

PRESENTS

StutterF&ST! 2321 Saturday, May 8th

> A 20-hour celebration of the worldwide stuttering community

> > worldstutteringnetwork@gmail.com

### Check it out!

We have something for everyone. Join when you can & stay as long as you like!

www.worldstutteringnetwork.net

### **Contacts:**



### **StutterFEST 2021 Overview**

Time	<b>Main Stage-</b> Breakout Room #1	<b>Research</b> <b>Symposium</b> Breakout Room #2	Specials/Podcasts/ Improv Breakout Room #3	World Friend- ing
5am EDT 9am UTC	:00 SEAtalk: Hanan Hurwitz :20 Nottingham Support Group :40 Stutter UAE			
6am EDT 10am UTC	:00 SEAtalk: Anita & Sigga :20 SAY: Australia :40 SAY:Australia			
7am EDT 11pm UTC	:00 SEAtalk: Satu Nygren :20 Scottish Stammering Network :40 "			WF
8am EDT noon UTC	:00 SEAtalk: Jurgen de Jong :20 STAMILY :40 STAMILY			
9am EDT 1pm UTC	:00 SEAtalk: Sam/Henry/Tom :20 Stutter Proudly (Baer) :40 STUC: Claire Norman		Podcast: Stammer On with Lynn Mackie	
10am EDT 2pm UTC	:00 SEAtalk: Anita :20 Global Work Initiative(Kunal) :40 Jane Fraser with SF		STAMMA: Women ONLY with Christine Simpson	
11am EDT 3pm UTC	:00 TISA :20 " :40 "	:00 Per Alm :30 SheikhBahaei		
Noon 4pm UTC	:00 Stuttering Scholarship Alliance :20 " :40 "	:00 Goncalo Leal :30 Pierpaolo		WF
1pm EDT 7pm UTC	:00 CSA :20 " :40 "	:00 Joseph Donaher :30 Shelly Jo Kraft		
2pm EDT 6pm UTC	:00 SEAtalk Mary Wood :20 " :40 Stutter Block Party (Marv)	:00 Gerald Maguire :30 EMALEX		
3pm EDT 7pm UTC	:00 SEAtalk: Angelica :20 FRIENDS	:00 Anelise Bohnen :30 Wrap up with	Podcast: Stuttering is Cool with Daniele	

	:40 Spero w/Ana Paula Mumy	Tricia Hedinger	Rossi	
4pm EDT 8pm UTC	:00 SEAtalk-Nina G :20 South Africa :40 with VR		Podcast: I-I-I am a podcast with Gen Lamoureux	
5pm EDT 9pm UTC	<ul><li>:00 SEAtalk Tricia Hedinger</li><li>:20 Open Stutter</li><li>:40 Open Stutter</li></ul>			
6pm EDT 10pm UTC	<ul><li>:00 SEAtalk Nathan Malipeddi</li><li>:20 Shared Voices</li><li>:40 Kunal- Work Initiative</li></ul>	SEAtalk: Jhoan Columbia LatinAmerica Danisa	Podcast: Stutter Stories with Tricia Hedinger & Jia Bin	
7pm EDT 11am UTC	:00 SEAtalk Dale Williams :20 30-10-0 :40 SEAtalk-Jia	Mitchel Jorge Ecuador (Liseth) Paraguay (Cinthia)	Improv: Dahlia	WF
8pm EDT midnight UTC	:00 :20 :40	Spanish St Assoc COACER - Chile APT (Peru)- Nico	:00 Stutter Block Party	
9pm EDT 1am UTC	:00 Tague Zachary :30 Bobby T	Brazil- Annelise S. America-Angelica		
10pm EDT 2am UTC	:00 SPEAKeasy Australia :20 Cody Packer-Mindfulness :40			
11:00 EDT 3am UTC				WF
12:00 EDT 4am UTC	:00 Transcending Stuttering with Uri Schneider			

## **Support Group Presentations**

### (join 20 minute presentations from organizations around the world)

PUNTO DE ENCUENTRO PARA PERSONAS QUE TARTAMUDEAN, SUS FAMILIAS Y PROFESIONALES EN TERAPIA DEL HABLA

### Asociación Paraguaya de Tartamudez (Paraguayan Stuttering Association)

*Cinthia Hieber.* "I am 47 years old, I stutter since I am 6. My husband and I have been happily married for 25 years now. I work as Administrative Director of an NGO and at honorem as Treasurer

of another NGO. I founded Paraguay's first stuttering support group 5 years ago and currently I am the President of the Paraguayan Stuttering Association that was founded on 22.10.2020. I have given talks and conferences at national and international level on the subject in both government institutions and NGOs and regularly give radio and television interviews to raise awareness of stuttering."

My presentation will be about my journey in life with stuttering, you can also call it "how to be happy despite of stutter". I have a love story to tell, about a girl who thought she would never get married, that no one would love her because of her severe stuttering. Trying to hide the stuttering all the time, not accepting it, 4 attempts of suiciede due to severe episodes of depression in her childhood and adolescence, without the capability to imagine a nice future for her life. Living three and a half years in Germany in my thirties, for the first time in my life I met a support group for people with stuttering and when I returned to Paraguay I wanted to attend one but there was not. I spent several years waiting for "someone" to form one until I had the notice that a 12-year-old committed suicide here in Paraguay for not tolerating bullying for his stammer. That was the moment when I realized my own purpose in life. That was the breaking point for me when I decided to start a support group for people who stutter. Since then I have been in countless radio & tv interviews, conferences, etc. making awareness work about stuttering in Paraguay, Argentina, Brazil and the USA (in person) and virtually in several webinars in Latin Amerika. My desire is to encourage others to not hide their stuttering, to be fulfilled despite this condition.

- 1. It is ok to stutter, you don't need to hide it.
- 2. You don't need to condition your dreams because of your stutter.
- 3. Life is worth living.



#### **Colombian Stuttering Foundation (Columbia)**

*Jhoan Gallego*. "I lead the community of people who stutter in Colombia. Call "free your speech". I am SLP and I would like to talk a little about the community of my country and the Foundation."

On April 16, we started the chat group "Free Your Speech." Designed to form the community of people who stutter only from Colombia. Now we

are 104 people publishing only through social networks. Many people have found comfort in knowing and recognizing that they are not the only ones, listening to other experiences, and being in the group is a good start for the acceptance of stuttering. Some have seen satisfactory changes with the support group. The foundation was created from the need to provide information, support, etc. .. in stuttering Colombia.

- 1. Support groups
- 2. Colombian Stuttering Foundation
- 3. Continuity will facilitate change



EN TARTAMUDEZ

## Centro Especializado en Tartamudez (specialized center for stuttering) (South America)

**Angelica Bernabe:** "I'm a person who stutters and director of a specialized center for stuttering in Peru. As many of us, I had bad experiences with speech therapists that wanted to "fix" my way to talk. For that reason, I decided to study Psychology and now I'm taking the prerequisite courses before the masters degree in Communicative Science and Disorders. I want to help people who stutter to accept themselves and to have the best life they could have."

The mission of my clinic is to provide both training for therapists and treatment for people who stutter. Our goal for SLP is to bring state-of-the-art information from first-world countries and make it accessible to everyone in South America (through free conferences, webinars, videos, and so on). On the other hand, for people who stutter, we provide treatment based on the message of "stuttering is ok." We work a lot on the psychological impact and the environment the person has.

- 1. To treat stuttering, the therapist needs to accept stuttering.
- 2. We have to be honest with the treatment we provide: no one can control their speech 24/7 ---> acceptance is key.
- 3. The more we can offer free resources for SLP, the more they will know how to treat stuttering.



## Nottingham Self Help Group for People Who Stammer (United Kingdom)

**Richard Seals.** "I have stammered, like many from the age of about 4. I currently consider myself to have taken back the control from my stammer, that had controlled me for many years in my life. I have had speech therapy throughout my life and now run a speech group that meets online (previously in person) which discusses everything speech and non speech related. I also help the NHS as a Peer

Mentor for stammerers of all ages and also the parents of children who stammer. I have recently been working 1 to 1 with members of the speech group and challenging them with their speech.

My presentation will discuss my life as a stammerer and what I have learnt and now practice. I will describe my self help group, peer mentoring with the NHS and working with parents. I will also touch on how I conduct 1 to 1 sessions with group members.

- 1. Inspiration
- 2. Guidance
- 3. Self Belief



#### Stutter Block Party (United States)

*Marvin Wiley Jr. (and a few others from the SBP Team).* Marvin Wiley Jr. is a person who stutters in Washington State, serving on the Board of the World Stuttering Network. Marvin is also the Conductor of Stutter Block Party, a monthly event that invites people who stutter and SLPs to play games, converse and connect. Marvin has been a Toastmaster since passing his

college public speaking course in 2013 and has learned to stop his stutter dictating the course of his life. Marvin now strives to help others handle their stutter in their own way, with the goal of encouraging others to act against their fears.

I will spend time talking about the beginnings, purpose, and what we have learned while starting and running Stutter Block Party.

- 1. Understanding the power of breakout rooms
- 2. How support is empowering
- 3. Tips on running a virtual event with breakout rooms



#### Friends: The National Association of Young People Who Stutter (United States) *Kristel Kubart*

FRIENDS aims to provide support, education and empowerment to children and teens who stutter,

their families and clinicians. Our annual conventions and regional one day conferences provide the opportunities for life-changing experiences that can impact long lasting feelings about stuttering and offer new hope for a life with stuttering. FRIENDS seeks to make life easier for young people who stutter and their families.



#### Stamily (Europe)

*Jurjen de Jong*. "Hi! We are Stamily, which is a new association (since January 2021) for people who stutter (pws) from all over the world. Our goal is to create a platform for pws, where everyone can share their stories/achievements and build friendships all over the globe. Besides that, we raise awareness by sharing

articles and organizing offline and online events. Our website already exists since 2018 and you can find it here: <u>https://stamily.org/</u> Very interesting is also our philosophy which guides our association: <u>https://stamily.org/our-philosophy/</u>"

First, we would like to share our story. So, who is behind Stamily, where we are coming from, and where we are heading to. Secondly we want to have an interactive part where we would like to motivate the participants to help us brainstorm how Stamily could play a unique role in the world of people who stutter. Thirdly we would like to invite people to follow Stamily on our social media channels and if people want, we can even explain them how to contribute to or collaborate with Stamily. If people are interested, we can also explain how to become a member of Stamily!

- 1. Know what Stamily is and does.
- 2. Know what Stamily's role is in the world of people who stutter.
- 3. Know what Stamily could mean for them.



#### Cody Mathieson Packer (New Zealand)

"I am a proud person who stutters. I'm interested in all things movies, health, spirituality, nature and of course, stuttering. I'm particularly passionate about sharing my stuttering journey, connecting with others through the healing powers of community and sharing my love for mindfulness and how it intersects the stuttering experience."

I've been on a rather personal and spiritual stuttering homecoming in the last two years. My experiences have led me to reconnecting with my

inner child, who still very much lives inside of me, and wants nothing but love and attention. We all have one. I've found it's such a huge psychological and emotional part of finding acceptance, self-love and a deeper connection with yourself and stutter. My presentation will firstly inform about what the inner child is and what role it has within you. I will begin on the conceptual level- what it is, why and how it exists and how you can form a relationship with him/her. Then that will branch into some personal stories and experiences of mine that will give some real life contexts of how they can show up on your journey. Then last of all, I would love to shift to something more interactive and personal for the audience. Together, we will close our eyes, go inward and do a guided meditation for ten minutes and meet our inner child. I've done this in my Mindful Stuttering group and people were blown away. Afterwards we will open it up for a brief discussion- what did people personally see? What emotions or memories came up? How did it feel? Did your child have something to say to

you? You will be amazed at the revelations. This is something that I believe can have a huge impact on the stuttering journey, regardless when that may be. And I'd love nothing more than to share at least the idea of it with our community.

- 1. Learning what the inner child is
- 2. Self-compassion/exploration
- 3. Being reunited with our own beautiful, playful and innocent child that is still very much alive.



#### Stutter UAE

**Farah Al Qaissieh** "I am a 31 year old mother of 3, who has a unique accent called stuttering." I will share a personal journey of how a cup of coffee resulted in building a community for people who stutter in the UAE. From which fostered a community for people who stutter, who found themselves not only embracing their stutter but also accepting as their own.

In addition, I will talk about Stutter UAE's achievements and how it

plans on continuing to support in the future. <u>www.instagram.com/stutteruae</u>

- 1. Accepting their stutter is the first step to being freed from stuttering
- 2. Potential collaboration opportunities
- 3. Meeting new people :)



#### Asociación Peruana de Tartamudez (Peru)

**Nico Palomino Florez** "I am vice president of the Peruvian Association of Stuttering, coordinator of the socio-emotional support group, fluency group and support group for parents. I am a clinical psychologist, with training in TREC and ACT psychotherapy, I am currently doing a master's degree in neurodevelopmental disorders

and I am a person who stutters par excellence. I believe that overcoming the stuttering complex is achieved when one says or does what he thinks or feels in front of who and where he is; I think that we can all achieve it and it is better if we do it in community. I believe that all people with stuttering can be good communicators and generate a positive awareness of stuttering in the world.

I am part of the Peruvian Association of Stuttering (APT), a non-profit organization dedicated to helping people who stutter, family members and professionals. My friends and I have created and organized groups at no cost. Stuttering affects various aspects: cognitive, affective, linguistic, motor and social. Due to these aspects our groups have different objectives:

1. Fluency Group 767 "GF767", group to learn and practice fluency strategies.

2. "GAM APT" mutual support group, cognitive-socio-emotional support group, groups to share and learn strategies or experiences of stuttering

3. GAP KARO Parent Support Group, offers pertinent information and strategies for families of children who stutter.

4. Resilient Group "GR Flexi", intended for children under 12 years of age.

The "GAM APT" has given me great satisfaction, it has directed my activities, it has given me the courage to believe that I can be a good communicator, the members have shown me that there is still a long way to go to achieve a positive awareness of stuttering. At the GAM APT I can listen, share, learn and support. I believe in an "active acceptance" of stuttering. I believe that the "overcoming the complex" of stuttering comes when we can really "say or do what we think or feel in front of whoever or wherever". I believe that all of us can change our adverse reality "every time we propose to do so. I believe that" we can achieve great things if we move forward organized, in solidarity and with a positive attitude."

- 1. Active acceptance of stuttering
- 2. Importance and effectiveness of mutual support groups
- 3. Construction of satisfaction in communication



#### **Stutter Proudly (United States)**

*Mark Baer:* "Hi there. My name is Mark Baer. I am a person who stutters and a speech therapist. I grew up feeling alone and isolated due to an inability to express myself in a way the world deemed acceptable. On top of that, there seemed to be a conspiracy of silence around stuttering -- at home; at school; with friends; with family. Since then, I have gained confidence to talk about stuttering and express myself in my own unique way, and I hope to inspire others to do the same."

I will introduce the organization I founded -- Stutter Proudly -- and discuss what inspired me to start the organization. Then I'll discuss the organization's mission and offerings and why it is beneficial to take pride in one's identity as a stutterer and in authentic self-expression. Then, I'll discuss the various ways Stutter Proudly is improving the lives of those who stutter, raising awareness, and reducing societal stigma. Finally, I'll discuss plans for the future and invite interested parties to take part in our offerings. I also plan to showcase some of the work I have done -- mostly visual and auditory content creation -- to raise awareness, reduce stigma, and build community.

1) It is not just OKAY to stutter; it is GOOD to stutter.

2) Participants will be acquainted with Stutter Proudly's mission and offerings.

3) Participants will learn why it is beneficial to have pride in one's identity as a PWS and in one's unique form of self-expression.



#### Supera tu disfluencia (Latin America)

**Danisa Alvarez:** "I am the coordinator of the Latin American support group, I am a future primary education teacher and also a puppeteer for two years. I am in love with every person with stuttering that I meet because I consider that we are warriors of life."

We are a mutual aid group formed to accompany the person who stutters. We provide moral and emotional support to each person who enters. We

carry out theater workshops, reading and vocalization workshops and different virtual meetings with specific themes that help to lose fear and strengthen ourselves on the path of acceptance and empowerment of the person.

- 1. Family of people with stuttering
- 2. Self-esteem development
- 3. Empowerment



#### **Open Stutter (United States)**

**Nicholas Brow and Ben Goldstein:** Nicholas Brow and Ben Goldstein are people who stutter and co-founders of the Youtube Channel "Open Stutter". They are also speech-language pathologists with a passion for supporting PWS. Ben currently resides in the Washington DC area, while Nic lives in Boston. Nic enjoys cooking, listening to radio storytelling, and surfing. Ben is particularly passionate about camping, being outside, and

playing guitar. We're excited to share this resource with the stuttering community!

We will discuss our YouTube Channel, "Open Stutter." We created this Youtube Channel in order to bring people who stutter together, provide an opportunity to hear others' stories, and to help PWS feel a little less alone. Open Stutter has also served as a resource for individuals who stutter around the globe to learn more about stuttering and for support groups and SLPs to use in service of PWS. We believe that PWS sharing their stories authentically has the power to positively impact our global stuttering community, the profession of speech pathology, and reduce stigma amongst the general public. Our presentation would explore how this free resource could be used to create community and inspire self-advocacy among viewers.

- 1 People who stutter can be happy and successful
- 2 Stuttering openly can be a great thing for some PWS.

3 - Personal examples of what people who stutter sound like, think about, and do for work, is now available on YouTube.



#### Queensland Speak Easy Association (Australia)

**David Dallow:** "I am the smooth speech coordinator but others interchange in the role, as needed. Others generally lead the practice session when a formal face to face meeting is held. Presently I'm helping members join a weekly Zoom practice session. Some found the technology a bit challenging at first, but almost all are comfortable with it now. The majority of members have been through

a speech restructuring course (Smooth Speech) but we recognize other forms of treatment are now available.

Queensland Speak Easy Association is a group of people who voluntarily get together on a regular basis, both virtually and in person, to practice skills and techniques they learned in therapy. It is a free group to join! *Queensland will present jointly with the Australian Speak Easy Association*.



### The Indian Stammering Association (TISA)

**Dr. Satyendra Srivastava (**Founder, Senior Advisor) A community health consultant working with the voluntary sector since 1993. Pioneered the self-help movement by spearheading the foundation of TISA. He has authored several books including the self-help bible of TISA- "Apna Haath Jagannath".

**Jai Prakash Sunda (**President, Advisor) From a techie to entrepreneur, a banker and now in Canada, JP as he is fondly known, has made tremendous contribution to the self help movement as the

past National Coordinator (2010 – 2015) and initiated the idea of National Conference, now the most awaited annual event.

**Harish Usgaonker** (National Coordinator, Chief Editor) A Software Engineer by profession, from multi-national corporate to being a freelance IT consultant at present, being a TISA volunteer is always dear to heart. Been with TISA since 2009, with roles like co-editor and Asst. National Coordinator. (More) (Interview)

**Dhruv Gupta** (Workshop and Events Coordinator) Passionate about environment and green movement, Dhruv has revived and revamped the Mumbai SHG to a different level altogether. Has been a part of exploring drama with self help with the play "People who Buffer". Co-facilitated numerous workshops with his exemplary facilitation skills.



### **Spero Stuttering (United States)**

**Ana Paula Mumy:** "I am an SLP, clinical professor, support group facilitator (through NSA), and family member of individuals who stutter."

We support SLPs and families needing guidance on their journey with stuttering. Our mission is to better equip SLPs who work with people who stutter, and to be a resource for families seeking SLPs who have better training and experience working with stuttering as "generalists".

- 1. Ally of Stuttering SLP program (free),
- 2. Stipends and scholarships we offer for training and research
- 3. Resources for connecting families and allies.



#### SMBC Workplace Disability Initiative (United States)

*Kunal Mahajan*: Kunal has been in the investment banking field for 13 years. He joined SMBC in the Americas in 2017 in their Leveraged Finance Group and is also part of their Corporate Development team. As a lifelong person with a stuttering disability, Kunal's stutter impacted his mental health substantially until he obtained acceptance of his stutter in July 2017. Kunal founded SMBC's Mental Health, Neurodiversity, and Disabilities Enterprise Resource Group called UNIQUE in June 2019. He Co-Chairs this employee resource group and leads the initiative with the support of SMBC management and SMBC employees from all over the globe.

Stuttering in the workplace remains top of mind for people who stutter and having a disability support organization is one of the most critical ways to raise awareness and receive support for those in need. This workshop will explore how to form a Disabilities Employee Resource Group at your organization and the type of programming and support resources to offer out of this group. With 70% of all disabilities being invisible and 1 in 4 individuals having a disability, all of us have a part to play to raise the awareness of stuttering and other disabilities in the workplace and each of us can be a leader in this initiative.

- 1. How to formulate a Disabilities Employee Resource Group,
- 2. type of programming the group can offer, and
- 3. the impact it will have on your organization.



# Stuttering Scholarship Alliance Nathan Malipeddi

The Stuttering Scholarship Alliance is a 501(c)(3) nonprofit organization transforming the access to and delivery of speech therapy services for persons who stutter. We provide a bridge to access, allowing people

who stutter -- otherwise facing barriers of access -- to achieve their fullest potential. We are committed to innovative solutions to provide more accessibility for people who stutter: including areas of:

- 1. speech therapy,
- 2. education/advocacy
- 3. community



#### SPEAKeasy Dina Lilian

SPEAKeasy is a support group for people who stutter, their family members and friends. Meetings are used to discuss issues around stuttering, to share new ideas and experiences, discuss

feelings, and to practice one's speech techniques. SPEAKkeasy has been running for approximately

15 years in Johannesburg. New branches of Speakeasy have been re-established in Durban, Cape Town and Port Elizabeth. SPEAKeasy was started by a group of people who stutter, their parents and speech therapists to address the issue of prevention and treatment in South Africa through:

- 1. Education
- 2. Self-help groups
- 3. Enhance training and skills of speech therapists

### Also look for presentations by these organizations:











## **Research Symposium**

(learn the latest in stuttering science during 30 minute blocks including Q&A)



### **Dr. Gerald McGuire**

Gerald Maguire, MD ("Jerry") is professor and chair in Psychiatry and Neuroscience at the University of California, Riverside School of Medicine. Dr. Maguire is a Distinguished Fellow of the American Psychiatric Association (DFAPA). He has been listed in the "Best Doctors in America every year beginning in 2008. As a PWS, Dr. Maguire set forth on his mission to become a physician to understand how best to assist the stuttering community. He served as Chair of the National Stuttering Association and Vice Chair of the International Stuttering support organizations across the world.

He amplifies the voice of his fellow persons who stutter through advocacy, research and education.

#### TOPIC: Advancements in the Comprehensive Treatment of Stuttering.

Dr. Maguire will discuss the latest updates on the pharmacologic treatment of stuttering and how these treatments may play a role along with talk therapies in a comprehensive approach to assist those who stutter in improving their qualities of life.



### Dr. Shelly Jo Kraft

Shelly Jo Kraft, PhD CCC-SLP, is an Associate Professor of Communication Sciences and Disorders at Wayne State University. Her current research focuses on the biological and behavioral genetics of stuttering. Other research interests include comorbidities and broader phenotypical features of people who stutter, auditory feedback mechanisms of speech control, new genetic analysis techniques for modeling epigenetic complexity and exploring the relationship between cognition, temperament, and

stuttering severity.

#### **TOPIC:** Advancements and Complexities in the Genetics of Stuttering

This talk will cover the current progress on 3 large studies investigating the genetics of stuttering. Comorbidities, genetic contribution, and complexities in familial inheritance with be discussed.



### Dr. Per Alm

Dr. Alm is a researcher and lecturer in the Department of Neuroscience (Speech-Language Pathology group) at Uppsala University in Sweden. He has a background in engineering, but his personal experience with stuttering motivated a career change into neuroscience and psychology, and into research on the neural underpinnings of this speech disorder. A main driving force for his research has been the impression that the symptoms of stuttering are still poorly understood, and that a more specific understanding of the underlying mechanisms could result in improved treatment

options. One outcome of this view has been an emphasis on critical reviews of published research data, with renewed data analyses relating to the current understanding of the brain, and the mechanisms of speech. In 2005, he completed his PhD thesis in neuropsychology entitled, "On the Causal Mechanisms of Stuttering".



#### Goncalo Leal

Mr. Leal is the ISTUTTER Center Clinical Director and senior speech language pathologist. He is the Co-founder and CEO at Speechcare/ Stuttering Treatment Center and a PHD candidate at Universidade Católica Portuguesa in Cognitive and Language Sciences. Goncalo is a professor and mentor in Diploma "Especialización en Disfluencias" at Faculty of Medicine of Concepción's University, Chile. He has a volunteer scholarship appointment at University of California, Riverside, School of Medicine

#### TOPIC: A Proposed Model Of Stuttering Therapy: Interdisciplinary Care".

Stuttering is a neurodevelopmental disorder that presents with not only challenges in fluency, but often co-existing conditions, affecting individuals in a very individual way. Individuals who stutter can also present other disorders, such as depression and ADHD, which require treatment. Interdisciplinary care involving health care professionals of complementary skills and training can work together to optimize care. A model of care will be discussed.



#### **Dr. Anelise Bohnen**

Dr. Bohnen is President of the Brazilian Institute of Fluency (IBF). She established partnerships with national and international institutions (USA, Portugal, Chile, Spain), headed the creation of the *Specialty in Fluency* established by The Federal Council of Speech, Language and Audiology and is presently is involved in the discussion with the National Congress about stuttering as a deficiency.

#### **TOPIC: Is Stuttering a Deficiency?**

The IBF has been systematically requested by federal institutions such as the Federal Council of Speech, Language and Audiology and the National Congress to discuss whether or not a Stuttering should be considered a disability or a deficiency. This discussion serves for legal purposes both for the recognition of people who stutter in the job market, among several other issues that involve this disorder. The presentation will be about the various descriptions of stuttering, according to the ICD and the ICF and the implications for diagnosis and therapy of those who stutter.

### Dr. Pierpaolo Busan

Pierpaolo Busan earned his Master Degree (M.D.) in Psychology at the University of Trieste (Italy), in 2004. He then completed a doctoral degree (Ph.D.) in Cognitive Neuroscience in 2009, at the Department of Life Sciences (University of Trieste, Italy). Finally, he has earned a Specialization Degree (S.D.) in Neuropsychology (University of Trieste, Italy), in 2013. He began his research program at the Department of Life Sciences (University of Trieste, Italy), successively working also at the Human Physiology Section of University of Ferrara (Italy), and the Neurology Section of the University Hospital of Trieste (Italy). Since 2015,

Pierpaolo is a researcher at IRCCS San Camillo Hospital (Venice, Italy), where he is now the Head of the Stuttering and Speech Therapy Lab. Compatibly, Pierpaolo's research is focused on the understanding of the neurophysiological correlates of Developmental Stuttering. He is experienced in using experimental tools such as Non-Invasive Brain Stimulation, Electroencephalography, and Magnetoencephalography, thus trying to translate research findings in suggestions that may be useful to ameliorate treatments and rehabilitative solutions.

## TOPIC: The modulatory effect of "social" stressors on the motor preparation of speech in developmental stuttering

Developmental stuttering (DS) is a multifactorial disorder characterized by abnormal brain structure/functioning, especially in sensorimotor networks. Previous research suggests that DS is characterized by impaired motor speech preparation. However, DS symptoms are strongly influenced by the "environmental" or "social" context: people with DS are usually more fluent in "relaxed" social conditions (i.e. no social or temporal pressure), while they are usually more dysfluent when they are facing potentially stressful conditions (e.g. "public speaking" in front of an audience). Here, by using magnetoencephalography, we started to investigate the modulatory effects of stressful conditions (i.e. the presence of an "audience"), on the motor preparation of speech, in DS.

Preliminary findings mainly suggest the presence of lower neural activity in brain regions such as the SMA "complex", in DS, especially when facing with "social" stressors (i.e. speaking to an audience). This effect was evident in discrete time windows of interest, i.e. hundreds of milliseconds before the start of activity in speech muscles. Interestingly, this evidence may be modulated by activations of the anterior/medial cingulate cortex (useful to regulate, for example, emotions and "reward-related" aspects of behavior).

These findings suggest that the social context (i.e. a potentially stressful condition) may modulate the preparation and the programming of complex motor acts (e.g. speech) in DS, possibly resulting in lower neural activity (or lower signal-to-noise ratio) of discrete motor networks, especially before action release. This could easily result in higher speech difficulties and higher levels of dysfluencies in DS, helping to explain how stressful conditions may worsen stuttering (as well as the potential

beneficial effects of "fluency-inducing" situations). If confirmed, these findings may help to implement new and focused rehabilitation programs for stuttering.



#### Dr. Shahriar SheikhBahaei.

Dr. SheikhBahei is Principal Investigator and Chief of Neuron-Glia Signaling and Circuits Unit at the Intramural Research Program of National Institute of Neurological Disorders and Stroke. His research is directed toward understanding mechanisms underlying the generation and control of voluntary motor behaviors in the mammalian brain at the cellular, circuit, and systems levels of neurons and glia interactions. His research also focuses on cellular and circuit mechanisms underlying stuttering as a motor control disorder.

TOPIC: The Link Between Stuttering and Breathing: A Fresh Insight

During this presentation, new data on breathing and vocalization from a mouse model for stuttering disorder will be presented.



#### Dr. Joseph Donaher

Dr. Donaher is the Academic and Research Program Director of the Center for Childhood Communication at Children's Hospital of Philadelphia. Dr. Donaher is an Assistant Professor of Otorhinolaryngology at the University of Pennsylvania. He is a board certified specialist in Fluency and Fluency Disorders. Currently Dr. Donaher serves on the Editorial Review Board for ASHA's Perspectives on Fluency and Fluency Disorders and the Research and Publications Committee of the International Fluency Association. His clinical and research interests focus on the assessment and treatment of school-age children who stutter and disfluency patterns secondary to neurological conditions such as

attention deficit hyperactivity disorder.



#### Dr. Atul Mahableshwarkar

Dr. Mahableshwarker is the responsible Medical Officer at Emalex Biosciences, Inc. He is a board-certified adult psychiatrist and leads Drug Development, Clinical Affairs and Operations, and Pharmacovigilance. He is responsible for advancing therapeutic candidates from pre-IND enabling studies through Phase 1 to Phase 3 clinical trials. Dr. Mahableshwarkar puts patients and science at the center of all actions with interdisciplinary leadership essential to Emalex Biosciences' scientific, clinical and commercial goals and patient-first ethos.

Dr. Mahableshwarkar was formerly an Associate Professor and Vice Chair of the Department of Psychiatry and Behavioral

Sciences at the Chicago Medical School of Rosalind Franklin University. Previously, he also led mental health services at the former North Chicago VA Medical Center, providing care to patients with psychiatric disorders.

Dr. Mahableshwarkar has two decades of drug development experience and has designed and conducted global clinical trials in Alzheimer's disease, anxiety disorders, bipolar disorder, major depression, Parkinson's Disease, schizophrenia, Tourette Syndrome, and childhood onset fluency disorder.



#### Kerensa Saljooqi

Ms. Saljooqi reports to Dr. Mahableshwarkar with responsibilities ranging from project management, vendor management, site relations, marketing, and of course, clinical trial operations. Mrs. Saljooqi has over 3 decades of clinical development and operations experience. She began her research and development career in medical writing before advancing to project management and clinical research associate responsibilities. Her multifaceted career is grounded in principles protecting the rights, safety and welfare of clinical trial participants and delivering accurate and reliable clinical trial data. Ms. Saljooqi leads the childhood onset fluency disorder program at Emalex Biosciences.

Dr. Mahableshwarkar and Kerensa Saljooqi are pleased to present at 2021 StutterFEST hosted by the World Stuttering Network!

**TOPIC:** "Drug Development and Clinical Trial Participation" is intended to inform the audience of the steps and phases of drug development required before new medications are available for the public. Attendees will also learn what volunteering as a participant in a clinical trial entails and how it differs from their general medical care.

## **SEAtalk Keynote Speakers**

(hear inspirational leaders give 20 minute talks dedicated to <u>Support</u>, <u>E</u>ducation & <u>A</u>dvocacy)



**Sam Wiggins** lives at home with his mom, big sister and 2 cats in the UK. He enjoys acting, modeling & sports, such as archery, cricket, darts and dodgeball. He has had a stammer since he was about 3 years old. Sam has been in and out of speech therapy over the years and learned some useful techniques such as slowing down his speech and sliding into words. However, Sam has learned that having a stammer is OKAY! Everyone is different; the world would be a boring place if everyone were the same. Sam embraced his stammer and never lets it hold him back. He wants to educate people about

stammering and help other kids to find their confidence!



**Tom Scharstein** is an entrepreneur and person who stutters from South Florida, USA. Involved in stuttering support for over 23 years, he served on the NSA Board of Directors. Adult Chapters experienced an unparalleled period of growth with his oversight. The dream of bringing together world support group leaders began to emerge. Connect. Share information. Get more done. August 2020 saw the birth of the WSN with one main concept, "Better Together." Tom is the WSN co-founder and Chairman of the Board.



### "Stuttering in China & Cross-Culture Communication" *Jia Bin*

Jia was born and raised in China. She has been a language teacher (English & Mandarin Chinese) who has taught in China, the UK and the USA. Jia's passion for helping others to communicate over the last 10 years has led her to become open about her own experiences of stuttering in various cultures. Jia is an active member of the NSA and has served as a regional chapter coordinator. She is the former host for StutterSocial, and

was featured on StutterTalk podcast on several occasions. Jia is also a founder of a Chinese podcast and hosted online support sessions for a Chinese community. Jia is currently a graduate student in communicative science and disorders at Michigan State University.



### "A Love Letter to the Support Group Community" *Tricia Hedinger*

Tricia Hedinger, MS, CCC-SLP, BCS-F is a clinical associate professor at the University of Tennessee Health Science Center in Knoxville, TN. She is a Board Certified Specialist in Fluency Disorders and has been a support group leader since 2013. Ms. Hedinger has published multiple articles related to stuttering, presented at national & international conferences, co-authored a

book titled "Bullyblossom: A Tale of Overcoming Bullies & Embracing Stuttering to Live a Life of Achievement" and focused on the anti-bully movement in schools. She is the host of the "Stutter Stories" podcast. She is also co-founder and Vice Chair of the World Stuttering Network (WSN).



#### Jhoan Gallego

Jhoan Stiven Gallego Bermúdez, was born on September 11, 1991 in the city of Cali in the country of Colombia in South America. Graduated as a Fonoaudiólogo (Speech Language Pathologist) in 2019. Diploma in Attention and Prevention of Stuttering with the Ibero-American Association of Stuttering, trained in disorders of Fluency with the Argentine Association of Stuttering. Leader of the support group for people who stutter in

Colombia called Libera Tu Speech. Founding President of the Colombian Foundation of Stuttering. Person who stutters, passionate about stuttering, recognizing it as his life mission, thus finding the why of stuttering in his life; to disseminate, guide, investigate, promote respect and inclusion towards the person who stutters and improve communication quality. Jhoan serves as the Chair to Central and South America on the WSN Board of Directors.



#### Nathan Malipeddi

Nathan graduated summa cum laude with honors from UCLA in June, where he received a B.S in Biology and B.A in Political Science. He is a Junior-elect to Phi Beta Kappa and a Fulbright Scholar. Nathan is founder and CEO of Stuttering Scholarship Alliance, a non-profit organization that tackles a critical issue in the field of speech therapy regarding its lack of access to low income communities. He also serves on leadership teams for several international speech disability awareness organizations.

Nathan has conducted both cell biology and public policy research at UCLA David Geffen School of Medicine and the Luskin School of Public Affairs, where he published his work in

top journals. As the senior policy intern for the City of Los Angeles Department on Disability, Nathan developed transformative public policy initiatives that created jobs for the thousands of unemployed or homeless persons with disabilities in Los Angeles. Nathan aspires to a career as a physician-researcher-policymaker focusing on improving the quality of care and reducing the disparities for disabled persons in healthcare systems. He will attend medical school next year to pursue a medical degree combined with a Master's in Business Administration from Stanford's Graduate School of Business. Nathan is the International Advocacy Chair for the WSN Board of Directors.



### "Alone We Are Strong- Together We Are Stronger" Anita Blom

Anita S. Blom, born and raised in the Netherlands, is living in Sweden. She worked as a teacher, and operation manager for the Workers' Educational Association. She has been active as a chairperson, board member and advisory board member of local, national, European and International stuttering organizations. She is a stuttering activist and has worked for several decades to break down barriers and improve the lives of people who stutter around the world. She was a national and international keynote speaker on stuttering, had her own consulting firm on stuttering and motivation, and has been a project leader of several

stuttering projects. She was also a leader of national and international children and youth camps for over 20 years.

Anita, aka Scatsis, has stuttered since she was 9 and had a troublesome youth because of her stuttering. She went from being silent, to giving stuttering a voice, from pre-school children to the European Parliament, now inspiring people who stutter of all ages, they can make a difference. Due to health issues she now has to take it slow, but is still an inspiration to many, acknowledged by <u>Voice Unearthed on the Wall Of Inspiration</u>, and many others. Her device, that's now been used all over the world is "Sure I stutter. What are you good at?"

The pandemic has clearly proven that "Better together" is the key to conquer tough situations. Together we are better, stronger, wiser. That goes for stuttering too. Clinicians working together with people who stutter, both just as important to the other. Teachers and students together finding the best way to take away hurdles. People who stutter and their parents finding they are not alone. Video chats and conferences erasing borders. National and international stuttering organisations working side by side. This presentation will hopefully inspire to see the positives in working together, using each others' strength and wisdom to create the ISA vision: " A World That Understands Stuttering".



### "Speaking Circles" Satu Nygren (presenting with Anita Blom)

Satu Nygren is a person who stutters from Finland. She currently lives and studies Psychology in the Netherlands. She has been involved in volunteer work in stuttering associations in Finland and Iceland, especially main focus in international events, such as the World Congress for people who stutter in Iceland in 2019. She has also been involved in the organization of the Erasmus+ youth exchanges for young people who stutter since 2016. She is also

involved with Erasmus+ innovation projects for creating manuals for youth workers and young people who stutter.

"Speaking Circles" is a public speaking practice where you increase your confidence as a public speaker by positive feedback. During the presentation, the listeners get an insight in what Speaking Circles is and how they can apply it as a part of their association's practice.



### "Creating Awareness and Understanding of Stuttering via Educational Activities and Outreach" *Hanan Hurwitz*

Hanan Hurwitz is an electronics engineer, working as an independent consultant at Hurwitz Consulting. He is a person who stutters (PWS) and was until recently the Executive Director of the Israeli Stuttering Association, AMBI.

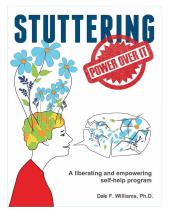
Mr. Hurwitz will discuss social and self stigma, the social model of disability, and educating teachers, HR managers, speech therapists, and others. "In my talk I want to describe my activities in lecturing to various groups about stuttering. The idea is to show other leaders another way of raising awareness, a way that I feel is particularly effective. I feel uncomfortable speaking about myself since, of course, it's not about me; it's about finding ways to effectively work towards creating a world that understands and accepts stuttering. In the introduction I will very briefly describe my journey."



#### Jurjen de Jong

My name is Jurjen de Jong. I come originally from the Netherlands, but lived in Belgium and Sweden. I have had a stutter since I was seven. I worried a lot about it for a long time, but the worry is much less lately. This is due to my attempt to step out of my comfort zone. I now experience more calmness in situations I always had much

problems with before. Besides, I noted that I like to hang out and talk with other people who stutter (PWS), because we all share a similar problem but in another way. So, I believe we can inspire each other.



### **Dale Williams**

Dale F. Williams, Ph.D., CCC-SLP, BRS-FD is a Professor of Communication Sciences and Disorders at Florida Atlantic University. In addition, he is a consultant for Language Learning Intervention and Professional Speech Services. A board-certified fluency specialist of the American Board of Fluency and Fluency Disorders, Dr. Williams served as President of the Specialty Board on Fluency Disorders from 2008 to 2010. Dr. Williams is also the coordinator of the Boca Raton NSA chapter. His publications include 3 books on stuttering with his most recent publication being "Stuttering: Power Over It - A Liberating

and Inspiring Self-Help Program." He also authored a children's storybook to be published this year. Dr. Williams lives with his wife Misty in Lake Worth Beach.



#### Sigga Fossberg

Sigríður, originally from Iceland and currently residing in Kiruna, Northern Sweden, will be graduating with a masters in adult education in 2021. She is an avid fighter for human rights, has a fondness for languages and is interested in different cultures, views, and politics. Sigríður has served as the chair of Málbjörg, the Icelandic Stuttering Association for the last few years. In 2019 she joined the International Stuttering Association's board of directors. Sigríður is currently involved in Swedish and

transnational projects, revolving around education, awareness and accessibility for people who stutter. Sigridur has found peer to peer meetings to be at the heart of any stuttering association. She believes that providing support for peer-to-peer meetings, will help stuttering associations grow and vice versa. An open and supportive community is key.

## **Podcasts**

(participate as a guest or member of the audience in popular podcasts!)

### Stuttering Is Cool (Daniele Rossi)

Join me as I offer encouragement and methods on how to manage your stuttering and live the life you want. I also interview other people who stutter, report on what's happening in the stuttering community around the world, the latest on stuttering research and therapy, and I also take you

behind the scenes in the creation of my Franky Banky comics.

### Stutter Stories (Tricia Hedinger & Jia Bin)

The #1 transformative moment we hear about: the day I met someone else who stuttered. Listening to the voices and journeys of people who stutter enhances our feelings of commonality and solidarity. The World Stuttering Network (WSN) brings forth a collection of stories shared by people who stutter (PWS) from around the world. With unforgettable challenges, inspirational narratives and life-changing moments, PWS pose as storytellers describing their real-life experiences with life and conversation. Our stories bring us together. Do you have a story to share? Join us.

### I-I-I am a Podcast (Gen Lamoureux)

The podcast is hosted by Judith Labonté, a speech therapist specialized in stuttering, and Geneviève Lamoureux, an adult who stutters and an SLP student.

This special live episode (in English!) for StutterFest will be hosted by Geneviève, who will receive Jean-Sébastien Bérubé, a cartoonist who stutters. Jean-Sébastien will talk about his experience with stuttering and how he includes his own stutter in his books.

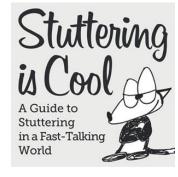
### Stammer On (Lynn Mackie)

StammerOn is a YouTube channel dedicated to stammering, stuttering and everything in between. Fluency not guaranteed, Lynne shares her experiences of living with a stutter, including work, media representation and more. Lynne is also a trustee for both the Scottish Stammering Network and Stamma









(British Stammering Association) and is on the board of Stamily.

## **Entertainment**



### Tague Zachary (Comedy)



**IMPROV** with Dahlia

Bobby Torkova (magician)



Nina G.



www.worldstutteringnetwork.net

worldstutteringnetwork@gmail.com

## **About the World Stuttering Network**

In August 2020, our non-profit organization realized that by working together we could offer support to people who stutter around the world. We can overcome our challenges much more efficiently with a unified approach to caring and sharing.

Our vision is to connect all support group leaders (SGLs) regardless of affiliation. We aim to share ideas, encouragement and best practices for stuttering support groups.

WSN is a place to learn how to create, build & enhance your own stuttering support group or network. We will help establish support group systems in countries where none exist.

### HOW DO WE HELP?

At World Stuttering Network (WSN), we are dedicated to stepping up our efforts in providing MORE than just a website. Through use of interactive Facebook groups, virtual meetings, world friending and a wealth of written resources from experienced support group leaders, we will provide you with ongoing, individualized support to meet your needs. We are always striving to make a difference! We invite you to learn more and lend your knowledge.

### **GET STARTED!**

### 1.) Log in to Facebook.

### 2.) Search for "World Stuttering Network."

### 3.) Click "Join Group."

It's that easy! You will have access to stuttering support group resources, experienced leaders & strategies for getting your group started.

### Thank you for joining us!



Saturday, May 8th Gelebrating the World Stuttering Community