

NEW JERSEY CENTER FOR TOURETTE SYNDROME AND ASSOCIATED DISORDERS INC.

MINUTES FOR THE April 19, 2018 BOARD MEETING

LOCATION: Asurion, Bridgewater, NJ

TIME: 4:30-6:30pm

IN ATTENDANCE: Faith Rice, Andrew Hendry, Tim Kowalski, Santina Reichenbach, Conrad Roncati, Rebecca Spar, Steve Lindenbaum, Tim Omaggio, Tim Yingling, and Barbara Chabner (present for Agenda item 3 only).

AGENDA:

- 1) Approval of minutes from December 7, 2017 Board Meeting
- 2) Treasurer's Report
- 3) NJCTS Leadership Academy Policy Discussion
- 4) TS Awareness Day
- 5) Other Business

Approval of minutes from prior meeting:

The December 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 of approximately \$100,000 (unaudited, pre-FYE AJE). 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. The proposed budget was unanimously approved and adopted.

NJCTS Leadership Academy Policy Discussion (Led by Andrew; Barbara Chabner present for discussion):

This discussion was precipitated by complaints regarding how the Organization handled the denial of entry to the Academy of Miki Brauch. Miki was initially accepted into the Academy for the 2017 session, but upon the disclosure of a new tic that involved hitting or kicking if she was touched during a staring episode the staff made the decision to deny entry just prior to the start of the session. This decision was based on the judgement by the Academy

review panel that the staff would not be able to appropriately ensure that Miki would not be touched by another participant during a staring tic, and that her response of hitting or kicking could endanger her or other participants. The Brauch family, while not happy that Miki could not attend the Academy, did not immediately express deep displeasure with the decision.

Several months later, however, they made the Organization aware of a letter written to Tim Howard detailing their view of what happened; this view clearly indicated that they were very upset with what had transpired. A letter was written to the Brauch family by Faith describing our process and why the Academy Review Panel came to their decision, and Andrew and Faith had a follow-up phone call. Andrew told the family that he would discuss this with the Board of Directors to determine what policy changes for the Academy, if any, would be needed regarding decision making and communication. The family suggested that we accept all applicants, and it was conveyed to them that we have an obligation to vet applicants to protect all attendees. They also indicated that touching was not sufficient criteria for exclusion of an applicant.

Several points and question were raised by Board members.

- 1) Is it appropriate to have a threshold for removal during the Academy or denial of acceptance?
- 2) Is touching others as a tic or a sequence of tics an appropriate threshold?
- 3) How deeply do we question the nature of the potentially discluding tic?
- 4) To what extent are we legally obligated to accommodate individuals?
- 5) How do we handle messaging when there may be individuals with tics that were excluding for one applicant because they appeared to not be under control and not for another because they had the skills to ensure no one was at risk of being injured?

The Board felt that having thresholds is appropriate and important for the protection of the attendees, coaches and staff. A tic that involves touching or hitting others will continue to be carefully considered by the review panel, along with other mitigating factors (maturity of the applicant, skills to remove themselves from an environment where they are at risk of touching/hitting etc). Barbara reviewed the process in place for the 2018 Academy, indicating that there is an extensive evaluation of each applicant. A Medical Advisory Team is available for additional consultation, with the understanding that they provide a perspective that is taken under consideration by the review panel.

At the conclusion of the discussion, two recommendations were made by the Board.

- 1) Ensure that the disclaimer in the application, which is reviewed and signed by the parents, is very clear regarding our review process and the possibility that the offer to attend may be rescinded in light of additional information.
- 2) Involve the Medical Advisory Team more in the review process. The nature of how this would be done is to be determined by the Review Panel.

TS Awareness Day:

NJCTS is scheduling an event at the NJ Statehouse on June 4th which will feature a State proclamation, and the recognition of Scholarship Awardees, Youth Advocates and top fundraising teams from the virtual walk. Families associated with NJCTS will be asked to secure Township proclamations, recognizing June 4th as TS Awareness Day in NJ. Additionally, the Education Outreach Coordinator will aim to schedule in-service presentations in schools by Youth Advocates to increase awareness of TS as part of our TS Awareness Day activities.

Other Business:

Tim Yingling is researching a TS Rocks event in South Jersey (Medford/Marlton area) for September 22, 2018. The venue identified is a farm that has the infrastructure to support hosting a concert. The Board was asked to reach out to contacts to identify bands that could be signed up for the event. It was also suggested that we reach out to the Philadelphia TS Chapter to enlist their support.

The date of the next board meeting is June 21. Time and location TBD.

Respectfully submitted by Tim Kowalski, Board Secretary

Financial Statements Report

	Budget 3/1/17 to 2/28/18	Actual YTD 3/1/17 to 2/28/18	Actual YTD 3/1/16 to 2/28/18	Proposed 3/1/18 to 2/28/19 Budget	Actual YTD 3/1/18 to 4/18/18	Actual YTD 3/1/17 to 4/18/17
Revenue	\$618,000	\$879,860	\$639,344	\$741,732	\$151,552	\$68,900
Expenses	\$800,280	\$779,250	\$750,959	\$914,676	\$104,372	\$84,645
Profit/(Loss)	(\$182,280)	\$100,610	(\$111,615)	(\$172,944)	\$47,180	(\$15,745)

Proposed Budget 3/1/18 to 2/28/19 Highlights:

Revenue:

- DOH grant is based on \$533,332, which includes the March through June monthly advance payments of the additional funds awarded. However, we still have \$241K of the \$800k that still needs to be expensed during this time frame.
- All other income is based on past performance and projections based on current information.
- Fundraising income is based on historical amounts generated, however, we currently have only one fundraiser scheduled for this year which is our virtual walk and will produce an estimated \$10K.

Expenses:

- Personnel is based on full staff projections, which the organization currently maintains. It also includes bonuses in lieu of raises to all employees. Bonus amounts/percentages have yet to be determined. It also accounts for a couple of summer interns that the organizations has utilized for the past several years.
- Benefits are projected at 12% of salaries. This includes medical coverage for 3 employees and projected dental and vision coverage for 3 employees. Currently the organization contributes 60% of the employees medical cost on a monthly basis.
- Consultants are estimated to be higher this FYE due to the addition of a program measurement consultant for 6 months and honorariums for the grand rounds that are currently scheduled.
- TS Practica was increased by \$25K due to the recently negotiated agreement to hire a full time clinical director to replace the resigned part time director.

- Leadership Academy is slightly lower this FYE as we have a slightly lower accepted applicant's rate than last year.
- Equipment purchases are relatively high this year as we are using the increased funding to purchase and upgrade our computers, phone systems, and other equipment needs.
- Program expenses were increased to account for updating and reprinting NJCTS brochures.
- All other expenses are based on historical numbers.
- This leaves an approximately \$173K net loss that will be offset by past FYE's net profits.

Actual YTD 3/1/17 to 2/28/18 Highlights:

- Net profit will change slightly after all year end adjusting journal entries are completed along with the audit.

Actual YTD 3/1/18 to 4/18/18 Highlights:

- Although currently operating at a net profit, we still have \$241K of expenditures slated to be use by 6/30/18 with only \$133,500 of income expected to be received.