



Executive Summary

2023

TTAG Panel Discussion at ESSTS Conference:

Support Associations and Patients' Rights: An International Perspective

Introduction

On June 7th, 2023, at the European Society for the Study of Tourette Syndrome (ESSTS) conference in Brussels, Belgium, a pivotal panel discussion titled "Support Associations and Patients' Rights: An International Perspective" took place.



TTAG Panel Discussion 2023



Marla Shea, TTAG Secretary (USA/UK), chaired the discussion, introducing renowned panelists, including Prof. Dr. Kirsten Müller-Vahl (ESSTS, Germany), Dr. Seonaid Anderson (TTAG, Belgium/UK), representatives from various Tourette organisations: Mr. Julian Fletcher (Canada), Mr. Stefano Carrara (TTAG, Italy), and Ms. Emma McNally (UK), along with individuals with Tourette's, Mr. E.G. Gidner (TTAG, USA) and Mr. Paul Stevenson (Genius Within, UK).

Overview

The discussion revolved around several key themes:

1. Collaboration: The panel focused on ways Tourette Support Associations can collaborate with stakeholders, both within their respective countries and internationally.

2. TS in Adulthood and Inclusive Employment Opportunities: The panel emphasised making workplaces more accommodating for individuals with Tourette Syndrome (TS) and the challenges and considerations of living with TS in adulthood. The organisation Genius Within was particularly noted for its efforts in educating corporate sectors about the condition. Topics also included the need for understanding and accommodations, how and when to disclose the condition during job applications, and a push for seeing the value individuals with TS bring to the workplace.

3. Social Costs of TS: Delving into the broader implications of TS, the panel shed light on the social costs that stretch beyond immediate healthcare expenses. These encompass lost productivity, hindered educational attainment, and reduced social participation.

4. Research Involvement: The panel highlighted the importance of making clinical studies known to patients, so they have the opportunity to participate and stay informed about the research results. Methods to disseminate this information through patient organisations, social media, and other channels were considered. There was a strong emphasis on Patient and Public Involvement (PPI) in the research process, especially involving those with lived experiences of TS in the research process, beginning right from the design phase.

5. Research Ethics and Next-Gen Involvement: The discussion addressed ethical and legal considerations in research on TS, such as the potential for remote participation and the need to obtain informed consent. The disparity in TS research across nations was addressed. The challenge lies in cultivating the next generation of researchers in the field, given the currently observed limited interest.

6. Shifting Perspectives: There was a consensus on the need to re-address the communication surrounding TS. The emphasis was on viewing the condition not just as a disability but understanding the strengths, assets, and value it brings to the community. This involves equipping medical experts with better tools for post-diagnosis communication and rethinking the identity built around the diagnosis.

7. Public Perception: The panel identified a discrepancy in public and political perception regarding TS. While many see it as a rare condition riddled with misconceptions, in reality, its prevalence is comparable to the population of significant countries. Addressing these misunderstandings is a primary focus for TTAG.

8. TTAG's Scope: A contemplative question was raised about whether TTAG should exclusively focus on TS or also include Functional Neurologic Disorder (FND). TTAG will revisit and discuss this issue with the entire Board prior to reaching any conclusions.

Conclusion

The panelists and participants provided invaluable insights, joining forces to foster a global understanding and advocacy for TS. The key takeaways from the discussion include:

- The importance of collaboration between Tourette Support Associations and other stakeholders.
- The necessity of making workplaces more accommodating for individuals with TS.
- Recognising the need for patient and public involvement in research.
- The urgency to shift perspectives on TS, focusing not just on its challenges but also on the strengths, assets, and value it brings.
- The imperative of addressing public and political misconceptions about TS.
- Recognising the broader social impacts and costs of TS.
- The importance of making clinical studies, and their results, known to patients.




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