

NEW JERSEY CENTER FOR TOURETTE SYNDROME AND ASSOCIATED DISORDERS INC.

MINUTES FOR THE DECEMBER 12, 2018 BOARD MEETING

LOCATION: NJCTS Main Office

TIME: 4:00-5:35pm

IN ATTENDANCE: Faith Rice, Andrew Hendry, Tim Kowalski, Santina Reichenbach, Conrad Roncati, Steve Lindenbaum, and Rebecca Spar and Tim Yingling via phone.

REGRETS: Tim Omaggio

AGENDA:

- 1) Approval of minutes from 21JUN2018 BOD meeting
- 2) Overview of 2018 Programs
- 3) Treasurer's Report
- 4) Bylaws
- 5) Sustaining NJCTS: Planning for the future, fundraising, growth

Approval of minutes from prior meeting:

The June Board meeting minutes were approved unanimously.

Overview of 2018 Programs:

Faith reviewed slides summarizing the Programs (attached, Appendix 2). Some highlights are as follows:

-Educational Outreach:

- More than 20,000 individuals were reached by NJCTS in 2018 through trainings, presentations, webinars and conferences
- Tabling and presentations across the State at conferences (Teacher's Convention, School Health Conference)
- Webinars, in the 11th year, reach families/individuals not only in NJ, but across the world.

-Medical Outreach Program:

- 13 Grand Round and patient centered medical education presentations
- A new Medical Outreach Coordinator, Sarah Holt, was hired
- 220 providers are on our Physician Referral Network list

-Community Outreach:

- Presentations were made to Community Service Organizations (CMO, FSO, FSA, FQHC), police departments and other first responders
- Tabling at Community events (NAMI, CNNH, Health Fairs, etc.)

-Family Outreach Services:

- 15th year of Camp Bernie family retreat weekend
- A new summer family picnic was added, and a winter event in S. Jersey is planned

- NJCTS provided direct support and referred families to NJCTS Community Partners, Physicians, and the NJCTS Clinic at Rutgers
- Youth Development:
 - 120 kids trained to date, many who have made presentations at schools, hospital Grand Rounds, and the NJ Dept. Ed. Dare to Dream program.
 - The 5th NJCTS Tim Howard Leadership Academy took place in 2018
- Research:
 - TIC Genetics at Rutgers, is the only federally funded TS genetics research program
 - Discussed scheduling tours of the repository for state Legislators (members of the Budget and Health Committees) and members of the Depts. of Health and Education
- Awareness:
 - The NJ Walks for TS Virtual Event and the TS Rocks Event were successful, and we will seek to do both in 2019
 - Discussed the desire to increase the attendance of the June 4th Tourette Syndrome Awareness Day event in Trenton

Treasurer's Report:

Copies of the Profit and Loss statement were circulated prior to the meeting for review. A summary of the Financial Statement update presented to the Board by Santina is in Appendix 1 on p.3. Our proposed operating budget for March 2018 through February 2019 has a net loss of approximately \$173,000 that was to be offset by past FYE's net profits (detailed in Financial Statement update), such that we are operating at a net profit of \$200,000. Although fundraising income was down, and donations were similar to the same period last year, total revenue was \$200,000 more than same time period last year due to second year receiving additional DOH grant funds and higher program income. Due to being fully staffed, personnel expenses are higher than last year; however, benefits are only slightly higher while spending on consultants was considerably lower. The Treasurer's Report was unanimously approved.

Bylaws:

It was acknowledged that the NJCTS Bylaws need to be updated. Andrew and Conrad will review and recommend changes for discussion at the next Board meeting.

Sustaining NJCTS:

- NJCTS will look to hire an Assistant Director, to be in place by 2Q2019. This critical position will seek to identify someone who can effectively transition to Executive Director.
- Grow programs
- Strengthen the Board of Directors by expanding, bringing on members with broad connections and fundraising capabilities.
- Revise and improve NJCTS branding and re-define deliverables. This includes marketing the NJCTS brand as a nationally/internationally recognized center of excellence for TS, and de-emphasizing the Organization as a solely NJ focused institution.

The date of the next Board meeting will be 12FEB2019 (location TBD)

Respectfully submitted by Tim Kowalski, Board Secretary

Appendix 1: Financial Statements Report

	Budget 3/1/18 to 2/28/19	Actual YTD 3/1/18 to 11/30/18	Actual YTD 3/1/17 to 11/30/17
Revenue	\$741,732	\$848,377	\$596,408
Expenses	\$914,676	\$645,136	\$566,919
Profit/(Loss)	(\$172,944)	\$203,241	\$29,489

Highlights:

Revenue:

1. Highest program income ever! In-service income was \$6,000, Grand Rounds income was \$5,500, Camp Bernie income was \$5,164 and Webinars income totaled \$1,440.
2. Fundraising income was down as we only had 2 fundraising events for the year. TS Rocks gross income was \$25,959 and Virtual Walk gross income was \$17,488.
3. Total revenue was \$200,000 more than same time period last year due to second year receiving additional DOH grant funds.
4. Donations are approximately the same as last year. However, due to in-kind pro bono attorney fees during 2017, donations appear \$18K more in 2017 than 2018.

Expenses:

- Personnel expenses are higher than the same time period last year as the organization is finally fully staffed. NJCTS has not been fully staffed for several years.
- Benefits are slightly higher than last year as the organization currently has 3 employees utilizing the medical benefits as opposed to 2 last year as well as the addition of a vision plan which was added in May. NJCTS is currently working on offering a limited dental plan as well.
- Consultants are considerably lower this FYE due to the successful renegotiation of the Academy Director's contract reducing her fee by 35% .

- After cancelling Camp Bernie last year, we had approximately 30 families attend this year with close to 100 individuals.
- Equipment purchases are above previous year's level due to computer and phone system upgrades and the purchase and installation of a kitchenette in the office.
- Fundraising expenses are down due to the switch from a physical walk to a virtual walk.
- The organization is operating at a significant net profit of \$200K.

Appendix 2: PPT Presentation

NJ Center for Tourette Syndrome & Associated Disorders

Collaborative Partnerships for the Tourette Syndrome Community



Established in 2004 as the nation's first Center of Excellence for Tourette Syndrome

2018 Educational Outreach



21 Youth Advocate Presentations



13 Grand Rounds



35 Faculty In-Services



34 Community Awareness Presentations



19 Tabling/Conference Events



10 Webinars



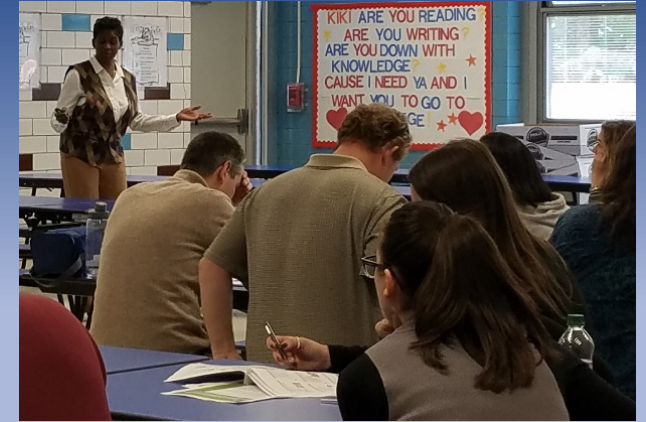
40 Research Articles Shared

**More than 20,000 individuals reached by NJCTS
in 2018 through trainings, presentations,
webinars and conferences.**



EDUCATION OUTREACH

- Faculty In-Service Presentations
- Youth Advocate Presentations in Schools and Hospitals
- Tabling and Presentations at Statewide Conferences: Teachers Convention, School Health Conference, Schools Nurses.



"Becoming a Youth Advocate for NJCTS has helped me build confidence in myself as I learn to live with my Tourette Syndrome, inspire others who live with it and educate those who don't. Now, I am a successful college student on my way to earning my degree in Early Childhood/ Special Education and Psychology. I am forever grateful for NJCTS and what they have done for me and my family." - Liane, NJCTS Youth Advocate

MEDICAL OUTREACH PROGRAM

- Hospital Grand Round and Patient Centered Medical Education Presentations
- Weekly Research Articles Sent to Physicians in Our Database
- Onsite Visits to Medical Practices
- Recruit Physicians through families, hospitals, referrals – 220 providers on NJCTS Physician Referral Network list



“Saint Peter’s University Hospital had an outstanding experience hosting a patient-centered Pediatric Grand Rounds on Tourette Syndrome, working with the New Jersey Center for Tourette Syndrome and Associated Disorders. Physician attendance was high and feedback extremely positive. Hearing from a young man with Tourette Syndrome and his family was very powerful. Our audience gained valuable insight into Tourette Syndrome and came away with a significantly expanded perspective on the difficulties patients and their families face.” – Dr. William Bernstein, The Children’s Hospital at Saint Peter’s University Hospital

COMMUNITY OUTREACH

- Presentations to Community Service Organizations: CMO, FSO, FSA, FQHC
- Presentations to Police and other First Responders
- Tabling at Community Events: NAMI, CNNH, Health Fairs, etc.

“Truly eye-opening information... I am much more educated on the broad spectrum of Tourette Syndrome and the associated disorders. I would highly recommend this training to anyone who is a care-giver, teacher, parent or guardian of toddlers or school-aged children. Our knowledge and understanding could be the key that opens the door for healing others suffering with this disorder.” - Carolyn McCombs, Executive Director, New Destiny Family Success Centers, Inc.



FAMILY OUTREACH & SERVICES

- Family Retreat Weekend, “Camp Bernie” – In its 15th year
- Summer Family Picnic – NEW
- Winter Event - NEW
- Referrals for services: NJCTS Community Partners; Physician Referral Network; NJCTS Clinic at Rutgers



“Met the nicest people, got a lot of information and my children met new friends and had a blast. Very worthwhile trip. Thank you!”

“The relationships and experiences we have formed have been invaluable.”

“She really can't do this consistently at school, it's hard for her to let her guard down. So, I had a much more open and relaxed daughter at Camp Bernie.”

“This weekend allows us to have a special moment of celebration for our child. TS has so many negative aspects that we all have to deal with and this weekend allows us to have some positive moments and memories to hold onto all year.”

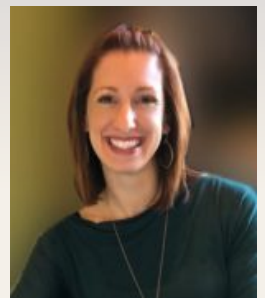
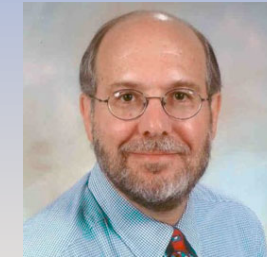


WEBINARS

- Entering its 11th year
- The NJCTS webinar series has featured more than 100 online seminars for parents, educators and professionals on topics of interest to the TS and associated disorders community, such as anxiety, OCD, sensory issues, bullying, school accommodations, and much more.

“Excellent presentation! I was interested in every word/concept. I have struggled with ADD all my life & will use the suggestions provided to help with focus. Thank you, Dr. A!” - Jeannine, school professional, New Jersey

“Fantastic! I could use a webinar on this weekly! It was particularly helpful that ideas for improvement were given for older teens and adults. So much of the material available today is geared toward young children.” - Heather, North Carolina



YOUTH DEVELOPMENT

- Youth Advocate Training – 120 kids trained to date
- Legislative Testimony & Proclamations
- School and Community Presentations
- Hospital Grand Rounds
- Dare to Dream – NJ Dept. of Education
- Scholarship Fund
- Mentoring Opportunities
- Event Involvement
- Fundraising
- Jeff Vitek Memorial Fund



NJCTS TIM HOWARD LEADERSHIP ACADEMY

- The 5th Academy took place this past Summer.
- The NJCTS Tim Howard Leadership Academy is designed to develop self-leadership, advocacy skills, and resilience in teens with Tourette Syndrome and its associated disorders. The program increases the participants' understanding of their disorders and provides opportunities and a safe environment to explore and identify their strengths, challenges, needs, and skills. The Academy provides an intentional space to build critical skills that will help young people with TS, like Tim Howard, to excel and, through that success, inspire others.



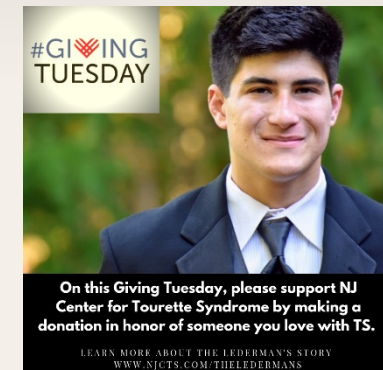
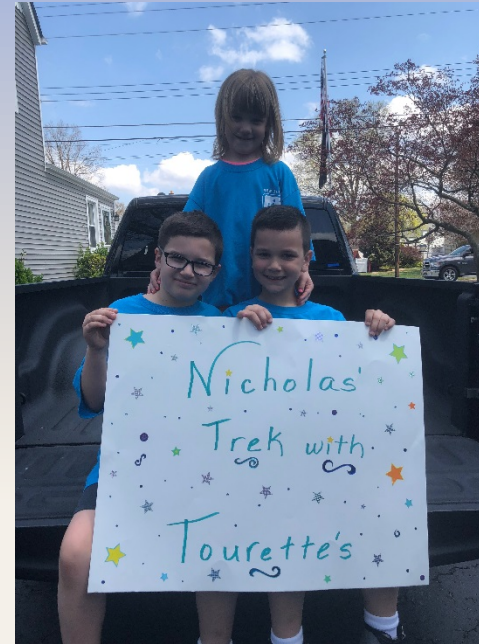
RESEARCH

- **TIC Genetics awarded \$10M for an additional 5-years to continue their work to understand the genetic causes of TS.**
- **TIC Genetics and collaborators identify a new high-confidence Tourette risk gene as well as two probable risk genes.**
- **TIC Genetics, based at Rutgers, is now the only federally funded TS genetics research program.**



AWARENESS

- Tourette Syndrome Awareness Day in New Jersey – June 4
- NJ Walks for TS – Virtual Event
- TS Rocks
- Social Media
- Newsletters
- Affiliates and Partners Sharing Around the World
- Literature



LOOKING FORWARD

- Child Mental Health Symposium – Voorhees. In partnership with Senator Troy Singleton, Virtua Hospital, NJ Academy of Pediatrics, NJAMHAA, NJDOE and NJDOH
- Winter Family Event – Medford
- Academy of Pediatrics NJCTS Youth Advocate recognition
- Expand Virtual Walk and June 4 event at NJ State House
- Expand multicultural and faith-based outreach
- Expand youth development training – ages 10 – 18
- Improve NJCTS branding and re-do deliverables
- Create youth development video for use in schools, marketing, etc.
- Build community

