

NEW JERSEY CENTER FOR TOURETTE SYNDROME AND ASSOCIATED DISORDERS INC.

MINUTES FOR THE JUNE 21, 2018 BOARD MEETING

LOCATION: Teleconference

TIME: 4:30-5:45pm

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

ABSENT: Tim Omaggio

AGENDA:

- 1) Approval of minutes from 19APR2018 BOD meeting
- 2) Treasurer's Report
- 3) Brausch Family Update
- 4) Virtual Walk
- 5) TS Awareness Day (04JUN)
- 6) TS Rocks Benefit Concert/Liability Insurance Coverage

Approval of minutes from prior meeting:

The April Board meeting minutes will be reviewed by the Board within the next few days and voted on via email.

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 I on p.4. We are operating at a net loss of \$14,970 however, this does not include \$66,666 from the NJ DOH which will be received at the end of JUN. Our proposed operating budget for March 2018 through February 2019 has a net loss of approximately \$173,000 that will be offset by past FYE's net profits (detailed in Financial Statement update). The Treasurer's Report was unanimously approved.

Update on Brausch Family:

Andrew responded to the Brausch family with the letter attached in Appendix II on 24MAY2018. The letter conveyed the decisions of the Board regarding our application review and acceptance policies for the Academy. These include the following:

- NJCTS written materials to families and participants need to more clearly state that admission to the program can be denied, and that approved admissions can be revoked if it is NJCTS' judgement that a tic or behavior could result in the injury of the applicant or other participant, given the resources available to NJCTS at the Academy and structure of the Academy. Staff has already made modifications to written materials accordingly.

- It is appropriate to ask on the application whether the applicant has a touching or striking behavior to ensure further scrutiny of whether the applicant can safely participate in the Academy, given the specifics of that applicant's tic, reaction or behavior.
- However, checking that box, or subsequently reporting that there is a touching or striking tic or behavior will not be considered an automatic disqualifier. It will instead potentially trigger additional discussion with the family and/or applicant so that staff can gather additional information to determine whether, in their judgement (and the judgement of any additional professional with whom they may consult), the touching or striking behavior can be safely addressed given the available resources and existing program structure.
- It must be recognized, however, that if after acceptance staff becomes aware of touching or striking tics or behavior without sufficient time, in their judgement, to determine whether such may be safely addressed, an applicant's admission will have to be revoked. As I said in our call, the safety of all of the participants is absolutely paramount. While this circumstance would be terribly upsetting to any family and participant - as you well know - it is all the more reason that the "notice" that this can happen needs to be made very clear, as per my first bullet.

To date we has not received a response.

Virtual Walk:

Due to the very limited interest in the Princeton Walk scheduled for 02APR2018 in Mercer County Park, West Windsor NJ, the Organization opted to move to a Virtual Walk which lasted for the entire month of APR. It was advertised as an opportunity for families to conduct their own walk and activities to raise both money and awareness of TS. The response was impressive, and the Organization raised ~\$18,000 with very modest expenditures.

Given its success, the plan moving forward is to maintain the Virtual Walk model. For 2019, the Walk is scheduled to take place during the months of MAR, APR, and MAY, building up to TS Awareness Day on 04JUN.

TS Awareness Day:

The NJCTS held a successful event at the NJ Statehouse on 04JUN which featured the passage of a state proclamation declaring 04JUN as TS Awareness Day in NJ. At the event, the Organization recognized Scholarship Awardees, Youth Advocates, and teams that raised the most money in the Virtual Walk. State Senators Singleton and Bateman attended and participated in recognizing the Awardees and Youth Advocates. Families associated with the NJCTS also secured Township proclamations, recognizing 04JUN as TS Awareness Day in NJ.

TS Rocks Discussion:

Tim Yingling updated the Board on the Event. The event is scheduled for 22SEP2018. The venue, Indian Acres Tree Farm in Medford NJ, has been secured. They have made the farm available on 23SEP2018 as a rain date if we choose to use it. Currently, 3 bands are confirmed to perform and others have been contacted.

Tim and staff are in the process of applying for permits to serve alcohol. A liquor license is required as well as liability insurance. At the 2017 TS Rocks event, a \$3MM policy was taken out at a cost of \$1,000. The Board was comfortable taking out a policy for the same amount this year.

While the name of the event will be TS Rocks, the Organization will market it as a family fun farm day with music, beer/wine, farm attractions for kids, playground equipment, an eight acre maze, and hayrides.

Other Business:

Rebecca commented on the Scholarship Program. There were many very impressive applicants this year. The essays were moving, and many of the applicants were Youth Advocates. To date, over 200 scholarships have been awarded since the Programs initiation.

We have state funds available that need to be spent. Andrew proposed that this money be used, in part, to award bonuses to the staff. This recommendation was well received by the Board. A final decision will be made by the Executive Committee and brought to the Board for a vote.

A MLS camera crew will be at the NJCTS office on Monday, 25JUN, to film interviews with the staff. These will be used as part of a video describing off-field TS advocacy work done by Tim Howard.

The date and location of the next board meeting TBD

Respectfully submitted by Tim Kowalski, Board Secretary

Appendix I: Financial Statements Report

	Budget 3/1/18 to 2/28/19	Actual YTD 3/1/18 to 6/20/18	Actual YTD 3/1/17 to 2/28/17
Revenue	\$741,732	\$234,041	\$114,686
Expenses	\$914,676	\$249,011	\$193,869
Profit/(Loss)	(\$172,944)	(\$14,970)	(\$79,183)

Highlights:

Revenue:

- DOH grant income does not show the June payment of \$66,666 that is still owed. The state withholds the last month's funds until all grant reports have been submitted, reviewed and approved. This can take up to several months before funds are released and the grant closed. This amount will be recorded as a receivable at the end of the month.
- The virtual walk was a success with almost \$18K raised.

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 slightly higher this FYE due to the addition of a program measurement consultant and honorariums for the grand rounds that are currently scheduled.
- After cancelling Camp Bernie last year, we had approximately 30 families attend this year with close to 100 individuals. Cost to date is \$15,249.
- Equipment purchases will continue to be above previous years' levels as we continue to purchase and upgrade our computers, phone systems, and other equipment needs.
- Fundraising expenses are down due to the switch from a physical walk to a virtual walk.
- Although our profit and loss statement indicates a \$15K operating loss at this time, the organization is operating on a profit level since funding from the state for June is still outstanding.

Appendix II: Letter sent by Andrew Hendry to the Brauch family

Dear Mr. and Mrs. Brauch:

I apologize that it has taken me this long to get back to you, but I do want you to know that we had a full NJCTS board discussion regarding consideration of tics, reactions or other behaviors involving touching or striking vis-a-vis admission to the Tim Howard Leadership Academy.

Following were the sentiments of the board on this topic:

- NJCTS written materials to families and participants need to more clearly state that admission to the program can be denied, and that approved admissions can be revoked if it is NJCTS' judgement that a tic or behavior could result in the injury of the applicant or other participant, given the resources available to NJCTS at the Academy and structure of the Academy. Staff has already made modifications to written materials accordingly.
- It is appropriate to ask on the application whether the applicant has a touching or striking behavior to ensure further scrutiny of whether the applicant can safely participate in the Academy, given the specifics of that applicant's tic, reaction or behavior.
- However, checking that box, or subsequently reporting that there is a touching or striking tic or behavior will *not* be considered an automatic disqualifier. It will instead potentially trigger additional discussion with the family and/or applicant so that staff can gather additional information to determine whether, in their judgement (and the judgement of any additional professional with whom they may consult), the touching or striking behavior can be safely addressed given the available resources and existing program structure.
- It must be recognized, however, that if after acceptance staff becomes aware of touching or striking tics or behavior without sufficient time, in their judgement, to determine whether such may be safely addressed, an applicant's admission will have to be revoked. As I said in our call, the safety of all of the participants is absolutely paramount. While this circumstance would be terribly upsetting to any family and participant - as you well know - it is all the more reason that the "notice" that this can happen needs to be made very clear, as per my first bullet.

Again, I am very saddened that this whole experience became such a negative for you, and particularly your daughter. Our board of directors, consisting of parents and people with TS alike, took your concerns very seriously and have addressed the issues raised in the manner we feel is most appropriate.

I wish you all the very best.