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PERSPECTIVE

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Scientists, society, and stuttering

Abstract

More than 70 million people worldwide are affected by developmental stuttering. It is important to reach out to the public, scientific and medical communities, and those who stutter with a goal to raise awareness about stuttering. In this short perspective, we argue that to educate, advocate, and spread awareness about stuttering, we need role models, support, and opportunities.

Every year, the National Stuttering Awareness Week is a time to educate, advocate, and spread awareness about this speech disorder. Although there are several types of speech fluency disorders, the childhood-onset fluency disorder (COFD, also known as stuttering disorder) is a neuro-developmental motor disorder¹ defined by the American Psychiatric Association (in cooperation and with acceptance from the American Speech and Hearing Association) as "a disturbance in the normal fluency and time patterning of speech that is inappropriate for the individual's age."² Recent data indicate that at some point in their life, ~10% of people are affected by this speech disorder and the prevalence of COFD is ~1% in adults,³ suggesting that most children who stutter will recover spontaneously.⁴ Although COFD is known for millennia, its aetiology is unknown, and despite some promising clinical results, no defined therapeutic agent has yet been approved to address the dysfluency of speech.⁵

In general, broken words, repetitions, prolongations, blocking, and excess physical tension are common amongst people who stutter.² Involuntary movements (such as tics, eye blinks, tremors, or breathing movements) may be present before or during disfluent speaking events (see Ref. (⁶) for comprehensive information regarding developmental stuttering disorder). The extent of these disruptions, which can be associated with the anticipation of stuttering, varies depending on the situations and could lead to increased anxiety. For many individuals who stutter, avoidance and social anxiety are often one of the main disabling features of this condition.⁵

The resulting anxiety and stress can exacerbate speech dysfluency and affect social participation and academic or occupational achievement. Adults who stutter are often underemployed and face stigma and discrimination in academic and occupational settings.⁷ Despite the efforts to help others identify with people who stutter,^{8,9} not being able to speak fluently is a struggle that only those who stutter *truly* understand. Therefore, as a scientist and a clinician who stutter, we believe if we want to confront this long-ignored condition, we should start in our scientific and medical communities. So, we urge scientists who stutter (SWS) and clinicians who stutter (CWS) in every career stage and all disciplines, especially in science, technology, engineering, and math (STEM) to step up and be more present in their community. We inspire SWS and CWS to give more seminars and conference talks and serve as a role model to show others who are experiencing the same disorder so that becoming a scientist or a physician should not be impeded.

Specifically, we *encourage* trainees who stutter to speak and volunteer to present oral and poster presentations at the national and international conferences. Principal Investigators, Academic Physicians, and group leaders can also help by nominating and mentoring their doctoral and post-doctoral trainees, and their students and residents who stutter to give presentations in lab meetings, department meetings, and international meetings. More presence from SWS and CWS will help to desensitise the scientific and medical societies to a dysfluent presentation, as there are so much impact aspects to communication than just verbal speech. Serving as a role model will set the stage for undergraduates and high school students who stutter to have a smoother and easier path than the one that we had in pursuit of their career in STEM.

Other than providing a paved road, and empowering role models, it is important to increase opportunities for SWS and CWS to engage more with the scientific and medical societies. We especially ask our colleagues who do not stutter to join our campaign to enhance the lives of our fellow people who stutter. Therefore, it is equally important that chairs of scientific sessions invite speakers with diverse backgrounds,¹⁰ including those with COFD. Conference organisers, by providing a positive, welcoming, and encouraging environment, can create and promote an environment where uniqueness is not viewed as destructive impediments and where individual strengths are recognised. By giving students, trainees, clinicians, and scientists who stutter an appreciation and respect for their potentials, we can promote a more inclusive society as a whole.

To increase public knowledge and awareness about COFD, it is important to provide support as well. We call our scientific and medical community to join our cause to research the aetiologies and develop more effective treatments. Federal and private funding

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LEY—CLINICAL PRACTICE

agencies should grant more opportunities to do research on stuttering as it is a common disorder affecting 70 million people worldwide. Conferences and societies by providing travel grants can provide opportunities for trainees who stutter to present their research at national and international conferences. Advocacy organisations, such as the National Stuttering Association (NSA), should also play a vital role and enhance these efforts by providing education to academic institutions and scientific societies.

We believe that opportunities, support, and role models are the minimum essentials to build a strong foundation of support within the laboratories, departments, hospitals, schools, and universities to educate, advocate, and spread awareness about COFD.

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Shahriar SheikhBahaei¹ D Gerald A. Maguire²

¹Neuron-Glia Signaling and Circuits Unit, National Institute of Neurological Disorders and Stroke (NINDS), National Institutes of Health (NIH), Bethesda, MD, USA ²Department of Psychiatry and Neuroscience, School of Medicine, University of California, Riverside, CA, USA

Correspondence

Shahriar SheikhBahaei, Neuron-Glia Signaling and Circuits Unit, National Institute of Neurological Disorders and Stroke (NINDS), National Institutes of Health (NIH), Bethesda, 20892 MD, USA. Email: SheikhbahaeiS@nih.gov

ORCID

Shahriar SheikhBahaei 🕩 https://orcid.org/0000-0003-4119-9979

REFERENCES

- Craig-McQuaide A, Akram H, Zrinzo L, Tripoliti E. A review of brain circuitries involved in stuttering. *Front Hum Neurosci.* 2014;8:884.
- American Psychiatric Association. Diagnostic and Statistical Manual Of Mental Disorders, 5th Edition: Dsm-5. 5th ed. Washington, DC: American Psychiatric Publishing; 2013.
- Yairi E, Ambrose N. Epidemiology of stuttering: 21st century advances. J Fluency Disord. 2013;38:66-87.
- Chow HM, Chang S-E. White matter developmental trajectories associated with persistence and recovery of childhood stuttering. *Hum Brain Mapp.* 2017;38:3345-3359.
- Maguire GA, Nguyen DL, Simonson KC, Kurz TL. The pharmacologic treatment of stuttering and its neuropharmacologic basis. *Front Neurosci.* 2020;27:158.
- Frontiers. The Neurophysiology of Developmental Stuttering: Unraveling the Mysteries of Fluency [Internet]. Research Topic the Neurophysiology of Developmental Stuttering: Unraveling the Mysteries of Fluency. 2019. https://www.frontiersin.org/researchtopics/8442/the-neurophysiology-of-developmental-stuttering -unraveling-the-mysteries-of-fluency#articles. Accessed July 8, 2020.
- Gerlach H, Totty E, Subramanian A, Zebrowski P. Stuttering and labor market outcomes in the united states. J Speech Lang Hear Res. 2018;61:1649-1663.
- 8. Tichenor SE, Yaruss JS. Stuttering as defined by adults who stutter. *J Speech Lang Hear Res.* 2019;62:4356-4369.
- Koedoot C, Bouwmans C, Franken M-C, Stolk E. Quality of life in adults who stutter. J Commun Disord. 2011;44: 429-443.
- Jones-London M. NINDS strategies for enhancing the diversity of neuroscience researchers. *Neuron*. 2020;107:212-214.