

NEW JERSEY CENTER FOR TOURETTE SYNDROME AND ASSOCIATED DISORDERS INC.

MINUTES FOR THE DECEMBER 7, 2017 BOARD MEETING

LOCATION: PSE&G Conference Center, Edison NJ

TIME: 4:00-6:00pm

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

ABSENT: Amy Colcher

AGENDA:

- 1) Approval of minutes from September 19, 2017 Board Meeting
- 2) Treasurer's Report
- 3) Recent Events and Accomplishments
- 4) Fundraising and Awareness Discussion

Approval of minutes from September 19, 2017 Board Meeting

The September Board meeting minutes were circulated prior to the meeting for review and were unanimously approved.

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 on p.3. We are operating at a surplus due to the additional State funding. The transition to a new Governor and State Congress may result in the freezing of State funding, and this will need to be considered in planning for 2018. The Treasurer's Report was unanimously approved.

Recent events and accomplishments (Faith):

1) The TS Rocks event was a success – an estimated 350 people attended throughout the day, and ~\$28.8K in profit was generated. It was noted that there were few attendees who were in the NJCTS “network”; most attendees were at the event to see particular bands.

2) The NJ Walks at Bergen took place on Saturday, November 18, 2017 at Overpeck Park Amphitheater. Unfortunately the event was poorly attended, and the overall response to requests for sponsorships and donations was less than the 2016 event. The Walk generated \$14.5K in profit thanks to Conrad's leadership.

3) Two major scientific breakthroughs were published in distinguished high-impact journals by our partner researchers at the Rutgers Dept. of Genetics and Human Genetics Inst.

of NJ using samples from the NJCTS Tourette Syndrome Cell & DNA Sharing Repository (established in 2008). Both of these publications (*Mol. Psychiatry*, 2017, doi:10.1038/mp.2017.179 and *Neuron* 2017, 94, 486–499) constitute a significant advancement in our understanding of the underlying genetics of TS.

4) The Year End Appeal was mailed out and highlighted the Regen's family story and the positive impact of NJCTS on their lives.

5) Outreach activities: Faith reached out to John Amos regarding an inner-city outreach campaign that will address the stigma associated with mental health issues. Will work with a PR firm and involve Tim Howard with initial focus on the Newark market, but the goal is to have a campaign with a message that is applicable to any urban area.

Fundraising and Awareness

1) Given the recent scientific advancements made by our partners at Rutgers, the Board feels that we can capitalize on this to raise awareness and donations to further support efforts. Suggested points of focus were to get more DNA samples from NJ families affected by TS into the Repository, and request that they, and prior participants, donate accordingly. Additionally, Andrew will request a Legislative floor resolution, and Tim Y will work to generate a video highlighting the Repository and the recent findings for awareness efforts.

2) The Organization needs Leadership Academy funding for 2018. It was suggested that Faith reach out to Tim Howard in an effort to attract sport-related sponsors/partners.

3) Faith indicated that the Organization will take a more proactive approach in our Outreach Programs. This has been instituted in our Medical Outreach, with more Grand Rounds conducted this year, and this will be applied to other programs. All Programs will be reviewed in January 2018 and a strategy will be developed and shared with the BoD.

4) The Board discussed the value of bringing the TS Rocks concept to other areas of the state. With the right mix of bands and location, this has the potential to be a successful annual fundraising event and the consensus was that it should be explored.

Other items:

NJCTS is interviewing for a Family Outreach Coordinator, who will also be responsible for Volunteers and Medical Education Outreach, and for a Youth Development Coordinator.

Respectfully submitted by Tim Kowalski, Board Secretary

Financial Statements Report DEC 2018

	Budget 3/1/17 to 2/28/18	Actual YTD 3/1/17 to 12/6/17	Actual YTD 3/1/16 to 12/6/16	Projected 3/1/17 to 2/28/18
Revenue	\$618,000	\$596,384	\$473,675	\$845,387
Expenses	\$800,280	\$570,827	\$564,657	\$752,510
Profit/(Loss)	(\$182,280)	\$25,557	(\$90,982)	\$92,877

Highlights:

- Operating at a surplus due to the state's additional funding. Current projections indicate finishing the fiscal year end with an approximate \$100K net profit.
- Salaries are slightly higher than last year's but currently have 2 positions that still remain open.
- The Bergen walk brought in \$16K resulting in a \$14.5K net profit while the TS Rocks concert in Oct. generated \$32,760 with a net profit of \$28,792.