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.

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

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.

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.

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.

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

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

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)
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 treatingtourettetogther.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