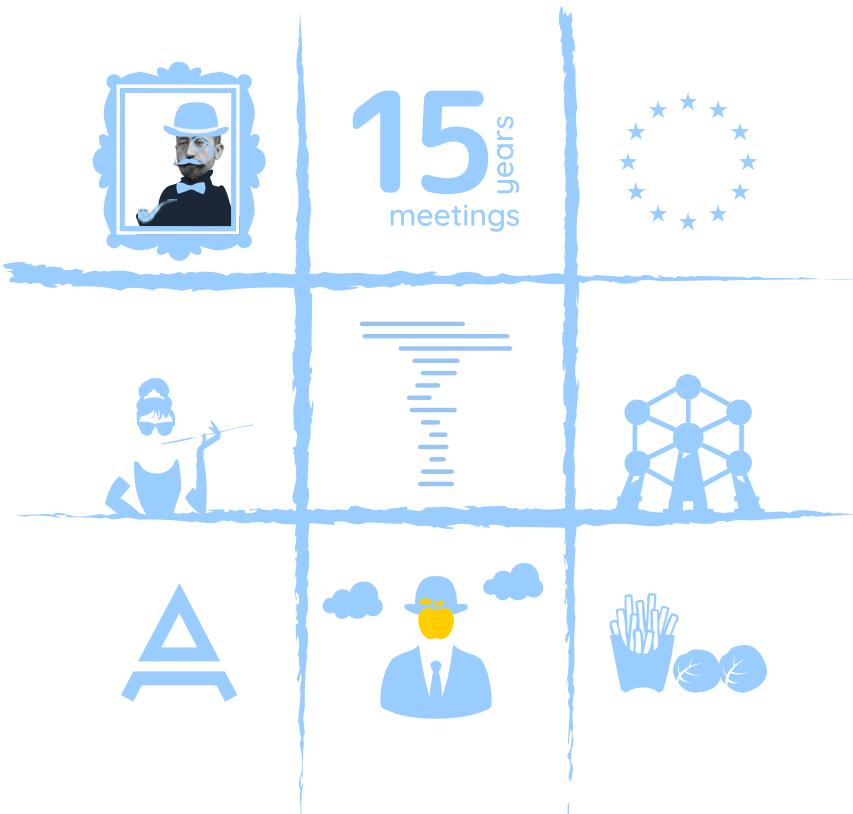


15th European Conference on Tourette Syndrome and Tic Disorders

7-9 June 2023
Brussels

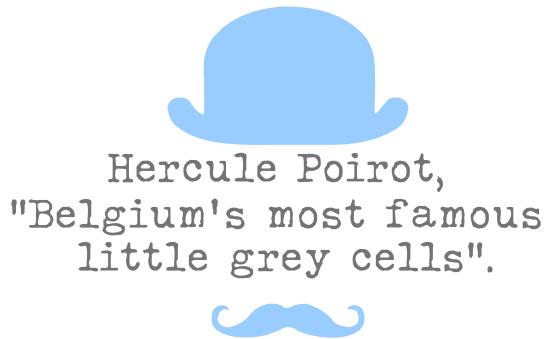
Royal Museum for Central Africa



European Society for the Study of Tourette Syndrome

As every year, we pay a little graphic tribute to the country hosting our conference...

Unless already familiar with, please meet...



Welcome message by the ESSTS board

Dear colleagues, dear patients, dear advocacy groups, dear local organisers, dear friends of ESSTS, dear sponsors, and all those interested in Tourette syndrome,

The ESSTS board cordially welcomes you to the 15th European Conference on Tourette Syndrome & Tic Disorders in Brussels, Belgium, beginning on 7 June, the International Tourette Awareness Day!

We are delighted to welcome you all to this beautiful city at the heart of Europe and to this fantastic venue!

We very much hope that we will have an interesting conference that not only brings experts together, but also offers young clinicians and researchers the opportunity to learn more about the current landscape on phenotype, pathology, and treatment of Tourette syndrome while also allowing them to share their work.

The overarching aim of this conference is to better understand patients' needs, to share the latest scientific news, and to discuss new research ideas to further improve treatment strategies and to better understand the pathobiology of TS.

We wish to sincerely **thank our sponsors**; this meeting has only been made possible thanks to their **support**.

Pharmaceutical companies have recently become more and more interested in developing new treatments. We are therefore very confident that further treatment strategies for people with tic disorders will be available **in the near future**.

With this conference, our **3-year term** as a board, **comes to an end**. It has been a great honour and pleasure serving the Society and we truly believe that ESSTS will only continue to grow.

We would like to thank you all for making this conference a...**triple record-breaking** event!

By the time these lines were written, we had received **110 registrations**, spanning **19 countries** from Australia to Canada, **57 abstract submissions** and **55 membership renewals**.

"E" in our initials might stand for *European*, yet we believe that this is a **global community** committed to working alongside to promote awareness, research and treatment of Tourette Syndrome while providing a platform for educational activities.

Finally, a loud thank you goes to our local organiser and host, **Seonaid Anderson**.

Have a great meeting and enjoy engaging in interesting conversations and enriching networking, and catching up with good friends!

Kirsten R. Müller-Vahl

Nanette Mol Debes

Natalia Szejko

Andrea E. Cavanna

Andreas Hartmann

Belgian flavour...

(welcome note from our host!)

I am truly delighted to be co-host organiser for this year's 15th European Society for the study of Tourette syndrome (ESSTS) conference being held in Brussels, in June 2023.

Having lived in Belgium for over 10 years as well as being secretary of the local patient support association **Iktic-Jetique** I am acutely aware of the potential impact of having the conference in Belgium. Being the co-host has given me the chance to reach out to politicians, journalists, different medical and psychological associations as well as to individual healthcare professionals in the country. Having worked for the UK and USA patient support associations I can see how far behind we are in terms of TS awareness, diagnosis and treatment in Belgium. So this conference will leave a **legacy** for years to come which I hope to use to the best of my ability to improve the lives of those with Tourette syndrome in Belgium.

There has been a Belgian theme running throughout the organisation of this conference since its confirmation in Lausanne last year. From the amazing and creative mind of Anna Kanta, came the **Hercule Poirot** theme on social media and the ESSTS website.



AFRICA museum

The stunning modern conference venue alongside the **Royal Museum for Central Africa** shows the juxtaposition between old and modern which is typical of Belgian culture. We hope that you enjoy the quintessential Belgian aspects that have been incorporated for your interest and pleasure during the conference.



The Royal Museum for Central Africa (commonly known as **AfricaMuseum**) and the conference centre are ideally placed for people to stretch their legs on any number of walks or runs in the stunning Tervuren Park. As is tradition with a courageous group of ESSTS attendees the morning run tradition continues.



Much thought was put into the cultural features on offer such as reserving the **AfricaMuseum** for private access for the ESSTS conference attendees for an additional **2 hours** after its closing time (attendees who register for the social event will receive a complimentary ticket to visit the museum during the late opening slot).



For the social event dinner, conference attendees will decant to the **Africa Palace** in the grounds of the park, 500m from the conference venue. You will notice famous Belgian specialities have been included on the menu to enrich your cultural experience.



Another cultural event especially organised for ESSTS attendees is the theatre performance "*Permit, oh permit my soul to rebel*" by two Belgian performers, **Aline Breucker & Quintijn Ketels**, who are parents of a young boy with Tourette Syndrome.



Enjoy a **taster** of their theatre skills during the opening ceremony!



If you are not joining the social event-dinner, you may attend the performance in Brussels on **Thursday 8 June at 8:00 pm**.

Practical information & reservations:



You will notice on television screens in the coffee area outside the auditorium there will be films about Tourette Syndrome being played on a rolling loop throughout the conference. The films include ones made by the patient association **Iktic-Jetique** to highlight some of the challenges of living with TS.

As well as a film by **Peter Dekens** a Belgian photographer with tics who has been able to capture an intimate angle of having tics by photographing objects that show signs of wear from the constant repetition of tics.



We have been truly delighted by the **record-breaking attendance** and **abstract submissions** this year, as well as endorsements of the conference by the **International Parkinson and Movement Disorder Society (MDS)** and the **International Association for Child and Adolescent Psychiatry and Allied Professions (IACAPAP)**.



The conference is graced with the presence of the wonderful **Professor Mary Robertson** with us on her birthday the **7th of June** – also marked as **Tourette Syndrome awareness day**!



A final personal message of my thanks to the **ESSTS** board for putting their faith in me to be a co-host of the ESSTS conference this year, to **TTAG** for supplying continued support and to the irreplaceable Anna Kanta who is a powerhouse of organisation, passion, kindness and creativity, who we are all grateful to.

Have a wonderful conference!



Seonaid Anderson PhD

2023
ESSTS conference host



TTAG Board Member
and Founder



Iktic / Jetique – Board
Member and Secretary



Founder of
neuro-diverse.org

the organising committee

Our host & co-organiser

Seonaid Anderson



Board members 2020-2023

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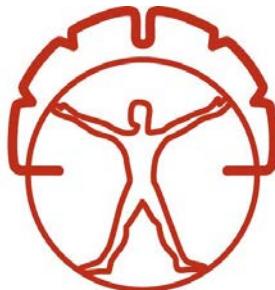
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ENDORSEMENTS

Thank you for your endorsement!



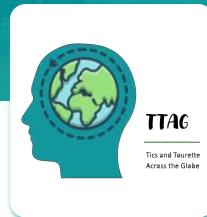
International Parkinson and
Movement Disorder Society



IACAPAP

International Association for Child and
Adolescent Psychiatry and Allied Professions

Tics and Tourette Across The Globe (TTAG)



2023
Brussels

TTAG is pleased to be a part of the 15th European Conference on Tourette Syndrome (TS) and Tic Disorders. We extend our gratitude to ESSTS for supporting people living with Tourette from countries worldwide and for supporting the **formation and registration of TTAG as an official association**. Our collaboration with ESSTS signifies an increasing trend of researchers, people with TS, and TS support associations coming together to discuss pressing issues that can improve the lives of those living with Tourette syndrome.

We are delighted to be welcomed by ESSTS in Brussels this year, and we hope to meet many of the researchers and clinicians present at the conference. All are welcome to our TTAG meeting, which is being held on **Wednesday, June 7th, from 1-5 pm**. It is also **TS awareness day**!

This year, we are excited to offer an interactive discussion panel of international speakers and representatives to discuss a crucial topic: **Support Associations and Patients' Rights: An International Perspective**.

You can view the TTAG meeting program here: essts.org/ttag

We would love for you to come and be part of the audience and add to this discussion.

This year, we are also privileged to have the **president of TTAG, Michele Dunlap**, address the main ESSTS conference on **Friday, June 9th, at 9 am** with a brief overview of the TTAG association, as well as an interactive vote on some of the issues discussed in the TTAG meeting's discussion panel. We also offer all researchers and clinicians at the conference the opportunity to take up **membership of TTAG**.

There will be a designated TTAG desk at the conference that you are welcome to visit. **Please interact with the board members of TTAG, who are present throughout the conference.** This year, we have included their names, titles, and photographs to make it easy for you to find them and catch up over coffee or similar.

We look forward to working and collaborating with researchers and clinicians worldwide to better support patients and their families affected by TS. Please support us and reach out to us with your ideas for collaboration.



info@ticsandtourette.org



<https://ticsandtourette.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.

TTAG BOARD MEMBERS



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TTAG Acting Treasurer
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Deutschland
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TTAG Secretary & Founder
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Mid Atlantic Chapter (TAAMAC)
Chair (2010-2015, 2019-2022)



Seonaid Anderson, Belgium
ESSTS 2023 conference host
TTAG Board Member & Founder
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Founder of Neuro-Diverse.org

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Olivier Bournat, France
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Gilles de la Tourette (AFSGT) - Treasurer

ORAL & POSTER PRESENTATIONS

Vote for "Best of"

Vote for best poster & best oral presentation!
The voting platform opens on **Friday 9 June** at **12:30** for Oral presentations and at **15:00** for Poster presentations.

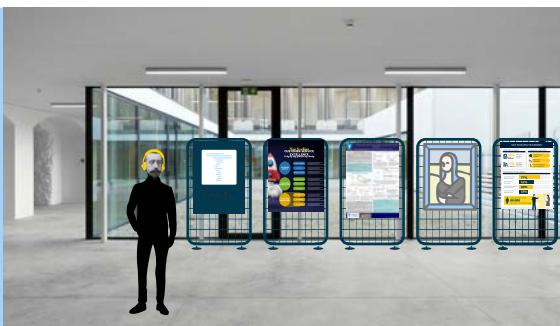


new feature

Listen to the T-playlist!

We are meeting at a museum after all, audio-guided tours are to be expected!

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



Board elections 2023



It's election year!

Active ESSTS Members for the calendar year 2023 will have the opportunity to exercise their voting rights.

This year, the voting will be held online; it will begin at 13:30 on 8 June 2023 during the general assembly at our upcoming meeting in Brussels.

ESSTS members will receive their unique voting link via email.

The voting platform will remain open for 24 hours to allow those ESSTS members not attending the conference to cast their vote as well.

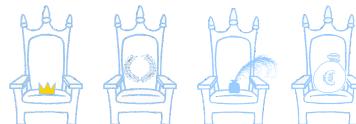
The results will be announced during the closing ceremony on 9 June 2023.

Online announcements will follow.

As per ESSTS Rules, each officer –including the immediate past chair– shall remain in office for a period of **3 years**.

The available board positions for 2023-2026 are: Chair, Vice-Chair, Secretary and Treasurer.

If you wish to vote, you may **renew your 2023 membership** until 12:00 on Thursday 8 June 2023.



[View candidates:](#)



[Become a member!](#)

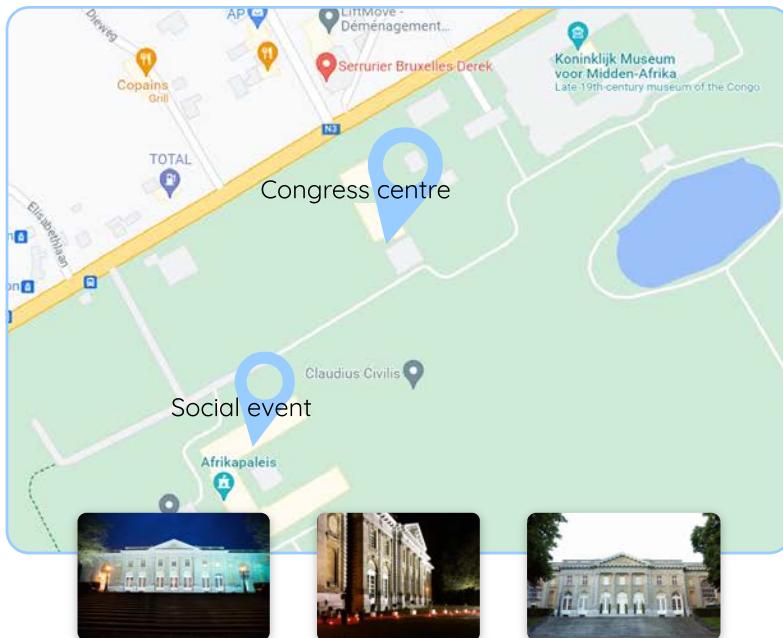


SOCIAL EVENT

Dinner at the Africa Palace

(adjacent to the congress centre & the AfricaMuseum)

Thursday, 8 June 2023, 20:00



AfricaMuseum private access

18:00-20:00

AFRICA
museum

We have reserved the museum for an additional 2 hours after its closing time.

Attendees who have registered for the social event above, will receive a complimentary ticket to visit the museum during the late opening slot.

THEATRE PRODUCTION

"Permit, oh permit my soul to rebel"

Theatre GC De Kriekelaar

If you are not attending the social event-dinner,
...this is a performance to consider!

Thursday, 8 June 2023, 20:00



An exciting and interesting performance, especially organised for ESSTS attendees, by **Aline Breucker & Quintijn Ketels** who are very kindly performing for us during the opening ceremony.

Aline and Quintijn conceived and directed this performance with the aim of making it accessible to audiences who need a **more relaxed environment**. They say...

"Our son Antoine, who is now 10, has a complex form of Tourette syndrome. So far, it hasn't been possible for him to watch our performances. Here in Flanders (northern Belgium), there is still an incredible amount of work to be done on inclusion.....and we want our son to be able to be part of an audience like everyone else. So we decided to take things in hand."



FUN TRADITIONS

Thursday, 8 June*

The morning run tradition continues...

07:00

Rastelli Hotel/Tervuren park



[View route:](#)



*Weather & participation permitting, we shall repeat the run on Friday 9 June.

...and so does the songwriting!



Courtesy of our Danish colleagues.



[View lyrics](#)





2023
Brussels

7-9 June 2023
Royal Museum for Central Africa

ESSTS
essts.org



BRUSSELS, 7-9 JUNE 2023 | CONFERENCE PROGRAMME

Wednesday 7 June 2023

Behavioural therapy workshops

13:00-17:00 (parallel sessions)



13:00-14:40

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

15:00-17:00

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

Focus area: Formulation and psychological intervention of tics in people with Autism

Trainers:

Tara Murphy
Zsanett Tarnok
Eve McAllister
Rebecca Akello

(Joining the advanced session via Zoom from Kampala, Uganda)



13:00-17:00

Workshop in **French**: Thérapies comportementales des tics et du syndrome Gilles de la Tourette

Trainers:

Virginie Czernecki
Velina Negovanska
Julie Moulin

13:00-17:00 (parallel session)

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



Programme

- Introduction to Tics and Tourette Across The Globe (TTAG)
(Mission-Vision-Values, Meet Our TTAG Board Of Directors, Organization Structure of TTAG, Introduction of TTAG Ambassador Program)
- Networking & Idea Exchange Coffee Break
- Words from ESSTS Current Chair
- Panel Discussion on Support Associations & patients' rights: an international perspective
- Tics and Tourette Across The Globe (TTAG) Closing Summary and thanks

18:00-19:00 (onwards)

Opening ceremony

I. Keynote lecture:

"Picking, pulling, and pinching: the role of habit and harm in TS"

Speaker:

[Carol Mathews](#)

II. Mary Robertson Award; winner & oral presentation

[Awarded by surprise guest...](#) 

III. Open-air apéritif at the AfricaMuseum terrace stage; getting together again!

Aline Breucker & Quintijn Ketels who have conceived and directed the performance "Permit, oh permit my soul to rebel" are very kindly performing a teaser for us during the opening ceremony.



Thursday 8 June 2023

09:00-09:15 Welcome message by our host & co-organiser

Genetics & imaging session

moderated by [Kirsten R. Müller-Vahl](#)

09:15-10:00 Update on genetics

[Carol Mathews](#)

10:00-10:30 Enhancing neuroimaging genetics through meta-analysis for Tourette syndrome (ENIGMA-TS)

[Peristera Paschou](#)

10:30-11:00

ePoster presentation:

“Brain morphological changes in patients with Tourette syndrome: a voxel- and surface-based morphometry multi-site study”

[Simon Schmitt](#)

Discussion

11:00-11:30 Coffee break



11:30-12:30 Clinical rounds

Session chair: [Tammy Hedderly](#)

12:30-13:30 Lunch break



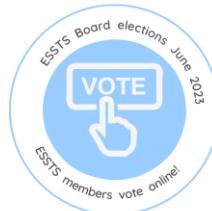
12:30-13:30 ENIGMA-TS session

(auditorium)

Organised by [Peristera Paschou](#)

13:30-14:00 General assembly

+ Board elections 2023; e-voting begins*!



*Active (2023) ESSTS members will be notified via email.

ASD sessions

moderated by [Tara Murphy](#)

14:00-14:45 Autism - past, present, and future

[William Mandy](#)

14:45-15:15

ePoster presentations:

- "Differential diagnosis of autism-spectrum-disorder in adults"
- "Evaluation of diagnostic instruments for Autism-spectrum-disorder in adults"

[Daniel Alvarez-Fischer](#)

Panel discussion

15:15-15:45 Coffee break



15:45-16:30

Poster rounds, session I

moderated by [Nanette Mol Debes](#)

16:30-18:00

Oral presentations of submitted abstracts, session I

moderated by [Natalia Szejko](#)

Vote for best poster & best oral presentation!

The voting platform opens on **Friday 9 June** at **12:30** for OPs and at **15:00** for PPs.



20:00

Social event-dinner at the Africa Place

(Adjacent to the conference venue)



Bonus: AfricaMuseum private access

We have reserved the museum for an additional 2 hours (18:00-20:00) after its closing time.

Attendees who have registered for the social event above, will receive a complimentary ticket to visit the museum during the late opening slot.

Friday 9 June 2023

09:00-09:15 Welcome address by Michele Dunlap, president of TTAG
([Tics and Tourette Across the Globe](#))

Pain & sex differences in TS session

[moderated by Kevin Black](#)

09:15-09:45 Pain in TS

[Seonaid Anderson](#)

09:45-10:15 Sex differences in TS

[Christelle Nilles](#)

[Natalia Szejko](#)

ePoster presentation:

“The Calgary and Paris Adult Tic Registry: Project description and initial analyses of sex differences in tic phenomenology”

[Christelle Nilles](#)

10:15-10:30 Panel discussion

10:30-11:00 Coffee break



11:00-12:30 Oral presentations of submitted abstracts, session II

[moderated by Andreas Hartmann](#)

Vote for best oral presentation!

💡 The voting platform opens at **12:30!**



12:30-13:30 Lunch break



13:30-14:15 Investigating the effects of median nerve stimulation on Tourette syndrome: clinical trial results

[Stephen Jackson](#)

[moderated by Andrea Cavanna](#)

14:15-15:00

Poster rounds, session II

moderated by Nanette Mol Debes

Vote for best poster presentation!

💡 The voting platform opens at **15:00!**



15:00-15:30 Coffee break



15:30-16:30 Best papers of 2022 on tics and TS



Kevin J. Black

moderated by Andreas Hartmann

16:30-17:00 Closing ceremony



-Best poster & best oral presentation awards

-New ESSTS Board; election results

-ESSTS Conference 2024 announcement; see you next year in... 😊

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Oral presentations of selected abstracts



Mary Robertson Award Winner 2023

O1. Localizing the neural substrates of premonitory urge in Tourette syndrome

Jade-Jocelyne Zouki¹, Daryl Efron^{2,3}, Valsamma Eapen⁴, Amanda Maxwell⁴, Daniel T. Corp^{1,5}, Timothy J. Silk^{1,3}

¹Centre for Social and Early Emotional Development and School of Psychology, Deakin University, Geelong VIC 3220, Australia,

²Department of Paediatrics, The University of Melbourne, Melbourne VIC 3010, Australia, ³Murdoch Children's Research Institute, Melbourne VIC 3052, Australia, ⁴Discipline of Psychiatry and Mental Health, UNSW School of Clinical Medicine, University of New South Wales, Kensington, NSW 2052, Australia, ⁵Center for Brain Circuit Therapeutics, Department of Neurology, Psychiatry, and Radiology, Brigham and Women's Hospital, Harvard Medical School, Boston, MA 02215, USA

Background:

The premonitory urge preceding tics is often described as the ‘core’ symptom of Tourette syndrome (TS). Like premonitory urge, many natural physiological behaviors are associated with an urge and may provide insight into the neural substrates of this sensory phenomenon in TS. Indeed, functional activity associated with the urge to micturate and swallow and the urge to tic in TS overlap in common brain regions (right insula and mid-cingulate cortex). However, it remains unclear whether the functional correlates of urges associated with natural physiological behaviors that are similar to common motor and vocal tics (blinking and coughing) also overlap with the urge to tic in TS. This study aimed to: 1) identify a neural network common to distinct physiological urges; and 2) identify convergence between this ‘urge network’ and a network we previously identified in TS using a novel network mapping method termed ‘coordinate network mapping’ (Zouki *et al.*, 2023, *Brain Commun.*).

Methods:

Systematic searches were used to identify functional neuroimaging studies (fMRI, PET, SPECT) reporting correlates of the urge associated with natural physiological behaviors (micturition, swallowing, blinking, coughing). Separate activation likelihood estimation (ALE) meta-analyses were used to localize neural networks associated with physiological urge in these four behaviors. These networks were then overlaid to demonstrate regions common to all (or most) behaviors, identifying an ‘urge network’. We then assessed the spatial convergence between structures of this urge network and the network we identified in TS to demonstrate regions which may underlie premonitory urge in TS.

Results:

Searches identified studies examining the functional correlates of the urge to micturate ($n=21$), swallow ($n=19$), blink ($n=6$), and cough ($n=9$). Using ALE, we identified an urge network underlying common yet distinct physiological urges. All four behaviors localized to the right insular cortex and left inferior frontal gyrus. Three of the four behaviors mapped to the bilateral precentral gyrus, left thalamus, and anterior cingulate cortex (ACC) (micturition, swallowing, coughing). Notably, all behaviors mapped to structures within the TS network, including the right insular cortex, left thalamus, and ACC.

Conclusions:

These results are consistent with previous neuroimaging findings highlighting the right insula and ACC as key structures in physiological and pathological urge. These regions are implicated in the mechanisms underlying bodily representations of the urge-for-action, while the thalamus may be more involved in the motor response to the urge. Our findings identify structures which may be associated with the urge preceding tics in TS. Future research examining the unique involvement of these regions in the genesis of tics and their differential modulation in response to behavioral therapies targeting the urge to tic will be valuable for understanding TS pathophysiology.

O2. First Results of a Randomized Controlled Trial to Compare CoPs and CBIT in Children and Adults: Another String to the Bow of Psychotherapy for Tics

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Background:

Clinical guidelines for tics recommend behavioural interventions as first-line treatments (Verdellen *et al.*, 2011; Andrén *et al.*, 2021). While studies show a significant decrease in tics for children and adults treated with psychotherapy, many patients were classified as non-responders (Cavanna *et al.*, 2013). The Cognitive-behavioural and Psychophysiological approach (CoPs) targets underlying processes rather than focusing on reversing the actual tic onset (O'Connor *et al.*, 2014). Previous studies have demonstrated that CoPs can significantly reduce tic frequency and maintain these improvements at follow-up (Leclerc *et al.*, 2016a, 2016b; O'Connor *et al.*, 2009, 2016). This treatment has also shown to improve performance on neurocognitive measures and sensorimotor processes following treatment (Lavoie *et al.*, 2011; Morand-Beaulieu *et al.*, 2018). Despite the efficiency of CoPs, a comparison with the current recommended cognitive-behavioural treatment is warranted. This study is the first randomized controlled trial to compare two cognitive-behavioural therapies across two age groups. The aim is to compare CoPs and CBIT in children and adults. We hypothesize that CoPs will show superior clinical improvements compared to CBIT.

Methods:

In this trial, 104 participants were randomized into treatment modalities: CoPs (n=53), 32 children/21 adults; CBIT (n=51), 32 children/19 adults. Participants meeting inclusion/exclusion criteria were assessed on a standardized tic scale (YGTSS) and global functioning assessment (CGAS, GAF). Participants were treated weekly by therapists trained in each modality, and blind evaluators assessed the outcome. The treatments were manualized and lasted 14 weeks post-randomization. Primary outcomes were measured at pre- and post-treatment with a six-month follow-up.

Results:

The baseline characteristics were similar between treatment groups in children and adults. The YGTSS scores significantly improved during the trial, as revealed by linear mixed model analyses ($F(2, 64.033) = 24.571, p < .001$), but no significant differences were observed between the treatment modalities ($F(1, 78.086) = 0.082, p = .776$). Participant age groups (children vs. adults) did not show a significant main effect ($F(1, 77.239) = 0.014, p = .905$). Results show a significant increase in global functioning during the trial ($F(2, 14.694) = 3.978, p = .042$), and individual analysis of each treatment modality shows only a significant increase for CoPs.

Conclusions:

Treatment effects are comparable across age groups with no differences across modalities in treatment refusal, dropout and treatment integrity. However, individual analysis of treatments shows a significant increase in global functioning for CoPs only. The CoPs approach, targeting underlying sensorimotor processes, is an effective treatment comparable to CBIT for reducing tics in children and adults, and its emphasis on the processes seems to improve overall functioning further.

O3. Effectiveness of Tackle your Tics, a brief, intensive group-based exposure therapy programme for children with tic disorders

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Background:

Behavioural treatment is the first-line treatment for tic disorders, but tic reduction and treatment availability remain relatively low. Patient associations emphasise the need for treatments that additionally improve children's tic-related coping skills and quality of life.

Methods:

Results will be presented of a randomised controlled trial (N=106, 2020-2022) studying the efficacy of *Tackle your Tics*, a four-day intensive group treatment for youth (9-17 years) with Tourette syndrome or chronic motor or vocal tic disorder. *Tackle Your Tics* offers exposure and response prevention treatment and supporting components, such as coping strategies workshops by experts-by-experience and active parent involvement. Assessments were performed pre- and posttreatment and at 3 and 6 months follow-up, to study the effects on tic severity (as measured with the Yale Global Tic Severity

Scale, our primary outcome measure), quality of life, tic-related cognitions, emotional/behavioural functioning, family functioning and treatment satisfaction.

Results and conclusions:

Outcomes directly post-treatment improved in both the treatment group (n=52) and waiting list (n=54), but showed no superior effect of Tackle your Tics compared to the waiting list. Importantly, on longer term this brief four-day group treatment was effective in improving tic-related impairment, quality of life and emotional/behavioural functioning. Moreover, at 6 months after the start of the brief treatment, 39% of the treated children were rated as responders in reduced tic severity.

O4. The effect of nabiximols on driving ability in adults with chronic tic disorders: Results of a substudy analysis of the doubled-blind, randomized, placebo-controlled CANNA-TICS trial

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Background:

Clear trends for the improvement of tics, depression and quality of life were found in a multicenter, randomized, double-blind, parallel-group, phase IIIb CANNA-TICS trial on adult patients with Gilles de la Tourette syndrome (TS) treated with the cannabis extract nabiximols versus placebo. It is however unclear whether treatment with nabiximols has an effect on driving ability of patients with TS and other chronic tic disorders. We hypothesized that treatment with nabiximols improves patients' "fitness to drive".

Methods: "Fitness to drive" was performed as a substudy of the CANNA-TICS trial conducted in two out of six study centers (Hannover, Munich) including N=64 patients. Using a computerized assessment at baseline and after 13 weeks of treatment with nabiximols or placebo, "fitness to drive" was assessed as a binary criterion according to the German Federal Highway Research Institute guidelines.

Results:

In the nabiximols group (N=43, male=33 (77%), mean age (SD)=38.0 (± 15) years), the number (%) of patients who were "fit to drive" increased from 24 (55.8%) at baseline to 28 (71.8%) at week 13. In contrast, in the placebo group (N=21, male=16 (76%), mean age (SD)=34.3 (± 11.1) years), these numbers decreased from 14 (66.7%) at baseline to 10 (52.6%) at week 13. The risk difference (nabiximols – placebo) was 0.17 (95% CI: -0.08; 0.43) in favor of nabiximols. Furthermore, patients with lower tic severity at baseline experienced greater benefit from nabiximols with respect to "fitness to drive".

Conclusion:

In line with our hypothesis, we could demonstrate non-inferiority of nabiximols over placebo regarding “fitness to drive”. In other words, treatment with the cannabis extract nabiximols does no impair driving ability in patients with TS, and even improves patients’ “fitness to drive”. This result is in line with data of the CANNA-TICS trial demonstrating beneficial effects of nabiximols on tics mainly in male patients with comorbid attention deficit/hyperactivity disorder (ADHD).

O5. A Functional Tics Psychoeducation Workshop and group follow up session for Parents and Carers

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Background:

There was an increase in Functional Tic Like Behaviours (FTLBS) over the course of the Covid 19 pandemic placing a significant strain on services and on the quality of life of affected young people and their families. Psychoeducation has been demonstrated to be an important component in managing functional neurological symptoms as part of a holistic management package. As a national specialist tics and neurodevelopmental movement service we aimed to develop a virtual psychoeducation workshop for parents of children with FTLBs to increase their awareness of the movements and to advise on management. In order to manage service constraints, a novel group follow up session was piloted to review the strategies that were implemented by families.

Method:

We ran two 3-hour workshops over the course of a year attended by a total of 22 parents. Outcomes were evaluated using a self-report 7 item likert scale measure designed to assess changes in several domains including knowledge of FTLBs and confidence in management. Qualitative feedback was also gathered in relation to the participant’s experience of the workshop. 16 parents completed the pre and post outcome measures. A month later a voluntary 1.5 hours virtual follow up session was offered to all carers that came to the second workshop which was attended by 3 families.

Results:

A Wilcoxon Signed Ranks Test showed that the functional tic psychoeducation workshop did elicit a statistically significant change in all seven factors measured by the questionnaire with the level of significance being within significance threshold ($p < 0.05$). Overall, there was an increased understanding of functional neurological movements and management strategies. There was also improved confidence reported in: helping young people with their symptoms, with liaising with school and with knowing where and when to ask for further information and help in relation to the functional symptoms. Although the follow up group session was not attended by many carers, qualitative feedback

obtained indicated that it offered a useful opportunity to share and consolidate some of the useful strategies discussed in the workshop.

Conclusion:

Given the increase in young people with Functional Tic Like Behaviours (FTLBS) and the demands that specialist services are having to face to offer interventions for this population, offering psychoeducation options in group format to families is a cost-effective option which is valued by families and which results in increased understanding of FTLBS and confidence in managing them. The longer-term influence and prognosis of our workshops is yet to be determined and we aim to evaluate this longitudinally. However, further research studies, including randomised controlled trials, will be needed in order to determine the true effectiveness of this type of intervention.

O6. Randomized controlled trial of supplementary motor area transcranial direct current stimulation in Tourette syndrome

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Background:

Transcranial direct current stimulation (tDCS) is a non-invasive method using small direct electrical currents to modulate cortical excitability. One sham-controlled study of 10 participants showed an improvement in tic impairment acutely following cathodal tDCS over the supplementary motor area (SMA). The purpose of the present study was to investigate effect of 5 sessions of cathodal tDCS over the SMA compared to sham stimulation on tic severity.

Methods:

A double-blind, randomized, sham-controlled trial was performed on participants with TS over the age of 16 with stable clinical status and medication regimen. The cathodal electrode was placed 1.8cm anterior to Cz according to the 10-20 electrode system, and 1mA direct current was delivered via constant-current stimulator. The intervention consisted of two 20-minute sham or tDCS periods per visit over five days, during which the participants were instructed to employ habit reversal training methods to suppress tics. Evaluations of tic severity were completed at baseline and on day 5 (visit 5) and one week after the final session (visit 6). Furthermore, questionnaires focusing on comorbidities (such ADHD and OCD) were performed at baseline and on visit 6. The primary endpoint was the total tic severity subscore of the Yale Global Tic Severity Scale (YGTSS-TTS).

Results and Conclusions:

22 participants were recruited to the study (11 treatment, 11 sham; 7 females; median age 25, range 17-61). There was a statistically significant reduction of YGTSS-TTS from visit 1 to visits 5 in both sham and treatment arms; this difference was larger in the

treatment arm (8.9, $p=0.004$) compared to the sham arm (5.9, $p=0.01$). This change was sustained 7 days after on visit 6 in the treatment arm (10.9, $p=0.003$), but not statistically significant in the sham arm (5.2, $p=0.059$). tDCS over the SMA may provide some benefit towards reducing tic severity in TS.

O7. fMRI-based neurofeedback of motor-related cortical regions as a new therapeutic strategy in tic disorders

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Background:

Tic disorders (TD) are neuropsychiatric disorders characterized by motor and/or vocal tics. Findings suggest that the cortico-striato-thalamo-cortical (CSTC) circuit plays an important role in the generation and execution of tics. The supplementary motor area (SMA), a key region within this circuit, is responsible for planning, initialization and execution of movements, and has been identified to be hyperactivated before tic onset in TD. A down-regulation of the SMA is thus expected to result in controlling the tics and lead to symptom reduction. Real-time fMRI neurofeedback (NF) is a promising and well-established technique in modification of dysregulated brain activities. Virtual environments (VE) broadened the scope of NF applications, recently. This study aims to investigate the effectiveness of real-time fMRI NF of the SMA in the treatment of patients with TD. The goal is to test if patients can gain control over the SMA and if this will result in an improvement of tic severity.

Methods:

Twenty-one participants (29.5 ± 8.2 y., 6 females) with TD were randomized to an experimental (EG) or control group (CG). The EG was given feedback from the SMA while the CG received feedback from a control region (cuneus). Participants underwent two days of NF training (3 runs each) with an interval of 1 week. Before the first day and after the second day of NF training, participants completed interviews and questionnaires for tic severity, quality of life and comorbidities. Functional T2*-weighted images of the BOLD contrast were acquired on a 3T Siemens Magnetom MRI scanner using a multi-band EPI sequence. Feedback is realized in gameplay in a first-person shooter VE. An in-house developed MATLAB-based NF toolbox was used to read real-time BOLD images, process the region of interest (ROI) signal and send it to the VE. Off-line data analysis was conducted with SPM12 software. After preprocessing, BOLD signal time courses of SMA ROI were estimated using MarsBaR toolbox v0.44. Percentage signal drift was calculated in relation to baseline block of each run.

Results and Conclusions:

ROI analysis revealed that participants in the EG showed a trend toward decreased SMA brain activity on day 1, particularly from run 2 to run 3 ($t(9)=1.83, p=0.0501$) and from day 1 to day 2. Participants in the CG showed no change in SMA activity. Based on a trend towards improvement in clinical measures of tic severity (ATQ) and quality of life (GTS-QOL), we expect to prove evidence of a significant statistical effect from the NF intervention, when more participants have been measured. NF may allow participants to develop conscious control over their SMA activity. This possibility is promising for TD, in which hyperactivity in the SMA has long been suspected to give rise to tic symptoms.

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O8. Mass Social Media-induced Illness presenting with Tourette-like behaviors: preliminary results from a follow-up study

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Background:

Starting in 2019, in Germany we identified an outbreak of mass social media-induced illness presenting with functional Tourette-like behaviours (MSMI-FTB). So far, the course of the disease and the effectiveness of therapies for MSMI-FTB is poorly understood. In this first longitudinal study on this population, we aim to collect information on the course of MSMI-FTB from patients' point of view to generate insights in mechanisms that could influence the course of MSMI-FTB. The baseline data of this sample (n=32) have been reported previously by Fremer et al. (2022) and had been collected between 5/2019 and 9/2021.

Methods:

As we are still collecting data for this long-term follow-up study, we present preliminary results obtained from semi-structured interviews with eleven participants (4 identifying as female, 5 as male, one as diverse and one as transgender; mean (age) = 20.5 years, SD (age) = 12.35 years) and/or their mothers who we contacted in a follow-up (mean = 862 days, SD = 77.5 days).

Results and Conclusions:

On a purely descriptive level, in our sample so far, three out of eleven participants reported a full remission of their symptoms, seven a significant improvement and one no change in comparison to baseline. Ten out of eleven patients received psychotherapy, nine of whom reported either a full remission or a significant improvement of their symptoms. Three out of the ten patients that received psychotherapy indicated that the psychotherapy included FTB-specific content. Four patients found psychotherapy helpful, three of whom received FTB-specific psychotherapy. Six patients reported that just knowing and understanding the diagnosis of MMSI-FTB and exclusion of the previously made diagnosis of Tourette Syndrome was already helpful in a way that it alone could have led to an improvement of symptoms.

The presented preliminary data suggest that the prognosis of patients previously diagnosed with MMSI-FTB is good. From the patients' perspective, psychotherapy as well as simply knowing the diagnosis and learning current psychopathological conceptualisations of its genesis during a brief psychoeducation could help reduce symptoms. Future studies should investigate which psychotherapeutic interventions lead to an improvement in symptoms in which subgroup of MMSI-FTB patients. Increasing our sample size will increase external validity of our results and allow new statistical analyses such as inferential statistical hypothesis testing that could generate valuable knowledge regarding factors influencing the course of MMSI-FTB, particularly the impact of psychotherapy.

O9. Symptom trajectories in functional tic-like behaviours: A prospective longitudinal cohort study

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Background:

From late 2020 to mid-2022 there was an unprecedented increase in clinical referrals for assessment and treatment of functional tic-like behaviours (FTLBs) in many countries. Very little is known about the long-term prognosis of patients with FTLBs. We previously performed a six-month follow-up study of the first 29 patients seen in our centre which suggested an overall favourable prognosis. In this study, we sought to characterize this clinical population, the trajectory of symptom severity over a twelve-month period, and confirm our previous findings in a larger sample of patients.

Methods:

Patients with FTLBs were included in our prospective longitudinal child and adult clinical tic disorder registries at the University of Calgary. Patients were clinically diagnosed with FTLBs by a movement disorders specialist and prospectively evaluated six and twelve months after their first clinical visit. Tic inventories and severity were measured with the Yale Global Tic Severity Scale (YGTSS), and the use of medications was recorded at each visit.

Results:

83 youth and adults with FTLBs participated in the child and adult clinical registries and were evaluated prospectively until February 2023. Mean age of participants was 18 years, with a range of 11 to 53 years. 95% of participants were female sex, and 16% identified as a gender minority. Comorbid conditions at the first clinical visit included ADHD in 35%, OCD in 7%, anxiety disorder in 65%, major depressive disorder in 42%, and autism in 4%. A history of tics in early childhood was present in 27%. Mean YGTSS Total Tic Severity Scores were high at the first clinical visit, with a mean score of 29.8 points (95%CI 27.6, 32.1). The most common tics in each category (simple motor, complex motor, simple vocal, complex vocal) at the first clinical visit were simple head jerks (86%), complex self-abusive behaviours (42%), simple whistling (30%), and complex words (54%). 55 participants were re-evaluated at 6 months and 30 participants were re-evaluated at 12 months. The number of tics on the YGTSS inventory significantly decreased at 6 months (raw mean difference 5.0, 95% CI 2.5, 7.5, $p=0.0001$) and at 12 months (raw mean difference 5.9, 95% CI 2.5, 9.3, $p=0.0004$) compared with the first clinical visit. The YGTSS total tic severity score decreased significantly from the first clinical visit to 6 months (raw mean difference 8.7 points, 95% CI 4.8, 12.6, $p<0.0001$), and from 6 to 12 months (raw mean difference 5.9 points, 95% CI 0.02, 11.8, $p=0.02$). Linear regression demonstrated that age was significantly associated with the Yale Global Tic Severity Score at initial evaluation (coefficient 1.1, $p=0.009$) and at 6 months (coefficient 2.1, $p=0.0001$), but not at 12 months (coefficient 2.1, $p=0.07$). SSRIs were the most common medication type used at each time point (ranging in use from 47 to 59% of participants) but use was not associated with tic severity. There was no association between comorbid conditions and tic severity at any time point.

Conclusions:

In keeping with earlier preliminary results, we observed a meaningful improvement in tic severity scores and a contraction in the tic repertoire in youth and adults with FTLBs over a period of 6 to 12 months. Long-term follow-up of this clinical population was challenging, with higher levels of attrition compared to our registry participants with Tourette syndrome.

O10. Integrated Cognitive Behavioural Intervention for Functional Tics (ICBiT): A Case Series

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Background:

The onset of Covid-19 pandemic saw a substantial rise in functional tic-like behaviours (FTLB). With the FTLB presentations on the rise, there is an urgent need for developing and testing effective interventions. These symptoms are historically difficult to treat with preliminary findings suggesting standard pharmacological treatments show no

benefit and the utility of Comprehensive Behavioural intervention for Tics (CBiT) is yet to be reported. While FTLBs share many common features with tic disorders, they also have unique biopsychosocial and pathophysiological underpinnings necessitating an integrated approach comprising biological, psychological and systemic interventions. In particular, the stress-arousal system is likely to play an important role both in precipitating and maintaining FTLBs. We present the clinical outcomes of 8 young people with FTLBs and propose an integrated cognitive behaviour intervention for tics (I-CBiT) that combines traditional tic exposure and response prevention with third wave cognitive behavioural acceptance models. The aim of the intervention is to increase the young person's acceptance of unwanted and aversive interoceptive sensations, in this case, the premonitory urge. They are then supported to generalise this learning to other sensations that the young person finds aversive or distressing, such as anxiety, anger or other physical symptoms.

Methods:

Eight female clients aged 13-20years with FTLBs received I-CBiT. The intervention has three phases namely, Phase 1: Psychoeducation and goal setting; Phase 2: Exposure and response prevention with urge acceptance and sensory grounding; Phase 3: Cognitive behavioral intervention targeting the stress-arousal system.

Results and Conclusions:

Following I-CBiT, all eight cases showed improvement in tic frequency. Pre-treatment all presented with tics every few seconds/minutes. Post-treatment 4 out of 8 had no tic symptoms or a mild tic once per month, two had a mild tic every few days or weeks, and only two presented with mild tics every few hours. Tic suppressibility increased, with 7 out of 8 young people able to suppress their tics for 1hour or more post-treatment. There was a significant reduction in Yale Global Tic Severity Rating Scale (YGTSS) total tic severity scores from baseline, $t(7) = 5.99, p < .001$ [$M_{pre} (SD) = 34.38 (10.72)$; $M_{post} (SD) = 8.75 (5.99)$] and a significant reduction in YGTSS impairment scores from baseline, $t(7) = 7.09, p < .001$ [$M_{pre} (SD) = 31.25 (12.46)$; $M_{post} (SD) = 0.00 (0.00)$]. All cases demonstrated an improvement in daily living function and mood.

Two possible mechanisms of change are suggested; one is improved self-efficacy through acceptance of uncontrollable urges together with an increase in perceived control of motor responses. The other is the development of beliefs that internal sensations are both safe and tolerable through graded exposure. Thus, this approach aims to promote acceptance of unwanted but uncontrollable interoceptive sensations such as tic urges, alongside associated thoughts and emotions. It is hypothesised that this learning is then generalised to other experiences that the individual finds aversive and distressing, including stress-arousal responses and other physical symptoms.

O11. Extra Movements in Healthy People: Challenging the Definition and Diagnostic Practice of Tic Disorders

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Background:

The occurrence of the extra-movements/vocalizations (i.e. motor/vocal tics) is the leading diagnostic criterion for tic disorders (TD). The critical question is whether the current diagnostically leading criterion for TD in DSM-5 is justified and clinically useful. To this end, we systematically assessed video recordings of a large group of participants with and without a diagnosed TD focusing on the frequency of EM.

Methods:

We examined N=127 individuals with a diagnosed TD according to DSM-5 criteria. N=129 participants reporting not to have tics in a thorough clinical interview and thus not fulfilling DSM-5 criteria for a TD were also included. In all individuals, extra movements and vocalizations were assessed on the basis of standardized video recordings following the protocol of the Modified Rush Videotape Rating Scale.

Results and Conclusions:

We show that a surplus of actions per se is not indicative of the presence of a diagnosed tic disorder, as we could not identify a clear number of extra-movements/vocalizations differentiating between individuals with and without this diagnosis. The rate of occurrence of such extra-movements/vocalizations in these two groups was largely overlapping. This questions the usefulness of current diagnostic criteria. Tic disorders are not sufficiently defined by a surplus of actions. Instead, a systematic focus on the characteristics of the extra-movements is required.

O12. Automated motor tic detection – a machine learning approach

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Background:

Video-based tic detection and scoring is useful to independently and objectively assess tic frequency and severity in patients with Tourette syndrome. In trained raters, inter-rater reliability is good. However, video ratings are time-consuming and cumbersome, particularly in large-scale studies. Therefore, we developed two machine learning algorithms for automatic tic detection.

Methods:

We used 64 videos of n=35 patients with Tourette syndrome. The data of six subjects (15 videos with ratings) were used as a validation set for hyperparameter optimization. For the binary classification task to distinguish between tic and no tic segments, two different supervised learning approaches were established. First, we manually extracted features based on landmarks, which served as input for a Random Forest classifier (Random Forest). Second, a fully automated deep learning approach was used, where regions of interest in video snippets were input to a convolutional neural network (deep neural network).

Results and Conclusions:

Tic detection F1 scores (and accuracy) were 82.0 % (88.4 %) in the Random Forest and 79.5% (88.5 %) in the deep neural network approach.

Machine learning algorithms for automatic tic detection based on video recordings are feasible and reliable and could thus become a valuable assessment tool, e.g., for objective tic measurements in clinical trials. Machine learning algorithms might also be useful for the differential diagnosis of tics.

O13. Symptom network analysis in 529 children and adolescents and 503 adults with a chronic tic disorder

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Background:

Chronic tic disorders (CTD) are multifaceted disorders characterized by multiple motor and/or vocal tics. They are often associated with complex tics including echo-, pali- and coprophenomena as well as psychiatric comorbidities such as attention deficit/hyperactivity disorder (ADHD) and obsessive-compulsive disorder (OCD).

Methods:

We used network and graph analyses to investigate how symptoms and comorbidities in CTD are associated in childhood / adolescence and adulthood. The main advantage of the network analysis over traditional ones is the possibility to uncover and characterize complex associations discovering the inter-relational structure of CTD pinpointing key symptoms as a main target for interventions. The sample included N=529 children and adolescents (4-17 years, female N = 108, 20.3%) and N = 503 adults (18-72 years, female N = 118, 24.3%). Data was extracted from medical records between the years 1995 and 2013 regarding: simple and complex motor and vocal tics, echopraxia, echolalia, palilalia, copropraxia, coprolalia, premonitory urges, suppressibility of tics, obsessions and compulsions (OCD), touching people, touching objects, hyperactivity, inattention, impulsivity (sub-components of ADHD), anxiety disorder, major

depression, substance use disorder, sleep disorder, self-injurious behaviour (SIB), and aggression against others.

Results:

Core symptom networks in young and adult patients with CTD included complex tics and tic-related phenomena such as echo-, pali-, and coprophenomena as well as touching people and objects. Core symptoms in childhood also included ADHD symptoms, while core symptoms in adults included symptoms of OCD instead. Interestingly, SIB did not play a core role in the young CTD network but became one of the central symptoms in adults with CDT. In addition, we found strong connections between complex motor and vocal tics, for example coprolalia and copropraxia as well as echolalia and echopraxia.

Conclusions:

Next to other complex tics, echo-, pali-, and coprophenomena can be regarded core symptoms of CTD. ADHD symptoms are closely related to CTD in childhood, whereas symptoms of OCD and SIB are closely associated with CTD in adults. Our results suggest that a differentiation between motor and vocal tics is somewhat arbitrary.

Poster presentations of selected abstracts

P1. Brain morphological changes in patients with Tourette syndrome: a voxel- and surface-based morphometry multi-site study

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Background:

Brain morphological imaging studies in Tourette syndrome (TS) mainly investigated grey matter volumes which have overall yielded mixed results. Brain folding parameters have rarely been explored. These cortical folding parameters could be a promising biomarker since the genesis of brain folding is more genetically influenced and TS is highly heritable. Additionally, brain folding markers are temporally more stable than biomarkers measuring grey matter volumes or cortical thickness increasing the validity of potential results. In this study, we would also like to address the issue that the quality of MRI scans may be worse in TS patients due to their tics, which has often not been considered in previous studies.

Methods:

We present a large sample of TS patients including data from four different studies (99 TS patients and 89 healthy controls). Using CAT12, we extracted grey matter volumes, cortical thickness and cortical complexity (based on fractal dimensions) from t1-weighted images. Weighted image quality ratings were calculated and compared across groups. We used a non-parametric TFCE-statistic (threshold free cluster enhancement) with $\alpha = 0.05$ and FWE (family-wise error correction) to analyse brain morphological differences between groups.

Results and Conclusions:

Average image quality was significantly poorer in TS patients compared to healthy controls. TS patients showed significant more cortical complexity in a vertex cluster ranging over the inferior parietal (65%), superior parietal (28%), postcentral (6%) and supramarginal cortex (1%) in the left hemisphere ($k=846$, $p=0.0016$, FWE-corrected). Groups did not differ significantly regarding grey matter volumes, cortical thickness and gyration.

All morphologically altered brain regions are part of the parietal lobe which plays a key role in the integration and interpretation of (somato)sensory information. This finding could help to understand the neurobiological basis of premonitory urges observed in TS patients. Interpretation of results from brain morphological studies in TS in general as well as in this study are discussed before the background of poorer image quality in scans obtained from TS patients.

P2. Differential diagnosis of autism-spectrum-disorder in adults

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Background:

Autism spectrum disorder (ASD) is a clinical condition defined by early onset and persistent impairments in social communication and the presence of restricted, repetitive, stereotyped behaviors and interests across multiple situations. ASD has historically been considered a childhood disorder, but it is, in fact, a severe, lifelong, pervasive neurodevelopmental disorder with a similar prevalence in children/adolescents and adults. Individuals with ASD may remain undiagnosed until adulthood; diagnosing ASD in adults, though, can be challenging, especially since the existing amount of evidence of diagnostics of ASD in adults is minimal. At the same time, ASD has a strong media presence leading to greater awareness but often inadequate understanding of the disorder among both laity and professionals.

Information on ASD in social media and textbooks is often incomplete, neglecting that many other disorders (e.g., developmental, mental, and behavioral disorders) are associated with symptoms similar to those in ASD. However, considering possible differential diagnoses is pivotal during the diagnostic process. The present study aimed to determine the ratio of confirmed ASD diagnoses vs. differential diagnoses in adults with suspected ASD presenting to a specialized ASD referral center.

Methods:

The inclusion criterion was patients with suspected or supposedly diagnosis of ASD from other institutions presenting to our center for validation or first diagnosing of ASD between 2017 and 2022. All included patients were thoroughly assessed according to the German S3-guidelines for diagnosing ASD according to the DSM-V criteria by an examiner experienced, certified, and trained in diagnosing ASD. The local ethics committee approved the study. A total of 357 patients were analyzed. Twenty-two were excluded from the study because they did not meet the inclusion criteria.

Results and Conclusions:

The cohort's mean age was 31.3 years (SD=11.2y, range 16-65). The age group 16 to 29 years was overrepresented (54.3%), resulting in a left-skewed age distribution. The cohort included 201 males (60.0%, 95% confidence interval (CI) 54.8-65.2%) and 134 females (40.0%, 95% CI 8.5-15.4%). 305 of the 335 patients (91%, (95% CI 88-94.1%) did not meet DSM-V criteria for ASD (ASD_{no}). ASD was confirmed in 26 individuals (7.8%, 95% CI 4.9-10.6%)(ASD_{yes}). In four individuals, the diagnosis could not be excluded with certainty (1.2%). The gender distribution among ASD patients was m:f = 2-3:1 (male 69.2%, 95% CI 51.5-86.9, female 30.8, 95% CI 13.0-48.5%). In the ASD_{no} group, major depressive disorder was diagnosed in 189 cases (62.0% vs. 30.8% in ASD_{yes}), AD(H)D in 126 (41.3% vs. 19.2% in ASD_{yes}), social phobia in 95 (31.1% vs. 0% in ASD_{yes}), avoidant personality disorders in 72 (23.6% vs. 0% in ASD_{yes}), agoraphobia with/without panic disorder in 50 cases (16.4% vs. 3.8% in ASD_{yes}), and obsessive-compulsive personality disorder in 50 (16.4% vs. 0% in ASD_{yes}).

We conclude that ASD in adults is suspected considerably to frequent, with major depressive disorder, ADHD, and personality disorders being the most relevant differential diagnoses. These data are particularly relevant from a patient management perspective.

P3. Evaluation of diagnostic instruments for Autism-spectrum-disorder in adults

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Background:

Autism spectrum disorder (ASD) is a clinical condition defined by early onset and persistent impairments in social communication and the presence of restricted, repetitive, stereotyped behaviors and interests across multiple situations. The prevalence of ASD is estimated at 0.62-0.7%. The diagnosis of ASD can only be made clinically and is challenging in many cases due to symptom overlap with many other disorders. Although many questionnaires and tests are available, their diagnostic value remains unclear. Clinicians lack good clinical tools for the diagnostic. We examined some of the most frequently used diagnostic tools in a sample of 335 subjects presenting in a specialized center to diagnose ASD in adults.

Methods:

The inclusion criteria of this retrospective chart analysis were presenting or being transferred to our center with the question of a suspected ASD between 2017 and 2022. All included patients had been thoroughly assessed according to the German S3-guidelines for diagnosing ASD according to the DSM-V criteria by an examiner experienced, certified, and trained in diagnosing ASD. The local ethics committee approved the study. We present the psychometric outcomes of the AQ and EQ self-assessment, reading-the-mind-in-the-eyes-test (RME), German prosody test, ADOS-2, module 4, and their relation with the final diagnosis. Finally, we compare the positive predictive value with a simple analysis of school report cards. To this end, we classified the descriptions of primary school report cards into three categories, namely 1= incompatible with, 2= not incompatible with, and 3= suggestive of an ASD. The interrater reliability was = Cohen's $\kappa = .875$ ($p = .00001$).

Results and Conclusions:

Of 335 subjects evaluated, 305 did not meet the DSM-V criteria for ASD (ASDno), whereas ASD was found in 26 individuals (ASDyes). Data on the AQ questionnaire were available from 250 individuals. The cut-off was proposed at >32 . The mean values were in the ASDyes group 28.4 and in the ASDno 33.8, resulting in a positive predictive value (PPV) of 4.0%. The EQ questionnaire was completed by 246 individuals. The cut-off value is < 30 . The mean values were 24.6 (ASDyes) and 21.1 (ASDno). The RME has no cut-off, and we used the value of 22/36 for calculation.

Values found were 19.9 in the ASDyes and 21.6 ASDno group (PPV=7.0%). The prosody test has no cut-off value. Values observed were 22.2 in the ASDyes and 22.73 in the ASDno group. The ADOS was performed in 303/335 subjects and differed significantly ($p < .001$) with a sensitivity of 56% and a specificity of 98.5% with a cut-off at 7 (7.32 ASDyes vs. 1.0 ASDno, PPV 77.8%). The best congruency in our sample was achieved by interpreting the school report cards (Cohen's $\kappa = .925$). Assessments based on school reports could be provided for 277 individuals (78.0%). In the ASDyes group, 17/26 report cards were available. Of those, two fell in category 1 (*incompatible with ASD*), two fell in category 2 (*not incompatible with ASD*), and 13 in category 3 (*suggestive for*). In contrast, for ASDno, we found 246 in category 1, 10 in category 2, and not even one in category 3. We conclude that self-assessment and other psychometric tests have no value in diagnosing ASD in adults. In turn, systematic observation of behavior, as in the ADOS, is the gold standard. We propose a simple analysis of school report cards as a valuable screening tool. It gives a good introspection into behavior during the first decade and is not influenced by biased memory effects or answers in self-assessment.

P4. The Calgary and Paris Adult Tic Registry: Project description and initial analyses of sex differences in tic phenomenology

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Background:

In adulthood, tic disorders are less common than in childhood, and sex distribution may be more even between males and females. There is comparatively less research on tic disorders and Tourette syndrome (TS) focused on adults. In this study, we sought 1) To present the objectives, design and methodology of the Calgary and Paris Adult Tic Registry (CAP Registry); 2) To assess tic frequency and tic phenomenology in adults with TS and 3) To investigate how sex influences tic phenomenology and comorbidity profile in this population.

Methods:

Adults with primary tic disorders have been prospectively included in the CAP Registry in Calgary (Canada) and in Paris (France). Participants are assessed during three visits over a one-year period (initially, at 6 months, and at 12 months). This registry aims to create a database of adults with tic disorders to meet various research objectives, including describing tic phenomenology in adults and characterizing the relationship between tic severity and tic-related impairment in women compared to men, evaluating the change in tic phenomenology over time, and standardizing screening methods for

mental health comorbidities in this population. This analysis describes data from participants from their first clinical visit, which took place between January 2021 to February 2023. We described tic frequency and phenomenology in French and Canadian participants, using the Yale Global Tic Severity Scale. We searched for differences between sexes in tic phenomenology, tic severity, tic-related impairment and in mental health comorbidities, using t-tests and logistic regressions.

Results:

A total of 164 adults with tic disorders were included (sex ratio 1.9 males:1 female; mean age: 32.9 years in French participants, 31.7 years in Canadian participants), of which 88% had TS. At first assessment, simple tics were the most frequent reported tics, among which eye blinking (56%), eye movements (51%), nose movements (32%), and throat clearing (35%) were most common. The most common complex motor tics were complex eye movements (19%). Coprolalia was found in only 9% of participants. In the Canadian subgroup, women had more complex motor tics, and greater tic-related impairment than men. The most common associated comorbidities were anxiety (51%) and mood disorders (36%), with a female predominance of anxiety and obsessive-compulsive disorders.

Conclusions:

Our study suggests that simple head/face tics and throat clearing are the most common tics in adults. The distribution of simple motor tics and phonic tics appears to be similar in adults to existing data in children, except for a few complex tics (e.g. tic-related compulsions seem less frequent in adults than in children). A more even sex ratio in the adult population than in the pediatric population suggests either that TS tends to persist longer in females for reasons to be determined, or that women consult more often than males because of greater tic-related impairment. In the future, the CAP Registry will continue exploring the questions of sex differences in tic presentation and outcome.

P5. Premonitory urge and tic severity, comorbidities, and quality of life in chronic tic disorders

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Background:

Tics have been found to be intimately associated with premonitory urges (PU) but knowledge about urges is still limited, with small sample sizes often limiting the generalizability of findings.

Methods:

N = 291 patients with a confirmed diagnosis of chronic primary tic disorder (age=18-65, 24% female) filled out an online survey assessing demographic data, comorbid conditions, location, quality, and intensity of PU, as well as quality of life. Every tic

was recorded, and whether the patient experienced a PU, the frequency, intensity, and quality of that urge.

Results and Conclusions:

PU and tic severity were significantly associated, and 85% of urge-related tics were followed by relief. A diagnosis of attention deficit/hyperactivity disorder (ADHD) or depression, female gender, and older age increased the likelihood of experiencing PU, while more obsessive compulsive (OCD) symptoms and younger age were associated with higher urge intensities. PU, complex vocal tics, ADHD, OCD, anxiety, and depression were related to lower quality of life. Motor and vocal, complex and simple tics did not differ regarding PU intensity, frequency, and quality, or relief.

The results shed light on the relationship between PU, tics, comorbidities, age, gender, and quality of life in tic disorders.

P6. Revision of the Rush Video-Based Tic Rating Scale

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Background:

To date, the Modified Rush Video-Based Tic Rating Scale (MRVS) is the most widely used video-based instrument for assessing tic severity in patients with Tourette syndrome (TS) and other chronic tic disorders. Nevertheless, various factors make it challenging to use the scale in a research context, even though video-based assessments are generally considered economical and objective options compared to more complex procedures. These limitations include a time-consuming recording procedure, unclear instructions and weak correlations with the Yale Global Tic Severity Scale (YGTSS), the gold standard instrument used for assessing tic severity. Therefore the study aimed to simplify and standardize the procedure and consequently improve correlation with the YGTSS by revising the MRVS (MRVS-R).

Methods:

We used 102 videos of patients with TS or chronic motor tic disorder filmed according to the MRVS. We compared the tic frequency assessed by MRVS with frequencies according to MRVS-R based on a 5- (instead of 10-) minutes video to investigate whether reducing the recording time leads to significant changes. In addition, we adapted the MRVS to the YGTSS and defined new anchor values for motor and phonic tic frequency based on frequency distributions as assessed in our sample. Finally, we compared the MRVS-R and MRVS regarding psychometric properties.

Results and Conclusions:

Halving the recording time did not result in significant differences. Psychometric properties of the MRVS-R were acceptable. Correlation between MRVS-R and YGTSS improved. Thus, the MRVS-R can be considered a standardized and economical scale with several significant improvements compared to the MRVS and, in this form, might be an additional, valuable instrument for tic assessment.

P7. Correlation of comorbidities and variability of tics in children with Tourette syndrome and chronic tic disorder

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Background:

Tourette syndrome (TS) and chronic tic disorder (CTD) are chronic neurodevelopmental disorders with onset in childhood. The disorders are characterized by the presence of motor and/or phonic tics, and is often accompanied by comorbidities, where obsessive compulsive disorder (OCD) and attention deficit hyperactivity disorder (ADHD) are the most predominant. The aim of this study was to investigate if a correlation between comorbidities and variability of tics exists in children with CTD or TS. Furthermore, the correlation between comorbidities and severity of tics was examined.

Methods:

A cross-sectional study was completed on a clinical cohort recruited from the Danish National Tourette Clinic. The cohort consisted of 167 children and adolescents who were examined Yale Global Tic Severity Scale (YGTSS), and data regarding comorbidity was collected on 152 of these patients. The patients were diagnosed with TS, CTD, OCD and/or ADHD using validated diagnostic instruments, and furthermore, divided into four comorbidity subgroups: CTD-only, CTD+ADHD, CTD+OCD and CTD+ADHD+OCD.

Results and Conclusions:

Presence of the examined comorbidities was statistically significantly associated with higher severity, impairment and total tic scores compared to patients with absence of comorbidities (p value = <0.001, 0.001, 0.003, respectively). The assessment of the association between variability of tics and comorbidities showed statistically significantly higher simple phonic tic scores in the CTD+OCD group compared to the CTD-only group (p value = 0.003).

To the best of our knowledge, this is the first study to show statistically significantly higher simple phonic tic scores in the CTD+OCD group compared to patients with absence of comorbidities. This finding suggest that professionals should be aware of the variability of tics in TS and CTD patients with comorbidities. Yet, there is a need for further studies to support this finding.

Furthermore, tic scores, severity of tics and impairment were found to be significantly different among the four comorbidity subgroups, with higher scores associated with comorbidities compared to the CTD-only group, which support findings from previous studies.

P8. What influence do persisting primitive reflexes have on the expression or triggering of tic disorders or Tourette?

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Background:

For more than 30 years we have seen many patients with tic disorders or Tourette's syndrome in our social psychiatric practice.

At the same time, we now routinely record the persistence of early childhood reflexes that influence affect, concentration, sensorimotor skills and motor development.

It is known that a high level of inner tension or an unstable emotional state contribute to the triggering of tics or lead to an increase in tics.

The question was whether working on persistent reflexes can contribute to an improvement in tic events.

Methods:

As part of the initial neurological examination, an approx. 2–3-minute screening for persistent reflexes is carried out after RIP®. ATNR, STNR, SG, TLR and MORO are recorded. The examination includes the general neurological examination and, in the case of a tic disorder, the recording and description of motor and vocal tics as well as special attention to hypersensitivity, stimulus openness in certain perception channels as well as additional examinations of the psychiatric status, cognition and concentration. Additional technical examinations include (age-adjusted) tests for cognition, the OPATUS CPTa and projective methods.

In the case of the persistence of early childhood reflexes, a neurophysiological exercise program is instructed, which is carried out by the client or together with partners or parents for 10-15 minutes a day.

Accompanying exercise instructions are coordinated at intervals of 4-6 weeks.

Medical checks take place every 3 months and record changes in the above parameters. If additional tic medication is required, a decision is then also made about dose adjustments, which necessitate a lowering of the dose if the stress and tic reduction is successful.

Results and Conclusions:

Parallel to the reduction in persistent reflexes, we usually also observe a reduction in the intensity of the tic and the level of suffering. Correspondingly, comorbidities such as disorders of social behavior and concentration decrease.

Medications can be avoided in milder cases or reduced in dose more quickly.

This relates to both specific tic medications and medications for comorbidities.

In addition to standard treatments such as HRT, psychomotor approaches are also effective in many cases and we recommend regular screening for persistence of early childhood reflexes at the beginning of tic treatment, which are more causal than behavioral and/or relaxation therapy approaches.

Further research is needed to provide a wider range of supportive therapy options.

Literature:

Meyers R, ADHD is curable, 2021, ISBN-13: 979-8404994049

Meyers R, Live or die – Persisting reflexes may cause emotional problems or ADHD - Volume 1, 2021, ISBN-13: 979-8583766956

P9. Microaggressions Experienced by Emerging Adults (16-25 years old) with Tourette Syndrome

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Background:

Microaggressions are brief, mostly unintentional, and commonplace daily indignities that communicate discriminatory slights and insults to marginalized groups. Between the ages of 16 and 25, emerging adults experience multiple changes that can affect their quality of life (e.g., starting college, having their first job, obtaining their driving license, experiencing new relationships). Emerging adults with Tourette Syndrome (TS) manifest motor and vocal tics, which put them at greater risk of experiencing discrimination since these tics are mostly visible. They may also experience additional challenges as a result of their tics, such as having to choose whether or not to disclose TS, explain what a tic is, or face the stigma of some colleagues or friends. Tic severity could also be related to the experience of microaggressions, since it has been shown that people with more severe tics are less socially accepted. Additionally, higher levels of experienced microaggressions by individuals with marginalized identities is inversely correlated with quality of life. The experience of microaggressions in emerging adults with TS could incidentally result in decreased quality of life. This study is the first to assess the experience of microaggressions in emerging adults with TS. The aims of this study are to evaluate: 1) the extent of microaggressions experienced by emerging adults with TS, 2) the association between tic severity and microaggressions, and 3) the association between microaggressions and quality of life in TS.

Methods:

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.

Results:

The vast majority of emerging adults with TS (94 %) has experienced at least one form of microaggression. Minimization ($M = 1.87$) and helplessness ($M = 1.36$) were the most experienced forms (e.g. 30 % of the participants mentioned that people express pity for them « frequently » to « very frequently »). Results show that tic severity (presence, frequency, intensity) is a significant predictor of perceived microaggressions ($p = .024$). Vocal tic severity is a greater predictor of perceived microaggressions ($p = .005$) but not motor tic severity ($p = .164$). Perceived microaggressions are a significant predictor of quality of life among participants ($p = .001$).

Conclusions:

Results are concordant with scientific literature concerning discrimination experienced by people living with TS. Indeed, adults with TS experience overt and covert discrimination in multiple dimensions of their life, which has an effect on their quality of life. Minimization of their needs and experiences can lead to significant education or work barriers in the beginning of these emerging adults' lives. Given the specific challenges faced by emerging adults with TS, is it essential to incorporate these findings into clinical practice to help reduce the effects of stigmatization.

P10. Cut-off values of Multidimensional Anxiety Scale for Children, Children's Depression Inventory and Conners Parent Assessment Report in Children with Tourette syndrome

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Background:

Psychiatric comorbidities such as attention-deficit hyperactivity disorder (ADHD), obsessive-compulsive disorder, depression and anxiety frequently co-exist in children with Tourette syndrome and chronic tic disorders. It is therefore crucial to screen for these comorbid conditions. Several instruments have been developed for this purpose, but it is not clear whether the proposed cut-offs for the general population are the same for patients with tic disorders who represent a more vulnerable and neurodiverse subgroup. The aim of our study was to evaluate whether proposed cut-off values used for assessment of anxiety, depression and ADHD in the general pediatric population are valid also in children with tic disorders.

Methods:

We have conducted a Receiver Operating Characteristic (ROC) Curve Analysis for three established instruments used for screening of anxiety, depression and ADHD in children - the Multidimensional Anxiety Scale for Children 2nd edition (MASC2), the Children's Depression Inventory 2nd edition (CDI2) and the Conners 3 Parent Report (Conners3) in a cohort of children with tic disorders from the Child Tic Registry of the University of Calgary. We have also complemented our analysis with a detailed report of sensitivity and specificity in order to select the best cutpoint for screening purposes in this population. We have used in our analysis total/global index T-scores for the aforementioned instruments.

Results and Conclusions:

We included 308 children with a confirmed tic disorder diagnosis, mean age 11.25+/- 4.95, 93 females. 228 of participants provided their responses to CDI2, 246 to MASC2 and 161 for Conners3. The results of the ROC analysis showed that ROC area for CDI was 0.89 (SE 0.03, 95% 0.84-0.95) and the empirical optimal cutpoint was 74.5 (sensitivity 0.79, specificity 0.88). For the MASC2, ROC area was 0.81 (SE 0.03, 95%

CI 0.75-0.86) and the empirical optimal cutpoint was 58.5 (sensitivity 0.8, specificity 0.7). Finally, ROC are for Conners3 was 0.84 (SE 0.03, 95% CI 0.78-0.91) and the empirical optimal cutpoint was 66.5 (sensitivity 0.78, specificity 0.8). Detailed sensitivity and specificity analysis aiming at selecting a more sensitive cutpoint with still acceptable specificity yielded the following desirable cutpoints: 64 for CDI2 (91.67% sensitivity, 71.08% specificity), 59 for MASC2 (80% sensitivity, 70.5% specificity), and 66 for Conners3 (81.48% sensitivity, 72.05% specificity). While in the general population a cut-point T-score of 70 is used to identify very elevated symptoms, the recommended cut-offs for anxiety, depression and ADHD in children with tics are lower, suggesting that screening tools for psychiatric symptoms should be adapted for this group of patients.

P11. Non-just-right experiences are more closely related to OCD than tics in Tourette patients

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Background:

Most adult patients diagnosed with Tourette syndrome report to perceive premonitory urges before tics occur. Likewise, patients with obsessive-compulsive behavior or disorder (OCB/OCD) report non-just-right experiences before performing corresponding behavior. OCB/OCD is known to be a frequent comorbidity to Tourette syndrome. Some not-just-right experiences have been associated to premonitory urges. Our aim is to assess whether non-just-right experiences (NJRE) are more closely related to tics and tic-associated premonitory urges or whether they are more closely associated with OCB/OCD.

Methods:

We assessed N = 111 patients at the Tourette specialty clinic at the Hannover Medical School (mean age = 34.77 +/- 12.93; N = 37 female) with a confirmed diagnosis of Tourette syndrome. They completed the premonitory urges for tic disorders scale (PUTS), the revised non-just-right experiences scale, and questionnaires regarding their tic severity, and comorbid OCB/OCD. A multi-trait-multi-methods matrix was calculated to examine associations amongst scales measuring tic-related and OCB-related phenomena.

Results and Conclusions:

The premonitory urges measured with PUTS correlated overall higher with tic questionnaires than with OCD/OCB questionnaires. NJRE correlated higher with OCB than with tic severity. These results indicate that even though some Tourette syndrome patients report NJRE, these are more closely associated with comorbid OCB/OCD than with tics.

P12. Somatosensory temporal discrimination in adolescents with Tourette Syndrome: a pilot study

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Background:

Temporal discrimination is the ability to determine that two sequential sensory stimuli are separated in time. For any individual, the somatosensory temporal discrimination threshold (STDT) is the minimum interval at which paired sequential stimuli are perceived as being asynchronous; this can be assessed, with high test-retest and inter-rater reliability, using a simple psychophysical test. Temporal discrimination is disordered in a number of basal ganglia diseases reported in adulthood. In Tourette syndrome (TS) an altered dopamine release in the meso-cortical and/or meso-striatal and an altered connectivity between prefrontal cortex and sub-cortical structures was reported as well. Thus, based on these assumptions, our aim was to investigate whether the somatosensory temporal discrimination threshold (STDT), or automatic time processing, is additionally altered in TS pediatric patients.

Methods:

We enrolled 11 TS subjects and 11 age-matched healthy controls (age range 12-18 years old, mean 14 years old; M: F=4:1). TS participants were selected with tic severity scoring from moderate to severe at the Yale Global Tic Severity Scale at the time of enrollment and any cognitive impairment at the Wechsler scales. Five patients were TS-only while 6 presented a TS-plus phenotype with further comorbidities (1 ASD; 2 ADHD; 3 OCD). The STDT was tested three times on the index finger of both hands, with a stimulus duration of 0.2 msec, and an intensity of 1 mA above the somatosensory threshold.

Results and Conclusions:

The TS group did not significantly differ from the control group (CG) in the STDT scoring (TS mean 93 msec; range 33,3-120 msec vs CG mean 76 msec; range 53,3- 93 msec) but towards the TS group a different trend of performance was observed among the TS-only (mean 70 msec; range 33,3 - 83,3 msec) and TS-plus subjects (mean 100 msec; range 86,7 -120 msec).

Although these preliminary findings seem to contradict the hypothesis of an altered somatosensory temporal discrimination threshold in Tourette pediatric patients, of relevance seems to be the different trend among TS-plus and TS-only subjects in STDT performance. Indeed, in TS-plus the STDT was more compromised, as reported also in the comorbid conditions only (i.e., ADHD/OCD), linked with the dysfunctional connectivity between basal ganglia and prefrontal cortex and altered dopaminergic transmissions. Instead, the improvement of time processing in children with TS-only was previously reported in literature and hypothesized consistent with an enhancement in the 'cognitively controlled' timing system, probably facilitated by the constant mechanism of the effortful tic suppression.

P13. Free or not free? – this is the question. Control over tics and free will in patients with Gilles de la Tourette syndrome

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Background:

Although, by definition, tics are characterized by involuntariness, one of the most typical features is the presence of some degree of control and suppressibility. However, both attributes are highly variable. In our study, we wanted to investigate whether patients with Gilles de la Tourette syndrome (GTS) change their basic convictions regarding the freedom of their own will and control over their tics after a comprehensive behavioural intervention (CBIT). As we are still in the process of data collection, we are currently presenting the baseline data on a descriptive level.

Methods:

Our sample consisted of 69 adults with GTS. We used the Symptomatology And Perceived Free will rating Scale that was developed, *inter alia*, for patients with GTS (SAPF, van der Salm, 2017) which was translated by a translator into German. The items of this questionnaire measure general appreciation about the existence of the free will, control over tics, the ego-syntonic appreciation of tics, suppressibility, interpretation of tics as disease, notion of decision over tics' performance, sensation of responsibility for tics, influence of tics on the personal freedom and the ability to perform voluntary actions that are not compatible with tics. Some elements were rated on a dichotomous scale (yes/no) and agreement with certain statements were measured using a visual analogue scale (VAS) ranging from 1-100 with higher numbers presenting a higher degree of approval.

Results and Conclusions:

We included 65 adults with GTS in our study. 59 GTS patients (91%) rated their tics as involuntary which corresponded to an average value of 85.73 in the VAS (18.86). 55 participants (85%) described their tics as being part of the disease that they cannot control. The participants rated on average 40 in VAS that their tics arrive unexpectedly (SD 31.81). When asked about the sensation of belonging of their tics to their personality, they rated on the VAS scale on average as 56.03 (SD 34.4). The ability of tic suppression was rated as 41.7 (SD 23.51), while control over tics as 38.75 (SD 21.9). 50 (77%) of participants tried to camouflage their tics with voluntary actions. The degree of voluntariness was rated on average as 9.67 (SD 14.91). The degree of purposefulness was estimated to be 18.11 (SD 25.34) in VAS and average degree of decisiveness as 20.98 (SD 22.74). 14 participants (22%) estimated that they could prevent their tics from happening and average degree of responsibility for tics was evaluated to be 23.22 (SD 22.4). When asked about the influence of tics on personal freedom, it was rated as being 42.94 (SD 33.67) on average.

It can therefore be concluded that patients' perception of tics stays mainly in line with their involuntary nature and our findings largely stay in line with the study by van der Salm et al. (2017). If convictions of patients can be influenced by CBIT, this psychological intervention might be a powerful tool that could decrease the experience of shame in GTS patients which could potentially increase their functional levels and

decrease comorbid depressive symptoms. Additionally, these results suggest that previously described features such as suppressibility is highly variable.

P14. Managing functional tic like Behaviours: the development of an advice sheet for use in schools

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Background:

There has been an increase in the occurrence of sudden onset functional tic-like behaviours (FTLBs) in adolescents during the COVID-19 pandemic, which has had a significant impact on the affected individual's ability to engage with education. There is a pressing need for health and education services to work together and share information regarding how to support young people with the unmet needs. Our aim was to generate a resource for professionals working in schools to support young people with FTLBs within this setting. Case examples are presented highlighting the importance and impact of these strategies. We highlight a need for further evaluation of the effectiveness of this advice sheet in collaboration with the schools and families.

Methods:

Ten young people with FTLBs attending our clinic were reviewed to determine which strategies had been trialed to support the young people with their symptoms and plans to increase their access to education. An advice sheet for schools was then produced based on a literature review and the information gathered from these young people and schools.

Results:

The most common strategies implemented by schools in our case studies were reducing attention around FTLBs, supporting the young person with their own identified helpful techniques/ management strategies, offering access to student support and adopting exam flexibility or accommodations, such as extra time and rest breaks. Six out of the ten children reported a reduction in FTLBs and all of them reported an improvement in the time and quality of access to education.

Conclusions:

The advice sheet developed by the TANDEM service and our collaborators aims to consolidate the most effective management strategies trialed by the schools of our service users and gives advice on how to determine which strategies might be most impactful. Our initial consultations suggest a potential positive impact of using these strategies within school to improve access to education and possibly reduce symptoms. This highlights that, if young people are well supported, they can manage within school despite FTLBs. The advice sheet has limitations as it has not yet been through a

rigorous evaluation process and, therefore, these preliminary, anecdotal findings must be treated with caution. Additionally, we are not able to claim correlation between the use of these management strategies in school and any symptom improvement as many of the young people have undergone other interventions as part of a recommended holistic care package. A more rigorous evaluation process is planned as the next step in our process and the publication of this leaflet should enable this process. There is a clear need to gain school and patient feedback to assess the accessibility, feasibility and effectiveness of the advice given.

P15. Tic Surf School Pilot: An Urge Acceptance Behavioral Intervention

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Background:

Behavioral interventions for tics are considered a first-line treatment for tic disorders. There is growing interest in incorporating newer, third-wave, cognitive behavioral interventions. Preliminary evidence suggests that urge-acceptance models may significantly reduce premonitory urge intensity and frequency, particularly when combined with traditional behavioral interventions. We aimed to pilot a group intervention (Tic Surf School) integrating an urge-acceptance model with a traditional exposure and response prevention (ERP) technique to increase acceptance of urges and perceived control over tics, with the intention of improving overall mental wellbeing. Tic suppressibility, perceived control, and parent outcomes were evaluated.

Methods:

Six children aged 9-12 years (M:F=5:1) diagnosed with a tic disorder participated in a 10-week group intervention for tics. Concurrent parent psychoeducation sessions were run in the first three weeks. Treatment components included: psychoeducation, urge awareness training, ERP with urge acceptance, sensory grounding strategies, and cognitive diffusion. During ERP sessions, participants imagined the premonitory urge as a ‘wave’ they would learn to surf. To help participants surf the ‘urge wave’ they were taught different ‘surfboards’, consisting of different sensory grounding strategies. Participants were encouraged to use the surfboards when they reached the top of the urge wave to alleviate the urge to tic. As their ability to suppress their tics increased, they were encouraged to drop the surfboards and move towards an acceptance of internal urges.

Results:

Participants reported that the intervention was helpful, with an average satisfaction rating of 89/100 points, demonstrating the acceptability and feasibility of the intervention. We identified significant increases in tic suppressibility, $t(5) = -4.24, p = .008$ [$M_{pre} (SD) = 13.99 (15.42)$; $M_{post} (SD) = 765.00 (433.92)$] and perceived control over tics, $t(5) = -7.36, p < .001$ [$M_{pre} (SD) = 23.33 (16.02)$; $M_{post} (SD) = 58.83 (19.14)$].

There was a *trend* towards a reduction in self-reported impairment as indicated by the Yale Global Tic Severity Rating Scale (YGTSS), $t(4) = 2.45, p = .070$ [$M_{pre} (SD) = 20.00 (7.07)$; $M_{post} (SD) = 14.00 (11.40)$]. Further, parents reported a significant reduction in self-reported worry, $t(5) = 2.97, p = .031$ [$M_{pre} (SD) = 80.83 (15.63)$; $M_{post} (SD) = 47.50 (32.52)$]. However, tic severity, as indicated by self/clinician rated YGTSS did not significantly reduce post-treatment.

Conclusions:

Our findings support the efficacy of the Tic Surf School as a behavioral treatment for tics. This pilot provides a proof of concept that increased perceived control over tics may significantly improve self-efficacy, and therefore overall mental wellbeing. While tic severity did not significantly reduce post-treatment, significant increases in perceived control and a *trend* towards reduced impairment were observed. These findings suggest that acceptance of the uncontrollable premonitory urges alongside increased perceived control over tics may result in improved mental well-being.

P16. Changes in tic suppression ability and urge intensity over a 10 week habit reversal training in adult patients with Tourette syndrome

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Background:

The urge to tic has been increasingly recognized as an important factor in the maintenance of tics in patients with chronic tic disorders or Tourette syndrome. Habit Reversal Training (HRT) is a behavioral technique that can reduce tics, but therapeutic mechanisms are still relatively unclear.

Methods:

In this study, $N = 21$ patients (mean age = 35.95; $N = 2$ female) received 10 weeks of HRT. Before and after each therapy session, patients were asked to report their urge to tic using the real-time urge monitor during 5 minutes of free ticcing and 5 minutes of tic suppression. Here, we present preliminary data of 11 patients (mean age = 35.95; $N = 0$ female) who have finished their course of therapy.

Repeated measures ANOVAs showed that tics were significantly reduced after each therapeutic session compared to before [$F(1,9) = 13.35, p = .005$, $\eta^2 = .60$], tics reduced when they were suppressed [$F(1,9) = 10.26, p = .011$, $\eta^2 = .53$], and tics subsided across sessions [$F(9,81) = 1.98, p = .052$, $\eta^2 = .18$]. No interactions were significant.

Regarding the urge to tic, there was a significant decrease across sessions [$F(9,63) = 2.95, p = .005$, $\eta^2 = .30$], a significant interaction between suppression condition and before/after therapy session [$F(1,7) = 13.94, p = .007$, $\eta^2 = .67$] showed that urge intensity during tic suppression was significantly ameliorated after therapy sessions as compared to before [$t(10) = 3.75, p = .005$, $d = 1.19$]. A significant interaction between tic suppression and therapy session [$F(9,63) = 2.72, p = .010$, $\eta^2 = .28$] showed that

the urge intensity during tic suppression was significantly lower towards the end of therapy (sessions 8-10) than in the first session [$t(7) = 2.95$, $p = .011$, $d = 1.04$]. In Support, a significant decrease in the YGTSS score before and after therapy [Mean pre = 29.7 ± 4.3 , mean post = 13.6 ± 7.6 ; $t(9) = 6.05$; $p < 0.001$] was found.

Results and Conclusions:

Our preliminary data suggest that tics subside across a 10-week HRT training, and that there is a decrease in subjectively experienced urge intensity during tic suppression due to each therapy session and therapy sessions across time. It is possible that patients learn new tools to control their tics during HRT that make tic suppression less uncomfortable.

P17. Online - open ended training group "Parents Living Well with Tics": A retrospective study

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Background:

Parents of children and adolescents with chronic tic disorders (CTD) frequently lack knowledge on CTD. They also suffer from increased caregiver burden and high levels of parenting stress. It is clinically well known that children's well-being regarding living with CTD is tremendously affected by their parents' functioning and perceptions. Nonetheless, the impact of parents' CTD related perceptions and well-being on patients is understudied. Additionally, parental training was not assessed in clinical guidelines and no recommendation regarding its use has been made. We have developed an online- open ended training group: "Parents living well with tics". This retrospective study evaluated the feasibility of this new intervention.

Methods:

Participants were parents of children and adolescents (age range 6-17) diagnosed with CTD (n=39). Pre and post participation questionnaires were administered: Yale Global Tic Severity Scale (YGTSS); Clinical global impression (CGI); The Child Tourette Syndrome Impairment Scale (CTIM); The Beliefs About Tics Scale (BATS); strength and difficulties questionnaire (SDQ). Brief Mental Health Outcome Measure (Parental well-being); Perceived stress scale adult self-rating (PSS-C); satisfaction from intervention and change in attitudes and knowledge about tics.

Results:

Out of the 39 parents enrolled, 28 attended the group and completed post intervention questionnaires. No significant differences were found between attendees (N=28) and drop outs (n=11). According to the pre-intervention clinical characteristics, parents mean age was 44.31 ± 5.2 with 92.3% (n=36) females, children's mean age was 10.37 ± 2.37 with 66.7% males (n=26). Mean tics' age of onset was 6.41 ± 2.47 with 28.2% (n=11) of patients with mild tics, 35.9% (n=14) with moderate severity of tics and 35.9% (n=14) of patients with marked to very severe tics. Major comorbid past diagnoses were ADHD - 46.2% (n=18), anxiety - 46.2% (n=18), behavioral difficulties - 17.9% (n=7), and OCD

- 15.4% (n=6). Parents attended at least one session (Range, 1-14), and mean attendance rate was 7.29 ± 2.62 . Pre-post analyses tests revealed that tic related impairment (YGTSS) significantly decreased after intervention (28.21 ± 13.07 vs. 18.93 ± 13.97 $t_{28}=2.45$ $p<0.05$). However, tic severity (YGTSS) and comorbid severity (SDQ) of patients did not differ before and after intervention (19.50 ± 11.93 vs. 17.57 ± 10.08 ; $t_{28}=0.83$, $p = 0.41$; 14.61 ± 7.83 vs. 15 ± 7.98 , $t_{28}=-0.44$, $p = 0.66$ respectively). Post intervention, 82% (n=23) of parents reported gaining new knowledge on tic disorders and 72% (n=20) reported attitudes changed. Finally, 89% (n=25) of parents reported high satisfaction from the intervention and 96% (n=27) will highly recommend it to a fellow parent.

Conclusions:

These preliminary results of the retrospective study show both the necessity and the feasibility of the newly developed online-open ended training group: "Parents living well with tics". Further prospective randomized controlled study is needed in order to evaluate its efficacy.

P18. Efficacy, Safety and Tolerability of Ecopipam in Tourette Syndrome with Psychiatric Comorbidities

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Background:

TS has a high frequency of psychiatric comorbidities which may be confounded by TS medications. Conversely, alpha-2 agonists may be more effective in TS patients with co-existing ADHD. Ecopipam is a first-in-class selective dopamine-1 receptor antagonist in clinical development for patients with TS. The recent Phase 2b D1AMOND trial of 153 children and adolescents from 6 to 18 years of age demonstrated a significant ($p=0.011$, LS mean [SE] difference: $-3.4 [1.4]$, 95% CI: -6.1 , -0.8) improvement in the Yale Global Tic Severity Score-Total Tic Score (YGTSS-TTS) without the weight gain, metabolic, or movement disorders associated with dopamine-2 antagonists. This work sought to determine if the efficacy and safety of ecopipam was similar in subjects with and without psychiatric comorbidities.

Methods:

Patients with TS were randomized 1:1 to ecopipam or placebo for a 4-week titration period, an 8-week maintenance period, and a 1-week taper period. The primary endpoint was mean change from Baseline (BL) to Week 12 for the YGTSS-TTS. The coexistence of OCD, ADHD and ANX were determined by the investigator at screening/BL from history. Adverse events as well as scales assessing ADHD, ANX, and OCD were collected at BL and all subsequent visits. The effect size on YGTSS-TTS was compared with subjects diagnosed with ADHD, ANX, and OCD both singly and those with multiple diagnoses in a post-hoc assessment. On study scales were also assessed for shifts in outcomes associated with ecopipam.

Results:

153 patients were randomized, and 149 were included in the modified intent-to-treat population (74 ecopipam, 75 placebo). Multiple comorbidities were frequent.

Participant subset	Number of Subjects	Drug-Placebo Difference in YGTS-TTS ¹	Lower Confidence Limit	Upper Confidence Limit
Total Population	149	-3.44	-6.1	-0.8
With ADHD	68	-4.40	-8.76	-0.03
Without ADHD	81	-2.18	-5.59	1.23
With ANX	51	-4.15	-8.56	0.26
Without ANX	98	-3.41	-6.96	0.14
With OCD	26	-7.84	-17.86	2.19
Without OCD	123	-3.42	-6.38	-0.46
With any ADHD, ANX or OCD	93	-3.88	-7.23	-0.52
Without any ADHD, ANX or OCD	56	-2.66	-7.49	2.17

¹Ecopipam - Placebo YGTS-TTS at end of study (Week 12).

Scales of ADHD, ANX, and OCD showed no shift by comorbidity subgroups over the 12-week study. No metabolic or movement disorders were seen in any participant.

Mean weight increase in the ecopipam group was 2.1 kg and in the placebo group was 2.5kg.

Conclusion:

Ecopipam reduces total motor and phonic tics among children and adolescents with TS. Although not powered for the subgroups, ecopipam shows strong trends for efficacy in patients with the psychiatric comorbidities of ADHD, ANX, and OCD with a safety profile similar to those without.

P19. Design of a Phase 3 Maintenance-of-Effect Trial of Ecopipam in Tourette Syndrome

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Background:

Ecopipam is a selective dopamine 1 receptor antagonist in development for TS. A 12-week, parallel group, Phase 2b trial of ecopipam in TS demonstrated a clinically meaningful, statistically significant reduction in tics without inducing weight gain, metabolic syndrome, EKG changes, or drug-induced movement disorders associated with dopamine 2 receptor antagonists. Ideally, a Phase 3 trial should both confirm efficacy and observe safety over a longer duration of exposure.

Design/Methods:

We designed an enriched-enrolment, randomized withdrawal (EERW) clinical trial to best meet maintenance-of-efficacy and safety objectives. All enrolled subjects receive ecopipam for 12 weeks. Those with a $\geq 25\%$ improvement in the Yale Global Tic Severity Scale-Total Tic Score (YGTSS-TTS) at both weeks 8 and 12 are randomized, double-blinded, 1:1 to continue ecopipam or down-titrate to placebo, for an additional 12 weeks. The primary maintenance-of-effect endpoint is time-to-relapse where relapse is defined as 1. a $\geq 50\%$ loss of the YGTSS-TTS improvement, 2. required use of tic rescue medication, or 3. hospitalization for TS. The trial completes when the number of relapses has reached the pre-specified target sufficient to differentiate ecopipam from placebo with 85% power. Trial simulations and sensitivity analysis were performed across key variables.

Results:

The number of relapses required is a function of the two relapse rates individually. Previous results suggest, conservatively, that 34% of participants randomized to ecopipam and 65% randomized to placebo will relapse, yielding a target of 49 relapse events for completion. Simulations informed both enrolment and duration requirements.

Conclusion:

This EERW design meets feasibility requirements, provides up to 24 weeks of safety data, and is powered to determine maintenance of efficacy of ecopipam for TS while reducing placebo exposure for this serious disorder.

P20. Promising preliminary results on a clinical trial to explore the safety and efficacy of sepranolone in pediatric and adult patients with Tourette syndrome

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Background:

Several neurotransmitters, including GABA, have been proposed to play a role in the pathophysiology of Tourette Syndrome (TS). Sepranolone is an endogenous neurosteroid that suppresses the effect of positive GABA-A receptor modulators and might therefore be of interest for development of new treatment options for patients with TS.

Methods:

An interventional, open-label, multi-center, randomized, parallel group study was performed to explore the safety and efficacy of Sepranolone in pediatric and adult

patients with TS. The patients were randomized to either standard of care (SoC) or standard of care + injections of Sepranolone 10 mg twice weekly for 12 weeks.

Results and Conclusions:

28 patients with TS were included: 3 adolescents and 15 adults, aged 12-47 years, 18 males and 8 females. Mean baseline Total Tic Score (TTS) as measured on Yale Global Tic Severity Score was 32. Nine patients were randomized to SoC and 17 patients to standard of care + injections of Sepranolone. Patient characteristics were evenly distributed between the two groups. Two patients (7%) one from each group dropped out of the study. TTS in the active group was reduced by 8.6 points or 28.0% versus 3.9 points or 12.6% in the control group ($p= 0.051$). No systemic side effects were observed and in 2% mild to moderate but reversible skin reactions were seen.

Treatment with Sepranolone might be a promising new treatment possibility for patients with TS.

P21. Development in pharmacological treatment of children with chronic tic disorders during the last two decades in Denmark

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Background:

The objective of this study was to investigate the development in pharmacological treatment of children with chronic tic disorders (CTD) during the last two decades in Denmark by comparing two clinical cohorts.

Methods:

Cohort 1 was collected in 2005-2007 and included 314 participants with Tourette Syndrome (TS). Cohort 2 was collected in 2019-2021 and included 243 participants with CTD. Both cohorts were further divided into four phenotype subgroups, depending on the presence of the comorbidities Attention Deficit Hyperactivity Disorder (ADHD) and/or Obsessive Compulsive Disorder (OCD). Statistical analyses were performed for comparison between the cohorts and the subgroups.

Results:

60.5% (n=190) received pharmacological treatment in cohort 1 and 30.5% (n=74) in cohort 2. Among those, the most prescribed medication was short acting methylphenidate (34.2%) and short acting melatonin (54.1%) in cohort 1 and 2, respectively. Risperidone and pimozide were more prescribed in cohort 1 compared to cohort 2 ($p<0.001$ and $p<0.001$, respectively) and aripiprazole was more prescribed in cohort 2 ($p=0.001$). Start of medical treatment was mostly because of tics and ADHD in cohort 1, and sleep problems and ADHD in cohort 2. 4.9% received cognitive behavioral therapy in cohort 2 and none in cohort 1. In all 4 subgroups in cohort 1, the participants had tried more medications than in cohort 2.

Conclusions:

In our study, the percentage of patients treated with pharmacological treatment has been halved during the last two decades. Furthermore, a change from first generation antipsychotics in the treatment of children with CTD towards medications with more favorable adverse reaction profiles has been seen. Also, treatment of sleep problems in CTD has become more frequent and more patients receive non-pharmacological treatment.

P22. Placebo effect in randomized clinical trials of patients with tic disorders –results of the systematic review and meta-analysis

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Background:

One previous meta-analysis by Cubo et al. published 10 years ago systematically analyzed the magnitude of the placebo effect in randomized controlled trials (RCTs) including patients with tic disorders and demonstrated that there is a small, but relevant placebo effect in patients with tic disorders. The aim of this systematic review and meta-analysis was to update these results considering new data published recently.

Methods:

We conducted a systematic review and meta-analysis to examine the magnitude of the placebo effect in RCTs including patients with tic disorders. Tic severity was measured using the total tic score of the Yale Global Tic Severity Scale (YGTSS-TTS). The placebo effect was defined as an improvement of at least 30% over baseline scores in the YGTSS-TTS and was considered clinically relevant when at least 10% of patients in the placebo-arm met that benchmark.

Results and Conclusions:

In total, N=26 RCTs were included comprising N=961 patients randomized in the placebo group and N=1429 in respective intervention groups. According to YGTSS-TTS, there was a statistically significant improvement of tic severity after placebo administration ($p<0.01$), but the magnitude of the placebo effect was small (Cohen's $d=0.35$).

It can be concluded that there is a significant placebo effect in patients with tic disorders, but it is still small. New data considering the increasing number of large and well-designed RCTs should be constantly evaluated to better understand the relevance of the placebo effect in this group of patients, since this is of relevance for designing and interpreting results from RCTs.

P23. Lessons learned from randomized-controlled studies in patients with Tourette syndrome and chronic tic disorders

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Background:

ONLINE-TICS and CANNA-TICS are multi-centered randomized controlled trials (RCTs) investigating efficacy of internet-delivered Comprehensive Behavioral Intervention for Tics (iCBIT) and the cannabinoid nabiximols, respectively, in patients with Tourette syndrome (TS). Both trials were designed similarly, particularly related to population and psychometric measurements. However, both studies did not reach their primary endpoint (but showed strong trends towards significance). A joint analysis of these studies using individual patient data enables more detailed insight into differences in patient populations and different treatments for TS and chronic tic disorders.

Methods:

Descriptive analyses of common baseline variables were performed to assess similarities and differences between trial populations using two-sample t-test. Furthermore, the Yale Global Tic Severity Scale-Total Tic Score (YGTSS-TTS) was compared over the course of the trials. Prognostic factors for study participation were identified exploratory in multivariable logistic regression.

Results:

The CANNA-TICS trial enrolled $n = 97$ patients while the ONLINE-TICS trial enrolled $n = 161$ patients. In the analyses, we excluded all ($n = 20$) patients that participated in both trials. Remarkably, patient populations differed substantially at baseline with respect to tic severity according to the YGTSS-TTS (ONLINE-TICS: Mean 24.4 ($SD \pm 8.1$) versus CANNA-TICS: Mean 28.8 ($SD \pm 8.7$), $p < .0001$). Consequently, only descriptive analyses on the course of the YGTSS-TTS were possible. We identified a YGTSS-TTS ≥ 28 (OR 2.2, 95%-CI [1.3; 3.9], $p = 0.0044$) as well as the housing situation “living alone” (OR 2.0, 95%-CI [1.1; 3.6], $p = 0.0179$) and presence of psychiatric comorbidities (OR 1.9, 95%-CI [1.1; 3.2], $p = 0.0253$) at baseline as factors favoring participation in the CANNA-TICS study. Although in both RCTs, the YGTSS-TTS had been used to assess the primary endpoint, different approaches in analysis were applied. While in ONLINE-TICS analysis of the YGTSS-TTS was applied continuously, in CANNA-TICS a dichotomous responder criterion was defined.

Conclusions:

We identified substantial differences in the CANNA-TICS population compared to the ONLINE-TICS population, yet the same study centers were involved in both studies, the same psychometric measurements were used and similar in- and exclusion criteria were applied. This may indicate selection bias and allows for a discussion about patients’ preconceptions in different treatments for TS and tic disorders.

A joint evaluation of different RCTs may provide valuable new insights into different kinds of treatment for patients with TS and other chronic tic disorders.

P24. Different autoantibody concentrations in serum and CSF in Tourette syndrome

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Background:

Gilles de la Tourette-Syndrome (GTS) is a chronic disease with childhood onset defined by a combination of simple or complex motor and vocal tics usually accompanied by behavioral disorders such as obsessive compulsive and attention deficit hyperactivity disorder. Several lines of evidence support the hypothesis of an autoimmune origin of GTS. Accordingly, in a recent study we detected positive oligoclonal bands (OCB) in cerebral spinal fluid (CSF) in >30% of adult patients indicating an intrathecal antibody synthesis. However, until today no corresponding antibodies could be identified. The aim of this study was to identify autoantibodies in GTS.

Methods:

In this prospective study, CSF and serum of 20 adult patients with GTS (male: female=18:2, median age 36.1 years \pm 14.34 SD) were included. All patients were thoroughly clinically characterized. During the search for autoantibodies, IgG antibodies with binding capacities to CNS proteins were identified with a protein macroarray fusing CSF and serum from four of these patients. Based on binding patterns, six autoantibodies were chosen and analyzed using solid-phase ELISAs in a larger collective of patients with GTS (N=70) and compared to non-inflammatory CSF controls and blood donors.

Results and Conclusions:

Significant differences of autoantibody concentrations in serum were found in 3 of the 6 selected autoantibodies namely against FAM 161a, E3 ubiquitin ligase and kinesin 5B. In comparison to controls, a lower concentration of serum autoantibodies against FAM 161a ($p=0.049$), a protein which is involved in dopaminergic signal conduction, was found in patients with GTS. As well lower antibody concentration were detected against E3 ubiquitin ligase ($p=0.031$). Conversely higher serum antibody concentration were measured against kinesin 5B ($p=0.021$), which belongs to a group of motor proteins involved in intracellular transport. In CSF, significant different autoantibody concentrations were only found against pleiotrophin (PTN), a protein involved in cell differentiation and survival. Compared to controls autoantibody concentrations against PTN ($p=0.0001$) were decreased in the CSF yet not in serum of patients with GTS. In different studies a dysregulation of these proteins was associated with GTS. Our results indicate that autoantibodies might play a role in this disease.

P25. Clarifying the differences between patients with Organic Tics and Functional Tic-Like Behaviors

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Background:

Due to the global increase in the number of patients with Functional-Tic Like Behaviors (FTLBs) it has become increasingly important to find reliable differences between this patient group and patients with organic tics (OTs), which can be used in differential diagnosis. The purpose of this retrospective journal study was to critically examine both established and suggested differences between the patient groups using one of the largest FTLB sample yet.

Methods:

A total of 53 FTLB patients and 200 OT patients were included. All patients' medical records were inspected, and information about patient demography, family history and tic expression was collected and compared between the patient groups.

Results and Conclusions:

Several findings from the current literature were replicated in this study. The results showed that compared to patients with OTs, patients with FTLBs had significantly more complex and extreme tics, were significantly older at symptom onset and more likely to be female but were significantly less likely to have family members with tics. Furthermore, the study also revealed important differences between the groups that had not previously been shown in the literature. The patients with FTLBs had significantly more family members with a psychiatric disorder, were more likely to have experienced an adverse psychosocial event immediately before symptom onset and had significantly fewer simple tics. The first two of these new findings contribute significantly to the understanding of FTLB's etiology, while the latter could be employed to improve diagnosis, as including the lack of simple tics as an emphasized diagnostic criterion may help differentiate FTLB patients from OT patients with severe, complex tics. Finally, this study was unable to replicate the previously found differences in comorbidities between patients with OTs and FTLBs. This, combined with the conflicting nature of other literature in this area, indicates that emphasis should be placed on other criteria than comorbidities when making the FTLB diagnosis.

P26. Literature review and clinical perspective in the management of functional tic-like behaviours within a tertiary children's hospital in England

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Background:

Since the start of the COVID-19 pandemic, tertiary centres for tic disorders and secondary care have witnessed a new surge in referral rates for sudden onset functional tic-like behaviours (FTLBs). Preexisting psychiatric and neurodevelopmental co-morbidities were found to be higher in this group of patients, with significant disease burden. As experienced worldwide, referral rates for functional neurological disorders, including FTLBs, increased within Birmingham Children's Hospital (BCH). Contemporaneously, there was no expert consensus with regards to diagnostic criteria for FTLBs or for its treatment in children and adolescents. This was evident from the referrals we received, with a potential risk for inadvertently misdiagnosing children with a tic disorder and therefore mistreating the symptoms, impacting negatively on prognosis. We welcome the ESSTS consensus on diagnostic criteria recently published for FTLBs which could help mitigate the diagnostic conundrum. The objective of this review is to evaluate existing evidence base for the management of FTLBs and discuss the challenges in treatment pathways within BCH where there is no commissioned multidisciplinary tic disorder service.

Methods:

We conducted a review of all literature published up until 05/03/2023 on various bibliographic data bases including; Pubmed, Embase, Medline and EMCare. A title and abstract search was performed on search terms "functional tics" OR "functional movements" OR "tic like" OR "Tic attack" OR "Tic-like" AND "treatment" OR "Management" OR "behaviour management" OR "psychological management" OR "therapy" OR "therapies". Electronic databases generated a total of 238 papers. 24 papers were shortlisted from a title and abstract review. Duplicates were excluded and the remaining 20 articles along with 4 further articles from relevant references were included for a full text read. A total of 7 articles have been included in this review meeting our inclusion criteria relevant to the management of FTLBs for under 18's. These included 2 Prospective Cohort, 2 Retrospective Cohort and 3 Case Series that have been summarised as below. Both the authors searched, shortlisted and read the articles independently.

Results and Conclusions:

Studies included in this review have highlighted the following:

Assessment- Multidisciplinary biopsychosocial assessments and formulation of the presentation to inform treatment pathway has been found to be effective.

Treatment- Non-pharmacological interventions such as Psychoeducation, multiagency work with schools, CBT for treatment of both FTLBs and co-morbidities, psychological therapy including metacognitive and attention training techniques have been found to be effective. Anti-tic medications have not been effective in treating FTLBs, however,

treating co-morbidities such as anxiety and depression with medications such as Selective Serotonin Reuptake Inhibitors have improved symptoms of FTLBs.

This evidence confirms our own experience from BCH, where assessments by multispecialty teams, including biopsychosocial formulations, along with clear guidelines such as the ESSTS consensus, are key for making an accurate diagnosis of FTLBs. We have found referral for ongoing interventions can be a challenging in already stretched mental health services. Further higher-level studies (RCTs) into these potentially effective interventions are needed and may help improve access to them in National Health Services.

P27. The retrospective analysis of outcomes of pediatric patients with functional tic-like behaviors – what lessons have we learnt?

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Background:

Since the beginning of the COVID-19 pandemic, a well-documented influx of adolescents presented into neurology and psychiatry clinics worldwide with acute onset of functional tic-like behaviors. Multifactorial causes that included stress related to the pandemic, social isolation, increased illness-related anxiety, family tensions, loss of extracurricular activities and increased social media use with exposure to online influencers likely played a role. We sought to evaluate additional predisposing psychosocial factors and to examine outcomes after pandemic isolation protocols were lifted.

Methods:

A retrospective chart review of 56 patients ages 10 to 18 seen at Boston Children's Hospital in Boston, Massachusetts with a diagnosis of functional tic-like behaviors (FTLB) was completed. Psychosocial factors such as previous neuropsychiatric diagnoses were recorded. To determine if patients improved, results from the Clinical Global Impression Improvement (CGI-I) and Severity (CGI-S) scales were obtained from August 2022 to December 2022. CGI-I assessed progression of FTLB and improvement or worsening over time; CGI-S assessed overall function.

Results:

The majority of patients (96%) were females assigned at birth; 45% identified as gender diverse. Sixty-eight percent had no prior history of tics, 45% had ADHD and 7% had autism. Most patients had preceding mental health struggles, including 93% with anxiety disorders and 71% with depressive disorders. On CGI-I scores, 79% of patients showed improvement in FTLB at follow-up. In terms of overall function, clinicians

rated most patients as normal to mildly ill (71.4%) at follow-up; a subset developed other functional neurologic disorders (FND). Eighty-four percent of our patients engaged in therapy and medication, and this combined approach yielded the most improvement, regardless of the type of therapy.

Conclusions:

Increase in functional tics in adolescents during COVID-19 pandemic resolved for 79% of patients in our cohort. A subset has received other neuropsychiatric diagnoses. Treatments targeted towards anxiety, depression and ADHD were essential. A modified comprehensive behavioral therapy for tics (CBIT) with comprehensive behavioral therapy (CBT) and sensory grounding warrants a development of a modified protocol for patients with FTLB. Patient's willingness to engage in therapy and commitment to practicing skills and shifting their mindset away from tics, regardless of the type of therapy seemed essential. We learned that social connectivity and spread of ideas among teens via social media has become a powerful, previously underestimated tool and we need to be cautious about future mass sociogenic illnesses. Even though for many patients FTLB have improved but anxiety driven illnesses including other FND presentations and eating disorders need to be monitored. The future research and recognition of contributing psychosocial factors will allow optimal support for these patients.

P28. Pilot surveillance study of a UK cohort of adolescents presenting with functional tic-like behaviours (FTLB)

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Background:

Around the start of the COVID pandemic, a cohort of adolescents with sudden onset of tic-like functional movements presented to clinics across the world (Heyman et al., 2021; Hull & Parnes, 2021; Pringsheim et al., 2021). The rise in the number of patients presenting was so stark that it was labelled as a “pandemic within a pandemic” (Olvera et al., 2021).

The current literature on the prognosis of children with functional neurological symptoms is scarce. With regards to FTLB symptoms, one large study found that 20% of children had remission without active treatment, but 55% relapsed (Martino et al., 2023). Prato et al reviewed 11 adolescents with FTLB and showed variable outcomes in anxiety and tics at 12 months (Prato et al., 2023). Howlett et al, followed up 15 adolescents reporting marked improvement in the majority, although two developed non-epileptic seizures within the 6 months follow-up (Howlett et al., 2022). Patients

with FTLB are also reporting reduced school attendance and around 80% of patients have psychiatric co-occurring conditions (Martino et al., 2023).

Methods:

We completed a clinical interview with parents/carers of patients diagnosed with FTLB between 1-2 years after symptom onset or diagnosis. We administered a structured questionnaire with collation of qualitative and quantitative data. Our primary outcome measure was the change in Children's Global Assessment Scale (CGAS) between diagnosis and follow-up. Our secondary outcomes include the progression of FTLB symptoms in terms of severity and frequency (Worsened symptoms/No change in symptoms/ Fluctuating/ Improving/ Recovered), as well as the severity, duration and impact on function of other functional movement disorders symptoms using the Psychogenic Movement Disorder Rating Scale as a guide. We additionally collated details on the following: types of treatment accessed (at diagnosis vs at follow-up), the presence of co-occurring conditions (at diagnosis vs at follow-up), any emergency department (ED) attendance (at diagnosis vs at follow-up) and amount of missed school (since diagnosis).

Inclusion criteria include teenagers diagnosed with FTLB in the Paediatric Evelina TANDEM service. All were aged under 18 years old at diagnosis. Some families could not be contacted and were therefore excluded. 34 have been contacted to date.

Results:

We will present data on the following; change in CGAS scores at 1-2 year post-diagnosis, FTLB symptom progression in terms of frequency and severity, and progression of other functional movement disorder symptoms. We will also present descriptive data such as age at diagnosis, gender and types of treatments accessed. We will be submitting for future publication data on changes in the frequency of ED attendance, changes in school attendance and in the number and type of co-occurring diagnoses.

The following preliminary data was collated, to be developed:

Table 1: Severity of FTLB symptoms at follow up (n=34)		
Worsened	9	26%
No change	4	12%
Improved	17	50%
Fluctuating	1	3%
Resolved	3	9%

Table 2: Frequency of FTLB symptoms at follow up (n=34)		
Worsened	9	26%
No change	3	9%
Improved	19	56%
Fluctuating	0	0%
Resolved	3	9%

Conclusions:

FTLB symptoms do appear to improve in some patients but there are multiple co-occurring conditions, including different FND symptoms that are persisting and not being effectively resolved to date in the UK cohort. The prognosis of the co-occurring conditions is also uncertain and needs to be subject of further research.

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P29. Functional Motor Disorders in pediatrics: clinical motor correlates and neuropsychiatric profiles

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Background:

Functional Motor Disorders (FMDs) in pediatric age represent an increasing challenge among acute movement manifestations, mostly for functional tic during the pandemic. The aim of our study was to distinguish possible specific clinical motor patterns as well as neuropsychological vulnerabilities in children and adolescents, by a multidisciplinary approach.

Methods:

38 FMD pediatric patients (9-18 years) were enrolled (timeframe 2016-2022) in our Pediatric Movement Disorders clinic of a tertiary center.

Motor patterns as well as neurocognitive and psychiatric profiles were retrospectively analyzed. A prospective study was possible in a subset of patients enrolled during the pandemic, reporting the short-term outcome at one year.

Results and Conclusions:

53% of cases were referred during the pandemic and in the 75% of them functional hyperkinetic manifestations were reported. Functional gait disorder was reported in 68%, mostly presenting an isolated pattern. During the pandemic years, a relative increase in functional tics-like was highlighted. Neurocognitive profiles were characterized by discrepancies between verbal and perceptual abilities, while anxious

and depressive symptoms arose by the psychopathological evaluations. The one-year positive outcome was mainly related to an early diagnosis in the 95%.

This data expanded the knowledge of FMD motor patterns in the pediatric age, represented mainly by an isolated pattern of functional gait disorders. An overall FMD increase was reported during the pandemic and relatively to Tic-like symptoms.

Specific neurocognitive and psychopathological profiles underlined the neuropsychiatric nature of FMD disorders in which a multidisciplinary treatment is suggestable, with positive outcomes strictly linked with early diagnosis.

P30. An exploration of attention deficit hyperactivity disorder in young people presenting with functional tic-like behaviours

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Background:

Attention deficit hyperactivity disorder (ADHD) is frequently present in young people with Tourette syndrome (TS) (Hirschtritt et al., 2015), and because of this it has been suggested that a personal or family history of ADHD may help differentiate TS from functional tic-like behaviours (FTLB; Malaty et al., 2022). However, studies of young people with FTLB have wide estimates of ADHD comorbidity, ranging 23%-50% (Buts et al., 2021; Martino et al., 2022), and little is known about the demographics and clinical details of this specific cohort. This study aimed to explore this cohort in detail, comparing ADHD in those with TS and/or FTLB.

Methods:

Young people (N=127) aged 4-17 years referred to the Tic Disorder Service between July 2019 and May 2022 who were diagnosed with FTLB and/or TS were identified retrospectively from clinical care notes. All cases underwent clinical assessment and undertook DAWBA and SDQ questionnaires as part of routine clinical practice. Information was also collected from electronic health records, including: demographics, co-morbid psychiatric and neurodevelopmental conditions, and family history of neurodevelopmental and psychiatric conditions. Within the FTLB cohort those with ADHD were compared to those without and within the ADHD cohort the FTLB and TS groups were compared.

Results:

54% of all cases with FTLB and/or TS had ADHD. 52% of patients with FTLB had ADHD, compared to 63% of patients with TS. Of the patients with ADHD presenting with 'tics', 52% were TS, 20% were FTLB, and 28% were both.

Young people with ADHD were more likely to have both TS and FTLB (25% vs 7%).

Young people with ADHD were also more likely to have additional neurodevelopmental conditions (91% vs 70%). Demographics were similar between the ADHD and non-ADHD FTLB groups, apart from a bimodal age of tic onset in the former (peaks at ages 6 and 13 vs 13), and fewer female at birth (76% vs 93%). This is

consistent with the increased likelihood of combined TS-FTLB in young people with ADHD, as the bimodal tic onset reflects early tic onset of TS and later FTLB exacerbation. This group has higher DAWBA and SDQ scores and higher rates of family history for both neurodevelopmental and psychiatric conditions indexing multiple co-morbidity and genetic vulnerability.

Only 42% of patients with ADHD and FTLB were diagnosed prior to clinical assessment for tics, and only 36% of those diagnosed were receiving active treatment for ADHD, compared to 52% treated in children with TS and ADHD. Nearly all FTLB patients diagnosed with ADHD in clinic or on follow-up were female compared to an equal percentage diagnosed prior (95% vs 50%).

Conclusions:

This study is the only study to examine young people with FTLB and ADHD. ADHD is found to be highly prevalent in both TS and FTLB, and young people with both TS and FTLB. This latter group are likely to reflect young people with mixed neurodevelopmental disorder who are likely to be particularly vulnerable to FTLB. Young people assigned female at birth, with ADHD in FTLB were less likely to have been diagnosed and/ or treated for ADHD. As anxiety is a known consequence of ADHD in females (Young et al., 2020), it is possible that anxiety generated from undiagnosed/untreated ADHD is a contributory factor to FTLB. Better identification, diagnosis, and treatment of ADHD in females may prevent FTLB.

P31. Functional Tic-like behaviours: A Comparison with Tourette syndrome and Functional Symptoms in Children and Adolescents

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Background:

Functional tic-like behaviours (FTLB) are characterised by multiple, complex, rapidly evolving, vocal, and motor tics, with rapid onset, usually in adolescence (Pringsheim et al., 2022). Like other functional disorders/symptoms, the diagnosis is made clinically from biological, psychological and social indicators. Clinical consensus (Pringsheim et al., 2022) indicates that FTLB are qualitatively different from TS and more likely aligned with Functional Symptoms (FS). To date few studies have directly compared these groups, especially in paediatric samples. The aim of this study was to explore whether young people with FTLB have different demographics, family history, and psychiatric co-morbidity to those with TS, and are instead more aligned to those with FS.

Methods:

Children (N=176) aged 4 to 17 ($M = 13$, $SD = 3$) years old presenting to a Tic Disorders Service between July 2019 and June 2021 and subsequently diagnosed with TS (N=88),

FTLB (N=63), and FS (N=59) are described. Information was retrospectively collected from electronic health records and clinic letters for all patients, including: demographic information of the children, co-occurring psychiatric and neurodevelopmental diagnoses, and neurodevelopmental and psychiatric diagnoses of first and second degree relatives, which were volunteered by the families. A case-control design was used. Young people diagnosed with FTLB were compared firstly, with young people with TS and secondly, with young people in the FS group.

Results:

21 cases had FTLB and TS (FTLB-TS), 4 cases had FS and FTLB (FTLB-FS), 2 cases had FS, FTLB and TS. These cases were excluded from further analysis and will be considered in more detail by additional research. There were 35 'pure' FTLB cases (without TS and FS), 48 'pure' FS cases (without TS and FTLB) and 61 'pure' TS cases.

When compared to young people with TS, the FTLB group were more likely to identify as female, older at symptom onset and assessment, 5 times more likely to have any co-occurring psychiatric condition (OR = 5.44), twice as likely to have ASD (OR= 2.44), and almost 5 times as likely to be depressed (OR=4.93). They were less likely to have a family history of any neurodevelopmental disorder (OR=0.40), a family history of ASD (OR=0.29) or a family history of tics (OR=0.1), and almost three times more likely to have a first degree relative with an anxiety disorder (OR=2.69).

Fewer differences were noted when the FTLB group were compared to young people with FS. Although children with FTLB were slightly more likely to be female and older at symptom onset, 4 times more likely to have co-occurring ADHD (OR=4.14), less likely to have a family history of depression (OR=0.32) and more likely to have a family history of anxiety (OR=3.25), no other significant differences with regards to demographic factors, comorbidity or family history were observed.

Conclusions:

Although FTLB can look like TS even to the clinical eye, there are significant differences between FTLB and TS that can be garnered from clinical history. There were fewer differences between the FTLB and FS groups, supporting the idea that FTLB are likely to represent an FND subtype (Pringsheim et al., 2022). Clinicians should gain comprehensive clinical history in adolescents with first presentation of tics to support accurate diagnosis making. This study did not explore FTLB-FS and FTLB-TS subtypes which may present as intermediary subtypes and require further exploration.

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P32. Characterising young people with functional tic-like behaviours in the context of functional symptoms: preliminary data analysis

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Background:

Functional tic-like behaviours (FTLBs) are characterised by multiple complex vocal and motor tics with rapid onset, usually from age 12. They lack the typical rostro-caudal progression, premonitory urge, suppressibility and medication response seen in classic tics and are considered a subtype of functional neurological disorder (FND) (Pringsheim et al., 2023). FND has been defined as altered sensory or voluntary function arising from changes to nervous system functioning rather than a clearly identifiable pathophysiologic disease (Yong et al., 2023). FTLBs are heterogeneous in presentation and can significantly impact functioning. Existing literature suggests that 32% of young people with FTLBs have comorbid functional symptoms (FS) (Martino et al., 2022). This study aimed to establish demographic characteristics, comorbidities, tic severity and impact on functioning in a FTLB-FS cohort.

Methods:

A retrospective case series of twenty-six young people with a prior diagnosis or history of additional FS and diagnosed with FTLBs by a specialist tic clinic between October 2021 and December 2022 is described. Demographics (age, gender) and comorbid diagnoses were collected. Tic severity was assessed via the Yale Global Tic Severity Scale (YGTSS). Impact on functioning was assessed using the Children's Global Assessment Scale (CGAS), school attendance and adjunct use (e.g., wheelchairs, crutches, nasogastric tubes). Data was extracted from clinical records.

Results:

The FTLB-FS cohort (n=26) predominantly identified as female (73%), with a mean age of 14.58 years (range 11 to 17 years, $SD = 1.63$).

Everyone in the sample had at least one co-occurring ND or psychiatric diagnosis; generalised anxiety disorder (58%), autism spectrum disorder (54%), depression (19%), attention deficit hyperactivity disorder (19%), any specific learning disorder (19%), obsessive compulsive disorder (15%) and post-traumatic stress disorder (12%).

Mean YGTSS was 66.05 ($SD = 15.56$; Range: 32-89) which is in the moderate to severe range. Mean CGAS score was 41.16 ($SD=7.90$), suggesting on average moderate to severe functional impairment. Less than half (42%) attended school full-time, with another 42% attending part-time and 15% not attending school at all. Ten (39%) young people used adjuncts, with 40% using more than one.

Conclusions:

Psychiatric or ND comorbidity was the rule not the exception in this group. Prior paediatric FND research (Yong et al., 2023) found lower comorbidity rates (e.g., 8% with ND conditions; 8% with diagnosed anxiety/depressive disorders), though this may be due to methodological differences or the sample not including young people with co-

occurring FTLBs, who may be additionally more susceptible to ND (Buts et al., 2022). Young people with FTLBs and co-occurring FS experience high levels of impairment with a sizable proportion using adjuncts such as wheelchairs and crutches; along with reduced school attendance, this suggests a significant impact on social and physical functioning, as well as academic attainment. This demonstrates a need for research to inform interventions that treat FTLB-FS and restore functioning.

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P33. Identifying autism spectrum disorder (ASD) in young people presenting with functional tic like behaviours

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Background:

Functional tic-like behaviours (FTLB) are characterised by multiple, complex, vocal, and motor tics, with rapid onset, usually in adolescence (Pringsheim et al., 2023). Like other functional disorders/symptoms, the diagnosis is made clinically from biological, psychological and social indicators. Emerging research highlights neurodevelopmental disorders as potential vulnerability markers for the development of FTLBs (Han et al., 2022), as unrecognised and unsupported neurodevelopmental disorders can lead to higher levels of anxiety and stress (Zener, 2019), which can lead to higher risk of comorbid psychiatric disorders (Vasa & Mazurek, 2015).

International studies using pooled data have reported rates of ASD in FTLB as 24% (Martino et al., 2023). However, it was evident from non-pooled data that ASD prevalence rates varied depending on clinic site, with GOSH Tic Disorders Service reporting higher prevalence rates. It was unclear whether this disparity was due to differences in population groups or ASD screening and diagnosing practices. The GOSH Tic Disorders Service uses the DAWBA at pre-assessment and direct clinical screening for ASD at assessment for all patients. This study aims to (1) estimate the prevalence of ASD in a group of young people with FTLBs and (2) explore the utility of the DAWBA in identifying ASD in young people with FTLB.

Methods:

The sample consists of young people (N=63) aged 8-17 years old seen at GOSH Tic Disorders Service between August 2020 and May 2022. All young people with a diagnosis of FTLBs were included. A retrospective chart review of their referral and assessment letters was undertaken to determine demographic and clinical variables.

Preliminary Results and conclusions:

47 (75%) of the young people with FTLBs were diagnosed with ASD. Of these, 21% were diagnosed prior to the assessment and 19% were diagnosed by the Tic Disorders Service. Following positive screen for ASD at assessment, 30% were subsequently diagnosed with ASD by external CAMHS/Paediatricians. As ASD was diagnosed by many different services as well as the Tic Disorders Service, increased identification of ASD is more likely due to more effective screening rather than ASD diagnostic bias within the Tic Disorders Service. 60% (n=28) of patients with a clinical ASD diagnosis had a <3% probability of ASD as predicted on the DAWBA. This indicates that within this group, the DAWBA is an ineffective screening tool for ASD.

Our data suggests a high rate of ASD (75%) amongst young people diagnosed with FTLB, 54% of which were undiagnosed with ASD at the point of referral, but later met threshold for an ASD diagnosis following assessment recommended by clinical screening. Our findings suggest the DAWBA has poor predictive value for identifying ASD in young people with FTLBs. This is in line with findings from Coscini and colleagues (2022), who found the DAWBA to have reduced specificity in children presenting to a Social Communications Disorder Clinic specialising in assessment of girls without learning disability. The FTLB cohort are more likely to be gender assigned females with preserved intellect and therefore the DAWBA is not a sufficient screen for ASD in centres diagnosing FTLB.

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P34. The Tourette OCD Alberta Network: Development of an Online Parental Peer Discussion Group

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Background:

The Tourette OCD Alberta Network (TOCDABN) is an organization that provides care navigation, education, and support to people with TS and OCD in the province of Alberta in Canada. Peer support is a pathway to increased knowledge and well-being

through empathetic discussion. Peer support opportunities for parents affected by TS are acutely limited in a province as geographically vast as Alberta, with previous research demonstrating a desire for this type of support for affected families. The aim of this presentation is to describe the development of a psychologist moderated peer support group for parents with children affected by TS.

Methods:

In 2021, TOCDABN invited families throughout Alberta to participate in virtual psychologist moderated peer support groups for parents of children with TS. Two peer support groups took place in blocks of 5 weeks, and a discussion agenda was devised, covering a range of TS topics, comorbidities, and associated issues. Participants were asked to propose topics and issues for discussion. This presentation describes the process of developing the peer support groups, and qualitative analysis of parent-interviews at the conclusion of the peer support group.

Results:

Two peer support groups were organized in October 2021 and March 2022 over 5 weeks, and a discussion agenda was developed. Agenda items included improving family relationships, coping with behavioural challenges, symptom management, emotional regulation, building confidence and self-efficacy, and managing schoolwork. 26 parents participated. The qualitative data from the post discussion interviews underline the extent of the social and psychological benefits of sharing lived experience. Strategies learned and practiced were also core benefits of discussions with peers. Parents reported on the limitations of the online peer support groups, and suggested possible improvements, such as the discussion being organized around specific comorbidities. Parents felt that the role of the psychologist was crucial, from preparing the weekly discussion agenda to setting strategies for practice at home. The psychologist not only provided knowledge expertise, but had to have the requisite interpersonal skills to explore parents' contributions and to create a forum for discussion in which they felt sufficiently comfortable to participate and connect with each other.

Conclusion:

Parents' satisfaction with, and the benefit of, peer support was expressed in post discussion interviews. Notwithstanding the stated limitations of the peer support group, the sharing of lived experience foregrounded how the lives of parents affected by TS are both similar and different. It is this knowledge and the social connection through discussion which enhances family well-being.

P35. Clinician network as a strategy for building and maintaining competence on Tourette Syndrome and Habit Reversal Training in the specialist health services

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Background:

The number of therapists with competence in behavioral treatments of tics (i.e. HRT; CBIT and ERP) are limited in Norway. The Regional Resource Center for autism, ADHD and Tourette syndrome in South-Eastern Norway (RRC) has since 2013 implemented training courses in HRT/ CBIT to specialist health services. This region has 3.1 million inhabitants, and health services are spread over a large area with both large and small outpatient clinics. The training courses are aimed at increasing numbers of qualified HRT therapists and making behavioral treatments for tics available in outpatient clinics for children, youths and adults across the health region. Patients with Tourette syndrome are a low-frequency group in outpatient clinics. Therefore, in 2016 RRC established a clinician network, inviting all therapists who had completed the training courses and therapists already working with HRT/ CBIT.

The network aims at building and maintain competence by:

1. Exchanging experiences and discussing challenges in assessment and treatment of tics.
2. Presenting new research and knowledge about Tourette syndrome (TS) / Chronic tic disorders.
3. Giving participants the opportunity to meet across geography, units, and professions.

Methods:

Two network meetings are held yearly, and each meeting lasts one day. RRC is responsible for all administration, such as sending out invitations, and responsible for the academic content of the program. Participation is free, and RRC covers all costs except travel expenses.

The network meeting is divided into two parts. The first part consists of lectures on updated research on Tourette Syndrome, covering topics such as assessment, diagnostics, comorbidities, intervention and treatment. The participants may suggest topics for the next meeting, based on challenges they encounter in their clinical practice. In the second part, the participants present cases from own clinical practice for discussions. Cases are presented anonymously as oral or video presentations. Patients must have given their consent. Sharing experiences in this way contributes to increased knowledge and competence for all clinicians participating in the network.

Results and Conclusions:

Our experiences as well as evaluations from the participants, show that these network meetings represent an important and valuable meeting point. Therefore, 7 years later, this meeting point still exists, and the number of participants is constantly increasing. An average of 35 clinicians attend each network meeting. Their experience of treating tics varies. Sharing experiences about how to organize the treatment, challenges concerning the treatment, comorbidities, and other related topics helps the clinicians to be more confident of their work on TS and HRT. The network may also facilitate

contact with other clinicians, for instance, clinicians working in small outpatient clinics, often being the only one working with tics, can access other clinicians across the region for discussion and help. This may further contribute to more equal health services for patients with TS.

P36. The Tourette OCD Alberta Network: Development of an Educational Outreach Program for Schools

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Background:

The Tourette OCD Alberta Network (TOCDABN) is an organization that provides care navigation, education, and support to people with Tourette syndrome (TS) and Obsessive-Compulsive Disorder (OCD) in the province of Alberta in Canada. Educational outreach is an in-school intervention, enabling students and educators to learn about TS, OCD and comorbidities. The knowledge imparted by an in-service presentation helps address the educational barriers students with TS and OCD face, and also has the potential to improve the child's focus and motivation in the classroom. This presentation provides an overview of how the education outreach program was formulated, promoted, and delivered in schools to students and educators in the province of Alberta, Canada.

Methods:

During stakeholder consultations, parents repeatedly expressed their concern about the effect the lack of knowledge about TS and OCD in schools was having on their child's academic attainment and mental wellness. In 2020, sets of presentations were devised for students and educators, specifically for an outreach program. In this presentation, we describe the incipient development of the program, how it was promoted, the challenges of communicating with school personnel, the different types of audiences presented to, and the qualitative analysis of post-presentation parent-interviews.

Results:

The program of in-service presentations was developed to provide basic information about TS, OCD and comorbidities, and primarily focused on the underlying benefits of acceptance and destigmatization of tics and obsessive-compulsive behaviours in the classroom. Convincing school boards, principals, and classroom teachers of the importance and essential relevance of the program to teaching and learning was challenging, frequently requiring the assistance and advocacy of parents. Between December 2020 and December 2022, 16 in-service presentations were delivered, 15 online and 1 in-person. They took place in elementary, junior, and high schools, to audiences of students, teachers, and teaching assistants, and in total 250 participants took part. All requests for in-service presentations were related to TS. Schools provided some evaluation of the presentations, which were generally extremely positive. The qualitative data from the post-presentation parent-interviews underline the impact the

outreach presentations had on teacher awareness of tics, family dynamics at home, and the child with TS. Parents reported altered teaching strategies in the classroom, the improvement of intra-family communication about tics, and the impact on both their child's confidence and perception of their own ticcing.

Conclusion:

The educational outreach program highlighted the positive impact knowledge of tics has in the classroom, in terms of decreasing stress levels and improving the learning chances of children with TS. Building on the relationship between parents and teachers is vital in gaining access to schools. The psychoeducation support and strategies at the core of in-service presentations are a means of proactively supporting the child with TS in the classroom setting.

P37. Exploring Services for Tics in Children and Young People in England

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Background:

Tourette syndrome (TS) and chronic tic disorder (CTD) are neurodevelopmental disorders that typically onset in childhood. Tics are characterized as “sudden, rapid, recurrent, nonrhythmic motor movement (motor tics) or vocalization (vocal tics)”. Reports of tic prevalence indicate 1% of children and adolescents in England are affected. Accurate diagnoses and treatment of tics require appropriate recognition of tics as well as their associated conditions, which can complicate the assessment and treatment process. It's imperative that tic disorders are identified quickly and accurately so that young people are offered appropriate support and treatment. The long-term impact of TS includes reduced quality of life, pain from non-intentional self-injurious tic behaviors, and mental health, educational and social difficulties.

The inherent variability of tics over time, along with an individual's propensity to suppress tic behaviors when in the clinic, makes assessing the severity and impact of tics challenging. Many young people in England are unable to access services due to a lack of provision in their local area. We've spoken to experts with clinical and lived experience in TS and they've told us that there are few specialist services for tics, whilst mental health, neurological and paediatric services often feel ill-equipped to assess and treat tics.

In this study we aimed to assess the number of commissioned services that offer assessment and/or treatment of tics in England and the type of service they offer. Here we report our initial findings and describe the next steps of our research.

Methods:

We utilized 'Freedom of Information' (FOI) requests to gather data from healthcare boards (known as 'Integrated Care Boards') in England. Each ICB is responsible for organizing healthcare within one geographical region in England. We asked a sample of

ICBs whether they offer a stand-alone commissioned service for young people with tics or Tourette Syndrome, and to provide details of this service. If they do not offer a stand-alone service, we asked them to describe what type of service they offer for these children, if any. We also asked them whether they plan to extend their service in the future and if they would be interested in accessing training in the assessment and treatment of tics for clinicians.

Results and Conclusions:

Data collection is ongoing. So far, five ICBs have responded. Three areas of England do not currently offer stand-alone commissioned services for young people with tics. Instead, they offer general therapeutic support, but this is often only offered when the child also has a confirmed mental health disorder. Further analysis will be conducted when more ICBs respond.

The findings will be used to inform our understanding of the current service provision in England for tics. Findings will be disseminated to a range of stakeholders, including those responsible for commissioning services for children and young people.

P38. Exploring Clinical Pathways for Tics and Tourette Syndrome: Perspectives from Healthcare Professionals and Patients

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Background:

Across Europe, multiple facilities and professionals specialize in consulting and treating patients with tics and Tourette Syndrome (TS). Children with TS are very likely to have comorbidities, and their quality of life is often adversely affected by these. One of the issues around the treatment and management of TS is that the patients often face long waiting times, unclear clinical pathways, and frustration at being passed between services and multiple healthcare professionals. The main objective of this project is to identify which healthcare professionals are involved in consulting and treating patients with tics and TS across different countries. Furthermore, this study aims to determine the initial referral of patients with tics and TS and patient satisfaction with the treatment options provided. A greater understanding of these factors will improve treatment approaches and could lead to a better quality of life for those affected.

Methods:

Two questionnaires were conducted, one for professionals and one for patients. The questionnaire for professionals was sent via the European Society for the Study of Tourette Syndrome (ESSTS) newsletter and via a mailing list. The questionnaire for patients was sent to various patient associations across Europe and shared with help of Tics and Tourette Across the Globe (TTAG) and Tourettes Action. The data was collected via SurveyXact and exported to SPSS for data analysis.

Results and Conclusions:

58 professionals completed the survey representing a diverse range of 12 different countries across Europe and The United States. The most common professionals who completed the survey were neurologists (25%), psychologists (23%), and psychiatrists (18%) and the most common type of facility was the Department of Psychiatry accounting for 31% of respondents. 92% of all participants had psychoeducation as a treatment being offered in their clinic, 81% offered behavioral therapy, 92% medication, and 27% deep-brain-stimulation (DBS). The results show that most of the professionals prioritized psychoeducation as their first choice of treatment, followed by behavioral therapy as their second choice, medication as third, and DBS as fourth.

78 patients from 10 different countries across Europe, The United States, and Australia completed the survey. Most of the patients were in the age group 10-20 years. The onset of tics occurred on average at the age of 8 years, while the average age of diagnosis with a tic disorder was 21 years. The initial referral for most patients was to a neurologist, independent of age at onset. The most common treatment experienced by patients was medication, and 40% of them reported being satisfied with this treatment. Behavioral therapy was the type of treatment with the highest reported satisfaction (75%). Additionally, patients were asked if they had any advice for their healthcare provider, and a greater focus on the quality of life rather than just reducing the frequency of tics was requested - this might add to the discussion of patients' treatment priorities.

In conclusion, this study finds that almost all facilities offer the recommended treatment options. Neurologists are the initial referral for most patients, and medication is the most common treatment receiving a satisfaction rate of only 40%, while behavioral therapy is offered by 81% of the professionals and is the treatment most patients were satisfied with.

P39. Tics in Children and Adolescents in Primary Care

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Background:

Transient tics are seen in up to 25 % of the pediatric population while the prevalence of Tourette's Syndrome is only about 1 %. Despite the relative common prevalence of tics, no studies have investigated how many of these patients are referred to secondary care by their general practitioners (GPs) or where these patients are referred to.

Currently there is no guideline for Danish GPs on how to treat pediatric patients with tics. Furthermore, it varies regionally whether the diagnosis and treatment of Tourette's Syndrome is done in somatic or psychiatric facility.

The aim of this study is to explore the reasons Danish GPs refer pediatric patients with tics to get secondary care and to investigate the potential differences between the patients who get referred to somatic care and psychiatric care.

Methods:

An online questionnaire regarding contact with pediatric patients with tics was sent out to 1660 GP clinics in Denmark. Data was collected and analyzed with the statistical program SPSS.

Results and Conclusions:

210 GPs who had contact to a pediatric patient with tics within the past year replied to the questionnaire. GPs from all five regions in Denmark were represented. We found that significantly more patients were referred to somatic care in the regions of Zealand and the Capital compared to the other three regions, where patients were more often referred to psychiatric care. This can be explained by the fact that diagnostics and treatment of tics and TS are carried on by somatic care in the two first regions while it is done in psychiatric care in the latter three regions. Furthermore, we found that patients with psychiatric comorbidities were more likely to be referred to psychiatric care. Additionally, we found that the severity of tics was an important factor in the decision to refer to somatic as well as psychiatric care, and that the functional impairment played a less important role.

This study shows that even in a small country such as Denmark, the geographical differences between where patients with tics get referred to vary. Further studies are needed to examine possible differences in diagnosing, treatment possibilities and outcomes in pediatric patients with tics who get referred to psychiatric and somatic care. This may lead to new national guidelines in diagnostics and treatment of pediatric patients with tics.

P40. “For the love of God just refer me” - A coproduced qualitative project into the struggles of accessing healthcare services for those living with Tourette Syndrome in the UK

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Background:

Living with Tourette Syndrome (TS) is associated with increased risk of depression, anxiety, suicide and social stigma and poorer quality of life, reduced educational and occupational attainment, and worse social outcomes across adult and child populations. While evidence-based treatments do exist for TS including pharmacological medications and behavioural therapies, there are currently no medical guidelines for TS in the United Kingdom. Further, throughout the country many people can't access care services. Further barriers to accessing care include stigma, a lack of trained professionals and information for patients and family members. We aimed to explore

the lived experience of accessing healthcare for children and young people living with tics in the UK, to inform scientific and public understanding.

Methods:

Young people and adults with tics, and parents of people with tics, were recruited via social media support groups, our project partners and through research registers to take part in online focus groups. Participants were also given a further opportunity to share their audio with Woven Ink, an external media company, who would co-design an animation video based on the data to increase public understanding. Online focus groups were held separately with different population groups. Online focus groups were led by a lived experience project partner and facilitated by researchers. The focus group guide focused on three areas; the impact of living with tics, experience accessing healthcare for tics and management of tics. Reflexive thematic analysis was used to analyse the data. In parallel, the team were involved in an iterative process to co-produce the animation with the media company which included the choice of script, artist, music, font and captions. This research project has been co-led with our project partners who comprise experts in TS, including people and parents with lived experience of tics and leads of charitable/third sector organisations.

Results and Conclusions:

Seven separate online focus groups were held between May and July 2022, with three young people, ten parents and ten adults. In total, five themes were developed. Two themes related to how the healthcare system and healthcare professionals do not support those with TS. Three themes identified the challenges and need for having a TS diagnosis, experience of treatment options and managing TS at home. The essence of these themes can be viewed in the animation which reached over 500,000 people during the launch: <https://www.institutemh.org.uk/research/candal/about-candal/1670-candal-team-up-with-tourettes-action-to-campaign-for-better-services> and was warmly endorsed by the TS community.

This coproduced research project captures the realities of accessing healthcare for those living with TS in the UK, highlighting areas of need and intervention in healthcare settings through thematic analysis and further illustrated by a campaign video to raise public awareness.

P41. Experiences of self-identification, diagnosis and support for adults seeking a late diagnosis of tic disorders in the United Kingdom

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Background:

Tic disorders are conceptualised as a disorder of childhood, that diminishes over time during adolescence and into adulthood. However, a growing body of research and lived experience accounts suggests that tics can persist longer (usually in a milder form) and that a recurrence of symptomology after asymptomatic periods is common. Without a

diagnosis, co-occurring conditions may increase in severity and are more likely to persist in adulthood. A sample of adults with tic symptomology completed an online survey about their experience and opinions regarding their tic symptom presentation, the process of attaining a diagnosis and/or self-identifying with a diagnosis of tic disorders within adulthood (past 18 years) in the United Kingdom (UK) and what post-identification support/validation they received.

Methods:

Forty-two participants aged 18-68 ($M = 36$ years) completed an online survey consisting of both multiple-choice and open-ended questions. The first part gathered information on sociodemographic characteristics. The second part explored the participants tics (history, severity, acceptance and action, interference with daily life and cooccurrence with other conditions) and incorporated a variety of measurement scales - the Adult Tic Questionnaire (ATQ), Acceptance and Action Tic Specific Questionnaire (AAQ-T) and the Daily Interference Scale. The third part focused on questions regarding the participants diagnostic or self-identifying journey and post-identification support and impact. Questions in the third part were adapted from questionnaires originally designed to assess the process of seeking a diagnosis of Autism in the UK. This section focused on gaining information on the time taken and information and professional groups encountered to get a formal diagnosis or self-identify, how the diagnosis was disclosed (if applicable) and their own reaction and support received to their diagnosis or self-identification. Recruitment of participants was achieved by survey link distribution via social media and by promotion through UK organisations such as Tourettes Action and Tourette Scotland. The survey was open to participants who were over 18 and resident in the UK when they sought a diagnosis or self-identified as having a tic disorder.

Results and Conclusions:

Adults reported an assortment of vocal and motor tics that varied in frequency and intensity. Tic onset varied between 4 years of age to 62 years. Higher reported levels on the AAQ-T, which provided a measure of experiential avoidance, was associated with total frequency of tics, motor tics and intensity of vocal and motor tics from the ATQ. The AAQ-T was not related to age or daily interference. The results revealed that the majority of adults had waited about a year from when they first reached out to a health professional with their concerns to the confirmation of a tic disorder. Nearly all adults surveyed reported being extremely dissatisfied with the diagnostic process, particularly in relation to the information provided at diagnosis and the lack of post-diagnostic support offered. The findings highlight the need for professional and clinicians to understand how to support adults seeking a late diagnosis.

P42. Science-society rifts on tics, compulsions, and Tourette's: A panel's perspective

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Background:

The relations between Tourette syndrome scientists and Tourette's communities are rapidly becoming contentious. Recent years marked a growing rift over differences in understanding changing societal contexts of Tourette, rapidly changing views on key symptoms and more diverse patient groups (Hedderly et al. 2020; Müller-Vahl et al 2021), research practices, and neurodiversity-inspired views around treatment and self-determination (Bervoets et al., 2023; Conelea et al., 2022). This paper explores how the tide can be turned to re-establish the possibilities for generative, collaborative ways forward.

Methods:

This panel of authors have sought to formulate new ways in (re-)establishing generative knowledge production about tics, compulsions, and associated phenomena in Tourette syndrome. They have done so by sharing their multiple perspectives as Tourettic people, neurodiversity activists, clinical experts, social scientists, and medical humanities scholars. Their analysis is based on shared concerns and the formulation of possibilities of collaborations with Tourette's scientists of various kinds.

Results and Conclusions:

The results generate new points of gravity for shared values and help develop methodological innovations across different disciplines and sectors. These address the power relations between involved actors and emphasize how collaborations could work to ameliorate the negative aspects of certain privileges held in tic-related ways of being. In conclusion, the panel offers new vantage points and sensitivities for future Tourette's-related research that chime with the priorities of Tourettic people.

P43. Letting Tourette's be: The importance of understanding lived experience in research and the clinic

Jo Bervoets¹ and Diana Beljaars² and Hanne De Jaegher³

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Background:

The intention to more fundamentally include patient perspective and the experience of living with Tourette syndrome has been growing over the past decade; both in Tourette's-specific research and more broadly in the rise of interest in neurodiversity. Reconciling the differences between quantitative deficit-based based models of Tourette syndrome through tic manifestations and qualitative neurodiversity concerns.

Methods:

This paper is based on a literature analysis of the portrayal of tics in neuropsychiatric literature, the underlying ethical principles of deficit approaches employed in the consideration of Tourette's as a human condition, as well as the uptake of context and compulsion in the formulation of the main problem that Tourette's incites.

Results and Conclusions:

On the basis of the analysis, the paper puts forward an enactive analytical approach of 'letting be', that is, approaching a phenomenon without forcing preconceived reference structures onto it. Prioritizing the perspective of the 'Tourettic patient', the paper urges attentiveness to the everyday issues diagnosed people encounter and how these are embedded in further life. This approach highlights the strong relationship between the Tourettic persons' felt impairment, their adoption of an outsider's perspective, and feeling under constant scrutiny. To this end, the paper suggests that this felt impairment of tics can be reduced by creating a physical and social environment in which the person is 'let be' but not 'let go of'.

P44. Representation of Gilles de la Tourette syndrome in visual art

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Background:

Gilles de la Tourette syndrome (GTS) has inspired both visual artists, film, and theatre directors as well as novelists. Art is frequently used as an avenue to talk about disease, but also as a possibility to obtain cathartic effect. The purpose of our work was to evaluate examples of the work of visual artist serving as representation of the disease and an avenue to overcome the boundaries of their illness.

Methods:

We conducted a narrative review of the information about visual artists whose work constitute representation of the illness experience in GTS.

Results and Conclusions:

We were able to identify several examples of visual artists who allude to the topic of GTS. Many patients with GTS use art as a cathartic means to present their lived experience with the disease. In terms of the formal representation, vast majority of these works constitute example of expressionist and abstract art. From the thematic and metaphorical perspective, frequent motive is a human figure entrapped in a closed space, which represents the relationship between the patient and disease with such examples as *Tourette syndrome* by John Fields. Another common representation is the body in motion with expressive example of the cycle of works *Disordered Moments* by the US based artist, Eli Smith. Similarly, to represent the body in motion, the images of disfigured

bodies are often used. Kevin Gavaghan, a UK based artist with GTS, uses contemporary baroque surrealism to present his tics using the aforementioned metaphor. Similar motives are presented in sketchbook by Lewis Rossingol that combined collage, comics, and watercolor. Others use their art as a direct therapeutic means to control their tics. Examples include a Hong Kong painter, Liane Chu, who uses painting as a relaxation technique and art therapy to alleviate her tics.

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