



# Goals of Treating Tourette Together

- Promote stakeholder engagement in defining research priorities for behavioral treatment of Tourette Syndrome.
- Comprehensive Behavioral Intervention for Tics (CBIT) = leading behavioral intervention
  - Identify stakeholder preferences for in-person CBIT, on-line self-guided CBIT, and tele-therapy CBIT
  - Identify perceived limitations of existing CBIT formats to ensure that future adaptations better fit the needs of stakeholders and healthcare systems.

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# The Team



**Matthew (Matt) Capriotti, PhD** is a clinical psychologist and Assistant Professor of Psychology at San Jose State University.



**Shannon Bennett, PhD** is an Assistant Professor of Psychology in Clinical Psychiatry at Weill Cornell Medical College and an Assistant Attending Psychologist at New York Presbyterian Hospital.



**Sara Hamilton** is a business consultant, marketing strategist and film producer. She's an active volunteer and member of the TAA Minnesota Chapter, and has a daughter with Tourette.



**Michael Himle, Ph.D** is a clinical psychologist and Associate Professor of Psychology at University of Utah



**Diana Shineman, PhD** is the Vice President of Research and Medical Programs at the Tourette Association of America (TAA)

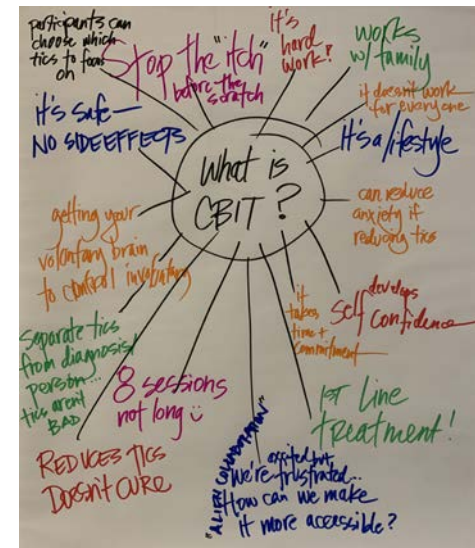


**Carolyn Hunt, MPA** has worked in community collaborative research for more than 20 years, bringing scientists together with patients, parents, providers, and others. Carolyn is serving as a facilitator for Treating Tourette Together.



**Christine Conelea, PhD** is licensed psychologist and Assistant Professor in the University of Minnesota Department of Psychiatry, Child and Adolescent Division

- Launched a website
- Pre-conference survey
- Organized an in-person summit
- Post-conference activity



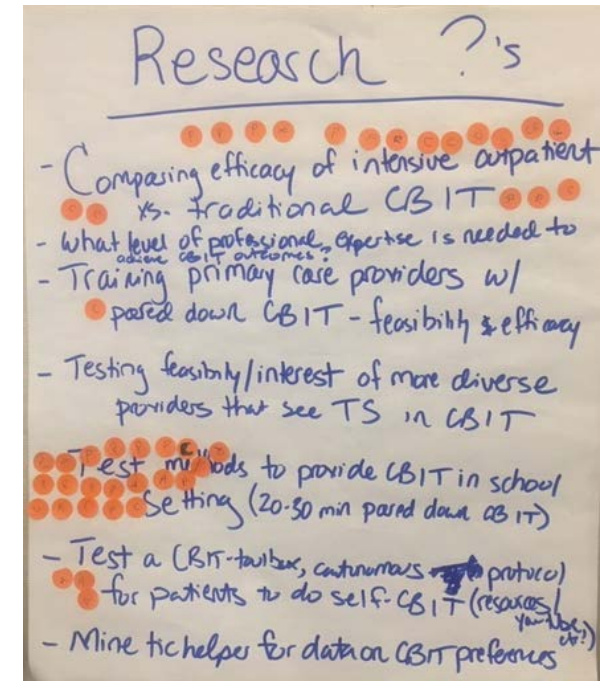
# The Summit

- We brought together a group of 45 individuals for the Summit in August 2019
  - youth and adults with TDs
  - parents of children with TDs
  - healthcare providers (including providers from neurology, psychiatry, psychology, pediatrics, occupational therapy, and primary care)
  - educators who work with people with TDs
  - TDs researchers
- Developed an application process and clear diversity principals to select participants fairly (*available on [treatingtourettetogether.org](http://treatingtourettetogether.org)*)



# What made the project successful?

- Pre-summit activities:
  - Pre-summit survey to gauge input from a wider summit (received close to 800 responses)
  - Webinars and pre-reading materials for participants
- The little things...
  - Name tags with first names, no degrees
  - Ice-breakers, interactive sessions, small group breakouts
- Communication!



***In a post-summit survey of attendees, 90% felt that their perspective was heard at the TTT summit. 95% said they would like to be involved in another summit like this in the future.***

# What was less successful?

- Achieving our diversity goals
- Reaching those not already connected to our community and “tapped” into available resources
- Post-summit outreach did not gain as much engagement (just over 50 responses vs. almost 800 in pre-conference survey)

# Key Outcomes

- Patient-centered research agenda (*available via [treatingtourettetogether.org](http://treatingtourettetogether.org)*)  
4 key areas
  - Increasing Access to CBIT
  - Increasing CBIT's Effectiveness
  - Optimizing How CBIT Fits into Individuals' Broader Care for TDs
  - Investigating CBIT's Impact on Outcomes that Matter to People Living with TDs
- Positive experience for researchers and patients
- New patient-researcher collaborations and relationships established
- Set a template for future projects at the TAA
- Hopefully more interest and funding toward related research projects