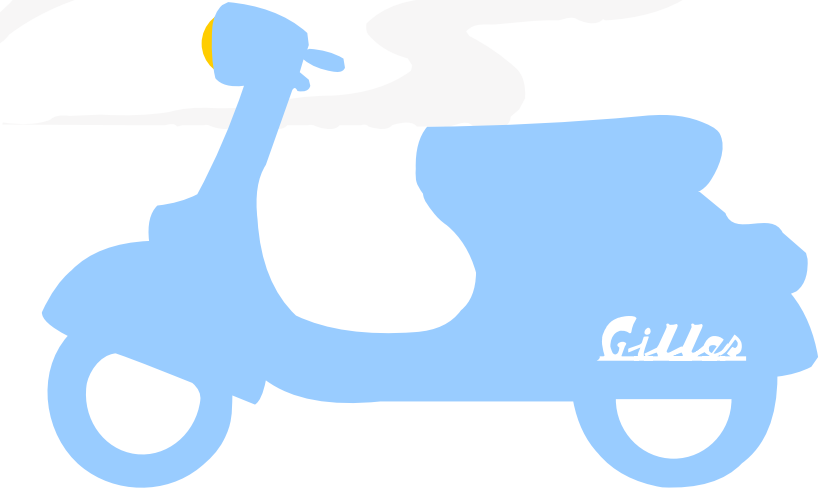
16th International Conference on Tourette Syndrome and Tic Disorders

12-14 June 2024

Palace Grand Hotel Varese

Varese



ESSTS

European Society for the Study of Tourette Syndrome

everyone is invited!

European Society for the Study of Tourette Syndrome

Welcome address by the ESSTS board

Dear colleagues, friends of ESSTS, advocacy groups, local organisers, and sponsors,

The ESSTS board, along with our country hosts **Professors Cristiano Termine** and **Andrea E. Cavanna**, are delighted to welcome you to the **16th International Conference on Tourette Syndrome & Tic Disorders** in Varese, Italy.

Our goal at ESSTS is to coordinate efforts focusing on the study of Tourette syndrome and associated disorders, and to provide a platform for global outreach and educational activities. This year, we can confidently say that we have gone global, with participants from **19** different countries and speakers from **12**.

We have put together an exciting scientific programme combined with social & cultural activities that we hope will inspire you both professionally and socially. We wish to contribute to disseminating the latest knowledge, inspire future research ideas, and strengthen our interdisciplinary and international network.

The number of submitted abstracts has been steadily growing the last couple of years, an encouraging sign that many young and promising researchers are joining the scientific TS community.

We wish to express our sincere *thank you* to our sponsors; this meeting would not have been possible without their support.

We wish you all a great and inspiring conference!

Nanette Mol Debes, Tammy Hedderly, Christelle Nilles, Natalia Szejko, Kirsten Müller-Vahl

Andiamo a...VARESE

Welcome address by the country hosts

As co-hosts of the 16th International Conference of the European Society for the Study of Tourette Syndrome (ESSTS), we take great pleasure in welcoming you here in Varese.

The organisation of the congress has been an opportunity for discussion and collaboration with the members of the ESSTS board: our special thanks go to our colleagues on the board for the opportunity of holding such an important conference in a special place.

During the conference days, you will certainly have a chance to discuss the scientific aspects of Tourette syndrome that will be covered during the main conference and the several satellite events.

On top of this, you will enjoy the unique experience of immersing yourself in the beauty of our country. The province of Varese offers a stunning array of artistic and natural beauties to explore, starting with Varese itself, a "***garden city***" located in a region rich in lakes and set atop seven hills.

The conference venue is a location of particular beauty: built on a hill overlooking the city of Varese, the **Palace Grand Hotel** is a historical Palazzo with bohemian-inspired features, an oasis of peace nestled in the **Colle Campigli** park.

Another spectacular setting is **Villa Panza**, where the gala dinner will take place: in addition to indulging in the delicacies of Italian cuisine, it will be possible to visit a hidden gem: the **world-class collection of modern art** donated to the Villa in 2022.



As a further artistic appendix to the conference, the theater production "**Lady Tourette**" will be on stage on the **12th of June**, after the cocktail party. The production aims to reach non-specialists, and **English translation** of the show will be provided.

This year too we are honored by the presence of **Professor Mary Robertson**, who will present at the opening ceremony of the congress the **Mary Robertson Award** and the newly introduced **Mary Robertson travel grants**.

For the second consecutive year, the **TS-school** will provide healthcare professionals with a tour-de-force of clinically relevant topics covered by world-renowned experts, including ESSTS board members.

Tics and Tourette Across the Globe (TTAG) will host the annual patient associations & advocacy groups meeting.

Speaking of traditions, it will be possible to participate this year as well in the **morning run**, scheduled at **7:00 am** on day 2 & day 3 of the congress.

Once again, we wish to express our heartfelt thanks to the members of the ESSTS board for allowing us to organise this important conference in Varese.

We add a personal…"thank youuu" to the wonderful Anna Kanta, for her fundamental support in organising and fine-tuning every detail of the event.

Have a great conference!

Cristiano Termine and Andrea Cavanna

2024 VARESE

the organising committee

Our hosts & co-organisers

Cristiano Termine and Andrea Cavanna

V-team

Letizia Alberio, Chiara Centomo, Chiara Frisoli, Eva Kraus, Raffaele Meli, Letizia Quadrelli, Ilaria Zecchin

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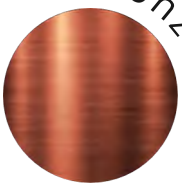

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DIPARTIMENTO DI MEDICINA E INNOVAZIONE TECNOLOGICA - DIMIT

Tics and Tourette Across The Globe (TTAG) ESSTS 2024

TTAG is thrilled to participate in the 16th International Conference on Tourette Syndrome (TS) and Tic Disorders. We extend our heartfelt thanks to ESSTS for their unwavering support of individuals touched by Tourette worldwide.

Our collaboration with ESSTS highlights a growing and positive trend of researchers, individuals touched by Tourette, and support associations coming together to address the most pressing issues, aiming to enhance the lives of those with Tourette.

We are delighted to join ESSTS once again this year in Varese, Italy and we look forward to connecting with researchers, clinicians, and patient organisations attending this year's conference. We warmly invite everyone to our TTAG meeting on **Wednesday, June 12th**, from **1-5pm**.

TTAG is thrilled to announce that **Dr. Erica Greenberg** will be TTAG's **2024 Keynote Speaker**. Dr. Greenberg is the **Director of the Pediatric Psychiatry OCD and Tic Disorders Program at Massachusetts General Hospital** and an **Instructor at Harvard Medical School**. Her keynote address, titled **"Tourette in Real Life - The Pendulum Swings"**, will delve into the interconnected realities of living with Tourette syndrome, including social life, family dynamics, stigma, external influences, age, and gender.

In addition, we are excited to present an interactive discussion panel featuring international speakers and representatives at our meeting. The panel will tackle the crucial topic: **"Shifting the Paradigm of Tourette: Embracing Opportunities, Acknowledging Challenges, and Cultivating a Fresh Perspective!"**. You can view the TTAG meeting programme in the following pages. We warmly invite you to join the audience and contribute to this important conversation.

TTAG is privileged to co-host this year with ESSTS on **Friday, June 14th at 9:15-10:15** addressing the **"Unrepresented Zones of the Community"**. Additionally, TTAG will have an interactive **LIVE ONLINE** vote during the ESSTS conference on **"The Future of Collaborative Vision for Tourette Research"**.

In the past year, TTAG has achieved notable progress, incorporating **six (6)** additional global Tourette patient organisations, increasing the total number of patient associations to **eleven (11)** - a membership growth over **100%**. We are also open for professional TTAG membership and we cordially invite all researchers and clinicians to consider joining TTAG as members. For more information, please see either our website: https://ticsandtourette.org/person-membership/ or email us at: info@ticsandtourette.org.

Professional membership

TTAG website

While in Varese, we welcome you to visit the designated TTAG desk at the conference. Additionally, we encourage you to engage with our board members, who will be available throughout the event. Below, you will find their names, titles, and photographs to help you identify them for a coffee and a chat.

TTAG eagerly anticipates collaborating with researchers, clinicians, and patient organisations worldwide to better support individuals touched by Tourette and their families. We invite you to support us and share your ideas for collaboration.

@
info@ticsandtourette.org

www
https://ticsandtourette.org/

TTAG 2024 Board Of Directors

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TTAG 2024 Board Of Directors

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Neuropsychologist, Acovastta
Association President (2019-2021)

Jerry Gidner, USA
TTAG Board Member & Founder

Seonaid Anderson, Belgium
TTAG Board Member & Founder
Iktic / Jetique – Board Member & Secretary
Founder of Neuro-Diverse.org

TTAG is an umbrella association representing a community of Tic and Tourette Syndrome (TS) associations collaborating at an international level to improve conditions for people touched by TS.

Introducing

the Mary Robertson

Travel grants

for junior researchers

Our ambition to offer a few travel grants to young researchers facing funding challenges has been on the books for many years.

The Society's vulnerable financial situation has been a prohibiting factor for any initiatives outside the core organisation of the annual conference.

This year, with the valuable support of **Professor Mary Robertson**, we were thrilled to introduce **3 travel grants**, (working on increasing this number in the near future!).

More precisely, ESSTS offers **complimentary registration** (in form of reimbursement) and additionally **funds the amount of €350** (per researcher).

ORAL & POSTER PRESENTATIONS

Vote for "Best of"

Vote for best poster & best oral presentation!
The voting platform opens on **Friday 12 June** at **12:15** for **Oral presentations** and at **14:45** for **Poster presentations.**

2nd year!

Listen to the T-playlist!

...Another (audio) guided tour after the visit to the Panza Art Collection!

Scan and listen to the audio presentations recorded by the authors themselves, while you wander around and browse the conference posters.

SOCIAL EVENT

Villa e Collezione Panza

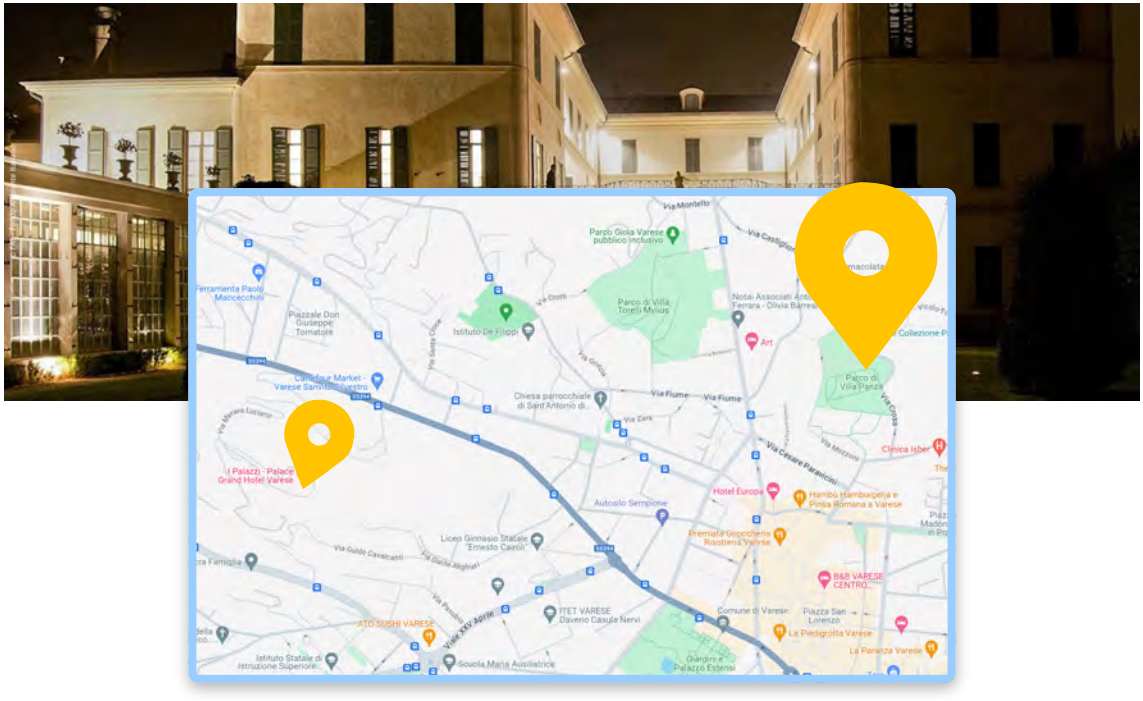
Thursday, 12 June 2024

8:00pm: Permanent collection guided tour

For social event attendees that will have confirmed their participation during the registration process

8:30pm (onwards): Dinner at the Villa Panza gardens

By Ristorante Luce & Etiqua Events



We are walking!

Public transport

THEATRE PRODUCTION

Free event

"Lady Tourette"

Wednesday, 12 June at 9:00 PM

Venue: Spazio Yak

English subtitles available

An initiative by **AIST Onlus, Italian Tourette Syndrome Association** and the **University of Insubria-Department of Medicine and Technological Innovation**. (DIMIT)

> "A brilliant and empathetic comedy narrating the daily life of a boy with Tourette."

For conference participants, a shuttle service to the theatre will be made available.

Info & registration:

FUN TRADITIONS

Thursday, 13 June*

The morning run tradition continues...

07:00

View route:

*Weather & participation permitting, we shall repeat the run on **Friday 14 June**.

...and so does the songwriting!

Courtesy of our Danish colleagues.

View lyrics

CONFERENCE PROGRAMME

Wednesday 12 June 2024

Behavioural therapy workshops

(AM session)

10:00-13:00

I. Workshop in **English** for participants with **basic** training

Programme

10.00: Diagnostics/assessment, psychoeducation
10.30: Habit reversal training (HRT)
11.30: Break
11.50: Exposure and response prevention (ERP)
12.30: Resource activation
12.50: Questions and closing

Trainers:
(in alphabetical order)

Tara Murphy
Zsanett Tarnok
Jolande van de Griendt
Cara Verdellen
Katrin Woitecki

(PM parallel sessions)

14:00-17:00

II. Workshop in **English** for **advanced** participants

Programme

14.00: Frequently asked supervision questions
15.00: Divide into 5 groups to discuss cases and questions (circling):

- Assessment in treatment
- Behaviour therapy and comorbidity
- Working with the system
- Stigma and self-esteem
- Functional tics

15.50: Break
16.10: Reflection/discussion
16.30: Developing supervision and consultancy skills
16.50: Questions and closing

14:00-17:00

Workshop in **italiano** per partecipanti con formazione **base**

Programme

114.00 Diagnosi e valutazione
14.30 Psicoeducazione
15.00 Habit reversal training (HRT)
15.30 Pausa/Break
15.50 Exposure and response prevention (ERP)
16.30 Resource activation
16.50 Discussione e domande

Trainer:

Valentina Baglioni

(PM parallel session)

13:00-17:00

Patient associations meeting organised by Tics and Tourette Across the Globe (TTAG)

TTAG Hour 1: Overview

- TTAG: Accomplishments of a Young Umbrella Organization, The Past Twelve (12) Months

New TTAG association members joining, a new European association on the verge of foundation and news about our TTAG Ambassador Program.
Presenting Michele Dunlap, TTAG President

TTAG Hour 2: Presentation

- Keynote Speaker Erica Greenberg: Tourette in Real Life - The Pendulum Swings

Exploring the interconnected realities: social life, family dynamics, stigma, external Influences, age, and gender in Tourette's experience

Erica Greenberg, Director of the Pediatric Psychiatry OCD and Tic Disorders Program, part of the OCRD Program at Massachusetts General Hospital and Instructor at Harvard Medical School.
Specific interests include Tourette Syndrome and related disorders, including OCD, ADHD, and anxiety, the combination of pharmacotherapy and therapy (behavioral and psychodynamically-informed), and teaching/mentoring/administration.

TTAG Hour 3: Panel Discussion

- Embracing Opportunities in Education and Work

Exploring strategies and success stories for individuals with Tourette in educational and professional settings and the role of neurodiversity in the corporate environment.
Panel members: students, employees and entrepreneurs touched by TS as well as representatives from the corporate world embracing neurodiversity.
Hosting Marla Shea, TTAG Secretary

TTAG Hour 4: Discussion

- Harmonizing Global Initiatives: Fostering Collaboration for Collective Success within the Tourette Associations

Strengthening national and international partnerships to enhance global Tourette Syndrome advocacy and support.
Guest speakers Donatella Comasini (President AIST Onlus) and Stefano Carrara (President and co-founder of Tourette Italia)

- TTAG Summary and Closing Remarks

18:00-19:00 (onwards)

Opening ceremony

I. Keynote lecture: Behavioural treatment of tics: past, present, and future
Speaker:
John Piacentini
moderated by: Cristiano Termine

II. Mary Robertson Travel Grants & Professor Mary Robertson Award; winner & oral presentation
III. Cocktail time

21:00 "Lady Tourette", theatre production
English subtitles available
Optional, FREE event
Venue: Spazio Yak

Thursday 13 June 2024

09:00-09:15 Welcome message by our hosts & local organisers
Cristiano Termine
Andrea Cavanna

09:15-10:00 Symposium talk
"How can parents live well with tics?" Parental burden in TS families

Speakers:
Noa Benaroya-Milshtein
Dana Feldman-Sadeh

moderated by: Christelle Nilles

10:00-10:30 Poster rounds, session I
moderated by Nanette Mol Debes

11:00-11:30 Coffee break
+ "Speed networking"
Bringing Senior & Junior colleagues together!

11:30-12:30 Clinical rounds
Session chair:
Tammy Hedderly

Round table:
Renata Rizzo
Carlotta Zanaboni

12:30-13:30 Lunch break

13:30-14:00 General assembly

14:00-14:15 Presentation of the MDS Tic Disorders and Tourette Syndrome study group
Presenter:
Tamara Pringsheim

14:15-15:00 MDS Task Force on tic disorders; developing a new classification scheme for tic disorders
Speaker:
Irene Malaty
moderated by: Tamara Pringsheim

15:00-15:30 Coffee break

15:30-16:00 Poster rounds, session II
moderated by Nanette Mol Debes

16:00-16:30 Controversy followed by a poll
Should we still use the YGTSS, or GTS/tic-QOL scales to measure tic severity and the impact of tics on day-to-day life ?

Arguing pro traditional assessment:
Davide Martino
Arguing pro AI-based:
Izhar Bar-Gad
moderated by: Andrea Cavanna

16:30-18:15 Oral presentations of submitted abstracts, session I
moderated by: Kirsten Müller-Vahl & Andreas Hartmann

20:00 Social event-dinner
(optional event)

Venue: Villa Panza

Friday 14 June 2024

09:00-09:15 Welcome address by TTAG
(Tics and Tourette Across the Globe)

09:15-10:15 TS-underrepresented zones around the world;
Latin America, South America, Russia, Nigeria
Remote (pre-recorded) and on-stage interventions

Speakers:
(in alphabetical order)
Joy Adama Legbo Nigeria
Konstantin Evdokimov Russia
Alex Medina Escobar Honduras & Canada
Daniela Muñoz Chesta Chile

moderated by: TTAG & Natalia Szejko

10:15-10:45 Coffee break
+ "Speed networking"
Bringing Senior & Junior colleagues together!

10:45-12:15 Oral presentations of submitted abstracts, session II
moderated by: Kirsten Müller-Vahl & Andreas Hartmann

Vote for best poster & best oral presentation!
The voting platform opens on **Friday 12 June at 12:15** for Oral presentations and at **14:45** for Poster presentations.

12:15-13:15 Lunch break

13:15-14:00 **Developing and testing an online therapist training program for CBIT: Development process and initial results**

Speaker:
Douglas Woods

With the participation of:
Suzanne Mouton-Odum
moderated by: Christelle Nilles

14:00-14:15 **Poster rounds, session III**
moderated by Nanette Mol Debes

Vote for best poster & best oral presentation!
The voting platform opens on **Friday 12 June at 12:15** for Oral presentations and at **14:45** for Poster presentations.

14:45-15:15 **Coffee break**

15:15-16:15 **Best papers of 2023 on tics and TS**
Speaker:
Kevin J. Black

moderated by: Andreas Hartmann

16:15-16:30 **Closing ceremony**

Best poster & best oral presentation awards
ESSTS Conference 2025 announcement; see you next year in...

Table of contents

Mary Robertson Award Winner 2024

Taming Tics Together (TTT): Evaluation of a telehealth-based intensive intervention for youth with tics and co-occurring diagnoses

Chelsea F. Dale, PhD[1], Michaela Sisitsky, MS[2], Karissa DiMarzio, MS[2], Megan Hare, PhD[2], Logan Cummings, MS[2], Caroline Gillenson, MS[2], Christopher Georgiadis, MS[2], Victoria Cabrera, MS[2], Juliana Acosta, PhD[1], and Justin Parent, PhD[2,3]

[1]University of Miami, [2]Center for Children and Families, Florida International University, [3]University of Rhode Island

Background:
Tic Disorders (TDs) are neurodevelopmental disorders characterized by sudden and involuntary motor and/or phonic tics. It is estimated that TDs impact between 1 and 3% of youth (e.g., Robertson et al., 2017, Tinker et al., 2022), and transient tics appear to impact up to 20% of children (Scahill, Specht, & Page, 2014). TDs often have a significant impact on youths' overall functioning across social, familial, and academic domains (e.g., Specht et al., 2011) and can lead to quality-of-life impairment (e.g., Storch, Lack, et al., 2007). Additionally, an overwhelming majority of children with a TD experience at least one co-occurring mental health diagnosis (e.g., Hirschtritt et al., 2015). For example, between 30 and 50% exhibit elevations in anxiety, one-third experience clinically significant obsessive-compulsive spectrum symptoms, and over 60% experience attention-deficit/hyperactivity disorder (Centers for Disease Control and Prevention, 2009).

Comprehensive Behavioral Intervention for Tics (CBIT) is an effective, first-line behavioral intervention for youth with TDs. While CBIT was originally designed to be offered in a weekly, one-on-one, in-person format, several alternative formats, such as internet-based/telehealth (e.g., Himle et al, 2010; 2012; Ricketts et al., 2016), self- or caregiver-guided (e.g., Rachamim et al., 2020), and group-based formats (e.g., Heijerman-Holtgrefe et al., 2020) have begun to emerge in the literature. Nonetheless, co-occurring diagnoses are typically not explicitly addressed within such formats. Intensive interventions are well-established for common comorbidities of TDs (e.g., intensive behavioral parent training, Graziano et al., 2020; intensive CBT for OCD, Storch, Geffken et al., 2007), and initial support for this format with TDs has been promising (e.g., Blount et al., 2014; Dale, Ramos, & Parent, 2021; Heijerman-Holtgrefe et al., 2024). As such, the intensive intervention format can be extended to CBIT as a mechanism to streamline intervention efforts to target TDs, co-occurring diagnoses, and enhance quality of life.

Taming Tics Together (TTT) is a five consecutive day intensive intervention that can be conducted entirely via telehealth, and consists of youth-only, caregiver-only, and individually-based sessions. Additionally, TTT includes an optional 30-minute booster session. TTT is a promising alternative treatment format to address both TDs and co-occurring diagnoses simultaneously. The current study aims to evaluate the impact of TTT offered to youth with TDs and their caregivers on tic- and co-occurring symptom trajectories, as well as on overall quality of life, using a randomized controlled trial design. Further, overall treatment acceptability and satisfaction data was collected.

Methods:
Twenty youth (Mchild age = 12.54 years, 50% male, 40% Latino/Hispanic) and at least one caregiver were randomized to either the immediate TTT group (I-TTT; n=13) or a one-month waitlist (WL; n=7). All participants received the same intervention;

however, the one-month waitlist group received the treatment at a later time point. Treatment groups were divided by age (i.e., 7- to 12-year-olds, 13- to 17-year-olds). All participants completed assessments at baseline (pre-treatment), immediately following the end of treatment (post), and at a one-month follow-up. Youth and caregivers completed the Yale Global Tic Severity Scale (YGTSS; Leckman et al., 1989) with a trained study clinician who was masked to their study condition at all time points. The Disruptive Behavior Disorder Rating Scale (DBD-RS; Pelham et al., 1992) was completed by caregivers to assess externalizing behaviors, and the Revised Children's Anxiety and Depression Scale (RCADS; Chorpita et al., 2000) was completed by caregivers and youth to assess internalizing symptomatology. Further, overall satisfaction, acceptability, and costs of and burdens associated with treatment were assessed using the Client Satisfaction Questionnaire (CSQ; Larsen et al., 1979), Treatment Acceptability Questionnaire (TAQ; Hunsley, 1992), and Burden of Treatment Participation (BTP) questionnaires, respectively.

Results:
Primary Outcomes. Participants within the I-TTT group reported higher scores across all YGTSS subscales (i.e., Impairment, Total Tic Severity) at baseline than those within the WL group. Marginally significant differences were found between groups on the YGTSS Total Tic Severity Score (B=-4.73, SE=2.72, p=.081. NOTE: groups were coded as such that negative scores indicate improvement in the I-TTT group). Notably, there was an improvement on all primary YGTSS outcomes for the I-TTT group, ranging from small to medium effect sizes. Additionally, while there were lower scores reported overall within the WL group at the 1-month follow-up, there was a larger average point decrease across all YGTSS subscales within the I-TTT group than within the WL group. Further, 30% of the I-TTT group dropped one clinical severity category (i.e., from marked severity to moderate severity, see McGuire et al., 2021 for proposed categorical cutoff scores) on the YGTSS at the 1-month follow-up (3 out of 10 participants who completed the assessment) as compared to the 16.7% (n=1) of the WL group.

Additional within-group evaluations of the I-TTT group were conducted to assess possible differences by age and sex. The effect of age on the YGTSS Total Tic Severity scores was marginally significant (b=6.79, p=.082), such that older age was associated with higher YGTSS Total Tic Severity at the 1-month follow-up. The effect of age on the YGTSS Impairment score, was significant, (b=14.20, $p < .05$) such that older age was associated with more impairment at the 1-month follow-up. Within-group evaluations of the I-TTT group were conducted to assess possible differences by sex. The effect of sex on the YGTSS Total Tic Severity scores was also significant (b= 6.85, $p < .05$), such that female sex was also associated with higher scores at the 1-month follow-up. Overall, older participants and female participants were less likely to improve at the 1-month follow-up.

Secondary Outcomes. Overall, the I-TTT group was associated with fewer ADHD-Hyperactive/Impulsive symptoms at the 1-month follow-up as compared to the WL

group. Within-group analyses suggested that there was an association by age, such that older age was associated with fewer oppositional symptoms at the 1-month follow-up, and by sex, such that elevations in depressive symptoms were associated with females at the 1-month follow-up.

Acceptability, Satisfaction, and Feasibility. Overall, caregivers reported high treatment acceptability and satisfaction, and low costs and burden of treatment. Attendance to treatment was 100% across each of the three types of treatment sessions (caregiver-only, youth-only, and individual sessions).

Conclusions:
The current study evaluates the feasibility, acceptability, and preliminary efficacy of TTT, a novel, five-day telehealth-based intensive intervention for youth with TDs and co-occurring symptomatology, using a randomized controlled trial design. Results suggest trending significance on improvements in tic-related symptomatology, namely tic symptom severity and some improvements in co-occurring diagnosis symptomatology. Further evaluation of within-group sex and age differences is warranted, particularly considering that the literature on the impact of sex on TD symptoms is limited and somewhat inconsistent (i.e., Garris & Quiggs, 2021; Lichter & Finnegan, 2015). However, possible differences in the trajectory of tic symptoms in females may highlight the need for adapted treatments to address their presenting concerns. Additionally, given that younger children may experience tics for a shorter duration when they first present to treatment, the differences in improvement observed in the current study may highlight the impact and importance of early intervention. Nonetheless, this study provides possible preliminary evidence for whom this treatment may be most beneficial.

This study was conducted during the height of the COVID-19 pandemic, which may impact the generalizability of the current findings. The COVID-19 pandemic undoubtedly increased mental health concerns in youth and limited access to traditional, in-person treatment formats (i.e., Comer, 2021). Nonetheless, the current study suggests that TTT may be a suitable alternative treatment format to increase access to evidence-based care. Given its abbreviated and intensive nature, implementing TTT via telehealth may aid in limiting or reducing the impact of weekly responsibilities from interfering with session attendance, and likely reduce the burden of and time lost due to travel required for in-person/in-clinic treatment. Additionally, telehealth-based formats may also provide a more naturalistic setting for in-vivo practice of strategies for youth and in-home feedback for parenting skill implementation. The videoconference and intensive format may also provide families with an opportunity to focus their full attention on strategies taught within each session. Importantly, the group-based format may offer both the caregivers and their children the opportunity to learn from others with similar experiences, gain support from each other, and give youth exposure to practicing using skills within the context of a group-based setting. Overall, TTT presents a promising treatment modality that is likely to increase access to treatment, be more cost-effective, and improve the quality of life for youth with tics and common co-occurring diagnoses.

Oral presentations of selected abstracts

Oral presentation session I

O1. Sex Differences in Action Planning Styles, Quality of Life, and Self-Esteem Among Youth with Tic Disorders

Ilana Singer[1,2,3], Méliza Gagnon[1,2,3], Julie B. Leclerc[1,2,3]

[1]Department of Psychology, Université du Québec à Montréal, [2]Research Center of the Centre intégré universitaire de santé et de services sociaux (CIUSSS), Nord-de-l 'Île-de-Montréal, [3]Institut universitaire en santé mentale research center, Montréal

Background:
Chronic Tic Disorder (CT) and Tourette Syndrome (TS) are neurodevelopmental conditions marked by motor and/or phonic tics, typically beginning between ages 4 and 6 and peaking in severity by age 11. The prevalence of CT and TS in youths is approximately 1.6% and 0.8%, respectively, with boys being up to four times more affected than girls. This gender disparity highlights the need to investigate these differences during key developmental stages. Beyond physical manifestations, tics are associated with cognitive and behavioral challenges, including difficulties with excessive mental preparation, inflexibility, and overactivity. According to the Cognitive Psychophysiological model, these challenges may exacerbate tic severity. Additionally, individuals with tic disorders often face diminished quality of life and self-esteem. To our knowledge, no study has looked at sex differences in the context of associated cognitive and behavioral challenges, the impact of tics on quality of life or self-esteem in children with tic disorders. Given the variability in tic presentation and the potential for sex-specific differences, this study aims to investigate sex differences in these areas.

Methods:
Participants in the study consisted of children and adolescents enrolled in a randomized controlled trial assessing a behavioral intervention for tics. The current study utilized data collected from assessments of both youth participants and their parents. A socio-demographic questionnaire was used to gather general information and validate inclusion criteria. The following validated instruments were used: 1) The Style of Planning Questionnaire to assess action planning styles; 2) The Gilles de la Tourette Syndrome-Quality of Life Scale to assess the impact of tics on quality of life; and 3) Culture-Free Self-Esteem Inventories, 2nd edition, to assess self-esteem. For continuous data, normality was checked with the Shapiro-Wilk test, using T-tests for normally distributed variables and Mann-Whitney U tests for data that is not normally distributed.

Results:
In 66 youths with tics (19 girls), aged 7-14 (mean = 10 years), sex differences were noted in action planning styles, quality of life, and self-esteem. In action planning, girls had lower levels of functional inflexibility (39.8 ± 8.3 vs 44.1 ± 6.2; t (62) = -2.12, p = .038) and daily planning effectiveness (102 ± 14.3 vs 114 ± 16.9; U = 255, p = .017), but similar over-preparedness, anticipation, and over-activity approaches. Quality of life was more impaired in girls, particularly in psychological well-being (39.4 ± 20.4 vs 26.6 ± 14.6; U = 252, p = .015) and general life satisfaction (31.6 ± 14.7 vs 24.0 ± 12.1; t (62) = 2.12, p = .038). Girls also showed significantly lower self-esteem only in the

social subscale compared to boys (1.7 ± .93 vs 1.1 ± .96; U = 247, p = .015), with no differences in other self-esteem areas.

Conclusions:
In keeping with earlier preliminary results, we observed a meaningful improvement in Our findings further demonstrate the complex nature of tic disorders, characterized by a combination of shared and distinct experiences across sexes. By deepening our understanding of these multifaceted disorders and highlighting the differences in their manifestations, we can enhance the detection of tic disorders. This would help address the specific needs of youth and improve interventions.

O2. Tic-Talk: Voices on Tourette labelling

Tammy Hedderly[1,2] and Giulia Raffaele[1], Nanette Mol Debes[3], Christelle Nilles[4], Natalia Szejko[4], Kirsten Müller-Vahl[5], Tamara Pringsheim[6], Davide Martino[6], Seonaid Anderson[7], Sara Sopena[8], Tamsin Owen[8], Lauren Corcoran[8], Kinga Tomczak[9], Osman Malik[8] On Behalf of wider groups of ESSTS, MDS, TTAG

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Background:
Tourette Syndrome (TS) is a neurodevelopmental disorder characterized by involuntary motor and vocal tics. The diagnostic label assigned to TS holds significant implications for individuals living with the condition, as well as their caregivers and healthcare providers. However, there is limited research examining the perspectives on TS labelling and the terminology used to describe the condition. This study aims to fill this gap by investigating the current attitudes towards TS labelling among patients, caregivers, and healthcare professionals.

Methods:
Three distinct survey forms were developed to capture the perspectives of patients, caregivers, and healthcare professionals. Each form included questions about demographic information, such as age, age of diagnosis, and current location. Participants were asked to provide their interpretation of the term "Tourette" and rate their sentiment towards it on a happiness scale. Additionally, respondents were presented with a list of terms for TS and asked to indicate their preferences. An open-ended section allowed participants to share any additional comments or concerns regarding labelling.

Results:
To date, this study examined responses from 373 individuals, including 156 patients, 142 carers, and 75 healthcare professionals. Of these, 61% are from the UK. The majority of patients who completed the survey fell into the 18-24 age bracket (24%), with carers/parents filling in the form for younger patients. 50% of the respondents were diagnosed between the age of 8-17.

Overall, patients and carer were found to be the most satisfied with the term Tourette Syndrome, with an average rating of 3.69/5 and 3.72/5 respectively.
Healthcare professionals rated the term slightly lower (3.07/5).
Of the 61 additional comments provided by patients, 82% expressed concern about changing the name of Tourette Syndrome, due to a sense of identity and community associated with this term. These individuals felt that other terms, such as neurodiversity or Tic disorder, would not be specific enough. However, some healthcare professionals and a percentage of carers emphasized the negative stigma associated with Tourette Syndrome and were in favour of an alternative new.
Overall, the majority of patients (62.9%) and carers (51.4%) preferred the name Tourette Syndrome over proposed alternatives, vs 29.3% of healthcare professionals.

Conclusions:
The results indicate variations in current attitudes towards TS labelling among patients, caregivers, and healthcare professionals. Notably, patients and carers exhibit a strong positive disposition towards the diagnostic term "Tourette Syndrome". Most patients reported that changing terminology would create confusion and consequential disinformation around TS and would rather channel resources into educational and informational campaign that would offer support. In addition, patients feel strongly about the sense of identity and relief that this diagnosis has given them.
This finding highlights the importance of directly involving patients in discussions surrounding diagnostic labelling and language choices.

Acknowledgements:
Thank you to all those who completed the survey and shared their views on this topic.

O3. Automated video-based approach for the diagnosis of Tourette syndrome

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Background:
The primary criteria for diagnosing Gilles de la Tourette syndrome (GTS) rest on the manifestation of tics, which are involuntary, abrupt, recurrent movements or vocalizations. Video-based evaluations, such as the Rush video rating scale, are often used for detailed assessment of tics frequency and severity. However, these video assessments are time-consuming, as they involve careful observation and analysis by clinical experts. In a previous study, a Random Forest (RF) classifier trained on GTS videos with second-wise manual tic ratings (Brügge et al., 2023, Movement Disorders) was used to detect 1s-intervals with tics. Building upon the existing classifier, the

current study tests to what extent video recordings of GTS patients *versus* healthy control (HC) participants can be differentiated based on the amount and temporal characteristics of automatically detected tics (or extra movements).

Methods:
A total of 107 videos from 42 adults diagnosed with GTS were analyzed, individually matched with HC with respect to sex and age. These videos adhered to the Rush video protocol and were compiled from three different studies. The RF classifier from the preceding study was employed to detect seconds with tics in each video. The quantity and temporal characteristics of predicted tics were assessed using five summary scores: the proportion of tic intervals, mean tic probability, maximum duration of contiguous tic segments, maximum duration of tic-free segments, and the number of tic clusters. Both univariate and multivariate logistic regression were employed to differentiate GTS patients from HC based on the calculated summary scores. Classification performance was quantified through balanced accuracy (the arithmetic means of sensitivity and specificity), as well as the area under the receiver operating characteristic curve (AUROC). Prediction probabilities from the logistic regression were used to evaluate a hybrid diagnostic approach, in which lower-confidence predictions are reviewed by a clinical expert.

Results and Conclusions:
The classifier demonstrated higher accuracy based on the summary scores of the number of tic clusters (AUROC 0.95, balanced accuracy 90.2%) and the proportion of tic intervals (AUROC 0.97, balanced accuracy 87.9%) compared to other summary scores. Complementing high-confidence model-based predictions with expert review for approximately 25% of the predictions with lower confidence could ensure an overall classification accuracy above 95% suggesting a hybrid decision-making approach, i.e., an assessment combining automated and expert based scoring.

Taken together, this automated video-based tic detection method, employing a machine learning approach, has great potential to support clinical decision-making in the diagnosis of Tourette syndrome.

O4. What the future held: A long-term video follow-up of Tourette's in adults

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Background:
In this follow-up study, we aim to examine the long-term outcomes and clinical progression of tic severity in patients with Gilles de la Tourette syndrome (GTS) over multiple decades in a cohort of 17 adults, utilizing the Modified Rush Video Scale (MRVS) and its revised version (MRVS-R). Aiming to explore the course of tics and psychiatric comorbidities, patients were observed over a period exceeding two decades. Through the assessment of changes in tic severity as well as comorbidities and quality of

life, this research sought to provide a detailed view of the enduring dynamics of psychopathological symptoms in patients with GTS. Additionally, we compared results obtained with the MRVS, a video-based tic assessment, with data using its recent revision, the MRVS-R.

Methods:
For this study, after a mean follow-up interval of 14.1 years (range: 7.5-18.41yrs, median: 13.6yrs), we reassessed a sub cohort (n=17, male: 16, female: 1) with a median age of 54 (range: 32-87, mean: 52.53; at the follow-up visit) from an initial pool of 112 patients with GTS with MRVS-compatible recordings made in our outpatient clinic between 1998 and 2009. The participants were relocated and reassessed using both the MRVS and the updated MRVS-R video assessment protocols at both timepoints.

Results:
The analysis revealed an average tics reduction in the total score of 2.53 using the MRVS, and a decrease of 4.76 with the MRVS-R. The initial average MRVS total score was 9.65 (range 5-17) and 15.35 (range 6-32) for the MRVS-R. At the follow-up, total scores were 7.12 (range 3-14) for the MRVS and 10.59 (range 5-27) for the MRVS-R. Wilcoxon Signed-Rank Tests for the MRVS total score testing significant changes over the both time points showed a test statistic (W) of 8.0 with a p-value of 0.0836. Comparing test results from the MRVS-R total score over both time points, we computed a test statistic (W) of 8.0 and a p-value of 0.0244.

Conclusions:
In this study, we observed a significant decrease in tic severity over a two-decade follow-up interval using the MRVS-R. This is the first study demonstrating that tics constantly decrease with decreasing age in adulthood. However, based on our data it remains unclear, whether this tic improvement stems from an actual decrease in tic severity or an enhanced ability among adults to suppress tics. Reductions in tic severity over time were marginally non-significant when using the MRVS. The fact that only the MRVS-R detected changes with statistical significance suggests it may be a more sensitive tool for measuring tics adding real world use case data to a current debate over tic assessment in the movement disorder community.

O5. The eye of a beholder: functional tic-like behaviors are a common comorbidity in Tourette syndrome

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Background:
Functional tic-like behaviors (FTLB) have been recognized as a clinically relevant phenomenon after the rise following the COVID-19 pandemic. Previously considered a rare manifestation of functional movement disorder, FTLB started to gain attention from the researchers and clinicians worldwide. Although organic and functional disorders often co-exist, co-occurrence of FTLB and tics has never been widely

investigated before. We present for the first time data on comorbid FTLB in patients with Tourette syndrome (TS).

Methods:
We analyzed clinical data of 71 patients (mean age=21.5 years, range: 11-55, n=27 females (38.0%)) who had been diagnosed in our specialized TS outpatient clinic with TS and comorbid FTB between 2016 and 2021. Data were compared with a large sample of patients with primary chronic tic disorders (n=1032) from the same center.

Preliminary Results and conclusions:
In all patients (100%), onset of FTLB (mean age=20.8 years, range: 10-47 years) was after the onset of tics (mean age=6.3 years, range: 0-21 years), on average 14.5 years (+/-9.5 (SD)) later. Sixty-one patients (86%) described FTLB onset as a sudden symptom worsening and 38 patients (53.5%) were able to precisely indicate the date due to abrupt onset of FTLB. Different from tics, FTLB mainly presented with complex movements (n=57, 80%) located at the upper extremities (most frequently presenting with throwing and breaking of objects, self-hitting, hitting others, and obscene gestures), involvement of several body parts or the whole body (e.g., lying on the floor) and thus did not follow the typical rostro-caudal distribution typical for tics. Most frequent presentation of vocal FTLB were complex vocalizations (e.g., obscene words and phrases, screaming, animal sounds, repetitive shouting of phrases) including functional coprolalia in 27 patients (38%). Thirty-three patients (46%) reported that FTLBs typically occur in clusters persisting for hours and therefore were often described as “tic attacks”. More than half of patients (n=38, 53.5%) reported concrete timely-related factors that preceded FTLB onset. While most patients reported stress being the most relevant triggering factor for tics, FTLB was mainly influenced by quite unusual factors such as the presence of a particular person or particular position of the body, specific locations, or situations. Forty-four patients (62%) reported a complete remission of FTLB in particular situations. In line with the diagnosis of TS+FTLB, 24 (34%) had a positive history of medically unexplained symptoms. Remarkably, nearly half of patients (47%) had been transferred to our clinic as being “treatment-refractory” TS. As a result, 7 patients (10%) had already received deep brain stimulation. Compared to our large sample of patients with primary chronic tic disorders (n=1032), we found no differences with respect to mean age and mean age at tic onset, but the TS+FTLB group comprised significantly more females (38% vs. 23%, p=0.003) and had significantly more coprophenomena (43% vs 28%, p=0.005), significantly less symptom suppressibility (72% vs. 85%, p=0.002), and significantly higher rates of comorbid obsessive-compulsive disorder (23% vs. 10%, p<0.001) and self-injurious behaviors (56% vs. 30%, p=0.009).

Conclusions:
Based on our data, it can be assumed that FTLB is a common comorbidity in TS, similar to functional overlay in other movement disorders and epilepsy. Before classifying a patient as treatment-refractory TS, FTLB should be ruled out.

O6. A Critical Examination of the clinical diagnosis of Functional Tic-Like Behaviors

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Background:
Since the COVID-19 pandemic, movement disorders clinics have seen an increase in patients with an unusual type of tic-like symptoms: young adults or teenagers with abrupt onset complex behaviors. It was quickly suspected that these patients suffered from functional neurological symptoms, later named Functional Tic-Like Behaviors (FTLB). Subsequent research on the differential diagnosis between FTLB and tics has been substantial and has led to the development of diagnostic checklists. We conducted a theoretical reappraisal of the FTLB literature to clarify the validity of the concept and its diagnostic implication.

Methods:
This paper addresses several key aspects of the current FTLB literature: circular reasoning, the complications of the FTLB phenomenology and demographics, the impact of FTLB on tic literature at large, and issues with the alignment of the FTLB concept with ICD and DSM diagnostic criteria for functional disorders.

Results and Conclusions:
The clinical approach to FTLB might involve a degree of circular reasoning due to a lack of clinical benchmarks. The FTLB phenomenology and demographics may need more work to ensure a lack of bias and a proper description of this patient group including a clear distinction from tics. The impact of the FTLB discussion on the wider literature needs consideration. The validation of positive signs may help with both these endeavors and pave the way to the inclusion of FTLB within psychiatric classification systems. Furthermore, the coexistence of FTLB and tics within the same patient needs to be addressed to assist clinicians facing this challenging differential diagnosis.

O7. Agreement between cluster analyses and diagnoses of Tic Disorder and Functional Tic-like behaviors in a Tourette clinic population

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Background:
Despite the substantial work done to establish functional tic-like behaviors (FTLB) as a separate diagnosis, it is still unclear whether it represents a distinct organic patient group. As such, this study will complete a series of cluster analyses on a population of both FTLB and Tic Disorder (TD) patients to examine whether clusters based on tic symptoms alone, symptoms and patient characteristics or patient characteristics alone will form around these two diagnoses.

Methods:
A total of 253 patients, 53 diagnosed with FTLB and 200 with TD were included. The following patient characteristics was extracted from their medical records: age at debut, age at first visit, time between debut and first visit, psychiatric diagnoses in first degree relatives, psychiatric comorbidities and presence of a psychosocial trigger. Tic symptom data was also collected for all FTLB patients and 88 of the TD patients, including: presence of self-injurious behaviors, uncontrollable speech, long bursts of tics and coprophenomena, along with number of simple and complex vocal and motor tics. There was no difference in the patient characteristics between TD patients with tic information and TD patients without it. Based on the data three different two-way cluster models were created: one with only the tic variables as input, one with both tic variables and the patient characteristics, and one with only the patient characteristics.

Results and Conclusions:
All three models were two cluster solutions. In the first model, with only the tics variables as inputs, cluster 1 consisted of 95 patients, while cluster 2 consisted of 46 patients. The most important discriminating variables between the clusters were number of complex motor tics, presence of self-injurious behaviors, and presence of uncontrollable speech, with cluster 2 having a more severe phenomenology compared to cluster 1. The FTLB patients were split between the clusters, with 32.1% being cluster 1 members and 67.9% being cluster 2 members, while 88.6% of the TD patients were cluster 1 members and 11.4% were cluster 2 members. In model 2, where both tics variables and patient characteristics were entered, age at debut was the most important discriminating variable, followed by presence of uncontrollable speech and number of complex motor tics. The 100 patients in cluster 1 debuted at a younger age, were younger at their first visit, were more likely to be male, were less likely to have a psychiatric comorbidity or a family member with psychiatric diagnosis and had milder tic phenotype compared to the 37 patients in cluster 2. In this model, all TD patients belonged to cluster 1, while 28.3% of FTLB patients also had cluster 1 membership with the remaining making up cluster 2. In the final model which included only the patient characteristics, age at debut was again the most important differentiating factor, followed by presence of a psychosocial trigger, and sex. The 194 patients in cluster 1 were younger at time of diagnosis and at debut, were less likely to have experienced a psychosocial trigger, more likely to be male and less likely to have any psychiatric comorbidity or a family member with a psychiatric diagnosis compared to the 52 patients in cluster 2. Here 93.5 % of the TD patients were cluster 1 members, while 84.9% of FTLB patients were cluster 2 members.
In conclusion, the cluster model based on patient characteristics alone most aligned with the TD and FTLB diagnoses, although none of the clusters fit perfectly.

O8. An exploration of the differences between children and adolescents with Tourette syndrome and those with persistent motor or vocal tic disorders

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Background:
According to the Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders, Tourette syndrome (TS) is defined by the presence of at least two motor tics and at least one vocal tic, whereas persistent motor or vocal tic disorders (PMVT) are defined by at least one of either motor or vocal tics. According to these definitions, tics must appear before the age of 18 years and last for more than a year. Our aim was to determine whether the clinical features and comorbidity profile of patients with PMVT differ from those of patients with TS.

Methods:
Children and adolescents with primary tic disorders have been prospectively included in our Registry in Calgary, Canada, since 2017. Patients with provisional tic disorder were excluded from the analyses. In this study, sex, age at tic onset, Yale Global Tic Severity Scale (YGTSS) scores including detailed tic inventory, mental health comorbidities and treatment were compared between participants with PMVT and participants with TS.

Results:
A total of 294 children and adolescents with primary tic disorders were included (76.9% males, mean age at first clinical assessment: 10.8yr, 95%CI=10.4-11.1); 262 (89.1%) had TS, 22 (7.5%) had persistent motor tic disorder and 10 (3.4%) had persistent vocal tic disorder. There was no significant difference in sex ratio (p=0.53) and in age at first visit. Children with PMVT had a later tic onset (7.4yr, 95%CI=6.3-8.5) than those with TS (6.3yr, 95%CI=6.0-6.7) (p=0.039). Regarding comorbidities, there was a higher proportion of children diagnosed with ADHD in the TS group compared to the PMVT group (53.8% vs 34.4%, p=0.038). There was no other difference in the comorbidity profile (obsessive-compulsive disorder, depressive and anxiety disorders). The YGTSS total tic score was significantly higher in participants with TS (20.5/50, 95%CI=19.5-21.5) compared to those with PMVT (11.0/50, 95%CI=9.2-12.7) (p<0.00001). There was no significant difference in total motor tic score between participants with persistent motor tics and those with TS (p=0.061), nor in total vocal tic score between those with persistent vocal tics and those with TS (p=0.25). Tic-related impairment score was similar in the PMVT group (16.8/50, 95%CI=11.7-21.8) and in the TS group (17.5/50, 95%CI=15.9-19.1) (p=0.76). There was no significant difference in treatment, besides a slightly higher proportion of individuals treated by botulinum toxin injections in the PMVT group (6.3%) vs in the TS group (0%) (p=0.0002).

Conclusions:
Children and adolescents with PMVT represented 11% of our sample of youth with chronic tic disorders. They did not differ from those with TS in terms of sex ratio or comorbidity profile, except for a higher proportion of ADHD among participants with

TS, which has already been described in the literature (Claudio-Campos *et al*, May 2021, *Movement Disorders,* doi:10.1002/mds.28593). There was no difference in tic severity (when considering motor and vocal tics distinctly), nor in tic-related impairment, the latter being the main concern when considering treatment. Limitations include the monocentric design, and the relatively small number of individuals with PVMT. We believe our results challenge the current state of classification of tic disorders. We suggest that TS and PVMT are part of a same clinical spectrum rather than distinct disorders.

Oral presentation session II

O9. Impacts of ADHD symptomatology on the response to cognitive-behavioural therapy with Gilles de la Tourette Syndrome patients

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Background:
Attention deficit and hyperactivity disorder (ADHD) is a common comorbidity with the Gilles de la Tourette Syndrome (TS) that adds further social and psychological burden. Cognitive-behavioural therapy (CBT) has shown efficacy in treating tics, yet its effectiveness in individuals with TS and comorbid ADHD remains unclear. Given the additional challenges faced by individuals with comorbid TS and ADHD, further investigations are needed among TS and ADHD populations regarding their clinical responses to CBT. It is suggested that ADHD characteristics such as executive dysfunction and inattention could hinder the response to CBT. This study aims to compare the response to CBT for tics and its maintenance six months after therapy among TS individuals with and without ADHD symptoms.

Methods:
The TS group (n=55) was paired with neurotypical controls (n=43) on age (mean=35 years) and biological sex. Each group was median split to obtain four subgroups with high (TS+ and Ctrl+) or low scores (TS- and Ctrl-) on ADHD as assessed with the short version of the CAARS (Conners' Adult ADHD Rating Scales). Outcomes were evaluated using the Yale Global Tic Severity Scale (YGTSS) regarding global tic severity and motor/vocal tics frequency post-CBT and at 6-month follow-up. The response to CBT in the TS- (n = 27) and TS+ (n = 28) groups were compared using an analysis of covariance with the groups as the independent variable, the post-treatment tic scores as the dependent variable, and the baseline tic scores as a covariate to consider any baseline variability across groups.

Results and Conclusions:
Results revealed significant tic reductions following CBT and six months later. No significant group difference was present across TS- and TS+ groups. Contrary to

expectations, ADHD symptoms did not hinder the response to CBT for tics or its maintenance at follow-up. It allow a broader understanding of how comorbid ADHD could interfere with TS treatments and can guide clinicians in the process of choosing adequate interventions for TS patients while taking comorbidities into account. These findings suggest that specialized CBT interventions for ADHD might not be necessary for TS individuals with ADHD symptoms.

O10. Botulinum toxin injections for tics: a registry-based naturalistic study

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Background:
One randomized controlled trial and a few cases series have provided evidence for efficacy of botulinum toxin injections for the treatment of both motor and phonic tics in people with Tourette syndrome (TS), but little data on practical use has been published in the past twenty years. Our aim is to describe our longitudinal experience using botulinum toxin injections for tics in adults followed prospectively in our adult tic registry at the University of Calgary. This data may aid clinicians in determining the types of tics that are amendable to this treatment, and appropriate muscle selection for injections.

Methods:
The Calgary Adult Tic Disorders Registry is a prospective longitudinal study of adults with tic disorders. Participants are evaluated for tic severity, tic-related quality of life, presence and severity of comorbid psychiatric conditions, and use of medications and behavioural therapies for tics three times over a period of 12 months. Our analysis focuses on medication use for tics in adults with primary tic disorders, and in participants receiving botulinum toxin injections, we describe the type of tics and muscles injected.

Results and Conclusions:
95 adults with primary tic disorders (81 TS, 12 persistent motor tic disorder (PMTD), 1 persistent vocal tic disorder) have participated in the registry between 2021 and 2024. Mean age at participation was 33.0 years (95% CI 30.0-36.0), with 33/95 (35%) female sex. Botulinum toxin injection was the most used medical treatment for tics at all three time points among registry participants, followed by antipsychotics, alpha agonists, and topiramate. Thirty-two of the 95 participants received botulinum toxin injections during their enrolment period in the registry. The following motor tics (and the associated muscle injected) were treated using botulinum toxin, in decreasing order of frequency: blinking (orbicularis oculi), head turns (splenius capitus, sternocleidomastoid or trapezius), shoulder raise (trapezius, levator scapulae), eyebrow raising (frontalis), head flexion/extension (semispinalis), eyebrow depression (procerus, corrugators), jaw clenching (masseters, temporalis), protrusion of lower jaw (platysma), nose wrinkling (nasalis), and mouth movements (depressor labii inferioris). No registry participants received botulinum toxin injections for vocal tics. Botulinum toxin injections are a

commonly used treatment for motor tics in adults with TS and PMTD, for a variety of tics affecting the face, neck and shoulder regions. The ability to provide this treatment will vary based on the specialty and training of the practitioner. Given the efficacy of this treatment, and general absence of major adverse effects, providers caring for adults with TS should consider botulinum toxin injections a first line treatment for bothersome motor tics of the face, neck and shoulder region.

O11. Neural correlates of voluntary tic suppression and response inhibition

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Background:
Even though motor and phonic tics are automatic and involuntary, they can be suppressed for short periods of time. Response inhibition has often been hypothesized as the cognitive process involved in such suppression, but this hypothesis has received little empirical support. In the current study, we aimed to assent to what extent the neural correlates of voluntary tic suppression overlap with those of response inhibition.

Methods:
EEG was recorded during tic suppression and Go/NoGo tasks in children with Tourette syndrome (TS). Functional connectivity was computed through a source-EEG connectivity pipeline. We then assessed whether functional connectivity in a subnetwork involved in tic suppression differed between Go and NoGo conditions. We also tested whether the conditional difference in functional connectivity in both tasks was associated with a behavioral marker of response inhibition (i.e., false alarm rate). EEG data were also used to assess frontal midline theta oscillations, which represent a neural marker of cognitive control. We tested whether frontal midline theta was differentially impacted by voluntary tic suppression and response inhibition.

Results:
Within the tic suppression subnetwork, we did not find a difference in functional connectivity between the Go and NoGo conditions. During the tic suppression task, the conditional difference in functional connectivity was negatively associated with false alarms, so that children who showed increased functional connectivity in the tic suppression condition (relative to the tic freely condition) had worse response inhibition during the Go/NoGo task. For frontal midline theta, it was as expected larger for NoGo relative to Go stimuli. However, we saw the opposite pattern during the tic suppression task: frontal midline theta was larger during the tic-freely than the tic suppression condition.

Conclusions:
These results suggest that, in children with TS, mechanisms of voluntary tic suppression are not the same as those of response inhibition as measured during a Go/NoGo task. Our results even suggest that these two processes may rely on opposing mechanisms, as (1) enhanced functional connectivity during tic suppression was associated with worse

inhibitory performance during a cognitive task and (2) a reliable marker of response inhibition was decreased during tic suppression.

O12. Inheritance and impact of parental gender on clinical expression of Tourette syndrome in offspring

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Background:
Previous studies have shown that Tourette syndrome (TS) runs in families. The relationship between genetic disposition and clinical symptoms still needs clarification. In this study we aimed to investigate the correlation between genetic predisposition to TS and clinical aspects of TS by examining differences in tic severity, presence of comorbidity, and age of onset between children with TS with patrilineal (affected father), matrilineal (affected mother) or bilineal inheritance (both parents affected) compared to a sporadic group (none of the parents affected).

Methods:
In total, 310 children with TS participated in this study. Validated diagnostic tools were used to assess tic severity and comorbidities in the TS patients. The diagnosis of TS and comorbidity in the parent group was based on self-reported information. The groups were divided into subgroups depending on the parental inheritance of TS; TS without Attention Deficit Hyperactivity Disorder (ADHD) or Obsessive Compulsive Disorder (OCD), TS with ADHD and/or OCD and further in subgroups depending on which parents were affected: paternal symptoms, maternal symptoms, symptoms in both parents or none of the parents affected. Overall, we compared the differences in maternal versus paternal predisposition and the difference in predisposition versus sporadic TS. We also compared the development in tic-severity in the same patient categories at follow-up 6 years later (T2).

Results:
When the mother was affected by TS-only (without ADHD or OCD), the offspring had a lower age of tic onset (mean age 4.3 years) compared to the paternal (mean age 5.6 years) ($p=0.003$) and sporadic group (mean age 5.4 years). However, if the mother was affected by TS +/- ADHD/OCD, symptom-onset was later in the offspring (mean age 5.5 years) than in offspring with an affected father with TS +/- ADHD/OCD (mean age 5.2 years) ($p<0.001$). In the group of children with an affected mother, the children were diagnosed earlier than if the father was affected ($p<0.001$). In the sporadic group, there were more boys affected with TS than in the group with parental TS-only ($p=0.030$). In general, more severe tics were seen in the offspring with a predisposition compared to the sporadic group. However, the children with a predisposition had a better improvement at T2 compared to those without a predisposition.

Conclusions:
TS has a high heritability. The relationship between the inheritance from either the mother or the father can have an impact on clinical expression in the offspring, both when it comes to age of onset, gender differences and the degree of severity.

O13. Habit Reversal Training in Adults with TS: underlying mechanisms, predictors of symptom reduction, and neural change

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Background:
Habit Reversal Training (HRT) is an effective behavioural intervention in patients with Tourette syndrome (TS). However, it is unclear what its' underlying mechanisms are.

Methods:
N = 22 adult patients (mean age = 35 +/- 11.74, range 22-62 years; 20 male) were included in this study. MRI measurements were taken at baseline, patients then received 10 weeks of HRT. At the beginning and the end of each session, patients reported their urge to tic continuously during a free ticcing and a tic suppression condition. Patients were scanned again after concluding the course of therapy.
Structural images were acquired with a Siemens T3 Scanner and preprocessed and analyzed in SPM, using the Cat12 toolbox.

Results and Conclusions:
While tics decreased significantly after HRT treatment $t(21) = 9.05$, $p < .001$, $d = 1.93$, suppression ability did not change across the HRT $F(9,189) = 0.43$, $p = .810$. Urge intensity decreased across treatment session $F(9,189) = 4.11$, $p = .011$, $eta^2 = .16$, suggesting habituation. Regression analysis showed that patients with higher OCD symptoms profited more from the intervention ($p = .023$), while patients with high childhood ADHD benefitted less ($p = .008$). Voxel based morphometry and Surface-based morphometry showed changes in middle and superior temporal gyrus after therapy.
It appears that the underlying therapeutic mechanism of HRT in adults with TS is habituation, while tic suppression ability does not increase. While the temporal gyrus has been consistently associated with tic severity, its' exact role in TS is unclear.

O14. Changes in tic suppression ability and urge intensity over a 10-week habit reversal training in children with Tourette syndrome

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Background:
In recent years the urge to tic has received increasingly more attention. Most patients develop an urge, and urges can sometimes be more problematic for patients than tics. Habit Reversal Training (HRT) can reduce tics and uses the urge to counter-act tic movements with non-tic movements. However, the therapeutic mechanisms remain largely unclear.

Methods:
This study examined preliminary data of N=14 children (10 – 16 years), who received 10 weeks of HRT. Before and after each therapy session the children indicated their urge (0-100) continuously, during a free ticcing and a tic suppression condition (2 minutes respectively).

Results and Conclusions:
Repeated measures ANOVAs showed a significant decrease of tics across therapy sessions [$F(9,117) = 3.20$, $p = 0.002$, $eta^2=0.20$], significantly more tics in the free ticcing compared to the tic suppression condition [$F(1,13) = 16.55$, $p = 0.001$, $eta^2=0.56$], and a significant interaction between therapy session number and the conditions tic suppression vs free ticcing [$F(9,117) = 2.48$, $p = 0.012$, $eta^2=0.14$], indicating that tics decreased more in the free ticcing condition ($d = .88$) than the tic suppression condition ($d = .75$). Tic suppression ability did not change over the course of treatment [$F(9,117) = 1.55$, $p = 0.139$, $eta^2= 0.11$].
Repeated measure ANOVA for the urge to tic showed that the urge intensity was higher in the suppression than the free ticcing condition [$F(1,13) = 11.37$, $p = 0.005$, $eta^2= 0.47$]. An interaction between therapy session number and pre vs post therapy session measures was approaching significance [$F(9,117) = 1.70$, $p = 0.96$, $eta^2= 0.12$]. While urges did significantly decrease across sessions when measured pre-session $t(13) = 3.15$, $p = .008$, $d = .84$), they were relatively low post therapy session from the start and did not significantly decrease further $t(13) = 1.10$, $p = .293$, $d = .29$), although this results needs to be interpreted with caution and confirmed in a larger sample.
Similar to the adult sample, the child sample may experience a reduction in tics due to a decrease in urge intensity after HRT, rather than tic suppression. The results need to be confirmed when the sample is fully recruited and sufficiently powered.

O15. Functional connectivity in Tourette syndrome during free ticcing and tic suppression

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Background:
Several studies have identified altered neuronal structural as well as functional connections in patients with Tourette syndrome. Mainly alterations in cortico-basal ganglia-thalamo-cortical circuits have been reported as possible underlying

pathophysiological mechanism of the movement disorder. Our aim in this project is to further understand and to discriminate circuits associated with free ticcing versus tic suppression.

Methods:
Using a Siemens 3 Tesla magnetic resonance imaging (MRI) Scanner equipped with a 64-channel head coil we collected functional MRI (fMRI) scans of N = 21 adult patients with a secured diagnosis of Tourette syndrome at Medical School Hannover. During 5-minute blocks of fMRI scanning participants were asked to either suppress their tics or to tic freely. Data was analyzed using the SPM DPABI toolbox. We applied seed-based functional connectivity analysis with movement and tic related areas (basal ganglia, thalamus, insula, ACC, cerebellum). P-values were FWE corrected and the significance level was set to <.05.

Results and Conclusions:
For tic suppression, higher functional connectivity was found between cerebellum, frontal regions, basal ganglia (caudatus, putamen), and parietal cortex. During free ticking, basal ganglia (particularly putamen), insula, supplementary motor area; and anterior cingulate cortex with frontal and precentral regions were strongly connected. Our findings show that the cerebellum and frontal regions appear to play a key role in tic suppression. Other studies suggested functional cerebellar changes as a correlate of Tourette syndrome. Our results raise the questions of whether functional changes in cerebellar regions are pathophysiological changes related to Tourette syndrome, or rather reflect patients' suppression abilities.

O16. Underlying Working Mechanisms of Exposure and Response Prevention in the Treatment of Tourette Syndrome and Tic Disorders

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Background:
Exposure and response prevention (ERP) has been shown to be an effective treatment for Tourette syndrome (TS) and chronic tic disorders (CTD). ERP is based on voluntary tic suppression in combination with prolonged exposure to premonitory urges preceding tics. This study aims to further explore the relation between urges and ERP in tics, by investigating the course of premonitory urges during ERP sessions.

Methods:
Using a data-driven approach, within-session habituation to premonitory urge intensity was investigated. In total, 29 TS patients rated urge intensity at seven timepoints during ten 1 hour ERP sessions. Latent growth modeling was used to find the best model fit.

Results and Conclusions:
Latent growth modeling showed an increase in urge intensity during the first 15 min of each session followed by a plateau in the remaining 45 min of the session. This does not support the idea of within-session habituation to premonitory urges as a working mechanism of ERP. Other potential underlying working mechanisms are discussed, with extra attention for the role of the premonitory urge.

Poster presentations of selected abstracts
Poster session I.

P1. Mapping Gilles de la Tourette Syndrome through the distress and relief associated with tic-related behaviours: an fMRI study.

Laura Zapparoli[1,2], Francantonio Devoto[1], Marika Mariano[1], Silvia Seghezzi[1], Giuseppe Banfi[2], Domenico Servello[3], Mauro Porta[3] & Eraldo Paulesu[1,2]

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Background:
Personal distress associated with tic urges or inhibition and relief associated with tic production are defining features of the personal experience in Gilles de la Tourette syndrome (GTS). These affective phenomena have not been studied using fMRI, hindering our understanding of GTS pathophysiology and possible treatments.
Here, we present a novel cross-sectional fMRI study designed to map tic-related phenomenology using distress and relief as predicting variables.

Methods:
We adopted a mental imagery approach and dissected the brain activity associated with different phases of tic behaviors, premonitory urges, and the ensuing tic execution or inhibition: these were compared with the mental simulation of "relaxed situations" and pre-determined stereotyped motor behaviors. We then explored whether the ensuing brain patterns correlated with the distress or relief perceived for the different phases of the tasks.

Results and Conclusions:
Patients experienced a higher level of distress during the imagery of tic-triggering scenarios and no relief during tic inhibition. On the other hand, patients experienced significant relief during tic imagery. Distress during tic-triggering scenarios and relief during tic imagery were significantly correlated.
The distress perceived during urges correlated with increased activation in cortical sensorimotor areas, suggesting a motor alarm. Conversely, relief during tic execution was positively associated with the activity of a subcortical network. The activity of the putamen was associated with both distress during urges and relief during tic execution. These findings highlight the importance of assessing the affective component of tic-related phenomenology. Subcortical structures may be causally involved in the affective

component of tic pathophysiology, with the putamen playing a central role in both tic urge and generation.
We believe that our results can be readily translated into clinical practice for the development of personalized treatment plans tailored to each patient's unique needs.

P2. Comparing the 'when' and the 'where' of electrocortical Activity in patients with Tourette's Syndrome, Body-Focused Repetitive Behaviors and Obsessive-Compulsive Disorder

Sarah Desfossés-Vallée[1,2,3], Julie B. Leclerc[2,4,5], Pierre Blanchet[2,7], Kieron P. O'Connor[2,6] and Marc E. Lavoie[1,2,8]

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Background:
Tourette Syndrome (TS), Obsessive-Compulsive Disorder (OCD), and Body-Focused Repetitive Behaviors (BFRB), which include trichotillomania (hair-pulling) and onychophagia (nail-biting) for instance, are three disorders that share many similarities in terms of phenomenology, neuroanatomy and functionality. However, despite the literature pointing towards a plausible spectrum of these disorders, only a few studies have compared them. Studying the cognitive processes affected by these clinical conditions would provide a better understanding of their differences and similarities. Moreover, using Event-Related Potentials (ERP) as a brain imaging technique offers the advantage of assessing brain activity with excellent temporal resolution. The ERP components can then reflect specific cognitive processes, notably attentional and memory processes, which are known to be potentially affected in these three disorders. Our first goal is to characterize 'when' in the processing stream group differences are the most prominent. The second goal is to identify 'where' in the brain the group discrepancies could be.

Methods:
Participants with TS (n=24), OCD (n=18), and BFRB (n=16) were matched to a control group (n=59) on the basis of age and nonverbal intelligence, and were recorded with 58 EEG electrodes during a visual counting oddball task. Scores obtained on the Beck Anxiety Inventory and on the Beck Depression Inventory were used as covariates to control for possible effects of comorbidities. Three ERP components were extracted: P200, N200 and P300, reflecting respectively early evaluation of task-related stimuli, attention orienting and working memory. Finally, generating sources were modelized with Standardized Low-Resolution Electromagnetic Tomography (sLORETA).

Results and Conclusions:
We observed no group differences for the P200 and N200 when controlling for anxiety and depressive symptoms, suggesting that the early cognitive processes reflected by these components are relatively intact in these populations. Our results also showed a decrease in the later anterior P300 oddball effect for the TS and OCD groups, whereas an intact oddball effect was observed for the BFRB group. Source localization analyses

with sLORETA revealed activations in the lingual and middle occipital gyrus for the OCD group, distinguishing it from the other two clinical groups and the controls. Indeed, these groups showed activations in the cingulate cortex to generate this oddball effect. Thus, it seems that both TS and OCD groups show deficits in working memory, as revealed by alterations in the P300 component, but reflect distinct brain-generating source activations.

P3. Long-Term Treatment with Cannabis-based Medicines in two Children with Tourette Syndrome

Natalia Szejko[1,2,3], Lara-Katharina Woerner[1], Carolin Fremer[1], Simon Schmitt[1], Kirsten-Müller Vahl[1]

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Background:
Cannabis-based medicine (CBM) is recommended for the treatment of tics in otherwise treatment-resistant patients with Tourette syndrome (TS) in adults. However, evidence in children with TS is very limited. Long-term effects of CBM in this population are unknown.

Case presentations:
We present two cases of long-term follow up in children with TS who were administered CBM. One child was treated with a vaporized medical cannabis (0.2g Hindu-Kush or Gorilla Glue, both containing 20-25% THC) twice per day and the other with oral tetrahydrocannabinol (THC) extract, Tilray 25:0, with a daily dose of THC 0.5ml/day for five and six years, respectively. We were able to determine that both patients continued to benefit from the CBM treatment and no adverse effects were observed. In neurocognitive assessments as measured with the Wechsler's Intelligence Scale for Children (WISC), both patients achieved average results in the domain of working memory and average to above average results in the domain of processing speed. The academic performance of both adolescents was not affected.

Conclusion:
All in all, we have shown that CBM are effective and safe, even for long-term follow up, for treatment of children with tics, including the impact on cognitive and academic performance.

P4. Assessing the factor structure of the Behavior Rating Inventory of Executive Function in a Tourette's population

Stella Haffner, MSc[1,2], Camilla Groth, MD, PhD[2,3], Hanne Elberling, MD, PhD[3,4], Kaja Andersen, BSc[2,3], Liselotte Skov, MD, MSc[2], and Nanette Mol Debes, MD, PhD[2,3]

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Background:
Significant attention has been paid to the role of executive functions (EF) in Tourette Syndrome (TS). One prominent method for measuring EF is the Behavior Rating Inventory of Executive Function (BRIEF). The nine subscales of the BRIEF allow clinicians to quantify and describe patients' executive functioning; in summarizing patient executive performance accurately, the BRIEF has practical implications such as being able to communicate with schools about the domains in which patients need the most support. Because of its clinical utility, the BRIEF's validity has been explored in multiple clinical populations, but no investigation has focused only on a TS population. It is therefore the aim of this investigation to evaluate the BRIEF's validity in a TS population by assessing its factor structure, comparing two prominent models: a second order two-factor solution and a second order three-factor solution.

Methods:
This study examined the BRIEF ratings from three cohorts: 215 TS patients, 211 patient relatives, and 127 teachers of patients. Confirmatory factor analysis with maximum likelihood estimation was run on each cohort, fitting the data to both a two-factor solution and three-factor solution for each informant cohort. Fit was assessed for favorable scores in the following indices: Root Mean Square Error of Approximation (<0.05), Standardized Root Mean Square Residual (SRMR) (<0.05), Comparative Fit Index (CFI) (>0.95), and Tucker-Lewis Index (>0.95).

Results and Conclusions:
None of the models met the threshold for good fit in all indices. However, the self-report model with a three-factor solution demonstrated good fit on two indices (CFI=0.951, SRMR=0.046), while additional models were on the borderline of good fit. Across all models, the three-factor solution was favored by the fit indices. These results align with previous evidence that a three-factor model best represents the internal structure of the BRIEF, indicating that the BRIEF performs similarly in a TS population as it does in other clinical populations and thereby supporting its validity. Despite this, clinical use of the BRIEF's Behavioral Regulation Index and Metacognition Index as aggregate scores assumes a two-factor structure; the implications of a favored three-factor structure should be considered in light of this.

P5. Cut-off values of the General Anxiety Disorder-7, Patient Health Questionnaire-9, Patient Health Questionnaire-2, Obsessive-Compulsive Inventory, and Adult ADHD Self Report Scale in Adults with Tic Disorders

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Background:
Attention-deficit hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD), depression, and anxiety are highly comorbid in primary tic disorders (TD). Screening instruments for these conditions have been validated in the general population but it remains uncertain whether identical cut-points are applicable to individuals with TD. This study assesses whether the established cut-points on five commonly used instruments (≥10 on General Anxiety Disorder-7 [GAD-7], ≥10 on Patient Health Questionnaire-9 [PHQ-9], ≥3 on Patient Health Questionnaire-2 [PHQ-2], ≥14 on Adult ADHD Self Report Scale [ASRS], ≥40 on Obsessive Compulsive Inventory [OCI]) are suitable for adults with TD.

Methods:
36 adults with TD completed these instruments and a diagnostic psychiatric interview. Measures of diagnostic accuracy were calculated (area under the receiver-operating characteristic curve [AUC], sensitivity, specificity, positive predictive value, negative-predictive value, positive likelihood ratio, negative likelihood ratio) for each instrument at various cut-points. Optimal instrument cut-point was suggested based off the lowest value derived by $\sqrt{||1-\text{Specificity}|2+|1-\text{Sensitivity}|2}$ (Euclidean distance method).

Results and conclusions:
Based on psychiatric interview the prevalence of anxiety, depression, OCD and ADHD were 41.7%, 16.7%, 27.8%, and 63.9%, respectively. In our sample of people with TD, the optimal cut-point for each instrument was: GAD-7 ≥13 (sensitivity 66.7%, specificity 90.5%, AUC 78.6%), PHQ-9 ≥15 (sensitivity 66.7%, specificity 73.3%, AUC 70.0%), PHQ-2 ≥ 3 (AUC 66.7%, sensitivity 66.7%, specificity 66.7%), ASRS ≥14 (sensitivity 82.6%, specificity 76.9%, AUC 74.9%), OCI ≥63 (sensitivity 70.0%, specificity 88.5%, AUC 79.2%). The best performing tools were the ASRS, followed by GAD-7 and OCI. The PHQ-9 and PHQ-2 performed least well. Further research is needed to adapt screening instruments for the assessment of some comorbidities in patients with TD.

P6. A weekly diary study of stressful events in children and adolescents with Tourette Syndrome

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Background:
Children and adolescents with Tourette Syndrome (TS) face multiple challenges in coping with their condition and frequently report increased levels of stress. From anecdotal reports of families with TS, we learned that certain events (e.g., birthdays, holidays, seasonal changes and school tests) and the anticipation thereof may be experienced as stressful and tic-triggering events. Yet, few empirical studies have investigated the types of stressful events children with TS. Understanding which

stressful events are experienced by youth with tic disorders could improve treatment and coping strategies for children and their families.

Methods:
This study was based on data from a large prospective cohort assessment (EMTICS, N=715), in which parents of children and adolescents with TS kept a weekly diary, over a maximum period of 18 months. Parents noted all stressful events or situations that the child had experienced on a weekly basis. The diary was reviewed by the clinician at 8-weekly scheduled interviews. The authors subsequently categorized the reported stressful events in type of stressors, covering the life domains: activities in daily life, school, peers, family, health, loss and threat. In addition, based on prior examples from the literature, the authors labelled the events as major or minor events. We will (1) present the proportion of different event types per life domains, using the Chi-square test of equal frequencies to test for significant differences between the frequencies identifying the most common stressors. We will also show (2) the proportion of children who did experience certain types of stress events (e.g., bullying) versus those who did not. We will also compare the frequencies of experienced daily stress events between children with tics and (age- and sex matched) controls, i.e., unaffected siblings, using Chi-square tests. Moreover, we will explore whether youth with a higher number of stress events will show higher average tic severity scores. Below, we present the first preliminary results, reporting the frequencies of stress events during the first (baseline) visit. The complete results will be presented at the conference.

Results:
Over an 8-week interval, 28.2% reported one or more stressful events, 20.7% reported one event, 4.6% reported two events, 2.1% reported three events and less than 1% reported four or more events. Most children who reported stressful events (total N=180) reported (1) school events (43.3%), especially examinations and school transitions: starting and ending of school; (2) health-related stress (18.9%), such as stress concerning one's own illness, or illness of a core family member; and (3) activities in daily life (15.6%) such as events regarding sports or leisure, and vacation.

Conclusions:
Our results support that school-related events such as examinations and school transitions are a frequent daily stressor in the lives of children and adolescents with TS.

P7. Tic Attire – An Occupational Therapy Concept Design Project to Reduce Tic-Related Pain and Injury

Ione Georgakis[1]
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Background:
Research suggests that experiences of tic-related pain and injury (TRPI) are common in individuals with tics and Tourette Syndrome (TS) and have a moderate to severe impact on activities of daily living, economic, social, and emotional wellbeing (Taylor, Anderson, Davies 2022). Additionally, TRPI is a known driver for accessing medical and cognitive behavioural intervention. However, numerous intrinsic, social, and economic factors impact access to care and treatment for TS within the UK and beyond.

This project aims to design adaptive apparel to reduce TRPI and increase occupational participation and wellbeing in individuals with TS in line with the compensatory and social model of disability.

Methods:
This undergraduate occupational therapy co-created concept design project utilised qualitative data generated by adults with TS via an online support community. The aim was to understand and explore the experiences of pain and injury and existing self-management strategies in individuals with tics and TS. Six participants shared their insights through brief online semi-structured interviews and product feedback sessions, which formed the basis of the market research and design principles. This project's guiding principles were accounts of TRPI, its social, emotional, or economic consequences, and experiences of accessing post-injury treatment.

Results and Conclusions:
Participant accounts highlighted that TRPI reduced participation in occupations related to productivity, rest, leisure, and social engagement. Participants reported preventable hospital admissions, loss of earnings, and self-injurious tics. Many participants wanted to reduce TRPI without medical or cognitive behavioural management. Several respondents had experienced negative and invalidating treatment during emergency hospital admissions, which resulted in anxiety, shame, and mistrust in professionals. Common TRPI included head and neck injuries, broken and bruised wrists, arms and hands, 'leg drop' tics and biting self and others. The project generated four key design concepts for adaptive apparel to target commonly reported TRPI. Firstly, adaptive headwear with changeable, washable covers to reduce the risk of injury caused by head and neck tics. Secondly, what our participants dubbed ‘the Poodie', a padded hoodie made from non-tear fabric, which includes a hidden neck pillow, padded sleeves, hand protectors and removable chest and back inserts. Thirdly, ‘Tough trousers’ include reinforced hip and knee inserts with optional 'pads only' to address 'leg drop' tics and frequent falls. Fourthly, padded fingerless gloves aimed to offer portable protection for hand and arm tics.

Conclusions:
The research highlights a significant gap in the market for products which reduce risk or injury for individuals with TS and other movement disorders. This compensatory and social design project aims to remove barriers to participation and engagement caused by TRPI. It offers people opportunities to engage in the occupations they want and need to do in any environment. Significantly, the intervention concept does not place the burden of change on the individual with tics, nor does it aim to reduce the tics themselves, something many participants shared was important to them.

P8. Clinical characteristics of youth with chronic tics experiencing tic exacerbations

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Background:
One of the hallmark features of tics is that they wax and wane in type, form, frequency, and intensity over the course of time. Several internal and external factors may trigger worsening of tic severity, including stress and anxiety. Less is known about individual differences between those experiencing tic exacerbations and those without exacerbations. This study aims to compare a range of clinical characteristics of youth experiencing moderate tic exacerbations in comparison with youth without. We expect higher tic and comorbid symptom levels, an earlier age of onset, and a lower level of everyday functioning in youth experiencing tic exacerbations.

Methods:
A sample of 715 children and adolescents (M_{age}=10.7 years, range 3-17) with a chronic tic disorder were followed bi-monthly up to 18 months in the European Multicentre Tics in Children Study (EMTICS). We compared clinical characteristics of youth who experienced one or more tic exacerbations (defined as a rise in 6 points on the Yale-Global Tic Severity Scale, YGTSS) during the study period, to youth who did not. We used logistic regression, independent t-tests, and Pearson's Chi-square tests for continuous and dichotomous predictor variables as appropriate, including demographic data, psychotropic medication use, age of onset of symptoms, tic severity, premonitory urges, comorbidities, psychosocial stress, global functioning and quality of life. We compared baseline assessments for all measures, as well as the mean scores across all visits for repeated measures. Below, we present the first preliminary results. The complete results will be presented at the conference.

Results:
Our first exploration of baseline characteristics indicates that 253 youth who experienced one or more tic exacerbations were younger in current age and age of onset of tics, compared to 456 participants without tic exacerbations. Parents also reported more stressful events experienced by the child in a weekly diary, yet no higher perceived stress levels (PSS-10). As expected, clinicians reported a higher level of tic severity and tic worsening (CGI tics severity and improvement) and worsening of overall well-being (CGI overall improvement) during the study in those with tic exacerbations.
Unlike hypothesized, both groups did not significantly differ in motor, vocal or total tic severity on the YGTSS or premonitory urges (PUTS), and neither regarding ADHD (SNAP), emotional (SDQ), and autistic symptoms (ASSQ). Also, the group with tic exacerbations was less affected by comorbid obsession and compulsion disorder (OCD) and -symptoms (CY-BOCS), oppositional defiant disorder (ODD) symptoms (SNAP), and conduct disorder symptoms (SDQ). Moreover, they had less peer problems (SDQ), and reported a higher family-related quality of life (KINDL-R). Results regarding the repeated assessments were similar.

Conclusions:
Our preliminary results suggest that youth who experienced tic exacerbations had more stressful events during the study period than those without tic exacerbations. This is consistent with the assumption that stressful events in daily life may be an important triggering external factor for the worsening of tics. Also, a younger age and earlier age of tic onset is associated with tic exacerbations. However, in contrast to our hypotheses, we did not find support for a more severe symptom profile in youth with tic

exacerbations than without. These results should be interpreted with caution awaiting further analyses.

P9. Sydenham's Chorea – A Case Report and Literature Review

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Background:
In this case report and literature review, we present the case of an 8-year-old girl who was diagnosed with Sydenham's Chorea (SC) and subsequently began to develop tic-like movements.

SC is a neuropsychiatric condition largely affecting children and adolescents, associated with post group-A streptococcal infection. There is an estimated incidence rate of 0.16 per 100,000 children aged 0-16 per year in the UK.

Case report:
An 8-year-old girl with a short history of involuntary movements was diagnosed with SC by Paediatric Neurology. Aetiology was suspected to be a soft tissue injury and skin infection to her knee sustained a few months prior to the diagnosis. She was initiated on Penicillin V prophylaxis, followed by Sodium Valproate, which did not improve her symptoms. Sodium Valproate was stopped, and Haloperidol was initiated, which also failed to improve her symptoms. Eventually, with a combination of Sodium Valproate and Haloperidol, symptoms of SC improved; however, with extrapyramidal side effects due to Haloperidol.
Referral to Paediatric Neuropsychiatry was made at age 12. Assessment, which included history, mental state & physical examination, revealed a range of co-morbid neuropsychiatric conditions, including anxiety with panic attacks. Some residual movements were distinct from the SC and likely subsequent onset facial motor tics in addition to some more functional tic-like behaviours. Finally, we also recognised symptoms of undiagnosed Autism Spectrum disorder. Treatment included stopping Sodium Valproate, swapping Haloperidol with a low dose of Aripiprazole and initiation of Sertraline for anxiety, combined with psychoeducation for the patient, their family and school. Self-reported symptom improvement of Anxiety: 70%, Tics: 50% and other movements (FTLBs/chorea): 70%, resulting in improved overall functioning.

Thirty-four adults with TS aged from 16 to 25 completed the questionnaires. The *Adult Tic Questionnaire* is used to measure tic severity. An adapted version of the *Ableist Microaggressions Scale* is used to measure microaggressions (scale of 0 to 5). The *Pediatric Quality of Life Inventory 4.0 – Young Adult Version* is used to measure the quality of life. Descriptive statistics and simple linear regression were conducted.

Methods
We conducted a review of literature published up until 05/03/2024 on bibliographic databases, including Pubmed, Embase, Medline, Psychinfo and EMCare.

After the removal of duplicates and irrelevant studies, our search yielded 18 papers, which were a mixture of case reports, RCTs, cohort studies, expert opinions, and systematic reviews. All studies were read to give authors an up-to-date overview of all aspects of SC, including presentation, assessment, diagnosis, and management.

Results:
A review of the literature revealed a range of common neuropsychiatric co-morbidities, including obsessive-compulsive disorder, affective disorders, anxiety, ADHD, tic disorders, executive function disturbances, and psychotic features. However, the relationship between symptom onset and the timing of the disease process is unclear, and the evidence for an association is less robust.

Regarding treatment, recent literature reviews have concluded that dopamine antagonists can serve as first-line agents, followed by antiepileptics. The role of immunomodulators warrants further investigation for conclusive recommendations. Penicillin prophylaxis appears to reduce the likelihood of further cardiac complications and the recurrence rate of chorea.

Conclusions:
Although SC is a rare condition, it remains prevalent in the UK, highlighting the need for collaborative work between Paediatric Neurologists and Paediatric Neuropsychiatrists with early assessment of neuropsychiatric co-morbidities. Further research is necessary to develop a consensus on the assessment and management of SC and its comorbidities.

Postersession II

P10. Stigma and Adults with Tourette's Syndrome

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Background:
Tourette Syndrome (TS) is often misrepresented in media and examined predominantly through a medical perspective, overlooking the lived experiences of those affected by it. This medical model frames tics as a deficiency to be cured, neglecting societal factors contributing to diminished wellbeing and social exclusion. While previous research has acknowledged stigma's existence, comprehensive studies on its nature and impact are lacking. This study aims to explore the subjective experiences of TS stigma and its impact. Four objectives guide the research: assessing stigma's extent and nature, evaluating sociodemographic and clinical influences, exploring daily challenges, and identifying coping strategies. By amplifying affected individuals' voices, this research seeks to inform effective interventions combating TS stigma

Methods:
This study employed a concurrent parallel mixed-method approach to comprehensively investigate Tourette Syndrome (TS) stigma. Through a national online survey and in-depth interviews, the prevalence, nature, and impact of TS stigma were assessed. Patient

and public involvement informed all stages of the research, ensuring user-relevance and cultural appropriateness. Recruitment utilized social media platforms and snowball sampling within the TS community. The online survey included demographic questions, the Discrimination and Stigma Scale (DISC-12), and the Perceived Quality of Life scale (PQoL). Interviews explored lived experiences, societal responses, and coping strategies related to TS stigma. Data collection occurred from May 2019 to April 2020.

Findings and conclusion:
The survey revealed a significant negative correlation between the quality of life (PoQ) of adults with Tourette's syndrome and both Enacted and Anticipated Discrimination measured by the DISC-12 scale. Discrimination was pervasive across various life domains, regardless of demographic factors such as age, education, gender, or ethnicity. The employment and educational systems were identified as particularly prone to discriminatory practices, limiting opportunities and hindering educational attainment, thereby contributing to the social and economic exclusion of individuals with Tourette's syndrome. Participants also revealed that healthcare encounters exhibit limited awareness and expertise, delaying diagnosis and treatment due to a lack of guidelines, indicating suboptimal care for this population. The narratives provided by participants shed light on the detrimental impact of disparagement humour and trivialization in perpetuating the marginalization of individuals with Tourette's syndrome. Many participants described resorting to concealment and internalized stigma as coping mechanisms to manage their "spoiled identity," thus hindered collective responses to stigmatization. Overall, the study underscores the urgent need to address Tourette's syndrome stigma comprehensively. It highlights the importance of implementing strategies targeting stigma at multiple levels, including education, advocacy, and policy reform, to improve the well-being and social integration of affected individuals.

P11. Cross-cultural knowledge, beliefs, attitudes, and responses to tics: A scoping review of evidence outside of Australia, Europe, and the USA

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Background:
Tic disorders (TDs) are common neurodevelopmental disorders, and stigmatisation of TDs has been found to be associated with exacerbation of tic symptoms and distress. However, stigma research in TDs is overrepresented in Europe, the United States of America (USA) and Australia, which poses a barrier to understanding experiences of TD-associated stigma in other cultures and countries.

Methods:
The current scoping review identified and summarised evidence pertaining to the components of stigma (knowledge, beliefs, attitudes, and responses) in TDs in countries outside of the USA, Europe, and Australia. 20 relevant studies were identified using a systematic search across five electronic databases.

Results and Conclusions:
Identified studies were conducted in Uganda, Nigeria, China, Japan, South Korea, Taiwan, Bali, Thailand, Israel, Saudi Arabia, United Arab Emirates and Costa Rica. Countries varied in knowledge and exposure to TDs, causal attributions of TDs, beliefs about treatment, severity and impact of TDs, TD-related attitudes, and responses to TDs. The review suggests some variation across cultures in causal attributions of TDs, though cross-cultural differences have not yet been statistically examined. Emerging evidence highlights the importance of considering intersectionality and individual differences in understanding cross-cultural experiences of stigma in TDs. Acceptance of TDs was reported to be supported through social support and acceptance by wider networks. Comparisons across studies and countries are constrained by heterogeneity and lack of reliability in study design and sample. Further research is required to examine cross-cultural differences in TD-associated stigma using statistical measures, as well as to investigate relationships between components of stigma to develop effective interventions to target stigma and acceptance of individuals with TDs.

P12. Ethnicity and Equity of Access to a National and Specialist Mental Health Tic Service

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Background:
Tourette Syndrome (TS) is thought to occur at similar frequencies across all ethnicities. Young people from minoritized ethnic backgrounds are often underrepresented in mental health services (Bansal et al., 2022). Unconscious biases around ethnicity can influence clinical judgements creating inequalities in access (Mui et al., 2022). National specialist services often offer the most expert advice yet are the most difficult to access (Ekanayake et al., 2022). Barriers to access may be higher for minoritized groups, and we test this within the Tic Service at Great Ormond Street Hospital. Specifically, aims were to determine; 1) if there are unconscious biases within the referral triage process, and 2) if there are systemic biases which impact the referral process and/or a patient's pathway through the service.

Methods:
We examined the triaged accepted/rejected referrals to the Tic Service between May 2021 and Nov 2022. As ethnicity was not explicitly known by clinicians when triaging, five independent raters estimated ethnicity based on each patient's full name. The modal ethnicity (with >80% interrater consensus) was taken as a 'proxy ethnicity'. Proxy ethnicity was compared against actual ethnicity (where recorded by the patient/parent), to assess accuracy. For patients who were accepted into the Tic Service, we examined differences in symptom severity on the Yale Global Tic Severity Scale (YGTSS) and Childrens Global Assessment Scale (CGAS) and appointment attendance rates, based on actual ethnicity.

Results:

Actual ethnicity data was recorded for 93 patients, with 85% registered as being white and 15% non-white, indicating a slightly higher proportion of white relative to non-white patients within referral data compared to national figures (82% and 18% for white and non-white young people respectively (Office of National Statistics, 2021)). There was no significant difference in acceptance rates based on actual ethnicity (χ^2 =0.0002 p = 0.990) between white (56%) and non-white patients (57%).

There was a 90% match between proxy and actual ethnicity. Out of 363 referrals, 329 (91%) were considered to be white and 34 (9%) from non-white presenting backgrounds using proxy ethnicity data. Of these, there was a trend towards greater acceptance rates for patients who were perceived to be white, 128 (39%), compared to non-white, 8 (23%), however this was not statistically significant (χ^2 = 3.11 p = 0.078). A higher proportion of non-white patients were likely to require repeated referrals compared to white patients.

There was no significant difference between groups on the YGTSS (t=3.7(7.7) p= 0.633), however the non-white group presented with significantly greater impairment rating on the CGAS (t= 6.1 (3.0) p=0.048). Finally, there were no significant differences between the two groups for appointment attendance rates.

Conclusions:
While there were no statistically significant differences between perceived ethnicity and referral acceptance, young people from non-white backgrounds are likely to face more barriers to being referred into the service. Accepted non-white patients exhibit greater overall impairment, although not specifically related to tics. While there were no differences in appointment attendance rates, the sample size of available data was small. Findings call for greater awareness of challenges faced by patients from minoritized ethnic backgrounds, and better recording of ethnicity is a requisite starting point for research.

P13. Explosive Outbursts in Youth with Tourette Syndrome: Implications for Dimensions of Parental Stress

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Background:
Around 50% of youths with Tourette syndrome also have explosive outbursts. These episodes are characterized by a sudden onset of physical or verbal aggression out of proportion to the trigger. The intensity, unpredictability and recurrence of these episodes distinguish them from ordinary temper tantrums. Parents of children with the syndrome report significant parental stress. This stress is said to be influenced by factors such as the parents' age and income, as well as the severity of the child's tics and difficulties. Parental stress comprises three dimensions: 1) parental distress about the child's behaviours; 2) perceived quality of interactions with the child; 3) perceived ability to manage the child's difficulties. Although explosive episodes are one of the

most disruptive manifestations of the syndrome, no study has specifically evaluated their effect on parental stress. This study aims to assess the effect of explosive outbursts on the three dimensions of parental stress.

Methods:
Thirty-seven parents of youths aged 6 to 14 (mean age = 9.89; gender = 10 girls, 26 boys, 1 non-binary) with Tourette syndrome completed online questionnaires. A socio-demographic questionnaire was used to validate inclusion criteria and gather general information such as parent's age and income. The following validated instruments were used: 1) The Parent Tic Questionnaire to assess tic severity; 2) The Rage Attack Questionnaire–Revised to assess explosive outburst severity; and 3) The Parental Stress Index–Short Form to assess parental stress. Multiple regression analyses were conducted with explosive episode severity and parental stress dimensions, controlling for parental age, income, and tic severity.

Results:
The model assessing parental distress as a dimension of parental stress explained 15.4% of the variance (4.2% of the adjusted variance). Severity of explosive episodes was not a significant predictor of parental stress when evaluating parental distress ($\beta = -.306$, $t[30] = -1.73$, $p = .095$). The model assessing the perceived quality of interactions with the child as a dimension of parental stress explained 21% of the variance (10.5% of the adjusted variance). Severity of explosive episodes was a significant predictor of parental stress regarding dysfunctional interactions with the child ($\beta = -.411$, $t[30] = -2.40$, $p = .023$). The model assessing the perceived ability to manage the child's difficulties as a dimension of parental stress explained 22.9% of the variance (12.6% of the adjusted variance). Severity of explosive episodes was a significant predictor of parental stress regarding child difficulties ($\beta = -.473$, $t[30] = -2.80$, $p = .009$). Parental age, income and child tic severity were not significant predictors of parental stress dimensions in any model.

Conclusions:
Explosive outbursts notably impact specific dimensions of parental stress, such as the perceived quality of interactions with the child and the perceived ability to manage the child's difficulties. This influence appears to be more noteworthy than factors like the child's tic severity, parental age, and income. Understanding these nuances is crucial for designing targeted interventions to support parents effectively in navigating challenges associated with Tourette syndrome.

P14. Music is in the air: relationship between music and tics

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Background:
Relationship between music and tics is still not clear. Preliminary data suggests that both active engagement and passive exposure to musical activities may hold promise in effectively managing tics. However, further comprehensive studies are needed to fully understand the potential benefits of music therapy in tic management.

Methods:
We have revised previous literature on the impact of music and tics and have illustrated our findings with the examples of musicians with tic disorders.

Results and Conclusions:
There are only two studies about the impact of music on tics (Bodeck et al., 2015; South et al., 2016). In the first study (1), 29 patients were asked whether listening or performing music had any impact on tic frequency. Afterwards, a small subset of 8 patients were tested before and after musical performance, listening to music and music imaginary. Both assessments revealed positive impact of music on tics which was mainly attributed to enhanced fine motor control, focused attention and goal directed behavior. In the doctoral thesis from the University of South Florida (2) impact of music engagement on tics was tested. Out of 183 patients who played instruments, 108 reported drastic and 58 moderate symptom improvement after playing musical instrument. These positive results were also confirmed by a number of examples of successful musicians with tic disorders including Wolfgang Amadeus Mozart (3), Kurt Cobain or Billie Eilish. Witty Ticcy Ray, a patient with Tourette syndrome (TS) described by Dr Oliver Sacks in his book *Man who Mistook his Wife for a Hat* (4) incorporated his tics in musical performance as a drummer, similarly to UK drummer, Greg Storey (5). Quebecoise composer and pianist Jean-Michel Blais (6) as well as singer and songwriter Esha Alwani, also report healing impact of music on their tics. Patricia Heenan, a mother of TS patient published her experience with musicotherapy as treatment of tics in her book *Kevin and Me: Tourette Syndrome and the Magical Power of Music* (7).All these testimonies fueled interest in musicotherapy for tics as shown by the initiatives such as Mind Music program (8).

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P15. Exploring the Use of the Tree of Life as a Narrative Intervention with a young person with Tourette Syndrome

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Background:
The Tree of Life is a creative and strength-based narrative intervention that supports young people who have experienced hard times and/or struggling with their identity or parts or their identity (e.g., tics). A Tree of Life group protocol, developed by the Tic Service at Great Ormond Street Hospital for Children, was adapted to an individual intervention due to the sample being limited to one participant. We aimed to explore how the Tree of Life was used as an acceptance-based intervention with a young person (age 14 years) with Tourette Syndrome who had experienced bullying and developed a negative relationship to his tics. The young person had previously engaged in behavioural tic treatment with the Tic Service, but he had found it difficult talking about his tics in the context of anxiety and previous negative experiences in relation to his tics. A referral was therefore made to the Tree of Life group, which has the following objectives: 1) improve and widen concept of self, 2) promote acceptance of tics, 3) improve quality of life, 4) reduce sense of loneliness and isolation and increase sense of connection.

Methods:
The suitability of the young person was assessed according to eligibility considerations, including being between 13-17 years of age and presenting with difficulties with accepting tics, worsening relationships to tics and/or themes of loneliness and being 'different' and 'othered' because of tics. Preparation included a screening call with the young person and his family and a formulation meeting between clinicians to explore the social context of the young person. The Tree of Life intervention was divided into four sections: The Tree of Life, The Forest of Life, The Storms of Life, and Endings and Certificate. A follow-up call was completed to collect quantitative and qualitative feedback and outcome measures. The intervention was delivered in-person, over the course of five hours, with two facilitators, one Clinical Psychologist and one Trainee Clinical Psychologist. The young person completed most of the intervention on their own, although a parent (mother) attended the initial set up of the intervention and was invited as an 'outsider witness' at the end of the day.

Results and Conclusions:
The young person identified one main goal that he wanted to work on: "to feel more confident talking about tics". At the start of treatment, he rated this goal 3 out of 10, with 10 representing full achievement of that goal. The outcome of the intervention was promising. Although the young person's engagement was limited to short answers initially, he engaged in extensive conversation with the facilitators about strengths, significant others, as well as difficult experiences (e.g., bullying, tics) as the intervention went on. The young person reported improved scores on his goal both immediately after (6/10) and 2 weeks following (8/10) the intervention, and provided positive qualitative and quantitative feedback, including reports of reduced anxiety in relation to tics, improved confidence, and increased willingness to talk about tics with family members. Challenges with parents being committed to an 'old narrative' about

their child and ensuring that a new strength-based narrative is sustained across the child's system long-term were considered. Although these findings are specific to one case, it offers helpful insight into the usefulness and challenges of delivering a narrative and acceptance-based intervention for young people with tics.

P16. Experiences of a functional tics diagnosis received by adolescents and their caregivers: A qualitative study

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Background:
From 2020, clinical services noted an unexpected increase in functional tic disorders, seemingly related in timing to the COVID-19 pandemic. Functional tics differ in origin with sudden onset of severe tics at a later age compared to 'classic' tics, which are those more typically seen in children with Tourette Syndrome and other chronic tic disorders. Evidence suggests that functional symptoms and tic disorders have a significant impact on family functioning and lower child and parent reported quality of life. However, little is currently known of the impact of a functional tics diagnosis in adolescence, both on the young person and their families.

Methods:
The current qualitative study explores adolescent and caregiver experiences of a functional tics diagnosis, associated symptoms, and experiences of post-diagnostic support. Seven females aged between 12 and 18 years with a formal functional tics diagnosis and eight caregivers were recruited through Tourette's Action, a UK-based charity for people with Tourette Syndrome and their families. Participants took part in individual semi-structured interviews. Transcribed interviews were analysed using thematic analysis within NVivo 14.

Results and Conclusions:
Themes generated from adolescent and caregiver interviews included (1) disbelieved and discounted, (2) the impact of fighting for help, (3) isolating and being isolated and (4) the importance of psychological and peer support. The findings emphasise the need for research to further an understanding of functional tics, in turn to improve service delivery and support for affected young people and their families.

P17. 'Bounce Back' - risk and resilience in coping with Tourette Syndrome or chronic tics: An international consortium

Annet Heijerman[1,2], Pieter J. Hoekstra[1,2], Andrea Dietrich[1,2], and the Bounce Back consortium in collaboration with international patient advocacy groups

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Background:
Living with a chronic condition can cause hardship. Not only for adults and children with tics, but also for parents and the family as a whole. Tic disorders and the presence of comorbid conditions have been associated with poorer functioning and quality of life (Conelea et al., 2013; Cutler et al., 2009; Storch et al., 2007). However, little is known about risk and resilience factors in dealing with tic disorders in daily life and which factors are related to better outcomes (Eapen, Cavanna & Robertson; 2016). Why do some families experience more distress than others in dealing with tic disorders and what can we do about it? We aim to identify risk and resilience factors within the individual but also in the interplay with their environment, such as the role of parents, family, peers and society as a whole in coping with the condition. We are particularly interested in finding an individual's and their parents' strengths and what is related to better outcomes.

Methods:
Our international research group (clinical centers in the Netherlands, Germany, UK, Hungary, Spain, USA) is planning to conduct a study on risk and resilience, differences in coping strategies, quality of life and stigma in children (N=300) and adolescents (N=300) with a chronic tic disorder and their parents (N=600), as well as in adults (N=300) with chronic tics. We aim to include a diverse group of clinical and non-clinical participants recruited from three main sources: (1) prior study participants, (2) patients recruited from participating clinics, and (3) patient organizations across European countries and the United States. Via a web-based link, shared by participating organizations and the clinical centers, participants can fill out an online survey. We expect the survey to be available in multiple languages in the second half of 2024.

Results and Conclusions:
The results are expected end of 2025 and will offer insights into the individual, family and societal factors that are most important in coping with tic disorders in daily life. This knowledge may help clinicians to better explore an individual's strengths in offering personalized treatment.

P18. I Tic, therefore I am - A qualitative analysis of adults with Tourette syndromes' experiences of leisure occupations

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Background:
Occupational therapists (OT) provide interventions to enhance wellbeing by considering the relationship between the self, the occupation, and the environment. Leisure is an occupational performance component defined as a non-obligatory, individualistic activity of one's own volition, separate from tasks of work or self-care. Within OT practice, leisure is widely considered a fundamental human need and research indicates its value in improving psychological, physical, and social health and wellbeing. Tourette syndrome (TS) in adulthood is associated with reduced quality of life, higher rates of mental health needs, self-stigma, and pain, which are all risk factors for occupational deprivation. Limited research suggests clients with TS may disengage

from previously enjoyed occupations due to their primary and secondary symptomology. This undergraduate dissertation examines the perceived benefits, facilitators, and barriers to engagement in leisure occupations in adults with TS to inform social and therapeutic approaches to enable participation.

Methods:
The researcher conducted a systematic literature search including allied healthcare databases, using CINAHL and AMED, identifying and critiquing relevant articles to inform the literature review. Qualitative data was obtained through online individual semi-structured interviews with five adults diagnosed with TS. The transcript was analysed utilising Thematic Analysis to generate themes and subthemes.

Results:
All participants in the study reported benefits from engagement in leisure, including a reprieve from tics without the negative or 'rebound' effect they associated with suppression. This led many to incorporate their leisure interests into their professional or educational pursuits examples include a musician and yoga teacher. Leisure participation was seen as a source of pride and accomplishment, and an outlet for excess energy associated with co-occurring ADHD and anxiety. However, barriers to engagement in leisure were also identified, including the internal experience of tics, related pain and fatigue from tic suppression, and the external physical, social, and sensory environment. A key finding was that a supportive community, and others being aware of the TS diagnosis, along with the strengths attributed to the condition itself, played a crucial role in enabling participation in leisure activities.

Conclusions:
These outcomes underscore the complex interaction between the self (person with TS), environment (social, physical, sensory), and occupation (leisure activities), which may inform universal design and intervention approaches to reduce barriers to engagement. The results indicate the value social prescribing may offer as an alternative targeted approach to enable a reprieve from tics and commonly co-occurring symptomology.

P19. Evaluation of Novel Pilot Short-Term Tic Intervention

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Background:
Behavioural therapies, such as Exposure Response Prevention (ERP) and Habit Reversal Therapy (HRT), are the main form of symptom management for tics. The Tics and Neurodevelopmental Movements Service (TANDeM) at the Evelina London Children's Hospital runs a six-week virtual tic tool kit that combines both ERP and HRT approaches with relaxation and externalised attention strategies. Due to school attendance concerns, many children are unable to commit to 6 sessions and, to respond to this need, the team devised condensed groups, incorporating the same elements as the six-week session. This

study aims to explore the efficacy and acceptability of the condensed versions of this group.

Method:
Two condensed groups were devised, a three- session group for the 8 to 11 years age group and a two-session group for the 12 years and over age group. Each session lasted for two hours. The Yale Global Tic Severity Scale (YGTSS) and child Gilles de la Tourette Syndrome Quality of Life (GT QoL) questionnaires were completed prior to and following the group. Seven children completed the older children's group and 10 children completed the younger children's group.

Results and conclusions:
With regard to the two-session condensed group, there were a total of six completed measures. Half of the children reported an improved tic-related quality of life and half reported a worsening of in tic-related quality of life. The YGTSS indicated an increase in tic severity in 4 children and a decrease in tic severity in two. For the impairment rating, four children reported a decrease in tic impairment and two reported an increase in tic impairment. With regard to the three-session group, as this group completed very recently, there are only partially completed measures to comment on and the remainder will be complete by the time of the conference. Seven out of seven children had a decrease in tic severity as measured by the YGTSS. With regard to the impairment rating, 6 showed an improvement and 1 remained the same. Four children in this group completed the QoL measure, three reported an improvement in tic-related quality of life and one reporting a worsening. Qualitative measures indicate that eight out of nine children reported that they felt more able to manage their tics after the group and one felt that they were the same in terms of tic management.

The condensed group produced mixed results in terms of impact on tic-related quality of life and tic severity. Regardless of clinician rated measures of tic severity demonstrating an increase in tic severity for some and a decrease in others, most children reported that they felt better able to manage their tics following the group. While the condensed tic tool kit group produced some positive outcomes and facilitated better attendance due to the shorter nature of the group, more research will be needed to determine whether, overall, it is more impactful than the six session Tic Tool Kit Group.

Postersession III – on display

P20. Accelerated Intermittent Theta Burst Stimulation of the Pre-Supplementary Motor Area Enhances Inhibitory Motor Physiology in Tourette Syndrome

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Background:
Motor control and underlying physiological disinhibition likely contribute to tics as well as disruptive and impulsive behaviors in Tourette Syndrome (TS). Examples of biomarkers of motor system inhibition altered in TS include the GABA-B-ergic cortical silent period (cSP) which is abnormally shortened in children with TS. In addition, cSP increases with age in parallel with development of better tic control. Thus, it may serve as a useful biomarker of symptom severity in TS.

Prior studies utilizing rTMS to modulate the supplementary motor area (SMA), which projects to the corticospinal system, did not significantly reduce tic severity. An alternate, more specific target may be the rostral pre-SMA, given its critical function in response inhibition and its primary connections with the striatum. We have previously shown pre-SMA-mediated cortical inhibition (SMACI) of left motor cortex was present in typically developing controls (TDC) but was deficient in TS and correlated with worse tic suppressibility.

Based on this impaired pre-SMA-mediated motor system regulation in TS, we propose to evaluate cSP and SMACI as inhibitory biomarkers of effects of accelerated iTBS. We hypothesize that pre-SMA iTBS will increase pre-SMA-mediated cortical inhibition. Positive results would support this approach as a means to achieve clinically meaningful tic reduction.

Methods:
Yale Global Tic Severity Score (YGTSS) and individualized Premonitory Urge for Tics Scale (i-PUTS) were collected. T1-weighted images were used for localization of the right pre-SMA, defined as the medial prefrontal cortex anterior to the vertical commissure anterior (VCA) line. On separate, single study days (minimum 7 days apart), in a randomized, single-blinded crossover design, participants received either active or sham accelerated iTBSS, consisting of two trains of iTBS separated by a mean of 36.6 minutes (range 27-50 minutes). We localized preSMA using BrainSight® Neuronavigation System (Rogue Research, Montreal, Canada), Magstim® SuperRapid2Plus1 to deliver iTBS (each train consisting 600 pulses at 70% RMT for intensity with three 30Hz pulses, repeated every 200ms for 2 seconds followed by 8-sec rest), and Magstim® BiStim2 to measure cSP and SMACI at baseline and after each iTBS session.

Results and Conclusions:
Seven right-handed children (mean age: 13.9 years, range: 11.3-17.4 years) with TS have completed the study protocol to date. Accelerated active pre-SMA iTBS significantly prolonged CSP ($p = 0.001$). Additionally, shorter baseline CSP was associated with number ($\rho = -0.6$, $p = 0.02$), intensity ($\rho = -0.63$, $p = 0.02$), and frequency ($\rho = -0.56$, $p = 0.03$) of premonitory urges. In agreement with previous studies, pre-SMA-mediated inhibition of left motor cortex (SMACI) was not present at baseline in children and adolescents with TS (baseline mean SMACI ratio was greater than 1 for both active and sham sessions). However, there was a trend ($p = 0.06$) towards restoration of SMACI with active accelerated iTBS. These findings provide evidence that pre-SMA iTBS enhances cortical inhibition in children with TS. Given these findings, accelerated pre-SMA iTBS appears to be a promising approach to improve inhibitory motor function and reduce tics in children with TS.

P21. Therapeutic approach to primary tic disorders and associated psychiatric comorbidities

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Background:
Treatment of tics and psychiatric comorbidities is a priority when they cause an impact on the patient's physical or psychological well-being and their relationships with the environment. However, the optimal pharmacological management according to the idiosyncrasies of each patient is not well defined. The objective of this study is to describe the clinical characteristics and the treatment received to control tics and psychiatric comorbidities in our cohort and compare it with what is described in the literature.

Methods:
Retrospective descriptive study of 39 patients with tic disorder under follow-up in the Functional Tic Unit of the Sant Pau Hospital from January 2022 to March 2024.

Results:
39 individuals with primary tic disorder were included (66.7% males, median age = 17 years, IQR 19). 89.7% diagnosed with Tourette syndrome, 7.7% with chronic motor tic disorder and 2.6% with provisional tic disorder. 82% had at least one psychiatric comorbidity, the most frequent being: obsessive-compulsive symptoms (69%), anxiety (53%) and ADHD (34%). 69.2% received pharmacological treatment for tics, 3 additional botulinum toxin and none behavioral therapy. The most used drugs for tics were aripiprazole (48%) and clonazepam (44%) and for psychiatric comorbidities: SSRIs (37%), methylphenidate (21%) and benzodiazepines (68.4%).

Conclusions:
Aripiprazole has been widely used in our cohort, in line with scientific evidence and expert preferences. We consider that clonazepam can be also useful as a first line monotherapy and as an adjuvant, to control tics and comorbidities

P22. Long-term safety and durability of effect of ecopipam in pediatric patients with Tourette Syndrome: Results of a 12-month open-label extension (OLE) study

Donald L. Gilbert, MD, MS[1], David JB Kim[2], Meredith M. Miller[2], Sarah D. Atkinson, MD[2], George B. Karkanias, PhD, MS[2], Frederick E. Munschauer, MD[2], Stephen P. Wanaski, PhD[3], Timothy M. Cunniff, PharmD[3]

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Background:
Ecopipam is a first-in-class dopamine 1 receptor antagonist that significantly reduced tics in a 12-week Phase 2b (D1AMOND) randomized, double-blind, placebo-controlled clinical trial in pediatric patients with Tourette syndrome (TS). The objective of this

OLE study was to assess the safety and durability of effect of long-term treatment with ecopipam.

Methods:
Children and adolescents who completed the D1AMOND study were eligible to participate. Patients received ecopipam (2 mg/kg/day oral dose) nightly for up to 12 months. The primary outcome was incidence of treatment-related adverse events. The primary efficacy endpoint was the Yale Global Tic Severity Scale-Total Tic Score (YGTSS-TTS).

Results and Conclusions:
The most frequent treatment-related adverse events were anxiety (6.6%), insomnia (5.8%), somnolence (5.8%), and depression (4.1%). No clinically significant changes were observed in lab values, vital signs, electrocardiogram, physical exams, the Columbia Suicide Severity Rating Scale, Abnormal Involuntary Movement Scale, Barnes Akathisia Rating Scale, Children's Depression Rating Scale-Revised, or the Pediatric Anxiety Rating Scale. Median YGTSS-TTS was 30.0 at baseline (n=121). YGTSS-TTS scores were meaningfully improved at 3 months (-7.8 ± 8.1; n=106), 6 months (-11.0 ± 8.8; n=87), 9 months (-11.6 ± 8.5; n=85), and 12 months (-11.8 ± 9.6; n=77); all $p < 0.0001$ compared to baseline. The Clinical Global Impression of TS-Severity, the YGTSS-Global Score, and the Child & Adolescent Gilles De La Tourette Syndrome-Quality of Life Total Score each improved at all time points; all $p < 0.001$. In this OLE study in children and adolescents with TS, ecopipam demonstrated an acceptable safety profile and continued or improved control of tics.

P23. Tourette Syndrome (TS) and Autism Spectrum Disorder (ASD) in a longitudinal perspective

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Background:
Tourette syndrome (TS) and autism spectrum disorder (ASD) are two neurodevelopmental disorders with an onset before the age of 18 years that frequently co-occur and share clinical and behavioral features. Literature studies reported that the comorbidity between both disorders might partly reflect common etiological factors and structural brain characteristics in children and adolescents affected by TS and/or ASD. In this study, we compared a clinical cohort of children and adolescents with a dual diagnosis of TS and ASD (TS + ASD group), with a group of patients with TS (TS group), to examine the prevalence and patterns of ASD symptoms in relation to TS and other associated comorbid disorders. We also aimed to examine the TS+ASD cohort according to their primary diagnosis to establish common clinical characteristics and significantly differences.

Methods:

We retrospectively analyzed the clinical data of 65 patients aged 5-18 years with a dual diagnosis of TS and ASD, and other 65 patients affected by a primary diagnosis of TS. All participants underwent a neuropsychological evaluation for ASD, TS and associated comorbidities.

Results:
Patients of TS+ASD group presented a higher percentage of family history of neurodevelopmental disorders (ASD, depression, OCD), but less other comorbid conditions respect to TS group. Participants of cohort with TS and ASD presented lower mean IQ and total YGTSS and CYBOCS score respect on patients with TS. According to their primary diagnosis, no significant differences were observed in both groups based on neuropsychological scores, except for oppositional score in CPRS, total RBS score, and ABC-inappropriate speech score. Finally, compared with TS, patients of TS+ASD group also presented a higher percentage of global developmental delay, but delay in socialization skills are reported not only in TS+ASD group, but also in TS group.

Conclusions:
This study suggests a significant overlap in clinical features between ASD and TS, and also the importance of a careful examination of ASD and TS symptoms in patients with this dual diagnosis. Conversely, the comparison between TS cohort and TS+ASD cohort revealed significant differences on their phenomenology. Further studies are needed to improve our understanding about the clinical presentation of TS + ASD cohorts to highlight common features and significantly differences respect on TS patients, focusing also on the role of the other associated comorbidities.

P24. A prospective observational cross-sectional study on the prevalence of digital addiction and its clinical correlations among preadolescents with Tourette syndrome.

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Background:
In the digital era, concerns have emerged about the widespread use of digital devices among youths, particularly regarding digital addiction. This phenomenon, characterized by compulsive device use, threatens daily functions, mental health, and well-being. Preadolescents, considering the crucial stage of psychosocial development, are especially vulnerable. This vulnerability may intensify in individuals with neurological conditions like Tourette Syndrome (TS), a neurodevelopmental disorder marked by motor and vocal tics, impacting quality of life, self-esteem, and social interactions. With about 80% of TS patients experiencing psychiatric comorbidities, the comorbidity of TS and digital addiction necessitates exploration in order to improve outcomes in vulnerable patients with TS. Specifically, the study aims at quantifying the prevalence of digital addiction and assessing its association with tic severity, quality of life, and psychological issues.

Methods:
Our observational cross-sectional study involves a sample of 100 preadolescents diagnosed with Tourette Syndrome (TS), who complete a battery of questionnaires and scales: the Yale Global Tic Severity Scale (YGTSS) for tic severity; the Digital Addiction Scale for Children for assessing digital addiction behaviors; the Gilles de la Tourette Syndrome – Quality of Life Scale for children and adolescents (C&A-GTS-QOL) for assessing the quality of life; the Child Behavior Checklist (CBCL) for evaluating the behavioral, emotional and cognitive profile. The prevalence of digital addiction, using the proportion of participants meeting digital addiction criteria based on the Digital Addiction Scale for Children and DSM-5 diagnostic criteria, is the primary goal. The association or correlation between digital addiction and tic severity, quality of life, and psychological issues will be explored through Spearman's rank correlation for continuous or ordinal variables and the Kruskal-Wallis test for categorical variables.

Results and Conclusions
The results of this study could establish a clear prevalence rate of digital addiction among preadolescents with TS and to identify any significant associations between digital addiction and factors such as tic severity, quality of life, and psychological issues. We expect to find that digital addiction is prevalent in this demographic and that it correlates with increased tic severity, reduced quality of life, and heightened psychological problems. Such findings would not only fill a significant gap in the current literature but also highlight the urgent need for targeted interventions to prevent and mitigate the adverse effects of digital addiction in preadolescents with TS.

P25. Adapting psychoeducation to accommodate neurodiversity among young people with Tourette syndrome.

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Background:
Clinical guidelines recommend psychoeducation as an initial intervention for Tourette syndrome (TS), irrespective of symptom severity. TS commonly co-occurs with other neurodevelopmental conditions, including autism, attention-deficit hyperactivity disorder (ADHD) and obsessive-compulsive disorder (OCD). Co-occurring conditions are associated with increased functional impairment and reduced treatment response. It is therefore critical that interventions for TS, which include psychoeducation in best practice models, consider the needs of young people with co-occurring conditions. To date, minimal guidance exists on how to adapt psychoeducation for TS when other conditions are present.

The Tic Service at Great Ormond Street Hospital for Children (GOSH) assesses young people with TS and routinely offers a psychoeducation group in their clinical care. This online program covers the nature of tics, their development over time and issues relevant to their management, related conditions, different forms of treatment, young people's experience of tics, and how to communicate to others about their tics. Given

the high rates of neurodiversity among those with TS, it is essential to explore the capacity of this program to meet the diverse needs of those attending and accommodate the intervention accordingly.

In the current study, we aim to conduct a qualitative investigation to gain feedback on a single-session psychoeducation group from young people who have TS and one or more co-occurring conditions. For the purpose of this focus group, we are particularly interested in feedback from young people with autism and/or ADHD, including how participants experience the content of the program and any adaptations they recommend to optimise its delivery. Future groups may consider focusing on feedback from young people with Tourette syndrome and obsessive-compulsive disorder. It is hypothesised that participants will have recommendations for adaptations to improve the suitability and accessibility of the program and that these recommendations will have relevance to many others in the neurodiverse population. The findings of this investigation will be discussed in the context of research that has explored diverse attributes and needs among those with complex neurodevelopmental presentation.

Methods:
We propose a focus group comprised of 6-8 participants, aged between 11 and 17 years, who have recently attended the TS psychoeducation group at GOSH and have co-occurring autism and/or ADHD. We will hold this group remotely and it will last for approximately 60-90 minutes. The focus group will address several key questions. Targeted questions will explore participants' beliefs regarding the structure and content of the program, reviewing each section in detail, paced so that young people can both consume the content and have opportunities to reflect on their views. This will be followed by specific questions related to methods of delivering the program, including the group format, use of icebreakers, in-session exercises, use of videoconference cameras and the chat function. Finally, open discussion questions will explore participants' recommendations to adapt and improve the program. A content analysis will be conducted to explore the feedback provided by focus group participants. The present investigation will therefore serve to further inform the development of psychoeducation programs to suit the needs of neurodiverse young people with TS.

P26. EEG functional connectivity patterns in children with Tourette syndrome and attention deficit hyperactivity disorder

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Background:
Tourette syndrome (TS) and attention deficit hyperactivity disorder (ADHD) frequently co-occur. Children with TS who also have a diagnosis of ADHD are more likely to have impairments in cognitive function and more psychosocial and behavioral difficulties. However, to what extent TS and ADHD have common or distinct neurobiological underpinnings remains unclear. Functional connectivity is a method to assess co-activation of different brain regions and may inform on differences in neural communication across different disorders or conditions. However, functional connectivity has been scarcely investigated in samples of children with both TS and

ADHD. Therefore, the current study aimed to assess how TS and ADHD separately and jointly impact functional brain connectivity. We also aimed to assess whether functional connectivity was associated with the severity of behavioral and emotional problems in TS and ADHD.

Methods:
Resting-state EEG was recorded from 137 children with either TS (n = 51), ADHD (n = 24), co-occurring TS and ADHD (n = 29), or who were typically developing controls (n = 33). Brain source activity was reconstructed from continuous EEG recordings. Functional connectivity was computed across 68 cortical regions in 5 frequency bands (delta, theta, alpha, beta, and gamma). Behavioral and emotional problems were assessed with the Child Behavior Checklist (CBCL). Network-based statistics were used to assess the main effects and interaction of TS and ADHD on functional connectivity measures, as well as the associations between functional connectivity and CBCL internalizing & externalizing scales.

Results and Conclusions:
By contrasting groups on measures of functional connectivity, our analyses revealed that TS and ADHD were separately associated with reduced functional connectivity across different brain regions. However, no interaction was found. Thus, it seems that both TS and ADHD are associated with decreased connectivity between several brain regions, though in different networks, suggesting additive effects of TS and ADHD. A different pattern emerged when looking at emotional and behavioral functioning. We found no main effect of either internalizing and externalizing problems, nor interactions with ADHD or TS. However, we found TS by ADHD by externalizing problems interactions across three frequency bands. Externalizing problems were significantly associated with increased functional connectivity in typically developing controls and children with TS+ADHD. For children with TS-without-ADHD and those with ADHD-without-TS, externalizing problems were either significantly associated with decreased functional connectivity or showed no significant association. These results suggest that different patterns of functional connectivity are associated with externalizing problems in children with TS+ADHD, relative to those with either TS or ADHD.

P27. Behavioral inflexibility and explosive outbursts in children with Tourette syndrome

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Background:
An important proportion of children with Tourette syndrome must also deal with recurrent episodes of sudden and intense anger, which are known as explosive outbursts. However, individual characteristics influencing the onset of such outbursts remain poorly understood. A few factors that may precipitate explosive outbursts have been identified, such as being reprimanded or having plans or routine changed. These latter difficulties could potentially reflect some level of behavioral inflexibility, which refers to a pattern of rigid, inflexible behavior in situations where it would be beneficial to adapt one's behavior to external demands. Behavioral inflexibility has however been

scarcely investigated in TS. Therefore, we aimed to assess whether behavioral inflexibility was associated with the severity of explosive outbursts.

Methods:
Data were aggregated from three ongoing online and in-person studies. Data were collected from parents of children with TS (Studies 1, 2, 3) and from children with TS themselves (Study 1). Children were aged 6-17 (Study 1: 10-14, Study 2: 6-14, Study 3: 9-17). Behavioral inflexibility was assessed with the parent-rated Behavioral Inflexibility Scale (BIS). Explosive outbursts were assessed with a parent-rated version of the Rage Attack Questionnaire-Revised (RAQ-R; Studies 1, 2, 3) and with the original self-rated version in children with TS (Study 1). In Study 1, we also collected self- and parent-reported BIS ratings in typically developing controls, in order to compare behavioral inflexibility across groups.

Results and Conclusions:
Across studies, we found positive associations between ratings on the BIS and RAQ-R. Also, children with TS showed increased BIS scores relative to typically developing controls. These results suggest that behavioral inflexibility may be an important feature in children with TS, and that it may also drive explosive outbursts. Behavioral inflexibility may thus be an important factor to address in interventions for explosive outbursts.

P28. Neuropsychological features, cognitive profiles, and clinical patterns in patients with Tourette's Syndrome and Specific Learning Disorder

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Background:
Tourette Syndrome (TS) is a neurodevelopmental disorder with an onset before the age of 18 years, frequently associated with other comorbid conditions, including Specific Learning Disorders (SLD). Children with TS are more susceptible to have an individual education program (IEP), and significant scholastic challenges. When TS is associated with SLD, the impact on educational outcomes results clearly amplified. Previous studies showed that the coexistence of other comorbidities including attention-deficit hyperactivity disorder (ADHD) and obsessive-compulsive disorder (OCD), can profoundly interfere with the learning process. The aim of this study was to compare a clinical cohort of children and adolescents with TS and SLD, with a cohort of patients affected by TS, to explore the cognitive, emotional, and behavioral aspects and to examine the impact of SLD on school performance.

Methods:
We enrolled 304 participants with a primary diagnosis of TS according to the Diagnostic and Statistical Manual for Mental Disorders (DSM-V). Participants were classified into two groups, the "TS group" (n=152), affected by TS, and the "TS+SLD

group" (n=152), characterized by the concomitant presence of TS and SLD. Each participant underwent a comprehensive neuropsychiatric evaluation to assess tics, SLD and other associated comorbidities.

Results and conclusions:
Compared to patients of TS group, patients of the TS+SLD group presented significantly higher severity of tics, anxious and depressive symptoms, and core-ADHD symptoms, as assessed by rating scales. Conversely, participants of the TS+SLD group displayed significantly lower performance on the IQ test, and higher severity of obsessive-compulsive and behavioral symptoms. The prevalence of previous speech disorder is significantly higher in patients affected by TS+SLD despite TS group. Furthermore, we found a significant prevalence of medication use in TS+SLD group. These data are in line with our hypothesis that TS+SLD groups present more severe tic symptoms than TS patients without SLD. Furthermore, a higher occurrence of oppositional behaviors, inattention challenges, and hyperactivity issues was probably related to learning difficulties in the school context. ADHD as a comorbidity TS, is associated with a significant impact on learning. Future studies conducted on large cohort are needed to explore the impact of SLD on tic symptoms, also evaluating the influence of other comorbid conditions.

P29. Perceived stress in children and adolescents with Tourette Syndrome: role of comorbidities

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Background:
Patient reports consistently point to an association between perceived stress levels and higher tic severity. Yet, to date, studies supporting this have been surprisingly sparse, with small samples sizes and primarily focusing on life events. Especially few have explored the influence of comorbid diagnoses and symptoms. Yet, prior research suggests that comorbid problems are particularly related to poorer outcomes. We hypothesized positive associations between perceived stress and tic severity/impairment in youth with chronic tics, being stronger in those with multiple comorbidities, and in those with comorbidities that may be particularly susceptible to psychosocial stress, such as internalizing problems (i.e., anxiety and depression, INT) and attention-deficit hyperactivity disorder (ADHD). We also expected associations between perceived stress and comorbid symptoms. Further, we aim to explore sex and age differences.

Methods:
This study includes 709 children and adolescents (M_{age} = 9.6 years, 3–16 years) with Tourette Syndrome (TS) or another chronic tic disorder and 200 unaffected siblings from the baseline assessment of the European Multicentre Tics in Children Study (EMTICS). The Perceived Stress Scale (PSS-10, Cohen et al, 1983) was used to assess parent and child reported perceived stress defined as the frequency of the child's feelings and thoughts related to stressful situations during the past month. Child self-

reports started as of age 11 years. Tic severity and impairment during the past week was based on the clinician-rated Yale Global Tic Severity Scale (YGTSS). We used analyses of variances (ANOVA) to compare mean levels of perceived stress in youth with TS versus (sex- and age matched) unaffected siblings, assessing whether children with tics perceive more stress than unaffected siblings. We also used ANOVA to compare mean levels in TS-only versus those with different comorbidities [i.e., obsessive-compulsive disorder (OCD), ADHD, oppositional-defiant disorder (ODD), INT, and autistic spectrum disorder (ASD)]. We applied linear regressions to analyze the association between perceived stress and tic severity/impairment, as well as comorbid symptom severity. All models are adjusted for covariates, additionally sex and age interactions are added.

Results

The correlation between parent and child reports of perceived stress was $r = .54$, $p < .001$ (n = 381). Our preliminary regression analyses indicate an association of parent-reported perceived stress (n = 672) with YGTSS total tic severity ($\beta = 0.31$, $p < 0.001$, adj$R^2 = 9.5\%$), motor tic severity ($\beta = 0.22$, $p < 0.001$, adj$R^2 = 4.6\%$), vocal tic severity ($\beta = 0.30$, $p < 0.001$, adj$R^2 = 9.1\%$), and YGTSS impairment ($\beta = 0.28$, $p < 0.001$, adj$R^2 = 7.7\%$). Similarly, we found associations of child-reported perceived stress (n = 400) with YGTSS total tic severity ($\beta = 0.28$, $p < 0.001$, adj$R^2 = 7.7\%$), motor tic severity ($\beta = 0.23$, $p < 0.001$, adj$R^2 = 4.9\%$), vocal tic severity ($\beta = 0.25$, $p < 0.001$, adj$R^2 = 6.0\%$), and YGTSS impairment ($\beta = 0.38$, $p < 0.001$, adj$R^2 = 14.2\%$). Effect sizes are in the moderate to large range, except for motor and vocal tics partially representing small effects. More complete results will be presented at the conference.

Conclusions

Our study confirms that higher perceived stress in youth with chronic tics is associated with higher tic severity and impairment due to tics. This was consistent across parent and child reports of perceived stress of the child.

P30. Knowledge about Tourette syndrome among the general population in Germany - a representative survey

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Background:

In our ambulance, patients and their relatives often have a false understanding of what Tourette syndrome is. This could also be due to the fact that misinformation about this disorder is circulating on various media platforms, sometimes with considerable reach. Patients with a functional movement disorder are often portrayed as having Tourette's syndrome.

Methods:

In this study, we would like to investigate what the general German population thinks Tourette syndrome is by conducting an elaborate nationally representative survey in co-operation with the company USUMA. This representative picture of opinion can only

be achieved by surveying several thousand people from different socio-economic groups and all regions of the country. Our survey includes different questions categories including
Our questions cover many different topics, including knowledge about typical symptoms that can occur with Tourette syndrome, limitations that patients with Tourette syndrome may have in everyday life, course of the disease, etc. Respondents are also asked to indicate their sources of knowledge and to describe how confident they are in their knowledge.

Results and Conclusions:
If our hypotheses are confirmed i.e. according to our data, there is little knowledge about Tourette syndrome in the general population in Germany, this study could provide an impetus for information campaigns. This potential lack of knowledge could hinder patients with Tourette syndrome to deal openly with their condition.

P31. Investigating the current organisation of tic services in England through Freedom of Information requests

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Background:
Parents and carers have reported struggling to access effective support for tics for their children in the UK using the National Health Service (NHS). Referral pathways were described as unclear, with insufficient availability of specialist tic services. This, combined with no NICE guidelines (National Institute for Health and Care Excellence), suggests that there are shortfalls in current tic services in England. Freedom of Information (FOI) requests were made to NHS Integrated Care Boards (ICBs) to understand how services for tic disorders are currently organized in England.
ICBs oversee geographical areas, which are commonly denoted by NHS organisations as 'Places,' where healthcare services are delivered to the local public. FOI requests can be a cost-effective research tool and organisations are legally required to provide a timely response.

Methods:
FOI requests were sent to all 42 ICBs in England who were asked to provide information on behalf of the Places they oversaw. FOI's enquired whether Places commissioned a standalone referral pathway for children and young people (CYP) with tics. If Places did not have a standalone pathway, ICBs were asked to provide information on how CYP with tics were supported. Contact details for contributing providers and lead commissioners were requested. Responses were subsequently tabulated and coded and used to map provision of tic services in different regions across England. These findings were then reflected upon by a PPI panel, consisting of 10 parents and carers of CYP who experienced tics.

Results and Conclusions:
Out of 42 ICBs, sufficient responses were obtained from 34 ICBs (81%), covering 234 Places. Only seven out of 234 Places (3%) were identified as having a standalone referral pathway. These were primarily located in the South of England and one Place in Northern England, none in the Midlands and East of England. Many Places had no plans to improve tic services (42.8%), despite current services being seemingly insufficient. Most Places were interested in receiving information about training (59.3%) and a best practice model (77.5%), reflecting that some services were open to improving tic service provision. Where Places did not have a standalone referral pathway, the most common other support provided included paediatric services, Child and Adolescent Mental Health Services (CAMHS) and neurodevelopmental (ND) services. Importantly however, acceptance of referral into services was sometimes dependent on co-occurring mental health or ND conditions being present, suggesting greater difficulty for CYP with only tics to access support.
Reported tic service provision differed lack of clear, standard referral pathways.
The PPI panel shared their difficult experiences of obtaining appropriate tic support for their children. We conclude there is an essential need to improve tic service provision in England. Although there are European clinical guidelines for tic disorders, England currently lacks, yet requires similar guidance. The next stage of FOI requests involves contacting NHS organisations managed by ICBs to gather more information about referrals for tics and number of CYP assessed and treated.

P32. Influence of medical cannabis on driving abilities in a patient with Gilles de la Tourette syndrome and comorbid ADHD

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Background:
There is increasing evidence that tetrahydrocannabinol (THC) and cannabis extracts are effective in the treatment of tics and psychiatric comorbidities in patients with Gilles de la Tourette syndrome (GTS). However, cannabinoids may cause side effects including sedation and dizziness. Furthermore, there is an ongoing discussion on the influence of cannabinoids on patients 'fitness to drive', since driving is a complex activity requiring sound visual-auditory-sensory motor coordination. In a recent large randomized controlled trial (n=64), we were able to demonstrate that treatment with the cannabis extract nabiximols has no detrimental influence on driving ability in patients with GTS, but even improves 'fitness to drive' in individual patients.
Here we present the results of driving tests in a patient with GTS and comorbid attention deficit/hyperactivity (ADHD).

Methods:
The 28-year-old male with GTS and ADHD presented in our clinic with ongoing treatment with high dose of inhaled cannabis flowers up to 10g/day. Treatment resulted

in an improvement of tics (reduction of the total tic score of the Yale Global Tic Severity Scale from 71 to 48 and the total score of the Rushed Video-Based Tic Rating Scale-Revised from 26 to 19 before compared to after treatment). No side effects were observed. To assess patient's 'fitness to drive', we used an objective assessment of psychomotor skills, the Vienna Test System. It is a validated, CE-marked, computerized assessment that has been approved by the German Federal Highway Research Institute. We assessed three domains: reaction time, stress behavior capacity, and perceptual speed at two days at different time points: before, during, and after inhalation of medicinal cannabis. In addition, we measured THC blood levels at different time points. At day 1, we assessed 'fitness to drive' immediately after inhalation of 1g cannabis and after inhalation of a total amount of cannabis of 3.3g at that day. At the same day, we again assessed 'fitness to drive' 100 minutes after inhalation of additional 0.8g cannabis and after intake of a total amount of 4.1g cannabis at this day. At the following day, 'fitness to drive' was assessed *before* cannabis intake at that day, but after intake of 8.8g cannabis the day before.

Results and Conclusions:
At all time points very similar results were measured with respect to patients driving abilities and the patient was considered "fit to drive" in all categories assessed at any time point according to German Federal Highway Research Institute guidelines. THC blood levels ranged between 59 - 364 ng/mL at day 1 and were 19 ng/mL at day 2 (before cannabis inhalation at that day).
This case study adds further evidence that cannabis-based treatment is not only effective in treating tics in patients with GTS, but also illustrates that patients may 'be fit to drive' even with a high dose cannabis treatment and corresponding high THC blood levels, highly above currently valid thresholds.

P33. Streptococcal Colonization in patients with tics and Tourette disorder

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Background:
Streptococcus pyogenes (Group A Streptococcus; GAS) is a Gram-positive host-adapted bacterial pathogen causing asymptomatic infection, benign human infections such as pharyngitis and impetigo, through to rare yet severe invasive diseases.
Repeated GAS infections may trigger autoimmune sequelae including rheumatic fever including Sydenham chorea or PANDAS (Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections). Pharyngeal infection can occur with periods of asymptomatic colonization, the frequency of which can reach 15-33%.
The consequences of being an asymptomatic carrier are not entirely clear, but subjects may be potential sources of infection and sensitive.

The aim of this study was to investigate the association between group A streptococcal (GAS) colonization detected by new genomic techniques more sensible than classical throat cultures and chronic tic disorders (CTDs) and to stablish the status as S. pyogenes carriers.

Methods:
The study was conducted at the outpatient Child and Adolescent Psychiatry Clinic of Hospital Clinic and Hospital Sant Joan de Deu (Barcelona) where 50 consecutive patients with chronic tic disorders between 7 and 17 years have been included between January 2022 and October 2023.
Streptoccoccus pyogenes colonization was determined by pharyngotonsillar culture plus quantitative polymerase chain reaction (qPCR) test on nasopharyngeal swabs. All cycle threshold (Ct) above 30 was considered colonization, whereas positive culture and/or qPCR Ct values under 30 were considered infections.
All statistical analysis was performed in R (version 4.0.1). Continuous variables are presented as median and interquartile range and to compare means between groups we used Wilcoxon rank sum test. Categorical variables were expressed as total number with percentages and compared between groups using Fisher's exact test.

Results:
The 78 % of the sample were boys, mean age of subjects included was 13 years. None of the patients had symptoms of streptococcal infection nor were positive for GAS in the pharygotonsillar culture. However, 16 (32%) of the 50 patients were positive for the PCR test that identifies colonization by streptococcus pyogenes.
We have found significant differences in the age of colonized patients, who are younger than those who are not colonized. There are no statistically significant differences in gender or other demographic variables, nor between the YGTSSS or CYBOCS scores between both groups.

Conclusions:
32% of patients with tics were colonized by streptococcus, and this was more frequent in prepubertal patients. These results suggest that rates of colonization and exposure to streptococcus in patients with tics are higher than those previously reported that were defined with antibody titers and throat culture.

Clinical rounds

CR1. Sensory phenomena in children with Tourette Syndrome (TS) or Autism Spectrum Disorder (ASD)

Adriana Prato[1], Federica Saia[1], Marianna Ferrigno[1], Valentina Finocchiaro[1], Rita Barone[1], Renata Rizzo[1]

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Background:
Tourette syndrome (TS) and autism spectrum disorder (ASD) are two neurodevelopmental disorders with an onset before the age of 18 years. TS patients frequently reported atypical sensory phenomena (SP). Sensory processing abnormalities are also particularly frequent in ASD individuals. Considering the higher rate of atypical sensory behaviors in both neurodevelopmental disorders, in the present study we analyzed sensory experiences in patients with ASD and in patients with TS.

Methods:
We enrolled patients with a primary diagnosis of TS or ASD. All participants were assessed for primary diagnosis and associated comorbidities. The presence of sensory behaviours was investigated using the University of Sao Paulo's Sensory Phenomena Scale (USP-SPS).

Results:
SP were significantly more represented in the ASD-group versus TS-group, except for sound just-right perceptions and energy to released. ASD participants presented higher mean scores in all fields of USP-SPS severity scale respect on TS patients and healthy controls. The USP-SPS total score had significant positive correlations with the CYBOCS and MASC total scores in the TS cohort. In the ASD group, the USP-SPS total score was significantly negative correlated with the total IQ and marginally positive correlated with ADOS total score.

Conclusions:
SP are a frequently reported characteristic both of ASD and TS. Considering the psychometric properties of USP-SPS for the assessment of presence and severity of SP, further research is required to understand the complexity and heterogeneity of these kind of symptoms, and to better evaluate the differences on their phenomenology in patients with TS and ASD, also exploring the possible influence of associated comorbidities.

CR2. Misokinesia in Tourette Syndrome

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Background:
Our previous research into misophonia in Tourette Syndrome (TS) has shown that children can report intense distress/irritability with specific sounds which negatively impact the frequency and severity of tics. Misokinesia is a condition in which significant distress or irritability is experienced when observing specific movements in others. We discuss the experiences of children with TS and related tic disorders who reported misokinesia phenomenon and their clinical relevance.

Methods:
We systematically asked about misophenomena over an 8-week period in our Neurodevelopmental Movement Disorders (TANDeM) clinic. 6 children with TS reported significant misophenomena. They were interviewed regarding common trigger movements, severity of misokinesia, presence of other misophenomena such as misophonia and we asked questions around emotional regulation.

Results
Results are shown in Table 1.

Conclusions:
To our knowledge, this is the first report of misokinesia within a population of children with tics. The cases presented show that observing specific movements can cause emotional distress, irritability and rage episodes, sometimes resulting in acute tic exacerbation. As with other misophenomena, misokinesia may have an underappreciated influence on tic expression and feelings of general wellbeing. Further research is planned around these phenomena and their optimal management.

CR3. The importance of assessing sensory and eating challenges in young people with tic disorders

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Background:
Eating and sensory challenges are noted in young people with tic disorders but are rarely assessed by clinicians during initial assessments in tic disorders (TD) specialist services. This project aimed to assess the impact of routine screening for sensory, eating, and mealtime (SEM) challenges during clinical assessments of young people with tic disorders under the care of a paediatric movement disorder clinic in England.

Methods:
This project was conducted following the principles outlined in the SHIFT-Evidence Framework and employed a multi-cycle Plan-Do-Study-Act (PDSA) approach. Clinicians participated in a workshop during Cycle 1 to enhance their awareness of SEM experiences in young people with TD. Insights gained from Cycle 1 informed the development of initiatives aimed at supporting routine SEM assessment during the subsequent 3-month trial phase (Cycle 2, N = 32). These initiatives included providing example SEM questions, educating team members about the project during meetings, and recruiting clinicians responsible for project implementation.

Results and Conclusions:
Results indicated that SEM issues were common in the selected sample (> 56%). Analysis of initial assessment letters during the trial phase demonstrated the effectiveness of the

initiatives implemented during Cycle 2. There was increased attention given to sensory experiences (including eating) when comparing trial assessment letters to baseline letters, 3 months apart. Analysis in Cycle 3 revealed a high number of unmet SEM needs, with limited documented evidence of interventions provided by clinicians.

The findings emphasise the need to assess and comprehensively address SEM challenges in young people with tics. While asking about sensory, eating and mealtime challenges is important, particular focus should also be paid to creating comprehensive protocols for responding to SEM challenges that are identified during assessments.

CR4. Can EMDR trauma therapy help with managing tics?

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Background:
Eye Movement Desensitisation and Reprocessing Therapy (EMDR) is a psychological therapy approach frequently used to treat Post Traumatic Stress Disorder (PTSD). Experiencing a traumatic event can exacerbate tics in children with existing tic disorders (TD). This case study illustrates how using EMDR can be an effective approach to support the management of tic severity whilst also improving emotional well being and quality of life.

Methods:
A total of 14 therapy sessions were offered to a 10-year-old boy of Caribbean origin with an existing diagnosis of Tourette's under the care of a National Specialist Movement Disorder Service in London (TANDeM). He had also experienced two previous traumatic events and met diagnostic criteria for PTSD. The Yale Global Tic Severity Scale (TGTSS), The Child Revised Impact of Events Scale (CRIES), The Strengths and Difficulties Questionnaire (SDQ) and the Revised Child Anxiety and Depression Scale (RCADS) were administered before and after therapy to evaluate treatment efficacy.

Results and Conclusions:
Results indicated that following EMDR therapy there was a marked reduction in both tics frequency and severity as well as in post-traumatic stress disorder symptoms. Improved emotional well being and overall quality of life was also evidenced through the outcome measures and qualitative report.

To conclude, it is important to assess whether traumatic/adverse experiences may have contributed to tic frequency and severity when assessing children and young people with tics. EMDR can be a useful therapeutic approach to indirectly or directly manage tic disorders.

CR5. Coughing OCTD: a clinical case

Prof. Carlotta Zanaboni Dina[1,2] & Prof. Mauro Porta[1]

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Background:
Giuseppe is an Italian 14-year-old patient suffering from OCTD as Tourette syndrome subtype, and consequent social anxiety. The main symptom is coughing, which determines his Social Impairment, principally because it enables him to regularly attend school, and sport workouts. After some improper diagnoses and treatments, he has finally been managed by a Tourette syndrome team (a medical doctor, and a cognitive behavioral psychotherapist).

Methods:
Baseline YGTSS result is 60%, with 40 points of Social Impairment, i.e. a quite severe Tourette syndrome; baseline CY-BOCS result is 25/40, and therefore meaning a severe obsessive-compulsive disease. Baseline CBCL 4-18 results 75% in the anxious/depressed internalising subscale, and 79% in the withdrawn/depressed internalising subscale, i.e. quite high anxiety/depressive symptoms.
The OCTD diagnosis has been defined, and a combined treatment of medications (e.g. antipsychotics and SSRIs) and weekly psychotherapy has been offered (65 sessions). The psychological intervention includes Habit Reversal Training (65 sessions), Parent Training (26 sessions), and school interventions (8 meetings); Home Schooling has been activated, as well.

Results and Conclusions:
Giuseppe recovers at age 17. Retest YGTSS results is 20%, with 5 points of Social Impairment, i.e. mild tic symptoms; retest CY-BOCS result is 7/40, and therefore obsessive-compulsive symptoms are subclinical. Retest CBCL 4-18 results 50% in the anxious/depressed internalising subscale, and 52% in the withdrawn/depressed internalising subscale, i.e. absence of anxiety and depression symptoms.
Now the patient attends school, he has come back to his sport workouts, and he globally conducts a good Quality of Life with no coughing nor other disturbances: Giuseppe's biopsychosocial health has been restored.

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