

Tics and Tourette Across the Globe

– DEDICATED PEOPLE AND ACTIONS COMMITTED TO A VISION



TTAG

Tics and Tourette
Across the Globe

ESSTS VIRTUAL MEETING II: PATIENT ASSOCIATIONS SESSION

OCTOBER 1ST AT 16:15–18.15 (CET)

AGENDA



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

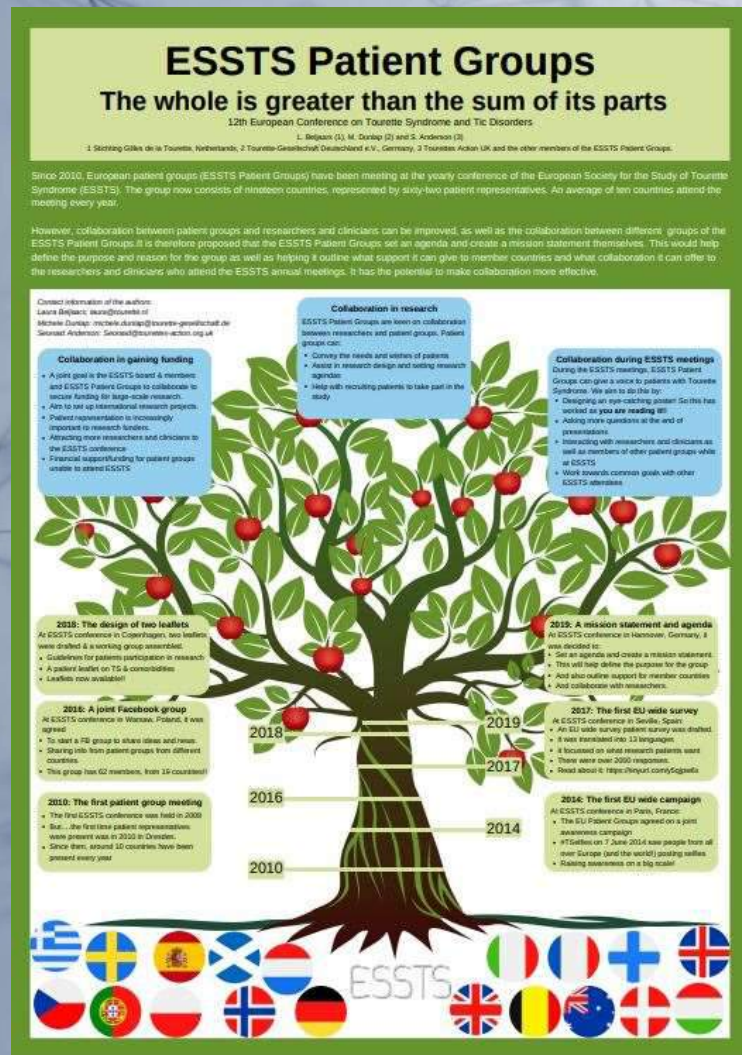
SESSION 7: Welcoming the past and the current ESSTS chair

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

ESSTS 2019 PATIENTS GROUP POSTER



2018: 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 19 countries!!

2010: The first patient group meeting

- The first ESSTS conference was held in 2008
- 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/y5qjp6x>

2014: The first EU wide campaign

At ESSTS conference in Paris, France:

- The EU Patient Groups agreed on a joint awareness campaign
- #TSelfies on 7 June 2014 saw people from all over Europe (and the world!) posting selfies
- Raising awareness on a big scale!

2018

2019

2017

2016

2014

2010

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 IT'S 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*

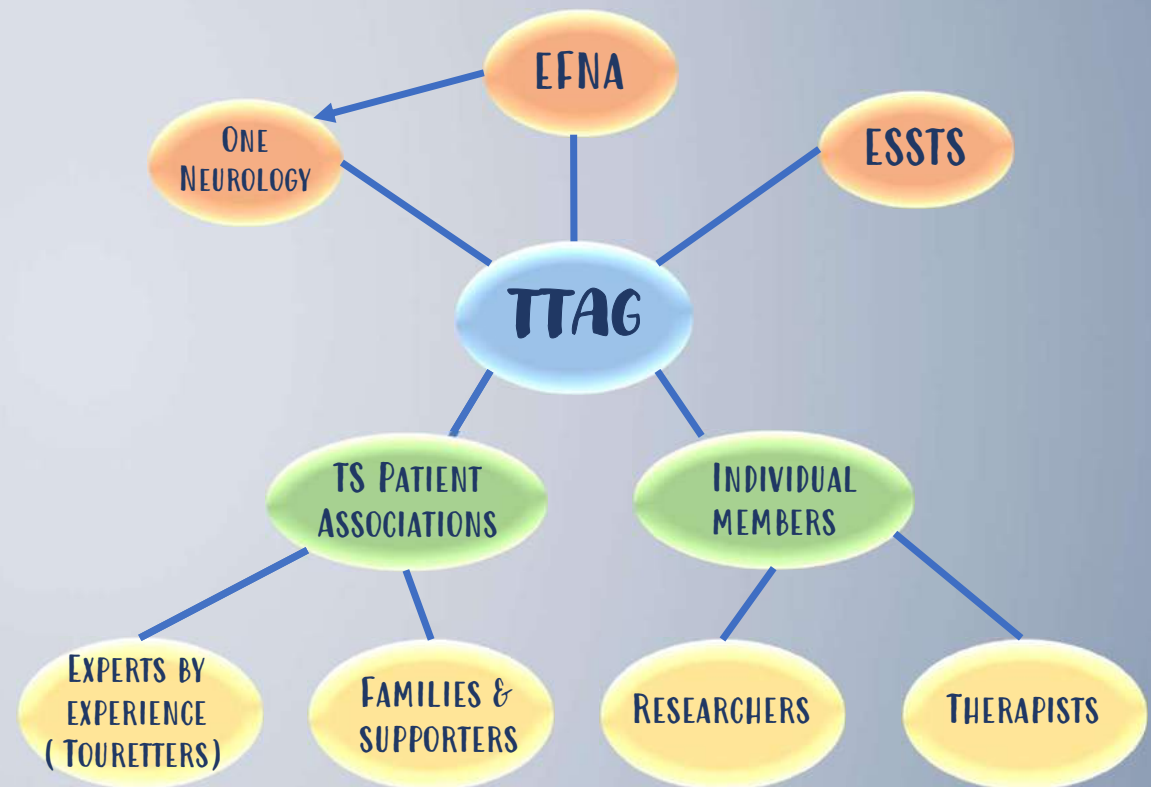
Presenter:
Fabrizio Barillari
Italy

SESSION 2: *Who are we*



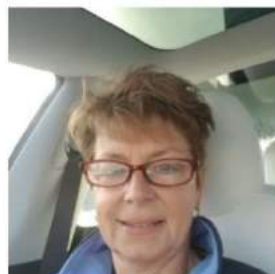
- Originating as a European TS advocacy Group
- Growing to be an umbrella organization for TS Patient Associations around the globe
- Linking different associations and individuals within interest in TS

Mindset:
Patient interests come first





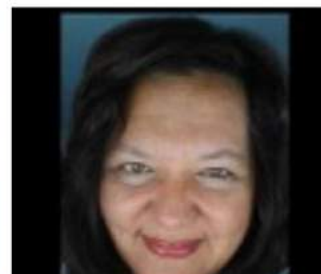
DR. SEONAIID ANDERSON
UK/Belgium



MICHELE DUNLAP
Germany



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COMASINI**
Italy



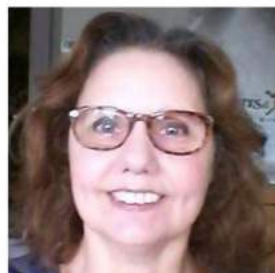
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CABRERA**
Spain



LISA KEENAN
Ireland



DR. KARIN MALISCH
Germany



MONIQUE VERSTAETEN
Belgium



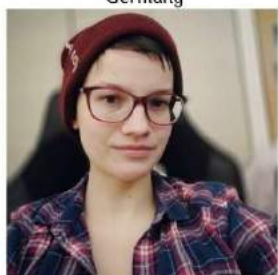
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**TICS AND
TOURETTE
ACROSS
THE GLOBE
TEAM**

CURRENT TEAM SET UP



ORGANIZING
COMMITTEE

*Central Structure
(backbone)*

WORKING
GROUPS

Topic specific focus



WORKGROUPS



TTAG

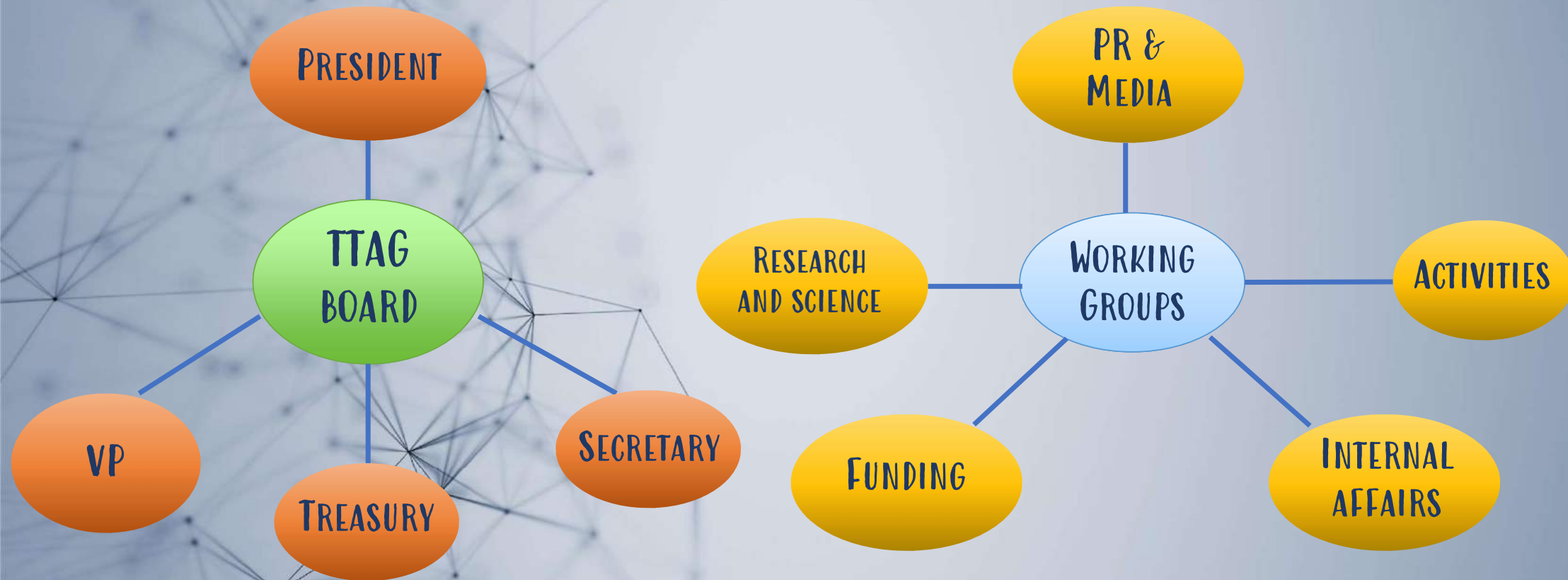
**ORGANIZING
COMMITTEE**

**WORKING
GROUPS**

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



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



TEAMWORK

TEAM = Together Everyone Achieves More
(Unknown)

TTAG

ORGANIZING
COMMITTEE

WORKING
GROUPS



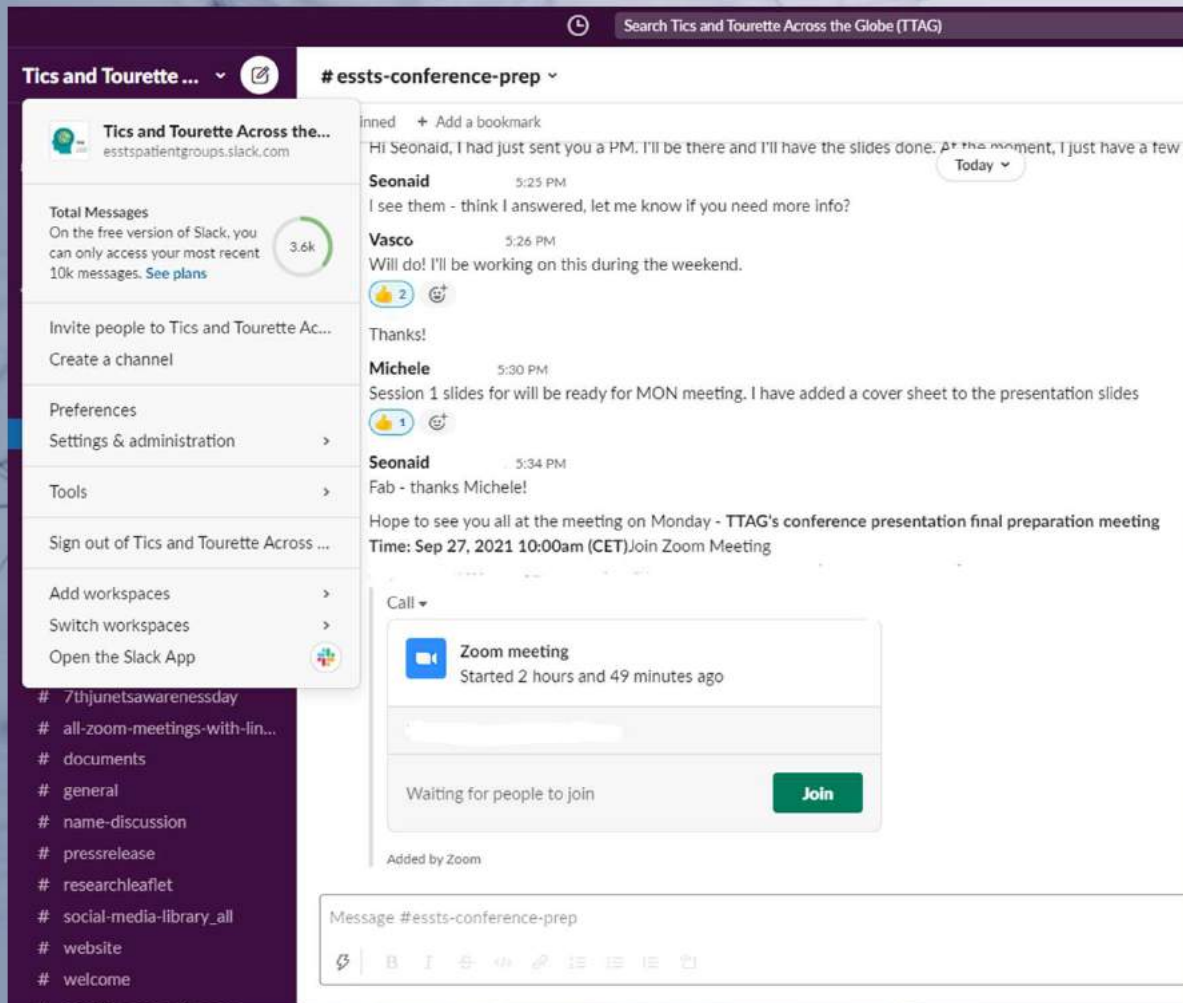
Monthly Meetings:

- Every month's first Monday at 10:00 (CET) on Zoom

Catch-up Meetings:

- Preselected days during evening time after Monthly Meetings on Zoom

INTERNAL COMMUNICATION & TOOLS:



- For staying connected between the meetings:



- For having the meetings:

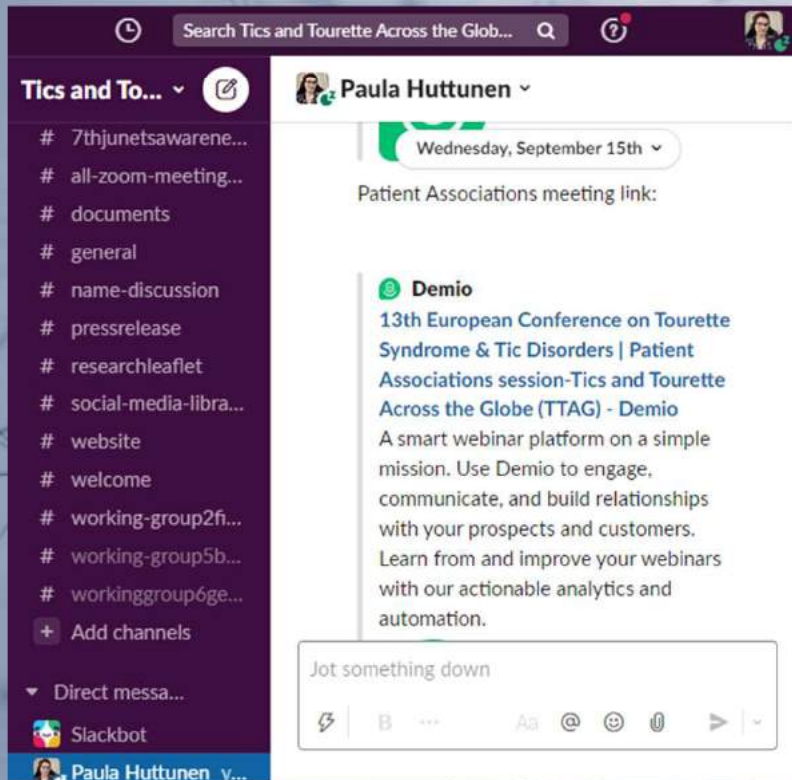


- For working together, sharing & storing our materials:



By SuperBubble26 - Own work, CC BY-SA 4.0, <https://commons.wikimedia.org/w/index.php?curid=97319597>

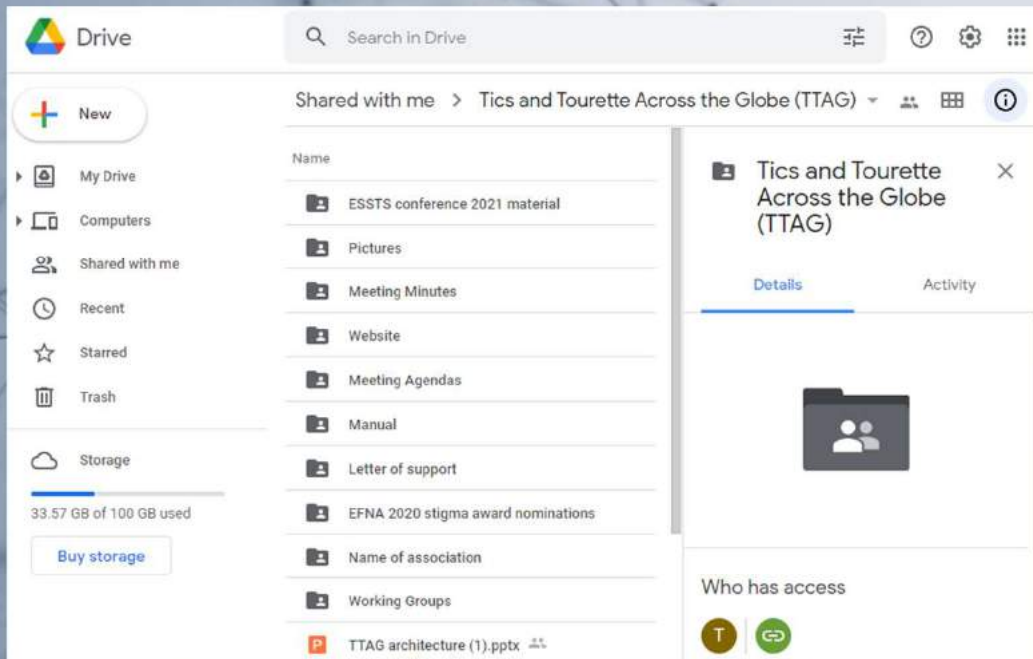
SLACK



- 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

LINKEDIN





 Home  My Network  Jobs  Messaging



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

[✓ Following](#) [Learn more](#) [More](#)

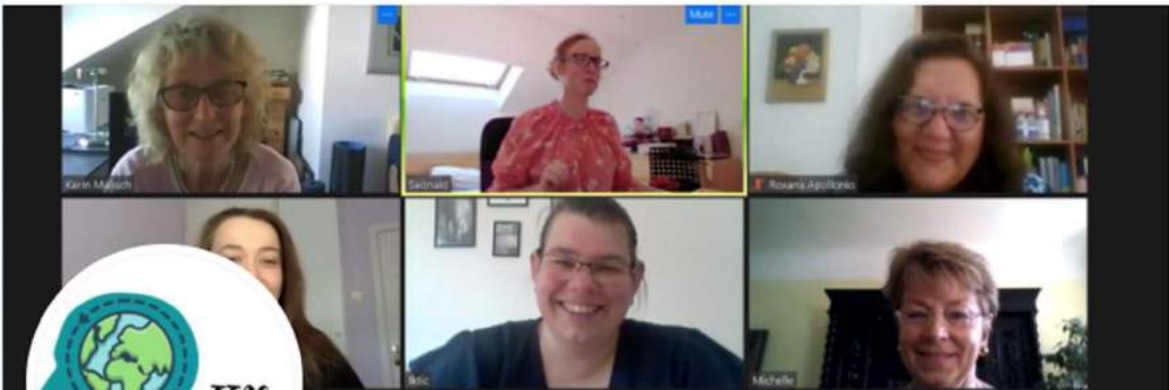
[Home](#) [About](#) [Posts](#) [Jobs](#) [People](#) [Videos](#)

www.linkedin.com/company/tics-and-tourette-across-the-globe-ttag

TWITTER



← **Tics and Tourette Across the Globe (TTAG)**
329 Tweets



⋮ 🔔 Following

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)



TTAG

Tics and Tourette's
Across the Globe

Edit

Tics and Tourette Around the Globe (TTAG)

Public group · 204 members

Joined ▼



+ Invite

About

Discussion

Rooms

Topics

Members

Events

Media



www.facebook.com/groups/546874306675377

INSTAGRAM



Instagram

Search



ttag_npo

Message



3 posts

58 followers

78 following

TTAG

Tics and Tourette Across the Globe (TTAG) | An international non-profit organization for TS patient associations | Find us on Twitter: @TTAGpatients

gofund.me/5d99559a

www.instagram.com/ttag_npo

YOUTUBE



ttag tourette across the globe



Tics and Tourette's across the Globe (TTAG)

17 subscribers

SUBSCREVER

INÍCIO

VÍDEOS

LISTAS DE REPRODUÇÃO

CANAIS

DISCUSSÃO

ACERCA DE



Carregamentos

▶ REPRODUZIR TODOS



Síndrome de Tourette

44 visualizações • há 3 meses



Sindrome di Tourette_AIST
Onlus Associazione Italian...

35 visualizações • há 3 meses



Le syndrome de Gilles de la
Tourette

33 visualizações • há 3 meses



Tourette Syndrome

195 visualizações • há 3 meses



Tourette Syndrom Deutsch

75 visualizações • há 3 meses

www.youtube.com/channel/UCISWoV8gsytpcoW02Z-NY2Q

SOCIAL MEDIA: Next step



APST
Associação Portuguesa de Síndrome de Tourette
Mês da Sensibilização
15 Maio > 15 Junho

AFSGT.

accueil | notre action | rubriques | relais | contact |   

Association Française du Syndrome de Gilles de La Tourette

Notre mission est d'aider les malades et leurs familles à vivre avec la maladie, informer le corps enseignant, susciter la recherche aux niveaux national et international et favoriser toute action destinée à améliorer la situation de ses membres.

[adhérer](#)



 3891641378

ASSOCIAZIONE ITALIANA SINDROME DI TOURETTE

...

FOLLOW & CONTACT US



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 Tics and Tourette Around the Globe

 @TTAGpatients

Instagram #ttag_npo

 TTAG

SESSION 5: *Finances*

Presenter:

Rosita Sunna

Australia

SESSION 5: *Finances*



Financial support allows us to plan, build and commit to **TTAG's** plans and objectives.

Currently we depend solely on **TTAG** fundraising, ad hock 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.

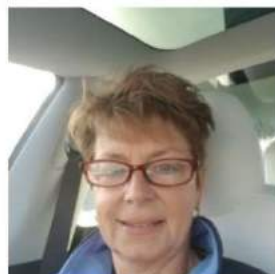
Team members have a wealth of professional experience, many of us also have personal/ lived experience with TS.

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.





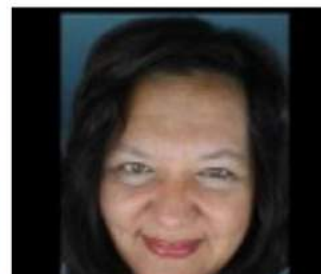
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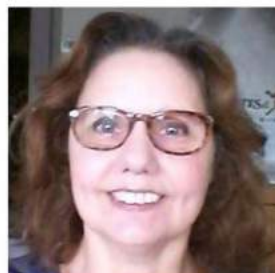
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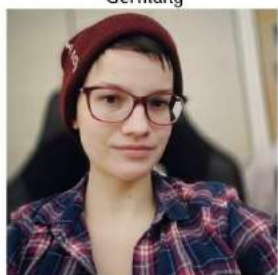
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**TICS AND
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TEAM**

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

Please support Tourette's across The Globe!



The Tourettes Across The Globe Team is organising this fundraiser.

€1,305 raised of €10,000 goal

17 donors 203 shares 22 followers

[Share](#)

[Donate now](#)

Oskari Korhonen
€100 - 2 months ago

Anonymous
€20 - 2 months ago

Paula-Riitta Huttunen
€20 - 2 months ago

Jerry gidner
€100 - 2 months ago

Robyn Twemlow
€30 - 3 months ago

[See all](#) [See top donations](#)



<https://gofund.me/c6cd2ce1>

CURRENT BALANCE



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)

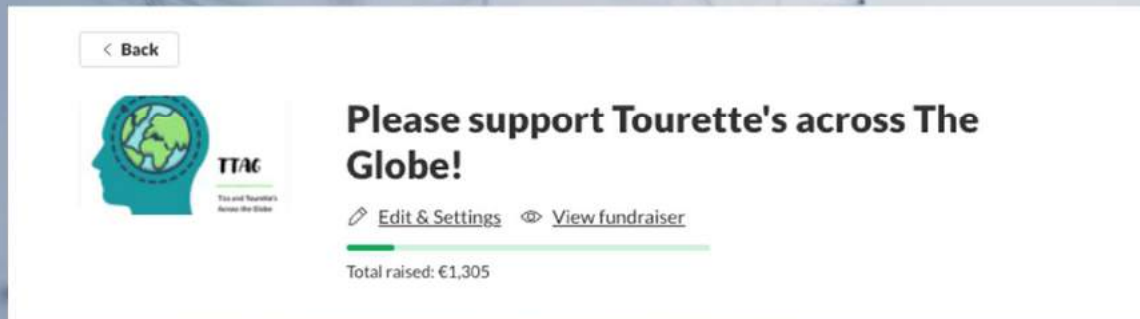
Our goal is to raise Euro 10.000

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



Please visit our GoFundMe campaign on:
<https://gofund.me/c6cd2ce1>
or scan the *GoFundMe*-barcode on the below:



We are very thankful for your
involvement and support!

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

FUTURE AIMS – PROJECT FUNDING



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 DEALINGS



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
German

Download

Guidelines in
Dutch

Download

Guidelines in
Italian

Download

EU GUIDELINES



[Review](#) > [Eur Child Adolesc Psychiatry](#). 2021 Aug 9. doi: 10.1007/s00787-021-01854-y.

Online ahead of print.

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

Seonaid Morag Anderson ¹,

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

GUIDELINES FOR RESEARCHERS



ESSTS **Guidelines for researchers**

Who is the leaflet for?
Anyone involved in research

Why is it needed?
Patients are the end users of health research; however, they are still rarely involved in the design of health research.

Some useful tips:

- † If not already doing so, adapt your budget where possible to include expenses and travel payments for research participants
- † Think about scheduling research participation sessions around work and school timetable

Researchers should involve patients in research design as it will:

- † Result in better/more accurate research outcomes
- † Brings the patients perspective into research
- † Benefit patients themselves
- † Maximize partnership and avoid exploitation
- † Benefit the support of patients for scientific studies and research as evidence of patients being involved in research design often required by research ethics committee

- 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.

TS ASSOCIATIONS DIRECTORY



- Collaborations include a chapter on patient associations around the world being included in a clinical textbook on Tourette Syndrome <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



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



ONENEUROLOGY ENDORSER



one
neurology



EFNA MEMBERSHIP



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?



WHY JOINING TTAG?



Benefits of joining TTAG:

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

FOLLOW & CONTACT US



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 Tics and Tourette Around the Globe

 @TTAGpatients

 #ttag_npo

 TTAG

SESSION 7: *Welcoming the past and the current ESSTS chair*

Speakers:

Andreas Hartmann

France

&

Kirsten Mueller-Vahl

Germany

Thank you for joining!



T TAG

Tics and Tourette
Across the Globe

SESSION 8: *Interactive part*



Moderator:
Seonaid Anderson
UK / Belgium

DISCUSSION AND POLLS



Polls:

- 1) Today's audience:
- 2) Your country/region and Tourette:
- 3) How you wish to join TTAG:

DISCUSSION



Topics:

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

OPEN DISCUSSION

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

OPEN DISCUSSION



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

OPEN DISCUSSION



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.

[illegible]