

MINUTES
NJCTS BOARD MEETING – NOVEMBER 15, 2011

Attendees:

Faith Rice
Tim Omaggio
Eliot Goldstein
Rebecca Spar
Cindy Yingling
Conrad Roncati

Unable to attend:

Paul DaCosta
Jamie Levitz

Financial Review (Faith):

- Current balance in NJCTS account ~ \$882,000; \$235,000 Restricted funds to support specific activities and programs (ex. Retreats, Advocacy etc.)
- Current balance in TSANJ account is ~ \$400,000; this will be transferred to an NJCTS account (Vanguard) by the end of the year. We may reach out to Bill Hoffman for investment advice. Mr. Hoffman is endorsed by Cindy and Eliot. Cindy was reaching out to Bill immediately.
- Total Balance for the organization: \$1,292,000.
- N.J. State Funding: remains at \$400,000 annually. Reminder, this funding is down from a high of \$1,250,000 three years ago.
- The 2012-13 NJ State Fiscal Year funding will become a Competitive Grant, which means that any NJ agency can bid for this funding. This is of itself a concern, but there will be specific support requirements for TS that would have to be met including some of our prominent programs. While this makes us more confident, Faith is still taking the step of meeting with DOH Asst. Commissioner in December regarding ongoing support from the State and to identify any potential issues.

Federal Grant and Federal Legislation (Faith):

- A Federal Grant of \$1.5 million has been secured to fund 26 locations around the world for participation in the DNA Repository. These collaborators began collecting samples effective September 15, 2011 using NJCTS/Rutgers model. All samples are sent to the NJCTS Sharing Repository at Rutgers for processing and storage and made available to researchers on request. This funding is a direct result of efforts led by Dr. Tischfield and it is currently the only federally funded TS research taking place. NJCTS continues to have financial responsibility for monthly visits by Dr. King, Yale Child Study Center. \$75,000 has been funded in the past through a gift from Mrs. Ruth Eni.

- Rep. Sires will soon introduce a Bill to support TS. The details of the Bill were previously shared with Board Members. Faith offered to answer any related questions. This Bill will hopefully lead to funding by the Federal Government of six regional Centers of Excellence across the country modeled on NJCTS. Draft of legislation is attached.

Treasurer Candidate (Faith):

- Faith announced that she had identified a candidate to be the NJCTS Treasurer and Board Member. He is Paul Romano. A short bio is attached. Tim and Eliot will meet with Mr. Romano in near future and hopefully soon after offer him the Board and Treasurer positions. Mr. Romano is a business neighbor and has no direct connection to TS or the work we do. It was noted by Faith and acknowledged by Board Members, that it is important that we re-establish a Treasurer on our Board. This has also been encouraged by our Accountant and Auditor. It was also noted that Santina Reichenbach would continue to do day to day Bookkeeping functions.

NJ Walks for TS (Faith):

- Faith reminded everyone that the NJ Walk for TS in Mendham is Saturday, November 19th. Tim and Conrad will attend as fundraisers and Tim will also co-MC the event. While we are not confident we will reach our goal of \$50,000 this year, with \$18,300 already collected, we do believe we will exceed last year's amount of \$27,000. Board Members were encouraged to attend and show their support. We expect a very well attended and supported event.

TS Awareness Day (Faith):

- We are planning a TS Awareness Day at nearby Patriot's Ballpark in Bridgewater on April 29th where a Governor's proclamation will be issued and we will recognize scholarship and teacher of the year recipients. We have an opportunity to raise money that day through 50/50 and Corporate Sponsors; we are also expecting the fulfillment of a \$10,000 pledge by the Patriot's owner.

No Show Ball (Faith and Cindy):

- We are hoping to stage a "No Show Ball" for Valentine's Day 2012. Cindy described a successful fundraiser done by Ronald McDonald House. "Guests" are asked to RSVP that they "won't attend" and will give donation instead. Board agreed to pursue this and Faith will contact Alan to prepare invitation. Sample of "no show" info is attached. Conrad suggested we do via eVite online and tap into our previous Dinner attendees list and to the broader membership. Faith indicated when e-mail is sent to 2100 individuals on list, only around 600 actually open the email. Office is now e-mailing and sending out hard copy.

Advisory Board (Faith and Eliot):

- Eliot raised the need for a Medical Advisory Board. It was noted that we've talked about this for years and haven't formally followed through. We all agreed that we need to do this and

that there are many friends of the organization who would be excellent candidates. Tim and Eliot will meet soon in Somerville to discuss.

Board Meeting Planning (Tim):

- Tim led a discussion about the need to improve our Board Meetings. Tim identified some fundamentals that could be implemented as a start:
 - Early identification of agenda.
 - Ownership by Board Members to lead on topics of interest for presentation at Board Meetings.
 - Formalize more through better visual communications; PPT etc.
 - Utilize Guest Speakers more often as subject matter experts and advisors.
 - Improved commitment from Board Members to attend meetings and avoid last minute no shows.
 - Clear documenting and follow up of identified initiatives.
- The discussion yielded more ideas including the need to establish sub-committees in important areas such as Communications/Outreach and Financial/Fundraising.
- Board Meetings will be every two months in 2012 with a preliminary plan for 4 in person meetings and 2 Conference Bridge Meetings.
- Tim offered the Conference facilities of his company, Asurion, in Bridgewater, on an ongoing basis.

Faith and Tim closed the meeting by committing to the Board that we will immediately begin to plan for the next Board Meeting in January and will utilize the suggested improvements.

The next NJCTS board meeting will take place on January 17, 2012