INTERNATIONAL CLUTTERING ASSOCIATION

#### THE T.R.A.D.E.

TREATMENT, RESEARCH, AWARENESS, DIAGNOSIS, EDUCATION

http://associations.missouristate.edu/ICA/

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### Dear friends,

As we close out another decade, we can reflect on another busy, productive year in the world of cluttering. In this (and every) issue of the TRADE, we find mounting evidence of education, advocacy and research on *cluttering*. The ICA is once again positioned to raise awareness of cluttering by participating in the 2021 World Congress in Montreal, alongside the International Stuttering Association and the International Fluency Association. As you will see on page 2 of this newsletter, we are very pleased to have filled the vacancy of ICA Membership Chair. And finally, the ICA had a very productive meeting at the American Speech-Language Hearing Association (ASHA) in November in Orlando, Florida (USA).

We are still in need of a webmaster, as our dear friend Klaas Bakker moves into retirement. The ICA will develop and post a job description on the ICA website; in the meantime, anyone interested in the position should contact me at: <a href="mailto:charley@sc.edu">charley@sc.edu</a>.



The ICA Board wishes all its membership a Happy New Year! Cheers,



Charley Adams, Chair

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## ICA ANNOUNCEMENTS

by Susanne Cook, ICA Chair Elect



## The ICA welcomes Joe Hughes as the new membership chair!

Joe Hughes will succeed our former membership chair, Ellen Bennett. At this point, we would like to thank Ellen for her years of services to the ICA and send a warm welcome to Joe Hughes.



Joe brings a wealth of experience from his job as a Procurement and Budget Coordinator and will be the point of contact for all membership related questions for the ICA. He can be reached at this email address: <a href="mailto:jhughes@Rollins.edu">jhughes@Rollins.edu</a>

If your contact information changes, or you have membership related questions, please let Joe know so he can update our membership database.

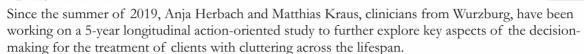


## International Highlights

by Isabella Reichel, the USA



#### GERMANY -





Dipl. Mus. Anja Herbach M.A.

Based on their many years of clinical experience, these clinicians have found that people with cluttering are confronted with serious problems in their environment due to their disorder and therefore need specific treatment.

#### Matthias Kraus B.Sc., M.A.

Using the available data, it is obvious that existing knowledge on treatment of cluttering has serious gaps, and must be systematically and responsibly addressed. These clinicians hope that perhaps one day, the results of their research in cluttering will fundamentally improve treatment. Their study aims to close the gap in knowledge and will resolve the associated action-related



uncertainty. To this end, the researchers are concerned with constructs of principle-led decision-making processes in the context of a case-oriented systemic-phenomenological reflection framework. The core element of this therapy-specific work is speech physiology and competence in perception-oriented change. For more information about the researchers, see www.berufsfachschule-looppaedie.de

We are looking forward to follow the research of Anja Herbach and Matthias Kraus.

#### HUNGARY



Johanna Pap, a PhD student at Elte Eotvos Lorand University, presented a paper on cluttering at the 9th Workshop on Disfluency in Spontaneous Speech (DiSS2019, Budapest, Hungary, 12-13 September, 2019). The title of her presentation was Effects of Speech Rate Changes on Pausing and Disfluencies in Cluttering. The link to her conference paper can be found at:

http://diss2019.elte.hu/wpcontent/uploads/2019/11/DiSS2019\_Proceedings.pdf

Judit Bona, from ELTE Eotvos Lorand University, of Budapest, announces the launching of the First Hungarian Conference on Fluency Disorders, to take place in the summer of 2020. This conference will commemorate 120 years since the courses in stuttering and cluttering were commenced at the university by Artur Sarbo. A workshop on Stuttering and Cluttering will be conducted by Isabella Reichel on June 22nd and 23rd. Participants from Hungary and other countries will be invited to submit their papers for short presentations and poster sessions on topics of fluency disorders for a program to take place on June 24. The website for the conference is in production, and more details will be forthcoming shortly. Please contact Judit Bona for further information (bona.judit@btk.elte.hu).



#### USA.



For the 2<sup>nd</sup> time, I have been invited to be the guest editor of a special issue dedicated to cluttering in ASHA's *Perspectives on Global Issues in Communication Sciences and Related Disorders.* Many thanks to the 20 dedicated authors participating in the current issue, representing 18 countries and 5 continents: Africa, Asia, Europe (East and West), and America (North and South), for their sharing of ideas with fellow professionals and their devotion that benefits so many who suffer from cluttering around the world. The issue will come out very soon and will include the following articles:

Reichel, I. (in press). An introduction to the forum on cluttering. Perspectives on Global Issues in Communication Sciences and Related Disorders. *Perspectives of the ASHA Special Interest Groups (SIG 17)*.

Reichel, I. (USA), Ademola-Sakoya, G. (Nigeria), Aumont Boucan, V. (France), Bona, J. (Hungary), Carmona, J. (Portugal), Cosyns, M. (Belgium), Filatova, J. (Russia), Haj-Tas, M. (Jordan), Kelkar, P. (India), Mayomoto, S. (Japan), Ozdemir, S. (Turkey), Remman Rmeih, R. (Lebanon), Sanghi, M. (India), Schnell, A. (Germany), Touzet, B. (Argentina), Yang, S. (Taiwan) (in press). A decade of collaboration among international representatives of the International Cluttering Association. *Perspectives of the ASHA Special Interest Groups (SIG 17)*.

Gosselin, E., & Ward, D. (in press). Selective attention in adults who clutter: A preliminary study. *Perspectives of the ASHA Special Interest Groups (SIG 17)*.

Van Zaalen, Y., & Reichel, I. (in press). Clinical success using the Audio-Visual Training for cluttering. *Perspectives of the ASHA Special Interest Groups (SIG 17)*.

Sønsterud, H. (in press). The therapeutic alliance in cluttering treatment in Norway: A neglected variable? *Perspectives of the ASHA Special Interest Groups (SIG 17)*.

#### Consumer Issues



by Rutger Wilhelm, the Netherlands

## Sharing the cluttering story

For more than 25 years I had been living my life as a person who stutters. The moment I found out I cluttered was mind blowing. Right away, many things fell into place. It has been the very reason why I am always so motivated to spread the word on this intriguing speech disorder.

In doing so, what better location could I choose than ISA's World Congress 2019 in beautiful Iceland? A perfect spot, where SLPs and people who stutter and clutter could mingle, discuss and connect. During the conference I had the privilege of giving 2 workshops, one by myself and one together with cluttering expert Manon Spruit.

My workshop focused on topics like: what goes on in a clutterer's mind, what problems do they encounter in daily life, and what tips, tools, strategies and suggestions can they use in order to better cope with it? The session turned out to be a great experience. Also, I was extremely happy and honored to notice that ISA (together with partners like IFA) recognized the importance of "making room" for cluttering.

Besides that, I am currently preparing a website on cluttering. I'll come back to that in the upcoming newsletter.

Best, Rutger

## The interview with James J.



by Kathleen Scaler Scott, the USA

[KSS]: Can you tell us the story of how you first came to find out you were a person with cluttering?

[JJ]: After a job interview, the interviewer discussed with me my rate of speech. Also, he had questioned if I had ever heard of Toastmasters. After the interview, I googled "fast talker", found out about cluttering, and took a Toastmasters class for several months. It was then that I realized there was something more serious to be taken care of.

[KSS]: What are some of the challenges you face related to communication on a daily basis?

[JJ]: In speaking to someone, recognizing communication breakdowns sooner, and having a mindset that I am not being rushed.

[KSS]: When you first began treatment, were you skeptical it could help? Why or why not?

[JJ]: Yes, because when I first started treatment, I heard of what a fairly new diagnosis cluttering was, and that there had not been much research on it.

[KSS]: What are some of the things that you have found helpful in therapy?

[JJ]: Learning to pause in a natural way, using eye contact, recognizing when my speech pattern is getting quicker, and responding to communication breakdowns.

[KSS]: If a person is talking to someone who may be cluttering, is there any advice you would give them on how to react as a listener?

[JJ]: Don't be judgmental and be patient.

[KSS]: For anyone who may have been recently diagnosed with cluttering, and isn't sure about their future in terms of communication, what advice would you give them?

[JJ]: Try to contact a speech-language pathologist, do as much research as possible, and don't be too hard on yourself. Also, recognize the little victories or achievements you have, such as positive feedback from others who know what you are going through.



### Cluttering at the World Congress for People Who Stutter in Hveragerdi, Iceland (June 23<sup>rd</sup> - 27<sup>th</sup>, 2019)

#### by Manon van der Aa-Spruit, the Netherlands and Germany

Since a few years ago Rutger Wilhelm (the chair of the ICA Consumer Issue Committee) and I have been working together on raising awareness about cluttering and the importance of getting the right diagnosis. Bringing together a person who clutters and a fluency specialist makes it possible to reach out to more people and to the right people. We think it is important to help people open their minds to other fluency disorders besides stuttering. In my clinic I meet a lot of people diagnosed with stuttering and getting treated accordingly; however, people who clutter find themselves not fitting into the diagnoses and treatments as stutterers do. We decided the World Congress for People Who Stutter would give us a perfect opportunity to let people know more about cluttering and the mix of cluttering and stuttering and about the importance of the right diagnosis. We wanted to reach out to both, the therapists that see people with a fluency problem and to the people with a fluency problem, especially to those that are not happy with their diagnosis, but do not know what else the problem might be. Therefore, in June we took off for beautiful Iceland. Rutger and I had prepared a presentation together and Rutger had one by himself. Rutger started his presentation with a Kahoot-quiz to find out how much people know about this other fluency disorder. It appeared (as we expected) that there is still a lot unknown. The winner of the quiz would be in Rutger's new book, *Too fast for Words*, in which he tells his story and talks about what helped him in the end.



Rutger Wilhelm during his presentation about his experiences as a person who clutters

A lot of people were surprised as they heard Rutger's story, who was diagnosed as a person who stutters, and who participated in all kinds of for people who stutter, including stuttering therapy. Nonetheless, he didn't feel quite right. Although the stuttering therapy helped him, he felt out of place, until an SLP told him it was not really stuttering that made his speaking difficult and sometimes difficult for others to understand. She told him his problem was called cluttering. She explained to him what the symptoms of cluttering are and he soon felt this was the right diagnosis. He explained how the new diagnosis changed his life completely. During his presentation he also showed the main characteristics of cluttering. The participants recognized themselves or people they know in Rutger's story and questions came up. They wanted to know the differences between Cluttering and Stuttering and what they could do to help the people whom they know have this disorder. We had to refer to the talk we would be doing together on the last conference day. A lot of people were eager to hear more about cluttering and the mix of cluttering and stuttering. Rutger Wilhelm during his presentation talked about his experiences as a person who clutters.

The next days were packed with meeting old friends, making new ones, talking about fluency disorders the way you only can with people that are as much interested as you are and handling more questions about cluttering. In addition, the Golden Circle Tour showed us some beautiful Icelandic treasures, like the Geysers and the great waterfalls of Gullfoss. Let me not forget to mention the Gala Dinner we had in a beautiful Icelandic Viking restaurant.

Some people had a hard time deciding which presentation they would like to attend on the last conference day. There were so many great and interesting presentations during the whole week and this was not different during the last day. Some people who really would have liked to attend our presentation were not able to make it (in time). After breakfast we started with our presentation called "Is this really stuttering?". I prepared some audio samples of different people, speaking less fluently. After listening to them we discussed with the audience what kind of fluency disorder (or not) they heard. We then discussed the differences and commonalities between stuttering and cluttering or the mixture of both, and how they could be identified. We listened to the same audio samples and again tried to identify the fluency disorders. Rutger and I were happy to see that after describing the symptoms and the differences, a lot of people suddenly realized that cluttering, stuttering and the mixture of both can be so much alike, but different as well.



Explaining why it is so important to know the differences between stuttering and cluttering

Rutger spoke about his experiences and was able to explain why it is so important to look further when you hear disfluent speech. You can change someone's life. It is not always (just) stuttering. And cluttering is not always (just) cluttering. The SLPs that joined the presentation were now aware of that fact and eager to look further with an open mind at the people in their clinics who have a fluency problem that did not quite match stuttering and could possibly be something else. I think Rutger and I achieved our goal. For the SLPs that have little or no experience in cluttering, it would mean they have to learn more. In any case, we are happy they are now aware of the fact that they have to ask themselves: "Is this really stuttering?" Some of them told us they would really like to be more prepared for doing thorough differential diagnostics and wanted to get trained in doing so. We will keep working on raising the awareness to help more people change their lives in the right direction.

# The report from the 31<sup>st</sup> IALP World Congress in Taipei, Taiwan 2019



by Shu-Lan Yang, Taiwan

IALP (International Association of Logopedics and Phononiatrics) was founded by Dr. Froeschels in Austria in 1924, when he and his colleagues held the first international conference. Although there were only 60 participants, they were from various fields, such as neurology, psychology, laryngology, etc. Taiwan Speech-Language Hearing Association (TSLHA) is one of the 55 affiliated societies in 35 countries. With great honor, we held the 31<sup>st</sup> World Congress of IALP from the 18<sup>th</sup> to 22<sup>nd</sup> of August, 2019, at the Convention Center of the Chang Yung-Fa Foundation, Taipei (http://www.ialptaipei2019.org/). A total of 961 participants, including researchers, practitioners, and students majoring in speech-language and hearing pathology and related fields from 46 countries/regions, attended the grand conference. Three keynote speakers were invited to give their main talks, as shown in Table 1.

Table 1. The three keynote speakers and their talks

Keynote speaker	Speech	Affiliation
Martine Smith	Innovations for Supporting Communication: Opportunities and Challenges for People with Complex Needs	Trinity College, University of Dublin, Dublin
Helen Grech	Impact of Forced Migration on Communication and Social Adaption	Department of Communication Therapy, Faculty of Health Science, University of Malta, Msida, Malta
Chia-Ying Lee	Neural Underpinnings of Early Speech Perception and Emergent Literacy	Institute of Linguistics, Academia Sinica, Taiwan; Institute of Neuroscience, National Yang-Ming University, Taiwan; Institute of Cognitive Neuroscience, National Central University, Taiwan; Research Center for Mind, Brain and Learning, National Chengchi University, Taiwan

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Due to the contributions of multicultural and multidisciplinary participants, this was a fertile conference filled with knowledge and experiences. A summary of the various sessions, forums and presentations in this congress is presented in Table 2.

Table 2. The summary of the 31st World Congress of IALP, 2019 at Taipei, Taiwan

Category	Number
IALP Standard Committee Sessions	12
WHO Session	1
International Communication Project Session	1
Invited Speech-Language and ENT Panel- Discussions	7 (6 and1)
Invited Hearing Sessions	12
Oral Presentations	179
Poster Presentations	179
Global leadership Forum	1
IALP Presidential Forum	1

In regard to fluency disorders, one IALP Standard Committee Session was held. One panel discussion entitled "Tone effect on stuttering" was presented by two teams from Taiwan and Hong Kong, respectively, and their studies sparked lively discussions among the participants (Chou & Yang, 2019; Chou, Zebrowski, & Yang, 2015; Law, Packman, Onslow, To, & Lee, 2019). There were 8 oral and 11 poster presentations published in this congress in both the research and clinical aspects. Unfortunately, only one poster presentation focused on cluttering, entitled "A Study on Comparing the Speech Rate, Intelligibility and Disfluency between Preschool Cluttering and Non-Cluttering Children" by Hsin-Chih Hsieh and the Yang (Hsieh & Yang, 2019). This study found that the speech features of the preschool children with cluttering (PCC) are rapidity, disfluency and poor intelligibility which are consistent with those obtained from the studies on English-speaking cluttering persons (Bakker et al., 2011; Scaler Scott & Ward, 2013). Based on the above performances in three tasks: conversation, story-telling and picture storytelling, of PCC, conversational and story-telling tasks were found to be more appropriate than picture story-telling for diagnosing preschool children with cluttering. In addition, a significant positive correlation was posited between speech rate and other disfluency (OD) in the 3 tasks, along with a significant negative correlation between speech intelligibility and OD in storytelling. Hsieh & Yang (2019) proposed that PCC may have insufficient time to plan and program their speech, thereby causing other disfluencies, such as multisyllabic repetition, pauses, revision-abandon, etc. For PCC, storytelling is more difficult than conversation and picture story-telling. While telling a story, the PCC must extract vocabulary, edit sentences, and organize the text, entailing a huge burden on the PCC's so that they have more occurrences of OD. Their bumpy speech interrupts a listener's comprehension and decreases the judged intelligibility. However, more research on early cluttering in children is needed to improve our understanding of it.



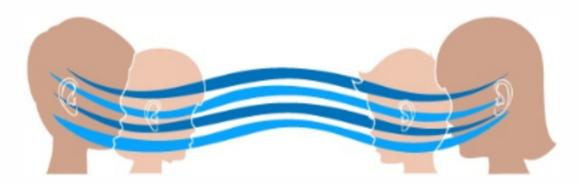
The author and student attendees from Japan and Taiwan whose major are in fluency disorders

Besides a lot of brain-stormed concepts mentioned above, unexpectedly, it was wonderful to meet with ICA members at the conference, including Dr. Katarzyna Wesierska from Poland, Dr. Shoko Miyamoto from Japan, Dr. Yvonne van Zaalen from the Netherlands. We welcome you all to visit Taiwan in the future.

Shu-Lan Yang, Ph. D. & Professor, Department of Special Education, National Pingtung University, Taiwan shuyang0928@gmail.com

## Fluency Bank: An Update

by Nan Bernstein Ratner, the USA



#### **TalkBank**

#### FluencyBank

FluencyBank (talkbank.fluency.org) continues to solicit donations of speech/language samples from individuals who stutter/clutter or have other fluency disorders, across the lifespan. While we always welcome research data, our most popular links are those used for teaching, including Voices of Adults who Stutter and Voices of Children who Stutter. Instructors and students have been able to explore fully open-access, free video and written contributions from over 30 adults and numerous children, in learning about the affective, cognitive and behavioral features of fluency disorders. Professors and students also can access numerous ideas for using the materials in classroom assignments and exercises.

Three years ago, the ICA worked with FluencyBank to develop a protocol for collecting samples from adults who clutter. However, to date, we have received only one contribution, and the site is not able to offer instructors and students the benefits of the other Voices projects. We'd like to ask ICA members to consider donating data to the FluencyBank project. Instructions for how to do so can be found here: <a href="https://fluency.talkbank.org/teaching/AWC.html">https://fluency.talkbank.org/teaching/AWC.html</a>

While we may not be able to use archival video that was not consented for this purpose, our federal funding (NIDCD) does allow us to extract audio and de-identify contributions. We are able to accept data in many languages, not solely English. If you are interested, we recommend that you write to Nan Ratner at <a href="mailto:nratner@umd.edu">nratner@umd.edu</a> to explore possibilities for your data to help educate clinicians around the world.

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# Virtual Learning by Stuttering Foundation



by Sara MacIntyre, the USA



Stuttering Foundation has launched the *Virtual Learning by Stuttering Foundation*, a free online series of interactive workshops with a variety of offerings for speech-language pathologists, parents, and individuals who stutter and or clutter.

The series includes monthly offerings ranging from clinical training opportunities to parent education, to a platform for people who stutter and or clutter of all ages to share their stories. Sessions are moderated by many of the world's leading clinicians, researchers, and self-help advocates—bringing learning and collaboration to you.

Over the course of this past year, we've hosted a wide range of sessions and the feedback from the community has been overwhelmingly positive—highlighting the combination of accessibility and high-quality nature of these learning opportunities. Topics have ranged from discussions on: ACT/Mindfulness and its application to stuttering therapy, to overcoming school-based service delivery challenges, to effective and comprehensive therapy planning, to panels of parents, kids, and teens sharing their stories.

Recently, Dr. Kathy Scaler Scott hosted one of the first panels exclusively with individuals who clutter, "Cluttering: Shared Experiences from the Child, Adult and Family Member Perspective." As a community, we are more accustomed to hearing panels from the stuttering perspective—individuals who clutter are not as commonly heard from, yet their experiences are unique and valuable. Viewers were able to gain insight into the lived experience of cluttering from the child, parent, sibling, and adult perspectives. This session, and many other sessions are archived and available on our streaming site: <a href="https://www.stutteringhelp.org/streaming">www.stutteringhelp.org/streaming</a>.



We are busy planning an exciting year ahead, and hope you will consider joining us. To learn more about Virtual Learning by Stuttering Foundation, and to sign up, visit our website: www.stutteringhelp.org/virtuallearning.

Invitation for the European Symposium on Fluency

Disorders!



February 15th 2020

February 12-14th pre-symposium workshops

More details here:

http://www.ecsf.eu/news-and-events/european-symposium-on-fluency-disorders-20201

## Invitation for the 12th Oxford **Dysfluency Conference!**



More details here: www.dysfluencyconference.com www.dysfluencyconference.com

Please let us know the good works you and others are doing in your country - emails reports to: Katarzyna Węsierska, the ICA Secretary and newsletter Editor at: katarzyna.wesierska@us.edu.pl