

NEW JERSEY CENTER FOR TOURETTE SYNDROME AND ASSOCIATED DISORDERS INC.

MINUTES FOR THE SEPTEMBER 26, 2019 BOARD MEETING

LOCATION: Asurion, 500 Somerset Corporate Blvd., Bridgewater, NJ 08807

TIME: 4:00 – 6:05pm

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

AGENDA:

- 1) Board minutes approval from June meeting
- 2) Youth Development Program overview (presented by Lisa)
- 3) Review of Education Outreach Strategic Plan (presented by Pat Phillips)
- 4) Financials
- 5) Review of revised Organization By-Laws

1) The minutes of the June 18, 2019 Board Meeting were unanimously approved.

2) Youth Development Program overview

Lisa provided an overview of the Youth Development Program to the Board. Key highlights were:

- Youth Advocate (YA) training program
 - NJCTS conducts 2 training sessions per year (most recent on Oct. 12, 2019)
 - Approx. 140 YAs have been trained to date; however, only ~15 are actively giving advocacy presentations
 - Re-evaluate training to make it more interactive; less instructional, more involvement.
 - Ensure that older YAs attend the training sessions
- Interactions with YAs
 - Instituting a buddy program, pairing older active YAs with recently trained YAs
 - Set requirements for YAs – nothing onerous – goal is to achieve more commitment from them
 - Institute more frequent check-ins with YAs to help them stay engaged
- Establishing a Focus Group to establish ways to engage kids affected by TS earlier (increase awareness of NJCTS) and build a community for the young adult community. Co-chaired by Tim Yingling.
- The Board screened a YouTube video that was created to promote the YA/Youth Development and Education Outreach Programs of the Organization

A summary of additional information presented is attached in Appendix I

3) Review of Education Outreach Strategic Plan (2019-2020)

The objectives of the Education Outreach Strategic Plan are to increase the number of communities reached, including underserved and urban, continue outreach to mental health agencies

serving underserved and urban communities (FQHCs) and to broaden the engagement of in-service presenters. The NJCTS will strive to be the lead organization, and nationally recognized as a model program, for the creation and delivery of solutions for the TS community.

There is a special focus on targeting underserved communities that has 3 key goals:

- Increase education, outreach and support for families in NJ's urban areas including Hudson, Essex, Passaic and Camden Counties
- Conduct outreach and training to pediatricians, family physicians, neurologists, and psychiatrists in urban areas to improve early diagnosis and treatment
- Provide training in schools in urban areas to improve diagnosis and strategies for accommodating children with neurological disorders in the classroom thereby improving learning and acceptance.

There are 6 primary target categories in the Outreach Program: families, schools, the medical community, law enforcement, the Dept. of Vocational Rehabilitation Services, colleges and universities, and government department heads. A description of efforts focused in each of these categories is summarized in Appendix II.

4) Financials

Santina provided a summary/review of the current financials. Total revenue is approximately \$52K higher than the same time period last year due to receiving additional DOH grant funds for the second year in a row. However, donations to the organization are down as no fundraising activity was held during this time frame. Personnel expenses are slightly lower than the same time period last year as the organization currently had one position open that has recently been filled on a part-time basis. Benefits remain unchanged from last year but will come in slightly lower as we currently have only 3 employees enrolled in our medical plan instead of 4. All other expenses remain in line with the previous year. However, due to higher income this year to date, the organization is operating at a strong net profit of \$57K.

The financial statement report is attached in Appendix III

5) Review of revised Organization By-Laws

Rebecca raised an issue with Article V Section 2. It currently states that the Executive Committee has the power to make decisions in the interest of the Organization without full Board approval and report these decisions to the Board. It was unclear what, if any problems, existed that necessitated this change other than certain financial decisions that Rebecca felt didn't constitute a sufficient rationale for this change. It was agreed that the wording would be re-evaluated.

Rebecca also indicated that it was unclear what exactly Article VIII Section I, (Indemnity) was stating and agreed to review and propose alternate language to make this clearer. Also, with respect to Article VIII Section 2 (Insurance), it is not clear who has the power to purchase insurance (the Board? Executive Committee?).

In Article IX, Conflict of Interest, the reference to "any other Committee" raised concern for lack of clarity.

Tim Yingling raised an issue with the wording in Section 2: Mission. It specifically refers to 'the advocacy of children and families with Tourette Syndrome' which is restrictive and doesn't represent

the broader population range that the Organization serves. The Board agreed that this should be revised, along with the mission statement to better reflect who we currently serve.

The Board agreed that we would table a vote to approve the revised by-laws and while we continue revising based on the concerns raised.

6) Other business:

There was a discussion on establishing a policy, or a practice, on how we disseminate information on recent research findings and opportunities to participate in clinical research without having this appear to be advocating for the research being conducted. Tim Kowalski agreed to review and bring a proposal to the Board at the next meeting.

Faith informed the Board on two potential new Board members, one of whom is a pediatric neurologist and the other a Chair of Rutgers Univ. Hospital Newark, and will keep us updated on any progress re: their appointment to the Board

Meeting was adjourned at 6:05pm.

Respectfully submitted by Tim Kowalski, Board Secretary

Youth Development Program

Youth Advocate Program:

- Youth Advocate Trainings
- Youth Advocate Presentations
- Grand Rounds Presentations
- PCME Presentations
- Participation in Dare to Dream Conferences
- Providing Legislative Testimony (when applicable)
- Participation in Various Mentor Panels (Family Retreat, Leadership Academy)
- Obtaining Proclamations for TS Awareness Day
- June 4th Celebration
- Event Involvement (ex. Virtual Walk)
- Read Across America
- Blogging

New items for Youth Advocates:

- *Bernie Buddies*
- *Family Picnic*
- *Teen Leadership Conference*
- *Training assistants*

Other Key Programs Under the Youth Development Umbrella:

- NJCTS Tim Howard Leadership Academy
- Scholarship program

To Strengthen and Grow the NJCTS Youth Development Program:

Youth Advocates Specifically:

- Targeted Outreach
 - Email Youth Development program brochures to superintendents, principals, guidance counselors and child study team members end of September/October for anti-bullying month; a second one done
 - Hard copy brochures to guidance counselors

- Design the YA training in such a way that it is more motivational and empowering so that our Youth feel comfortable venturing out; meet them where they are
 - Tool kit
 - Youth Advocate mentors at training
- Set forth specific requirements to be a Youth Advocate:
 - Create a Gmail account specifically for YA information and commit to checking it
 - Commit to two events per year
 - Complete a “bio” to be placed in their personnel file; helpful information that can be utilized when highlighting them to our NJCTS community and beyond
 - Tracking hours and check in with YDC when a project is complete
 - YA t-shirts; advertising for the organization and conversation starter
- Routine Check ins
 - Monthly check-ins with Youth Advocate roster; pointed questions that elicit a response to keep them engaged
 - Check-ins every other month in order to keep these groups connected to what we are doing as an organization
 - graduated Youth Advocates
 - scholarship winners
 - academy attendees
 - academy coaches
- Focus group made up of academy coaches and academy graduates to strategize on how to build a solid community for young adults (14 – 34) with TS.

Other important connections that will help build our community and in turn, our YD program:

- As needed basis for the following:
 - Approach graduated Youth Advocates with presentation opportunities when available
 - Enlist graduated YA's to participate in Youth Advocate trainings
 - Enlist graduated YA's, Sch. Winners, academy attendees/coaches to take part in our annual virtual walk
 - Enlist graduated YA's, Sch. Winners, academy attendees/coaches to be on the Camp Bernie Mentor Panel
 - Enlist graduated YA's, Sch. Winners, academy attendees/coaches to be coaches at the Leadership Academy

- Bill Freeman-Department of Education; collaborate on how to improve the break-out sessions for Dare to Dream
- Resources Page on Website
 - Pamphlets/information that can be handed to teachers, other parents, family members, etc.
 - Links to relevant, useful articles
 - Tips for IEP, 504 planning meetings
 - Downloadable version of ID cards and “business cards” for younger kids that explains what TS is; email address to request a hard copy of the card
 - Other...
- Family Reach Out List
 - Survey some of our known families to see who would be comfortable being on our contact list
 - Design the list so that you have a mix of age ranges
 - Have a specific list for young adults and utilize Academy Coaches for this
 - List is available to all staff so that at any given time we have can help make connections with new families

Appendix II: NJCTS Education Outreach Strategic Plan

NJCTS Education Outreach Strategic Plan

July 1, 2019– June 30, 2020

Summary

NJCTS's education outreach plan will utilize a proactive approach for increasing awareness of Tourette Syndrome and its associated disorders in the state of New Jersey. Through our many programs and services we will educate the public, medical community and teaching professionals about the complexity of the disorder. *NJCTS will be the lead organization and nationally recognized as a model program for the creation and delivery of solutions for the Tourette Syndrome community.*

Tourette Syndrome often goes unrecognized and under-diagnosed in minority children with less ready access to health care. Therefore, the plan includes a special focus on targeting underserved communities. These underserved communities have been defined by an analysis of the District Factor Group (DFG), Medically Underserved Areas (MUA), and Abbott School Districts indicators. The focus of the outreach to underserved populations has three key goals:

- 1) Increase education, outreach and support for families in New Jersey's urban areas including Hudson, Essex, Passaic, and Camden Counties.
- 2) Conduct outreach and training to pediatricians, family physicians, neurologists, and psychiatrists in urban areas to improve early diagnosis and treatment.
- 3) Provide training in schools in urban areas to improve diagnosis and strategies for accommodating children with neurological disorders in the

classroom thereby improving learning and acceptance.

Hudson, Essex, Passaic, and Camden Counties are inner cities we have identified foremost. However, the model outlined below will be used for all counties in our efforts to increase education, outreach and support for families. The specific underserved counties are as follows: 10/14/2019

Camden County Districts

- ☐ Camden City
- ☐ Gloucester
- ☐ Clementon Borough
- ☐ Pine Hill Borough

Essex County Districts

- ☐ East Orange
- ☐ Irvington
- ☐ Newark
- ☐ City of Orange

Hudson County Districts

- ☐ Union City
- ☐ West New York

- ☐Harrison
- ☐Jersey City
- ☐Hoboken

Passaic County Districts

- ☐Passaic City
- ☐Paterson City

II.Outreach To Families

Identify the sources where families, people of color and those in the underserved communities seek supportive services, medical attention, recreation and education. Emphasis will be placed on reaching families through various community, government, and professional organizations as well as parent groups. The implementation of the education outreach will be done through our faculty in-service, community, and/or youth advocacy presentations.

Care Management Organizations (CMOs) provide a single point of accountability to ensure services are accessed, coordinated, and delivered in a strength based, individualized, youth focused, family driven, ethnically, culturally, and linguistically relevant manner.

- ☐Presented to Community Resource Directors for the state
- ☐Continue to reach out to individual CMOs in key counties
- ☐Conducted Community Awareness presentation to staff
- ☐Promote Wednesday Webinars
- ☐Maintain Connection with CMO liaison
- ☐Add to Constant Contact

Family Support Organizations (FSOs) are family-run, county-based organizations that provide direct family-to-family peer support, education, advocacy and other services to family members of children with emotional and behavioral problems.

- ☐ Presented to FSO Directors for the state
- ☐ Continue to reach out to individual FSOs in key counties
- ☐ Conducted Community Faculty In-Service or Community Awareness presentations for staff and families
- ☐ Promote Wednesday Webinars
- ☐ Maintain Connection with FSO liaison
- ☐ Add to Constant Contact

Family Success Center (FSCs) offer primary and secondary child abuse prevention services to families and brings together concerned community residents, leaders, and community agencies to address the problems that threaten the safety and stability of families and the community.

- ☐ Presented to FSC Directors for the state
- ☐ Presented to individual FSCs in key counties
- ☐ Conducted Community Awareness presentation for staff and families

- ☐ Promote Wednesday Webinars
- ☐ Maintain Connection with FSC liaison
- ☐ Add to Constant Contact

Children's Interagency Coordinating Councils (CIACCs) are entities that foster cross system service planning for children with behavioral health problems.

- ☐ Presented to all CIACCs
- ☐ Presented at Education Partnership meetings
- ☐ Promote Wednesday Webinars
- ☐ Maintain Connection with CIACC liaison
- ☐ Add to Constant Contact

The Arcs

The Arcs work to help people with intellectual and other developmental disabilities achieve their fullest potential. The wide range of services offered span the lifetime of the person with a disability, and support both the individual and their family.

- ☐ Presented to Arc of New Jersey
- ☐ Investigate presenting to Executive Directors for the Arcs
- ☐ Reached out to individual Arcs in key counties
- ☐ Promote Wednesday Webinars
- ☐ Maintain Connection with Arc liaison
- ☐ Add to Constant Contact

Professional Organizations

Identify professional organizations that aid underserved families or have connections to these communities. Organizations that empower families through advocacy and education. (e.g. NASW, Council for Exceptional Children, Learning Disability Association)

- ☐ Conducted Community Faculty In-Service or Community Awareness presentations for staff and families
- ☐ Presented at organization conferences
- ☐ Promote Wednesday Webinars
- ☐ Maintain connection with professional organization liaison
- ☐ Add to Constant Contact

Local Community Organizations

Identify local community organizations that service children and their families. Organizations that work with families on health and wellness and social and emotional concerns.

(e.g. Center for Family Services).

- ☐ Conducted Community Faculty In-Service or Community Awareness presentations for staff and families
- ☐ Promote Wednesday Webinars
- ☐ Maintain connection with community liaison

- ☐ Add to Constant Contact

Local Parent Organizations

Identify special education support groups for parents (e.g. La Casa de Don Pedro, Parents for Greater Camden Schools, SEPAC)

- ☐ Conducted Community Faculty In-Service or Community Awareness Presentation for families
- ☐ Emphasize NJCTS Youth Advocacy Program
- ☐ Emphasize NJCTS services and programs- PRN, Camp Bernie, Walks
- ☐ Promote Wednesday Webinars
- ☐ Maintain connection with parent organization liaison
- ☐ Add to Constant Contact

II. Outreach To Schools

The outreach to schools is critical as TS can affect students' academic performance. Informed teachers and staff can incorporate effective accommodations and strategies to use in the classroom. Also, because TS is a stigmatizing disorder, students are often the targets of bullying. Peer to peer education on TS can be effective in destigmatizing the condition and creating healthy learning environments.

Identify schools in the community and promote the benefits of faculty in-service and youth advocacy presentations.

- ☐ Extend reach beyond traditional public schools. Identify charter schools, alternative schools, schools for students with special needs, parochial schools
- ☐ Presented to special education directors, child study team supervisors, principals, school social workers,
- ☐ Presented at roundtable meetings, county superintendents, county roundtables, county special education directors, professional development trainings, workshops
- ☐ Presented to School Nurse Associations
- ☐ Conducted 2 workshops for NJPSA
- ☐ Presented/Tabled at conferences on education/mental health (e.g. NJEA)
- ☐ Followed up with NJCTS parents to schedule in-service and youth advocacy presentations

III. Outreach to Medical Community

Educating the medical community is instrumental. Emphasis will be made to reach hospitals, medical colleges/universities, professional health organizations, and health centers that serve urban and underserved communities.

Hospitals & Medical Colleges and Universities – Through Grand Round presentations and PCMEs we will educate physicians and residents about Tourette Syndrome.

- ☐ Identify hospitals in key underserved communities (e.g. St. Joseph's, Newark Beth Israel Medical Center)
- ☐ Identify medical education department at hospitals

- ☐ Contact directors of residency programs, department heads for neurology, pediatrics, family medicine, psychiatry
- ☐ Conduct Grand Rounds & PCMEs for staff
- ☐ Maintain connection with hospital/medical college liaison
- ☐ Add to Constant Contact

[Note: The Medical Outreach plan to hospitals and medical teaching colleges/university is currently managed by the Family Support Coordinator]

Federally Qualified Health Centers (FQHCs) deliver health care to all people regardless of their ability to pay. They serve the uninsured as well as patients with Medicaid, NJ Family Care, Medicare and private insurance.

- ☐ Present to NJ Primary Care Association Board
- ☐ Establish connection to Chief Medical Officers at FQHCs to disperse literature and information
- ☐ Educate providers at FQHCs
- ☐ Connect with Horizon Health, Zuffall, North Hudson, Newark Community Health University Hospital
- ☐ Present/Table at NJ Primary Care Association (NJPCA) Conference
- ☐ Maintain connection with liaison at NJPCA
- ☐ Add to Constant Contact

Professional Health Organizations of Color

Identify professional health organizations of color that aid underserved families or have connections to these families (e.g. Latino Mental Association, Association of Black Psychologist, Black and Latino Nurses Association)

- ☐ Conducted Community Faculty In-Service or Community Awareness presentation for staff/members
- ☐ Present or table at organization conferences
- ☐ Promote Wednesday Webinars
- ☐ Maintain Connection with professional organization liaison
- ☐ Add to Constant Contact

Special Child Health Services (SCHS) DOH

Works with parents, physicians and/or specialists to evaluate an affected child's strengths and needs. Collaborates with the family and community based organizations to develop an individual service plan.

- ☐ Identified statewide meeting for unit coordinators
- ☐ Conducted Community In-Service presentation w/family
- ☐ Promote Wednesday Webinars
- ☐ Maintain Connection with unit coordinator liaison
- ☐ Add to Constant Contact

IV. Outreach to Law Enforcement

Educating law enforcement professionals and emergency first responders about TS will augment the skills and training they already have and is not designed to dictate how they do their job.

- ☐ Identified the various police academies across the state
- ☐ Identified law enforcement and first responders associations, conferences
- ☐ Conducted Community In-Service for officers, first responders
- ☐ Presented at Crisis Intervention Trainings
- ☐ Present at association meetings or conferences on mental health

V. Outreach to Department of Vocational Rehabilitation Services

- ☐ Identified various DVRS offices across the state
- ☐ Conducted Community In-Service for counselors, job coaches, social workers
- ☐ Promote Wednesday Webinars
- ☐ Maintain Connection with liaison at DVRS offices
- ☐ Add to Constant Contact

VI. Outreach to Colleges/Universities

- ☐ Members of NJ Ahead
- ☐ Presented to NJ Ahead members
- ☐ Contacted all NJ Ahead members (Special Services Dept.) sent Iceberg flyer
- ☐ Promote Wednesday Webinars
- ☐ Maintain membership with NJ Ahead
- ☐ Guest Lecturer at Rutgers GSAPP, Montclair University, Rowan

VII. Outreach to Government Department Heads

Greater emphasis on establishing partnerships with the Department of Health, Department of Children and Families, and Department of Education. Connecting with these departments can expand reach to larger audiences.

- ☐ Identified decision makers for the different agencies
- ☐ Identified special programs on mental health
- ☐ Identified special programs for children and families
- ☐ Presented at state meetings – county supervisors child study
- ☐ Conducted Community Awareness or Community In-Service for staff or families (e.g. CCYC)

Appendix III: Financial Statement Report

	Budget 7/1/19 to 6/30/20	Actual YTD 7/1/19 to 9/16/19	Actual YTD 7/1/18 to 9/16/18
Revenue	\$984,000	\$205,881	\$153,135
Expenses	\$884,250	\$148,171	\$153,346
Increase to Net Assets	\$ 99,750	\$ 57,710	(\$ 211)

Highlights:

Revenue:

1. Total revenue is approximately \$52K higher than the same time period last year due to receiving additional DOH grant funds for the second year in a row.
2. However, donations to the organization are down as no fundraising activity was held during this time frame.

Expenses:

1. Personnel expenses are slightly lower than the same time period last year as the organization currently had one position open that has recently been filled on a part-time basis.
2. Benefits remain unchanged from last year but will come in slightly lower as we currently have only 3 employees enrolled in our medical plan instead of 4.
3. All other expenses remain in line with the previous year. However, due to higher income this year to date, the organization is operating at a strong net profit of \$57K.