Tics and Tourette Across the Globe
- Dedicated people and actions committed to a vision

ESSTS Virtual Meeting II: Patient Associations Session
October 1st at 16:15–18:15 (CET)
SESSION 1: Introduction
SESSION 2: Who we are
SESSION 3: How we work
SESSION 4: Social Media
SESSION 5: Finances
SESSION 6: Recent Activities – Forward thinking
SESSION 7: Welcoming the past and the current ESSTS chair
SESSION 8: Interactive part
Session 1: Introduction

Presenter:
Michele Dunlap
Germany
ESSTS Patients Group evolution

Emerging from annual ESSTS Patients Group meetings within framework of ESSTS conference

Long-standing desire to

- collaborate and share pool of information, best practices and experience within TS community
- work more closely with clinicians and researchers

Patients meeting at ESSTS conference 2019 in Hannover sparks hands-on initiative to work on creating a legal entity
2016: The design of two leaflets
At ESSTS conference in Copenhagen, two leaflets were drafted & a working group assembled.
- Guidelines for patients participation in research
- A patient leaflet on TS & comorbidities
- Leaflets now available!!

2016: A joint Facebook group
At ESSTS conference in Warsaw, Poland, it was agreed
- To start a FB group to share ideas and news.
- Sharing info from patient groups from different countries.
- This group has 62 members, from 10 countries!!

2018: The first patient group meeting
- The first ESSTS conference was held in 2006
- But....the first time patient representatives were present was in 2010 in Dresden.
- Since then, around 10 countries have been present every year

2019: A mission statement and agenda
At ESSTS conference in Hannover, Germany, it was decided to:
- Set an agenda and create a mission statement.
- This will help define the purpose for the group
- And also outline support for member countries
- And collaborate with researchers.

2017: The first EU wide survey
At ESSTS conference in Seville, Spain:
- An EU wide survey patient survey was drafted.
- It was translated into 13 languages
- It focussed on what research patients want
- There were over 2000 responses.
- Read about it: https://tinyurl.com/y5cjq6x

2014: The first EU wide campaign
At ESSTS Conference in Paris, France:
- The EU Patient Groups agreed on a joint awareness campaign
- #TSTselfies on 7 June 2014 saw people from all over Europe (and the world!) posting selfies
- Raising awareness on a big scale!!
**Scope and Vision**

**Scope:**

*Tics and Tourette Across the Globe (TTAG)* is an umbrella association representing Tic and Tourette Syndrome advocacy groups across the globe thus creating a united voice for those affected by this neurodevelopmental disorder.

**Vision:**

Advocates, clinicians and scientists across the world collaborate to benefit those affected by Tourette Syndrome or tic disorders.

*The whole is greater than the sum of its parts*
Objective

- Raise TS awareness and information by promoting evidence-based treatment
- Reduce ignorance, stigma and intolerance
- Increase access to better treatment and management for those seeking help
- Increase research with particular emphasis on early diagnosis and intervention
- Provide better education for teachers, healthcare professionals, employers, etc.
- Support other countries to establish and/or enhance services provided
- Initiate international activities and projects
TTAG creation timeline

Challenges:

- manpower
- 3rd party consulting
- finances
- ..... 

Legal entity to be registered by end 2021, alternatively by mid 2022
SESSION 2: Who we are

Presenter:
Fabrizio Barillari
Italy
**Session 2: Who are we**

- Originating as a European TS advocacy Group
- Growing to be an umbrella organization for TS Patient Associations around the globe
- Linking different associations and individuals within interest in TS

**Mindset:**
Patient interests come first
CURRENT TEAM SET UP

Organizing Committee

Working Groups

Central Structure (backbone)

Topic specific focus
Current active Working Groups:

- WG1 Vision and Mission
- WG3 Statutes
- WG2 Finance
- WG4 Membership
- WG5 Board
- WG6 General Assembly
- WG7 Website and Social media
Future Board/Committees set up

TTAG Board
- President
- VP
- Secretary
- Treasury

Working Groups
- PR & Media
- Research and Science
- Funding
- Activities
- Internal Affairs
SUPPORT US

To create a global network and redefine TS awareness

WALK WITH US
SESSION 3: How we work

Presenter:
Paula-Riitta Huttunen
Finland
Session 3: How we work

Monthly Meetings:
- Every month’s first Monday at 10:00 (CET) on Zoom

Catch-up Meetings:
- Preselected days during evening time after Monthly Meetings on Zoom

TEAMWORK
TEAM = Together Everyone Achieves More (Unknown)
**INTERNAL COMMUNICATION & TOOLS:**

- For staying connected between the meetings:
  ![Slack](image)

- For having the meetings:
  ![Zoom](image)

- For working together, sharing & storing our materials:
  ![Google Drive](image)
- **SLACK** is the official communication platform for the TTAG's communication

- All written communication between TTAG's members happens in **SLACK**
  - channels for different discussion themes
  - possibility to private group and private direct messages between the members

- Invite is needed to get access to TTAG's **SLACK** group
  ➜ contact paula.huttunen@gmail.com to get the invite
Google Drive

TTAG’s Drive folder is for:

- storing documents (such as meeting minutes and meeting agendas) and other files
- working together on document (online and offline)
- sharing documents and other material internally
Get involved

Contribute to our global network:

• join our meetings
• become active in one or more of our working groups
• follow us on social media
• provide pro bono expertise
• make a donation
• become a member
• ...

...
Session 4: Social Media

Presenter:
Vasco Conceição
Portugal
Tics and Tourette Across the Globe (TTAG)
A global collaboration of patient groups & healthcare professionals for people affected by tics & Tourette Syndrome.
Health, Wellness & Fitness · Durbuy · 71 followers

www.linkedin.com/company/tics-and-tourette-across-the-globe-ttag
Tics and Tourette Across the Globe (TTAG)
@TTAGpatients

An international group of Tourette Syndrome patient support associations
#Tourette Syndrome

Joined April 2020

203 Following    317 Followers

Followed by ESSTS, Dr Seonaid Anderson, and 3 others you follow

https://twitter.com/TTAGpatients
Facebook (public group)

www.facebook.com/groups/546874306675377
www.instagram.com/ttag_npo
Tics and Tourette's across the Globe (TTAG)
17 subscribers

Tic and Tourette Syndrome are neurodevelopmental disorders characterized by involuntary movements and vocalizations. The TTAG channel aims to provide information and support for individuals and families affected by these conditions worldwide. Through videos and discussions, the channel seeks to promote awareness, understanding, and community support.
SOCIAL MEDIA: Next step
Session 5: Finances

Presenter:
Rosita Sunna
Australia
Financial support allows us to plan, build and commit to TTAG’s plans and objectives.

Currently we depend solely on TTAG fundraising, ad hoc donations and TTAG volunteers.

What is the team’s capabilities for form and run TTAG?

Our team consists of volunteers:

➢ all of them working for many years for TS Patient Associations and other TS advocacy, medical and research groups.

Team members have a wealth of professional experience, many of us also have personal/lived experience with TS.

Although this is the start-up of a new global umbrella organisation, our knowledge about Tics and Tourette Syndrome is very comprehensive and we possess a plethora of knowledge and experience as part of our broader professional life.
**What are our current goals?**

**Immediate goal:**
- TTAG Registration (Belgium)
- Lawyer and notary fees
- Accountancy fees and software
- Office (virtual)
- Bank Fees
- Website, hosting, domain name
- Membership Database software (CRM)

**Ongoing funding and support goal:**
- Funding for TTAG to continue in a sustainable way in the future
Funding Activities

Active:
GOFundMe Crowdfunding Campaign!

- Grants
- Fundraising strategy (in development)
- Membership

https://gofund.me/c6cd2ce1
How would the funds be used?

The funds raised will go towards the registration and start-up of our global umbrella organisation. All TTAG team members are volunteers.

Any funds remaining from start-up costs fundraising will be used on campaigns to raise awareness and acceptance of TS, producing materials that can be shared around the world and materials to lobby for better treatment and management for patients.

Fund Allocation:

- 40% to cover lawyer fees, registration and notary fees
- 20% to cover accountancy fees and accountancy software
- 40% to cover cost of website, hosting, domain name and membership database software (CRM)

Our goal is to raise Euro 10,000

Achieved so far:

- GoFundMe Campaign: Euro 1,305
- Direct donations (Bank Account): Euro 1,200
- Available funds: Euro 2,505
- Funds needed: Euro 7,495
Please support our work

Deposit directly in our bank account:

**Bank:** BNP Paribas Fortis  
**Address:** Warandeberg 3 B-1000 Brussel  
**IBAN:** BE49 0019 0830 7571  
**BIC:** GEBABEBB

For donations or In-kind contributions email to:  
**ttagcontact@gmail.com**

Please visit our GoFundMe campaign on:  
[https://gofund.me/c6cd2ce1](https://gofund.me/c6cd2ce1)  
or scan the **GoFundMe**-barcode on the below:

We are very thankful for your involvement and support!
Activity Plan for future funding:

- **TTAG** Website
- Direct donations to **TTAG** Bank Account
- Grants, Trusts and Foundations
- Sponsorships
- Major Donors
- Individual Giving
- Community / Peer to Peer Fundraising ➔ using various digital fundraising platforms in participating countries and Facebook
- In-kind contributions (non-monetary contributions)
SESSION 6: Recent Activities – Forward thinking

Presenter: Seonaid Anderson
UK / Belgium
SESSION 6: Recent activities and plans

Recent activities/collaborations and forward thinking:

- Psychreg article
- Media guidelines
- ESSTS poster
- EU guidelines
- EFNA Provisional membership
- One Neurology Endorser
- Platform sharing (open library, testimonies with subtitles, research articles with aided conclusion, links to local support groups and associations/organizations)
- Bringing people with TS together
- What do YOU want to see?
Recent activities and plans

Psychreg article (2021):
Creating a Pan-European Tic and Tourette Syndrome Patient Umbrella Association – During a Pandemic

www.psychreg.org/pan-european-tic-tourette-syndrome-association
Media Guidelines - presented at the ESSTS conference

Now translated into different languages from our collaborations!

These will be on the TTAG website in the future:
https://www.neuro-diverse.org/blog/guidelines-for-engaging-with-the-media

Guidelines in English
Download

Guidelines in Spanish
Download

Guidelines in Dutch
Download

Guidelines in Italian
Download

Guidelines in German
Download
European clinical guidelines for Tourette Syndrome and other tic disorders: patients' perspectives on research and treatment

Seonaid Morag Anderson

Tics and Tourette Around the Globe (TTAG) representing Tic and Tourette Syndrome (TS) patient associations around the world

Affiliations  + expand

PMID: 34370120  DOI: 10.1007/s00787-021-01854-y
• One of the main aims of TTAG is to have an ongoing, mutual beneficial relationship between patient groups and researchers.

• TTAG looks forward to opportunities for a debate about the role, opportunities and challenges of the involvement of TS patients in research.
• Collaborations include a chapter on patient associations around the world being included in a clinical textbook on Tourette Syndrome [https://tinyurl.com/tfnjca68](https://tinyurl.com/tfnjca68) (updated version in press 2022 edited by Davide Martino and James F. Leckman).

• As well as the creation of an online TS patient association directory found on the ESSTS website [www.essts.org/directory](http://www.essts.org/directory)
Directory of Tourette Syndrome Patient Associations

An overview of the most important services and contact details of TS Patient Associations around the world. Get to know what the organisation in your respective country has to offer. Professionals can easily share this information with their patients and open the way to support in an accessible manner.

If you are a Patient Association representative and wish to update any of the details below, or to be included in this directory, please submit your content via this online form, or contact us directly here. We appreciate your help in making this online directory a useful tool for patients, their families and professionals all around the world!

A very special thank you to Dr Seonaid Anderson and Dr Annet Heijerman who have worked tirelessly on compiling information from all around the world and have meticulously drafted this valuable database.
EFNA AWARD

'ACTION AGAINST STIGMA'
Outstanding achievement by a patient advocate

Deadline for nominations:
Friday, 4 December, 5pm CET
Provisional membership of EFNA:

A provisional member (PM) is an organization who does not, as yet, meet the criteria for membership as outlined in the Membership Policy.

However, they are committed to doing so within a set time frame, with the support of EFNA.
People with TS getting together

• Youth exchange programmes
• Provide an online platform —via TTAG website:
  ➢ to access online support
  ➢ information about diagnosis and treatment
  ➢ in multiple languages
  ➢ share people’s personal experiences on our website through blogs, photos and videos

… around the globe?
Benefits of joining TTAG:

- A stronger and united voice
- TS awareness
- Potential collaborating
- Sharing information and experiences
- To collaborate with researchers
Follow & Contact us

Gmail: ttagcontact@gmail.com

facebook: Tics and Tourette Around the Globe

twitter: @TTAGpatients

Instagram: #ttag_npo

LinkedIn: TTAG
SESSION 7: Welcoming the past and the current ESSTS chair

Speakers:
Andreas Hartmann
France
&
Kirsten Mueller-Vahl
Germany
Thank you for joining!
Polls:

1) Today’s audience:

2) Your country/region and Tourette:

3) How you wish to join TTAG:
Topics:

1) What do you want TTAG to do
2) Conflicts?
3) Any other suggestions?
What do YOU want TTAG to do?

We are thinking:

• Newsletters, Website, centralized platform, open access library for papers (with lay overview)
• Multiple language resources
• Contact/influence with researchers, Lobbying to governments
• Info and advice from other patient associations, in how to grow patient associations, how to support patients in that country, what are other countries doing
• Pooling our resources and not replicating our efforts
• Being influential in/or supporting research, communications across countries – activating and mobilizing people with TS to become active.
• Sharing experiences via blogs etc. on website
• Raise funds
• Increasing awareness across countries
• Projects we feel passionate about – international exchange programs etc and other initiatives
Do you have potential conflicts? Colliding Interests?

We will deal with any potential misunderstandings – and not compete for resources with your patient association, how voting will work for national vs regional associations
Anything missing? Was there anything else you wish to discuss?

We wish to know if everything is clear

Structure, decision taking process, objective, mission, finances, etc.