keep the water at bay.

Earlier in the day, there was a crack. After AP History class, the teacher pulled me aside and told me that for the remainder of the semester, I would not be allowed to ask questions during class time.

His explanation was that my stuttering disrupted his teaching, took up much-needed class time and it made the other students uncomfortable. I didn't buy the latter because my stut-

tering wasn't something that I was either skilled or smart enough to hide from anyone.

It just was a part of me — like a birthmark that I wasn't particularly proud of, but had to deal with.

When that teacher (obviously not a particularly good one), said that to me, I came to a bleak realization.

My stuttering was going to define me. My stuttering was going to limit me in life. I have to go away to college and be in an environment where not everyone will know me and accept me and I will have to speak for myself for the rest of my life.

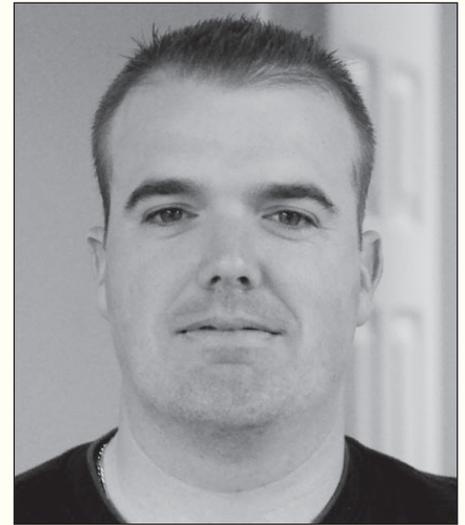
I have no chance at the life I want to have. I stewed on that for the rest of the day, and forgot about it long enough to get through my tennis match and homework, but I couldn't shake those feelings when I finally put my head on the pillow that night.

After rolling around in the bed for about an hour, I finally got out of bed, and wrote all of my feelings in what became, "Your Everyday Senior?". As I pounded at the keyboard, everything came out.

My insecurities, my fear, all of that fake bravado was gone. I had no desire for anyone else to read this — except for Annie. At that time, Annie Bradberry was the Executive Director of the National Stuttering Project (now the National Stuttering Association) and we had somehow grown to have this little brother-big sister relationship over the phone and through e-mail. I shared my story with her and she convinced me to let her publish it in the NSP's newsletter, *Letting Go*.

Annie thought that I had a talent for writing, and after many years and broken roads, I am here — an award-winning community journalist and the new editor of *One Voice*.

As I have said on many occasions, I would run through Hell wearing gasoline shorts for Annie B., and this is my way of paying her back for helping me through some trying times in my



life. My hope is that I will be able to use my tools to help the worldwide stuttering community.

So now that you know a little piece of my back story, this is me in the present tense.

That fearless arrogance has been replaced with a mature realization that my stuttering cannot define me unless I allow it. In my eyes, stuttering might crack the top-five in defining characteristics, regardless how others see me. I am the sports editor of my hometown newspaper and a respected voice in a community I adore and for high school sports in the state of North Carolina.

And that voice stutters like a boss — as do my daughters, Katie (10) and Emily (8). My most important and difficult job is that as daddy of four and husband to my amazingly patient wife, Autumn. As the new editor of *One Voice*, my job is rather simple — tell your stories and share your experiences. I plan on learning more about the International Stuttering Association, its mission and goals and how *One Voice* can better serve you.

Kelly Snow is a 24-time state press association award winner in three states and is currently the sports editor of *The Courier-Times* in Roxboro, NC.

SUFFERING FROM PERFECTION

This coming July marks the end of my first year serving you as your chair.

It's been a mixture of feeling renewed, exhilarated, and often insecure.

Understanding the common dynamics of non-profit boards, a major goal for me is keeping communication open. With this in mind, my first year has been spent in developing our new board, cultivating volunteers, as well as learning about the business side, reviewing and some dreaming, too.... and I'm not done.

Building a unified board is also more difficult when the team is physically spread out around the world. In an effort to remedy this, we have been working hard to keep to our monthly video board meeting schedule. This is allowing us to get to know each other, our visions and promoting trust within the group.

The desire to make an impact motivates us, but it also can create anxiety, including feelings of disappointment and frustration when there is so much to be done.

Each of us needs to know our organizational strategy and our focus and a lot of time and discussion

is surrounded around this so we can fulfill our mission and work in unison as we move forward.

Working at a pace that meets the expectations of my fellow board members and mostly all of you,

I've found myself asking the troubling question: am I making an impact?

Despite our best efforts, change doesn't seem to come quickly enough. However, I feel it is crucial to first do the work mentioned above. This will allow us to function as a group to meet goals and work through the frustrations that can occur as result from the pressure of trying to make big change happen....as well as build a foundation we can pass on...

In my attempt to learn and create solidarity and for us to be clear in our roles on the board, I recently asked each member a few questions.

1 — *What are your expectations being a board member?*

2 — *How do you see yourself participating?*

3 — *Name your No. 1 top priority*

In summary, we found though we might have used different words to describe our thoughts, we all shared the common goal - to make the world a better place for people who stutter.

We said:

— Want to give back for what has been gained from stuttering community over the years.

— Help with public education and getting more resources on the website.

— Put more resources out there for people in

Message from the CHAIR



different communities and countries; practical manuals and agendas.

— Want to be able to officially start self-help movements in other countries.

— Shift perspective and limiting beliefs about stuttering.

— Expand stuttering self-help and participation around the world

MY IMPERFECTIONS...

Each of us involved in the stuttering community are determined to leave a

'WE WILL GET THINGS DONE. I HAVE NO DOUBTS. WE STILL HAVE LOTS TO DO, BUT WE HAVE THE NEED TO SHIFT OUR WORK NOW TO PROVIDING THE SUPPORT THE ORGANIZATION IS SET TO DO. WE ARE STILL LOOKING FOR VOLUNTEERS AND WE NEED TO HEAR FROM YOU.' **from page 4**

lasting and positive impact on our world; changing lives. This motivates me as well, and keeps me up at night.

We all want to make a real and meaningful difference. We came together last July with high hopes and excitement. Our desire was to be a model of excellence! Then we found we weren't to do that...just yet. We had to look at things not through our dreams but through our external reality. There is distance, time change, limited resources, our jobs, home life and even illness....life. This can lead to frustration. "We want it now!" This frustration can be taken out against each other within the board. Thus we now have anxiety or a fear of failure or not measuring up. Are we actually making an impact?

This internal mindset can be the factor that can get in the way from us achieving our goals. This can also be the beginning of internal fighting and burnout. Instead, we are learning to count on each other to do get things done, understand our differences, our individual limitations, and believe in the work we are doing. This is establishing a new way of measuring up "together", learning what we can actually achieve



collectively...and believing in ourselves.

We will get things done. I have no doubts. We still have lots to do but we have the need to shift our work now to providing the support the organization is set to do.

We are still looking for volunteers and we need to hear from you. Help us. The information you provide will assist in our discoveries of

setting priorities.

And now...to the future. I'm taking my insecurities and turning them into energy. I feel so blessed to be part of the ISA.

The stuttering community is so beautiful and supportive.

I envision the ISA to be a leading example of all of that and more! Together we can accomplish this! I look forward to working

with each of you to accomplish this!

Respectfully,

Annie Bradberry is the chair of the International Stuttering Association

COVERT STUTTERING

by Pamela Mertz

Do you stutter? Do you do anything possible to hide your stuttering from others? If so, there's a name for what you do.

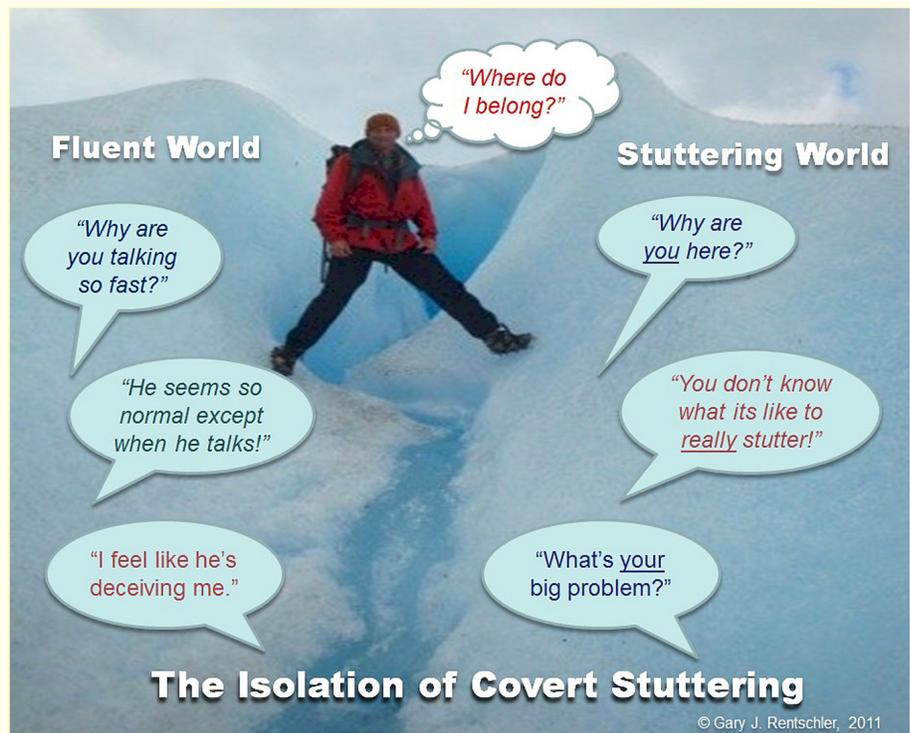
It's called covert stuttering.

First, let's talk about what stuttering is, so we can more deeply understand covert stuttering.

Stuttering is the involuntary interruption of the normal flow of speech. Stuttering often manifests itself in repetitions of sounds or whole words, prolongations of sounds or a complete stoppage of sound, known as a block. People who stutter can stutter mildly or severely and most will find that it can be tiring to stutter. Stuttering is also variable – some people can be fluent for periods of time then have other times when they can barely get a word out. That's what is most often frustrating about stuttering. There are also secondary behaviors associated with stuttering – usually something that the person who stutters does to try not to stutter. These secondary behaviors can include: squeezing one's eyes shut; tapping a finger; facial grimaces; slapping a leg; or stomping a foot. In some instances, the secondary behavior draws more attention than the actual stutter itself.

WHAT IS COVERT STUTTERING?

Covert stuttering can be defined as successfully hiding stuttering from listeners most of the time. People who covertly stutter use various behaviors and social techniques to not stutter. Examples include: coughing to hide a stutter; clearing the throat; scanning ahead and switching words; pretending to be shy or aloof; silence; and avoidance. Some people who stutter can "pass as fluent,"



meaning that people in their circles don't know that they stutter. People who covertly stutter will go to great lengths to hide their stuttering, for it is shameful to them to be exposed as someone who stutters. In fact, it is more shameful to be discovered as a person who stutters than the actual stuttering may be.

People who covertly stutter do so for many reasons. Some have been exposed to negative social reactions in the past and want to avoid experiencing them again. Some of these reactions include rudeness, pity or exclusion. People who try to hide their stuttering may have been teased as a child – either in school or socially. They may have had a hard time making friends. They may have learned early on that stuttering is bad and something to be ashamed of and therefore needs to be kept hidden. People's reactions to stuttering reinforces that something is wrong

and needs to be hidden.

'A HIGH PRICE TO PAY TO SUCCESSFULLY HIDE STUTTERING'

Many people who stutter get excited when they realize that they can hide it well enough to pass as fluent. When they meet someone new and find they are not discovered as someone who stutters, it can seem like a victory. The covert stutterer will try to pass as fluent again and hiding slowly becomes the norm.

But stuttering covertly can be tricky. As successful as the person feels she is with hiding stuttering, she always feels the threat of exposure –so she is constantly living in verbal jeopardy. One slip up and the secret is exposed. One slight repetition or block might trigger panic or that fear we, as people who stutter, know so well.

Most people who hide stuttering

Moving from covert to overt stuttering

FROM PAGE 6

struggle silently. It's very hard to pretend to be fluent if you actually stutter. Many covert stutterers have master vocabularies gained through painstaking word substitutions over the years. Coverts will sometimes rather say something that makes no contextual sense than risk having a stutter be heard. In order to live like this, one has to be constantly on guard, one step ahead of conversations, so difficult words can be anticipated and either switched or avoided. Often, the covert stutterer will choose to avoid speaking situations all together and just choose silence — even if they are bursting to say something.

That's a high price to pay to successfully hide stuttering. Stuttering covertly can be very isolating. The person who stutters who can pass as fluent may feel like they are caught between two worlds — the stuttering world and the fluent world. Sometimes, it may feel as if they belong to neither one.

COMING OUT OF THE 'COVERT CLOSET'

Quite often, the person who stutters when have an "aha" moment when he or she reach the point where it's time to stop hiding. The fear of discovery may finally become greater than the actual stuttering. The person may snap when being asked for the hundredth time if he's forgotten his name.

Maybe he was passed over for a job promotion or maybe lost a job

due to stuttering. The person usually knows when it's time to make a change. Behaviors and tricks that the person who stutters uses to hide his speech may begin to not work anymore and the person may feel exposed and scared.

These feelings may lead the person to say "enough" and be interested in making a change.

'As successful as the person feels she is with hiding stuttering, she always feels the threat of exposure — so she is constantly living in verbal jeopardy.'

"Coming out" of the covert closet is not easy. It means that you are going to reveal to the world that you have a speech difference.

It's a matter of baby steps and the person who stutters may find that he will fall back into hiding habits again

and again while trying to be open. It's probably a good idea that covert stutterers come out gradually — maybe find one or two trusted people to tell that you stutter and that you've hidden it for a very long time out of fear and shame.

Then, move on to telling more people in situations that you feel comfortable. It gets easier each time you tell someone.

Consider advertising that you stutter. Letting other people know that you stutter lessens the surprise factor when a listener hears a stutter or sees stuttering behavior. You can advertise at the beginning of a talk or presentation that you have to do at work with trusted colleagues, or at the start of a job interview.

Advertising puts the issue out in the open and can greatly reduce anxiety and actually be a big relief.

Advertising to every person you

meet that you stutter might feel weird or uncomfortable but if an opening comes up to talk about it, consider doing so.

You can also practice advertising that you stutter by calling random places and having a short conversation to ask directions or at the times the store is open. Indicate at the beginning of the conversation that you stutter and to please bear with you. Most people are patient and understanding. You might also want to practice voluntary stuttering. As counter-intuitive as this may sound, stuttering on purpose gives you some control over stuttering and allows you to desensitize yourself to the feelings you may have by stuttering openly. Voluntary stuttering is another form of advertising. You can choose when and how to stutter.

'The fear of discovery may finally have become greater than the actual stuttering.'

You should start by purposely stuttering on words that you don't typically stutter on. One of the things people who stutter struggle with most is the lack of control when we stutter.

Stuttering on purpose gives you that control and allows you to gradually shake off any negative feelings you may have.

People who covertly stutter struggle just as much as people who overtly stutter. The listener just might not see or hear that struggle. There are many people who covertly stutter. Stuttering is individual and unique for each person.

No two people stutter exactly the same. So if you stutter and find yourself trying to hide it most of the time, know that you are not alone.

Pamela Mertz is from Albany, NY, USA and is the Secretary of the International Stuttering Association's Board of Directors.

WORLD CONGRESS JAPAN 2018



Information about the World Congress Japan 2018

Hello, everyone who stutter in the world!! Here is the latest information on the upcoming 12th World Congress Japan 2018 (WCJ2018).

The date and venue of the Congress has been decided.

The WCJ2018 will be held in the International Conference Center Hiroshima July 13-16, 2018.

This venue is very wonderful location within the Hiroshima Peace Memorial Park.

The "Atomic Bomb Dome" of world heritage is in front of this venue. We want you to visit Hiroshima Peace Memorial Park during your time at WCJ2018.

This experience will be give attendees a glimpse into Japanese history.

The theme of WCJ2018 will be "One World, Many Voices : Science and Community" — 2018

In the Summer of 2018, "Many Voices" with voice of stutter will be gathering. People who

stutter, people who clutter, researchers and clinicians will make "One World". How wonderful it is!!

JSGA (Japan Stuttering Genyukai Association), a self-help group, and JSSFD (Japan Society of Stuttering and Other Fluency Disorders), an academic society, will organize the program which have experience Japanese culture and party, let's fun with us!

In addition, "Itsukushima Shrine" of world heritage and "Okonomiyaki" of most famous Japanese food in Hiroshima will wait you. The IFA/ICA/ISA joint team is doing the Skype meeting every month, in preparation for WCJ2018.

We look forward to seeing everyone of all over the world in Hiroshima of Japan.

Keisuke Saito serves as a core member of the International Stuttering Association World Congress in Japan 2018. He was elected to the ISA Board in 2016 and is the Vice Chair of the Japan Stuttering Genyukai Association and is the director of the Japan Society of Stuttering and Other Fluency Disorders



ISA SECRETARY, BOARD MEMBER RECEIVES AWARD

International Stuttering Association Secretary and Board Member Pamela Mertz was recently presented a special award from one of the co-founders of Stutter Social. Mitchell Trichon, also an ISA Board member, gave a keynote speech at The College of St. Rose in Albany, New York and Mertz was there as a supporter. Little did she know, Trichon planned to surprise her with an award toward the end of his speech.

With Stutter Social hosts looking on via Google Hangout, Trichon presented Mertz with the first-ever Stutter Social Service Award for Outstanding and Dedicated Service to Stutter Social and the Greater Stuttering Community. Pam blogs about stuttering at Make Room For The Stuttering and also hosts a podcast exclusively for women who stutter.

Mertz is also on the Board of the National Stuttering Association in the U.S., serving as Special Projects Co-Chair. Stutter Social was started in 2011 by Trichon and co-founders David Resnick and Daniele Rossi. Stutter Social is a virtual stuttering support group using Google Hangout software as the platform to bring people from all over the world together for a live video chat with other people who stutter. Mertz is a long-time host, sharing the Sunday evening spot since August 2013.

Hangouts usually have between 8-10 participants in a call and the host acts as a facilitator to keep the conversation flowing. Hangouts are scheduled for 90 minutes and members can come in anytime during the call and stay as



(left) ISA Board Member Pamela Mertz with Stutter Social co-founder Mitchell Trichon after being presented the first-ever Stutter Social Service Award for Outstanding and Dedicated Service to Stutter Social and the Greater Stuttering Community.

little or as long as they would like.

Anything related to stuttering is discussed at hangouts. Members can suggest a topic or the facilitator has one prepared for the session. Visit www.stuttersocial.com for more information.

Why do I stutter?

*Why is my hair red
just like Uncle Fred?
Why do I dance like Daddy
And hate pickles like cousin Maddy?*

*Why does my smile look the same
As Grandpa James?*

Why do I stutter?

*Why does my mouth feel tight
My tongue in a fight
My stutter tries to flee
While I am saying the word th-th-three*

Why do I stutter?

*Before you were born
You had a great grandfather*

*He also stuttered
And also his mother*

*Your part of this family
Through and through
Stuttering has been around for ages
It's not anything new*

*You stutter my child
Because of family history
There is nothing wrong with you
It's not a big mystery*

*Just like your family before you
You need to be strong
And teach other people
Don't worry, there's nothing wrong!*

It's not a big deal

BY KIM BLOCK

*When your lips want to dance
You still have plenty to say
So dance, dance, dance!*

*Please don't interrupt me
And guess what I say
It just adds pressure
You get in my way.*

*I expect patience and respect
No doubt about that
Could you trade places
And not want to trade back?*

*I am so excited
And have lots to say
I expect patience
So have a seat, and I'll tell you about my day*

current activities of the AMBI

<http://ambi.org.il/>

LECTURES TO SCHOOL CHILDREN

This year, the book "Paperboy", by Vince Vawter, was chosen by the Department of Education as part of the program to encourage reading in middle school.

AMBI is participating by giving talks to school children about stuttering. These talks include:

- Explaining what stuttering is, and what it is not (the facts).
- Explaining and demonstrating the experience of the child who stutters at school (with much thanks to videos created by The Stuttering Foundation).
- Explaining and discussing the need to accept "the other", i.e. people who are different from us.

EMPOWERMENT (SELF-HELP) GROUP

In this group we do activities designed for empowerment of PWS. Those activities include:

Stuttering Championship

In such meetings, each one of the participants stands in his turn on stage and speaks while stuttering. The goal of the speech is to stutter the best way (speech subject is of no importance).

Participants are free to stutter naturally or intentionally. It is up to the participant how natural he or she wants to be. At the end of the meeting, all participants vote for the best stutterer or the stuttering champion.

Empowerment Discussions

In this kind of meeting, we are discussing important topics for people who stutter. Typical topics are:

- Stuttering and family life

– Stuttering on job interviews.

– Stuttering at work

– Stuttering on dates

Such meetings are usually divided into three parts in which:

– Discussion about the bad aspects of the topic.

– Good aspects of the topic are discussed

– We try to take a look on the future (relative the discussed topic).

Until now, all AMBI activities were in Hebrew, but recently we started empowerment group in meetings in English.

The rationale of making meetings in English is that there are PWS whose stuttering is different in a alternatives languages. Meetings in English provide AMBI members an opportunity to experience English speaking.

AMBI TOASTMASTERS GROUP MEETINGS

It appears that Toastmaster is highly beneficial for PWS. The AMBI Toastmasters is still not officially chartered, but are looking to do it soon.

AMBI DEBATE GROUP

Debates gives members an opportunity to experience a state of verbal confrontation

LECTURES FOR SLP STUDENTS AT UNIVERSITIES

In these lectures given at universities for speech language pathology students by experienced AMBI members, speakers (who are people who stutter) explains what are the problems of PWS and what they feel while stuttering.

AMBI SCIENTIFIC MEETINGS

These are lectures given by professionals or researchers mainly SLPs. Sometimes we also have lectures given by mature and experienced PWS.

AMBI HOTLINE

This is a telephone number to which people may call and get information about:

- Treatments possibilities
- AMBI activities
- Immediate support

SUPPORT TO PARENTS AND YOUNG PEOPLE WHO STUTTER

Supporting young people who stutter by private meetings with adult people who stutter. This is done, as are all AMBI activities, on an entirely voluntary basis.

EXPLAINING STUTTERING TO PROVIDERS OF CUSTOMER SERVICE

AMBI is starting to participate in training seminars about disabilities, being given to people who provide customer service. Our first such event will be in May, when training on disabilities will be given to people who work at the main duty free store at Ben Gurion International Airport in Israel.

STUTTERING RECOGNIZED AS A DISABILITY

After working for many years on this topic, we have succeeded in having stuttering recognized as a disability by the Social Security Agency, so that PWS can get support if needed.

Partnerships between stuttering self-help and business

Thinking of cooperations between NPO and companies often means to raise money for donations for social projects in different ways.

But there are much more possibilities for us to cooperate with companies and to gain an impact on our interests for people who stutter. They have much more resources to provide and to invest for our stuttering self-help activities than we respond.

In this context, professionals talk about the so-called "Corporate Citizenship Mix" – the social and civil engagement of companies. It consists of nine instruments how companies engage for social and civil society purposes.

Companies can spend financial or material resources or can dedicate their products, services and logistics for free to stuttering self-help organizations or groups.

We all understand what financial resources mean, but what about the others.

For example, companies can provide us their event equipment, like a beamer or meeting rooms for free, which we can use for our national stuttering conferences. They could

sponsor the catering or provide us their website solution for free to inform about stuttering and our self-help offers to affected people.

They could potentially print our marketing materials for free.

These engagements are called Corporate Giving.

Another well-known cooperation possibility is to provide helping hands, know-how and knowledge from employees of companies to support our self-help activities – referred to as corporate volunteering.

Currently, the ISA board is getting team coaching and organizational counseling for free. Two coaches from Germany (both worked in big counseling agencies and are now self-employed) provide their knowledge and time for free.

In two or three meetings, they help us to grow together as a team and to work in an efficient and effective way.

Others possible cooperations could be, if an information technology professional of a company builds or hosts the website of a self-help organization for free, or employees help design a flyer or create and produce a fundraising clip to put on

social media.

Companies are also good multipliers, have a lobby, contacts, networks and can have an active influence on specific topics – like stuttering and self-help.

We should use these strengths for our interests, as well.

Companies can inform their own employees via staff magazine and customers via social media about perceived disabilities, like stuttering and how to deal with it.

For example, they send information about stuttering and other vocal difference to their business partners, or a newspaper could publish a story about people who stutter and their success in dealing with it through self-help activities while publicizing self-help events. These social engagements of companies are called social lobbying.

There are some more cooperation possibilities.

This list should provides an idea of the wide range in collaborations with companies, which can have a major impact.

Anja Herde is an International Stuttering Association board member

Stuttering syndrome: Light at the end of the tunnel

The presence of the International Stuttering Association (ISA) and the International Fluency Association (IFA) has, without mincing words, helped to open the doors of stuttering to the outside world and Africa, in particular. Stuttering has long been interpreted as a witchcraft in developing countries, but is now an open topic in Uganda. People have started to see it scientifically as hereditary in nature, thanks to ISA

stuttering campaign. The sharing of stuttering research findings among world associations has had practical impact in stuttering awareness through congresses. I am happy and bravely admit that the ISA scholarship program has had a positive impact on developing countries attendees and as a result several people attended the ISA Congress in Atlanta. I was honored to be nominated as an ISA board mem-

ber, representing not only Uganda and East Africa but also Africa in general. World congresses unite and effectively make information sharing result-oriented where professionals get first hand questions from people who stutter and vice versa.

Joseph Nsubaga is the founder and coordinator of the Easy Speak Association



TISA CELEBRATES NATIONAL CONFERENCE

The anxiously-awaited TISA event, the national conference finally happened on the shores of Varca beach, amidst the choirs of waves and winds in the land of sea and sand – Goa.

DAY 1

The lobby and reception area of Varca Le Palms beach resort, the venue of the conference were soon witnessing the hustle of PWS arriving from across the country. The banners with TISA logo and captions saying "Haklao magar pyaar se..." hung at the entrance.

Registrations began, with TISA volunteers manning the registration desk. After a quick cup of coffee and biscuits, we all gathered in the conference hall. Harish welcomed all participants and announced that the conference will kick off with four informal parallel group sessions:

1. *Techniques Group*: Targeted towards the newcomers, this session was about learning different

techniques – bouncing, prolongation, cancellation and practice in group. Vikas Ranga and Dhruv Gupta facilitated these sessions, and with their great facilitation skills they made it interactive and participative. The sessions gave opportunity for the newcomers to experiment with their speech, practice and have fun at the same time.

2. *WWS (Women who stutter) group*: Led by Mansi, Soumya and Anita, this group was dedicated to the women who stutter, and a space to discuss their issues. The girls discussed several issues and time was just not enough to complete the agenda for this group.

3. *Parents and Family members*: Dr. Sachin led this group of parents / family members who had come along with the participants.

4. *Personal Sharings*: The fourth group was about personal sharing. This was led by Ravi Kant Sharma, Amitsingh Kushwaha and Harish.

Here, participants just came forward and shared their stories of courage, journey of acceptance, coordinating SHGs and just anything that they wanted to share.

After lunch, we had a formal welcome address by Harish. This was followed by open-mic sessions for the newcomers and first timers. Most of the members had the stories to tell about their schools, colleges, roll calls, buying things at a shop – all those stammering issues that makes us think – "yes, I have been through this as well".

During the group-sharing activity, the four groups that were formed in morning sessions came forward and shared what was done during their sessions.

Finally, after dinner, a talent show was organized by Vikas Ranga and Vishal Gupta from Delhi. This gave an opportunity for the PWS to come forward and display their talent. While some displayed their acting

THE INDIAN STAMMERING ASSOCIATION

'THE INTERESTING THEME AND PARTICIPANTS ENTHUSIASTIC PERFORMANCES MADE THIS ONE OF THE MOST AMUSING SESSIONS OF THE DAY' from page 12

skills, some read out their poetry. Dance performances, storytelling and various other hidden talents were exhibited during this fun session that happened on the shore of the Varca beach.

DAY 2

We kicked off day two with an insightful session by Dr. Farida D'Silva Dias, a Goa-based psycho-therapist and counsellor.

Dr. Farida spoke about "Cognitive Distortions": how our mind programs itself to start thinking negative with self-blame, guilt and self-victimization. She explained various 'categories' of cognitive distortions and gave tips on how to recover. The session was interactive with members sharing their experiences and a question-and-answers session.

The WWS team followed with an amazing skit highlighting the issues faced by a girl who stammers at various stages of her life. The skit revolved around a fictional character named "Bhavna", and her story from denial to acceptance of stammering.

After the skit, Soma from Bangalore gave a presentation on her journey of acceptance. It was a story of her ups and downs, how her father helped in pumping confidence, how acceptance and spiritual practice helped her deal with all the not-so-easy moments of her life.

Post tea, we had two parallel sessions. Tarunidhar from Bangalore conducted a Yoga session, which covered some asanas that would help not just speech, but overall well-being. Tarunidhar says, the session focused on achieving compassion in heart – most essential for one's acceptance of himself.

On the other end, a role-play activity called "Hakla planet" was going on. The theme of this activity was interestingly reverse of real life –



"What if 99 -percent of the people on the planet stammered, and 1-percent had a 'fluency disorder'?"

Five groups had to prepare and act out a role play on this theme. Different teams performed on different situations- Some of the role plays were: "People forming an association called 'The Indian Fluency Association', and revolting that 'fluency' is not a crime", "Parents demanding additional dowry because the potential bride is 'fluent' speaker", and "A fake self-proclaimed godman who claims to cure fluency". The interesting theme and participants enthusiastic performances made this one of the most amusing sessions of the day.

Post lunch, there were again groups split. The WWS (women who stutter) group spent time with Dr. Sachin to discuss their issues. On the other side, a session was taken on communication skills by a Toastmaster from Goa, and also a PWS.

The Bangalore SHG then had a skit learning session on 'How to coordinate an effective SHG meeting'. In a

unique way of delivering the message by recreating the SHG meeting scene, the Bangalore group gave some very good tips on how to conduct a SHG, some do's and don'ts and even took questions from other coordinators. The professionalism showed in the performance as the group also distributed pamphlets which covered all the tips to the audience for reference.

It was finally the time for the most awaited performance of this year's national conference. The team behind successful and unique experiment conducted by Mumbai and Pune SHGs, sphere-headed by Dhruv Gupta, of a Theatre Workshop for people who stammer was here. The team consisted of the PWS who participated in the workshop, professional actors and a director of the play. The play was titled "People who Buffer", and every participant was eagerly waiting to witness the performance of this play live. The people who buffer team put out a splendid performance and enthralled the audience with the

THE INDIAN STAMMERING ASSOCIATION

'THE SONG AND DANCE WITH VARUN BROUGHT ABOUT A LOT OF ENERGY AND IT TURNED OUT TO BE A FESTIVE ATMOSPHERE' from page 13

play which revolved around the life of a PWS, and challenges faced in daily life.

It was evening as the play ended, but the agenda was not done yet. We had a special celebrity guest – Varun Carvalho from Goa. Varun Carvalho is a Goan music composer, singer and lyricist and also a PWS.

He also came out open in public about his stammering, and after learning about the TISA National Conference in Goa, promptly agreed to visit for a special musical session. Varun spoke about his stammering journey, and said that it was because of his stammering that he chose to become a singer. He owes all his success to his stammering. After a few musical performances, the PWS also joined Varun and sang on the stage. The song and dance with Varun brought about a lot of energy and it turned out to be a festive atmosphere – indeed a celebration of our diversity. Varun also distributed copies of his music album CDs to all participants.

Post dinner, the celebrations continued with DJ party on the dance floor. The PWS across the nation danced to their heart's content and showed how crazy the PWS can sometimes get.

DAY 3

It was finally the closing day of the national conference. The day began with prize and certificate distribution to appreciate and recognize some of the wonderful voluntary contributions done by SHG coordinators, PWS and even parents. Awards were given in categories like 'Best Innovation in SHGs', 'Prolific Blog writer', 'Most energetic volunteer', 'Women of Courage', 'Teenager with Courage' and so on.

Then it was time for some for-



mal presentations by senior TISA members on some serious topics. Dr. Akash Acharya, from Surat, one of the founding members of TISA, spoke about his own perspectives of speech therapy and his learnings of the same.

Virendra Sirse from Pune spoke about how his acceptance helped his career and how his company encouraged his new attitude towards stammering. Anupam Saxena from Bangalore gave a presentation on 'Benefits of Stammering' and Vishal Gupta from Delhi gave a presentation on "Iceberg analogy of stammering".

After the formal presentations, there was open-mic session for all those who had not got a chance to speak. Participants came forward and talked just about anything. Finally, the NC final session was concluded by the "Ha-Ha-Ha-Hakla..." song from the People who buffer play.

During the lunch time, people exchanged numbers, contacts and finally the big ritual of the group picture of all conference participants

was completed.

The 6th National Conference was thus concluded with success and celebrations.

HIGHLIGHTS FROM THE NATIONAL CONFERENCE

– This was the first time when a TISA National Conference was streaming live on Facebook.

– This was the first time when a TISA National Conference had a media partner. A local newspaper, Gomantak Times came forward to be the media partner of the Sixth National Conference of TISA, and covered the entire event as part of this partnership.

- A local celebrity who stammered participated and acknowledged about his stammering.

- The participants consisted of 88 male, 10 females and 5 among family and friends.

advice for conducting communication workshops

These guidelines are not mandatory. These are only good practices, offered as advise. PWS who are organizing Communication Workshop or such events may adopt or adapt these ideas, based on their requirements and local realities.

1. NUMBER OF PARTICIPANTS SHOULD NOT BE MORE THAN 25 (IDEALLY 20)...Girls, young and new participant should have preference over old TISA regulars AFAP. In larger groups, new comers and shy people may not get much chance to speak or individual feedback from the facilitator.

2. FACILITATORS SHOULD BE A TEAM OF TWO (OR THREE) EXPERIENCED, WELL-INFORMED PWS.. who have spent some time on the path of self-help. Focus should be on learning-by-doing — group activities where people learn about themselves and their stammering. Like role plays, videography, stranger talk, stammering interviews etc. rather than "expert lectures"

3. THE FACILITATORS SHOULD DEVELOP AN AGENDA IN ADVANCE ...and think through minutely every activity and should get it vetted by other experienced facilitators in or outside TISA.

4. THE SCREENED AND SELECTED PARTICIPANTS SHOULD BE PUT IN AN WHATSAPP OR EMAIL GROUP... at least 6 weeks in advance for getting to know each other and cover as much ground as possible, BEFORE they meet. Many new-comers may need to read some basic documents on Acceptance and other ideas promoted by TISA.

5. FOR ADVANCE PREPARATION- THE PARTICIPANTS SHOULD BE ASKED TO PUT UP A TEXT BIO AND A SELF-VIDEO ...on TISA blogsite plus therapy history or whatever they have done in the past, to help themselves. (TISA cannot help them unless they are willing to open up and go public); a conference call /Skype /Hangout with all the participants 1-2 weeks before workshop can also be a very useful step.

Facilitators get to actually hear the participants and accordingly prepare and decide, who needs more attention or help.

6. WORKSHOP CAN BE EITHER 1, 2 OR 3 DAYS LONG...depending on facilitators, venue and other factors. Even in one-day workshops, outdoor activity should take precedence over indoor discussion. Intellectual discussions never end. What benefits us is confronting our fears in real life situations — with help of a group.

7. SOCIAL ACTIVITIES - DANCING, SINGING, RECITING POEMS, ROLE PLAYS, MINI SPEECHES SHOULD BE ACCOMMODATED... since PWS often have under-developed social skills.

8. A T-SHIRT WITH A BOLD STATEMENT ABOUT ACCEPTANCE OF STAMMERING SHOULD BE WORN... on all the days of the workshop wherever possible.

Communication workshops are not just about promoting good communication skills - but it is also about empowerment. Wearing such a t-shirt and going out in public can be a big step in that direction.

9. IF ALL PARTICIPANTS CAN STAY CLOSE TOGETHER...to promote feeling of belonging to a community - it will be helpful.

But it is okay if some local participants join during the day only.

10. LAST ACTIVITY, SHOULD BE PERSONAL GOAL PLANNING...which can and should be followed up, by the group, through Whatsapp or other means.

11. ATMOSPHERE SHOULD BE FOCUSED BUT NEVER BORING...Serious and joyful. Also, we should maintain atmosphere fair to everyone- women, young, ethnic / linguistic minority etc. Let there be respect for everyone.

12. THESE WORKSHOPS SHOULD ALWAYS BE SELF-SUSTAINED... Registration fee should take care of almost all the direct expenses. It should not become a financial burden on any one person. Financial details should be shared on the blog, website, or with national coordinator.

13. ON SOME EVENING, ON THE SIDE LINES, TRY AND ACCOMMODATE AND OPEN SESSION...for those PWS, parents of PWS, curious people, who come to know about TISA through media coverage and promotions and who have not registered in advance. This can be kept on the final day, only if workshop duration is more than one-day. If a journalist wants to participate in this open session, he or she too should be welcomed.

14. THE FACILITATORS SHOULD ALSO ENGAGE IN FOLLOW-UP... through emails or whatsapp, answering questions and offering hand-holding post workshop.

15. A BRIEF REPORT, WITH COUPLE OF PICTURES, ON THE BLOG IS A GOOD IDEA...for future reference. The report should describe briefly the activities and also have a crisp analysis OR important lessons learned and training resources used in the workshop.

Remembering...

Dr. Akash Acharya

It is with much sadness that I report the recent death of Dr Akash Acharya. Akash was a person who had a severe stammer.

He was a founding member of the Indian Stammering Association. In his role of core group member of TISA, Akash had been active in trying to develop linkages with other such associations around the world in countries like Nepal, Pakistan, Mauritius, Germany, China, Denmark and Poland. Akash also served on the Advisory Board of the International Stuttering Association. He was a gifted academic with a great sense of humour and lived in Surat, India. He will be sadly missed by all who knew him. Blessings to his family and those who shared his life. The following is from Harish Usagonker

On Tuesday morning, I woke up to the sad and shocking news of Dr. Akash's death. Dr. Akash, who had been a great source of inspiration- humble and down-to-earth, and yet a proud stammerer who opened his presentations accepting he has a stammer. Though it was difficult to digest this development and the circumstances, all we can say is life can never always be fair. Yes, we also have to accept this bitter truth!

My memories with Dr. Acharya goes back in 2009, when I was taking my first steps towards acceptance. I had started writing very often on TISA blog. Little did I know that there was this co-founder of TISA from Surat, who silently followed all TISA blog posts. One fine day, Dr. Akash Acharya contacted me on Orkut (popular social network in those days) and told me that he read my blogs, and wanted to connect with me for a

long time. He then introduced himself to me, and I was pumped up with his encouraging words, to write more. My first meeting with Dr. Akash was in Feb, 2010 in Pune. Keith Boss from the British Stammering Association (BSA) was visiting India and SHGs in India. We had a 2 day interaction with him. Dr. Akash Acharya came all the way from Surat, with his mother for this interaction. I had gone there with Santosh (Now in Mumbai).

Dr. Akash and his mother were staying in the adjacent room in the lodge. When we got some free time, Dr. Akash invited me to his room- for some time together with him and his mother. This was my first interaction with him in person. He was cheerful, little humorous and loaded with ideas. He shared some of his ideas for TISA, which was beginning to evolve. He discussed about NSA conferences, and how he has a vision for a TISA national conference. He even jokingly said- "Now that we found someone from Goa, we can think of our first National Conference in Goa!". We then discussed a few more things about our personal lives, careers and hobbies. Dr. Akash's mother was very loving and she also participated by telling us how she encouraged her son and helped him with his stammering. Fast forward to 2016, and I was indeed organizing a TISA National Conference in Goa (though not the first edition). Dr. Akash was very much keen in attending the National Conference in Goa. He said on mail- "I have been disconnected from TISA for some time, with this I would love to reconnect..." He did it, and in style.



On Day 3, he gave a presentations on "Reflections on Speech Therapy". He shared his therapy experiences, and his reflections and learnings from the same. He took all the questions patiently.

My second meeting with Dr. Akash Acharya in Goa was also fulfilling. Interacting with him and his mother after a long time was a great feeling. This time, I noticed a more mature and composed Dr. Akash Acharya, much more focussed about his ideas. After the conference, he told me how happy he was to reconnect with TISA and contribute by giving the presentation. He wanted to go back and revive the Surat SHG.

Dr. Akash Acharya will be missed dearly. He will stay in our memories. The footprints of inspiration that he left behind him will continue to make us strong.

Finding victory at the NSA conference

Anyone who knows me can attest to the fact that I constantly strive to be the victor and not the victim.

Before the National Stuttering Association (NSA) conference, I always thought, being a victor meant remaining aloof from the struggle. In other words, don't identify with it or accept it — rise above it because you're better.

I love to write and speak about this very concept. I even dream about it. That very vision of myself crumbled when my husband sweetly confided in me that he found this "conference thingy happening soon about stuttering and that we should probably join."

Yeah, about that.

There was nothing to talk about really. He didn't even have to finish the word "stuttering" before I knew that there was absolutely no way in Hell that I would be joining such a thing. End of story...except not.

Fast forward to a few months later.

We arrived in Atlanta and I can feel this weird feeling like I have never felt before. All these thoughts were swirling in my head. How could I have been convinced by my hubby to come here.

Like actually?!

Yes, he managed to arrange a scholarship for us since we were flying in from Israel.

Yes, he consistently reassured me that he would be there for me the whole time to support me.

But we were here now.

"You got this."



(No, I didn't...I soon learned that was okay.)

We entered into the massive conference hall and I was so surprised at how inviting and fun it all looked. There were so many people. A friend of ours came right up to us and helped us sign in and made us feel right at home. We had one workshop, another, 'forced' time to talk to others and do talking experiments

together.

It was liberating. No actual word in the entire English language can describe what I felt and thought in these moments. I felt like I was able to open a part of myself that was closed for too many years.

It humbled me to look into another person's eyes and listen to them talk so beautifully with a stutter. I met people with stutters far more severe

NATIONAL STUTTERING ASSOCIATION

'IT HUMBLLED ME TO LOOK INTO ANOTHER PERSON'S EYES AND LISTEN TO THEM TALK SO BEAUTIFULLY WITH A STUTTER' from page 17

then mine. It made me want to shake because it's not fair they have to be in pain. And then I met others who stuttered more easily and comfortably than I do, but I have never seen such patience, love, acceptance, and the 'we got you' feeling.

One part that was such a breakthrough for me was the open mic.

Everyone is encouraged to take a chance, grab the mic and talk — and say whatever they want. I so badly wanted to go up, but I was too scared, shy, nervous, and embarrassed.

My husband kept trying to persuade me. Finally, at the last big open mic ceremony, aided with a big much-needed hand squeeze from my husband, I took the stage.

And boy did I take the stage.

I got up there and started deliciously speaking.

It was so nerve-racking at first but felt so good. I had so many supportive, caring, patient, understanding eyes that were waiting to hear me. I spoke and spoke and didn't want to stop, even though I was bawling. The stories I heard from other people moved me to a place like no other.

I left that conference changed.

It was way too overwhelmingly intense for me to process it. I never experienced something like this before. The culmination of such beautiful people, so raw, pure, as-is, determined, and open.

Such light, I tell you.

You really have to be there to believe it and feel it for yourself. One of the numerous lessons I internalized is there is only one you and you are needed.

All of you.

All those unfinished, tarnished, dusty, ragged-edges lined with



triumph and falls tied with pushing and trying and fortified with love and strength that only the bravest of you have seen.

A strong person falls seven times and yet still brushes himself off and gets back up. That's a victor — not being afraid to fall and to still get back up and keep climbing.

Accepting that we are so gorgeously imperfect and human and whatever we've got to work with, will

only be a stepping stone to dig deep and rise higher.

Every person is struggling and trying his or her best — whatever that might be, so never judge a fellow soul because we all are on our own journey and together, we've got this.

Riki Druin-Holtzman attended her first National Stuttering Association annual conference last year in Atlanta. This year's conference will take place July 5-9 in Dallas, Texas.