



2023
Brussels

7-9 June 2023
Royal Museum for Central Africa

ESSTS
essts.org



Tics and Tourette Across The Globe (TTAG) session

Wednesday 7th June 2023, 13:00-17:00

Agenda

13:00 – 13:10	Welcome note from TTAG Chair
13:10 – 13:30	Tics and Tourette Across the Globe (TTAG) - 1st anniversary
13:30 – 14:00	Introduction to TTAG Ambassador Program
14:00 – 14:40	Networking with coffee and treats
14:40 – 14:50	Welcome note from ESSTS Chair
14:50 – 14:55	Quick break
14:55 – 16:30	Panel Discussion: Support Organizations and Patient's Rights – An International Perspective
16:30 – 17:00	TTAG Closing Summary

TTAG Panel Discussion: Support Organizations and Patient's Rights – An International Perspective

Panel Members

ESSTS Member/Researcher

1. Prof. Dr. Kirsten Müller-Vahl - ESSTS Chair (MHH, Germany)

TTAG Member/Researcher

2. Dr. Seonaid Anderson – TTAG, Belgium (Neuro-Diverse.org)

Patient Organization Representative

3. Mr. Julian Fletcher - Tourette OCD Alberta Network, Canada
4. Mr. Stefano Carrara - Tourette Italia EST, Italy
5. Ms. Emma McNally - Tourettes Action, UK (virtual attendance)

Expert by Experience

6. Mr. Jerry Gidner – TTAG, USA
7. Mr. Paul Stevenson - Genius Within, UK



Questions

Section I: Working Together

1) How can Tourette Support Associations collaborate with stakeholders to advocate for patient rights and engage in effective ways within their own country and lobbying efforts across countries?

Section II: Campaigning for Change

- 1) What are some effective approaches to lobbying for patient rights, and how can Tourette Support Associations and stakeholders use these strategies to advance their goals?
- 2) In your experience, what types of lobbying activities have been successful in promoting patient rights in your country?

Section III: Rights of Individuals with Tourette Syndrome: Inclusive Employment Opportunities

1) In what ways can the workplace be made more accommodating for individuals with Tourette's?

Section IV. The Role of Support Associations in Research

- 1) How can individuals with lived experience of Tourette syndrome be more involved in research and contribute to the development of new studies? What steps can be taken to foster collaboration between TS experts and individuals with TS?
- 2) There is a significant disparity in Tourette syndrome research across different countries. How can we generate greater interest and awareness in TS research, and who can we collaborate with to raise our profile?

Section V: Audience Questions and Answers

Closing Statement



The **Tics and Tourette Across the Globe (TTAG)** session is open to everyone interested in, or touched by, tics and Tourette Syndrome (TS).

For example, support association representatives, people with TS, educators, researchers and clinicians. TTAG's vision is to bring all individual stakeholders together so we can work more closely together for a stronger impact on our community.

During this informative session we will be providing a brief overview of TTAG activities and plans for the future including our new TTAG Ambassador program.

The TTAG session will be an exciting interactive opportunity to explore international perspectives including a diverse panel discussion and networking opportunities.