

MEMORANDUM

TO: Campaign Planning Study Participants

FROM: Graham-Pelton

RE: **Tuberous Sclerosis Alliance Campaign Planning Study Findings**

DATE: October 7, 2019

Graham-Pelton is pleased to share this summary report of the findings and recommendations of the Campaign Planning Study that the firm conducted for Tuberous Sclerosis Alliance (TS Alliance) between July 2, 2019 and October 4, 2019.

Thirty-eight (38) strategic discussions were held with a total of 52 individuals (when considering discussions during which both spouses were present) representing current and former TS Alliance Board and Endowment Board members, volunteers, and community members to assess the organization's capacity to raise \$56 million in new funding over five years in support of the priorities detailed in its Research Business Plan. The preliminary case for support highlighted the five following investment priorities:

- Natural History Database and Biosample Repository
- Preclinical Consortium
- Clinical Research
- Innovative Research
- General Research

Data was also collected from 411 e-survey respondents. TS Alliance President and Chief Executive Officer Kari Rosbeck, the Board of Directors, and TS Alliance staff received the Campaign Planning Study report on October 4, 2019.

PLANNING STUDY OBJECTIVES

- Test a \$56 million campaign goal
- Assess the preliminary case for support
- Identify leaders and volunteers
- Discover perceived obstacles that could negatively impact a campaign
- Determine TS Alliance's position as a philanthropic priority
- Provide fact-based recommendations and next steps

- Identify strengths and challenges
- Develop the prospect pool through wealth screening analysis

SELECT PLANNING STUDY FINDINGS

PERCEPTIONS OF TS ALLIANCE

- Ninety-seven percent (97%) of all discussion participants and 90% of e-survey respondents have a favorable impression of TS Alliance. Based upon similar studies, 97% and 90% favorable ratings are well above the industry standard 80% favorable response.
- The most frequently cited organizational strengths were:
 - Passion and trustworthiness
 - Organizational efficiency and sophistication relative to small size
 - Ability to facilitate access and drive solutions
 - Commitment to research
 - Event fundraising
 - Volunteer stewardship
- The most frequently cited opportunities for the future were:
 - Engagement of donors beyond the TSC community
 - Establishment of direct connection to epilepsy, autism, and other disease research
 - Growth of major gift culture
 - Clear definition of support, research, and advocacy roles
 - Board engagement in fundraising

IN REACTION TO PROPOSED PLANS

- Sixty-three percent (63%) of discussion participants and 79% of e-survey respondents had a “favorable” reaction to the preliminary case for support document that was shared. Thirty-four percent (34%) and 11% of discussion participants and e-survey respondents, respectively, noted they had a “mixed” reaction. Ten percent (10%) of e-survey respondents offered no opinion.
- Three percent (3%) of discussion participants had an “unfavorable” reaction to the proposed preliminary case for support—a notably small number. Those participants cited the need for additional information on outcomes, specifically how the proposed research funding priorities will positively impact those affected by TSC.

- The Natural History Database and Biosample Repository was seen as the top investment priority by discussion participants, while e-survey respondents identified Clinical Research as the highest priority research investment.
- General Research was identified as the lowest priority investment area by both discussion participants and survey respondents, indicating a need for greater specificity on research efforts that would fall into this category, as well as their expected impact.
- Eighty-eight percent (88%) of discussion participants ranked TS Alliance as either “high” (44%) or “highest” (44%) on their list of philanthropic priorities. In the e-survey, 69% of respondents ranked TS Alliance as “high” or “highest” on their list of philanthropic priorities. These rankings exceed the industry benchmark of 65%.
- The study measured the willingness of discussion participants to personally get involved in the proposed campaign:
 - One hundred percent (100%) of discussion participants would (94%) or would possibly (6%) give to the proposed campaign. Eighty-five percent (85%) of e-survey respondents also indicated that they would (55%) or would possibly (30%) give to the proposed campaign.
 - Sixty-eight percent (68%) of discussion participants would (37%) or would possibly (31%) serve on a campaign committee. Fifty-six percent (56%) of e-survey respondents would (20%) or would possibly (36%) serve in this role.
 - Fifty-four percent (54%) of discussion participants would be (20%) or would possibly be (34%) willing to serve as a campaign leader. Forty percent (40%) of e-survey respondents indicated a willingness to serve (10%) or possibly serve (30%) in this capacity.
 - Sixty percent (60%) of discussion participants would talk to prospective donors on behalf of TS Alliance, and 34% would host an event. E-survey respondents indicated willingness to talk to prospective donors on behalf of TS Alliance (21%) and host events (12%) as well.
- Participants were asked to self-identify the amount or range of their potential contribution to the proposed campaign. Thirty-nine percent (39%) of discussion participants agreed to do so. When combined, the range of these self-identified gifts totaled between \$4,000,000–\$7,000,000. Additional potential of up to \$1,400,000 was uncovered through the electronic survey.
- Eighty-five percent (85%) of discussion participants felt that TS Alliance should proceed with a campaign, and 82% of e-survey respondents agreed.

MAJOR PLANNING STUDY RECOMMENDATIONS

Based on the results of the Planning Study and Graham-Pelton's evaluation of the findings, the following recommendations were made to TS Alliance:

- Take immediate steps to launch the Organizational Phase of a targeted fundraising campaign in support of research with a preliminary working goal of \$40 million. The recommended timeline for this campaign is seven years, divided into an Organizational Phase, a Quiet Phase, and a Public Phase. The goal and timeline recommendations are based on the observation that TS Alliance's major gifts program is in the developmental stage. An ongoing commitment to further development of the major gifts program through donor-centric cultivation and solicitation techniques and appropriate resourcing will increase organizational capacity and may ultimately lead to an increased campaign goal.
- Recognizing that the potential for philanthropic commitments totaling in excess of \$40 million exists within TS Alliance's prospective donor pipeline, the working goal will be evaluated based on progress and will be confirmed or adjusted prior to the Public Phase of the campaign.
- The campaign preliminary timeline should progress in the following phases:
 - Organizational Phase: Campaign organization and planning, including campaign plan, policies, and timetable development, campaign committee recruitment, executive briefings.
 - Quiet Phase: Lead and major gift fundraising; continued executive briefings; communications and PR effort; cultivation events; prospect research; planning for public launch.
 - Public Phase: Campaign continuation and conclusion.

The campaign should proceed according to recognized principles of successful fundraising, including strategic prospect management systems, volunteer campaign leadership supported by professional staff, and proven major gift solicitation techniques.

PATHWAY TO SUCCESS

TS Alliance is favorably positioned to execute a transformational fundraising effort that, with disciplined planning, inspirational support, and stretch giving, can provide much-needed funding for TSC research. Graham-Pelton urges TS Alliance to commit to best

practices in campaign fundraising to drive a philanthropic culture and grow individual giving in support of its mission to find a cure for TSC while improving the lives of those affected.