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Message from the ISA Board of Directors

In this first edition of One Voice of the new ISA Board of Directors, we would like to take this opportunity to introduce ourselves and our ideas in the context of the worldwide stuttering awareness and self-help for the coming years.

As the International Stuttering Association seeks to improve the conditions of all those whose lives are affected by stuttering in all countries, the new ISA Board of Directors wants to get more in contact with the ISA member associations and wants to work more closely together with you.

Since the new Board of Directors was elected in June 2019 in Iceland, we used the last months to settle our selves in our new roles and functions. For your information, these persons were elected to the new board:
- Anja Herde (Germany) - Chair
- Arni Birgisson (Iceland) – Vice Chair, Treasurer
- Rodney Gabel (USA) - Secretary
- Sybren Bouwsma (The Netherlands)
- Sigþrúður Fossberg Thorlacius (Iceland)
- Dina Lilian (South Africa)
- Dieudonne Nsabimana (Rwanda)
- Doug Scott (USA)
- Rutger Wilhelm (The Netherlands)

More information you can find on the ISA Website. Our goal is to have a better idea of your needs and build more international collaboration to learn from each other and to be able to support you in a better way to raise awareness for people who stutter worldwide and in each country.

To realize the ISA mission and vision, the ISA Board has worked out the following activities and goals by June 2022:
1. Intensify the contact to the ISA member association, convince more associations to become a member of the ISA and supporting the international collaboration and knowledge transfer.
2. Developing the ISA constitution: The ISA constitutions from July 23, 2001 contains a suggestion a „development of the ISA constitution, (which) will involve revision of the document such that there will be a brief basic document followed by a set of bylaws. The board of directors will create a draft of this stage of the revision of the constitution, and will submit it to member associations for ratification.“ The current ISA board would like to make such a revision of the ISA constitution and drafting a basic document followed by a set of bylaws which will submit to member associations for ratification.
3. Increasing support to developing countries and starting a pilot of the International Speech Project – Stuttering in Rwanda.
4. Developing the ISA website to make it more use-friendly.
5. In addition, we want to know how we can be more helpful for you as an ISA Member Association. To discuss this with you, we are aiming on hosting an online conference with all member associations in 2020. More information follows.

We appreciate all your ideas and looking forward to work more closely with you. Feel free to contact us any time. We wish you a wonderful and healthy 2020 and all the best for the future!

The ISA Board of Directors
Netherlands: European Erasmus+ Youth Exchange
Sybren Bouwsma, The Netherlands

Over the past years different youth exchanges have been organised for young people who stutter between 18 and 30 years old. A youth exchange is a meeting of young people between 18 and 30 years old from different European countries. It is funded by Erasmus+, a programme from the European Union that supports education, training, youth and sport. The youth exchanges for people who stutter are organised in cooperation between different national stuttering associations and coordinated by the Anatta Foundation from the Netherlands.

This summer it will be 5th time that this youth exchange will be organised, the first three times it was in a small Piedmontese village in Italy and last summer it was in the village of Lemele, in the nature-rich eastern part of the Netherlands. This summer the Youth Exchange will be held again at Erve Aaftink’s group accommodation in Lemele between 25.7-2.8.2020. The theme of the year will be ‘Natural Story-telling’. We will have different activities and workshops on how we can tell our story in a natural way, and what you can do to reach your public. The main focus of the youth exchange will be on cultural learning, non-formal learning, self-growth, and expanding comfort zones. Themes will be discovered during various workshops, which includes for example: acting, cultural learning, relaxation exercises, and sharing experiences about stuttering in a safe environment. The youth exchange week is not intended as a speech therapy course, but it is focused on the acceptance of stuttering, together with cultural and non-formal learning aspects and a lot of fun! The participating countries of this year are the Netherlands, Finland, Sweden, Estonia, Italy, Portugal, and Spain. Every national association of the participating countries is looking for 3-4 participants between ages 18-30. For more information on the Youth Exchange and how you can contact the participating organisations you can look at the website of stamily.org. To give a better idea about what we do at a youth exchange, take a look at a video of the exchange from 2019.

Next to this Youth Exchange for people who stutter only there will also be Training for Youth Workers and a Youth Exchange for a mix of people who stutter and who do not stutter. The participating countries for these activities are Greece, The Netherlands, North-Macedonia, Finland, Estonia, Iceland and Spain. For more information about all these youth exchanges, you can contact sybren.bouwsma@gmail.com
Europe: Stuttering is beautiful - Transnational European Union Funded Project, aimed at Supporting Youth Workers to Empower Young People Who Stutter

Sigríður Fossberg Thorlacius, Chair of Málbjörg, the Icelandic Stuttering Association

"Stuttering is beautiful" is the name of a transnational project, funded by Erasmus+, the EU program which supports education, training, youth and sport in Europe. The project is 18 months long, with a formal kick-off meeting in August 2019 and a final multiplier event in October/November 2020. Three associations are currently involved in the project: EKÜ, The Estonian Stuttering Association, Málbjörg, The Icelandic Stuttering Association and the Dutch Anatta foundation, which promotes mental health through nature. Representing Málbjörg are Sigríður Fossberg Thorlacius and Satu Nygren, representing EKÜ are Hardi Sigus and Raul Isotamm and representing the Anatta foundation are Sybren Bouwsma and Jurjen de Jong.

The goal of our project is to raise awareness of stuttering among youth workers, who can help us in building and maintaining inclusive spaces for young people who stutter, where they can feel comfortable in communicating at all times. Through the project, we are creating and developing a comprehensive manual with general information about stuttering for youth workers as well as a guide for empowering young people who stutter. Through the manual, we hope to enable youth workers to understand, encourage and empower young people who stutter in respectful and meaningful ways. The manual includes a step to step guide aimed at empowering young people who stutter to speak more freely and openly. Material is drawn from stuttering research and experiences of people who stutter themselves, such as definitions of stuttering, common misconceptions and a list of do’s and don’ts when interacting with people who stutter.

The manual, which is currently under production, is largely based on themes from positive psychology. The final product will be an online, interactive tool, where youth workers learn ways to encourage young people who stutter to set goals for themselves and find ways to meet them. Throughout the process, the young stuttering participants will be guided by the youth workers to self-monitor their progress, discuss challenges as they arise as well as contemplate their own views and values regarding any related issues, such as stuttering and self image. Through the use of the manual, youth workers can create an environment where young people who stutter can gradually create and sustain a positive outlook on their speech and build a strong self image, while becoming more inclined to communicate actively with youth workers, teachers and peers instead of avoiding situations where oral communication is required such as at school, clubs, sport et cetera. We believe this is very important as interviews with adult stutterers show that stuttering can have a negative impact on communication with teachers, peers (Crichton-Smith, 2002; Daniels et al., 2012; Klompas & Ross, 2004). People who stutter also tend to have a negative view on their capacity to communicate in general (Erickson & Block, 2013).
While stuttering can be an obstacle to speech, I don’t believe that it needs to be seen as a hindrance to open and effective communication. Through taking steps to communicate more openly, I believe that there is an increased possibility for a shift in mindset of the young person who stutters. Through working with the youth worker, guided by the manual, our hope is that young people who stutter will gradually learn to see stuttering as an integral part of who they are, as an imperfect and beautiful asset.

Sources:


Great Britain: 50 Million Voices – 15 country leaders transforming the world of work for people who stutter
Helen Carpenter, Coordinator & 50 Million Voices, London, Great Britain

Globally, 50 million people of employable age stutter – each with a unique voice.

However, experience and research (Butler, C. (2014) Wanted: straight talkers – stammering and aesthetic labour. Work, Employment and Society, 28, 5, 718-734) tell us there is widespread bias globally against people who stutter at work. So what can we do to improve employment opportunities for people who stutter?

At 50 Million Voices we believe the answer lies in stuttering associations in different countries sharing experiences between each other and in educating employers to understand stuttering, so they become more confident in recruiting and promoting people who stutter.

What is 50 Million Voices?

50 Million Voices is an ambitious global initiative providing leadership to help transform the world of work for people who stutter – benefitting employers and society too.

Launched in Spring 2019, we’ve brought stuttering leaders from 15 countries together (Australia, Canada, France, Germany, Ghana, India, Ireland, Israel, Japan, Kenya, Rwanda, South Africa, Spain, UK and USA) to share ideas and best practice, including with some leading employers.

Our vision is: A world where everyone who stutters can have a rewarding working life.
50 Million Voices is led by Iain Wilkie, a former senior partner at global firm EY, who brings 30 years experience leading large global teams. Iain stutters and previously founded the UK's Employers Stammering Network.

Rapid progress

“50 Million Voices has really helped us get started. It opens the door for international cooperation to empower people who stutter at work. Sharing ideas with people from different cultures and points of view is the best way to come up with innovative ideas” Juliette Blondeau and Mounah Bizri, France

We’re now working on our two year goals and strategy. Iain was speaking about 50 Million Voices at Business Disability Forum’s Global Summit in London in February 2020, inviting more employers to hear and embrace stuttering as a different way of speaking and to get involved. Also in February, Pamela Mertz spoke about stuttering at the MITRE corporation in the USA, as they build their employee resource groups. Several 50 Million Voices leaders were suppose to meet in person in March in Paris to take our work forward, coinciding with the Association Parole Bégaiement’s one day conference. Unfortunately because of the Corona Virus the personal meeting was cancelled and we met online instead. And we’re developing further resources to share.

People who stutter often make valuable employees

Research suggests stuttering results in developing strengths such as creativity, resilience and listening, all of value to employers: Stammering can be seen as something that can impart strengths, such as empathy and compassion for others, personal growth and strength of character and working to compensate through higher resilience or greater creativity. Hughes, S., and Strugalla, E. (2013): Recognizing Positive Aspects of Stuttering: A Survey of the General Public. Poster presented at Stuttering Attitudes Research Symposium (Morgantown 2013). Brocklehurst, P (2014): The Hidden Strengths of People who Stutter. www.stammeringresearch.org: “Respondents identified a variety of strengths associated with their stammering and a number of ways in which their stammering had a positive impact on others.”

The recent book Stammering Pride and Prejudice: Difference not Defect includes provocative food for thought from Chris Constantino, suggesting stuttering can be stigmatized and stigmatizing, but also seen as a gain, opening up opportunities for more authentic and meaningful conversations. As technology evolves, so millions of jobs will require different ways of leading, thinking and working together with interpersonal skills at a premium. These changes are a real opportunity for employers, people who stutter and their colleagues. Opening up conversations and learning about stuttering and what good communication really means will make for better recruitment, recognition of talent and better workplaces.

An invitation

Interested in knowing more? We’d love to hear from you – as a person who stutters, on behalf of an employer, a leader for a country interested in getting involved, or a volunteer wanting to help.

Iain Wilkie iain@iainwilkie.com, Helen Carpenter helenjcarpenter@gmail.com www.50MillionVoices.org, Twitter: @50MillionVoices
India: Stuttering Awareness Day Report, India Manipal
Chanchal Chaudhary, Ph.D. Scholar, Manipal College of Health Professions MAHE, Manipal

India, having the second largest population in the world still lags in understanding what stuttering is and the challenges that a person with stuttering (PWS) faces daily in the majority of communication settings. Understanding the impact of this communication disorder, we, at the Department of Speech and Hearing, Manipal College of Health Professions, Manipal Academy of Higher Education, India, conducted an awareness program on International Stuttering Awareness Day on October 22, 2019. The main aim of the event was to create awareness in the general public, school teachers and university-going students about the challenges faced by PWS. The undergraduate and postgraduate students of the department conducted various activities such as Street Play at a prime location in Manipal and were successful in attracting the public. The play focused on challenging communication settings for the PWS and how people’s reaction to the stuttering events creates a negative impact on the speaker. Along with this, the students created an awareness video, directed and enacted by students of the Speech and Hearing department. The video was played for and shared with the university students to sensitize them about the impact of stuttering. The students also participated in a poster making competition following the theme of the event (challenges faced by PWS). The posters together with information about stuttering were displayed in the outpatient department of Kasturba Hospital, Manipal and encouraged visitors at the hospital to stop and read more information about stuttering.

We also conducted an awareness talk for primary school teachers of two schools. The talk focused on “how to identify stuttering in the classroom” and “what to do with a child who stutters”. We were happy to see the interest of the teachers and discussions that followed the talk.

Overall, we were pleased to conduct the program and see the amazing response of people’s interest in knowing more about stuttering. As we know, “A journey of a thousand miles begins with a single step” (– Confucius), this is just a beginning and we wish to reach out to a larger population next time!
Left-Right): Dr. Krishna Y (Head of the Department of Speech & Hearing), Dr. H.J. Gowri (A renowned pediatrician and the Chief guest for the inauguration ceremony), Dr. G Arun Maiya (Professor & Dean), Dr. B. Rajashekhar (Professor, Department of Speech & Hearing) and Dr. KM Sabu (Associate Dean)

Dr. Krishna Y. taking a stuttering awareness talk for primary school teachers at Madhava Kripa School, Manipal
The 13th World Congress for People who Stutter took place in the beginning of June, 2019 in Iceland. This was the first time that such a congress is hosted in Iceland, an exciting challenge and a great honour for our organizing team.

This was the first time I took part in organizing and hosting such a congress, a meaningful, but challenging experience. It was exhilarating to have participants flying in from far away to attend the congress, which took place in a quiet village in the south of Iceland.

We purposely decided on a small venue to encourage participants to explore the local scene and have a better chance of getting to know one another. Small villages come with challenges, such as fewer options of services, restaurants and entertainment. I do believe, however, that over all, the choice of venue was good and provided a homey feel to an international conference.
For me, I wanted participants to feel at ease and experience the relaxed feel of our annual Nordic meetings in Northern Europe. The Nordic meetings generally aim to strike a balance between lectures and workshops and on the other hand social events. That way, there is ample opportunity to make new connections and strengthen old ones within a community that understands stuttering.

It is wonderful to be able to give back to the stuttering community by participating in organizing and hosting a world congress. While it can be challenging, the rewards are worth the struggles!

www.Iceland2019.com
South Africa: Stuttering in South Africa for ISAD
Dina Lilian, Chair of Speak Easy

Sandra Nkosi, a representative of the NAPS (National Association for People who Stutter) in Johannesburg, delivered pamphlets about stuttering on ISAD and informed colleagues she works with about stuttering. She says "As a person who stutters, I took it upon myself to do something to embrace International Stuttering Awareness Day. I believe this is another form of therapy added to the traditional therapy I'm already attending". Some of the Cape Town members of the NAPS took to the streets with family and friends to also hand out pamphlets to spread awareness and to embrace the day. "We wore turquoise coloured ribbons to show unison, to embrace the day and to show support for those who stutter," noted Sandra.

Istutter South Africa, a non-profit organization spreading awareness and seeking support for Persons Who Stutter especially in the disadvantaged communities organized an inaugural run/walk for stuttering awareness on the 19th October 2019 in Sebokeng. Phule Dube-Tlhapi – the founder of Istutter South Africa - says ‘the run was a success.” Dina Lilian, Chair Person of Speakeasy South Africa (which was initially established in 1998), was invited to partake in numerous radio and TV interviews to educate the public about stuttering and ISAD. South Africa is very proud of the diverse activities organized for ISAD by the numerous associations.
In much of the developing world, there is a paucity of appropriate treatment for people who stutter. This is unfortunate because over 68 million people (1% of the population) in the world suffer from this chronic condition. Stuttering can have an extreme impact not only on communication, but also on all parts of a person’s life. Individuals who stutter of all ages are often marginalized, missing out on equal access to educational and employment opportunities. The inability of this segment of the population not able to be equal contributors to the economy can limit growth in the developing world.

In the last decade, helping people who stutter has been a growing concern in Africa. The African Stuttering Centre (ASC) has been a leader in this movement. According to the ASC, there is an extreme lack of treatment for people who stutter in most African countries. The state of affairs in Rwanda offers an example of this shortage. Currently, there are only 2 speech-language pathologists (SLPs) in Rwanda for a population of over 11 million people. Using the universally accepted incidence rates of stuttering (1 percent of the population), there are 110,000 people who stutter in Rwanda, resulting in an estimate of 1 SLP for 55,000 people who stutter. Thus, the care of people who stutter often falls to physicians, who have little to no training in stuttering or speech therapy. Thus, people who stutter often cannot access accurate information about appropriate treatment for stuttering, which causes many people who stutter to be treated with disrespect and in ways that are very harmful to their well-being. People who stutter and their families may then use spiritual or faith healing, unnecessary surgeries like cutting the membrane beneath the tongue (lingua frenum), or ingesting different materials, all of which can be dangerous.

Telepractice - FAU student clinician Shaye Drake, provides stuttering therapy to Francois in Rwanda
The ASC has worked with two University programs in the United States to provide therapy to people who stutter. These Universities deliver treatment to people who stutter through a tele practice program (using video conference software). These programs have been successful, but have been very focused on treating individuals, thus there are limitations to the number of individuals who can be helped. Also, student clinicians deliver the therapy, not a specialist in stuttering. Clearly access to treatment for stuttering is not available to all who need it.

Though the availability of general practitioners is much higher than that of SLPS, only a limited number of general practitioners have been trained to provide treatment to people who stutter. A program to train clinical practitioners to work with this population is one solution to increasing the availability of treatment for people who stutter. The project is a partnership between Rodney Gabel (a Professor and SLP in the United States) and the ASC. This relationship would lead to a training program for general practitioners and students in Rwanda and Ghana. This project would leverage current technologies available to the ASC as well as the University of Toledo, two Universities in Rwanda and two Hospitals. The utilization of technologies (e.g. video conferencing software, University websites for coursework sharing) would allow for a cost-effective means of delivering training, coursework, and treatment. Over the past 20 years, there has been growth in the application videoconferencing and cloud-based platforms to deliver effective educational courses and speech therapy for people who stutter in Africa. The ASC has enjoyed some initial success with this mode of treatment delivery. The purpose of this project is to expand treatment options for individuals who stutter in African countries, and continue to expand the self-help movement in Africa. This will be done through the following steps:

1) Dr. Gabel will develop recorded courses to train professionals, families, and individuals who stutter at the ASC and partnered universities.
2) Live courses in stuttering will be offered from the US to the ASC through software available at and participating partners.
3) Eventually, the partners will coordinate and delivering training in stuttering therapy through videoconferencing from the US. These trainings will educate general practitioners and student health professionals from partnered universities and hospitals in Africa.
   • The participants will observe Dr. Gabel delivering treatment and then have time to conference.

In early 2020, Rod Gabel and the ASC will begin offering coursework to partner organizations in Rwanda. These courses will be recorded lectures. Following this initial step, the program will progress based on opportunities that are presented to move to steps two and three. Funding to support the program is being sought, but this early stage is being done through volunteer time and freely available recording software.
USA: What's Happening in the USA's NSA?
Douglas Scott, National Stuttering Association, NSA/ISA Liaison, Houston, Texas, USA.

The NSA had another great annual conference, its 36th Conference for people who stutter was held on July 3-7, 2019 in Ft. Lauderdale, Florida. One of the approximately 777 attendees, Arni Por Birgisson, who came all the way from Iceland said, "Attending NSA Conference is a fantastic experience. There are lots of interesting workshops and lectures about stuttering related matters, everyone at the conference is extremely friendly and it’s so easy to get to know people there. And it’s not only about workshops and lectures, as the social part of the conferences is what I enjoy the most."

The LettingGo Fall 2019, post-conference issue cover (on your left) completely captures the excitement and camaraderie you will experience by attending a NSA annual conference. More information you can find [here](#).

**National Stuttering Association - Washington D.C. Chapter, January 21, by Haley Mitchem Aguayo**

Chapter Member Spotlight: Charles White, III

Charles White, III is a proud native Washington born and raised in NW DC. His passions are dancing, karaoke, and befriending new people. He has stuttered since he began talking and took intensive speech therapy for 13 years as a child. He learned many fluency techniques to attempt to manage his stuttering.

In the midst of his stutter, Charles has attained various ranks from President of his high school student council, the Sports Editor of his college student newspaper, to now being a U.S. Secret Service Uniformed Division Officer for almost a decade.

Charles has made a daily choice to accept his stutter as simply one small part of himself, but not a defining part. He has vowed never to let his stutter stop him from pursuing his dreams and goals. Charles did not know about the National Stuttering Association as a child, but he is so grateful to be a part of the NSA family today as an adult. They have revolutionized how he views himself and his stutter. With the NSA, truly, “If you stutter, you are not alone.”

Some brief facts in numbers will give you the sense of the impact, from this annual gathering of people who stutter, their families, and SLPs.
In 2020 the NSA is heading to the West Coast of USA for its annual conference. Come join US!
Sweden: Invitation to the The Nordic Stuttering Seminar in 2020
Anita Scatsis, Sweden

The Nordic Stuttering Seminar is a joint, annual event, originally organized by and for stuttering associations from the Scandinavian countries (Norway, Sweden, Denmark). Later, Iceland and Finland joined in, transforming it into a Northern European event. In 2018, Estonia, a Baltic country, joined the team!

Every year, one of the now six stuttering associations takes a turn organizing the event when it is their country's turn to host.

Instead of the Nordic Stuttering Seminars being held in one of the Nordic languages, and later on bilingually, the main language has now become English, attracting visitors from even other continents! (Listen to this podcast about a Canadian’s first experience at the Nordic seminar in Finland 2016.)

The event also attracts a lot of young adults who stutter, thanks to the European Youth Meetings, organized since 1995, and fostering many of today’s chairs and trustees. The young adults are now themselves hosting a new generation of youth meetings, and from there founding the fast-growing community ‘Stamily’, raising stuttering awareness and offering support.

The Nordic Seminars are unlike any other stuttering event, which entices past attendees to return year after year: small with 50 to 80 participants enabling you to make friends with all of your fellow attendees; spanning only 48 hours but are packed with a great variety of activities, from lectures and workshops to social events; and… we are one big family!

The Saturday night evening entertainment is one of the highlights, where attendees from each country get together and put on a show! In the past, groups sang a song, gave a funny presentation, wrote and acted a comedy sketch, and even had a quiz program. We’re looking forward to see the shows this year!

Speaking of this year, the Swedish Stuttering Association, Stamningsförbundet, will be hosting the Nordic Seminar from 4 to 6 September 2020 at the hotel Scandic Ariadne in Stockholm, Sweden.

The program will consist of lectures with Dr Per Alm (about brain research), Ineke Samson (stuttering amongst women) and Andrea Stéen (Projektprata), workshops and cultural and social activities. For those of you who want to extend your stay, we might add an additional tour if enough people are interested. Check out stamning.se/nordic2020 for the program, registration, costs and the latest news about the planning. Also follow our Facebook event page with the latest updates.

Hope to see you in Stockholm! The Nordic program committee, nordic2020@stamning.se
PS. To all who are interested in the latest news from Stamningsförbundet, sign up for our online newsletter (available in Swedish).
Israel: Update on plans for the 14th ISA World Congress in 2022
Hanan Hurwitz, Israel

AMBI, the Israeli Stuttering Association is organizing the 14th Word Congress of People Who Stutter on 19.-22. September, 2020 in Israel, Tel Aviv.

The Congress Theme will be **Stutter ahead and evolve:** Breaking self-limiting behaviors and launching into self development

**Explanation of the Theme**

Choosing to hide stuttering often seems to be the best way to be socially acceptable, and to avoid insult and injury.

But in fact, hiding stuttering is an exhausting task for the PWS, one which enslaves the best of his energies and exacts from him a heavy price thus preventing him from personal growth.

It is actually overt stuttering, which does not hide or apologize, that breaks the barriers of fear and shame - it is the one that allows prosperity, growth and potential fulfillment. Open and liberated self-expression, even if accompanied by stuttering, allows a PWS to express who he really is in the best possible way, to integrate into society, to develop professionally and to fulfill his true aspirations.

More information follows in the **ISA Website**.
Join us for the 2nd Joint World Congress of the International Fluency Association, International Stuttering Association and the International Cluttering Association at the Centre Mont-Royal from 22 July 2021-25 July 2021 in the beautiful city of Montreal, Quebec, Canada.

The Centre Mont-Royal is nestled in the heart of the city nearby local arts, entertainment and eateries. With the success of the Inaugural Joint World Congress in 2018, we are sure that this second collaboration will be a success. We look forward to seeing you in Montreal!

The theme of the Congress and the logo will be announced soon. Find more information soon on the [ISA website](https://www.isa-world.org).

Photo: Eva Blue_ Tourisme Montreal

Photo: Anne-Marie Pellerin_ Tourisme Montreal
We want to see and hear from you!

Send in your stories and photos and we will publish them in the next issue of One Voice.

We want to know what’s going on in your part of the world in the stuttering community. Email your stories and images to admin@isastutter.org.

Want to get involved?

We are looking for someone to help us produce our newsletter One Voice. Sent twice a year, we are open to creative ideas. Interested please email us at admin@isastutter.org.

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