

Minutes of November 30, 2012 NJCTS Board Meeting

Location: Cole, Schotz, Meisel, Forman & Leonard offices, Hackensack, NJ

In Attendance: Elliot Goldstein, Tim Omaggio, Faith Rice, Rebecca, Conrad Roncati

Unable to Attend: Jamie Levitt

Topics of Discussion:

1. **Board Membership:** It was decided to increase Board membership to a minimum of nine members. Eight candidates for the Board were discussed. Stuart Green, social worker and expert in anti-bullying, will be invited to serve on the Advisory Board. Offers for Board membership will be extended at this time to Martin Topiel, physician in Cherry Hill, and Mark Brummer, Newark Deli owner. Faith will extend the offers and if they accept, a formal letter and member packet including the document describing the responsibilities of Board Membership and background information will be sent to them. In addition, new Board members will be invited to NJCTS for a more in-depth review of the organization.

In January and February, offers will be extended to Jeff Lederman, a physician in Howell, and/or his wife Tracy who has been active in presenting in-service sessions for educators; and Tim Kowalski from Princeton and a scientist in a pharmaceutical company. All of these individuals have children with T.S. and have been active in supporting NJCTS. Depending on the response of these four individuals, other possible board members discussed were Andrew Hendry and Barbara Silvers. Faith will get more information about another possible board member, Leo Gronoski as well. One of the objectives of the Board invitations, in addition to leadership and fundraising, is representation across the State.

In addition to the informational packet and a visit to NJCTS by new Board members to meet staff and discuss services being offered, Rebecca suggested taking some time at upcoming Board meetings for presentations by those carrying out NJCTS programs.

Honorary Board Member: Faith will reach out to Tim Howard regarding becoming an Honorary Board Member.

2. **Fundraising Committee:** Jamie Levitt, Conrad Roncati and Tim Omaggio have agreed to serve on the Fundraising Committee.

The three fundraising objectives are: 1) operational; 2) Advocacy Academy; and 3) Building

We continued the discussion initiated at the previous Board meeting on how we can develop supporters who can bring other influential people to NJCTS.

- a. We discussed whether to hold some fundraising events in New York City where several supporters of NJCTS live or work. Although in the past the organization had hesitated to do this, we decided that it now makes sense to capitalize on the supporters we have living or working in the city. It was decided to hold a cocktail/dinner fundraiser in Conrad's restaurant in New York City in March/April 2013. Jamie and Conrad will take the lead role in planning this event. Craig Carton, Tim Howard, Lonn Trost (N.Y. Yankees) and professionals who provide services are among those who would be invited to attend and to give us their lists of other to invite.
- b. The Advocacy Academy: Tim and Faith previously drafted a concept paper for an Advocacy Academy which we would hope to ultimately house in a building with the other NJCTS programs. Since funding and completing a building will take some time, it was decided to focus now on reaching out to WFAN Radio Personality Craig Carton and see if he will agree to lead fundraising efforts for the Academy. Vivian Stringer, Rutgers coach, has indicated a willingness to support NJCTS. The idea is to involve Rutgers' athletes with the young people attending the Academy. Participants would be housed in Rutgers dorms. NJCTS has \$35,000 in seed money to plan the Academy but will need funding for on-going operations.
 - i. Tim and Faith will revise concept paper and send to Board members to review;
 - ii. Faith will let Mark Chernoff, General Manager at WFAN, know through Mark Brummer that Craig Carton will be contacted concerning the Advocacy Academy.
 - iii. Conrad and Jamie will arrange for a meeting with Craig Carton (lunch or in his office) in January/February 2013 to discuss the Carton Advocacy Academy, give him the concept paper and ask for his financial and other support. Faith will reach out to Craig to help set up the meeting.
- c. Conrad and Faith will reach out to Joseph Piacentile about contributing towards the Advocacy Academy or underwriting educational outreach services.
- d. Conrad is also reaching out to Audrey Hepburn's son who he met in connection with the Audrey Hepburn Children's Center at Hackensack Hospital. Faith will send Conrad a one page summary of NJCTS and the deck on TS. The same information will be sent to all Board members.

e. Fundraising efforts in process are the Mendham walk rescheduled for November 2013, Ramapo College walk in April 2013 and a Princeton walk in June 2013.

Other fundraising efforts will be discussed at the next Board meeting. At that time, Eliot will also report on the status of the Medical Advisory Board.

3. **Board Terms:** Current members will have three year terms; new members will have two year terms.
4. **Board Meetings:** Three in-person and three telephone conference meetings will be held in 2013.
5. **Federal Legislation:** Faith updated us on the status of the legislation. There are now 42 co-sponsors. The legislation will have to be re-introduced when Congress reconvenes in January and at that time, we will do a media event. Many of the co-sponsors have agreed to do "Dear Colleague" letters urging others to co-sponsor.