

# International Stuttering Awareness Day

22 October

## ISAD 1998-2012: Some History and Many Positives

by Judith Kuster - First published in 2017

About the Author: Judith Kuster CCC-SLP, BCSF-R, M.S. in speech-language pathology and M.S. in counseling, is an ASHA Fellow and emeritus professor of Communication Disorders at Minnesota State University, Mankato. She has maintained the Stuttering Home Page (<a href="http://www.mnsu.edu/comdis/kuster/stutter.html">http://www.mnsu.edu/comdis/kuster/stutter.html</a>) for the past 22 years (starting as a Gopher site) and put together the ISAD online conferences from 1998-2012. Kuster is a member of the ASHA Special Interest Group #4: Fluency and Fluency Disorders and the International Stuttering Association. She is the recipient of the two Fulbright Specialist Awards (Bulgaria 2007 and China 2010) and has presented on fluency disorders nationally and internationally. She was awarded the ASHF DiCarlo Award for Outstanding Clinical Achievement, the 2003 IFA Distinguished Contributor Award, the 2007 ISA Outstanding Contribution Award, the 2008 ASHA Distinguished Contributor Award, in 2009 was named to the National Stuttering Association's Hall of Fame, the 2009 MSU, Mankato Global Citizen Award, and Bethany Lutheran College 2017 Alumna of the Year.

2017 is the 20<sup>th</sup> anniversary of the International Stuttering Awareness Day (ISAD) online conferences. Perhaps it is appropriate to review some of the history of the ISAD online conferences. An invited article published in an Australian journal (Kuster, Judith (2002) Online Conferences: A New Way To Reach Out And Around The World, *ACQ*) reported on the first four online conferences (from 1998-2001). This introduction will share some background from that article, as well as information about how this project has withstood the test of time, as there have now been 20 online conferences dedicated to stuttering.

The Internet provides an important meeting point where professionals can share information and provide support to people who stutter (PWS), and their families. It also offers a means for students to learn, and for practicing clinicians to update their information and skills in the area of stuttering.

October 22, 1998, marked the first International Stuttering Awareness Day (ISAD), supported by the International Fluency Association (IFA), the International Stuttering Association (ISA), the European League of Stuttering Associations (ELSA) and the American Speech-Language and Hearing Association (ASHA). The stated purpose of the ISAD was "to promote awareness and

understanding and to show appreciation for people who stutter and the speech-language professionals who work with them."

The idea for an online conference, one of the first ever online conference endeavors, grew when Michael Sugarman posted a challenge in 1998 for everyone to "do something" for the International Stuttering Awareness Day, October 22, 1998. Among the many ideas was to host a chatroom on October 22 to disseminate information and raise public awareness of stuttering.

#### How Did a Chatroom Become an Online Conference?

In fact, the first online chatroom for stuttering had already been started on The Stuttering Home Page (SHP – <a href="http://www.stutteringhomepage.com">http://www.stutteringhomepage.com</a>) in late 1997, but at that time the technology and level of Internet connection required excluded many potential participants. Furthermore since this was to be an international effort, a chatroom, which provided the opportunity for synchronous live discussion, did not seem feasible for an international endeavor due to time zone differences around the world. With the level of technology and access available in 1998, and with the work involved for a single day of an online chat, along some basic web savvy the seemingly insurmountable obstacles were overcome. The idea of a global conference using the Internet was born (with some objections not worth sharing) with the decision to hold an online conference beginning on October 1 and culminating on October 22, the International Stuttering Awareness Day.

#### The Event

The freely-available ISAD Conference began with 1000-3000 word invited papers written around a specific topic, written in a "reader friendly" style, appealing to both professionals and consumers. The first conference included opportunities for people to post conference feedback and other ISAD events scheduled locally. The 2009 ISAD online conference featured a movie of several world-wide events announced and carried out on previous October 22 International Stuttering Awareness Days.



A special section of the conference added in 1999 was "Office Hours: the professor is in," where consumers could ask questions of professors who specialize in stuttering.

The goal was to invite both consumers (people who stutter and their support community of family members and friends) and professionals (clinicians, professors, and researchers), men and women, from various countries. Occasionally children and adolescents became presenters and often participated by posting comments and questions on the Prof is In and even to some papers. Professionals (researchers and professors) often invited their students to collaborate on papers. Occasionally professionals and consumers collaborated on papers as well.

Each panel, paper, poster session, and office hours was linked to a "threaded discussion (TD)," an open bulletin board where participants could comment or ask questions, and authors could respond. There were also two additional threaded discussions created for "individual comments about the conference" and for organizations and individuals around the world to "announce other ISAD events." All threaded discussions were "closed" at the end of the conference, but the conference papers. as well as information posted on the TDs during the conferences, continue to remain online in the conference archive for anyone to access.

https://www.mnsu.edu/comdis/kuster/isadarchive/onlineconference.html

## **Progression**

The first number is the year of the conference, followed by "hits" to the front page of the conference as of September 4, 2017. It does not necessarily reflect how often the conference was accessed when it was "live" since people are still accessing the conferences in the archive. When flags from participating countries were added, the number follows.

- 1998 14016
- 1999 14994
- 2000 15633
- 2001 13205
- 2002 19111
- 2003 17616
- 2004 21000 94 flags
- 2005 17347 96 flags
- 2006 18536 95 flags
- 2007 19717 89 flags
- 2008 21874 82 flags
- 2009 22946 77 flags
- 2010 12035 69 flags (cluttering conference)
- 2010 20874 84 flags (ISAD conference)
- 2011 18756 85 flags
- 2012 21425 96 flags

### The Positives

## Learning opportunities for me

A conference template was created and continued to evolve over the years.

Challenges created learning opportunities as features were added over the years. Some examples:

- Several Sections
- Invited Papers 1998-2012
  - Divided to feature The Experts (PWS) Speak For Themselves 2005 2012
- Poster sessions (up to 1500 words) reporting on current research projects. 1999-2000 combined with Invited Papers in future conferences in 2001
- Panel Discussions short reports by several people about a given topic 1998-2002??
- Clinical Nuggets short papers of therapy by clinicians added 2007-2012
- The Researcher is In 2004-2005
- Especially for "kids" 2002 and 2008
- Creative expression included poetry, songs, PPT story, video, etc. 2012 and more
- Interactive opportunities
  - o Announcing ISAD events 1998-2012
  - o If I Could Tell You One Thing for kids and teens 2000
  - o Telling Your Own Story 2001
  - o Become an official Geography Genius 2004
  - Downloadable Jeopardy Game 2006
- Buttons
  - Occasionally papers were presented or translated in another language (Spanish, German, French, and Hebrew). Links to various translating software were added from 1999-2012
  - Back to the main conference page link first added 2001
- Practice threaded discussions 2001-2012
  - before the conference (for presenters)
  - during the conference (for participants)
- Conference downloads by Viren Gandhi, a volunteer in India
  - o for PCs added 2002-2003
  - for PCs and Macintosh 2004-2012
- CD-ROMs of the conference created and distributed
  - o 1998 hybrid which would open on either PC or MAC
  - o 1999 separate CDs one for MAC, one for PC
  - o 2002 separate CDs one for MAC, one for PC
  - o 2003-2005 CD that would open in either PC or MAC
- Pictures of presenters added 2002-2012
- Audio presentations first added 2003
- Conferences in which people who were already deceased
  - were included as co-presenters (Charles Van Riper, Dean Williams, Joseph Sheehan, Marty Jezer)

- paper accepted but Bernard-Thomas Hartman 2005 died before the conference
- Flags of countries added 2004-2012
- Music first added 2004
- Sea-Green ribbon campaign 2009-2012
- Various Special Features 2010-2013
- Including a Video: PWS Inspire and Talking to You a song in honor of ISAD- 2010
  - o Online books shared and created for various conferences
- Special advertising downloads
  - brochures to download and distribute 2000
  - o brochures for ISAD in English and Chinese 2009
  - o conference posters
  - o poster translated into 15 languages for distribution 2009
  - o full page posters developed for download 2010-2011
- Free downloadable cluttering software for PC 2010

## Support received

I have received incredible support from the stuttering community starting with Michael Sugarman, who inspired me to "do something", offering invaluable advice and support. I NEVER had anyone who was asked to write a paper or serve as the "Prof is In" decline the invitation. They participated writing significant papers and nearly always were active in following comments/questions about their papers as well as reading and responding to other presenters. They provided encouraging feedback about the conferences and in numerous cases professionals and consumers have become life-long friends.

A very important positive was the support received (and still being received) for producing and managing the online conferences. At the university level, without the technology support for which I am profoundly grateful, it would have been impossible. My angels included, among others Jeff Henline for initial technical assistance and support, Jerry Anderson for support in getting videos and audios online, and especially Jeff Hundstad for his mentorship and continuing support. The 2002 conference was supported by a small grant from the Minnesota State Center for Teaching and Learning. Several years my department supported offering CEUs and granted one credit in my course load by listing the online conference for credit.

And finally, my husband, Tom Kuster, provided unending support and patience, solved many of my technical problems and did video and audio recording and editing.

## The authors and where they came from

I recruited many presenters after I saw their postings on various mailing lists I monitored, or at conferences (state, national, and international) where professionals presented their information about fluency issues or current research. In the 15 conferences, there were 520 different presenters from 56 countries: Albania, Argentina, Austria, Australia, Belgium, Benin, Bolivia, Bosnia Herzegovina, Brazil, Bulgaria, Burkina Faso, Cameroon, Canada, Chad, China, Croatia, Czech Republic, Denmark, England, Equatorial Guinea, England, Finland, France, Germany, Ghana, Iceland, India, Ireland, Israel, Italy, Japan, Kenya, Korea, Kuwait, Luxemburg, Mali, Mauritius,

Nepal, Netherlands, New Zealand, Nigeria, Norway, Russian Federation, Rwanda, Slovakia, Slovenia, South Africa, Spain, Sudan, Sweden, Turkey, Venezuela, Uganda, United States, and Wales.

Some presenters provided a single full-length paper only once while others participated in various ways more than once – writing several full-length papers, participating in a panel or poster session reporting research, sharing a clinical nugget or serving in the Professor is In and the Researcher is In. Many chose to co-present with students, colleagues, or clients, including twelve children who were typically identified by initials unless their legal guardian gave permission to use their full name. At times, individuals requested to submit a paper. Their ideas were welcome and most were worked into the current conference if there was room and the topic was not already being addressed that year. Occasionally they were asked to submit their paper for the following year or to revise their idea to fit the purpose of the online conferences.

The ISAD online conferences may have been the only conferences in which persons who had already passed away were included as presenters when Anders Lundberg from Sweden copresented with Charles Van Riper, Bob Quesal co-presented with Dean Williams, Eugene Cooper co-presented with Charles Van Riper and Joseph Sheehan, and Lisa Vadnie co-presented with Marty Jezer. Short offerings by Charles Van Riper and John "Scatman" Larkin were also included in two conferences.

There are several conference presenters who have passed away. Those that I am aware of include Marty Jezer, Richard Curlee, George Shames, Eugene Cooper, J. David Williams, Joseph Agnello, Charles Diggs, Mike Hughes, Catherine Montgomery, Konrad Schaefers, and Peter Kissigizlis. Their lasting words to the stuttering community are their conference presentations.

### The participants

The individual participants that I can account for are only those who signed up for credit or CEUs, or those who posted questions and comments on the threaded discussions and shared their names. I can however count the countries from which individuals checked into the front page of the conferences at least one time. As each one visited, I added flags of participants on the opening page of the conferences from 2004-2012; here are the flags of the 169 countries from every continent except Antarctica (although one presenter had been there).



Many university programs, including mine, used the ISAD online conferences as requirements in their fluency disorders courses. In a 2016 and 2017 three-credit graduate course I required reading and feedback on eleven relevant individual papers from past conferences. My department allowed me to offer the online conferences for 15 hours of CEUs or 1 graduate credit. The online conferences became one of the first online CEUs offered by my university. Over the years many students at my university and a few from other universities took conferences for credit and many others from around the United States signed up for CEUs.

## Some results for authors and participants

- Publications
- Many authors include their papers in their professional vitae
- Several papers are cited in professional books and articles about fluency disorders
- Several ISAD presentations were re-published in print. Most of the articles in early conferences were republished with permission of the authors by Mike Hughes in the Canadian *Speak Easy* newsletter.
- Connections were made by professionals to collaborate on research which was then published in peer-reviewed publications.
- Connection were made by consumers for finding help, locating stuttering support organizations, for suicide ideation, and more.

#### Some results for me

It was very satisfying to receive positive feedback from presenters, from students taking the conferences for credit and from clinicians taking the conferences for CEUs. The online conferences introduced me to good friends around the world, both professionals and consumers, and created opportunities for me to present at local, state, national, and international conferences. A national and two international stuttering organizations recognized my efforts with honors. I was also invited to add to my professional vita with invitations to write articles for various publications.

But the most satisfying benefit for me was witnessing a growth in understanding of students in communication disorders programs and a difference in the lives of some people who stutter as reflected in some of the many comments I received. Two individuals who were blind emailed me saying the format of the online conferences was perfect for them. My goal of making information about stuttering accessible to people in developing nations was also reinforced.

A few comments on the conference feedback threaded discussion are below:

- "You have allowed the experts, the laymen, the fluent and the none fluent to reach out and touch one another in a way that has probably never been done before. . . . the best learning experience on stuttering I have had."
- "i came in knowing nothing about stuttering, and left with array of knowledge that i will never forget. i had the chance to meet people through their story and gained a lot of respect for people who stutter."
- ".....Thank you again for this conference and opening up this world to me! Croatia."
- "As a parent of a child who stutters and specially being so far away from real help I am so eager to learn as much as possible about this disorder in order to help my son. This

- time I didn't need to be on a plane for hours in order to learn so much. Thanks for all you do to improve the lifes of the people who stutter." (Central America)
- "Last year, spurred on by an article on this conference, I joined Toastmasters and that benefited me greatly."
- "I wish you (and the Internet) had been around for me 60 years ago. It sure makes a difference to have this information so readily accessible. Your work continues to be a milestone in the field."
- "Speak Easy S.A. contacted me via this conference and there just happened to be a person in Port Elizabeth from Johannesburg Speak Easy on the night we had our second meeting. He came to our meeting and offered some very valuable advice. This has really helped to open doors for us in Port Elizabeth South Africa. "
- "You've played a big role in building a powerful community by gathering vital information on stuttering making it easily accessible to PWS, parents, students, and anyone with an interest in solving this complex puzzle. We all owe you a big vote of thanks."
- "What you have done and continue doing in organizing the online conference is amazing and a real inspiration and hope to the millions of people who stutter on the global platform. The level of interactions and participation at the conference between PWS has never been better." (Zambia comment)

3242 total views, 1 views today

## **Comments**

ISAD 1998-2012: Some History and Many Positives (Judith Kuster) — 14 Comments

1. Scott Palasik on October 4, 2017 at 12:44 am said:

Judy,

HI! It is so good to see this history of the conference. Especially coming from you! I just wanted to say hi and say I enjoyed reading this tremendously! I hope you are well! Always,

Scott

o Judy on <u>October 4, 2017 at 4:49 pm</u> said:

Hi to you, too, Scott! Thanks for being interested in the history of the online conference, and for being a leader in how the next generation has not only continued the vision, but expanded it in so many creative ways as technology continues to advance! Best always to you, Scott. It is fun to watch you continuing to grow in your career! You know how I feel;-) **Judy** 

2. Benny on October 7, 2017 at 3:07 pm said:

Judy, thank you so much for writing this beautiful and comprehensive paper. Somehow the history of the online conference is also my personal history with the stuttering community.

As far as I can recall my first hit of the stutteringhomepage.com and of the conference online occurred somewhere in 1998....

Wish to read more and more good papers from you in the future.

o Judy on October 7, 2017 at 11:31 pm said:

Thank you for reading the paper, your kind comments, your papers and participation in past online conferences, and your friendship, which I value a lot. It has lasted longer than some of the people participating in this year's conference have been alive!! How can that be? ③

3. Michael Sugarman on October 7, 2017 at 10:49 pm said:

Thank you for adding those who had passed away and contributed not only to the online conference—contributed to the stuttering community.

Look forward to seeing you again—Glad we met way back (oh my in late 90's.

Michael

o Judy on <u>October 7, 2017 at 11:41 pm</u> said:

Thank you, Michael. We've worked together on several very important and professionally-satisfying projects! I'm glad we met, value your advice and support for so many years, and hopefully will be seeing you again in Los Angeles at the ASHA convention in a few weeks. I've put together a panel on how some people in Africa are now being served online by telepractice. The roots of that started many years ago with the Internet (and the online conferences) open our eyes to the need for information and therapy for people living with stuttering in Africa. The ISA continues to play an important role today as well. It has been exciting to watch (and be a small part of).

4. John Paskievich on October 21, 2017 at 4:19 pm said:

Congratulations and thank you for the tremendous amount of excellent work that you have done over the years.

o Judy on <u>October 22, 2017 at 12:18 am</u> said:

How nice of you to stop by and thank you so much for your kind comments. We've both been around for a long time, John;-) and I admire the work you've done and your active and helpful participation on the mailing lists for many years! I suspect we will both die with our boots on (American idiom you are undoubtedly familiar with;-) God willing it will be a long time from now;-)

5. Ana Paula Mumy on October 22, 2017 at 7:37 am said:

Judy,

Getting to meet you was a highlight of my summer this year! I have learned so much from your labor, your heart, your passion! Thank you for this thorough overview.

#### Ana Paula

o Judy on <u>October 22, 2017 at 12:38 pm</u> said:

Thanks, Ana Paula! It was wonderful meeting you in person as well, although I feel as if I've known a kindred spirit for a long time online;-) I wish I had had more time to respond to papers this year, but I was getting another online conference paper ready (that conference opens tomorrow) and working a lot on a paper for ASHA this year so my online time to respond to ISAD papers was limited (although I read several, including yours). I'm glad papers are archived because I hope to read all of them. Your support of the online conferences is appreciated, as are your kind words.

6. Anita S. Blom on <u>October 23, 2017 at 8:28 am</u> said:

The ISAD online conference is such an amazing event that brings pws of all ages, parents, SLP and students, friends and family together. We all learn so much from each other. About people's journeys, about therapies and research, about what it's like to stutter in different countries. I'm so happy you started this and I know about the struggle and frustrations that occurred every year, but still you kept going. You left some big shoes to fit into, and we're trying to fill them as good as we can, but we do miss you a lot and hope we can come back to you for guidance if we need help.

Hugs and keep talking!

Anita

o Judith Kuster on October 23, 2017 at 11:04 pm said:

I see the comments section hasn't been closed yet so I will reply to your nice message. Anita, you and the team keeping the ISAD online conferences going have done and are doing an incredible job and I'm delighted this venture has now finished 20 years of conferences. Do you realize that many of the people enjoying and learning so much about stuttering through the current conference weren't even born 20 years ago!! You are serving some of the old timers, but more importantly, an entirely new generation. Congratulations on another terrific conference!!

• Anita S. Blom on October 24, 2017 at 7:47 am said:

Yes, that's a startling thought. Are we getting old? 😉

• Judith Kuster on October 25, 2017 at 1:37 am said:

Older yes. Old never;-)

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